Twelfth Meeting of the
National Statistician's Data Ethics Advisory Committee

Minute, Agenda and Papers

Tuesday 24 April 2018

10:30 – 14:15

Board Room, UK Statistics Authority
London

UK STATISTICS AUTHORITY

NATIONAL STATISTICIAN'S DATA ETHICS ADVISORY COMMITTEE

Agenda

Tuesday 24 April 2018
Board Room, Drummond Gate London
10:30am – 2:15pm

Chair: Dame Moira Gibb

Apologies:

(10:30am to 12:10pm)

1 10:30 am	Welcome and introductions	NSDEC Chair
2 10:45 am	Minute and matters arising from the previous meeting	NSDEC Chair
3 11:50 am	Update to the NSDEC Terms of Reference	NSDEC(18)09 Simon Whitworth
4 10:55 am	Digital Economy Act and NSDEC	Oral report Ross Young
5 11:15 am	Investigating suicide risk among high risk occupations using coroners' inquest records in England	NSDEC(18)10 Ben Windsor-Shellard
6 11:30 am	Census–Refugee Matching: Feasibility study, 2009 cohort	NSDEC(18)11 Steve Bond
7 11:45 am	Update on IDEAS	Oral report Jon-Wroth Smith

Lunch (12:10am to 12:35pm)
(12:35pm to 2:15pm)

8 12:35 pm	GDS: Update on the Data Ethics Framework	Oral report Sarah Gates
9 01:00 pm	Linking reconvictions data with offender risk assessment data to inform the evidence base on reducing reoffending	NSDEC(18)12 Phillipa Haxton
10 01:15pm	Using mobile phone data for research and statistics	Oral report Susan Williams
11 01:35 pm	MRP: Measurement of Vulnerability of Children and Young People in England	NSDEC(18)13 Peter Stokes
12 01:50 pm	MRP: Understanding the split between NHS and non-NHS income for community pharmacies	NSDEC(18)14 Peter Stokes
13 02:00 pm	MRP: Projects considered via precedent	NSDEC(18)15 Peter Stokes
14 02:10 pm	Any other business	

Next meeting: Tuesday 24 July 2018
Location: One Drummond Gate, London

National Statistician's Data Ethics Advisory Committee

Minute

Tuesday, 24 April 2018
Board Room, Drummond Gate, London

Present
Members
Dame Moira Gibb(Chair)
Mr Stephen Balchin
Mr Robert Bumpstead
Ms Vanessa Cuthill
Mr Keith Dugmore
Mr Colin Godbold
Ms Annie Hitchman
Dr Brent Mittelstadt
Ms Isabel Nisbet
Ms Marion Oswald
Dr Emma Uprichard

UK Statistics Authority
Dr Simon Whitworth
Mr Petros Saravakos

Office for National Statistics
Mr Ben Windsor-Shellard (for item 5)
Mr Steve Bond (for item 6)
Mr Jon Wroth-Smith (for item 7)
Ms Susan Williams (for item 10)
Mr Adil Deedat (for items 11, 12 and 13)
Mr Nick O'Donnell (for items 11, 12 and 13)

Other
Ms Sarah Gates, Department for Culture Media and Sport (for item 8)
Mr Thom Townsend, Department for Culture Media and Sport (for item 8)
Ms Phillipa Haxton, Scottish Government (for item 9)

Apologies

1. Welcome and introductions

1.1. As it was the Chair's first meeting the Chair introduced herself to the committee members and the rest of committee introduced themselves to the Chair.

2. Minutes and matters arising from the previous meeting

2.1. Members were informed that the minute of the eleventh meeting had been agreed by correspondence. The minute, agenda and papers from the last meeting are now published on the UK Statistics Authority website.

2.2. The Chair invited the NSDEC Secretariat to provide an update on projects previously considered by NSDEC. The meeting heard that the project proposal which looks to measure the quality of, and further develop a tool to estimate ethnicity from names was still undergoing revisions. All other projects had been revised and signed off by the Secretariat.

2.3. Members also heard that four previously approved projects had published the outcomes of their research.

3. Update to the terms of reference [NSDEC(18)09]

3.1. Dr Simon Whitworth introduced an update on the terms of reference which had been amended to reflect recent changes. These changes included:

i. the inclusion of a precedent process as a method of ethical consideration for projects via the Approved Researcher Scheme which are similar to projects previously approved by NSDEC;
ii. the production of an annual report of NSDEC's activities which would be included in the National Statistician's annual report on data access and sharing; and
iii. a change of name of the Virtual Microdata Laboratory to the Secure Research Service.

3.2. The Secretariat was asked to make it clear that NSDEC had sight of projects approved via precedent but did not consider these projects.

Action: The NSDEC Secretariat to amend the terms of reference according to feedback by NSDEC members.

4. Digital Economy Act and NSDEC

4.1. Dr Whitworth provided an update on the Digital Economy Act 2017 (DEA). The meeting was informed that the DEA provides:

i. a statutory right of access for UKSA to information held by Government Departments, other public authorities, and large/medium-sized undertakings (businesses and charities) where the information is required to support any of UKSA's functions;
ii. a new gateway to permit UKSA to share information with statisticians in the devolved administrations to support the production of devolved statistics and the production of consistent statistics in the UK as a whole; and
iii. a new statutory framework to support the UK research community, both within government and beyond, that permits public authorities to share de-identified information with accredited researchers for the purposes of public good research.

4.2. Members heard that the UK Statistics Authority would be the statutory body overseeing the accreditation of researchers, projects and processors and secure access environments. NSDEC would play a pivotal role in ensuring that access to data meets the highest ethical standards.

4.3. Members identified that the relationship between NSDEC and the Research Accreditation Panel (RAP) would be a key relationship in the future and suggested that the chair of the RAP should be invited to attend a future NSDEC meeting to present their work.

5. Investigating suicide risk among high risk occupations using coroners' inquest records in England [NSDEC(18)10]

5.1. Mr Ben Windsor-Shellard, from the ONS Life Events team, presented a project to link identifiable ONS mortality data to coroner's inquest records. It was reported that this would enhance the evidence base about suicides among occupations which have high mortality risks. It was reported that this research was based on previous analysis undertaken by the ONS Life Events teams and aimed to understand why some occupations experience higher mortality risks due to suicide.

5.2. The following points were made in the discussion that followed:

i. Given the sensitivity of the data used in the research it was considered important that support is provided to the researchers. Mr Windsor-Shellard informed members that in similar project a support helpline, staffed by the Samaritans, was provided and this could also be put in place for this project.
ii. The language in the application should be amended to make it clear that no causality can be inferred about the relationship between occupations and suicide risk.
iii. Members recommended that the data should only be retained for as long as it is needed for the specific research purposes in the application.
iv. The committee sought clarity as to why the sample was restricted to 20 to 65 year olds. Members were informed that this was due to the limitations of the data sources used in the proposed analysis and this provided a large enough sample to ensure to reduce any biases in the data. It was suggested that this explanation should be included in the application.

5.3. This project was approved subject to minor revisions

Action: Mr Ben Windsor-Shellard to:

i. clarify in the application whether additional support mechanisms will be offered to researchers to mitigate any risk of harm;
ii. amend the application to explain why the specific age group was selected;
iii. limit the data retention period and provide justification for the retention period selected; and
iv. amend the language in the application to ensure that no causality is inferred between occupations and risk of suicides.

6. ADRN: Census–Refugee Matching: Feasibility study, 2009 cohort [NSDEC(18)11]

6.1. Mr Steve Bond, from ONS Data as a Service, introduced a feasibility study commissioned by the Home Office which involved ONS linking ONS 2011 Census data to one year's Home Office Asylum grant data (2009) within the Secure Research Service and providing aggregate data on linkage rates to inform possible future Home Office data linkages between asylum grant data and administrative data.

6.2. Members rejected this proposal as the public benefit from doing this work was not clear and no engagement had taken place with groups representing asylum seekers.

7. Update on IDEAS

7.1. Mr Jon Wroth-Smith, from ONS Data as a Service, presented an update on developments on the Integrated Data Enabling Analysis and Statistics (IDEAS). The meeting was informed that IDEAS aimed to enable a more systematic data linkage within ONS, by storing separate de-identified data sets in such a way that they can be consistently and coherently joined together.

7.2. Members heard that the ways of public engagement were considered carefully as there are both benefits and potential sensitivities from this approach. Mr Jon Wroth smith also informed the committee that there is ongoing work to manage areas with opt outs. Members requested to see the Privacy Impact Assessment for IDEAS.

Action: Mr Jon Wroth-Smith to share the Privacy Impact Assessment with NSDEC.

8. Department of Culture, Media and Sport (DCMS): Update on the Data Ethics Framework

8.1. Ms Sarah Gates, from the Department of Culture, Media and Sport, provided an update on the second iteration of the Government Digital Service (GDS) data ethics framework. The meeting heard that the GDS data ethics framework provided practical advice for analysts to ensure that "good" data science was practiced across Government.

8.2. Members noted that in comparison to NSDEC's ethical principles the GDS placed less emphasis on public good, consent, and public acceptability. Members highlighted that he updated framework only required consideration of the law and there was no explicit need to consider human rights principles. NSDEC welcomed the fact that the role of NSDEC in providing ethical guidance to researchers within the GSS was recognised.

9. Linking reconvictions data with offender risk assessment data to inform the evidence base on reducing reoffending [NSDEC(18)12]

9.1. Ms Phillipa Haxton from Justice Analytical Services of the Scottish Government presented a project to link criminal proceedings data held by the Justice Analytical Service (JAS) and risk assessment data held by the Risk Management Authority (RMA) to assess the risk of reoffending posed by offenders and allow policy planning for support services.

9.2. NSDEC heard that the project will not be used to make predictions or decisions about individuals. Members suggested that more safeguards are put in place to prevent the re-identification of individuals from the anonymised extracts given that criminal proceedings data are already in the public domain.

9.3. Members heard that the Scottish Government and the Risk Management Authority will be joint data controllers of this data. It was suggested that more clarity is required on the role of RMA in this project. It was also stated that the statistical research should be clearly separated from any future operational use of the data which would not be considered by NSDEC given that NSDEC's remit was to provide ethical guidance around the ethics of data use for research and statistics.

9.4. Members recommended that more work is required on the legal aspects of the project and this should be reflected in the language used in the application to explain the legal basis for the research. Public acceptability work should also be carried out to determine the views of the public on this proposed project.

9.5. This project was approved subject to minor revisions

Action: Ms Haxton to:

i. provide more clarity on the legal basis of this project;
ii. introduce additional measures to ensure that the identity of data subjects is adequately protected;
iii. undertake more work to understand public perceptions of the project; and
iv. clarify in the application the role of RMA and clearly separate statistical research from any potential operational use of the data.

10. Using mobile phone data for research and statistics

10.1. Ms Susan Williams, from ONS Big Data Team, and Mr Darran Tucker, from the Admin Data Programme, presented some early thinking on the opportunities that existed for ONS to use mobile phone data for the production of research and statistics for the public good. The meeting also heard about some of the methodological and ethical challenges that the use of this data presents.

10.2. Members suggested that a task and finish group should be established to develop a policy to ensure the consistent, legal and ethical use of mobile phone data for the production of statistics and research for the public good. The scope of the policy should not be limited to ONS but apply across the GSS. This policy should be considered by NSDEC at a future meeting.

