



Second Meeting of the Administrative Data Research Network Board

Agenda and Papers

Tuesday 3 June 2014

10:30 - 14:45

Board Room, UK Statistics Authority Drummond Gate, London

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD (ADRN)

Minutes

Tuesday, 03 June 2014 Boardroom, Drummond Gate, London

Present

Board Members

Professor David Hand (Chair)

Professor Peter Elias (Deputy Chair)

Dr Fiona Armstrong

Mr Jonathan Athow

Dr Norman Caven

Mr David Frazer

Dr Andrew Garrett

Mr Guy Goodwin

Mr Colin Godbold

Mr Roger Halliday

Mr Glyn Jones

Ms Jil Matheson

Mr Luke Sibieta

Ms Melanie Wright

UK Statistics Authority

Mr Robert Bumpstead

Dr Simon Whitworth

Economic and Social Research Council (ESRC)

Ms Vanessa Cuthill

Apologies

Ms Penny Young

1. Minutes and matters arising from previous meeting

- 1.1 The minutes of the previous meeting held on 14 April 2014 were agreed. The meeting reviewed progress with actions.
- 1.2 There were no declarations of interest.

2. Highlight Report [ADRN(14)07]

2.1 Ms Wright introduced the highlight report for June which details the progress made since October 2013. Phase one of the ADRN website has been launched and the Board were invited to comment on the website. Staff recruitment and the development of the infrastructure are progressing well. The overall RAG (Red, Amber, Green) status for the Project is amber. This is due to uncertainties about securing data from data providers and on-going activities to establish the Approvals Panel.

- 2.2 The Board were impressed with the amount of progress that had been made since the last meeting on the 14 April.
- 2.3 Government Departments will require assurance about the security of the IT infrastructure before they send data to the ADRN. It was agreed that Ms Wright would prepare a short summary paper about IT security and to present this paper to the next meeting of the ADRN Board.
- 2.4 The Highlight Report was considered to be a useful document for capturing the progress made by the ADRN. Future reports should include an indication of the metrics to be used once the ADRN is fully active and additional metrics to record the progress made e.g. staff numbers. The Board requested that the Secretariat send regular updates on progress made between meetings by correspondence.

3. Legislative Issues [ADRN(14)08]

- 3.1 Professor Peter Elias introduced a report on legislative issues. This included updates on UK data sharing legislation, EU data protection regulation and other relevant activity. In the UK, the Cabinet Office is currently progressing discussion towards a vision of making the UK "a world leader in research using de-identified administrative data". Officials in the Cabinet Office are arranging meetings to progress an "Open Policy Making" approach, with an ambition to explore all options by the end of June 2014, draft a paper in mid-July 2014 for agreement with ministers in September 2014 and publish for consultation by the end of 2014. Professor Elias reported that the Wellcome Trust has been coordinating a group of UK funders in their response to the issues raised by the draft EU Data Protection Regulation, which would severely restrict the use of personal data for scientific research purposes without specific consent.
- 3.3 The Board noted that current data sharing legislation in the UK is very restrictive, and that the Cabinet Office work is seeking to potentially make it easier to share administrative data more efficiently and enable more data to be shared. They noted that this has the potential to improve how the ADRN works but that the ADRN is not dependent on new legislation.
- 3.4 In discussion about the implications of the EU Data Protection Regulation, the Board stressed the importance of ensuring that the voice of the research community is heard within the officials groups negotiating on the EU legislation. The Ministry of Justice has been leading on this, and it was suggested that the ESRC should discuss with the Department for Business Innovation Skills the preparation of a coordinated response to the legislation from the social research community.
- 3.5 It was agreed that public engagement will be important for the ADRN and that the use of case studies would illustrate the benefits of data sharing. The ADRN should also stress the safeguards that are in place and that identifiable data will not be used by ADRN researchers. The Board agreed that the ADRN needs to be strategic in who it engages and when it engages.

4. ADRN Policies and Procedures [ADRN(14)09]

4.1 Ms Wright presented a report on the ADRN Policies and Procedures. This set out the high-level policy principles by which the ADRN will operate, listed the supporting policies and procedures which are being developed and provided an update on their progress. These overarching principles will guide all ADRN practices across all Administrative Data

Research Centres (ADRCs) and the Administrative Data Service (ADS). The Board were asked to comment on the draft principles, advise where additional supporting policies may be needed and to note the progress to date.

- 4.2 The Board agreed that the policies and procedures were sensible and noted that the paper showed how busy the ADRN had been.
- 4.3 The Board suggested that a crisis action plan should be produced to set out what would happen if there were any data breaches or alleged data breaches. In addition, a formal process should be set up with the data providing Departments to review how the policies and procedures are working in practice.
- 4.4 The policies and procedures have been developed at a high level. There may be differences between the ADRCs in how the details of these high level policies and processes are implemented in each of the ADRCs. This may occur due to differences in local infrastructures or different legal frameworks among the devolved administrations. The high level policies and procedures have been developed in combination with the ADRCs.
- 4.5 The Board asked that the paper is amended to remove dates, to make it clear which groups approve which of the policies and procedures, and be clear about the status of approval of each policy. The Terms of Reference of the different groups need to be linked to the relevant policies in Annex B.
- 4.6 With these comments in mind, the Board asked for an update on progress of the policies and procedures at the next Board meeting.

5. ADRN Approvals Panel [ADRN(14)10] and Definition of an ADRN Project [ADRN(14)11]

- 5.1 Ms Wright introduced reports setting out the basic structure of the ADRN Approvals Panel (AP) and an ADRN Project. Both papers were revisions of papers that were presented at the ADRN Board meeting on the 14 April 2014. The Board were asked to approve both papers as formal ADRN policies, applicable for the first active phase of the ADRN (May 2014 to March 2016.
- 5.2 The Board agreed that both of the policies should apply until a review at some point in the future and that the policies should also be subject to on-going review during this first phase. In addition, the policies should be discussed with research funders to check how these policies work for them.
- 5.3 The Board commented that further thought was needed as to how the AP will function and grant approval. For instance, whether approval will be granted by a majority decision or whether more weight will be given to the opinion of experts on the group.
- 5.4 It was suggested that the AP should make a distinction between research projects that are funded by research bodies and those that are not funded. Funded research is likely to have already undergone a test of scientific merit as part of the funding process and where possible this should be received by the AP.
- 5.5 It was noted that one member of the Board would be part of the AP. The Board were made aware that this was likely to involve a significant workload. The Board also agreed

- that it would be beneficial to ensure that the panel had representation of a member with an awareness of devolution/country issues.
- 5.6 The Board commented that further guidance is required so that researchers are clear about whether the ADRN is suitable for their project, how projects will be prioritised, and how long the approvals process will take. This guidance is being prepared but uncertainty about the volume of projects in the initial stages of the ADRN makes this difficult at this point in time.
- 5.7 The Board noted that at the point of approval all Approved Projects will be published on the ADRN website. The minimum information would be the project title, the lead investigator and a brief description of the project. Discussions are on-going in the ADRN about whether to publish those projects not approved on the website.
- 5.8 The Board approved the structure of the ADRN AP and an ADRN Project, subject to the points made above.

6. Critical Success Factors [ADRN(14)12]

- Dr Fiona Armstrong introduced the ADRN Critical Success Factors (CSFs). This paper set out an initial draft of the CSFs that have been drafted by the ESRC in consultation with the ADRN Leadership Team. The CSFs will assist the Board in fulfilling its assurance role to Parliament and more practically when compiling Annual Reports and mid-term reviews. Some of the CSFs are quantifiable, and the project managers within the ADRN will be developing indicators to measure success, where possible. The Board were invited to discuss the CSFs and consider how these can be used to develop metrics and measure success.
- 6.2 The CSFs should be grouped into themes such as impacts, security and efficiency. An international aspect such as maintaining the UK's position as a world leader in the linking of the administrative sources needs to be added to the CSFs. Some Key Performance Indicators need to be developed and effective powerful case studies will be important to be able to illustrate the success of the ADRN. Metrics such as website hits and followers on social media could be also be used to measure the success of the ADRN.
- 6.3 With these comments in mind, this paper will be expanded and then discussed again at the next Board meeting.

