# ACP021 Data Governance and Ethics: Assessment Brief

## Assessment Overview

On the basis of the task brief and project summary outlined below, and your independent research, you will write a **3,000-word (-10/+10%) report** (including appendices). The report should use a logical structure and maintain a consistent standard of presentation throughout. References to external literature and sources should be made using the Harvard referencing standard. The deadline is **12 noon Friday 13th November 2020**. Please submit via the link on Learn. You will be able to submit multiple files to the submission link if necessary.

## The Task

You are a researcher at Loughborough University and are leading on a bid for external funding to work collaboratively with University Hospitals of Leicester (UHL). As with all projects data governance needs to be considered at the project design stage. The funding agency to which you are bidding for funds is the Economic and Social Research Council (ESRC). The ESRC requires that all bids include a Data Management Plan.

The proposed project involves human participants and will include discussions with individuals about their health. The project will also potentially involve sharing personal data between UHL and Loughborough University. On the basis of the project summary provided below you must provide a report identifying what the legal and ethical issues are in relation to privacy and outline the steps that need to be taken to comply with the UK Data Protection Act, 2018\*. In the report, you must also identify any particular issues relating to data anonymisation and sharing. You must append to the report a Data Management Plan (a requirement of the ESRC).

\* Given that the purpose of the data processing for is academic research conducting a Data Protection Impact Assessment is not a requirement for GDPR compliance. It is recommended, however, that in the main body of the report and, where appropriate, in the Data Management Plan you give careful consideration to the elements of data processing covered in the Information Commissioner’s Template for Data Protection Impact Assessments.

## Project Summary

*Making sense of health information: Patients’ access to and use of health information in decision making*.

This will be a collaborative project between Loughborough University and University Hospitals of Leicester. The purpose of the project is to explore how patients locate and access health information and the role that information plays in their decision-making processes. Patients over 18 years of age will be recruited to the study from across five University Hospitals of Leicester (UHL) outpatient clinics: urology, gynaecology, cardiology, clinical immunology, and Rheumatology.

The methodology will be based on mixed-methods using a questionnaire-based survey with patients registered with the five UHL clinics and qualitative applied storytelling workshops with a sub-group of patients across the five clinics. The questionnaire-based survey will be co-designed with UHL staff and the project Principal Investigator based at Loughborough University. The applied storytelling workshops draw on expertise as Loughborough University.

The survey questions will focus on participants’ health information seeking behaviours. The applied storytelling workshops will encourage participants to reflect on the ways in which they make sense of the information provided to them by clinicians and the role that information they find from other sources (e.g. friends, family, alternative health practitioners and the Internet) play in conversations with clinicians and their decision making process. It will involve participants’ creating short videos of their experiences. These videos will be shared amongst the project team for purposes of analysis.

## Marking Criteria

You should aim to provide strong evidence of the following in your report and appendices:

* Capacity to evaluate the project summary being presented.
* Engagement with the General Data Protection Regulations;
* Ability to apply the relevant principles of the General Data Protection Regulations to practical settings.
* Understanding of the privacy issues that should inform measures to protect research participants’ data.
* Ability to plan for data management and data sharing

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| **Criteria** | **Allocation of marks** |
| Evidence of evaluating and reporting on potential ethical, legal and data management issues, with reference as appropriate to external sources | 30 |
| Evidence of the identification and critical analysis of data protection compliance requirements and the development of appropriate solutions | 30 |
| Evidence of the development of effective approaches to the management and preservation of research data | 30 |
| Standard of written presentation | 10 |
| Total | 100 |