Action: Ms Williams to work with the NSDEC secretariat to establish a task and finish group and present a policy a future meeting for further consideration.

11. MRP: Measurement of Vulnerability of Children and Young People in England[NSDEC(18)13]

11.1. Mr Nick O'Donnell and Mr Adil Deedat presented a proposal referred to NSDEC by the Microdata Release Panel. This proposal by Alma Economics, an economic consultancy company, was commissioned by the Children's Commissioner for England.

11.2. The study uses data from the ONS Crime Survey of England and Wales (both adult and 10-15 module) on the number of children in England who face different types of vulnerability. This includes 32 types of vulnerability as defined by the Children's Commissioner for England.

11.3. The meeting heard that any analysis would be at a Government office region and all outputs from the secure environment, in which the analysis will take place, will be aggregate outputs which would be subject to strict disclosure controls to ensure that the no individual could be identified.

11.4. This project was approved subject to minor revisions.

Action: Mr O'Donnell to:

i. amend the application to ensure that the statistical disclosure controls and geographic level of the outputs are reflected in the application; and
ii. provide more detail on whether the Crime Survey of England and Wales captures information about online crime.

12. MRP: Understanding the split between NHS and non-NHS income for community pharmacies[NSDEC(18)14]

12.1. Mr O'Donnell presented a project by London Economics, a specialist policy and economics consultancy, commissioned by the Department of Health and Social Care (DHSC), to update and validate the Reference Pharmacy model. The Reference Pharmacy model is a financial modelling tool used by DHSC to provide insight on the commercial viability of the community pharmacy sector.

12.2. The meeting heard that the research would not just focus on the most deprived areas based on the Multiple Deprivation Index but instead would take a wider view on community pharmacies. Members suggested that this should be reflected in the application.

12.3. Members also noted that there was no information in the application on how the DHSC model would be used to inform the development of policy. This should be added into the project application.

12.4. This project was approved subject to minor revisions.

Action: Mr O'Donnell to:

i. amend the language of the application to make clear that the project will not focus on specific geographical areas based on the Multiple Deprivation Index; and
ii. provide more detail on the Reference Pharmacy model developed by DHSC.

13. MRP: Projects considered via precedent[NSDEC(18)15]

13.1. Members agreed that the precedent tables included in this meeting's papers will be reviewed by correspondence.

Action: The NSDEC Secretariat to circulate the precedent tables via correspondence and provide any feedback to the Microdata Release Panel.

14. Any other business

14.1. There was no other business.

1. 2. 3. 4. 5. 6. 7. 8. 9. 10 11. 12

National Statistician’s Data Ethics Advisory Committee

Minute

Tuesday, 16 January 2018
Board Room, Drummond Gate, London

Present
Members
Mr Ian Cope (Chair)
Ms Vanessa Cuthill
Mr Keith Dugmore
Mr Colin Godbold
Ms Annie Hitchman
Dr Brent Mittelstadt
Ms Isabel Nisbet
Ms Marion Oswald

UK Statistics Authority
Dr Simon Whitworth
Mr Petros Saravakos

Office for National Statistics
Ms Fiona Aitchison (for item 3)
Mr Neil Bannister (for items 4 and 5)
Mr Peter Fullerton (for item 8)
Mr Owen Abbott (for items 9 and 10)
Mr Steve Bond (for items 12 and 13)
Mr Nick O’Donnell (for item 14)
Mr Jonathan Tinsley (for item 15)

Other
Mr Paul Jackson and Mr Leon Feinstein (for item 6)
Mr Nicholas Dodd (for item 7)
Mr Glyn Jones (for item 11)

Apologies
Professor Martin Severs
Mr Robert Bumpstead
Dr Emma Uprichard

1. Minutes and matters arising from the previous meeting

1.1. The Chair welcomed members to the eleventh meeting of the National Statistician’s Data Ethics Advisory Committee (NSDEC).

1.2. Members were informed that the minute of the eleventh meeting had been agreed by correspondence. The minute, agenda and papers from the last meeting are now published on the UK Statistics Authority website.

1.3. The Chair updated the meeting with progress on actions from previous meetings. Most actions were complete or in progress and would soon be complete.

2. Chair's report

2.1. The Chair provided members with an update on projects previously considered by NSDEC. The meeting heard that all projects which received major revisions in the previous meeting had been revised and these projects would be presented at this meeting.

2.2. Members received an update on the ongoing engagement between the NSDEC secretariat and staff from the Department for Culture Media and Sport (DCMS) about the development of the Centre for Data Ethics and Innovation to enable and ensure safe, ethical and ground-breaking innovation in Artificial Intelligence and data-driven technologies. The secretariat had also participated in a series of workshops organised by the Government Digital Service (GDS) to provide feedback on the next iteration of the GDS Data Ethics Framework, expected to be formally published within the next month.

2.3. The meeting also heard that the NSDEC Secretariat had provided advice on setting up an ethics committee to the West Midlands Police (WMP), who are establishing an independent ethics committee which will advise the Commissioner and the Chief Constable on whether proposed data analysis projects meet certain ethical standards.

2.4. The Chair concluded his report by informing members that Osama Rahman will be stepping down from NSDEC after two and a half years. The meeting was also informed that the Chair will be shortly starting a secondment to Stats New Zealand and thus he will be stepping down as NSDEC Chair after two and a half years. A new chair will be appointed by the National Statistician in due course.

3. Ethical review of the Crime Survey of England and Wales [NSDEC(18)01]

3.1. Ms Fiona Aitchinson, from the ONS Crime Team, presented a re-submitted application to review the Crime Survey for England and Wales (CSEW), a well-established ONS survey conducted by a third party (Kantar Public) on behalf of ONS.

3.2. Members agreed that significant improvements had been made in this application. However, they suggested that the following further improvements should be made:

i. ONS should collaborate with the National Society for the Prevention of Cruelty to Children (NSPCC) to strengthen the language in the supporting material and advance letter to make clear the voluntary nature of the survey;

ii. members requested more clarity on how parental consent was obtained for survey participants between 16-17 years old;

iii. the committee asked for further assurance that survey participants were only re-contacted when they had provided their permission to do so; and

iv. members recommended that it be made clear to respondents that information would be passed to other research organisations only if respondents opted to be re-contacted for further research.

3.3. This project was approved subject to minor revisions.

Action: Ms Aitchison to update the application to:

i. ensure that informed and voluntary consent is obtained, especially when parental consent is required, and this is clearly communicated to participants in the advance letter;

ii. clarify in the application how parental consent is acquired for participants aged between 16-17 years old;

iii. provide assurance that the confidentiality of data subjects is protected and that participants cannot be re-contacted without their permission after completing the survey; and

iv. consult with NSPCC to make clear the voluntary nature of the survey in the advance letter.

4. Linking mortality and prescription data [NSDEC(18)02]

4.1. Mr Neil Bannister, from the ONS Life Events team, and Ms Margaret Dockey, from the NHS Business Services Authority (NHSBSA), presented an updated proposal to conduct a feasibility study to develop an evidence base to investigate the relationship between suicide statistics and prescription drugs.

4.2. The meeting heard that no information about specific drugs would be disclosed in any research outcomes, which would be subject to strict ONS mortality statistical disclosure controls.

4.3. Members were satisfied with the proposed confidentiality safeguards put in place by ONS but requested more assurances regarding the training and accreditation of the research team and the confidentiality safeguards in place at NHSBSA.

4.4. The meeting requested that Mr Bannister also liaise with the NHS Health Research Authority to determine if the project would require additional ethical approval by a health research ethics committee.

4.5. This project was approved subject to minor revisions.

Action: Mr Neil Bannister to work with NHSBSA to:

i. clarify whether the Health Research Authority (HRA) would need to consider the ethical aspects of the research via a research ethics committee; and

ii. clearly articulate in the application the level of accreditation and training of researchers from NHS Business Services Authority (NHSBSA) as well as the confidentiality safeguards in place in NHSBSA.

5. Linking suicide deaths data to Higher Education Student Registry Data [NSDEC(18)03]

5.1. Mr Neil Bannister presented a proposal to link individual higher education record data to suicide mortality data to improve the quality of information around student suicides. This information would provide better intelligence to relevant public health and higher education bodies to help prevent student suicides and feed into national policy around suicide prevention measures (e.g. National Suicide Prevention Report).

5.2. Members required more information on how students are defined within the scope of this research project. This should also provide assurances that minors are not included given that some higher education institutions follow more flexible admission age criteria.

5.3. The meeting heard that any research outcomes will be presented at a regional level subject to ONS statistical disclosure controls to prevent the re-identification of data subjects. These statistical disclosure controls should be made clear in the application.

5.4. This project was approved subject to minor revisions.

Action: Mr Neil Bannister to make clearer in the application:

i. how students are defined and ensure that minors are not included in the age groups examined; and

ii. how the risk of re-identification is mitigated by applying appropriate disclosure controls.

6. ADRN: Developing persistent dataset for projects within the Data for Children research theme

6.1. Mr Paul Jackson, from the Administrative Data Research Network (ADRN), and Mr Leon Feinstein, Director of Evidence for the Children’s Commissioner for England, presented on the thematic ADRN proposal, Data For Children, to create a persistent dataset by linking data from the National Pupil Database and other sources.

6.2. The linked dataset, stored in a secure research environment, would potentially enable research into the household, family, social, educational, and economic determinants of different life outcomes for children.

6.3. Members were supportive of the suggested approach for research in the public good but recommended additional exploration on the public acceptability of this initiative and additional information on the future role of NSDEC in providing ethical oversight of the resulting projects which used the linked data.

Action: Dr Simon Whitworth to discuss with Mr Paul Jackson the potential role of NSDEC in providing ethical oversight for potential projects using this dataset.

7. Update on the Ethics Commission on Data Use

7.1. Mr Nick Dodd from the Data Use and Ethics team in DCMS provided an update to the NSDEC members on the recent developments in establishing the Centre for Data Use and Innovation.

7.2. Members heard of the potential to develop collaborative relationship between NSDEC and the new body and offered advice on establishing the new body given their extensive experience in a variety of research ethics subjects.

8. Self-assessment process for ethical consideration

8.1. Mr Peter Fullerton, from the ONS Data Science Campus, and Mr Petros Saravakos presented an update on the plans to develop a process of ethical self-assessment based on the NSDEC principles and precedents established over the past three years. The self-assessment, would be used across ONS to identify ethical issues in research projects and determine which projects require further ethical consideration by NSDEC. Self-assessments would be reviewed by senior managers and the NSDEC secretariat, to ensure that robust, consist decisions are reached. Researchers would receive training to enable them to complete the self-assessment.

8.2. It was reported that the NSDEC secretariat had tested the process in several ONS research areas and received positive feedback. The process was presented to the Data Governance Committee who were supportive of the suggested approach. The meeting heard that the ONS Chief Security Officer had endorsed the proposed self-assessment framework as a necessary and sensible way forward.

Action: The NSDEC Secretariat to:

i. present the outcomes of the self-assessment six-month pilot to future NSDEC meetings; and

ii. arrange for an audit of the piloted projects by one or two committee members to ensure its consistency.

