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| **http://www.abdn.ac.uk/iahs/uploads/media/aberdeen.jpg** |

# **North Node Privacy Advisory Council (NNPAC) Application Form**

Please refer to the *NNPAC Guidance Notes for Applicants* when completing this form. The form should be completed in collaboration with the Grampian Data Safe Haven (DaSH).

Document available at [www.abdn.ac.uk/clinicalresearchgovernance](http://www.abdn.ac.uk/clinicalresearchgovernance)

**After completion please return form to: North Node Privacy Advisory Committee (nnpac@abdn.ac.uk)**

**Email: nnpac@abdn.ac.uk**

**Section 1**

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| **Full Project Title** |
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| **Documents to be submitted with the Application** | | |
| Peer Review | (this application will not be reviewed if this is not included) | |
| Protocol | Version no: | Date: |
| Data Linkage Plan | Version no: | Date: |
| CV for researchers |  |  |
| Evidence of Information Governance Training |  |  |
| Evidence of funding (if applicable) |  |  |

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| **Overview of project data** |
| Is the purpose of the study to identify small geographical areas or rare events (e.g. rare adverse clinical events)? (Yes/No) |
| If yes, please provide details: |
| Is the data being accessed from outside the UK? (Yes/No) |
| If yes, please provide details: |
| Does the study involve a commercial partner? (Yes/No) |

**Section 2 – Applicants**

Please provide details for the Chief Investigator and any other collaborators including students who will have access to the generated data.

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| **Chief Investigator/Academic Supervisor** | | | |
| Full Name: |  | | |
| Position |  | | |
| Organisation Name (please select): | University of Aberdeen or NHS Grampian | | |
| Departmental Address |  | | |
| Email: |  | Tel: |  |
| **Please tick to confirm you will undertake appropriate information governance training before accessing linked data as per DaSH standard processes** | | | |
| **Student** | | | |
| Full Name: |  | | |
| Position |  | | |
| Organisation Name: | University of Aberdeen | | |
| Departmental Address |  | | |
| Email: |  | Tel: |  |
| **Please tick to confirm you will undertake appropriate information governance training before accessing linked data as per DaSH standard processes** | | | |

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| **Other Collaborators who will be accessing the de-identified research data** | | | |
| Full Name: |  | | |
| Position |  | | |
| Organisation Name: |  | | |
| Departmental Address |  | | |
| Email: |  | Tel: |  |
| **Please tick to confirm you will undertake appropriate information governance training before accessing linked data as per DaSH standard processes** | | | |
| **Other Collaborators who will be accessing the de-identified research data** | | | |
| Full Name: |  | | |
| Position |  | | |
| Professional Registration No.: |  | | |
| Organisation Name: |  | | |
| Departmental Address |  | | |
| Email: |  | Tel: |  |
| **Please tick to confirm you will undertake appropriate information governance training before accessing linked data as per DaSH standard processes** | | | |

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| **Do any of the researchers or collaborators have a conflict of interest in relation to the study? (see guidance for examples)** |
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**Section 3 – Research Proposal/Research Project or Study**

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| **Proposal Essentials** | | | |
| Provide a **clear and concise lay** outline of the proposal (max. 250 words); this will be made available on the DaSH website along with the name and email address of the Chief Investigator or Academic supervisor**.**  **All applications MUST be accompanied by a copy of the study protocol.** | | | |
|  | | | |
| Please tick the box to indicate who carried out the peer review for your project and their role.  **All applications must be accompanied by a copy of an independent peer review of the proposed research protocol.** | | | |
| Internal staff | External body | Funding body | Other |
| Name of Reviewer(s) | ………………………..  ……………………….. | Academic  Specialist |  |
| If other, please provide further details. | | | |
| How have the statistical aspects of the research been reviewed? *Tick as appropriate:* | | | |
| Independent statistician | Statistician within Chief investigators institution | Educational supervisor | Other review by individual with relevant statistical expertise |
| In all cases please give details below of the individual responsible for reviewing the statistical aspects: | | | |
| Name of Reviewer  Email: | ………………………..  ……………………….. | Organisation/ Institution | ……………………….. |

