



Public Health
England

Protecting and improving the nation's health

Genetic Processing User Guide for NHS Genetics Services

February 2020

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-leading science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health and Social Care, and a distinct delivery organisation with operational autonomy. We provide government, local government, the NHS, Parliament, industry and the public with evidence-based professional, scientific and delivery expertise and support.

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Introduction

From 1st January 2019, all Genetics Services on the N3 network (nhs.net) must submit genetic requests for cancer diagnosis information for English patients to Public Health England (PHE) and the National Cancer Registration and Analysis Service (NCRAS) via the Genetic Information Request Portal (https://nww.api.encore.nhs.uk/genetics/genetics_requests). After these dates, genetic requests will not be accepted by email, post, or fax apart from known exceptions i.e. requests from abroad. Please contact the appropriate British registry for genetic requests for cancer diagnosis information for non-English patients residing in Northern Ireland, Scotland, and Wales – contact details and submission processes are provided in the Appendix.

Generic nhs.net accounts will be needed to log into the portal to submit genetic requests for each genetics service; individual named nhs.net accounts will not have access to the portal. Shared generic nhs.net email addresses will be added to and maintained on a whitelist of authorised users. The whitelist will ensure that only authorised personnel have access to the portal, and it will be reviewed annually to ensure appropriate continued access. Requesting Consultant must also be provided for each genetic request for GDPR and audit purposes.

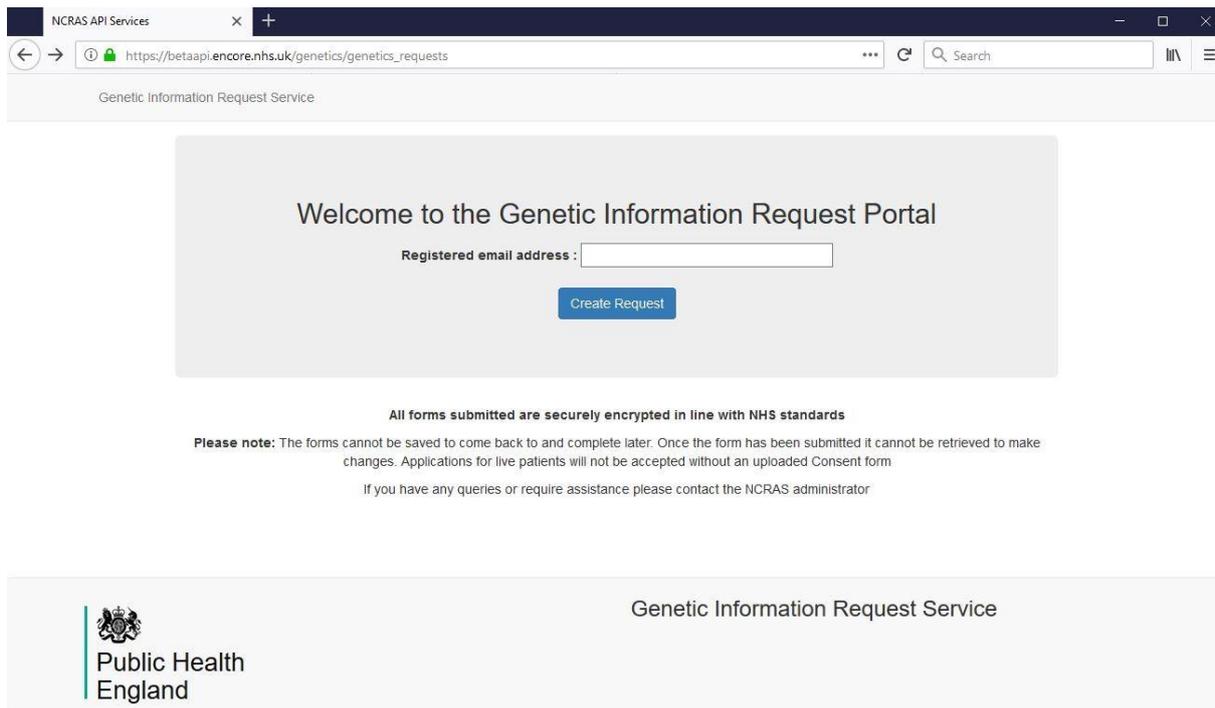
Responsibility for appropriate use of access rests with the requesting genetics service, and genetics services take on sole data controller responsibility for any confidential patient information received from PHE.