9. Ethical guidelines for social media research[NSDEC(18)04]

9.1. Mr Owen Abbott, from the ONS Big Data team, presented early work on the development of a policy to set out the practices and procedures that ONS staff would follow if using social media data for research and statistical purposes. Any policy would be developed in line with the NSDEC ethical principles.

9.2. Members recommended that the policy should provide clear guidance to researchers on:
   i. the legal frameworks which allow access to the data;
   ii. the retention of social media data;
   iii. mitigating re-identification risk via data linkage;
   iv. assessing the privacy impacts; and
   v. general robust assurance about the use of social media data to safeguard public trust and confidence.

Action: Mr Abbott to work with the NSDEC Secretariat to establish a task and finish group to address the NSDEC comments and present a policy at a future meeting for further consideration.

10. Ethnicity from names [NSDEC(18)05]

10.1. Mr Abbott provided an update on the project proposal which looks to measure the quality of, and further develop a tool to estimate ethnicity from names. The project will be run in collaboration with University College London (UCL).

10.2. Members were satisfied with the progress that had been made since they last discussed the project. Members suggested that the application should provide more information on the predictive accuracy of the estimates produced by the tool. Mr Abbott reassured the committee that the tool would provide information about the accuracy of the estimates produced and was more accurate than commercially available software.

10.3. Members agreed that the project could proceed subject to:
   i. further engagement with other population groups to provide them with the opportunity to feedback on the tool; and
   ii. completion of the additional security testing of the tool and the hosting website.

10.4. This project was approved subject to minor revisions.

Action: Mr Abbott to:
   i. liaise with other population groups to provide them with the opportunity to feedback on the tool; and
   ii. ensure that additional security testing of the tool and the hosting website is completed before the project can proceed.

11. ADRN - An Exploratory study for estimating the outflow of Welsh Speakers from Wales to England from the 2011 Census and the Patient Register [NSDEC(18)06]

11.1. Mr Glyn Jones presented a re-submitted proposal to link 2011 Census to Patient Register data in England to estimate the outflow of Welsh speakers from Wales to England. The meeting heard that the project was of considerable importance to public authorities and the general public in Wales.

11.2. Mr Jones assured the committee that statistical disclosure controls were in place and results would be presented at a high enough geographical level to fully mitigate against any risk of re-identification.

11.3. Members also recommended that the project outcomes should not be used to inform national and local policy in a way that would disadvantage other population groups. Mr Jones informed the committee that a wide array of sources would be used to avoid any direct or indirect dis-benefits to population groups outside the scope of this research.

11.4. The committee approved this project.

12. ADRN – Identifying household and family risk factors for hospital admissions in children [NSDEC(18)07]

12.1. Mr Steve Bond, from ONS Data as a Service, presented a proposal by University College London, via the Administrative Data Research Network, to examine environmental, household and risk factors for hospital admissions in children. It was reported that the research would be conducted within the ONS Secure Research Service and would use a linked dataset comprising of Hospital Episode Statistics, ONS birth and death registration data and NHS birth notification data.

12.2. The committee approved this project.

13. Social and Economic Predictors of the severe mental disorders, the SEP-MD study [NSDEC(18)08]

13.1. Mr Steve Bond presented a proposal by Kings College and South London and Maudsley Trust, via the Administrative Data Research Network, to link census data to electronic Patient Records to assess mental health inequalities within the Trust's area and to inform the development of social and public health interventions.

13.2. Members suggested that any consent arrangements currently in place should also comply with the updated Caldicott Principles. Furthermore, members recommended that the application should provide further clarity on whether minors would be included in the study and improve the language in the application so as not to confuse correlation and causality.

13.3. The meeting heard that the dataset would be retained in the Secure Research Environment for 12 months after producing the linked dataset. Members noted that the proposed retention period was not proportional to the three year length of the study and suggested that the application considered a longer retention to ensure the availability of data throughout the project life cycle and the reproducibility of the outcomes of the study.

13.4. This was approved subject to minor revisions

Action: Mr Bond to:

i. provide more information on whether the proposed arrangements regarding consent meet the Caldicott principles;
ii. tighten the language in the application and the title;
iii. clarify whether minors are included in the research; and
iv. provide more clarity on the retention of the data to ensure it is proportional to the duration of the project.

14. MRP: Transport Model development for West Berkshire Council [NSDEC(18)09]

14.1. Mr Nick O'Donnell presented a proposal referred to NSDEC by the Microdata Release Panel which was made by WSP, a global professional services firm, to use de-identified 2011 Census travel to work data in the SRS together with aggregate GPS data from mobile phone networks and traffic survey data. This project aimed to inform the development of local transport policy and evaluate current plans in line with West Berkshire Council's local transport model plan.

14.2. The committee approved this project.

15. Ethical considerations of ONS acquisition of NHS Digital Data

15.1. Mr Jonny Tinsley invited the committee to advise on the ethical aspects of using activity and clinical data from the Hospital Episodes Statistics dataset for research and statistical purposes. ONS could access this data using the legal gateway provided by the Statistics and Registration Service Act 2007 as amended by the Digital Economy Act 2017.

15.2. The meeting heard that the acquisition of health data to produce new and improved existing statistical outputs presented a wide array of potential significant public benefits. Mr Tinsley reassured the committee that all projects using these datasets will be subject to ethical consideration by NSDEC.

15.3. Members recommended further engagement with the public to capture their views on the acquisition and use of datasets containing clinical data. It was suggested that it was important that ONS was transparent in communicating the potential benefits of research projects using this data.

16. Any other business

16.1. The Committee thanked Mr Ian Cope for his work as chair of NSDEC.

UK Statistics Authority

National Statistician’s Data Ethics Advisory Committee

NSDEC(18)09

Updated terms of reference of the National Statistician’s Data Ethics Advisory Committee

Purpose

1. This paper presents some updates to the National Statistician’s Data Ethics Advisory Committee’s (NSDEC) terms of reference. These updates are presented in red in Annex A.

Recommendations

2. Members of NSDEC are invited to consider and agree the proposed updates to the terms of reference.

Background

3. The terms of references of NSDEC are updated to include the following:
    i. the introduction of the precedent process as a method of ethical consideration for projects via the Approved Researcher Scheme which are similar to projects previously approved by NSDEC;
    ii. NSDEC will provide an annual report of its activities in the National Statistician’s annual report on data access and sharing; and
    iii. a change of name of the Virtual Microdata Laboratory to the Secure Research Service.

4. The Secretariat has updated the terms of reference and an updated version is presented at **Annex A**. The terms of reference will be reviewed as part of NSDEC’s self-assessment later in the year.

Simon Whitworth, NSDEC Secretariat, UK Statistics Authority, 16 April 2018

List of Annexes

Annex A: Updated NSDEC Terms of Reference

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Annex A: Updated NSDEC Terms of Reference

UK Statistics Authority

National Statistician's Data Ethics Advisory Committee

Terms of reference

Introduction

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

Role and responsibilities

2. The role of the National Statistician's Data Ethics Advisory Committee (NSDEC) is to advise the National Statistician on the ethical considerations concerning the accessing, sharing and use of data.

3. Specific responsibilities of the NSDEC include to:

   i. provide ethical consideration of proposals to access, share and use data;
   ii. advise on individual policies and research projects against NSDEC's ethical principles;
   iii. develop a consistent ethical framework for relevant projects related to official statistics;
   iv. promote transparency around data shares;
   v. provide ethical approval for some government, and third sector researchers who wish to use ONS data for research and statistics that serves the public good;
   vi. provide ethical approval for proposals to access ONS data from the commercial sector via the Approved Researcher Scheme. These requests are referred to NSDEC for ethical consideration by the Mircrodata Release Panel (MRP) which governs access to the Secure Research Service (SRS); and
   vii. provide ethical advice on other data issues within the National Statistician's remit, which includes his role as head of the Government Statistical Service.

4. At the invitation of the Chair of the Administrative Data Research Network (ADRN), provide ethical consideration for government and third sector researchers wishing to access data via the ADRN. These requests are referred to NSDEC by the ADRN Approvals Panel.

5. In reviewing proposals NSDEC will provide advice by consensus.

6. To facilitate timely access to data NSDEC can consider proposals referred to it
   i. by the MRP or the ADRN Approvals Panel via correspondence; or
   ii. by the MRP via precedent.

Meetings

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

8. The Chair may invite other relevant experts as appropriate to advise the committee.

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Reporting

9. NSDEC will provide reports following each of its meetings to the National Statistician.

10. At least seven days prior to its meetings, NSDEC will receive reports on:
    i. proposed new data shares;
    ii. relevant projects and programmes and other information as it requires; and
    iii. reports from any sub-committees.

11. NSDEC will operate transparently. Meeting agendas, papers and minutes will be made publicly available on the UK Statistics Authority website.

12. Where expedited review is sought and NSDEC approve the proposal by correspondence, the application and summary of members' comments will be presented at NSDEC's next meeting and published as part of the meeting papers.

13. Where projects are approved via precedent, the precedent tables will be presented at NSDEC's next meeting and published as part of the meeting papers.

14. NSDEC will provide an annual report on its activities in the National Statistician's annual report on data access and sharing.

Membership and role of members

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

Quorum

16. NSDEC meetings will be considered quorate when four or more members are present including at least two independent external members as well as the Chair or the Chair's delegated nominee.

17. Substitutes will not be permitted to attend meetings, unless with the invitation of the Chair.

18. In order for any expedited proposal to be formally approved by correspondence a sufficient number of members would need to respond in accordance with a quorate meeting.

Secretariat

19. Secretariat for the NSDEC will be provided by the staff from the Central Policy Secretariat within the UK Statistics Authority.

Review

20. NSDEC will review the effectiveness of its meetings and its terms of reference annually.

Digital Economy Act 2017 and

National Statistician’s Data Ethics Advisory Committee

Oral report

Ross Young

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National Statistician's Data Ethics Advisory Committee

Application for Ethical Review

Please consult the guidance document before filling in the application form

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Project Title

Please provide a title indicative of the project

Investigating suicide risk among high risk occupations using coroners' inquest records in England, focusing on deaths registered between 2011 and 2015

Start Date:	01/06/2018	**End Date:**	31/05/2019

Project Sponsor(s)

Please list the project sponsor(s)

Office for National Statistics (ONS)

Project Summary

Please provide a brief high level summary of the research giving necessary background (max 250 words)

ONS recently published a report on suicide by occupation in England for deaths registered between 2011 and 2015. The findings fed into the government's suicide prevention strategy for England by identifying groups of individuals with whom to focus suicide prevention measures.

This study aims to further investigate the risks *associated* with suicides among occupations we found in our research to have the highest risks, namely, low skilled labourers in construction, care workers and home carers, and those working in arts-related occupations. Little is currently known about why these occupations have high risk suicide risk compared to that found in the general population. For instance, it could be that the occupation itself produces the high risk. Alternatively, it could be the case that a variety of different, and complex, factors, impact the suicide risk. This study hopes to provide further clarity on the risks we found in our previous research.

To meet our aims, we will collect data from coroners' inquest records, sampling from the deaths included in our published National Statistics. Inquest records are a rich source of qualitative data; they contain rich demographic information, and detailed accounts on the circumstances surrounding the death. We are hopeful that the study will provide data on risk factors such as the misuse of alcohol and drugs, access to a method of suicide, job instability/debt, return to work following a period of sickness absence, recent bereavement, and exposure to suicide (e.g., through their work). The collected data will be used to address our main research question; can we identify specific risk factors associated with occupations at high risk of suicide?

