Information request form - please return

UKACR - United Kingdom Association of Cancer Registries

Patient Identifiable or Potentially Identifiable Data

REQUEST FORM

NB. These rules apply to England and Wales only

IMPORTANT – PLEASE READ

About this form

This form is a support document, and does not replace the requirement for a study protocol, where relevant.

It covers the release of data that are potentially identifiable or identifiable only. Do not use this form if you require non-identifiable data (see Appendix for details)

Please read and retain Guidance Notes - pages 5-6

Return form only (pages 1-4) – this form can be filled in electronically (MS Word), then printed out to sign.

Please return the completed and signed form, by post or fax only, to the address shown on the right.

Research or Audit

If requesting data for research or audit you must send a copy of your study protocol where relevant.

For research, when requesting identifiable data, you must also include a copy of the appropriate Ethics Committee approval, along with PIAG approval or evidence of patient consent.

Please send copies of all these documents with this form to the Registry

Caldicott Guardian Informed

A signed copy of this release form may be forwarded to the appropriate Caldicott Guardian

Where the recipient is based at another organisation, a further copy may be forwarded to the Caldicott Guardian of that organisation.

Declaration

Applicant should sign declaration on page 3 in all cases, but the level of identifiable data requested will determine which (if any) co-signatory is required

Data Items

Please request only the data items that you actually need for the requirements of your work. Do not request additional data items.

Although there are many data items listed, we are obliged to restrict data release to the minimum required for your study, at the highest level of anonymisation possible.

The list of data items is only intended as a starting point in a dialogue with the registry, who can help you explore the needs of your study and to inform whether particular data items are complete or robust enough for analysis

Data Interpretation

Please consult the cancer registry on the interpretation of data – for example, changes in coding practice over time can have large impacts on data, which may be artefactual and not epidemiological

Publication

If you intend to publish works containing the data in any form, please consult the cancer registry

ukacr
United Kingdom Association of Cancer Registries

SEND COMPLETED FORM TO (pages 1-4 only)

Address:	South East Knowledge and Intelligence – Cancer Public Health England 4150 Chancellor Court Oxford Business Park South Oxford OX4 2GX		
Tel:	01865 334 700	Fax:	01865 334 715
Email:	enquiries@ociu.nhs.uk		

CONTACT DETAILS

Person To Whom Data Are To Be Released	
Title	
Full Name	
Job Title	
Organisation	
Address (work)	
Postcode	
Telephone	
Fax/Mobile/Bleep	
Email	

STUDY DETAILS

Purpose

Purpose for which data are required (please explain why non-identifiable data will not meet your needs). Please attach your study protocol, if relevant.

Scope - ☐ National / ☐ Multi-Registry / ☐ Single Registry (registry involvement, please give details in text box above - all requests will be co-ordinated through the registry shown)

DATA RANGE REQUIRED

Data Requirements

☒ **Tumour site**(s) and/or ☐ **morphologies**

Sex - ☐ Male / ☐ Female / ☐ Both

Years of - ☒ Diagnosis / ☐ Death / ☐ Treatment

☐ **Geographical areas /** ☐ **Organisations** (eg Specified PCT, Electoral Ward, Trust, Hospital, Cancer Network):

Age Groups - ☐ 5 Year Groups (0-4, 5-9 …80-84, 85+) or ☐ Other (specify) **NB. These are only for potentially identifiable data**

Any other details (please continue on page 4 if necessary)

Is there a deadline for receipt of data?

☐ YES / ☐ NO - If yes, please give date and reason:

Preferred form for receipt of data

☐ Paper / ☐ EXCEL / ☐ ASCII / ☐ Other (Specify):

DATA ITEMS REQUIRED

Discuss data requirements with the Cancer Registry

Please note that this is not meant to be an exhaustive list, but primarily a tool, intended to open a dialogue between the applicant and the Cancer Registry.

Although there may be capacity to collect all of these data items, they are not always recorded. The Cancer Registry will advise you about the completeness of these variables in relation to your request.

For example, some data items may only be available only for specific cancer sites or recent years. It may be possible to extract further details if these exist (eg. treatment types or dates). Please consult the Cancer Registry for advice.

