use MY data

Cancer Data - Frequently Asked Questions

use MY data aims to build confidence in the use of patient data for analysis and research and increase the involvement of patients in decisions about how their data is used.

As part of this work, the patient advocates of use MY data, along with data workshop attendees, have raised a series of questions related to cancer data. Those questions form the basis of this document.

"Data improves services and develops new treatments; data adds to knowledge and understanding; data saves lives."

Patient advocate,

use MY data

Contents

Cancer Registration

What data are collected, and why?

Cancer registration underpins what we know about cancer in the UK. Traditionally cancer registration was about manually finding and counting new cases of cancer, and only recorded a few items of data. These were to identify the person and link their data from different hospitals, and to know something about the actual tumour, such as what type of cancer it was, where in the body it was, when it was diagnosed and how it was diagnosed.

Registration is now of a much higher quality than in the past, as the data are 'fed' directly from hospital and lab systems, without the need for data to be re-entered. This makes the data feeds much quicker, and improves reliability, because the data are taken directly from the systems which are used to treat patients, and the different data can be cross-checked to look for data anomalies.

Having this extra data means that registration is not just about incidence (the number of new cases in a year), mortality (the number of deaths in a year) and survival (the numbers of people alive after a diagnosis). Registration now allows us to look at differences in the actual care given, whether this is surgery, radiotherapy or chemotherapy. It allows us to look at the detailed routes by which people are diagnosed, and also to look at delays in this process.

And because all this relies on actual patient records, we are also able to look at differences across the country, differences between the sexes, differences for ethnic groups, and other factors.

Now that we have linked the patient experience records into the registration records, we can directly map the care given to a patient, with the experience and outcomes that they themselves are reporting.

Because we have the data, we are able to produce tools, reports and analyses which identify variation across the country, at hospital, commissioning group and locality levels. We can do this by types of cancer and many other factors.

When was 'occupation/industry' dropped from cancer registration process & why?

The fields for occupation and industry were in the national dataset from the late 1960s, but were poorly completed over the years and were not used in any national analyses.

The Office for National Statistics (ONS) undertook a review, which concluded that the data were not routinely available across the NHS and therefore were not obtainable by the registries.

The fields were dropped in the 1990s, though they do still exist in the historic datasets.

How do we know cancer registration data are accurate?

By its very nature, data which is taken directly from the systems which are used in the hospitals to treat the patients should be high quality. Feeding this data directly to the registration process removes possible transcription errors.

However, there are errors in virtually all data sources, so additional processes are needed to check the accuracy.

First is the principle of multiple sources – taking data for the same patient from different data systems. If there is an error in one source, you should see this when it is compared to another source.

The second method is to use highly trained registration staff, who double-check each record before it is used for analysis.

A key stage in quality assurance is to reflect the data back to the clinical teams that supplied it in the first place. This is done at different stages and different time points, to ensure errors are spotted quickly and also to provide useful intelligence back to the clinical teams.

The most recent check is to let patients have access to their own data. Initially this was for a small subset of patients – those with a brain tumour. The initial brain tumour portal, developed with brainstrust, has now begun to extend with the support of Cancer Research UK.

Is my disease covered?

The types of cancer which are registered are dictated by the legal coverage within which registration works. There is a list of 'registrable conditions', which comprise a set of codes used across the world to record the types of cancer. The codes, called ICD (International Classification of Diseases) codes, have developed through the years, and as each new version is issued, they are assigned a number. The current version in use across the NHS is ICD10.

Whose responsibility is it to get the collection right and manage my data?

This is what cancer registration is all about. In legal terms, this translates as being the legal body which hosts the cancer registry:

- for England – Public Health England (PHE)
- for Scotland – the Information Services Division (ISD) of the Scottish government
- for Northern Ireland – the Cancer Registry is hosted by Queens University Belfast
- for Wales – the Welsh Cancer Intelligence and Surveillance Unit is hosted by Public Health Wales.

Are the data that are collected correct?

This could be answered in two ways – are the data which are a collected technically accurate; or are the data that are collected the right things to collect in order to answer the questions we need answering.

