UKCCMP DPIA

This template is an example of how you can record your DPIA process and outcome. It follows the process set out in our DPIA guidance, and should be read alongside that guidance and the Criteria for an acceptable DPIA set out in European guidelines on DPIAs.

You should start to fill out the template at the start of any major project involving the use of personal data, or if you are making a significant change to an existing process. The final outcomes should be integrated back into your project plan.

Submitting controller details

Name of controller	The University of Birmingham
Subject/title of DPO	Data Protection Officer
Name of ~~controller contact~~ /DPO (delete as appropriate)	Carolyn Pike

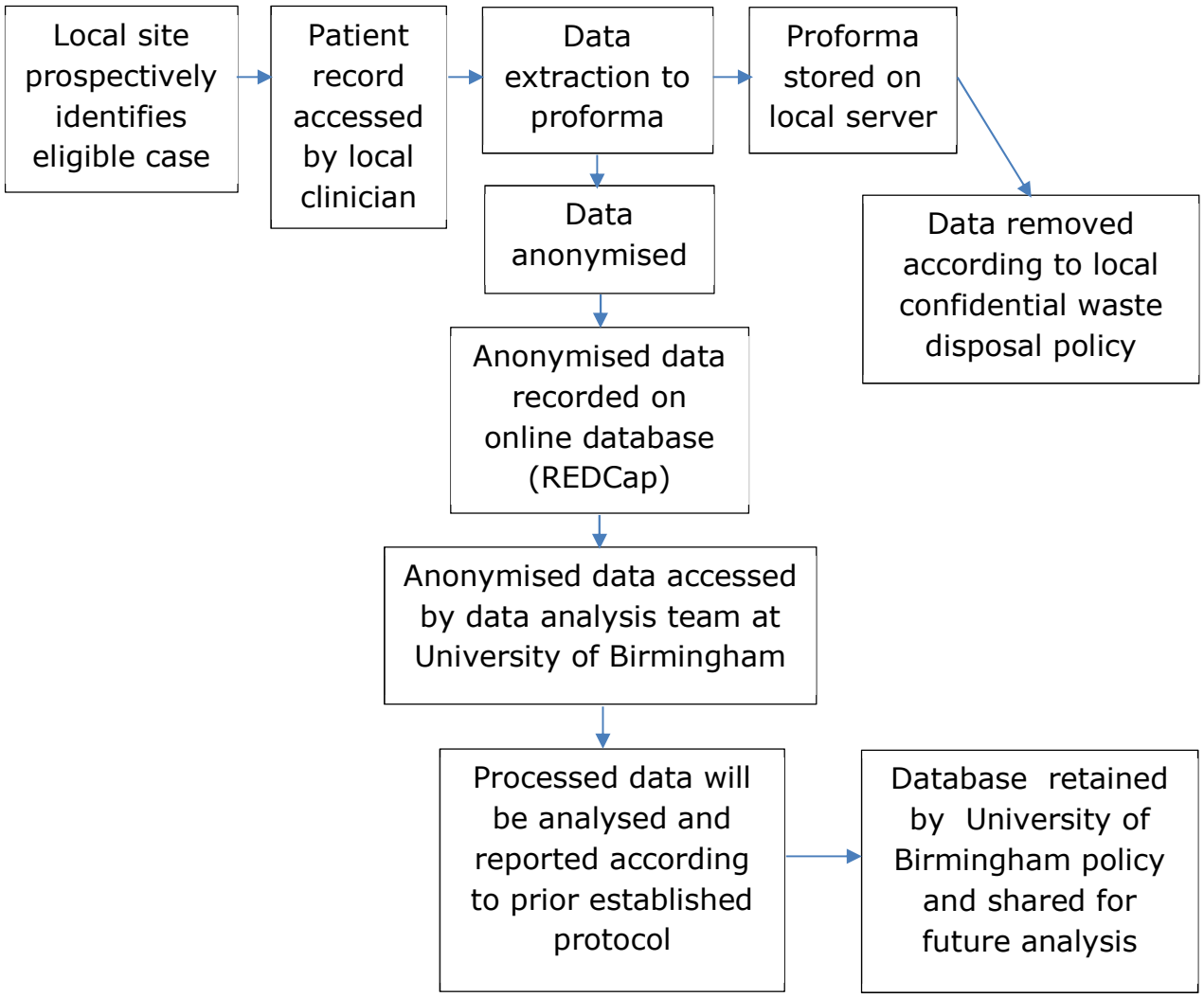
Step 1: Identify the need for a DPIA

Explain broadly what project aims to achieve and what type of processing it involves. You may find it helpful to refer or link to other documents, such as a project proposal. Summarise why you identified the need for a DPIA.
The UK Coronavirus cancer monitoring project (UKCCMP) is a national project which pioneers the use of a clinician-led reporting project to enable tracking of cancer patients who have tested positive for COVID-19 infection across the United Kingdom. The attached protocol outlines the project rationale and process for case reporting. Briefly, UKCCMP involves clinicians identifying confirmed COVID-19 cases in cancer patients and reporting data relating to the diagnosis and management of these patients. The data will be extracted from patient records accessed by clinicians providing direct care for these patients. It will not require any information that extends beyond existing patient care. Hospital sites across the UK involved in treating cancer patients will be invited to participate in the project, subject to local information governance approval. The data will be anonymised at source and then forwarded for inputinto a central, online secure database hosted at the University of Birmingham. The anonymized data will be analysed by data scientists at the University of Birmingham. I have identified the need for a DPIA due to the following points: • Personal data relating to individual characteristics of cancer patients will be collected, including age, gender, ethnicity, cancer diagnosis and co-morbidities, selected according to a minimum viable dataset • Data collection will require access to confidential information held in patient records, in electronic or paper formats • Data extraction occur according to a standardised proforma (attached). This proforma will remain securely held at the local site, and will not be accessible by the University of Birmingham • The patient identifiable key will not be disclosed to or forwarded to the University of Birmingham • The extracted data will be de-identified at source, before input into the online database • Access to the centralised online database will be regulated by a unique username and password. Only approved users, as designated by the Network Lead, will be given access to the database • Access to the database does not enable access to data entered from other sites • Data entry is expected to take place on a large scale by hospital sites across the UK

- Data analysis may involve pooling of the anonymised data across organisations, regions or nations
- Data will be reported at suitable timepoints to the cancer care community, to the general public and to institutions that maximises expected beneficial impact.

Step 2: Describe the processing

Describe the nature of the processing: how will you collect, use, store and delete data? What is the source of the data? Will you be sharing data with anyone? You might find it useful to refer to a flow diagram or other way of describing data flows. What types of processing identified as likely high risk are involved?



Describe the scope of the processing: what is the nature of the data, and does it include special category or criminal offence data? How much data will you be collecting and using? How often? How long will you keep it? How many individuals are affected? What geographical area does it cover?