7. Communication and Impact Strategy for the ADRN [ADRN(14)13]

- 7.1 Ms Wright introduced a paper which presented the draft Communications and Impact Strategy for the ADRN. This early draft has been produced by the ADRN Communications Working Group, which includes representatives from each ADRC and the ADS, together with the ADRN Leadership team and the ESRC Communications team. The Board were invited to discuss and comment on the draft strategy.
- 7.2 It was noted that there are numerous key messages. It was suggested that there only needed to be a small number of key messages and the main one should be about the benefits of the ADRN. The other key messages should concentrate on how the ADRN will make the situation better and how data is going to be handled securely. International examples of how linked data has been used to achieve beneficial results should be incorporated into the key messages. The main messages for the public should be differentiated and more nuanced messages should be developed for different sections of

- the public. Government Department Press Officers could be used to help to develop these messages. There also needs to be more in the paper on the impact.
- 7.3 The ADRN need to be proactive in getting their messages out early so they can set the direction rather than be responding to others. The ADRN needs to engage with their likely critics as well as those who will be more supportive of their work.
- 7.4 It is important that the main messages from each of the different ADRCs are coordinated and are consistent. The ADRCs will be in constant communication and a communication working group has been set up to try to coordinate this.
- 7.5 The way in which the ADRN will communicate with the Board between meetings was discussed. It was agreed that the Secretariat would regularly circulate to the Board the highlight report and any press coverage. The Secretariat will also make the Board aware of any ADRN issues that are likely to attract media interest.
- 7.6 The paper will be revised and will be discussed at the next Board meeting on the 29 September.

8. Demand management [ADRN(14)14]

- 8.1 Ms Wright introduced a paper which outlined a strategy for managing demand within the ADRN. The ADRN have no indication currently of what will be the scale of emerging demand for a free service when and after it opens. Estimates of ADRN capacity indicate that approximately five to ten projects per year per ADRC would be low, with twenty to thirty projects per year being maximum capacity. The exception is England where extra ONS capacity in its role with government will increase the maximum capacity for ADRC-E. Staff numbers at the ADRCs reflect these capacity estimates. These estimates and assumptions will be reviewed in October 2015 (after the first year of operation).
- 8.2 The Board agreed with Ms Wright that the "initial low demand, (rising sharply to high demand)" scenario was the most likely scenario to happen. This opinion was based on what has happened with other secure research settings.
- 8.3 In the autumn 2014, the ADRN will be advertising they are open for business. They will then assess demand before deciding how pro-active their marketing should be or whether demand management strategies will be required.
- 8.4 A list of datasets that are available to researchers through the ADRN will be published on the ADRN website and there will be communication with researchers when new datasets become available. The levels of ADS support that researchers require to use each dataset will be made clear.

9. The data journey

- 9.1 Ms Wright presented the data journey. The aim of this presentation was to enable Board members to understand what happens to the data within the ADRN from beginning to end. The Secretariat will circulate the short summary of the data journey to the Board after the meeting.
- 9.2 The Board commented that there needs to be standard protocols for matching agreed by the Trusted Third Parties (TTP) and the Data Providers. The TTPs need to be transparent

- about the methods that they use. As data matching is not a precise science, the TTPs need to clearly inform users about the issues that exist with their matching methods.
- 9.3 Whenever possible, data will be provided in the ADRC most conveniently located for the researcher even where the datasets are involved are GB or UK wide datasets.
- 9.4 It was agreed that initially the linked data should be destroyed at the end of a project, as set out in the ADRN data destruction/retention policy. The syntax used to create the linked data would be kept. However, the longer term aim should be to keep the data created, assuming legislation allows for this. There are research benefits for keeping the data (e.g. it can be used to inform future research). It is also inefficient to spend money on linking data that has to be recreated to be used again. It was noted that Australia moved to a position of keeping the linked data, from a position initially of destroying it, in the space of five years.
- 9.5 The risk of re-identification was discussed. There was acknowledgment that the risk of re-identification can never be completely ruled out despite the safeguards in place. It was noted that the risk of re-identification is higher for certain niche groups, and for these niche groups the risks need to be carefully assessed. It is important that, as far as possible, the ADRN are consistent with what other infrastructures (e.g. Care.data) are saying about the risk of re-identification. It would be helpful to have independent experts who could reassure the public about the risks.
- 9.6 The Board viewed a video, produced by the ESRC, aimed at the public which described the work of the ADRN. It was suggested that the video should be shared with members of the public and privacy groups to get their feedback. It was suggested that a Welsh version of the video should be produced.

10. Any other business

- 10.1 The ESRC updated the Board on plans for the 3 July Ministerial ADRN event, and informed that invitations were due to be sent to members within the next week.
- 10.2 The ADRN Board will meet next on Monday 29 September 2014.

Simon Whitworth, Head of Secretariat and Project Lead, Administrative Data Research Network Board, 5 June 2014,

6 of 6

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

Agenda

Tuesday, 3rd June 2014
Board Room, One Drummond Gate, London
10:30am - 2:45pm (coffee from 10:00am)

Chair: Professor David Hand

Apologies:

Part A (10:30am to 12:00pm)

1	Minutes and matters arising from previous meeting	Professor David Hand
10:30am	Declarations of interest	
2	Highlight Report	ADRN(14)07
10:40am		Ms Melanie Wright
3	Legislative Issues	ADRN(14)08
11:00am		Professor Peter Elias
4	ADRN Policies and Procedures	ADRN(14)09
11:20am		Ms Melanie Wright
5	ADRN Approvals Panel	ADRN(14)10
11:40am	Definition of an ADRN Project	ADRN(14)11
	20	Ms Melanie Wright

Lunch (12:00pm to 12:30pm)
Part B (12:30pm to 2:45pm)

6	Critical Success Factors	ADRN(14)12
12:30pm		Dr Fiona Armstrong
7	Communication and Impact Strategy for the ADRN	ADRN(14)13
1:00pm		Ms Melanie Wright
8	Demand management	ADRN(14)14
1:30pm		Ms Melanie Wright
9	The data journey	Presentation
1:50pm		Ms Melanie Wright
10	Any other business	
2:30pm		

Next Meeting: Monday 29 September 2014, Drummond Gate, London

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

Minutes

Monday, 14 April 2014 Boardroom, Drummond Gate, London

Present

Board Members

Professor David Hand (Chair)
Professor Peter Elias (Deputy Chair)
Dr Fiona Armstrong
Mr Jonathan Athow
Mr David Frazer
Dr Andrew Garrett
Mr Guy Goodwin
Ms Jil Matheson
Mr Luke Sibieta

UK Statistics Authority

Ms Penny Young Ms Melanie Wright

Mr Robert Bumpstead Mr Mervyn Stevens

Economic and Social Research Council (ESRC)

Ms Vanessa Cuthill

Other attendees for items 1 to 4

Professor David Ford, Director, Administrative Data Research Centre (ADRC) Wales Professor Peter Smith, Director, ADRC England Professor Dermot O'Reilly, Director, ADRC Northern Ireland Professor Chris Dibben, Director, ADRC Scotland Ms Melanie Knetsch, ESRC

Apologies

Dr Norman Caven Mr Colin Godbold Mr Roger Halliday Mr Glyn Jones

1. Minutes and matters arising from previous meeting

1.1 The minutes of the previous meeting held on 14 April 2014 were agreed. The meeting reviewed progress with actions.

UK STATISTICS AUTHORITY

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(14)07

ADRN Highlight Report – June 2014

Purpose

1. This paper presents a ADRN highlight report for June.

Recommendations

- 2. Members of the ADRN Board are invited to:
 - i. note and discuss the content of the highlight report at Annex A; and
 - consider the format of the highlight report and whether it meets the Board's requirements.