Data Required

Please tick only the identifiers and data items that are absolutely essential for the requirements of your work

☒ *please check items required*

Personal Details

- ☐ **NHS number**
- ☐ **Patient Name** (Surname, Forename, Initials)
- ☐ **Surname at birth** (previous surname)
- ☐ **Address** (at time of diagnosis)
- ☐ **Sex** ☐ **Age** (at diagnosis)
- ☐ **Date of Birth** ☐ **Ethnic origin**
- ☐ **Postcode** (at time of diagnosis)

Various geographies can also be derived from postcode:

- ☐ *Cancer Network* ☐ *Electoral Ward*
- ☐ *Strategic Health Authority* ☐ *Local Authority*
- ☐ *Primary Care Organisation* ☐ *ONS Super Output Area*
- ☐ *Government Office Region* ☐ *Deprivation Index*

Diagnostic, Tumour And Treatment Details

- ☐ **Site** of primary neoplasm (or main presenting secondary when primary site is not known)
- ☐ **Morphology** (type of neoplasm)
- ☐ **Laterality** (side) for paired organs
- ☐ **Stage** (limited information – available for breast, cervix, melanoma and colorectal cancer only)
- ☐ **Grade** of tumour (degree of differentiation – available for breast and cervical cancer)
- ☐ **Basis of diagnosis** (histology, cytology, haematology, clinical opinion, other tests)
- ☐ **Date of diagnosis** ☐ **Year Only**
- ☐ **Treatment indicators** (treatment within first six months after diagnosis, where intent was curative - surgery, radiotherapy, chemotherapy, hormone, other)

Hospital Details

- ☐ **Hospital** ☐ **Trust**
- ☐ **Consultant** (Surname, Initials, Specialty, GMC Code)
- ☐ **Unit number** (PAS Number)

Death Details

- ☐ **Alive/dead**
- ☐ **Date of death**
- ☐ **Cause and place of death**
- ☐ **Post mortem**

CONFIDENTIALITY/ ETHICS APPROVAL

Considerations for Identifiable Data Release Only

☒ *please check all boxes that apply and give any further details in the space provided*

Patient Information Advisory Group (PIAG)

PIAG considers the use and transfer of identifiable patient data under Section 60 of the Health and Social Care Act 2001 (http://www.advisorybodies.doh.gov.uk/piag/)

Note: Identifiable data cannot be released without Ethical Committee Approval and either (A) Patient Consent or (B) PIAG approval, except to (C) authorised personnel in approved organisations– please see the Guidance Notes for further information

Type of Identifiable Data Request

Consent type obtained (please complete relevant sections)

☐ (A) Patient consent ☐ (B) PIAG approval ☐ (C) Other approved signatory

A - Individual Patient Consent

☐ I have received proof of written consent for all patients

☐ I have enclosed a copy of a blank consent form, to which all patients have agreed

B - PIAG APPROVAL (for research requests)

Has PIAG approval been given?

☐ *Yes* ☐ *No* ☐ *Application submitted*

☐ I have enclosed copies of the application and the approval letter *(essential before data can be released)*

If application submitted, please give an indication of when approval is expected:	

Ethical Committee Approval (for research requests)

Has ethical committee approval been given?

☐ *Yes* ☐ *No* ☐ *Application submitted*

Type of approval sought ☐ *MREC* ☐ *LREC*

REC name

☐ I have enclosed copies of the application and the approval letter *(essential before data can be released)*

If application submitted, please give an indication of when approval is expected:	

USE OF DATA

Use of Identifiable Data

Do you intend to use the data provided to contact anyone? (see note 5 of DECLARATION opposite)

☐ *Treating clinicians* ☐ *Pathologists*

☐ *Patients' GPs* ☐ *No party to be contacted*

☐ *Other (please specify) -*

☐ I have enclosed copies of the letters to be used for contact *(essential before data can be released)*

Dissemination of results (all types of data)

Do you intend to publish your results or present the data provided in a public forum? (see notes 2 and 4 of DECLARATION opposite)

☐ *Internal meeting* ☐ *External meeting*

☐ *Internal report* ☐ *External report*

☐ *Conference* ☐ *Publication*

☐ *Other (please specify) -*

Please give full details of the name of meeting/conference (or title of report/publication)

DECLARATION

The signature required on the declaration is dependent upon the geographical area or organisation for which the information is required. Details of this can be found in the attached APPENDIX Guidance Notes. Please contact Cancer Registry for advice.

Declaration for (potentially) Identifiable Data

I understand that, in accordance with the Data Protection Act 1998 and the UKACR Policies on the Release of Patient Identifiable Information and on the Release of Potentially Identifiable Information, data will only be released to me providing:

1. the data are only used for the purpose(s) for which they were supplied
2. the data are not passed on to other third parties unless directly concerned with their analysis or interpretation, nor will they be released into the public domain (see guidance notes - page 5)
3. any results of my/our work which are disclosed shall not be able to identify an individual
4. any results of my/our work which are disclosed into the public domain shall not show potentially identifiable information
5. no attempt will be made to identify information pertaining to particular individuals or to contact individuals, unless appropriate consent is obtained
6. the data will be kept secure at all times, will not be kept for longer than can be justified by the stated purpose, and will then be destroyed
7. no attempt will be made to link the data to other data sets, unless agreed with all data providers
8. any public domain reports or papers resulting from analyses of the provided data will be shared **prior** to publication with the Cancer Registry and appropriate acknowledgement given.