It is anticipated that the results of the study will further contribute to the government's suicide prevention strategy, inform suicide prevention measures, and will be published on the ONS website as an article with aggregated tables.

Section A
Project Details

A1 Legal gateways

Please provide the assessment of the legal gateways of the project as provided by Legal Services

Data from coroners can be used for research purposes by gaining their consent. Coroners have full ownership of their data, and it is common for coroner's records to be used for research purposes (see here for an example, section on "genealogy/past cases"). We will request consent from coroners after ethical approval has been gained (see Section B3), and some of the coroners will be those with whom we have previously collected data for a separate study.

The Statistics and Registrations Service Act (2007) applies to this work. This allows ONS to use deaths registrations data, provided by the Register General, for statistical purposes. The proposed research supplements our existing mortality data with information collected for coroners' inquests. Further information on the legalities is detailed in Section B5.

A2 Ethical approval

Has the project being reviewed or is it expected to be reviewed by another ethics committee? ○ **Yes** ● **No**

If Yes please provide the name of the committee, the outcome and the date approved

A3 Proposed site of research select all that apply

☑ ONS	☐ ADRC - England
☐ SRS (formerly VML)	☐ ADRC - Scotland
☐ HMRC Data Lab	☐ ADRC - Northern Ireland
☐ Other	☐ ADRC - Wales

please specify

A4 Data subjects to be studied

Does the study include all subsections of the population (i.e. all ages, sex, ethnic groups etc?) ○ **Yes** ● **No**

If no please detail which subsections with justification(s) below:

Subsections of the population (including vulnerable groups) the project focuses on:

Given the number of suicides registered in the period between 2011 and 2015 (13,232), it is necessary to restrict data collection so that the study focuses on occupations with the highest risks. This study proposes to collect further data on the occupation specific risks of suicide for low skilled workers in construction (males), care workers and home carers (males and females), and those working in arts-related occupations (males and females). All deaths are for those aged 20 to 64 years.

Justification for focusing on these subsections or groups:

When ranking occupations on their risk of suicide, among males, our research found that the highest risk was found among low skilled labourers in construction; for this occupation, the risk was 3.7 times higher than that observed in the broader population. Previous research has attributed the high risk of suicide in low skilled occupations to low pay, low job security, and lower socio- economic status.[1] When looking at the suicide risk in the construction industry, past research has found that suicides may be preceded by high levels of alcohol consumption, relationship problems, and multiple stressful life events.[2, 3] It is also possible that people in these occupations may be at increased risk of suicide prior to starting the job. That said, previous research has tended to focus on skilled workers in construction, and most of the research has been conducted abroad. As such, there is currently a substantial gap in our knowledge on the occupation specific risks among low skilled workers in construction.

Those working in arts-related jobs and those working as care workers and home carers were the only occupations to have similarly high risks of suicide for both sexes – our main rationale for their investigation. The risk of suicide among care workers and home carers was around twice that observed in the broader population for males and females. This occupation concerns those who are paid to attend to the personal needs and comforts of the elderly and the infirm, providing care and support in residential care and day care establishments and service users' homes. To our knowledge, our research is the first to identify this occupation as high risk, highlighting another gap in knowledge. Similarly high risks were found among males and females working in arts- related occupations including artists (males and females), musicians (males), and actors, entertainers and presenters (males). Although past research has found elevated risk among some arts-related occupations, our research shows that the risk affects a wider range of arts-rated occupations.[4]

Our analysis is restricted to those aged 20 to 64 years, following the approach of that used in our published research.[5] This age range was selected due to our work, on occupation, being focused on those of working age. This age range helps to reduce the likelihood that other individuals who could bias the findings, such as retirees, are excluded from the analysis.

The inclusion of the above occupations is also supported on account of conversations with academics and policy makers in Public Health England (see Appendices 1 and 2 – letters of support).

A5 Please provide details of the research protocol or methodology (e.g. data linkage, web scraping etc) (max 500 words)

Data source

The study will be completed by collecting data from individual coroner's inquest records, sampling from the death registrations (2011-15) included in our suicide by occupation report. These deaths included all those amongst people aged 20 to 64 years where occupation was recorded on the death certificate and where the underlying cause of death was coded as intentional self-harm or injury or poisoning of undetermined intent (this is the National Statistics definition of suicide; ICD-10 codes: X60 to X84, Y10 to Y34). Coroner records will often contain information on demographics, and detailed accounts on the circumstances surrounding the death (e.g., witness reports, police reports, medical reports and medical records). Here it should be noted that coroner's records are not compiled for research purposes, and substantial differences in how information is recorded by each coroner should be expected.[6] Despite this, collecting data from coroner's records to further understand occupation specific risks of suicide has proved useful in previous research.[7]

Occupations proposed for inclusion in the study

For the reasons outlined in the background, the following groups of occupations will be included in this study. For each occupation, the Standard Occupation Classification (SOC) code has been specified:

1. Low skilled workers in construction, males only (9120);

2. Care workers and home carers, males and females (6145);
3. Arts-related occupations:
4. Artists, males and females (3411)
5. Musicians, males only (3415)
6. Actors, entertainers and presenters, males only (3413)

The data to be collected

To further understand the risks surrounding the deaths, a data collection form has been designed (see separately attached data collection form). The data collection items have been informed by previous coroner's deep dive studies[7,8,9,10,11] in addition to conversations with academic experts. The items include:

1. Demographics not already held on the deaths registration file (e.g., employment status, ethnicity, living circumstances);
2. Circumstances surrounding the death (e.g., method of suicide, toxicology);
3. Specific information on prescription medications;
4. Previous/current misuse of alcohol and/or drugs;
5. Physical health conditions;
6. Mental health conditions, including previous history of self-harm and suicide attempt
7. Recent contact with health services;
8. Other specific risk factors (job related stressors such as job security, stress at work, recent sickness absence; financial difficulties; access to a method of suicide via one's occupation; exposure to suicide through work and/or the internet; bereavement; loneliness).

Researchers will be instructed not to record information that could be used to identify individuals such as names, addresses, geographical information, and companies of work (etc). Audits will be in place to ensure that any personal identifiable information is redacted.

Sampling approach

A subset of the occupations included in our suicide by occupation analysis will be taken. On the advice of an academic expert, our sampling approach is to be pragmatic. Specifically, we plan to target coroners with the most data for the occupations of interest, while also trying to get a good national coverage and, where possible, a good sample in urban and rural areas.

Methods

The analysis will mainly be descriptive, looking at the main trends for each of the occupation groups and then comparing these to findings to those from comparable population studies that have investigated similar risks. The analysis will also be quantitative by looking at correlations between different risk factors where possible. The mode of collection is a PDF form, and data would be stored on secure laptops / servers in SPSS, and be accessible only to ONS staff, in Health Analysis and Life Events (HALE), taking part in the research. The data would be handled in line with the National Statistics Code of Practice and the high standards applied by ONS.

Pilot study

Before data collection begins, a pilot study will be conducted using data from 1 or 2 coroners. This pilot will be used to test and improve the data collection form.

Staff wellbeing

In the study, staff wellbeing will be of upmost importance. All staff working on the project will be offered the below.

- Before data collection begins: We will provide staff with resilience training. This training will be provided by a third party. The training will be designed to prepare staff as best as possible: we will give them an idea on the type of information they can expect in coroners' inquest files, and we will provide staff with psychological techniques that can help to make them more resilient to the information in the files.

- Before and during data collection: We will be making it clear to all staff that there is no obligation to collect data, and they won't need to provide any justification if they change their mind.
- After data collection: The lead researcher, for a given session, will conduct a debrief session: if they wish, staff will be given the opportunity to discuss challenging topics they may have on their minds. Staff will also be provided with additional resources, such as information on organisations they can contact if they require any further help.

A6 Data use

Please specify the data used **by the research team** including any timeframes *e.g. LFS data 2014-15*

Type of data	**Data Level** *Please specify the name of the data set*			
	Aggregate Data	**Identifiable Data**	**De-identified personal data**	**Anonymised/ pseudo anonymised**
Administrative data *(please specify, e.g. Patient Register 2011, School Census 2012 etc, in the relevant options adjacent)*		Person level ONS mortality data for the subset of deaths chosen for investigation- for the purpose of obtaining the sample. Only available to 2 data managers in HALE & the project lead.	The analytical dataset will contain de-identified person level data, including ONS mortality variables such as sex, age, occupation, place of usual residence. This level of detail, on any death, is available to all ONS researchers in HALE; the analytical dataset, detailed below, will only be available to researchers working on this project.	
Big Data *(please specify e.g. Twitter data, smart meters and mobile phones, in the relevant options adjacent)*				

Survey Data *(please specify e.g.LFS, BRES, etc in the relevant options adjacent)*				
Census Data *(please specify year, e.g. Census 2011 in the relevant options adjacent)*				
Other *(please specify e.g. Ordinance Survey Address register in the relevant options adjacent)*		Person level	The analytical dataset will contain de-identified person level data collected via the PDF form (see attached) in addition to the mortality that we already have access to.	

Section B
Assessment against NSDEC ethical principles

B1 Principle 1: The use of data has clear benefits for users and serves the public good.

Please outline the proposed benefits of the project (max 500 words)

In the UK government's latest update to the suicide strategy for England (see sections 52 and 53), they describe the importance of collecting data on specific occupation groups in order to identify trends within high risk groups and steer thinking to inform better interventions.

Our previous research helped to identify occupations with the highest risk of suicide in England, and provided the government and other users, such as charities, with evidence on where interventions should be targeted. Little is currently known, however, on *specific* risk factors associated with the deaths among occupations with the highest risks, namely low skilled workers in construction, care workers and home carers, and those working in arts-related occupations. This study builds on our previous research by providing more detailed information on specific risks factors, something that will enable users to inform *better* interventions.

Our pre-established working relationship with Public Health England will help us to get the key messages of the research out to policy makers in relevant government departments and professional bodies in addition to organisations that run sector specific mental health programs. One such program is Mates in Mind. This charitable program aims to raise awareness and understanding of poor mental health in the construction sector. Launched in 2017, at the end of its first year it is anticipated that the program reached 100,000 people. When looking at the success of similar programs abroad, such as Mates in Construction in Australia, studies have shown that they can result with knowledge on risk factors, stigma, and help seeking behaviours;[12] basic mental health training for managers has also been found to have a positive impact on employee's sickness absence.[13] Understandably, our research, which aims to investigate specific risk factors, could feed into training programs, ultimately helping to save lives.

In summary, the research outcomes should enable us to identify specific risk factors for occupations at high risk of suicide, informing policy makers, government departments, professional bodies and voluntary organisations.

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B2 Please outline any intended future use for products (such as linked data sets or tools) produced as a result of the research and how they will be accessed. (max 250 words)

Our analytical data set, which includes information from our deaths registration data in addition to the data collected from coroners, will be held for as long as it is needed for research and statistical purposes. In other words, ONS will retain the data until it is no longer needed for the following purposes: reproducibility of the research; further analysis to support the National Suicide Prevention Strategy, further/follow-up research to support the National Suicide Prevention Strategy; parliamentary questions.