**Section 4 – Datasets**

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| **DaSH has NHS Grampian Caldicott approval to access and process patient identifiable data from the following datasets for research purposes, on behalf of NHS Grampian (the Data Controller). Which datasets do you want to use in your study? Please tick the appropriate boxes.** | |
| Scottish Morbidity Record (SMR) 00 - Outpatient attendance |  |
| Scottish Morbidity Record (SMR) 01 - General / Acute Inpatient and Day Case |  |
| Scottish Morbidity Record (SMR) 02 - Maternity Inpatient and Day Case |  |
| Scottish Morbidity Record (SMR) 04 - Mental Health Inpatient and Day Case |  |
| Scottish Morbidity Record (SMR) 06 - Cancer Registry |  |
| National Records of Scotland (NRS) Deaths |  |
| Community Health Index Register (including deaths) |  |
| Prescribing Information System (PIS) |  |
| Laboratory Data (APEX) – Clinical biochemistry |  |
| Laboratory Data (APEX) - Haematology (including immunology) |  |
| Laboratory Data (APEX) – Microbiology (including virology) |  |
| Laboratory Data (APEX) – Pathology (including Gynae-cytology) |  |
| Imaging Data (NHS Picture Archiving and Communication System (PACS) – imaging data |  |
| Imaging Data (NHS Picture Archiving and Communication System (PACS) - reports |  |
| Scottish Care Information – Diabetes Collaboration (SCI-DI) for NHS Grampian patients |  |
| TrakCare Data   * TrakCare Inpatient Admission Measures Grampian * TrakCare Emergency Department Attendances Grampian * TrakCare Outpatient Activity Grampian * TrakCare Waiting List Grampian |  |
| Clinical letters (e.g., Outpatient Clinic and GP Referrals) |  |
| Glomerular and rheumatic diseases dataset |  |
| Badgernet |  |
| Child and Adolescent Mental Health Services (CAMHS) data |  |
| Psychological Therapies data (via Integrated Care pathways) |  |
| COVID-19 testing data |  |
| COVID-19 shielding data |  |
| Vaccination data (including COVID-19 and flu data) |  |
| Care Home Addresses |  |
| Fracture Liaison Service (FLS) database |  |
| Patient Reported Outcome Measures (PROMs) |  |
| OPERA (theatre records) |  |
| GP Out of Hours (Adastra) |  |
| GP Local Enhanced Services (GP LES) data |  |
| NHS 24 data |  |
| Scottish Ambulance Services |  |
| Grampian Renal Unit Data including Renal Replacement Therapy (RRT) |  |
| Genetics data |  |
| Haematology Clinic Dataset |  |
| Aberdeen Fertility Clinic (AFC) |  |
| Cancer Care Pathways Data (CCPD) |  |
| Health visitor / MORSE data |  |
| Scottish Medical Imaging (SMI) data |  |
| CHI database |  |
| Grampian Kidney and Vasculitis Dataset |  |
| Hospital Electronic Prescribing and Medicines Administration (HEPMA) |  |
| RotaWatch |  |
| Chemocare |  |

**Section 4 – Other Dataset Permissions**

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| **If your project includes any of the data sets listed below, or other datasets, please indicate the status of your application to the Data Custodians for permission to use the data. e.g. Aberdeen Maternity & Neonatal Databank, Children of the 1950s** | | | |
| **Data Set** | **In Progress** | **Conditional Approval** | **Approved** |
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**Section 5 - Data Variables**