Background

- 3. The Administrative Data Service (ADS) and the Administrative Data Research Centres (ADRCs) were commissioned in October 2013, following a competitive tender. This highlight report sets out key areas of progress since October and anticipates future activities for the next quarter.
- 4. At the last ADRN Board meeting it was agreed that "future reports should focus particularly on strategic issues and risks, including their current statuses. The Board would also receive information on forecast demand, the number of applications received, and the length of time from application to access to data and the current status of research projects. Management reports to the board should aim to make good use of information provided to the Management Committee".

Discussion

- An overall RAG (Red, Amber or Green) status is shown for the Project. This status is currently derived from project management discussions within the ESRC. From June 2014, the RAG status will be discussed by the Management Committee of the ADRN and reported to the ADRN Board.
- 6. The highlight report also identifies risks and actions planned to mitigate risks, and sets out achieved and planned activities. The report is structured around workstreams that reflect the specific responsibilities of the ADRN Board (paragraphs 8i to 8iv of the terms of reference).

Simon Whitworth, Head of Secretariat and Project Leader, Administrative Data Research Network Board, 23 May

List of Annexes

Annex A ADRN Highlight Report

Tab 2.1 Highlight Report / Annex A Highlight Report

Annex A: ADRN Highlight Report

Overall RAG status this	Α	Overall RAG status last	Α	Report date: 20 May 2014
reporting period		reporting period		

Provide a brief account of progress on the project since the last report. Please include metrics, including number of project applications received and approved, and the average length of time from application to approval and from approval to access to data. Please include a list of approved project titles and their current status.

Please include a look forward to the next quarter. What will be the key priorities? What are the risks and what are the actions planned to mitigate these risks?

Progress to date:

- Progress has continued to establish the physical and e-infrastructure, security and processes, across the ADS and 4 ADRCs, ready for beta-testing this summer using a suite of research project proposals from the 4 ADRCs.
- Most key staff have now been recruited across the Network and are currently being inducted.
- The Network Directors and their teams have been working together on harmonising operating practices, with the aim of the Network being a 'seamless' whole from the user perspective.
- The Network-wide working groups have progressing workstreams on: Communications; Stakeholder Engagement; User Services and Support; IT and Security; Research (Substantive and Methodological); and Training and Capacity Building.
- A draft Communications strategy has been prepared, for review by the ADRN Board at their meeting on 3 June.
- Extensive work has been undertaken on the phase 1 website, which will go live end of May.

'Live' Project Titles and current status:

n/a for this edition of the Highlight Report.

Key metrics:

n/a for this edition of the Highlight Report.

Key strategic priorities for next quarter:

- To launch and promote the website: www.adrn.ac.uk.
- To beta-test the ADRN infrastructure, using a suite of research projects from the 4 ADRCs.
- To monitor awareness of the ADRN and anticipate demand.
- To intensify programme of engagement with data owners, sister infrastructures, and activist groups in preparation for full service launch in Autumn.

ADRN Board - 03/06/14

Annex A: ADRN Highlight Report

Risks:

The overall RAG status for this project is amber. A risk register has been prepared by the Administrative Data Service. The risks include: unknown level of demand for administrative data by the research communities; policies and procedures not being followed; lack of public trust; loss of key staff; network outages; data owner concerns; delays in the supply of data by government departments and agencies.

Actions to mitigate these risks:

The risk register includes actions to mitigate the above risks. A demand management strategy is being developed. UKSA and ESRC officers are continuing to talk with data owning government departments and agencies about the ADRN, what the benefits are, and the key role that they fulfil. A breaches and penalties policy is also being developed.

Workstream Progress Reports:

Workstream 1:	ADRN infrastructure and Network coherence ¹	Report date:	20 May 2014

Main achievements

Infrastructure:

• Staff recruitment is continuing apace across the Network. Project Managers have now been recruited at all ADRCs and the ADS.

Network coherence:

- The Directors of the ADRCs and the ADS, together with ONS, met on 28 April at the University of Southampton to progress harmonised procedures for the 'user journey'. This work is being carried forward by the Working Groups.
- The website is designed to be a 'one stop shop', providing information on administrative data and guiding researchers towards accessing the Network. The Phase 1 website will be primarily promotional and informational, whilst phase 2 will be focused more prominently around service provision.

Outlook for next quarter

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

Annex A: ADRN Highlight Report

Infrastructure:

• A suite of project proposals from the 4 ADRCs will be used over the next few months to 'beta-test' the ADRN infrastructure. The intention is to launch the ADRN to all *bona fide* researchers in Autumn 2014.

Network coherence:

- The ADRCs and ADS will be implementing harmonised processes with effect from end May 2014.
- The Comms Working Group will take forward the development of the phase 2 website.

Workstream 2:	ADRN principles and policies ²	Report date:	20 May 2014

Main achievements

- Principles and policies have now been agreed by the ADRN Board, on:
 - o the definition of an ADRN project; and
 - o how projects will be assessed and approved.
- Principles and policies have been developed, for approval by the ADRN Board, on:
 - o the data journey, including data linkage
 - o appeals.

Outlook for next quarter

- A summary paper on policies and principles for information security and governance will be prepared by the ADRN Information Technology Working Group, to be reviewed by the ADRN Board at their meeting of 29 September.
- Work will continue on developing a network-wide breaches penalties policy
- The Independent Approvals Panel will be convened

Tab 2.1 Highlight Report / Annex A Highlight Report

² Board responsibility (from ToR): ii) Agree the principles and policies for access to the Network, identifying and resolving any high-level issues which inhibit access to the Network.

Annex A: ADRN Highlight Report

Workstream 3:	ADRN standards and performance ³	Report date:	20 May 2014

Main achievements

- The ADRN User Services working group will have standards and performance monitoring within their remit.
- The ADRN working group on substantive research has as its remit:
 - To ensure efficient coordination of substantive research projects across the network.
 - To minimise duplication of substantive research across the network
 - To harmonise similar research strands and build partnerships across the network
 - To provide evidence of research impact across the network
 - To foster and encourage best practice in the use of administrative and sensitive data across the network and within the wider research community.
- The ADRN methodological research working group is meeting on 29 30 May in Manchester to discuss how best to synchronise research on methodology in data linkage, and linked data quality and quality assurance.

Training and capacity building:

- ADS is nearing completion of a prototype training course on data security. This will be mandatory for all approved researchers.
- The ADRN Training and Capacity Building working group has been tasked with developing and delivering an ADRN-wide skills training strategy for researchers.
- The working group has also been tasked with the development and delivery of an ADRN-wide capacity building strategy.

Outlook for next quarter

- Beta-testing of the ADRN will commence from 27 May, using a suite of research project proposals from across the ADRCs
- The User Services Working Group will continue to meet and to monitor the quality and consistency of standards and services across the ADRN. *Training and capacity building:*
- The ADRN Training and Capacity Building working group will meet monthly to progress the skills training strategy and the capacity building strategy.
- Each ADRC will be marketing and delivering ADRN training courses.
- Each ADRC will be identifying and advertising capacity building opportunities eg PhD studentships.

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

Workstream 4:	ADRN Public Engagement and Communications ⁴	Report date:	20 May 2014

Main achievements

- A draft Communications Strategy has prepared by the ADRN Leadership Team, for oversight by the Board.
- A Communications Manager has been recruited for the ADS.

Outlook for next quarter

- An awareness raising event aimed at Parliamentarians and Senior Civil Servants is planned for 3 July in London, hosted by the Minister for Science and Universities, Rt Hon David Willetts MP;
- ADRCs are also planning official openings of their new facilities over the coming months.
- The Communications Strategy will be implemented across ADRN, ensuring consistency of messages, etc.
- The Public Engagement working group will take forward the development of an overarching ADRN PE Strategy, and nest the individual centre strategies and planned activities within it.

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

UK STATISTICS AUTHORITY

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(14)08

Legislative Issues

Purpose

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

Recommendations

- 2. Members of the ADRN Board are invited to:
 - i. note and discuss the content of the paper; and
 - ii. consider the potential implications of the activities discussed for the ADRN.