Access to this data will be limited to those working on the project. After the project has been completed, we will hold the data on a restricted and secure server; access will be restricted to the lead senior researcher and data managers in HALE. Researchers and data managers with access to the data will have had comprehensive training on access and outputting these types of sensitive data; these staff will be those with additional security clearance (see Section B3).

The results of the research will be published on the ONS website as an article with aggregated tables.

B3 Principle 2: The data subject's identity (whether person or organisation) is protected, information is kept confidential and secure, and the issue of consent is considered appropriately.

Please outline how data security, confidentiality and informed consent is safeguarded in this project(max 500 words)

After ethical approval has been gained, we will contact individual coroners to get consent for using their data. To do this we will explain to coroners the purpose of our study and what it hopes to achieve; we will explain how we intend to protect the data and we will emphasize that personal identifiable information will not be recorded; we will explain that the data may be held by ONS for as long as it is needed (for the reasons described above); we will also explain what will be required of the coroner's office (see Appendix 3- letter to coroners).

Throughout the study, each subject's personal information will be protected. To do this we will be taking the following steps:

- When identifying individual records for the sample, HALE Data Managers will extract the first name, middle name, and surname of the identified records (by coroners' jurisdiction) from our restricted copy of deaths registrations data. These data will be stored in a secure area of the HALE research environment, only accessible to data management and the project leads. After obtaining consent from individual coroners, we will send the names of the records we need via our secure data transfer system, MoveIT, to the Coroner's Office. Coroners will then send back their anonymous unique identifier for each record and pull out the relevant records for ONS researchers to access in the coroner's office. The data will be collected using a PDF form, using encrypted ONS laptops and saved in a restricted area of the HALE research environment. Researchers will identify each record using the *anonymous identifier*.

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- Data from coroners will be collected at the coroner's office; inquest files will not be removed from these locations.
- Researchers will be trained not to record information that could be used to identify individuals such as names, addresses, geographical information, companies of work (etc).
- The data will only be accessible to those working on the project, in a restricted area of the HALE research environment.

ONS researchers in HALE have a high level of training in handling sensitive death registration data, including:

- additional security vetting to the level of Security Cleared. This has been provided due to the sensitive nature of the data they have access to;
- trained in data protection through Office wide courses and have a thorough understanding the mortality disclosure control policy;
- the research and outputs from the analysis will be overseen by the Assistant Deputy Director of the division, an expert in Health Related Disclosure Control;
- all staff are highly aware of the sensitive nature of the data we hold.

B4

Principle 3: The risks and limits of new technologies are considered and there is sufficient human oversight so that methods employed are consistent with recognised standards of integrity and quality.

Please describe how the any risks from new technologies are been mitigated as well as any quality assurance activities in the project (max 500 words)

No new technologies are involved in the process and safeguards are in place (see Section B3) to make sure that any risks are mitigated.

B5

Principle 4: Data used and methods employed are consistent with legal requirements such as the Data Protection Act, the Human Rights Act, the Statistics and Registration Service Act and the common law duty of confidence

Please describe the legal frameworks pertinent to this project (max 500 words)

- The Statistics and Registrations Service Act (2007) applies to this work. This allows ONS to use deaths registrations data, provided by the Register General, for statistical purposes.
- The Data Protection Act (DPA) does not apply to this project due to the analysis being undertaken on deceased individuals. The DPA only applies to living individuals.
- Human Rights Act (HRA). There is no interference with the right to family life and privacy (HRA Article 8) of the deceased or their surviving family members. No information will be collected about family members and they will not be contacted or identified in any circumstances. Any published data will be anonymised and subjected to strict Statistical Disclosure Controls so there is minimal risk of causing any harm or distress by a breach of confidentiality. The small risks are proportionate to the public interest in the protection of health.

- Data from coroners can be obtained by getting their consent. Coroners have ownership of their data, and hence we only need their permission to use the data for statistical and health improvement purposes.

B6 Collaboration and Sponsors

Please describe the project sponsors and the **legal gateways** to acquire, process use and share their data

List of Collaborators/Sponsors	**Details and relevant documentation relating to collaboration (you may attach copies of relevant documentation)**
University of Bristol	Assistance in designing the analysis and interpretation of results. No access to disclosive data will be provided (see Appendix 1).
National Programme Manager for Public Mental Health, Public Health England	Providing guidance in how to report the findings of the work to reduce to ensure we take account of the sensitivities around ‘copy cat’ deaths. No access to disclosive data will be provided (see Appendix 2).

B7 Principle 5: The views of the public are considered in light of the data used and the perceived benefits of the research

Please list any public engagement activities (max 250 words)

Due to the niche nature of the research, we have not sought the views of the public. Despite this, the research is of clear public benefit as the findings will be used to inform suicide prevention measures. ONS has received very positive feedback on our previous research in this domain from the National Suicide Prevention Strategy Advisory Group. The membership is a mix of government bodies, charities, health providers, academics and family champions bereaved by suicide. The two sponsors, named above, are members of this group.

B8 Principle 6: The access, use and sharing of data is transparent, and is communicated clearly and accessibly to the public

How will the findings of the research be disseminated? (max 500 words)

Non-disclosive aggregated tabulations of this project will initially be shared with our key collaborator, University of Bristol. We will also present the findings of the research to the National Suicide Prevention Strategy Advisory Group and Public Health England. These individuals and groups are well placed to advise on the data, to help with its interpretation, before we report to the public.

An assessment will be made about what we release into the public domain; it is important not to release highly sensitive information that might result in "copy cat" deaths. This is type of assessment is common when ONS are handling suicide data as we do not want to put in the public domain new methods of suicide, or highlight publicly current clusters of suicides. Discussions would be had with Public Health England, the lead government agency on suicide prevention, to agree the best approach in using the data in these circumstances.

After this assessment has been made, we intend to publish the findings, and data tables, via the ONS website.

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[1] Agerbo E, Gunnell D, Bonde J, Mortensen P, and Nordentoft M (2007). Suicide and occupation: the impact of socio-economic, demographic and psychiatric differences. *Psychological Medicine, 37,* 1131 to 1140.

[2] Heller T S, Hawgood J, and De Leo D (2007). Correlates of suicide in building industry workers. *Archives of Suicide Research, 11,* 105 to 117.

[3] Australian Institute for Suicide Research and Prevention (2006). *Suicide in Queensland's Commercial Building and Construction Industry: An Investigation of Factors Associated with Suicide and Recommendations for the Prevention of Suicide.* Griffith University, Mt Gravatt Campus: Nathan, Australia.

[4] Meltzer H, Griffiths C, Brock A, Rooney C and Jenkins R (2008). Patterns of suicide by occupation in England and Wales: 2001-2005. *The British Journal of Psychiatry, 193*, 73 to 76.

[5] Romeri E, Baker A and Griffiths C (2007). Alcohol-related deaths by occupation, England and Wales, 2001-05. *Health Statistics Quarterly, 35*, 6 to 12.

[6] Palmer B, Bennewith O, Simkin S, Cooper J, Hawton K et al. (2015). Factors influencing coroners' verdicts: an analysis of verdicts given in 12 coroners' districts to researcher-defined suicides in England in 2005. *Journal of Public Health*, *37*, 157-165.

[7] Hawton K, Simkin S, Rue J, Haw C, Barbour F et al. (2002). Suicide in females nurses in England and Wales. *Psychological Medicine, 32,* 239-250.

[8] Bennewith O, Hawton K, Simkin S, Sutton L, Kapur N et al. (2005). The usefulness of coroner's data on suicides for providing information relevant to prevention. *Suicide and Life- Threatening Behavior, 35,* 607-614.

[9] Bennewith O, Gunnell D, Kapur N, Turnball P, Simkin S et al. (2005). Suicide by hanging: multicentre study based on coroner's records in England. *British Journal of Psychiatry, 186,* 260-261.

[10] Chen Y, Bennewith O, Hawton K, Simkin S, Cooper J et al (2012). Suicide by burning barbecue charcoal in England. *Journal of Public Health, 35,* 223-227.

[11] Cooper C, Donovan J, Wilson C, Barnes M, Metcalfe C et al. (2015). Characteristics of people dying by suicides after job loss, financial difficulties and other economic stressors during a period of economic recession (2010-2011): A review of coroners' records. *Journal of Affective Disorders, 183,* 98-105.

[12] Milner A, Page K, Spencer-Thomas S and LaMontagne A (2014). Workplace suicide prevention: a systematic review of published and unpublished activities. *Health Promotion International, 30*, 29 to 37.

[13] Milligan-Saville J, Tan L, Gayed A, Barnes C, Madan I et al. (2017). Workplace mental health

training for managers and its effect on sick leave in employees: a cluster randomized controlled trial. *Lancet Psychiatry, 4*, 850 to 858.

Appendices

1: Letter to coroners to seek access to their data 4: Data collection form (see separate attachment)

UK Statistics Authority

Section C
Responsible owner and applicant details

C1 Responsible Owner

Full Name: [redacted]

Position: [redacted]

Address: [redacted]

Email: [redacted]

Telephone: [redacted]

Organisation: [redacted]

Declaration to be signed by the responsible owner

I have met with and advised the applicant on the ethical aspects of this project design (applicable only if the responsible owner is not the Applicant).

I understand that it is a requirement for all researchers accessing the data to have undergone relevant training and to have either relevant security clearances or approved researcher status in order to access the data.

I am satisfied that the research complies with current professional, departmental and other relevant guidelines.

I will ensure that changes in approved research protocols are reported promptly and are not initiated without approval by the National Statistician's Data Ethics Advisory Committee.

I will provide notification when the study is complete if it or fails to start or is abandoned.

I will ensure that all adverse or unforeseen problems arising from the research are reported in a timely fashion to the National Statistician's Data Ethics Advisory Committee.

I will consider all advice received from the National Statistician's Data Ethics Advisory Committee and should I be unable to implement any of the recommendations made, I will provide reasoning in writing to the Committee.

Signature: [redacted]

Date: 10 April 2018

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C2 Applicant Details (if applicant is not the responsible owner)

Full Name: [redacted]

Position: [redacted]

Address: [redacted]

Email: [redacted]

Telephone: [redacted]

Organisation: [redacted]

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Appendix 3: Letter to coroners

Office for
National Statistics

April 2018

Dear [insert coroner name],

I am writing to seek your permission to access a selection of inquest files for health research purposes.

Last year we published a report on suicide by occupation in England for deaths registered between 2011 and 2015. The findings fed into the government's suicide prevention strategy for England by indentifying groups of individuals with whom to focus suicide prevention measures.

The purpose of our study is to investigate the risks associated with suicides among occupations we found to have the highest risks, namely, low skilled labourers in construction, care workers and home carers, and those working in arts-related occupations. Using data from inquest files, we hope to identify specific risk factors that may have contributed to the deaths such as the misuse of alcohol and drugs, access to a method of suicide, job instability and debt, sickness absence, bereavement, and exposure to suicide (e.g., through their work). In all, we are hoping to collect data from a dozen coroners' areas.

It is anticipated that the results of the study will further contribute to the government's suicide prevention strategy, inform suicide prevention measures, and will be published on the Office for National Statistics website as an article.

If you're happy for us to access your records, in total we require access to [insert number] files that we have identified for the study using our deaths registration data. To protect the information, we propose collecting the data at your office on days and times that are convenient to you; we expect that data collection will take no longer than [insert number] days.