Applicant	
Signature	
Date	
Designated Signatory (see appendix for guidance)	
Title / Full Name	
Job Title	
Organisation	
Capacity signing under (see page 6)	
Signature	
Date	

VERIFICATION

☒ **For Registry Use Only**	Data Request Number
☐ Protocol received	
☐ LREC/MREC approval	PID Type of Request
☐ Patient consent seen	
☐ Caldicott Guardian Informed	
☐ PIAG approval & application number	
☐ Approved for release – signature and date	

ADDITIONAL INFORMATION

Any other information in support of your application

UKACR - United Kingdom Association of Cancer Registries

Patient Identifiable or Potentially Identifiable Data

GUIDANCE NOTES

CONFIDENTIALITY GUIDELINES

The accompanying form covers the release of data that are identifiable or potentially identifiable only. Do not use this form if you require non-identifiable data. Please return it by post or fax only.

The Need for Guidelines

To provide adequate safeguards for the individuals right to privacy at the same time as preserving the right for his/her fellows to benefit from the knowledge on cancer causation, prevention, treatment and survival that can be obtained from cancer epidemiology

Disclosure of Identifiable Data (or potentially identifiable information*) by Cancer Registries:

Regulation 2 of the Statutory Instrument (SI) on confidentiality – No. 1438, The Health Service (Control of Patient Information) Regulations 2002 – permits cancer registries to receive patient identifiable data without the need for informed consent and it permits registries to process said data for the medical purposes stipulated in regulation 2.

Data are released subject to the Confidentiality and Disclosure Guidelines, as agreed by the UKACR. Identifiable patient information (or potentially identifiable information*) will only be released to authorised personnel in legitimate organisations, as detailed in the UKACR Policy on the Release of Identifiable Patient Information (see *'Consent for release of Data'*). Full details of this policy and the guidelines covering the release of potentially identifiable information can be found under the section *'UKACR Guidelines on Confidentiality: Approved policies'* www.ukacr.org

Identifiable patient data

Include any of the following: name, address, postcode, date of birth, date or cause of death, NHS no., hospital no.

* As a general rule, the following categories should be regarded as being potentially identifiable data:

1. Individual records even if they do not include variables, such as names, full postcodes, and dates of birth which would make them obviously identifiable
2. Tabular data, based on small geographic areas**, with cell counts of fewer than five cases/events (or where counts of less than five can be inferred by simple arithmetic)
3. Tabular data containing cells that have underlying population denominators of less than 1,000

** As a general rule, the following categories should be regarded as potentially identifiable data for small geographic areas:

1. Those areas where the total denominator population is less than that of a Primary Care Trust, e.g. wards or aggregation of wards. (The smallest PCT in England has a total population of approximately 62,000 i.e. 1550 if divided into 40 single sex, 5-year age group assuming an equal size distribution)
2. Any geographic area (e.g. local authority) which, when released, may provide information regarding small population non-contiguous areas ("slivers") when combined with Primary Care Trust information. These should be regarded in the same way as ward level data
3. Any geographic area when publication in five-year age groups between 0 and 24 years is required. In this age range, particular scrutiny should be paid to tabulations and appropriate aggregations used. (Due to the rarity of cancer in children and young adults, there may be a non-negligible risk of information disclosure by for any geographic area.)

Conditions for Release of Identifiable and Potentially Identifiable Data:

Releases of both identifiable and potentially identifiable data are governed by the following principles:

1. the intended use(s) of the data should be stated clearly
2. the use(s) of the data should be justified and the data should not be used for any other purpose(s)
3. the registry should not release data that are more detailed than necessary to fulfil the stated purpose
4. the data should not be passed on to other third parties or released into the public domain***
5. the data should be kept securely for the period of time that can be justified by the stated purpose, and then destroyed
6. no attempt should be made to identify information pertaining to particular individuals or to contact individuals (unless patient consent has been obtained via the patient's clinician)
7. no attempt should be made to link the data to other data sets, unless agreed with the data providers
8. any public domain*** reports or papers resulting from analyses of the provided data should be shared prior to publication with the cancer registry (or registries) supplying the information.
9. recipients of data should be aware of their responsibilities, and should sign an agreement to this effect prior to the release of data by a registry

***Public Domain – Definition

Publication of data on a website and in unrestricted circulations of reports or documents containing data should be regarded as being in the public domain.