Background

- 3. The Cabinet Office is currently progressing discussion towards a vision of making the UK "a world leader in research using de-identified administrative data, routinely collected by government departments and other public bodies. Such data, made accessible for research in ways that prevent the identification of individuals, will provide a robust UK-wide evidence base to inform research, thereby guiding the development, implementation and evaluation of policy."
- 4. The Wellcome Trust has been coordinating a group of UK funders in their response to the issues raised by the draft EU Data Protection Regulation, which would cover the use of personal data across a wide range of sectors and will affect how data are used in research. The original draft Regulation set out a mechanism for protecting privacy, while enabling research to continue; it included a requirement for specific and explicit consent for the use and storage of personal data, but provided an exemption for research, subject to certain safeguards. This recognised that individuals' interests can be protected through strong ethical and governance safeguards, such as approval by a research ethics committee. However, in October 2013, the Civil Liberties and Home Affairs (LIBE) committee of the European Parliament adopted amendments to Articles 81 and 83 that would severely restrict the use of personal data for scientific research purposes without specific consent. Unless further amendments are made, the regulation in its current form would hinder important and highly valued social science research.
- 5. The Expert Advisory Group on Data Access (EAGDA) was established by the Wellcome Trust, Cancer Research UK, the ESRC, and the Medical Research Council to provide strategic advice on the emerging scientific, legal and ethical issues associated with data access for human genetics research and cohort studies. The EAGDA is chaired by Professor Martin Bobrow (Cambridge University) and currently has 14 members, with expertise spanning genetics, epidemiology, social sciences, statistics, IT, data management and security, law, and ethics.

Discussion

Update on the UK Data Sharing Legislation

- 6. Officials in the Cabinet Office are arranging meetings to progress an "Open Policy Making" approach, with an ambition to explore all options by the end of June 2014, draft a paper in mid-July 2014 for agreement with ministers in September 2014 and published for consultation by the end of 2014.
- 7. During May interested parties in each sub-strand of the potential legislation have met to explore the issues and opportunities and on Thursday 15 May 2014 there was a meeting to focus on the de-identified data strand of the legislation. This meeting was attended by a mix of government officials, third sector representatives and academics, which included the Director of the Administrative Data Service and one of the Administrative Data Research Centre (ADRC) Directors, plus three other key ADRC colleagues. The meeting progressed discussions around the:
 - i. rationale for legislation Why greater sharing of de-identified data is desireable from academic, government and third sector perspectives; and
 - ii. the safeguards that exist and would exist with a focus on Governance and transparency; handling of data; accreditation and training of individuals; and sanctions.
- 8. The next meeting of the de-identified data strand is expected to be on 13 June 2014, when the group should be discussing the options paper. Ahead of that meeting, the Cabinet Office are seeking further clarity around: the evidence base for legislation (i.e. case studies illustrating the limitation for research of the current legislative situation); the policies and safeguards that the ADRN will have in place (i.e. a number of the policy papers considered by the ADRN Board at its meetings will be made available as background materials); and further detail (to the extent this is available) on the proposals for 'safe havens' and the role the UK Statistics Authority would have in oversight and accreditation.
- 9. There will be single joint open policy making meeting on 29 May 2014 to bring together participants for all the legislation discussion (including statistics and research strands, with the fraud error and vulnerable population strands). The Director of the Administrative Data Service, the Head of Secretariat of the ADRN Board and Professor Peter Elias will attend that meeting. Reflections on this meeting will be presented to the ADRN Board at its 3 June 2014 meeting.

EU Data Protection Regulation

- 10. Following the amendments adopted by the Civil Liberties and Home Affairs (LIBE) committee of the European Parliament there has been a coordinated approach to voice concerns, which has included:
 - a letter expressing concerns signed by the Chief Executives of funders to the Rt Hon Chris Grayling MP, Lord Chancellor and Secretary of State for Justice, both of whom have strongly encouraged continued efforts to highlight the concerns for research;
 - ii. a joint statement issued on 29 January 2014, which sets out the position on the LIBE committee's amendments, signed by a large number of UK and European funders and organisations, including the ESRC;
 - iii. an open letter published in the Times on 29 January 2014, which expressed concerns, and was signed by a number key figures in research;

- iv. a letter to UK MEPs ahead of the plenary vote in the European Parliament on the 12 March 2014, signed by a number of UK research funders also signed; and
- v. meetings with key figures including Anne Glover, CSA to President of the European Commission, to highlight the concerns of the research community.
- 11. At the European Parliament debate in March a number of MEPs spoke in support of research, including UK MEP Vicky Ford and Viviane Reding Vice-President of the European Commission in charge of Justice, Fundamental Rights and Citizenship. However the European Parliament voted for the legislation with a majority, and it will next move to triologue discussions with the Council, probably in the autumn.
- 12. The European elections in May have necessitated a pause in efforts to raise the concerns of researchers. However funders, coordinated by the Wellcome Trust, are meeting in early June to agree next steps. In addition the ESRC is keen to raise awareness that the concerns for research apply not only for health but social science, as many of the voices on behalf of research have come from health funders. The ESRC is planning to raise the visibility of social science in the discussion, through use of case studies and open and targeted letters, and hopes to work with other social science funders in the UK and across Europe.

Other relevant activity

13. In its first eighteen months the EAGDA has been undertaking a work programme with a focus on three issues: Data Access Committees (DACs), Identifiability and Incentives for data sharing. The statement on 'Identifiability' was published on the 10 March 2014, and there was an accompanying piece in Research Fortnight, and Nature also picked it up in their blog. On 29 May 2014 EAGDA plan to publish the report on 'Incentives' which will highlight the need for a fundamental culture shift in the research community to recognise the importance of data sharing, and provide incentives and rewards for researchers who make high quality datasets available to others. The remaining report from the initial work programme, a report on Data Access, will follow later in the year

Vanessa Cuthill, Economic and Social Research Council, 27 May 2014

UK STATISTICS AUTHORITY

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(14)09

ADRN Policies and Procedures

Purpose

1. This paper provides the policy principles by which the ADRN will operate, lists the supporting policies and procedures which are being developed and gives an update as their progress.

Recommendations

- 2. Members of the ADRN Board are invited to:
 - i. to comment on the draft principles;
 - ii. advise where additional supporting policies may be needed; and
 - iii. to note the progress to date.

Background

- The aim of this paper is to set forward the high-level policy principles by which the ADRN
 will operate throughout its life. Supporting each of these principles will be a range of
 documents: specific policies, strategy documents, procedural documents, and legal
 forms and agreements.
- 4. 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.

Discussion

- 5. **Annex A** lists the relevant procedures, methods of governance and oversight and documents and training for the ADRN policy principles. The number in brackets refers to where they can be found in Annex B.
- 6. Annex B shows the full list of ADRN Policies/Procedures and their current status.

Simon Whitworth, Head of Secretariat and Project Leader, Administrative Data Research Network Board, 23 May.

List of Annexes

Annex A Policy principles

Annex B List of ADRN procedures for development

UK STATISTICS AUTHORITY

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(14)09

Annex A - Policy Principles

1. ADRN will always operate to protect the privacy and confidentiality of data subjects.

Relevant Procedures:

- Definition of an ADRN project (1)
- II. Definition of a 'fit and proper person' (2)
- III. Procedure for confirming applicant affiliation and identity (3)
- IV. Procedure for confirming institutional guarantor identity (4)
- v. Criteria for assessing privacy impact (5)
- VI. Criteria for assessing project feasibility (6)
- VII. Ethical review procedure (7)
- VIII. Approvals Panel operating procedures (8)
- IX. ADRN IT security standards and operating procedures (11)
- x. Principles for assigning security levels to 'safe settings' (12)
- XI. Principles for assessing 'impact level' of linked data (13)
- XII. Principles for applying government security settings to ADRN data (14)
- XIII. Procedures for ADRN accreditation training delivery (16)
- XIV. Procedures for ADRC training (17)
- xv. Breaches policy (18)
- XVI. Statistical Disclosure Control Procedures (19)
- XVII. Data transfer procedures (20)
- XVIII. Data linking principles (21)
- XIX. Trusted Third Party' procedures (22)
- XX. Data destruction (and retention) policy (24)
- XXI. ADRN Staff vetting procedures (27)
- XXII. Procedures for auditing of ADRC security (28)
- XXIII. Procedures for auditing safe setting security (29)
- XXIV. Procedures for auditing outputs (30)