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| **Data protection law requires that the use of either directly or indirectly identifiable data variables is minimised to those which are strictly necessary. This is known as the ‘data minimisation’ principle. In the table below please justify the need for all of the** **identifiable or potentially identifiable variables to be included in your de-identified research dataset (e.g. postcode, age, sex):** | | |
| **Identifying or Potentially Identifying Variable** | **Justification** | |
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|  |  | |
| Are you looking to identify small geographical areas or rare events (e.g. rare adverse clinical events)? | | |
| Yes | | No |
| If yes, please justify. | | |
|  | | |
| **Please include a copy of a data linkage plan for your study with your application** | | |

**Section 6 – Disclosure Control**

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| **What steps will be taken to ensure that individuals cannot be identified in published findings? Please give details and confirm what disclosure control policy will be applied.** |
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**Section 7– Timescale for Data Access & Data Storage**

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| **Data Access & Data Storage** | |
| What is the proposed duration of the study |  |
| **Proposed Start Date** (the date when the study starts) |  |
| **Proposed End Date** (the date when the study is finished and all the data for the study has been collected) |  |
| How long will the data be stored after the end of the study? |  |
| If storage/archive is greater than 5 years, please provide suitable justification: |  |

**Section 8 – Funding**

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| **As the Grampian Data Safe Haven is a cost recovery service assurance that funding is available or will be sought is essential.** | | | |
| Is funding available? | Yes | | No |
| If yes, who is funding the study? | | | |
| If no, what is the potential source of funding? | | | |
| If a grant application is to be submitted, what is the status of it? | | | |
| Pre-application | | Application outcome pending | |

**Section 9 – Declaration**

* I DECLARE THAT this application is accurate, and that, should it be successful, any health data made accessible will be used for no other purpose, and in no other way, than as described above.
* I UNDERTAKE TO notify NNPAC of any future changes to the purpose or manner in which data is processed in accordance with this application.
* I AGREE TO abide by any conditions attached to the application by NNPAC during the approval process. I understand that failure to comply with these conditions may result in any future applications by me, or my employing or sponsoring organisation, may be refused.
* I CERTIFY THAT all those who have access to health data in this proposal are aware of the requirements of confidentiality and understand that any breach (e.g. disclosure of confidential information to a person not authorised to receive it) will be reported to the Data Protection Officer for the University of Aberdeen, in the first instance.
* I UNDERSTAND THAT the Data Controller, and agents acting on its behalf, reserves the right to inspect the data on the sites where it is being processed.

To be signified by the APPLICANT

|  |  |
| --- | --- |
| Name (in Capitals): | Date: |

To be signified by the Academic SUPERVISOR (if applicable)

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| --- | --- |
| Name (in Capitals): | Date: |

* I DECLARE THAT (the applicant named above) is a *bona fide* worker engaged in a reputable project and that the data he/she asks for can be entrusted to him/her in the knowledge that he/she will conscientiously discharge his/her obligations, including in regard to confidentiality of the data, as stated in the declaration above.

**For Office Use only (to be completed by the NNPAC Administrator)**

**Section 1**

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| **Documents included with the application** *if any required documents are not included - return to researcher for inclusion* | | |
| Peer review evidence | Yes | No |
| Project Protocol | Version number: | Date: |
| Data Linkage Plan | Version number: | Date: |

|  |  |  |
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| **Overview** *a yes for small area/numbers or access from outside UK requires* ***review by full committee*** *otherwise continue with approval assessment.* ***NNPAC will not approve commercial studies*** *- advise researchers to make separate approval applications.* | | |
| Small area/numbers | Yes | No |
| Data being accessed from outside the UK | Yes | No |
| Commercial Project | Yes | No |