Firstly, experience shows that data always contains errors, particularly when it is used out of the context of the actual recording of the data. That is why we spend so much time and energy checking and assuring it.

Data always contains errors, particularly when it is used out of the context of the actual recording of the data. To counter this there are many mechanisms for checking and assuring the data.

See '**How do we know cancer registration data are accurate?'** for further information about data accuracy.

On the second angle (are we collecting the right data in the first place) there are regular reviews about this across the UK, driven by thing such as national strategies, changes in treatments (or new treatments being introduced), or changes in organisational structures.

Why can't the four nations work towards a more unified approach of collection, management and use of cancer patients' data?

One key point is the legal framework. Whilst the Health Act 2006 covers England and Wales, it does not extend further than that. Moving patient data across legal boundaries is subject to challenge, and is a definite problem.

The biggest physical obstacle has been England. Until 2013 there were 8 (previously 9) regional registries. Across England there were differences in practice, systems, and regional priorities. When the National Cancer Intelligence Network (NCIN) was launched in 2008 it did two things to address this. One was to agree and implement a standard set of data definitions across the NHS, and the other was to work with the regional registries to pull them together and lay the groundwork for a single, unified system. This went live in 2013.

Other factors relate to the size of England and the perception that the English agenda dominates the other countries. Each country has developed its own cancer strategy and moving towards better integration has been slow.

However, there is some current work which started in late 2015 looking at how the different parts of the UK can integrate their cancer registration processing in better ways, which will certainly make UK-based analyses much easier.

What is the reporting cycle for cancer data?

There is slight variation in the timing that the data are processed in the different countries of the UK, but in general data begins to arrive at the registry (from hospitals, path labs, etc.) by the fourth month after diagnosis. So for anyone diagnosed in January, the first three months of their data will start to arrive in April. Further data continues to arrive (for treatments, follow ups, etc.) from that point.

Around eight months after diagnosis these data flows are relatively complete, so the cancer registration process can compute a coherent picture of the diagnosis (and initial treatments), so summary records (about activity and some initial outcomes) are made available for the clinical teams. Data will continue to arrive from that point, whenever a patient has a hospital interaction, or any treatments are given.

Is the onus on Trusts to report cancer data accurately?

The Trusts have a legal duty to make sure that any patient data that they hold is correct.

Trusts are mandated to report the data to registries via one of two routes.

- The first is the NHS national contract, which effectively commissions them to report the data to registries. If they don't comply with this the Trusts could (potentially) lose money.
- The second is via a range of national clinical audits, which don't have the same commissioned route, but which are to ensure high quality clinical practice.

Part of the cancer registry role recognises that, for any particular patient, different data are supplied by different organisations, and this needs collating into a single record. This collation often highlights discrepancies, which are then flagged and resolved with the supplying organisations.

Has the Cancer Outcomes and Services Dataset (COSD) changed?

It's mostly static, but yes, it does undergo minor changes through time (as do all datasets).

The Cancer Outcomes and Services Dataset (COSD) is a large dataset, which covers a range of activities such as audit and registration, which applies to England. Having one dataset means that whenever data are recorded across the NHS, it is done consistently and to the same rules.

The COSD has had small developments through the years, but these are now mostly modifications or clarifications. No major changes are anticipated at present.

The COSD only applies to England, though it is largely consistent with dataset definitions across the rest of the UK.

Are data retrospectively fed into the registration system?

Yes. All the data which feeds registration is retrospective, though some data arrives faster than others.

Once a registration is started, it remains active or 'open', so that data will continue to flow when clinical activity is recorded for the patient. This allows long-term effects to be recorded, and is the best way to look for recurrence, or disease-free survival, both of which remain difficult to measure accurately.

Is it true that correct coding information isn't available for all people and therefore isn't registered?

No, this isn't true. All disease conditions are coded, using an international classification scheme such as ICD (see '**Is my disease covered?'** question). The NHS across the UK has been using these coding systems for over 30 years. Other coding schemes are used in particular specialist areas, such as pathology (uses a coding scheme called SNOMED). Again, these have been used across the NHS for many years. One of the things that the registries do is to provide a 'mapping' between ICD and SNOMED coding.