The extracted data includes details relating to the patient's COVID-19 status, cancer diagnosis, cancer treatment, existing health status and health outcomes. No data is collected beyond what is routinely available as standard of care for cancer patients with confirmed COVID-19 infection. If prospectively obtained, the data will need to be collected at the time of diagnosis and then the time of patient outcome. The local data collection form is attached with highlighted fields indicating the mandatory reporting dataset. This form remains with the reporting centre and is not disclosed to the project. The data will be stored on secure servers at the University of Birmingham. Each site confirms that they "agree to collect personal data and special category data required, in accordance with the requirements of the GDPR and to submit anonymised participant data for storage on secure University of Birmingham servers for analysis in accordance with this project. Data stored is only identifiable using a key which is held by the reporting centre and must not be disclosed. The number of individuals affected at each centre is presently unknown, as it involves reporting a new infection. However, the expected number of cases per centre is between 10 to 20. Anonymised data, obtained from local data extraction, will be entered into a secure REDCap database, hosted at the University of Birmingham. The data will be uploaded at the convenience of the local reporting clinician/ERRI In line with UoB Code of Practice on Research and Policy on Data Research Management, anonymised research data will be preserved indefinitely to facilitate future scientific research. The geographical area covered includes the whole of the United Kingdom. The total estimated number of affected individuals is between 1,200-20,000.

Describe the context of the processing: what is the nature of your relationship with the individuals? How much control will they have? Would they expect you to use their data in this way? Do they include children or other vulnerable groups? Are there prior concerns over this type of processing or security flaws? Is it novel in any way? What is the current state of technology in this area? Are there any current issues of public concern that you should factor in? Are you signed up to any approved code of conduct or certification scheme (once any have been approved)?
The source of the data will be individual cancer patients diagnosed with COVID-19 infection. This data will be collected by local clinicians, termed the Local Emergency Response Reporting Group (LERRG), who are directly involved in the patient's care. Direct patient consent to process the data is not being sought however wherever practical participants will be informed of the study and a patient information sheet is available on the patient website. HRA have confirmed that this study does not fall under their jurisdiction; they do not consider the study a research study. Collection of data by the sites will be in accordance with GDPR requirements, and managed locally. All data provided to the University fo Birmingham will be anonymous. The data processing does not form part of routine care for patients. However, as directed by the Secretary of State for Health and Social Care, the COVID-19 outbreak raises a unique situation requiring the sharing of data to enable planning and managing the response (https://www.nhsx.nhs.uk/key-information-and-tools/information-governance-guidance/ig-professionals). The data requested for processing is of substantial public interest and will be vital for public health purposes. Although individually, patients may not be consulted for their data to be included, there is an openly accessible website (https://ukcoronaviruscancermonitoring.com) and Twitter feed (@UKCORONACANCER), which transparently sets out the project aims and progress.

Describe the purposes of the processing: what do you want to achieve? What is the intended effect on individuals? What are the benefits of the processing – for you, and more broadly?
The aim is to report the impact of COVID-19 infection on the cancer community. Cancer services have been negatively impacted by the outbreak directly through loss of workforce from infection or self-isolation and indirectly due to re-distribution of resources to tackle the outbreak. The results will be of substantial interest to affected individuals alongside the medical community. Understanding how the outbreak has affected cancer care is necessary to build resilience in the system to minimise harm in any future recurrence and to enable targeted allocation of resources to facilitate service recovery following the COVID-19 outbreak. The legal basis of the processing is public task- both for the local NHS Trusts, and also for the University of Birmingham. In so far as the local NHS Trusts and the University of Birmingham will be processing Special Category Data , they will be doing so for the purposes of research. However, the data will be submitted to the University by the local NHS Trusts in an anonymized form, so that the University will not have access to the 'key' to unlock the data.