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| **Decision Tree for project review:** | | |
| **Section** | **Guidance** | **Approval** |
| Section 2 - Applicants | All details for applicant and collaborators/students complete. | Yes/No |
| Section 3 - Proposal | All details complete and appropriate. | Yes/No |
| Section 4 - Datasets / Other Datasets | Datasets from core list with ‘pre-approval’ for which NNPAC ‘fast track process’ applies.  Other local datasets with their own steering groups which also provide permissions (outside NNPAC process). NNPAC conditional approval can be given pending data custodian / steering group approval. | Yes/No |
| Section 5 - Data Variables | Researchers should justify the need for all of the identifiable or potentially identifiable variables to be included in their de-identified research dataset (e.g. postcode, age, sex).  If not, return the application to the researcher for completion.  All projects looking to identify small geographical areas or rare events (e.g. rare adverse clinical events) should be justified and will be reviewed by the full committee.  If no justification provided, reject and return application to researcher for completion. | Yes/No |
| Section 6 – Disclosure Control | Researchers should state they will follow the DaSH disclosure control policy and any additional requirements of other data custodians. Researchers should explain how they will handle small numbers (<5) when requesting release of their analysis from DaSH or presenting their data for publication e.g. obscuring/not reporting low numbers or merging data categories. They should demonstrate they understand it is their responsibility to ensure published results do not contain any information or combination of information that could identify an individual e.g. the Principle Investigator signs a DaSH Investigator Declaration agreeing to the terms and responsibilities for accessing data for research within DaSH and is responsible for ensuring the research team are aware of their obligations.  If insufficient information is provided, reject and return application to researcher for completion. | Yes/No |
| Section 7– Timescale | If insufficient information is provided, reject and return application to researcher for completion. | Yes/No |
| Section 8 – Funding | To confirm that funding has at least been considered and an application is under way or funding has been secured.  If no funding – NNPAC conditional approval pending confirmation with DaSH of resource to undertake the work. | Yes/No |
| Section 9 – Declaration | If not signed/dated as required reject and return application to researcher for completion. | Yes/No |

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| **Application Details** | | |
| Application Number |  | |
| Date of Submission |  | |
| Date sent for NNPAC review (if applicable) |  |  |
| Approved | Yes | No |
| Approval Start Date |  |  |
| Approval End Date |  |  |

**Post Approval – Progress Reports**

|  |  |  |
| --- | --- | --- |
| **Progress Reports – Year 1** | | |
|  | **Date Sent** | **Date Received** |
| Email to be sent 6 months after approval to check start date |  |  |
| Request for Progress Report to be sent 12 months after approval |  |  |
| Actions Required from information received |  | |
| **Progress Reports – Year 2** | | |
|  | **Date Sent** | **Date Received** |
| Request for Progress Report |  |  |
| Actions Required from information received |  | |

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| **Progress Reports – Year 3** | | |
|  | **Date Sent** | **Date Received** |
| Request for Progress Report to be sent 12 months after approval |  |  |
| Actions Required from information received |  | |

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| **Progress Reports – Year 4** | | |
|  | **Date Sent** | **Date Received** |
| Request for Progress Report to be sent 12 months after approval |  |  |
| Actions Required from information received |  | |

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| **Progress Reports – Year 5** | | |
|  | **Date Sent** | **Date Received** |
| Request for Progress Report to be sent 12 months after approval |  |  |
| Actions Required from information received |  | |

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**Post Approval – Amendments**

|  |  |
| --- | --- |
| **Amendments** | |
| Amendment Number |  |
| Date Received |  |
| Brief Description of the Amendment |  |
| Reviewed by |  |
| Decision with Date |  |
| Date of decision sent to Researcher |  |
| Notes |  |
| **Amendments** | |
| Amendment Number |  |
| Date Received |  |
| Brief Description of the Amendment |  |
| Reviewed by |  |
| Decision with Date |  |
| Date of decision sent to Researcher |  |
| Notes |  |
| **Amendments** | |
| Amendment Number |  |
| Date Received |  |
| Brief Description of the Amendment |  |
| Reviewed by |  |
| Decision with Date |  |
| Date of decision sent to Researcher |  |
| Notes |  |
| **Amendments** | |
| Amendment Number |  |
| Date Received |  |
| Brief Description of the Amendment |  |
| Reviewed by |  |
| Decision with Date |  |
| Date of decision sent to Researcher |  |
| Notes |  |