Primary care coding in GP practices uses a different method, using terminology which gives a greater granularity which better suits primary care. Again, this is all mappable to standard national codes.

Registries only record cases within a defined list of codes (see '**Is my disease covered?'** question).

What happens to those who fall off the pathway?

If we consider the pathway to start with a suspicion of cancer by a GP, then if test results rule out cancer, the registry does not record further information about the patient.

Once a patient is diagnosed, their data will continue to flow from that point onwards, up to the point of death.

If a patient chooses to pay for their own private medical care, the data held by those private providers does not usually flow to the cancer registry.

What happens to data at referral, if a cancer diagnosis is not made? Particularly if, at a later stage, there is diagnosis? Would it be linked to the earlier non diagnosis? Can you identify poor performers & locations to aid improvement?

The registry would see the referral details if cancer was suspected, and would also see the fact that this turned out to be negative.

If a further referral occurs for suspected cancer, the registry would also see this. And if this showed a positive diagnosis, the data would begin to flow to the registry in the normal manner.

When this question was asked, we checked to see whether anyone had looked at a negative followed by a positive referral, and the answer was no.

However, it could be done (and sounds not dissimilar to the way that interval cancers are monitored) and this is now being looked at by the National Cancer Registration and Analysis Service (NCRAS), as a direct result of this question being asked.

DATA COLLECTION

How many types of national data are collected (to a national data standard)?

There are a whole series of Commissioning Datasets in England, which cover a range of (not disease-specific) clinical activity. These are then used to generate Hospital Episode Statistics (HES). Not all are mandatory:

010 Accident and Emergency Attendance

020 Outpatient
(Known in the Schema as Care Activity)
May also be used to submit a Referral To Treatment Clock Stop Administrative Event

021 Future Outpatient
(Known in the Schema as Future Care Activity)

030 Elective Admission List End of Period Census (Standard)

040 Elective Admission List End of Period Census (Old)

050 Elective Admission List End of Period Census (New)

060 Elective Admission List Event During Period (Add)

070 Elective Admission List Event During Period (Remove)

080 Elective Admission List Event During Period (Offer)

090 Elective Admission List Event During Period (Available/Unavailable)

100 Elective Admission List Event During Period (Old Service Agreement)

110 Elective Admission List Event During Period (New Service Agreement)

120 Finished Birth Episode

130 Finished General Episode

140 Finished Delivery Episode

150 Other Birth

160 Other Delivery

170 Detained and/or Long-Term Psychiatric Census

180 Unfinished Birth Episode

190 Unfinished General Episode

200 Unfinished Delivery Episode

There are several cancer-related national data standards covering England. These are:

- CWT – Cancer Waits
- RTDS – Radiotherapy
- SACT – Chemotherapy
- DID – Diagnostic imaging
- COSD – Cancer Outcomes and Services

It's worth noting that the COSD dataset incorporates key audit fields and CWT fields, so in some respects is an overarching dataset which draws things together.

Cancer data collection seems unnecessarily complicated – is it?

It's complicated because the way that patients get diagnosed and treated is complicated. And it all happens in different places. We talk about a pathway, but it's more about a range of different pathways.

How much does cancer registration and intelligence cost?

In England, national cancer registration costs around £8m per year, and then national cancer intelligence costs about £2.5m per year.

We spend approximately £6.7bn per annum on cancer in the NHS. Spending on cancer registration and intelligence is just over 0.1% of total spending.

How are private patient data collected?

Private medicine is not required to submit data to the NHS. It is up to the private provider.
Private medicine has to comply with the Data Protection Act.

If a private hospital undertakes care which is paid for by the NHS, the data are collected under the same contractual framework as any other NHS data.

How do you know that the collected data are good enough for research purposes?