Step 3: Consultation process

Consider how to consult with relevant stakeholders: describe when and how you will seek individuals' views – or justify why it's not appropriate to do so. Who else do you need to involve within your organisation? Do you need to ask your processors to assist? Do you plan to consult information security experts, or any other experts?
The opinions of cancer patients have been sought through individual consultations with patient representatives from several cancer charities. Their view is that such a project is considered important on an individual and national basis. Cancer patients recognise the negative impact the COVID-19 situation is having on cancer care delivery and are concerned about the impact on their own health. The feedback is that they would be happy for data to be shared, as long as appropriate safeguards are in place to protect their privacy and that the data collected is necessary to reach meaningful conclusions. Within the organisation of the University of Birmingham, data experts are involved in handling the data and have established a data reporting procedure that minimises the risk of harm.

Step 4: Assess necessity and proportionality

Describe compliance and proportionality measures, in particular: what is your lawful basis for processing? Does the processing actually achieve your purpose? Is there another way to achieve the same outcome? How will you prevent function creep? How will you ensure data quality and data minimisation? What information will you give individuals? How will you help to support their rights? What measures do you take to ensure processors comply? How do you safeguard any international transfers?
As outlined in step 2, the processing complies with data protection through access to patient records by approved users, i.e. clinicians directly involved in the patient's care, and anonymisation of data before it is shared externally. The data processing is of substantial interest to the cancer community and to the wider public. The dataset and project proposal have been widely consulted and reviewed within the community, including amongst cancer experts who are involved in direct patient care. Although similar data is being collected by Public Health England relating to the COVID-19 outbreak and separately on cancer services, these datasets lack granular detail on the direct impact of COVID-19 on cancer patient management and outcomes. Therefore, the proposed dataset is uniquely designed for reaching meaningful conclusions about how COVID-19 is affecting cancer care. To prevent function creep and ensure data quality, a standardised data collection tool has been created for the ERRI to use. Where practicable, if patients are prospectively identified as eligible for recruitment they will be verbally informed about the project and that data about them will be collected. Their rights will be explained and they will be given the opportunity to opt out of participation. Each site is required to seek approval within their local organisations to conduct data collection to participate in the project. No international transfer of data is currently anticipated. Anonymised data may be shared with other researchers, internationally if appropriate.

Step 5: Identify and assess risks

Describe source of risk and nature of potential impact on individuals. Include associated compliance and corporate risks as necessary.	**Likelihood of harm**	**Severity of harm**	**Overall risk**
	Remote, possible or probable	Minimal, significant or severe	Low, medium or high
Inability to exercise rights – where patients may be incapacitated due to acute illness	Possible	Minimal	Low
Loss of control over the use of personal data	Remote	Minimal	Low
Loss of confidentiality	Remote	Minimal	Low
Re-identification of pseudonymised data	Remote	Minimal	Low
Illegitimate access to, modification of or loss of personal data	Remote	Minimal	Low
Discrimination	Remote	Minimal	Low
Identity theft or fraud	Remote	Minimal	Low
Reputational damage	Remote	Minimal	Low
Physical harm	Remote	Minimal	Low
Any other significant economic or social disadvantage	Remote	Minimal	Low

Step 6: Identify measures to reduce risk

Identify additional measures you could take to reduce or eliminate risks identified as medium or high risk in step 5				
Risk	**Options to reduce or eliminate risk**	**Effect on risk**	**Residual risk**	**Measure approved**
		Eliminated reduced accepted	Low medium high	Yes/No
Re-identification of anonymised data	A reporting protocol has been put in place whereby with low number of patients (less than 10 reported cases), the cases will be pooled into categories to avoid the anonymised patient data being identified by cancer type, geographical location or treatment type. . Data analysis scripts have commands build in to automatically avoid making plots or to collapse data into groups if there are insufficient datapoints, in line with the protocol.	Reduced	Low	Yes

Step 7: Sign off and record outcomes

Item	Name/position/date	Notes
Measures approved by:		Integrate actions back into project plan, with date and responsibility for completion
Residual risks approved by:		If accepting any residual high risk, consult the ICO before going ahead
DPO advice provided:	CAROLYN PIKE Director of Legal Services/DPO 18/5/20	DPO should advise on compliance, step 6 measures and whether processing can proceed
Summary of DPO advice: Provided each site complies with its own DP requirments, and the University recieves only anonymised data, this should be adequate.		
DPO advice accepted or overruled by:		If overruled, you must explain your reasons
Comments:		
Consultation responses reviewed by:		If your decision departs from individuals' views, you must explain your reasons
Comments:		

This DPIA will kept under review by:	Lennard Lee	The DPO should also review ongoing compliance with DPIA