Public Health England

Protecting and improving the nation's health

Completing the Office for Data Release data request form, version 2, April 2016

The Office for Data Release (ODR) data request form captures a summary of the proposed project and confirms that the necessary approvals are in place to proceed with the application.

It is the applicant's responsibility to ensure that he or she submits all the documentation necessary to initiate the ODR review process (see Appendix 1). Not doing so will cause delays to the processing of the request.

Submission of data requests

All requests for personal or sensitive data should be submitted to the ODR by email to ODR@phe.gov.uk or in writing to the Office for Data Release at the following address:

Office for Data Release
C/o Rachael Brannan
Public Health England
Skipton House 2nd Floor – Zone D
80 London Road
SE1 6LH

Deadlines for submission

Unless otherwise stated, the initial assessment of a request will take approximately five working days. On occasions where there is a significant demand for ODR services, this may take longer. The ODR will contact applicants regarding any significant delays and provide a new estimated timescale for review.

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Section 1: applicant and organisation information

All fields in this section are mandatory and will be used to draft a Data Sharing Contract between the applicant and PHE. On release of the data, PHE will publish a summary of the request in the PHE Data Release Register.

Applicant title, name, job title and contact information:	The contact information of the person with overall responsibility for directing the project (such as the principal investigator, audit or clinical lead)**.**
Applicant email address and telephone	Email address and a telephone number to allow us to contact the applicant or forward the information once a decision has been made.
Organisation name and registered address:	The registered organisation name and address of the applicant.
Organisation type:	The relevant organisation type from the categories provided.

Section 2: funding and sponsorship (optional)

Where applicable, all fields in this section should be completed.

Name and address of awarding institution	List all sponsor or funding bodies related to the project.
Reference for project/activity:	List all project references assigned by the sponsor or funding body named above.

Section 3: project summary

All fields in this section are mandatory and will be used to draft a Data Sharing Contract between the applicant and PHE. On release of the data, PHE will publish a summary of the request in the PHE Data Release Register.

ODR reference	The reference assigned by the ODR for this project. Leave blank if you are yet to be assigned a reference number.
Data Sharing Contract Reference:	The reference number of any pre-existing Data Sharing Contracts or Data Re-use Agreements (pre April 2015) that relate to this request. If the request is new leave blank.
Project title:	The project title should be descriptive and concisely indicate the subject of inquiry. Any abbreviations should be spelled out in full.
End-use:	The end-use category of the data request. If the request has more than one end-use, select those that are relevant.
Provide a summary of the project's aims, objectives, methods and anticipated outputs:	Provide a summary of the request (max 500 words). Ensure the summary contains no information attributable to an individual (such as their name, address or NHS number). Forms which fail to include a summary of their purpose will be deemed invalid. To support the application, applicants should enclose a detailed protocol and affirm that all processing shall be conducted for the purpose(s) outlined in the protocol. The purpose for processing the data must be consistent with your organisation's Data Protection Registration.
Do you intend to use the data provided to contact anyone? If yes, who?	Describe all instances where the data will be processed during the course of the project to contact a data subject, relative of the data subject or care professional. Any supporting documentation that is descriptive of this communication process must be included in the project application.
Please indicate the estimated project start date and project duration (months)	Provide an overview of project start date and the planned duration of the project (ie start date 01/01/2017. Project to be delivered within 18 months).

Data already held for this project	Identify all data that has already been provided by PHE or other data controllers (such as the Office for National Statistics (ONS), primary care databases, the Health and Social Care Information Centre (HSCIC)) for the project purpose of outlined in this form. This should include: • dataset name • classification of the data (ie identifiable) • legal basis for processing • dataset period

Section 4: data specification

All fields in this section are mandatory and will be used to draft a Data Sharing Contract between the applicant and PHE. On release of the data, PHE will publish a summary of the request in the PHE Data Release Register.

Data specification:	Applicants should enclose a detailed data specification and affirm that the data specification is the **minimum necessary** to fulfil the purpose(s) for processing. In the data specification ensure that: • each dataset is clearly defined, labelled and where more than one table is required, this should be indicated • variable names and codes are consistent with the asset data dictionary • identify if aggregated or row level data is required • all relevant coding classifications are included • all relevant geographies are identified • all relevant times periods are defined as YYYY-MM-DD • where you require PHE to derive a data field from a pre-existing source, this is agreed locally with the relevant PHE team • where a project specific identifier (such as a pseudo ID) is provided, each subject should be identified by a single, unique subject identifier.