Prior to releasing data, Public Health England's (PHE) Office for Data Release (ODR) works closely with the researchers to understand their requirements and to help the researchers understand what data are available and how 'good' the data are. This is a complex process and the ODR is working to produce a more detailed 'dictionary' which describes not just what data we have, but some of the quality assessments and problems relating to different parts of the data.

Historically, one of the first jobs that the researchers have done is to examine the data carefully - 'data cleaning'. The ODR needs to work more closely with researchers to understand and fix any problems that they find with the data.

How do GPs provide data?

GPs do not send your data outside of the GP practice, unless it is to do with your direct care. For example, the referral data from GPs for suspected cancers will arrive at the cancer registry via the Cancer Waiting Times database, but the cancer registry does not receive routine datasets from GPs.

What is happening with the DAHNO head & neck audit? And head & neck cancer?

After more than ten years, the provision, development and management of the National Head and Neck Audit has moved from the Health and Social Care Information Centre to Saving Faces – The Facial Surgery Research Foundation. The new contract commenced on 1st July 2015 and transition activities ran until December 2015.

Under the new management the audit will be named the Head and Neck Cancer Audit (HANA) and the informatics element will be provided by Dendrite Clinical Systems.

The audit will continue to be commissioned by the Healthcare Quality Improvement Partnership, on behalf of NHS England and the Welsh Government and as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). Data collected by the HSCIC to date will be transferred to the new audit provider as soon as appropriate permissions are in place.

DATA LINKAGE

Does linking cancer patient data across the NHS work (for general treatment)?

The cancer registration infrastructure will link details about a patient's cancer diagnosis with their subsequent treatment. Some of the subsequent inpatient treatment might fall under the "general" category, but this would still be linked.

How does cancer data get into hospitals?

All hospitals have their own IT systems, which hold details about the patients they treat (or have treated). The information comes from:

- the patient when they attend an appointment and give information, which is entered into the IT system
- the GP, who will send information about you to the hospital if they refer you for suspected cancer, or if they are asked by the treating clinical team for particular information to support your care.

Any form of treatment or investigation that a patient has is recorded by the hospital. It is common for hospitals to have different IT systems in different parts of the hospital, although more hospitals are now running more integrated systems, often called the EPR (Electronic Patient Record).

Where hospitals have more than one system, patient data may be on both systems. Hospitals should keep the data on the different systems aligned, but sometimes the data can be out of step. This can result in patients being asked to give their details again when they visit different departments of the same hospital. This is much less common than it used to be, but it usually happens when specific departments are still running their own 'standalone' systems.

DATA ACCESS

What are the benefits to patient data being accessed?

Please refer to 'The rewards of using patient data', on the use MY data website.

What are the main risks of sharing and using my data? How are these risks mitigated?

The main risk of sharing and using patient data is identification.

Patient data are held on NHS computers and databases and there is the risk that any computer system could be hacked. The NHS runs a separate, secure, encrypted national network (N3), to which only approved organisations can get access. All personal data which moves across the network is encrypted, including NHS to NHS email.

Before any data is released from the cancer registration system, there are formal processes to assess the potential risk of a release of data, including where the data contains small numbers. This includes a 'privacy impact assessment', which is used to identify and minimise confidentiality risks.

By default, all data released should be anonymised. Rather than de-identifying data by removing a patient's name or address, applying anonymisation techniques minimises the possibility that someone could be re-identified from other data (such as a geographical location or dates related to admissions/treatments).

As part of the privacy impact assessment of data where name, address and NHS number have already been removed, there is an assessment of whether the data are anonymised in accordance with an anonymisation standard developed by the Health and Social Care Information Centre (Standard ISB 1523: Anonymisation Standard for Publishing Health and Social Care Data). This is a 'k-anonymity' check.

K-anonymity is used to limit the unique fields in a dataset, so that no single individual can be identified. These fields are often called indirect identifiers because they can be used in combination to identify individuals. These include:

- any derivation of date of birth (such as age range)
- gender
- ethnic category
- any derivation of postcode (such as area code)
- event dates (such as hospital admission date, whereas hospital admission month and year is acceptable)
- employer
- occupation or staff group.