To ensure access rights are maintained, the Registration Lead – Molecular and Genomics or NDRS Programme Manager – Genomics should be notified of any new email accounts which require access and of any changes in consultant staff. When requesting portal access for a new email account, the generic nhs.net account, service name as it will appear on the screen, and the associated genetic service are needed, as well as the email address of an individual contact in the event of any issues with the shared account.

Dedicated national Genetic Processing Officers will process and return genetic requests for cancer diagnosis information by automation to the requesting nhs.net email account within ten working days from date of submission. Patient demographics provided on the genetic request will be used to locate a match to patient data stored on Encore, the database used by NCRAS, as well as local legacy systems. The standard of returned data should remain consistent or improve during this transition, and molecular test data will now be included where available.

Logging in to the Portal

Visit https://nww.api.encore.nhs.uk/genetics/genetics_requests to log in to the Genetic Information Request Portal using a registered nhs.net email address and click Create Request. Email addresses must be generic rather than belong to a named individual within a genetics service and will be maintained on a whitelist to ensure only appropriate staff are allowed access to the portal. Any email address amendments or additions will need to be supplied to the Registration Lead or NDRS Programme Manager to ensure access is provided to and maintained for valid services.



The screenshot shows a web browser window with the title 'NCRAS API Services'. The address bar contains the URL 'https://betaapi.encore.nhs.uk/genetics/genetics_requests'. The page content includes a header 'Genetic Information Request Service', a central grey box with the text 'Welcome to the Genetic Information Request Portal', a text input field labeled 'Registered email address:', and a blue 'Create Request' button. Below this, there is a note: 'All forms submitted are securely encrypted in line with NHS standards'. A 'Please note' section states: 'The forms cannot be saved to come back to and complete later. Once the form has been submitted it cannot be retrieved to make changes. Applications for live patients will not be accepted without an uploaded Consent form. If you have any queries or require assistance please contact the NCRAS administrator'. At the bottom, there is a footer with the Public Health England logo and the text 'Genetic Information Request Service'.

Genetic Information Request Portal welcome page

Genetic Information Request Form

After logging in, you will be taken to the Genetic Information Request Form. The top of the page includes the email address and service name of the requester and the Genetic Service Information held. If any of this information appears incorrect and needs updating, contact the PHE NCRAS administrator, PHE.GeneticRequests@nhs.net. Family (Proband) number/reference should be input and a Requesting Consultant must be chosen from the dropdown list. Both are mandatory fields, as indicated throughout the form by an asterisk.

If the requesting consultant's name does not appear in the dropdown list, use the 'Other' option and type the consultant's name into the free text box which will appear below the Requesting Consultant field. If a consultant is not chosen from the dropdown list, or if 'Other' is selected and no name is entered into the text box, the request will not be submitted and an error will appear stating 'Please choose or provide a consultant'. If 'Other' is selected and text is entered into the text box which appears, but then a consultant name is chosen from the dropdown to replace the 'Other' choice without removing the text, the same error will appear.

If a genetics service makes frequent use of the 'Other' option, this can be audited to identify whether a consultant should be added to the dropdown list. Please contact the Registration Lead or NDRS Programmes Manager if a consultant needs to be added to or removed from the dropdown list for your Service.

Genetic Information Request Form

- Applications for live patients will not be accepted without an uploaded Consent form
- Please complete as many fields as possible
- Mandatory fields are identified with a *
- Without a valid NHS number a positive patient match will be greatly reduced

Requested by

Email

*** Name**

Genetic Service Information

Service

*** Family (Proband) number/reference**

*** Requesting Consultant**

Please choose or provide a consultant

If the requesting consultant is not listed please contact the NCRAS administrator, PHE.GeneticRequests@nhs.net

Top of the Genetic Information Request Form with Requested by and Genetic Service Information, including mandatory field Family (Proband) number/reference and Requesting Consultant. Error alert shown when 'Other' Requesting Consultant is chosen without entering a name into the text box.

Patient Information

NHS number

A valid NHS number greatly increases the chance of a positive match/trace

Old NHS Number

* Surname

* Forename

Surname at birth

Surname (previous)

Also known as

* Sex

* Date of birth

Date format help

* Vital Status

Date of death

Date format help

Consent form

 No file selected.

By ticking this box you confirm that your organisation has obtained explicit consent from the data subject to enable the lawful processing of their personal and special category data.