Classification of the data requested:	The classification of the data requested. Whenever it is possible and practicable to do so, data released by PHE will be anonymised. Anonymisation will be conducted in accordance with the rules set out in the ISB Anonymisation Standard for Publishing Health and Social Care Data Specification (2013). Detailed guidance on good practice in anonymisation has been produced by the Information Commissioner's Office in Anonymisation: Managing Data Protection Risk – Code of Practice (2012) If you are unsure if the data you are requesting would meet the requirements of the ISB Anonymisation Standard for Publishing Health and Social Care Data Specification, contact the ODR.
Data source:	The data source(s) applicable to the request.
Specify any data linkage requirements and data flows:	Provide a summary of any data linkages required as part of this project. Where there are multiple data linkages required, involving two or more data processors, the protocol must include a diagram to illustrate the proposed data flows.
Frequency:	The frequency an extract will be required for this request. Where 'other' indicate the frequency.
Preferred form for receipt of the data:	Check the appropriate box. If 'Other' is checked, specify.
Is there a deadline for receipt of the data?	Indicate the deadline for receipt of the data. Where feasible, the ODR will honour deadlines for the receipt of data, however this will be dependent on the nature of request and volume of requests with the ODR. Apply as early as possible to allow sufficient time for your application to be reviewed.
Data retention period required:	By default, all Data Sharing Contracts issued by the ODR will stipulate a term of twelve months. If you require the data to be processed in excess of this term, indicate and justify the retention period required. Requirements for retention and archiving, such as those required by funding bodies, should be clearly stipulated.

Section 5: PHE programme support (where relevant to data asset)

Please identify any contacts within PHE your request has been discussd with:	Indicate the name of anyone with PHE who has been involved in the development of your project.
Has programme support been sought/ granted?	Some datasets require you to gain programme level approval before submission to the ODR. Identify if you have approval from a specific PHE programme. Enclose any supporting documentation detailing this support (ie letter from the Bowel Screening Evaluation Committee). **NHS Screening Programmes** It is a mandatory requirement for all projects requesting access to data from the NHS Screening Programme to obtain programme specific approval. Prospective applicants are advised to contact in advance of contacting the ODR: Rachel Crowther (rachel.crowther@phe.gov.uk) in regards to access to the cancer screening programmes. Siohan Ryan (siobhan.ryan@phe.gov.uk) in regards to the non-cancer screening programmes.
Reference and date of programme approval:	Cite any reference given to this project and dates associated with this approval.

Section 6: legal gateway to process identifiable data

For Applicants requesting access to patient identifiable data (including name, address, postcode, date of birth or date of death) completion of this section is mandatory.

A summary of the legal basis to process patient identifiable data (where applicable) will be published by PHE on release of the data.

Direct care	Where data for the purpose of direct care, applicants should evidence support from an appropriate signatory and enclose evidence of this support. See Appendix 2 for more information. The Caldicott Review defined 'direct care' as a clinical, social or public health activity concerned with the prevention, investigation and treatment of illness and the alleviation of suffering of individuals by one or more registered and regulated health or social care professionals and their team with whom the individual has a legitimate relationship for their care.
Informed patient consent	All requests which stipulate informed consent as their legal gateway must enclose a copy of a blank consent form AND associated patient information leaflets. The Information Commissioner's guidance says that the consent must be absolutely clear: it should cover the specific processing details, the type of information (or even the specific information), the purposes of the processing, and any special aspects that may affect the individual, such as any disclosures that may be made.
Regulation 3, Health Service (Control of Patient Information) Regulations 2002	All applicants requesting to access data held by PHE under this legal gateway are required to contact ODR@phe.gov.uk prior to submission.
Regulation 5, Health Service (Control of Patient Information) Regulations 2002 (Section 251 exemption)	In England and Wales, Section 251 of the NHS Act 2006 (originally Section 60 of the Health and Social Care Act 2001) provides the statutory power to permit the use of patients' medical information without their consent. All letters documenting that Section 251 support has been granted by the Health Research Authority should be forwarded to the ODR to support your application. Include the CAG reference, date of first approval and the date of next review (CAG annual review) for the project by the Confidentiality Advisory Group (CAG).
Other	Specify.

Section 7: legal gateway to process ONS mortality data

Applicants requiring access ONS mortality data (date of death, place or cause of death) must be granted approval by the ONS Micro Data Release Panel, unless exemptions are in place.

Applicants requesting **linked cancer mortality data are exempt** from this process. Please note, where cancer screening data is requested, PHE is unable to provide data on screening participants who **do not** have a diagnosis of cancer.

For more information about access to ONS mortality data, visit: www.hscic.gov.uk/onsmortality

Legal gateway held to process ONS mortality data	Indicate the legal gateway held to process ONS mortality data.