Governance and oversight:

- Approvals Panel (3)
- II. Scientific Advisory Body (4)

Documents and training:

- Researcher application form (1)
- II. Project application form (2)
- III. Guidelines for ethical review panels (3)
- IV. Approvals Panel Terms of Reference (4)
- v. ADRN accreditation training (5)
- VI. Site/Centre specific training (6)
- VII. Scientific Advisory Body Terms of Reference (7)

- VIII. Scientific Advisory Body operating procedures (8)
- IX. Expert Advisors Terms of Reference (9)

2. ADRN will operate as transparently as possible

Relevant Procedures:

- I. Definition of an ADRN project (1)
- II. Definition of a 'fit and proper person' (2)
- III. Criteria for assessing privacy impact (5)
- IV. Criteria for assessing project feasibility (6)
- v. Ethical review procedure (7)
- VI. Approvals Panel operating procedures (8)
- VII. Project appeals procedure (9)
- VIII. Breaches policy (18)
- IX. Statistical Disclosure Control Procedures (19)
- x. Data transfer procedures (20)
- XI. Data linking principles (21)
- XII. Trusted Third Party' procedures (22)
- XIII. Syntax deposit and preservation policy (23)
- XIV. Data destruction (and retention) policy (24)
- xv. Final reporting procedure for researchers (26)
- XVI. ADRN Staff vetting procedures (BPSS, Non-disclosure agreements) (27)
- XVII. Key performance indicators (31)
- XVIII. Public engagement strategy (33)
- XIX. ADRN operating model (decision making, procedures approval, network structure) (34)

Governance and oversight:

- ADRN Board (1)
- II. ADRN Management Committee (2)
- III. Approvals Panel (3)

Documents and training:

- I. Feasibility guidelines for IAP (3)
- II. Guidelines for ethical review panels (4)
- III. Approvals Panel Terms of Reference; criteria checklist; notification of approval templates (5)
- IV. ADRN Management Committee Terms of Reference (8)
- v. ADRN Board Terms of Reference (9)
- VI. Scientific Advisory Body Terms of Reference (10)

3. ADRN will only support research with potential public benefit

Relevant Procedures:

- I. Definition of an ADRN project (1)
- II. Approvals Panel operating procedures (8)
- III. Project appeals procedure (9)
- IV. Final reporting procedure for researchers (26)

- v. Key performance indicators (31)
- VI. Communications and impact strategy (32)
- VII. Public engagement strategy (33)

Governance and oversight

I. Approvals Panel (3)

Documents and training

- I. Project application form and guidelines (1)
- II. Guidelines for ethical review panels (4)
- III. Approvals Panel Terms of Reference; criteria checklist; notification of approval templates (5)

4. ADRN will ensure data are accessed safely and securely

Relevant Procedures:

- I. Definition of a 'fit and proper person' (2)
- II. Procedure for confirming applicant affiliation and identity (3)
- III. Procedure for confirming institutional guarantor identity (4)
- IV. Criteria for assessing privacy impact (5)
- v. Principles for assigning projects to an ADRC (10)
- VI. ADRN IT security standards and operating procedures (11)
- VII. Principles for assigning security levels to 'safe settings' (12)
- VIII. Principles for assessing 'impact level' of linked data (13)
- IX. Principles for applying government security settings to ADRN data (14)
- x. ADRN User Services standards (15)
- XI. Procedures for ADRN accreditation training delivery (16)
- XII. Procedures for ADRC training (17)
- XIII. Breaches policy (18)
- XIV. Statistical Disclosure Control Procedures (19)
- xv. Data transfer procedures (20)
- XVI. Data linking principles (21)
- XVII. Trusted Third Party' procedures (22)
- XVIII. Data destruction (and retention) policy (24)
- XIX. ADRN Staff vetting procedures (BPSS, Non-disclosure agreements) (27)
- xx. Procedures for auditing of ADRC security (28)
- XXI. Procedures for auditing safe setting security (29)
- XXII. Procedures for auditing outputs (30)

Governance and oversight:

- I. ADRN Management Committee (2)
- II. Approvals Panel (3)
- III. Scientific Advisory Body (4)

Documents and training:

- I. Researcher application form and guidelines (2)
- II. Approvals Panel Terms of Reference; criteria checklist; notification of approval templates (5)

- III. ADRN accreditation training (6)
- IV. Site/Centre specific training (7)
- v. Scientific Advisory Body Terms of Reference (10)
- VI. Expert Advisors Terms of Reference (12)
- VII. Working groups terms of reference (13)

5. ADRN will be accountable and operate under appropriate governance

Relevant Procedures:

- I. ADRN Staff vetting procedures (BPSS, Non-disclosure agreements) (27)
- II. Key performance indicators (31)
- III. ADRN operating model (decision making, procedures approval, network structure) (34)

Governance and oversight:

- ADRN Board (1)
- II. ADRN Management Committee (2)

Documents and training:

- I. ADRN Management Committee Terms of Reference (8)
- II. ADRN Board Terms of Reference (9)
- III. Working groups terms of reference (13)

6. ADRN will be independent

Relevant Procedures:

- I. Definition of an ADRN project (1)
- II. Approvals Panel operating procedures (8)
- III. Project appeals procedure (9)
- IV. Breaches policy (18)
- v. Statistical Disclosure Control Procedures (19)
- VI. ADRN Staff vetting procedures (BPSS, Non-disclosure agreements) (27)
- VII. Procedures for auditing of ADRC security (28)
- VIII. Procedures for auditing safe setting security (29)
- IX. Procedures for auditing outputs (30)
- x. Communications and impact strategy (32)
- XI. Public engagement strategy (33)
- XII. ADRN operating model (decision making, procedures approval, network structure) (34)

Governance and oversight:

- I. Approvals Panel (1)
- II. Scientific Advisory Body (2)

Documents and training:

- Guidelines for ethical review panels (3)
- II. Approvals Panel Terms of Reference (4)
- III. Scientific Advisory Body Terms of Reference (7)

- Scientific Advisory Body operating procedures (8)
- v. Expert Advisors Terms of Reference (9)

7. ADRN will support and enable excellence and innovation in research

Relevant Procedures:

- I. Definition of an ADRN project (1)
- II. Definition of a 'fit and proper person' (2)
- III. Procedure for confirming applicant affiliation and identity (3)
- IV. Criteria for assessing project feasibility (6)
- v. Ethical review procedure (7)
- VI. Approvals Panel operating procedures (8)
- VII. Project appeals procedure (9)
- VIII. ADRN User Services standards (15)
- IX. Procedures for ADRN accreditation training delivery (16)
- x. Procedures for ADRC training (17)
- XI. Breaches policy (18)
- XII. Statistical Disclosure Control Procedures (19)
- XIII. Syntax deposit and preservation policy (23)
- XIV. Procedure for returning data enhancements to data owners (25)
- xv. Final reporting procedure for researchers (26)
- XVI. Procedures for auditing outputs (30)
- XVII. Key performance indicators (31)
- XVIII. Communications and impact strategy (32)
- XIX. Public engagement strategy (33)
- xx. ADRN operating model (decision making, procedures approval (34)

Governance and oversight:

- I. ADRN Management Committee (2)
- II. Approvals Panel (3)
- III. Scientific Advisory Body (4)

Documents and training:

- I. Project application form and guidelines (1)
- II. Researcher application form and guidelines (2)
- III. Feasibility guidelines for IAP (3)
- IV. Guidelines for ethical review panels (4)
- v. Approvals Panel Terms of Reference; criteria checklist; notification of approval templates (5)
- VI. ADRN accreditation training (6)
- VII. Site/Centre specific training (7)
- VIII. Scientific Advisory Body Terms of Reference (10)
- IX. Scientific Advisory Body operating procedures (11)
- x. Expert Advisors Terms of Reference (12)

8. ADRN will operate ethically

Relevant Procedures:

- Definition of an ADRN project (1)
- II. Definition of a 'fit and proper person' (2)
- III. Procedure for confirming applicant affiliation and identity (3)
- IV. Procedure for confirming institutional guarantor identity (4)
- v. Criteria for assessing privacy impact (5)
- VI. Ethical review procedure (7)
- VII. Approvals Panel operating procedures (8)
- VIII. Project appeals procedure (9)
- IX. Breaches policy (18)
- x. Statistical Disclosure Control Procedures (19)

Governance and oversight:

I. Approvals Panel (3)

Documents and training;

- Project application form and guidelines (1)
- II. Researcher application form and guidelines (2)
- III. Guidelines for ethical review panels (4)
- IV. Approvals Panel Terms of Reference; criteria checklist; notification of approval templates (5)
- v. ADRN accreditation training (6)
- VI. Scientific Advisory Body Terms of Reference (10)
- VII. Scientific Advisory Body operating procedures (11)
- VIII. Expert Advisors Terms of Reference (12)

9. ADRN will provide good value for money

Relevant Procedures:

- I. Definition of an ADRN project (1)
- II. Criteria for assessing project feasibility (6)
- III. Approvals Panel operating procedures (8)
- IV. Project appeals procedure (9)
- v. Principles for assigning projects to an ADRC (10)
- VI. ADRN User Services standards (15)
- VII. Procedure for returning data enhancements to data owners (25)
- VIII. Final reporting procedure for researchers (26)
- IX. Key performance indicators (31)

Governance and oversight:

- I. ADRN Board (1)
- II. ADRN Management Committee (2)

Documents and training

- I. Feasibility guidelines for IAP (3)
- II. Approvals Panel Terms of Reference; criteria checklist; notification of approval templates (5)
- III. ADRN Management Committee Terms of Reference (8)
- IV. ADRN Board Terms of Reference (9)

v. Working groups terms of reference (13)

Appendix B: List of ADRN Procedures for development

	Procedure	Status	Documents	Body
1	Definition of an ADRN project	complete and approved	Project application form and guidelines	
2	Definition of a 'fit and proper person'	in development, expected completion 08/06	Researcher application form and guidelines	
3	Procedure for confirming applicant affiliation and identity	in development, expected completion 08/06		
4	Procedure for confirming institutional guarantor identity	in development, expected completion 08/06		
5	Criteria for assessing privacy impact	in development, expected completion 19/06		
6	Criteria for assessing project feasibility	expected completion 19/06	Feasibility guidelines for IAP	
7	Ethical review procedure	expected completion 19/06	Guidelines for ethical review panels	
8	Approvals Panel operating procedures	expected completion 19/06	Approvals Panel Terms of Reference; criteria checklist; notification of approval templates	Approvals Panel
9	Project appeals procedure	expected completion 19/06		
10	Principles for assigning projects to an ADRC	in development, expected completion 08/2014		
11	ADRN IT security standards and operating procedures	expected completion 29/06		
12	Principles for assigning security levels to 'safe settings'	expected completion 29/06		
13	Principles for assessing 'impact level' of linked data	expected completion 29/06		
14	Principles for applying government security settings to ADRN data	expected completion 29/06		
15	ADRN User Services standards	expected completion		

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ADRN Board - 03/06/14

ADRN Board - 03/06/14

@BCL@F408E5CB May 2014

		29/06	
16	Procedures for ADRN accreditation training delivery	expected completion 29/06	ADRN accreditation training
17	Procedures for ADRC training	expected completion 19/06	Site/Centre specific training
18	Breaches policy	expected completion 19/06	
19	Statistical Disclosure Control Procedures	expected completion 29/06	
20	Data transfer procedures	expected completion 19/06	
21	Data linking principles	expected completion 19/06	
22	Trusted Third Party' procedures	expected completion 29/06	
23	Syntax deposit and preservation policy	expected completion 29/06	
24	Data destruction (and retention) policy	expected completion 19/06	
25	Procedure for returning data enhancements to data owners	expected completion 29/06	
26	Final reporting procedure for researchers	expected completion 29/06	
27	ADRN Staff vetting procedures (BPSS, Non-disclosure agreements)	expected completion 19/06	
28	Procedures for auditing of ADRC security	expected completion 08/2014	
29	Procedures for auditing safe setting security	expected completion 08/2014	
30	Procedures for auditing outputs	expected completion 08/2014	
31	Key performance indicators	complete and approved	
32	Communications and impact strategy	draft with ADRN Board	

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Tab 4.2 ADRN Policies and Procedures / Annex B List of ADRN Procedures for Development

@BCL@F408E5CB May 2014

33	Public engagement strategy	draft with Management Committee/Leadership Group		
34	ADRN operating model (decision making, procedures approval, network structure)	expected completion 08/2014		
			ADRN Management Committee Terms of Reference	ADRN Management Committee
			ADRN Board Terms of Reference	ADRN Board
			Scientific Advisory Body Terms of Reference	Scientific Advisory Body (SAB)
			Scientific Advisory Body operating procedures	
			Expert Advisors Terms of Reference	Expert Advisors to SAB
			Working Groups Terms of Reference	

ADRN Board - 03/06/14

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(14)10

ADRN Approvals Panel

Purpose

- 1. This paper is a revision of that presented at the ADRN Board meeting on the 14 April 2014. The aim of the paper is to establish the basic structure of an ADRN Approvals Panel (AP).
- The paper is submitted for the Board's approval as a formal ADRN policy applicable for the first active phase of the ADRN (May 2014-March 2016). At the end of this period all ADRN operations will be reviewed.

Recommendations

- 3. Members of the ADRN Board are invited to:
 - i. note and discuss the paper; and
 - ii. consider whether they approve of the proposed policy for the first active phase of the ADRN (May 2014 to March 2016).

Background

4. The aim of the AP is to ensure that there is a transparent process for assessing and approving research project proposals. This transparency is necessary to minimise the perception of risk among members of the public by reassuring them that there is an expert, disinterested body overseeing projects applying to access sensitive administrative data to ensure that they are suitable, ethical and in the public interest. It also helps ensure that academics and other researchers perceive ADRN as a level playing field with no privileged access, and to provide data owners with expert assessment of projects to minimise their burden in processing applications for data access and linkage.

Discussion

- 5. It is recommended that the AP core membership consists of 10 people:
 - i. 3 representatives of data providers (including ONS);
 - ii. 3 senior academics (with different primary research areas);
 - iii. 1 non-executive member of the ADRN Board;
 - iv. 1 representative with special expertise in privacy and data protection; and
 - v. 2 lay members
- 6. The Administrative Data Service (ADS) Director or their nominee will serve an as exofficio member of the AP with no voting or decision making rights. The ADS member will provide additional information prepared ahead of discussions on ethical review, project feasibility and privacy implications as outlined below. The ADS will also provide a secretariat function for the AP. The chair will be drawn from the academic membership and may receive an honorarium; the other posts would be unpaid apart from travel expenses.
- 7. In addition to the standing panel members, the AP will have access to a wide list of experts in particular data or research areas who can be called on to advise on topics within their areas of expertise. This expert list could include members of the ADRN in

- order to harness their significant knowledge and experience, and provide a realistic assessment of the feasibility of projects.
- 8. The AP will be responsible for reviewing all formal proposals for access to data through the Network and recommending whether they should be approved as ADRN projects.
- 9. The criteria for approval include:
 - i. an outline of an acceptable process for review of the ethical implications;
 - ii. clear understanding of and approaches to address any potential privacy issues acceptably;
 - iii. a feasible project for being undertaken in the ADRN with the data proposed;
 - iv. a project is of sufficient scientific merit to warrant the use of Network resources; and
 - v. a convincing case is made for potential public benefit.
- 10. All research projects wishing to use ADRN facilities and services to access data whether from academics, government researchers, or researchers from other accredited organisations, will have to undergo this independent review.
- 11. In order to inform these decisions the AP may ask the ADS to approach anyone on a list of experts that will be administered by the ADS. After the initial consultation, the AP may also request further expert views before concluding their review.
- 12. Ethical review of projects will normally be undertaken by a researcher's home institution. For researchers whose home institution does not have an appropriate board, the ADRN will make alternative arrangements.
- 13. The initial assessment of the feasibility and privacy implications of a project will be the responsibility of the ADS, drawing on advice and expertise from the ADRCs and data owners. The ADS will provide the AP with a report on each project outlining ethical review status, feasibility issues, and privacy implications to be taken into account by the AP when making approval decisions regarding the project.
- 14. The AP will have monthly virtual meetings and will meet face to face quarterly. At each meeting all projects in the system should either be: i) approved, ii) rejected, iii) referred to an expert for additional specialist opinion, or iv) returned to ADS/the researcher for further refinement/clarification. Proposals which are referred or returned will ordinarily be reconsidered at the next available meeting.
- 15. The AP will report its rulings to each meeting of the ADRN Board.
- 16. Researchers will have a right to appeal AP decisions. The Appeals Procedure will be available on the ADRN website, and appeals should be submitted to the ADS which may then escalate, where appropriate, to the ADRN Board.