The data may need to be transformed so that there is a minimum of three people (k-3) who all share the same controlled characteristics.

What are my rights with regard to the protection and use of my data?

The Data Protection Act controls how personal information is used. Everyone responsible for using personal data has to follow the Act's 'data protection principles' and ensure the data are:

- used fairly and lawfully
- used for limited, specifically stated purposes
- used in a way that is adequate, relevant and not excessive
- accurate
- kept for no longer than is absolutely necessary
- handled according to people's data protection rights
- kept safe and secure
- not transferred outside the European Economic Area without adequate protection.

Is data access more difficult now?

In recent years, there are certainly more steps to go through, and checks/balances to be in place, around data access. This In part reflects the growing complexity of data, and in part the general increasing interest across society around how data is being used. So data access is more difficult, but in general this is for the right reasons.

Are there extra protections in place for those having rare & less common cancers, in terms of protecting their anonymity (as they may be more easily identified at certain geographical levels)?

The Office for Data Release (ODR) assesses the potential risk of a release of data, including where the data contains small numbers, or is for a rare cancer.

The ODR applies a 'privacy impact assessment', to identify and minimise confidentiality risks.

By default, all data released by PHE should be anonymised. Rather than de-identifying data by removing a patient's name or address, applying anonymisation techniques minimises the possibility that someone could be re-identified from other data (such as a geographical location or dates related to admissions/treatments).

As part of the privacy impact assessment of data where name, address and NHS number have already been removed, the ODR applies an assessment of whether the data are anonymised in accordance with an anonymisation standard developed by the Health and Social Care Information Centre (Standard ISB 1523: Anonymisation Standard for Publishing Health and Social Care Data). This is a 'k-anonymity' check.

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- event dates (such as hospital admission date, whereas hospital admission month and year is acceptable)
- employer
- occupation or staff group.

The data may need to be transformed so that there is a minimum of three people (k-3) who all share the same controlled characteristics.

What is tissue sample availability for data release? What happens to tissue samples after diagnosis?

This complex area is covered in depth on the website of the Human Tissue Authority (HTA), which can be found at https://www.hta.gov.uk/faqs/research-faqs

40% of Office of Data Release (ODR) requests are from academic researchers, though some struggle to reference National Cancer Intelligence Network (NCIN) datasets in proposals. Does the ODR receive feedback from researchers?

Currently no, not routinely.

The Office of Data Release (ODR) is looking at ways to make it a requirement for researchers to reference where the data they have used came from (e.g. “uses data from the National Cancer Registration Analysis Service”).

Work is underway to produce a citation for all data releases, to reflect that the data are actually provided by the patient as part of their care.

What if a patient wants access to data beyond a certain amount of time?

Under the Data Protection Act, if you are the Data Subject, there are no time limitations for requesting access to the data that an organisation holds about you, by using a Subject Access Request.

However, organisations will have a data retention policy, and after a set period of time, they may delete data.

How are applications to use cancer patient data evaluated?

All applications for cancer data are evaluated by the Office for Data Release (ODR), against the following criteria:

1. Will the data be collected and used fairly and inside the law
2. Will then data only be used for the reasons given to the Information Commissioner and is there a clear, detailed protocol to underpin the use
3. Is the data being requested adequate, relevant and not excessive when compared with the purpose stated in the protocol.
4. How long will the data be needed? It must not be kept longer than is necessary. The data cannot be held indefinitely.
5. Will the data be kept safe and secure, to a similar level of security as Public Health England?
6. Will the data be transferred outside of the UK or European Economic Area (the European Union plus Iceland, Liechtenstein and Norway)?

Under what circumstances, and why, would an individual patient's data be requested?

Patient level data is usually requested for one of the following reasons:

1. To answer a specific research question
2. For direct care, including clinical audits, to inform delivery of best care
3. For service evaluation designed to answer: 'Does this service reach a predetermined standard?
4. Surveillance activities.

There is a research programme trying to generate personal treatment for pancreatic cancer – could individual tissue samples be requested?

The Medical Research Council has established a National Tissue Directory and Coordination Centre, led by University College London in collaboration with Nottingham University.