UKACR POLICY

UKACR Policy - www.ukacr.org

*The following section has been extracted from **Appendix 2** of the UKACR Policy on the Release of Identifiable Patient Information follows (for full details see UKACR Guidelines on Confidentiality at* www.ukacr.org*)*

Policies for Data Release – Full Documents

Full details covering the policies on the release of identifiable information and the release of potentially identifiable information are available from the UKACR website under section *UKACR Guidelines on Confidentiality: Approved Policies* in www.ukacr.org). These policies are part of the documentation submitted to and subject to annual review by the Patient Information Advisory Group (PIAG: **http://www.advisorybodies.doh.gov.uk/piag/**).

PIAG was established to provide advice on issues of national significance involving the use of patient information and to oversee arrangements created under Section 60 of the Health and Social Care Act 2001.

CONSENT FOR RELEASE OF DATA

Appropriate Signatories - Designated Individuals

Wherever possible, a **registered health professional** should sign requests for the cancer registration information. We recognise that people with other training are appointed to some of these posts; for example, Directors of Public Health for some Primary Care Trusts, where they could reasonably be expected to sign *ex officio*.

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, **Cancer Registry Directors** should use their discretion as to who should sign, and for some requests, several signatories may be needed. For some purposes, signatories may be specified in Service Level Agreements between registries and particular organisations.

CONSENT FOR RELEASE OF DATA

Appropriate Signatories - Designated Individuals

Table to help you discern the most appropriate people to sign your form, depending on your organisation type and nature of data requested.

Type of Data	Possible Signatories
NHS Trust	
Clinician's own data or data regarding patients of predecessor	Clinician (needs to sign stating taken over care of patients from predecessor) Caldicott Guardian (for patients not now managed by any clinician in trust) Medical Director (for patients not now managed by any clinician in trust)
Cancer Site-Specific data	Lead Cancer Clinician Lead Tumour Site-Specific Clinician Trust's Lead Clinician for Audit (if data request stated for audit) Caldicott Guardian Medical Director
Data for the whole Trust	Lead Cancer Clinician Trust's Lead Clinician for Audit (if data request stated for audit) Caldicott Guardian Medical Director
Data for Split Site Trusts / Cancer Centres	Lead Cancer Clinician from each unit Trust's Lead Clinician for Audit from each unit (if stated for audit) Caldicott Guardian from each unit Medical Director from each unit
Private Hospital	
Clinician's own data	Clinician
All hospital / unit: only the data they sent us if possible (assumed purpose is audit)	Signatures of all Clinicians of patients involved Medical Director
All NHS Trusts they serve for pathology cases only, and only the data they sent us if possible	Senior Pathologist/ Clinical Head of Pathology Service Caldicott Guardian from each of the Trusts Medical Directors from each of the Trusts
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	Signatures of all Clinicians Medical Director
GP Practice	
Own patients – either at diagnosis or registered at time of request	Lead GP for Cancer Signatures of all GPs Head of Practice Caldicott Guardian of relevant PCT
Quality Assurance Reference Centres	
Relevant patients – screening age groups	Covered by Service Level Agreement
Cancer Network	
All Network – either patients diagnosed or treated in the network or for cases resident in the network geographical boundaries	Network Lead Cancer Clinician Network's Lead Clinician for Audit (if data request stated for audit)
Multi-Disciplinary Team – either patients diagnosed or treated in the network or for cases resident in the network geographical boundaries	Network Lead Cancer Clinician Network Lead Tumour Site-Specific Clinician Network's Lead Clinician for Audit (if data request stated for audit) Signatures of all Clinicians in the MDT Lead Clinician for the MDT
Cancer site-specific data – either patients diagnosed or treated in the Network or for cases resident in Network geographical boundaries	Network Lead Cancer Clinician Network Lead tumour Site-Specific Clinician Network's Lead Clinician for Audit (if data request stated for audit)
Primary Care Trusts	
Own Patients – by GP practice register or geographical boundaries	Director of Public Health (DPH) Caldicott Guardian
Consortium analysis arrangements where one PCT is doing some work on behalf of others (say in an area previously covered by a single HA)	Signatures of all DsPH of the participating PCTs Caldicott Guardian of all DsPH of the participating PCTs

CONSENT FOR DEATH INFORMATION

Release of Date and Cause of Death Information

Where possible a registered health professional should sign requests for death information, as this information forms part of the complete cancer registration record.

Type of Data	Possible Signatories
Audit data	Signatory should be the Lead Clinician for Audit for the unit.
Clinical Trials data	Signatory should be the leading investigator within the unit (the signatory is actually signing that the patient had given informed consent to take part in the trial and to be followed-up, as part of the research trial).
Medical Records data	Signatory should be the Lead Cancer Clinician for the unit.
Cancer Site-Specific Audit or any other Audits	When clinicians are requesting information on their own patients, or as part of a Trust or Network site-specific audit, and are providing information on the patients concerned such as names & dates of birth, then release of information is allowed without obtaining the individual signatures.