Address

Postcode

Reported diagnosis

Date of diagnosis

Date format help

Age of diagnosis

Hospital where treated

Comments

Traceable strength

Cancel

Submit

Blank Genetic Information Request Form displaying all possible fields.

The remainder of the request form is where patient demographics and any known cancer details can be populated. The mandatory fields which must be populated are:

- Surname
- Forename
- Sex
- Date of birth
- Vital Status

Date of birth, date of death, and date of diagnosis fields can be recorded as a full date, a month range within a specified year, a year range, or a range between two specific dates. Date ranges for all date fields can be given by including a space between two dates. Date format help is available beside all date fields: the more precise and accurate the provided dates, the greater the likelihood that a match will be found.

The Encore database cannot search for dates of birth prior to 1880 and matches for old records tend to be less common and, if found, may be less detailed.

Genetic Information Request Service

Patient ID

Date of birth

Sex

Surname

Also known as

* Sex

* Date of birth

Date format help

Date Format Help

Format	Example
Full Date Known	
DD/MM/YYYY	07/01/1948
Year only is known	
YYYY or a range see example	1923 Or Any date between 1st January 1923 and 31st December 1923 inclusive
Year and month are known	
MM/YYYY	09/2000 Or Any date between 1st September 2000 and 30th September 2000 inclusive
A date range	
DD/MM/YYYY(space)DD /MM/YYYY	05/12/1956 04/12/1957 Any date between 5th December 1956 and 4th December 1957 inclusive

Close

Date Format Help. More specific, accurate dates increase the likelihood of a patient match.

If you attempt to submit a genetic request which does not include a mandatory field or for a living patient without uploading a consent form, the request will not be submitted and any missing fields will be highlighted in red with a note that they can't be blank or that a consent form must be uploaded.

Patient Information

NHS number

A Valid NHS number greatly increases the chance of a positive match/trace

Old NHS Number

*** Surname**

*** Forename**

Surname at birth

Surname (previous)

Also known as

*** Sex** can't be blank

*** Date of birth** [Date format help](#)

*** Vital Status** If patient is still alive a consent form must be uploaded

Consent form No file selected.

By ticking this box you confirm that your organisation has obtained explicit consent from the data subject to enable the lawful processing of their personal and special category data.

Requests with missing mandatory fields will not be submitted and missing fields will be highlighted in red text with a comment beneath.

For patients with Vital Status Alive, a consent form signed by the patient or a relative with legal Power of Attorney must be uploaded by clicking Browse and selecting the appropriate PDF. Consent forms must be in PDF format and the check box must be ticked to indicate a signed consent form has been provided. Proof of power of attorney must also be included in the PDF where a living patient has not signed the consent form themselves.

Consent and power of attorney forms will be stored and regular audits will be carried out to ensure organisations comply with data regulations.

Submitting genetics services have legal responsibility for ensuring data compliance by providing appropriately signed consent and power of attorney forms. Any genetics service which fails to supply signed consent and power of attorney forms may be liable to have their access to the portal revoked.

* Vital Status

Consent form No file selected.

By ticking this box you confirm that your organisation has obtained explicit consent from the data subject to enable the lawful processing of their personal and special category data.

Patient Information fields for living patients include a consent form attachment section with check box.

When Vital Status Deceased is chosen from the dropdown menu, a Date of death field will appear instead of the consent form field. Deceased patients on requests who appear alive on NHS Summary Care Record tracing will be returned unactioned with a response comment that the patient is alive on tracing. A new request will need to be submitted with either a signed consent form if the patient is living or with proof of death emailed securely to PHE.GeneticRequests@nhs.net beforehand. A note in the comment box that proof of death has been emailed should be included to ensure appropriate return.

* Vital Status

Date of death [Date format help](#)

Patient Information fields for deceased patients include a Date of death field.

Date of death is not mandatory but will help with a positive result if completed.

A traceable strength bar at the bottom of the page updates as fields are populated to indicate the likelihood – low or good – that a patient can be traced or a match identified on Encore. A valid NHS number greatly increases the chance of a positive match: including an NHS number is the gold standard to identify the correct patient.

Traceable strength Insufficient information, the chance of getting a positive match is low.
Provide complete NHS number, Postcode in an accepted format to increase the chance.



Low traceable strength when only mandatory fields Surname, Forename, Sex, and Date of birth are completed for a deceased patient with suggested fields to populate to improve traceable strength.