We have extensive experience with the handling of sensitive data, including suicides. If you are happy for us to access your records, we will ensure that the data of each subject are protected. Our researchers have a high level of training in the handling of sensitive deaths registration data, and we will not record any information that could be used to identify individuals such as names, addresses, geographical information, and companies of work (etc). The data will be collected on encrypted laptops, and will be stored on a restricted area of our secure research environment. Please note that, if you agree for us to access your records, the de-identified data we collect may be held for an indefinite period of time in a secure server.

Please let me know if you would like to further discuss the project. I look forward to hearing from you.

Yours sincerely,

UK Statistics Authority

National Statistician’s Data Ethics Advisory Committee

NSDEC(18)11

ADRN: Census–Refugee Matching: Feasibility study, 2009 cohort (CRM:2009)

This project proposal has not been approved by the committee

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Update on IDEAS

Oral report

Jon Wroth-Smith

Government Digital Service

Update on the Data Ethics Framework

Oral report

Sarah Gates

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UK Statistics Authority

National Statistician’s Data Ethics Advisory Committee

NSDEC(18)12

Linking reconvictions data with offender risk assessment data to inform the evidence base on reducing reoffending

This project is undergoing minor revisions and will be published in due course

Using mobile phone data for research and statistics

Oral report

Susan Williams

UK Statistics Authority

National Statistician's Data Ethics Advisory Committee

Application for Ethical Review

Please consult the guidance document before filling in the application form

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Project Title

Please provide a title indicative of the project

An Evidence Project on: The Measurement of Vulnerability of Children and Young People in England

Start Date:	19.02.18	**End Date:**	31.07.18

Project Sponsor(s)

Please list the project sponsor(s)

Children's Commissioner for England

Project Summary

Please provide a brief high level summary of the research giving necessary background (max 250 words)

The Children's Commissioner for England (CCE) works to enhance the recognition and support for vulnerable children. Without evidence on the prevalence and the needs of England's children, the appropriate support cannot be granted.

Alma Economics has been contracted by the Children's Commissioner for England to perform a study on the number of children in England who face different types of vulnerability (e.g.: bullying, alcoholism, victims of crime etc). This builds upon the 2017 CCE research, done by Alma Economics with three other firms, (https://www.childrenscommissioner.gov.uk/publication/childrens-commissioners-report-on-vulnerability) which used publicly available information to provide estimated numbers of 32 categories (as defined in the research report) of the nation's vulnerable children. That report also identified shortcomings in the current information and recommended ways to improve the statistics available.

That report was widely reported in the media and was debated in the House of Lords on 6 July 2017 (https://hansard.parliament.uk/Lords/2017-07-06/debates/77125697-3A7B-46B2-A960-067DD2DBF01B/VulnerableChildren) and 14 December 2017 (https://hansard.parliament.uk/lords/2017-12-14/debates/E935D747-34C4-430C-9128-04218F9496A5/VulnerableChildren)

This project will build on that previous work by using the Crime survey for England and Wales (CSEW) to provide more accurate and up-to-date data on the number of children facing different vulnerabilities.

This project will only access de-identified data and all outputs will be checked to ensure that no person is at risk of identification. Location information will be limited to the local authority level.

The CSEW asks people aged 16 and over, living in households in England and Wales, about their experiences of crime in the last 12 months (as of 2015 this includes questions regarding online fraud and identity theft). Since January 2009 it has also interviewed children aged 10 to 15 (http://www.crimesurvey.co.uk/10-15yearOldsSurvey.html). The researchers will access this dataset in the Secure Research Service (SRS). The adult module of the CSEW can be used to produce an estimate of the exposure of children to family or household-related vulnerabilities.

Alma Economics will aggregate the relevant data by area, by nature of vulnerability and by year to identify trends. The results will be published on the Children's Commissioner's website allowing people to see the aggregated results and the methodology and data sources used to create them. The results, including any trends identified, will be used by the Children's Commissioner to inform policy-makers and partner organisations of where more support is needed, and what kinds of support will have the greatest impact on children at risk.

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Section A
Project Details

A1 Legal gateways

Please provide the assessment of the legal gateways of the project as provided by Legal Services

The ONS Approved Researcher scheme is the legal gateway being used to access the data. This is in compliance with the Statistics and Registration Service Act 2007.

The ONS Microdata Release Panel (MRP) have approved the proposal on the grounds that there is a legal gateway to access the data, it is deemed appropriate use of ONS data and a public benefit has been demonstrated.

The researchers are accredited as Approved Researchers.

A2 Ethical approval

Has the project been reviewed or is it expected to be reviewed by another ethics committee? ○ **Yes** ● **No**

If Yes please provide the name of the committee, the outcome and the date approved

A3 Proposed site of research select all that apply

☐ ONS

☑ SRS (formerly VML)

☐ HMRC Data Lab

☐ Other

please specify

☐ ADRC - England

☐ ADRC - Scotland

☐ ADRC - Northern Ireland

☐ ADRC - Wales

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A4 Data subjects to be studied

Does the study include all subsections of the population (i.e. all ages, sex, ethnic groups etc?) ○ **Yes** ● **No**

If no please detail which subsections with justification(s) below:

Subsections of the population (including vulnerable groups) the project focuses on:

Children in vulnerable circumstances who are included in the de-identified CSEW data.

Justification for focusing on these subsections or groups:

Project commissioned by the Children's Commissioner for England.

A5 Please provide details of the research protocol or methodology (e.g. data linkage, web scraping etc) (max 500 words)

The purpose of the project is to update and improve the Children's Commissioner for England (CCE)'s 2017 statistical report on the scale of vulnerability among children in England.

There are no comprehensive publicly available data sources on children in vulnerable circumstances and so use of the ONS Crime Survey for England and Wales (CSEW) is necessary for Alma Economics to gather this information. All access will take place in the ONS Secure Research Service (SRS) using only de-identified data.

The CSEW asks people aged 16 and over, living in households in England and Wales, about their experiences of crime in the last 12 months. Since January 2009 it has also interviewed children aged between 10 and 15. The children's module will supply direct information on various types of children's victimisation and anti-social behaviour (e.g. children involved with street gangs or bullying).

The researchers will also make use of adult's module of the CSEW, which covers drug use, drinking behaviour and interpersonal violence (domestic violence, sexual victimisation and stalking). Additionally, this module asks about the number, age and sex of any children in the household. This will allow Alma Economics to produce estimates of the exposure of children to family-related and household vulnerabilities (for example, children exposed to domestic violence or children whose parents use substances problematically).

In the 2017 report, the CCE identified 32 categories of vulnerable children and estimated their numbers based on the limited publicly available information. For this project, Alma Economics will update those numbers based on more accurate information from the CSEW, as well as generating estimates for ten new categories that the CCE has since identified.

This will give clearer data on the number of children in each vulnerable group as well as the start of a record of changes over time. Geographical and personal characteristic variables in the CSEW will allow Alma to disaggregate the results by age group, gender and region.

Note that the CSEW does not contain names or address details of respondents. Geography will be provided at the local authority level within the SRS. All outputs removed from the SRS will also be checked by ONS to ensure they cannot be used to identify individuals.

The project will also examine those cases where children have more than one vulnerability to study concurrence of vulnerability. This work was not possible for the 2017 report because of the lack of a single source of information for multiple vulnerabilities. The researchers are particularly interested in the probability of children in one vulnerable group also being in another specific group. For example, the probability of a child using drugs if he/she is involved in gang-related activity. This will allow the researchers to identify any groups whose circumstances place them at a compounded risk, which will be highlighted in the report to be published by the CCE.

A6

Data use
Please specify the data used **by the research team** including any timeframes *e.g. LFS data 2014-15*

Type of data	**Data Level** *Please specify the name of the data set* **Aggregate Data**	**Identifiable Data**	**De-identified personal data**	**Anonymised/ pseudo anonymised**
Administrative data *(please specify, e.g. Patient Register 2011, School Census 2012 etc, in the relevant options adjacent)*				
Big Data *(please specify e.g. Twitter data, smart meters and mobile phones, in the relevant options adjacent)*				
Survey Data *(please specify e.g.LFS, BRES, etc in the relevant options adjacent)*			Crime Survey for England and Wales (1996-2016)	
Census Data *(please specify year, e.g. Census 2011 in the relevant options adjacent)*				
Other *(please specify e.g. Ordinance Survey Address register in the relevant options adjacent)*				

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Section B
Assessment against NSDEC ethical principles

B1 **Principle 1: The use of data has clear benefits for users and serves the public good.**

Please outline the proposed benefits of the project (max 500 words)

Established under the Children Act 2004 as a result of a recommendation by Lord Laming in the Victoria Climbié Inquiry, the Children's Commissioner for England (CCE) has a statutory remit to understand what children and young people think about things that affect them and encourage decision makers to always take their best interests into account as well as to serve as a public advocate for them.

The 2017 Children's Commissioner's Report on Vulnerability brought together a range of information published by various government departments, agencies and others to reveal the scale of vulnerability among children in England. It also identified the limitations of the available information as well as ways it could be improved.

This project's goal is to build on this research and improve the quality of statistical information about vulnerable children in the UK. This will improve the CCE's ability to advocate for vulnerable children, and to be an informed influence on public policy. Identifying trends will help the Children's Commissioner to direct policy-makers and service delivery organisations such as local authorities to where more support is needed, and identifying what kinds of support will have the greatest impact, protecting the most vulnerable children in the country.

Identifying coincidence of vulnerabilities will help to highlight particularly at-risk subsets of vulnerable children. By bringing these concurrencies to light, the CCE helps to direct public support where it is needed most, anticipating the likely requirements of children in need.

As identified in the 2017 Children's Commissioner's Report on Vulnerability, there is a paucity of statistical information about vulnerable children. By collating and publishing this information, the CCE is contributing a great deal to the public body of knowledge, making it available for use by future researchers, professionals and the public.

B2 **Please outline any intended future use for products (such as linked data sets or tools) produced as a result of the research and how they will be accessed.** (max 250 words)

This project does not involve any linked datasets, tools, or products other than its statistical outputs.

B3 Principle 2: The data subject's identity (whether person or organisation) is protected, information is kept confidential and secure, and the issue of consent is considered appropriately.

Please outline how data security, confidentiality and informed consent is safeguarded in this project(max 500 words)

Access, analysis and use of the data will only take place within the secure ONS Secure Research Service (SRS) environment. All outputs will be checked by the Statistical Support team to ensure that they are not personally identifiable and to confirm that they are proportional and necessary to the project. This process ensures that disclosure control and the confidentiality of data subjects is protected. Outputs that identify small groups or individuals will not be allowed out of the Secure Research Service environment.

The researchers are accredited as ONS Approved Researchers. ONS will have sight of the final report before it is published.

The Statistics Support staff use a principles-based (rather than rules-based) process to suppress groups that are small enough to risk identifying individuals (for example, no specific numbers for groups containing ten or fewer individuals). Therefore, where outputs are groups of children with concurrent vulnerabilities, suppression will be applied based on the risk of identification, rather than only the size of the group.

The CSEW dataset does contain postcode-level information, but the survey is not large enough for this to be statistically useful. As it cannot be used for their purpose, the researchers will not be given access to this variable. They will be working with the data at local-authority-level geography and all statistical outputs will be at that level or higher.