Tissues samples would need to be sourced from the Human Tissue Authority (HTA) licensed tissue banks.

To find out what type of samples are available, the National Cancer Research Institute has created a directory: **http://biosampledirectory.ncri.org.uk/** (this will be moving to the Medical Research Council.

After a patient's death, will relatives be asked to give consent for access to their dead relative's data?

No.

How long from an Office of Data Release (ODR) application to the release of data?

The turnaround time, from the initiation of an enquiry to the sending out of data is between 20 and 60 working days, depending on the complexity of the application.

What are the data release processes for the three devolved nations?

For completeness England and the Republic of Ireland are included in this answer.

Northern Ireland

In summary:

- anonymised data are freely available with caveats that small numbers are suppressed
- any clinician can have access to data on their patients
- a clinician requiring data on patients from several clinicians may have that data, with the signed agreement of all the other clinicians.

Requests from researchers are supported if they have ethical approval and they should have a medical data guardian associated with the project. Where possible the data is anonymised e.g. year of birth instead of date of birth, time of survival instead of diagnosis date and date of death, deprivation score instead of postcode.

The full details of the release of information procedure may be found in the N. Ireland Cancer Registry Policy Regarding Security, Confidentiality and Issue of Data, via the following link: http://www.qub.ac.uk/research-centres/nicr/CancerInformation/requests/

Scotland

The Information Services Division Scotland (ISD) runs an Information Request Service to all other information users. This Information Request Service is subject to resource constraints, prioritisation and potentially a charge. Further details can be found at: https://isdscotland.scot.nhs.uk/About-ISD/Information-Requests/_docs/information-request-protocol-130927.pdf

There will be additional constraints as far as personal data or potentially disclosive data are concerned. Releases of the former need to be approved by the Public Benefit and Privacy Panel (http://www.informationgovernance.scot.nhs.uk/) and the latter may require the application of disclosure control.

Wales

The Welsh Cancer Surveillance and Intelligence Unit (WCSIU) runs an Information Request Service to all other information users. The Information Request Service is subject to resource constraints, prioritisation and potentially a charge. Further details can be found at: **www.wcisu.wales.nhs.uk**

There will be additional constraints as far as personal data or potentially disclosive data are concerned. Releases of the former need to be approved by the Public Benefit and Privacy Panel (http://www.informationgovernance.scot.nhs.uk/) and the latter may require the application of disclosure control.

Republic of Ireland

The policy is for anonymised data to be freely available, either in aggregate or single-record format, the latter subject to some restrictions to ensure non-identification. The National Cancer Registry Ireland also provides single-record data on its website. There is no charge for providing data, unless an element of processing is required for data being used for commercial purposes.

Identifiable data on living patients can be released only with written patient consent; this applies even to the doctor or hospital originally supplying the data. Identifiable data on dead patients is released subject to ethical approval; there are no data protection restrictions.

England

PHE provides information to organisations that first must go through an application process to show that they will use the information to support the provision of health and social care or the promotion of health. The PHE Office for Data Release (ODR) manages the release of explicitly or potentially identifiable information from PHE, and is responsible for scrutinising applications for data.

The ODR ensures that all releases are conducted in accordance with the rights of the data subject, the legislative framework including the principles set out in the Data Protection Act 1998 and the seven Caldicott Principles.

The ODR will provide applicants for data with a named contact to facilitate their application and will provide:

- help for applicants to understand the ODR process
- guidance on protocol design and analysis
- assistance to applicants in navigating the data access and governance approvals process
- advice on available datasets and their content.

In order for an application to be assessed appropriately by the ODR, applicants are required to submit the ODR request form and provide a number of supporting documents (depending on the scope of the request). These are available at www.ncin.org.uk/collecting_and_using_data/odr The ODR has a dedicated email address: ODR@phe.gov.uk

LEGALITIES

Do you assume that there will be a data leak and work back from that?

There are many things in place to mitigate this risk, with multiple layers of checks. However, despite the precautions, the reality is that some point, there will be a data breach.