Traceable strength The chance of getting a positive match is good.



Good traceable strength when NHS number is populated in addition to Surname, Forename, Sex, and Date of birth for a living patient. A consent form would need to be provided before submitting.

If submitting requests for multiple family members, it can be helpful to include in the comments box the family/proband or genetic request reference number (provided on the submission confirmation page pictured below) for requests for other family members. Correlating surnames and addresses for family members with a cancer diagnosis can help confirm a potential match where patients have married or moved if other information is inaccurate or not supplied, such as providing a current address for a patient when they were diagnosed while living with or close to family.

Submitting a Request

Review all fields carefully, because requests cannot be amended once submitted. After clicking submit, the following page will confirm the request has been submitted and will be completed within ten working days. It is not possible to flag requests as urgent, so please ensure when submitting genetic requests for cancer diagnosis confirmation that you have factored in the ten working days response time.

Genetic Information Request Submitted

Reference : GRQ00002487, created 14-Nov-2018

Request will be completed within 10 working days

[Click here to make another request](#)

All forms submitted are securely encrypted in line with NHS standards

Please note: Once the form has been submitted it cannot be retrieved to make changes.

If you have any queries or require assistance please contact the NCRAS administrator

Genetic Information Request Submitted confirmation screen and reference ID

Important Patient Search Notes

Genetic requests for cancer diagnosis confirmation submitted by genetics services are received and returned by a small national team of genetic processing officers.

When searching for patient matches to return information to a genetics service, the only search fields the genetic processing officers can populate are:

- Forename(s)
- Surname(s)
- Date of birth
- NHS number

There is no way to search the Encore database used by NCRAS by sex, date of death, or address.

When returning database search results, only the first 100 possible patient matches are shown.

A patient with a common forename and surname and a large birth date range may return no search results at all, due to the system's inability to search a vast range of potential matches.

Due to these search restrictions, if the majority of returned search results for a unisex name are female, but the patient is male or vice versa, or if a patient has a common or commonly misspelled name, the number of possible correct matches to manually choose from could be dramatically reduced.

How to Improve Rate of Patient Match Return

To identify the correct patient match from hundreds of thousands of patients on the Encore system, genetic processing staff manually check additional patient information provided at the time of the patient's cancer diagnosis.

To increase the chances of a patient match being found, genetics services should provide as much information as possible. This can be done by:

1. populating more fields
2. including vague information where specifics are not known rather than leaving fields blank
3. adding extra information in the comment box, including whether additional requests were sent for the same proband number to correlate family location and historic names

While an NHS number is the gold standard for finding a patient match from specific information, any information a genetics service knows and provides can be used to narrow down a patient match – the more specific this is, the better.

Please also remember that demographic information first enters Encore at point of diagnosis. If additional information is not received after the diagnostic period due to lack of treatment, lack of recurrence, or a long lapse between diagnosis and later cancer events, this demographic information may not be updated. For this reason, please ensure patient demographic information is provided for the time of diagnosis or, if this is not known, it is specified in the comment box that demographic information provided on the genetic request form is not from date of diagnosis.

Consent forms will not be checked for supplementary demographic information. Genetics services must provide all known information on the Genetic Information Request Portal form.

Examples of varying levels of information specificity to include on the Genetic Information Request Portal to help identify a patient match include:

Field	Bad	Better	Best	Ideal	Explanation
Forename(s)	Meg	Meg Juliet	Margaret Juliet	Margaret Juliet with 'Meg' in Also known as field	Use legal forenames rather than nicknames and include middle names in the forename(s) field. Middle names increase chances of a match for patients with common forenames. Populating the Also known as field for patients with common and commonly misspelled names can further improve chances of a match
Surname	Jones	Hobb	Jones with 'Hobb' in Surname at birth field	Jones with 'Hobb' in Surname at birth field and 'Hobb at diagnosis' in comment box	Most patient names enter Encore at diagnosis, so provide the name at diagnosis if different to time of recurrence or death, as well as providing any later names. Inclusion of surname at birth and surname(s) (previous) improves chances of a match
Date of birth	1950 1959	1950	01.09.1950 30.11.1950	13.11.1950	A space between two dates in any portal date field allows a date range to be entered. If it's believed the patient was born in autumn 1950, this smaller date range of three months is more specific than a full year date range and can help limit and re-order the search results produced
Date of death	None supplied	None supplied, but comment box populated with 'Died in their 80s'	1995 2000	25.08.1999	For date fields which are not mandatory e.g. date of death and date of diagnosis, a date range of several years is more useful than no date at all or needing to calculate a date range from free text in another field
Address at diagnosis	None supplied	Greater London	Westminster, London	Buckingham Palace, London with 'SW1A 1AA' in Postcode at diagnosis	If no specific address at time of diagnosis is known, providing city, county, or other regional information can all help find a patient match. The comment box can also be used to add further information e.g. 'lived near the coast'. A