Tanvi Desai and Melanie Wright, Administrative Data Service, 8 May 2014

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(14)11

Definition of an ADRN Project

Purpose

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

Recommendations

- 3. Members of the ADRN Board are invited to:
 - i. note and discuss the content of the paper; and
 - ii. consider whether they approve of the proposed policy for the first active phase of the ADRN (May 2014 to March 2016).

Background

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

Discussion

- 6. It is proposed that an ADRN project needs to meet the following criteria:
 - i. the project is for non-commercial research purposes;
 - ii. the project has evident potential public benefit;
 - iii. there is a demonstrable value from using unit level administrative data to answer the research question;
 - iv. the project would not be more appropriately served by other existing services (e.g. Farr Institute of Health Informatics Research, UK Data Service Secure Lab, Longitudinal Studies, HMRC Data Lab, etc.); and
 - v. the project does not constitute normal operational functions undertaken by government departments or their agencies.
- 7. To be classed as an eligible person to use the ADRN it is proposed that a person must meet the following criteria:
 - i. They must be capable of carrying out the research either independently or under the direction of an appropriate supervisor or lead investigator;
 - ii. They must have completed the ADRN Accreditation Training; and
 - iii. They must be from academia, the public sector or a research organisation on the Research Councils UK list of eligible independent research organisations (http://www.rcuk.ac.uk/funding/eligibilityforrcs/).

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

Tanvi Desai, Administrative Data Service, 8 May 2014.

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(14)12

ADRN Critical Success Factors (CSFs)

Purpose

- 1. At the ADRN Board meeting on the 14 April 2014 the Board discussed and requested information on the ADRN's critical success factors.
- 2. An initial draft of these critical success factors has been drafted by the ESRC in consultation with the ADRN Leadership Team.

Recommendations

- 3. Members of the ADRN Board are invited to:
 - i. note and discuss the CSFs;
 - ii. consider how these can be used to develop metrics and measure success; and
 - iii. consider how key performance indicators could be developed to gauge progress.

Background

4. The CSFs are designed to assist the Board in fulfilling its assurance role to Parliament and more practically when compiling Annual Reports and mid-term reviews. Some of the CSFs are quantifiable and the project managers within the ADRN will be developing indicators to measure success, where possible.

Simon Whitworth, Head of Secretariat and Project Leader, Administrative Data Research Network Board, 23 May 2014

List of Annexes

Annex A ADRN Critical Success Factors

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(14)12

Annex A - ADRN Critical Success Factors

Critical Success Factors

- I. delivery of the ADRN within the overall budget and to time;
- II. a robust, efficient and harmonised operating model for the ADRN, with appropriate safeguards in place;
- III. demand and use managed appropriately and efficiently;
- IV. an engaged and enthusiastic researcher community;
- v. evidence of the impact of the ADRN in terms of unlocking the research potential of administrative data, for the benefit of society and the economy;
- VI. engagement of, and participation by, data owners and statistical agencies;
- VII. public confidence and engagement; and
- VIII. robust and transparent governance.

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(14)13

Communication and Impact Strategy for the ADRN

Purpose

1. This paper presents the draft Communications and Impact Strategy for the ADRN.

Recommendations

Members of the ADRN Board are invited to discuss and comment on the draft strategy, at Annex A.

Background

- 3. The Terms of Reference of the ADRN Board state that the Board will provide "oversight of the Network's public engagement and communications strategy".
- 4. During discussion at its first meeting in April 2014, members noted the importance of joined up communications and that a draft ADRN strategy would be presented to its next meeting in June 2014.
- 5. The initial stages of drafting the strategy was guided and supported by the ESRC communications team, who also provided the strategy template which all managed ESRC investments are expected to follow.
- 6. The ADRN communications working group, which includes representatives from each ADRC and the ADS, together with the ADRN Leadership team, have followed this template and have been preparing a Communications and Impact strategy for the ADRN as a whole.
- 7. Following feedback from the ADRN Board discussion, the ESRC expects to sign-off the strategy, and that each ADRC and the ADS will prepare their own communications and impact plans that fit with the overarching ADRN strategy but highlight their own contexts.

Vanessa Cuthill, Economic and Social Research Council, 28th May

List of Annexes

Annex A ADRN Communications and Impact Strategy (October 2013 to October 2018)

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN(14)13

Annex A - ADRN Communications and Impact Strategy (October 2013 to October 2018)

About the ADRN

The ADRN is a UK-wide partnership between academia, government departments and agencies, national statistical authorities, funders and the wider research community that will facilitate new economic and social research based on routinely collected government administrative data.

The ADRN comprises four Administrative Data Research Centres (ADRCs):

- ADRC-England: led by University of Southampton
- ADRC- Northern Ireland: led by Queen's University Belfast
- ADRC Scotland: led by University of Edinburgh
- ADRC Wales: led by Swansea University

Administrative data refers to information collected primarily for administrative (not research) purposes. This type of data is collected by national and local government and other public sector organisations for the purposes of registration, transaction and record keeping, usually during the delivery of a service.

These data sets also have the potential to be a valuable resource for economic and social research, potentially with a significant impact on policy making and evaluation.

The ADRN will enable *bona fide* researchers to access linked de-identified government administrative data, in order to undertake new research into economic and social issues.

This new research will improve knowledge and understanding of the action required to tackle a wide range of complex social, economic, environmental and health issues, and provide new approaches to the development, implementation and evaluation of policy across government.

Our Vision

To benefit society and quality of life through intelligent use of administrative data Objectives

The impact and communications objectives are:

- I. To instil trust in the ADRN, both by active positive communications and by being prepared to respond to public challenges (reactive communications)
- II. Build awareness and confidence in the ADRN among key stakeholder audiences, particularly amongst data set providers, privacy activists and decision makers

- III. Ensuring the Network 'speaks with one voice' and gives consistent messages in order to promote confidence in, and secure commitment to the ADRN
- IV. To establish and promote the world class reputation of the Network
- V. To encourage active participation in the network from academic researchers and partner organisations
- VI. To work with other organisations, including data sharing initiatives, to ensure compatible messages around data sharing, linkage and use

Audiences

The following table summarises audiences for the strategy.

Urgent Priority (within 6 months)	Important Priority (within 1 year)
Data set providers	Data set providers
 Devolved/ regional 	 Local authorities
Central	
Gov't and parliament	Gov't and parliament
BIS	• EU
 Cabinet office 	National Audit Office
• ICO	• PAC
 Devolved governments 	UKSA
Other funding bodies	Other funding bodies
MRC	
Wellcome Trust	
Public	Public
Media	 Interest/community groups
 Privacy activists 	General
	Young people
National stats authorities	Think tanks and professional bodies (including
	Learned Societies)
Partners of ADRN (internal	International and sister services
communications)	
• Funders	
Stats authorities	
Academic	
Governing board	
Other governance structures	
Other training/ data services	Business/commercial
Key advocates	Other advocates
	Third sector
	Researchers
	Data users Assatzaria
	Academic
	Third sector
	Commercial
	Government
	 Research enablers

Key messages

The key messages aim to be receptive, engaging, involving and collaborative. These are broken down by target audience.