If the greatest hazard is the basic cancer database being hacked, can it be encrypted?

The cancer registration data sits on a machine inside the NHS Network (NHSNet).

NHSNet is a physically separate and secure network, which is only accessible from within a NHS building, or by using smart-tokens, which are assigned to a specific person. All the data and transactions which move across the NHS Network are encrypted.

If there is huge pressure to be risk averse and therefore we are not making enough use of data, how are rewards measured?

The rewards of using data have not been routinely collated or published. To begin to address this use MY data has produced 'The rewards of using patient data', which is available on the use MY data website.

When using online websites, such as tracing one's ancestry, you can pay to link data – is this regulated? Do we need to publicise the risks in this?

When you sign up to a website such as this, you also sign-up to a set of terms and conditions (T&Cs). These should include enough information for you to assess any risks and benefits.

The T&Cs will explain what the company will do and won't do with your data, what your rights are. Though evidence shows that not many people actually read these.

All organisations need to comply with the Data Protection Act.

What security protocols are in place with regard to cancer registration staff?

All staff are subject to standard security checks, and have to undertake manual information governance and security training, which is assessed annually.

All staff must sign separate agreements reflecting the sensitive area in which they work, which also describes the steps that will be taken if any member of staff breaches these conditions.

Many hope that their data will benefit others. It is difficult to understand why everything is so concentrated around anonymisation – why can't the data be in the public domain?

There is a legal duty to protect the identity of the individual, so it would be wrong just to put people's records into the public domain.

However, there is a contrasting requirement that all non-identifiable data must be made available in the public domain. This is true for all parts of the UK, and is why you should be able to access aggregated data which is free to use.

Requesting information under The Data Protection Act is often subject to fees, yet there seems to be discrepancies as to what is charged by different organisations. Why is this and what should the charges be?

When an individual (termed the Data Subject by the Data Protection Act) requests information that an organisation holds on them and processes, this is called a Subject Access Request.

Each organisation has their own way of handling a Subject Access Request and it is up to them whether or not they charge a fee. Most organisations charge a maximum amount of £10. However, this figure can increase when dealing with Health Records and the fees are:

- up to £10 if health records are held only electronically
- up to £50 if the health records are held either wholly or partly in non-electronic form.

Detailed information can be found on The Information Commissioner's Office (ICO) website – **https://ico.org.uk/**

The Subject Access Request Code of Practice:
https://ico.org.uk/media/for-organisations/documents/1065/subject-access-code-of-practice.pdf

Can you ask for another patient's records?

This can only be done if the patient has given their permission.

There seem to be a variety of responses in response to requesting the release of medical records, e.g. may only be released to view with a clinician – why is this?

One of the conditions which needs to be considered is whether the release of data to an individual could cause that individual harm in some way. Medical data are often recorded in complex ways, so it is sometimes advisable for a patient to go through the records with a medical professional.

If there is no potential for harm, the data should be released directly to the patient, although it is seen as good/helpful practice to do this with a medical professional.

Who owns my data?

There is no clear answer to who 'owns' your data.

You, as the 'Data Subject', have clearly defined rights regarding:

- the collection and use of your data
- seeing what data people hold about you
- asking for the data to be corrected if you think it is wrong, or asking for it to be deleted (in certain circumstances).

The 'Data Controller' is probably the closest thing to a data owner. Data controllers of personal data are those that determine the purposes and the way in which that personal data are processed.

Each GP Practice, NHS Trust etc. is generally the sole data controller for the data held within its IT system. They have certain rights to the data and powers over the use of the data but are also controlled and governed by strict principles and must respect and comply with your rights.

How can you give consent for access to your records, if they are something that you don't own?

Your consent is sought to ensure that the processing (collection and/or use) of your data is lawful.

Consent is one of the foundation stones of both the Data Protection Act and the Common Duty of Confidentiality. The first data protection principle requires, among other things, that the Data Controller must be able to satisfy one or more "conditions for processing" in relation to your personal data.

The Data Controller can only give someone access to your data under strict conditions. One of these is that you, as the Data Subject, can agree. The Data Controller can then act upon your instruction.