					patient's relative may not know a street name, but may recall they lived in Wimbledon because it made them think of tennis
Hospital treated	None supplied	North of England	Yorkshire	Hull Hospital	A county or region within the country is preferred to no information at all if a specific hospital is not known. This can be used to corroborate a patient match who may not have an exact date of birth and/or address or who may have moved after diagnosis
Reported diagnosis	None supplied	Pelvic cancer	Gynaecological	Right ovary	Diagnostic information can be used to identify a match for patients with a common name and/or sparse demographic information, particularly for less common cancers
Date of Diagnosis	None supplied	None supplied, but Age at diagnosis field populated	2010	08.04.2010	Date of diagnosis can be used to help identify a patient match where other demographic information may be lacking due to time elapsed from diagnosis or patient relocation. Again, a date range of several months is more useful than no date at all or needing to calculate a date range from free text in another field

Take Away Message

Encore holds millions of patient records to search, with new data received by NCRAS every day. The more patient demographic information genetics services provide, the better the chances that the correct match can be found.

Less specific information or information known with less confidence is always more useful for returning a patient match than leaving genetic request fields blank.

To help PHE genetic processing officers to provide the best service for genetics services to aid patients and families, please try to ensure information from patients and their relatives is present and as specific and detailed as possible on the Genetic Information Request Portal form.

Genetic Response Emails

Returned Request

Genetic request responses will be generated by Genetic Processing Officers on Encore and emailed by automation from PHE.GeneticRequests@nhs.net to the nhs.net account used to submit them. Replies to automated emails will not receive responses.

If a patient has not been found from potential lack of accurate or precise information e.g. a large date range with a common forename and surname, or if there is a vital status mismatch and a patient still appears living on NHS Summary Care Record tracing, a new request with additional information may be submitted. In exceptional cases, the Registration Lead or NDRS Programme Manager may be contacted about specific requests, but the need for this should be rare. All available data from Encore and local legacy systems will be checked to ensure a match is identified where possible, and no additional data will be obtainable without more specific new information such as post code or NHS number to increase the chances of a match, and in this case a new request could be submitted.

Genetics services take on sole data controller responsibility for confidential and sensitive patient identifiable data received by Public Health England and the National Cancer Registration and Analysis Service. Genetics services should ensure the appropriate handling, storage, and sharing of any data, including printed out genetic response emails.

Below is the format the automated email response will take and the fields which will be included where provided.

From: GeneticRequests (PUBLIC HEALTH ENGLAND)
Sent: 07 November 2018 16:01
To: Requesting Geneticist
Subject: Genetic Request Response #abc 123

Genetic request reference: GRQ00005924

Requester Details

Submission Date	06.11.2018
Requester Email	forename.surname@nhs.net
Requester Name	Forename Surname
Service	Test Service
Requester's ref	abc 123

Response Details

	Submitted Request	Registry Information
Surname	PATIENT	PATIENT
Forename(s)	TEST	TEST
Surname at birth		
Previous surnames		
Also known as		
NHS number	1234567891	1234567891
Sex	M	M
Alive	Deceased	D
Date of birth	01.10.1950	01.10.1950
Date of death	12.2017	15.12.2017
Address		123 ROAD, CITY, COUNTY
Postcode		AB12 3CD
Reported diagnosis	Lung Ca	
Date of diagnosis	2016	
Hospital where treated		

Comments	
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Tumour Details

Tumour 1	Final
Hospitals attended	Maidstone And Tunbridge Wells Nhs Trust Maidstone District General Hospital The Royal Marsden Nhs Foundation Trust
Postcode at diagnosis	AB12 3CD
Diagnosis date	07.08.2009
Site	T78000 Testis
Histology	9061/3 Seminoma
Laterality	Right
Molecular	No