B4 Principle 3: The risks and limits of new technologies are considered and there is sufficient human oversight so that methods employed are consistent with recognised standards of integrity and quality.

Please describe how the any risks from new technologies are been mitigated as well as any quality assurance activities in the project (max 500 words)

No new technologies are being employed.

B5 Principle 4: Data used and methods employed are consistent with legal requirements such as the Data Protection Act, the Human Rights Act, the Statistics and Registration Service Act and the common law duty of confidence

Please describe the legal frameworks pertinent to this project (max 500 words)

Access to the potentially disclosive data will be in the Secure Research Service environment and via an approved legal gateway (Approved Researcher scheme). This is in compliance with the Statistics and Registration Service Act 2007. The methods used are compliant with the principles in the Data Protection Act.

B6 Collaboration and Sponsors

Please describe the project sponsors and the **legal gateways** to acquire, process use and share their data

List of Collaborators/Sponsors	**Details and relevant documentation relating to collaboration (you may attach copies of relevant documentation)**
Children's Commissioner for England	Client/Contractor relationship. No CCE data shared as part of the project.

B7 Principle 5: The views of the public are considered in light of the data used and the perceived benefits of the research

Please list any public engagement activities (max 250 words)

Whilst the views of the public have not been sought with regards to the research, there is a clear public benefit for the analysis (as described in B1 above). A public consultation on the Approved Researcher scheme in 2015/16 recommended that commercial organisations should be allowed to access ONS research data where there is a clear public benefit.

B8 Principle 6: The access, use and sharing of data is transparent, and is communicated clearly and accessibly to the public

How will the findings of the research be disseminated? (max 500 words)

ONS has a commitment to transparency and publishes a register of all Approved Researchers on their website. This includes their organisations, current projects, sponsors and the datasets being used.

The results will be published on the Children's Commissioner's website in spreadsheet format, accompanied by a technical report on methodology and data sources. This will be added to their existing publications on vulnerability in children (https://www.childrenscommissioner.gov.uk/publication/childrens-commissioners-report-on-vulnerability/).

ONS will have first sight of the report and aggregated findings before publication to ensure that there are no ethical or data protection issues.

Section C
Responsible owner and applicant details

C1 Responsible Owner

Full Name: [redacted]	**Position:** [redacted]
Address: [redacted]	**Email:** [redacted]
	Telephone: [redacted]
	Organisation: [redacted]

Declaration to be signed by the responsible owner

I have met with and advised the applicant on the ethical aspects of this project design (applicable only if the responsible owner is not the Applicant).

I understand that it is a requirement for all researchers accessing the data to have undergone relevant training and to have either relevant security clearances or approved researcher status in order to access the data.

I am satisfied that the research complies with current professional, departmental and other relevant guidelines.

I will ensure that changes in approved research protocols are reported promptly and are not initiated without approval by the National Statistician's Data Ethics Advisory Committee.

I will provide notification when the study is complete if it or fails to start or is abandoned.

I will ensure that all adverse or unforeseen problems arising from the research are reported in a timely fashion to the National Statistician's Data Ethics Advisory Committee.

I will consider all advice received from the National Statistician's Data Ethics Advisory Committee and should I be unable to implement any of the recommendations made, I will provide reasoning in writing to the Committee.

Signature: [redacted] **Date:** [redacted]

C2 Applicant Details (if applicant is not the responsible owner)

Full Name: [redacted]	**Position:** [redacted]
Address: [redacted]	**Email:** [redacted]
	Telephone: [redacted]
	Organisation: [redacted]

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UK Statistics Authority

National Statistician's Data Ethics Advisory Committee

Considered via correspondence

Microdata Release Panel: Understanding the split between NHS and non-NHS income for community pharmacies.

Purpose

1. This paper presents a proposal by the Microdata Release Panel for use of ONS data by London Economics, a specialist policy and economics consultancy, who have been commissioned by the Department of Health and Social Care(DHSC), to update and validate the Reference Pharmacy model. The Reference Pharmacy model is a financial modelling tool used by DHSC to provide insight on the commercial viability of the community pharmacy sector.

Background

2. The Microdata Release Panel (MRP) governs access to the secure ONS Secure Research Service(SRS), and provides approved researchers access to de-identified ONS data in order to undertake approved projects.

3. In 2016, following a public consultation on the Approved Researcher process, it was agreed that where necessary, the MRP would refer applications to use ONS data via the Approved Researcher gateway to NSDEC for ethical review.

4. In the NSDEC meeting on 24 January 2017 the Committee were informed that some of these proposals would need to be considered via correspondence in order to ensure equality in timeliness of access to ONS data.

5. In March 2018 members reviewed the project via correspondence and raised the issues which are summarised in Annex A. The researcher's responses to these comments are also presented in Annex A.

Recommendations

6. Members of NSDEC are invited to consider the researcher's responses providedin **Annex A** and advise the National Statistician to:

   i. approve the proposal and allow it to proceed;
   ii. approve the proposal subject to minor revisions;
   iii. recommend major revisions to the proposal and request the proposal be resubmitted to a future meeting once implemented; or
   iv. reject the proposal advising it be stopped from proceeding.

Petros Saravakos, Central Policy Secretariat, UK Statistics Authority, 13 April 2018

List of Annexes

Annex A: Minutes via correspondence

Annex B: Application: Understanding the split between NHS and non-NHS income for community pharmacies

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Annex A: Minutes of correspondence with regards to the application, 16 April 2018

Draft Minutes of Correspondence 16/04/2018

Participating Members
Mr Rob Bumpstead
Ms Vanessa Cuthill
Mr Keith Dugmore
Mr Colin Godbold
Ms Annie Hitchman
Mr Brent Mittelstadt
Ms Isabel Nisbet
Ms Marion Oswald
Ms Emma Uprichard

UK Statistics Authority
Mr Petros Saravakos

Office for National Statistics
Mr Pete Stokes (Microdata Release Panel)

1. Public good and user benefit

1.1. Most members agreed that the project presents a strong public benefit in terms of ensuring the viability of the Community Pharmacy provision across the UK and inform savings for the National Health System. The creation of a more robust evidence base presents a clear benefit in maintaining and improving the health services provided by pharmacies. However, members suggested that any negative consequences to areas and households should considered and assurances are provided in the application.

Response: The tool will also be used to identify pharmacies and locations that might be at risk of reduced pharmacy access detecting pharmacies that are at risk of being below a given profitability threshold. The tool could then be used to inform how and what additional funding might be needed to protect access in these locations.

2. Data, methods, confidentiality and security

2.1. Members recommended that researchers should make clear that the anonymity of individuals pharmacies is preserved and specifically state in the application that neither researchers or staff from the Department of Health and Social care should be able to use the data to issue interventions against individual pharmacies.

Response: Data will be presented in aggregate so that no individual information is identifiable. The analysis will not be used to issue intervention against individual pharmacies. DHSC is not the commissioner of these services, NHS England is, so the former does not have authority to issue interventions against individual pharmacies.

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2.2. Members suggested that more clarity is required in the data sharing agreement between the Department of Health and Social Care and London Economics and if a non-disclosure agreement is in place between the two parties.

Response: A Non-Disclosure agreement is in place between London Economics and DHSC.

2.3. It is no clear how the datasets used can help in estimating the costs of businesses since only income and turnover information is been examined by London Economics. If additional publicly available datasets are included in the research they should be included in the application.

Response: Cost data is available through a bespoke survey conducted for DHSC by PwC. This data is not publicly available.

2.4. Members requested more information on the current Pharmacy Reference model as there are not enough details available online. It would be useful to present which will be the main changes to the new model which be developed for this project.

Response: The reference pharmacy model will be updated to include non-NHS income through this analysis. Pharmacies make income on retail sales which had not been included in this model previously.

2.5. The application should make clearer how the 20% most deprived areas in England will be geographically defined.

Response: This is defined as locations in the bottom two deciles of the Index of Multiple Deprivation. More information is available on the ONS website.

2.6. Given that non-NHS income could be from a diverse range of activities it is not clear how the proposed benefits will be realised.

Response: The project is only concerned with a site’s total non-NHS income. The Reference Pharmacy model does not require a breakdown of it by source.

2.7. Members recommended that the application made clear whether consent from businesses is required for collecting the Annual Business Survey and the NHS business data. In that case any proposed use of data should fall within the original consent.

Response: NHS business data is administrative data and so consent was not required for collecting. The use of ABS data falls within the bounds of what respondents were told that their data would be used for.

Petros Saravakos, NSDEC Secretariat, Central Policy Secretariat, UK Statistics Authority, 16 April 2018

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National Statistician's Data Ethics Advisory Committee

Application for Ethical Review

Project Title

Please provide a title indicative of the project

Understanding the split between NHS and non-NHS income for community pharmacies

Start Date:	1-Mar-18	**End Date:**	1-Feb-19

Project Sponsor(s)

Please list the project sponsor(s)

Department of Health and Social Care (DHSC)

Project Summary

Please provide a brief high level summary of the research giving necessary background (max 250 words)

The Department of Health and Social Care (DHSC) is responsible for policy and legislation for NHS pharmaceutical services, relevant medicines legislation and pharmacy regulation.

The Community Pharmacy Clinical Services Review (aka The Murray Review[1]) was commissioned to inform the future provision of clinical pharmacy services. Based on its recommendations, DHSC announced plans[2] on 20th October 2016 for modernising community pharmacies[3] to secure optimal deployment of community pharmacies, the pharmacy workforce and value for money for the taxpayer.

DHSC use a bespoke financial modelling tool called "Reference Pharmacy" to provide insight into the commercial viability of the community pharmacy sector. However, some of the data it employs is out of data and data gaps remain. Therefore, DHSC have commissioned London Economics (LE) – a private economics and policy consultancy – to finalise and validate the Reference Pharmacy tool.

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[1] https://www.england.nhs.uk/commissioning/primary-care/pharmacy/ind-review-cpcs/

[2] https://www.gov.uk/government/news/new-plans-to-modernise-community-pharmacies

[3] https://www.gov.uk/government/publications/community-pharmacy-reforms

Community pharmacies receive NHS funding but also generate their own income. The data gap to be addressed by this project is understanding this split between NHS and non-NHS income. The reference pharmacy model will be updated to include non-NHS income through this analysis.

The researchers will use DHSC data detailing NHS income pharmacies receive from their pharmaceutical services contract. ONS will link this data to turnover information from the Annual Business Survey (ABS) in the Secure Research Service. By subtracting NHS income from total turnover, LE can determine each pharmacy's non-NHS income. This information will be aggregated by size of pharmacy and region, ensuring that individual pharmacies are not identifiable in the outputs.

Section A
Project Details

A1 Legal gateways

Please provide the assessment of the legal gateways of the project as provided by Legal Services

The ONS Approved Researcher scheme is the legal gateway being used to access the data. This is in compliance with the Statistics and Registration Service Act 2007.

The ONS Microdata Release Panel (MRP) have approved the proposal on the grounds that there is a legal gateway to access the data, it is deemed appropriate use of ONS data and a public benefit has been demonstrated.

Administrative pharmacy data is owned by DHSC and is used by London Economics under the terms of their contract, including a non-disclosure agreement.