Data set providers/owners

- 1. This is a great way to safely share data without having to do it yourself
- II. You also gain benefits from enabling others to link and research on your data these include maximising the value of your data assets, enabling research which is of interest to you and feeding into the transparency agenda
- III. You will receive quality feedback on your data and enhanced metadata, as well as the use and impact of the data through a two page Plain English Summary of the research
- IV. This is a great way of harnessing expertise in academia on issues you need answered
- V. Using the ADRN will save you the need to set up systems to deal with users directly and will remove the burden of assessment and governance
- VI. But you will still have ultimate 'yeah or nay' control over who accesses your data for what purposes and what it is allowed to be linked to
- VII. We won't stop engaging with you and we are listening to the concerns different people and organisations have
- VIII. The UK statistics authority support and oversee this initiative as it is a government priority

Government

- I. This is a service whose governance has been carefully thought through and will help UK Plc stay at the forefront of research, science and data
- II. All the data is secure
- III. The ADRN is a world leading infrastructure which enables global competitive advantage for UK PLC
- IV. The ADRN provides good value for money
- V. The ADRN forms part of the Chancellor of the Exchequer's announcement of capital funding for the eight Great British technologies in his Autumn 2012 Statement
- VI. Our work is different to care.data including how we are set up and governed, and who we have been engaging with
- VII. All research is directed to public benefit and all results will be freely available and in plain English which could help you inform/evaluate your policies
- VIII. This initiative will enable you to answer many questions you were not able to previously
- IX. We won't stop engaging with you and we are listening to the concerns different people and organisations have
- X. We believe that much more could be accomplished if there was new data sharing legislation

Researchers

- I. Using linked administrative data opens up new horizons of potential research
- II. We have set a processes that if you follow will enable you to access different or new data in the correct way
- III. The ADRN will support you along the process to access data
- IV. Researchers have many responsibilities when accessing and using data
- v. Researchers will benefit from the process by developing new skills, accessing new data, answering questions that were not previously possible and improving society
- VI. You are a key part of this to make this safe and successful
- VII. The ADRN is building a community of responsible and expert data users
- VIII. The ADRN provides a 'one stop shop' for accessing admin data from many different sources; we do the negotiations with multiple data owners on your behalf so you don't have to
- IX. We won't stop engaging with you and we are listening to the concerns different people and organisations have

Public

Note: Need to add examples of the types of data sets which could be used and the research areas this might contribute to

- The ADRN is providing a highly secure way of accessing administrative data; security and confidentiality protection are at the heart of everything we do
- II. The ADRN will benefit society and you as researchers who need access to data help improve our understanding of society and inform good policy
- III. Contrary to what you might believe, government data are not routinely linked; the ADRN is a secure infrastructure that allows linkage to happen in a secure controlled way only for the benefit of the public
- IV. The ADRN will enable researchers to answer questions we couldn't before due to access challenges
- v. Your personal identifying information (names, addresses, NI/NHS number, etc) will be removed from any data set prior to researchers accessing them
- VI. The ADRN has put many security and ethical measures in place
- VII. Everything we do is open and above board you can read all about our policies, procedures and practices, who uses the data and for what purposes
- VIII. The ADRN ensures that all researchers are trained and vetted and there are severe sanctions for misuse of data
- IX. We won't stop engaging with you and we are listening to the concerns different people and organisations have
- X. The ADRN is completely independent of government control, but accountable to the government and UK taxpayers and has the support of government at the highest levels
- XI. This is not commercial and no commercial access is allowed to the data sets
- XII. Your data will be used to answer important societal questions, leading to improvements in the society we live in
- XIII. The ADRN is putting measures in place to ensure all research is for public benefit
- XIV. Our work is different to care.data including how we are set up and governed, and who we have been engaging with

- XV. ADRN works with non-consented data this is important in order to create an accurate picture of the world (policies based on biased data won't be effective), and this is just as safe as any other data [including safe settings, governance, responsible researchers, training and penalties]
- XVI. The ADRN is building on the many best practices and security measures from what has been taking place in academia for a long time
- XVII. The ADRN is accountable and transparent
- XVIII. The ADRN is value for money as it brings all processes together, saves on the costs of rerunning identical surveys
- XIX. The ESRC is providing a long term investments this initiative
- xx. The ADRN collectively has many years of experience in sharing and using data safely

Advocates/Activists

- I. The ADRN policies and procedures are all transparent
- II. The application process is careful, robust and independent
- III. ADRN security standards are fit for purpose and transparent
- IV. ADRN data linkage procedures are secure and transparent
- v. ADRN penalties are severe and enforceable for any misuse or attempted misuse of data
- VI. The ADRN really want to understand your concerns and work to implement appropriate measures
- VII. The ADRN collectively has many years of experience in sharing and using data safely
- VIII. Our work is different to care.data including how we are set up and governed, and who we have been engaging with

Partners of the ADRN (internal communications)

- We are going to keep communication lines open and plan to coordinate activities
- II. We are open and communicative
- III. We want to ensure we are all deploying the same messages

ADMINISTRATIVE DATA RESEARCH NETWORK BOARD

ADRN (14)14

Demand management

Purpose

- 1. This paper outlines a strategy for managing demand within the ADRN.
- 2. The paper highlights the inherent challenge of predicting demand for a new service, and issues relating to assessing the capacity across the ADRN to meet demand. That said, an estimate of capacity for the first year of ADRN operation is included at the end of the paper.

Recommendations

3. Members of the ADRN Board are invited to note and discuss the content of the paper.

Background

4. At its meeting of 14 April, the ADRN Board requested a demand management strategy for the ADRN. The ADRN Leadership Team has produced a strategy, as set out in this paper, for review by the Board.

Discussion

- 5. Fundamentally, we have no indication currently of what will be the scale of emerging demand for a free service when and after it opens.
- 6. In terms of ADRN capacity, although we have included estimates below in terms of number of projects, these do not take into account the diversity of projects. The time taken to complete a project is very variable, depending on: the size and complexity of the project/dataset; the length of the project development and researcher training stages, as well as the research stage; and the time taken to secure permission from data owners to access data (the burden on ADRCs in respect of negotiating for data access can be minimised if ADRCs make full use of the service offered by the ADS).
- 7. There are also issues to be considered around workload management. The regularity of the flow and size of the projects will be as important as the number in determining what constitutes high or low demand. For example evidence from the Centre for Longitudinal Study Information and User Support (CeLSIUS) team indicates that there is a spike in demand during the Easter holidays with the lowest demand being during the first week of January.
- 8. Key demand management controls may include i) waiting time and ii) convenience of appointment (notably location for accessing secure settings).

9. The table below sets out a range of demand scenarios and how the ADRN might respond. Funding for the ADRN is finite and has been allocated over a five year time horizon (for physical and e-infrastructure, and staff time), thus, if demand exceeds ADRN capacity, there are limited options and these mostly relate to reducing or slowing demand.

Scenario	Management Strategy
Low demand (remaining low)	 Investigate reason(s) for low demand, including perceptions of the service (in particular, is the perception of the user journey a barrier?) Awareness raising activities and events Consider 'tweaking' user journey – if resourcing and governance restraints permit
High demand (remaining high)	 Prioritisation by Approvals panel against agreed set of criteria Manage expectations among research community re: excess demand, waiting times, etc
Initial low demand, (rising sharply to high demand)	 Accelerate training and capacity building activities 'Smooth' capacity across ADRCs (ie optimising use of each Centre)
Initial high demand, (falling sharply to low demand)	Investigate reason(s) for drop in demand, especially in relation to user journey experience
Steady rise	Implement capacity building strategy – eg PhD studentships, etc

10. Estimates of ADRN capacity indicate that approximately five to ten projects per year per ADRC would be low, with twenty to thirty projects per year being maximum capacity. The exception is England where extra ONS capacity in its role with government will increase the maximum capacity for ADRC-E. Staff numbers at the ADRCs reflect these capacity estimates. These estimates and assumptions will be reviewed in October 2015 (after the first year of operation).

Tanvi Desai, Administrative Data Service and Susan Cassell, ESRC, 29 May 2014

The Data Journey

Presentation

Ms Melanie Wright

Any Other Business