Tumour 2	Final
Hospitals attended	Alliance Medical Guy's And St Thomas' Nhs Trust Guy's Hospital King's College Hospital (Denmark Hill) Maidstone And Tunbridge Wells Nhs Trust Maidstone District General Hospital
Postcode at diagnosis	AB12 3CD
Diagnosis date	23.04.2016
Site	C341 Upper Lobe, Lung
Histology	8046/3 Non Small Cell Carcinoma
Laterality	Right
Molecular	Yes

Lab code	Date	Test status	Gene	Inheritance
UNIVERSITY HOSP BIRMINGHAM LABORATORY (695Q0)	28.05.2016	Normal	EGFR	Somatic / Tumour Specific

Response Comments

Comments will be provided here if needed.

Response Comments will confirm if no patient has been found, and there will be no patient demographics or tumour details from PHE. Patient demographics sent by genetics services will still appear for patients with no trace, and this should not be confused for a cancer confirmation.

Response Comments is also where a request for a deceased patient on the submitted request with a living patient on NHS Summary Care Record tracing will explain why the request has not been actioned and explain that a new request should be submitted with either a signed consent form uploaded on the portal or a death certificate emailed to the Registration Lead as proof of death and notification included in the comment box. The new request will be returned within a new ten working day timeframe. The response time for a repeat request due to a vital status mismatch or insufficient or incorrect information is not included in the ten working days of the initial request.

Tumour Details

Tumour registrations held by PHE may be recorded as the following statuses:

- Final - A complete registration for a confirmed cancer diagnosis. As data continues to be provided from various sources, these registrations may accumulate further details of molecular testing, treatment, recurrence, or nodal or metastatic spread.
- Provisional - An open registration undergoing current investigation.
- Treatment only - Used in rare instances of an extra-regional diagnosis with local treatment given. Little or no diagnostic information may be available.
- Referenced - A closed case appropriately investigated for a cancer diagnosis which was not confirmed. Tumours are referenced if a definitive cancer diagnosis was not made in context with full information; if the cancer diagnosis related to an existing final registration (such as recurrence or nodal or metastatic spread from a finalised primary); or a patient with cancer lived abroad at date of diagnosis. Referenced cases will not be included on genetic request responses.

Genetic responses will include all final and provisional tumour registrations held for a patient. Molecular data received for genetic tests carried out by participating laboratories since 2016 will be included if present. This will include:

- the laboratory name
- the date the test was performed, reported, or authorised
- test status
- gene
- whether the sample was somatic (tumour specific) or germline (inherited, familial)

Genetic request cancer information sent to genetics services by PHE relate to cancer diagnosis data extracted from various data sources. Genetic request responses will supply:

- tumour site
- histology/morphology
- laterality
- all diagnosis and treating hospitals
- molecular/genetic status if known

The most current, specific confirmed information available is provided, though it may be a non-specific tumour site or histology/morphology e.g. carcinoma NOS if a more specific diagnosis could not be confirmed.

Appendix

Glossary

CRO: Cancer registration officer

DOB: Date of birth

DOD: Date of death

Encore: The database used by NCRAS

GPO: Genetic processing officer

IG: Information governance

LPI: Local patient identifier (hospital number)

NCRAS: National Cancer Registration and Analysis Service

NDRS: National Disease Registration Service

PHE: Public Health England

PID: Patient identifiable data

Contact List

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British Registry Contact Details

Northern Ireland

N. Ireland Cancer Registry
Centre for Public Health
School of Medicine, Dentistry & Biomedical Sciences
Queen's University Belfast
Mulhouse Building
Grosvenor Road
Belfast
BT12 6DP
Tel: +44 (0)28 9097 6028

<https://www.qub.ac.uk/research-centres/nicr/CancerInformation/requests/>

Scotland

Genetics Genealogy Service
NHS National Services Scotland
Area 151A, First Floor
Gyle Square, 1 South Gyle Crescent
Edinburgh
EH12 9EB
Email: NSS.geneticsgenealogy@nhs.net
Tel: 0131 275 6453; 6823 or 0131 314 1074

<https://www.isdscotland.org/Health-Topics/Cancer/Genetics-Genealogy/>

Wales

Public Health Wales
Knowledge Directorate
Welsh Cancer Intelligence
Floor 5, Capital Quarter 2
Tyndall Street
Cardiff
CF10 4BZ

Tel: +44 (0)29 2037 3500

https://www.api.encore.nhs.uk/genetics/genetics_requests