Section 8: Research Ethics Approval (REC) to process potentially or explicitly identifiable data

REC name and approval reference:	Outline all relevant oversight from a recognised research ethics committee (REC) and enclose copies of the approval letter(s) and/or acknowledgement of amendments to an exisiting REC approval. If you are unsure if the data you are requesting would meet the ISB Anonymisation Standard for Publishing Health and Social Care Data Specification (2013), contact the ODR. The ODR will conduct a privacy impact assessment using the rules set out in the standard. The ODR will advise if the data would be considered anonymised (therefore not requiring REC approval) or potentially identifiable (REC required). Applicants requesting to process potentially or explictly identifible data outside the UK should contact the ODR to discuss ODR requirements for REC oversight.

Section 9: data management and security – applicant's organisation (mandatory)

Data Protection Act Registration	Indicate the relevant organisation code and name (as registered). The ICO publishes the complete Data Protection Register on line.You can search for your institution's Registration Number and Register entry at: ico.org.uk/esdwebpages/search It is a criminal offence to process (which includes sharing) personal data in a manner which is inconsistent with your registration. Ensure your organisation's registration is consistient with the reasons/purposes for processing information and type/classes of information processed within your request.
Data security	Indicate from the list and provide supporting evidence as indicated. • IG Toolkit score and organisation code • ISO 27001 certification • System Level Security Policy (SLSP)

Section 10: data management and security outsourced organisation (mandatory if any processing activities will be outsourced)

Name(s) and address of data processor(s) (if different from applicant):	The data processor is the named individual or organisation who will process the data on behalf of the applicant. This includes organisations commisioned to send out surveys, conduct analyses or store data for the applicant.
Processing	Check the appropriate box for the location where the data processing will take place. If 'other' is stipulated or multiple locations will be required, list all associated organisation names and addresses.
Storage	Check the appropriate box for the storage of the data. If 'other' is stipulated or multiple locations will be required, list all associated addresses. Where cloud storage is utilised, you will be required to provide

	guarantees that the servers are within the EEA. Applicants should contact the ODR to discuss.
Data Protection Act Registration	Indicate the relevant organisation code and name (as registered). The ICO publishes the complete Data Protection Register on line.You can search for your institution's Registration Number and Register entry at: http://ico.org.uk/esdwebpages/search It is a criminal offence to process (which includes sharing) personal data in a manner which is inconsistent with your registration. Ensure your organisation's registration is consistient with the reasons/purposes for processing information and type/classes of information processed within your request.
Data security	Indicate from the list and provide supporting evidence as indicated. • IG Toolkit score and organisation code • ISO 27001 certification • System Level Security Policy (SLSP)

Section 11: expected outputs and dissemination of results

Expected outputs	Specify the outputs expected from this project.

Section 12: any additional information

Stipulate any other information relevant to this project you think the ODR should be aware of.

Section 13: declaration

The declaration must be signed and dated by before being submitte to the ODR for review.

Accompanying documentation/evidence

Where evidence is required list each document provided, including the file name and version in Appendix 1.

Appendix 1: application requirements

Requirement	Research	Clinical audit	Service evaluation
ODR data access request form	√	√	√
Data specification	√	√	√
Protocol (detailed)	√	√	√
Ethics approval	√	x	x
Legal gateway (identifiable data only)	√	√	√
IG Toolkit Level 2 or equivalent	√	√	√
Programme level approval (NHS Screening programmes only)	√	√	√

Appendix 2: approved signatories for requests for data for the purpose of direct care

All requests for data for direct care (including local audit and service evaluation) should be accompanied by a signed letter of support from the host organisation. Possible signatories for the different organisations requesting different types of data are listed below, but their inclusion does not necessarily mean that anyone or only one of them can sign for a given request. Depending on the purpose of the request, the ODR will use their discretion as to who should sign, and for some requests, several signatories may be needed.

NHS trust	
Clinician's own data	Treating clinician Caldicott guardian/medical director
Disease or site-specific data	Lead clinician for disease area (ie cancer lead clinician) Lead clinician for audit (if data request stated for audit) Caldicott guardian/medical director
Data for the whole trust	Caldicott guardian/medical director
Data for split site trusts/centres	Caldicott guardian from each unit Medical director from each unit
Private Hospital	
All hospital/unit	Caldicott guardian/medical director
Private Pathology Laboratory	
Own pathology patients only, and only the data they sent us if possible	Head of pathology service
Hospice	
Own patients – complete records	Caldicott guardian/medical director
GP Practice	
Own patients – either at diagnosis or registered at time of request	Signatures of all GPs Caldicott guardian