In many cases it is unfeasible for patients to be asked. That is why ethics committees will 'vet' all research applications, and why research groups must obtain Section 251 exemption. This permits the Data Controller to release data to the research group without asking every patient, so long as the request is justified, is not excessive and the data will be managed securely.

If a patient has consented to be part of a study, can they be opted out of it after death (by relatives for example)?

The rights of an individual are different once they are deceased. The Common Law Duty of Confidentiality is still relevant but the Data Protection Act isn't. In this particular case the relatives would not be able to opt the deceased patient out of the study.

Can consent to record access be given by parents for their children?

When trying to decide whether a child is mature enough to make decisions, professionals may reference 'Gillick competency' or 'Fraser guidelines'. These methods are used to help assess whether a child has the maturity to make their own decisions and to understand the implications of those decisions.

Even if a child is too young to understand the implications of subject access rights, data about them is still their personal data and does not belong, for example, to a parent or guardian. So it is the child who has a right of access to the information held about them, even though in the case of young children these rights are likely to be exercised by those with parental responsibility for them.

Data controllers must consider whether the child is mature enough to understand their rights. If they are confident that the child can understand their rights, then they should respond to the child rather than a parent. What matters is that the child is able to understand (in broad terms) what it means to make a subject access request and how to interpret the information they receive as a result of doing so.

When considering borderline cases, data controllers should take into account, amongst other things:

- the child's level of maturity and their ability to make decisions like this
- the nature of the personal data
- any court orders relating to parental access or responsibility that may apply
- any duty of confidence owed to the child or young person
- any consequences of allowing those with parental responsibility access to the child's or young person's information
- any detriment to the child or young person if individuals with parental responsibility cannot access this information
- any views the child or young person has on whether their parents should have access to information about them.

Can lower super output areas be processed, but not published?

Lower layer Super Output Areas (LSOAs) are designed for the collection and publication of small area statistics. They allow for more accurate comparison between areas than electoral wards, as they are composed of a more similar population size. Most LSOAs have over 1000 people (the population denominator) but there are places in the UK where the LSOA population does not meet this number of people.

In order to be able to publish health and social care data, a number of rules have to be met. These rules are contained in a standard developed by the Health and Social Care Information Centre (Standard ISB 1523: Anonymisation Standard for Publishing Health and Social Care Data). The standard provides analysts with a set of tools to anonymise information to ensure that, as far as it is reasonably practicable to do so, information published does not identify individuals.

In applying these rules, we have to ensure that no individual count released relates to a population size of fewer than 1,000 people. If this is satisfied, the data can be published.

Do the same levels of data protection apply to psychology services data? Who would monitor this?

The Data Protection Act (DPA) has very few exceptions and the monitoring of compliance with the DPA resides with the Information Commissioner. Psychology services data must comply with the DPA.

What happens to the data when private providers contracted to the NHS lose their contract?

When any organisation loses a contract, and where they have been processing patient data under that contract, there are strict safeguards to ensure that data is deleted, archived securely, or transferred to a new organisation. The exact details are built into the termination section of the specific contract.

How often is mortality and survival information updated?

Currently the information is updated annually. In both cases, mortality rates and survival rates are generally quite stable. Month to month changes would be negligible (and untrustworthy). On a year to year basis, things change, but very slowly.

What is the difference between type 1 & type 2 objections for patient data leaving a GP practice?

The Health and Social Care Information Centre (HSCIC) 'guide to confidentiality in health and social care' states that "any patient may object to confidential information about them being sent from a GP practice being shared onwards by the HSCIC."

- If patients "do not want information about them leaving a GP practice in identifiable form for purposes other than direct care, then confidential information about them will not be shared" - this is referred to as a type 1 objection.

- If patients "do not want information about them leaving the HSCIC in identifiable form, then confidential information about them will not be sent to anyone by the HSCIC". This is referred to as a type 2 objection.

Does the Secretary of State for Wales, own Welsh patient records?

Please see the '**Who owns my data?**' question.