A2 Ethical approval

Has the project been reviewed or is it expected to be reviewed by another ethics committee? ○ **Yes** ● **No**

If Yes please provide the name of the committee, the outcome and the date approved

A3 Proposed site of research select all that apply

☑ ONS

☑ SRS

☐ ADRC - England

☐ ADRC - Scotland

☐ HMRC Data Lab

☐ ADRC - Northern Ireland

☐ Other

☐ ADRC - Wales

please specify

A4 Data subjects to be studied

Does the study include all subsections of the population (i.e. all ages, sex, ethnic groups etc?) ● **Yes** ○ **No**

If no please detail which subsections with justification(s) below:

Subsections of the population (including vulnerable groups) the project focuses on:

All segments (project focus is Community Pharmacies)

Justification for focusing on these subsections or groups:

n/a

A5 Please provide details of the research protocol or methodology (e.g. data linkage, web scraping etc) (max 500 words)

The researchers will carry out their analysis in the Secure Research Service. Note that all linking and matching of external data will be performed by ONS. The LE researchers will only handle the resulting linked dataset in the SRS.

To quantify the share of non-NHS income, LE propose to:

- Import a DHSC-provided list of community pharmacies with company reference numbers and NHS income
- Match community pharmacy company registration numbers with the Inter-Departmental Business Register (IDBR) dataset
- Using the reporting unit identifier in the IDBR, link single entities to the Annual Business Survey dataset (ABS). This will provide a sample of community pharmacies for which there is total turnover data
- For each pharmacy, subtract NHS income from total turnover to estimate non-NHS income at a firm level
- The researchers are not interested in the precise breakdown of non-NHS income, only the total

Outputs taken from the SRS will take the form of non-NHS income as a percentage of total income by:

- Firm size (i.e. micro firms, SMEs and large enterprises)
- Geography (e.g. government office region)

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- ONS area classifications

The outputs will consist entirely of aggregated statistical information and will be checked by ONS to ensure that they do not allow individual pharmacies to be identified. These outputs will be taken out of the SRS and incorporated into the Reference Pharmacy model to improve its ability to project the income and cost structure for a well-run "new entrant" community pharmacy. It will help to assess what it should cost a Community Pharmacy to perform its dispensing function at particular levels of return. This income and cost base will account for both NHS and Non-NHS income and running costs to allow a full understanding of the effect on service delivery of different income levels.

The Reference Pharmacy model is essential in informing the development and evaluation of healthcare service policies affecting the Community Pharmacy sector in light of the Murray review.

The Reference Pharmacy tool uses cost and income data (including non-NHS income data) to estimate the profitability of a community pharmacy. The cost data is available on a anonymised basis from the Cost of Services Inquiry commissioned by the Department. The income data is collected via payments made to pharmacies through the NHS Business Services Authority. Non-NHS income is estimated by matching the payments data from NHS BSA to the IDBR. The costs of the median efficient pharmacy is compared to the income of a median pharmacy to estimate the profitability of an average pharmacy. This tool is then used to assess what the impact of different funding scenarios would be on pharmacies.

A6

Data use

Please specify the data used **by the research team** including any timeframes *e.g. LFS data 2014-15*

Type of data	**Data Level** *Please specify the name of the data set*			
	Aggregate Data	**Identifiable Data**	**De-identified personal data**	**Anonymised/ pseudo anonymised**
Administrative data *(please specify, e.g. Patient Register 2011, School Census 2012 etc, in the relevant options adjacent)*		Income data on payments through the pharmaceutical services contract 2014-2016		
Big Data *(please specify e.g. Twitter data, smart meters and mobile phones, in the relevant options adjacent)*				

Survey Data *(please specify e.g.LFS, BRES, etc in the relevant options adjacent)*			ABS IDBR (RU ref for linking purposes) 2014-2016	
Census Data *(please specify year, e.g. Census 2011 in the relevant options adjacent)*				
Other *(please specify e.g. Ordinance Survey Address register in the relevant options adjacent)*				

Section B
Assessment against NSDEC ethical principles

B1 The use of data has clear benefits for users and serves the public good.

Please outline the proposed benefits of the project (max 500 words)

The anticipated public benefits of this project are to ensure:

- more efficient use of limited NHS funding by avoiding unnecessary overspends and identifying areas in need of more support
- that the mandated changes in funding are applied fairly across the country and do not result in diminished access to vital services
- that areas at risk of reduced pharmacy access are identified so that additional support can be allocated

The Independent Review of the future of Community Pharmacy Clinical Services (the Murray Review) recommended the community pharmacy model that this project is working towards and it identified three potential high level areas of improvement:

- Helping to close the Health and Wellbeing Gap, by extending its role in improving public health and building on the solid evidence of both clinical and cost effectiveness for a range of existing public health services provided by community pharmacy;
- Helping to close the Care and Quality Gap, particularly by providing additional services to support patients and the public better manage their own long-term conditions; and
- Helping to close the Funding and Efficiency Gap, not just through better management of medications but also, for example, by meeting the demand for urgent care services from patients that would otherwise need to be met by other, more expensive services such as A&E or general practice. Public Health England has already identified 6 interventions involving pharmacy that would save money over the next 5 years, contributing both to efficiency and health

The Reference Pharmacy model is needed to provide evidence so that these changes can be made efficiently as part of an informed process. The model will allow Government to investigate different funding packages against a baseline efficient pharmacy business to gain an insight on:

- The impact of different funding packages on the sector
- The financial viability of different location types in order to identify the most effective locations to site a pharmacy
- Ensuring pharmacies offer maximum support to local communities and the health service
- The impact of different funding packages on patient access

The savings made will go into improved NHS services throughout the country, to ensure that patients get the highest-quality provision possible.

DHSC does not commission pharmacy services (this is being done by NHS England) so does not have authority to issue interventions against individual pharmacies. This research is not intended to be used to make operational decisions targeted at individual pharmacies or areas, except in as much as the policies developed are applied to the whole sector.

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Outside the scope of this project, DHSC have been running a new pharmacy access scheme to ensure coverage of pharmacy service by introducing further protections for pharmacies in the top 20% most deprived areas in England (as defined by the Index of Multiple Deprivation). This aims to mitigate any risks of underserved areas and protect people in isolated areas.

B2 The data subject's identity (whether person or organisation) is protected, information is kept confidential and secure, and the issue of consent is considered appropriately.

Please outline how data security, confidentiality and informed consent is safeguarded in this project(max 500 words)

Access to data will only take place within the secure ONS Secure Research Service (SRS) environment and all outputs will be checked by ONS prior to release to ensure disclosure control and the confidentiality of data subjects is protected. All analysis and use of the data will be at a secure SRS setting at one of the ONS offices. The researchers are accredited as ONS Approved Researchers. ONS will have sight of the final report before it is published. Detailed data on individual pharmacies will not be allowed out of the Secure Research Service environment.
A non-disclosure agreement is in place between DHSC and LE to protect all data and research findings owned by DHSC.

B3 The risks and limits of new technologies are considered and there is sufficient human oversight so that methods employed are consistent with recognised standards of integrity and quality.

Please describe how the any risks from new technologies are been mitigated as well as any quality assurance activities in the project (max 500 words)

No new technologies are being used.

The Reference Pharmacy model itself is a bespoke tool that will not be made publicly available as it is owned by the Department of Health and Social Care. Nevertheless the research methods employed during this project will be openly available for further scrutiny or replication of results.

B4 Data used and methods employed are consistent with legal requirements such as the Data Protection Act, the Human Rights Act, the Statistics and Registration Service Act and the common law duty of confidence

Please describe the legal frameworks pertinent to this project (max 500 words)

Access to the potentially disclosive data will be in the Secure Research Service environment and via an approved legal gateway (Approved Researcher scheme). This is in compliance with the Statistics and Registration Service Act 2007. The methods used are compliant with the principles in the Data Protection Act.

B5 Collaboration and Sponsors

Please describe the project sponsors and the **legal gateways** to acquire, process use and share their data

List of Collaborators/Sponsors	**Details and relevant documentation relating to collaboration (you may attach copies of relevant documentation)**
Department of Health and Social Care	Contract between DHSC and London Economics Non-disclosure agreement further controls LE's use of data NHS income data belongs to DHSC and is used in accordance with the original consent

B6 The views of the public are considered in light of the data used and the perceived benefits of the research

Please list any public engagement activities (max 250 words)

Whilst the views of the public have not been sought with regards to the research, there is a clear public benefit for the analysis (as described in B1 above). A public consultation on the Approved Researcher scheme in 2015/16 recommended that commercial organisations should be allowed to access ONS research data where there is a clear public benefit.

B7 The access, use and sharing of data is transparent, and is communicated clearly and accessibly to the public

How will the findings of the research be disseminated? (max 500 words)

ONS has a commitment to transparency and publishes a register of all Approved Researchers on their website. This includes their organisations, current projects, sponsors and the datasets being used.

Analysis will be referenced in publicly available DHSC policy documents, and DHSC will present summary analysis in an annex to these policy documents.

ONS will include a link to the policy documents from the Approved researcher web pages and we will work with London Economics and DH to investigate producing a detailed case study showcasing the impact of the research.

B8 Please outline any intended future use for products (such as linked data sets or tools) produced as a result of the research and how they will be accessed. (max 250 words)

The outputs of this project will be used as data for DHSC's Reference Pharmacy tool. This will make use of data from multiple sources, to illustrate how much it should cost to service a particular prescription volume on the level of an individual Community Pharmacy at a particular level of return. Data used by DHSC in constructing this tool includes internal DHSC administrative data, and other DHSC-commissioned research, for example a prior PriceWaterhouse Cooper project used anonymised data from a survey of 600 pharmacies to improve understanding of the characteristics of an efficient pharmacy.

The Reference Pharmacy tool will provide an insight into the potential impact of any reforms and will form an important part of the evidence base for DHSC policy. It is only for internal use by the Department for Health and Social Care and only incorporates data that DHSC owns or has been legally released to them for use.

Section C
Responsible owner and applicant details

C1 Responsible Owner

Full Name: [redacted]	**Position:** [redacted]
Address: [redacted]	**Email:** [redacted]
	Telephone: [redacted]
	Organisation: [redacted]

Declaration to be signed by the responsible owner

I have met with and advised the applicant on the ethical aspects of this project design (applicable only if the responsible owner is not the Applicant).

I understand that it is a requirement for all researchers accessing the data to have undergone relevant training and to have either relevant security clearances or approved researcher status in order to access the data.

I am satisfied that the research complies with current professional, departmental and other relevant guidelines.

I will ensure that changes in approved research protocols are reported promptly and are not initiated without approval by the National Statistician's Data Ethics Advisory Committee.

I will provide notification when the study is complete if it or fails to start or is abandoned.

I will ensure that all adverse or unforeseen problems arising from the research are reported in a timely fashion to the National Statistician's Data Ethics Advisory Committee.

I will consider all advice received from the National Statistician's Data Ethics Advisory Committee and should I be unable to implement any of the recommendations made, I will provide reasoning in writing to the Committee.

Signature: [redacted] **Date:** [redacted]

C2 Applicant Details (if applicant is not the responsible owner)

Full Name: [redacted]

Position: [redacted]

Address: [redacted]

Email: [redacted]

Telephone: [redacted]

Organisation: [redacted]

Any other business