**Evaluation of the quality of discharge summaries for patients with colorectal cancer in London hospitals using a novel evaluation tool**

*IRAS Number* 298417

**Participant Information Sheet and webpage**

We are looking for people to share their discharge summary with us for a study organised by Imperial College London aimed at improving patient safety following discharge from hospital to primary care.

Please take time to read the following information carefully and discuss it with others if you wish.

Your care will not be affected by whether you chose to take part in this study or not.

**Background**

Discharge summaries are the primary the primary piece of communication between the hospital and the primary care setting, usually the GP practice, that details what care patients received in hospital, and what care they should receive after their hospital stay.

Studies have shown that discharge summaries are not always completed to the highest quality and that there are often gaps in key details of information, such as medication, follow up appointments or basic personal details, such as their address, that identify them. There is a lot of guidance and information about what good discharge summaries should look like but the guidance varies in quality and it is often not followed by clinicians well.

We are developing a tool to help evaluate discharge summaries. This could help hospital teams improve the quality of discharge summaries by identifying key deficits and used to help inform future research on how to improve the overall quality of care that patients receive when being discharged from hospital.

This study also forms part of a Masters thesis.

**Aims of the Study**

1. To develop a new tool for evaluating the quality of discharge summaries
2. To evaluate the quality of discharge summaries for patients who have undergone surgery for colorectal cancer in hospitals in North West London

**Why have I been asked to take part?**

Suggest adding: You have been asked to take part because you have recently been discharged from hospital following an elective operation for colorectal cancer.

In order to evaluate the quality of discharge summaries, we need to access the discharge summaries of patients who have been discharged from hospital recently following a similar procedure. We are therefore asking patients who have been discharged from hospital after colorectal cancer surgery if they are willing for their discharge summaries to be used in this study.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you decide to take part, please indicate your consent by responding YES to the text message you received from your GP practice.

**Advantages of taking part**

There are no specific advantages to you from taking part. However, by allowing us to use your discharge summary we will be able to better understand what improvements need to be made to discharge summaries, which may benefit patients in future.

**Disadvantages of taking part**

There are no anticipated disadvantages to taking part. If you take part, the study team will review your discharge summary using the developed tool. **Any identifiable information such as name, address and date of birth will be redacted by the primary care teams prior to forwarding the discharge summary to the research team**. The research teams will only be able to see whether or not the information is present in the discharge summary itself.

**Confidentiality**

All responses will be **anonymised in the research paper and personally identifiable information will be redacted (removed) from your discharge summary**. All personal and research data will be stored in line with the Data Protection Act and will only be accessible by the research team.

**What will happen to the results of the research study?**

The anonymous data generated from this study will be used to in a dissertation report on the quality of discharge summaries in London. Data will be stored for 10 years following the end of the study.

**Who is organising and funding the research?**

This study has been organised and is being funded by the Imperial College London NIHR Patient Safety Translational Research Centre, with support from the Clinical Research Network. We are currently seeking adoption onto the NIHR portfolio in order to support primary care sites involved in this study.

**Who has reviewed the study?**

This study has been reviewed by the National Institute for Health Research and the Joint Research Compliance Office at Imperial College London.

**GDPR statement**

Imperial College Londonis the sponsor for this study based in the United Kingdom. We will be using information from your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Imperial College London will keep identifiable information about you for:

* 10 years after the study has finished in relation to data subject consent forms.
* 10 years after the study has completed in relation to primary research data.

Further information on Imperial College London’s retention periods may be found at https://www.imperial.ac.uk/media/imperial-college/administration-and-support-services/records-and-archives/public/RetentionSchedule.pdf.

A link to Imperial College London’s data protection webpage may be found at https://www.imperial.ac.uk/admin-services/legal-services-office/data-protection/ but this is the notice most applicable to the information provided by participants and therefore takes precedence for all purposes described hereunder.

**YOUR RIGHTS**

Your usual statutory rights to access, change or move your information are limited, because of exceptions applicable to some types of research, and also because we need to manage your information in specific, lawful ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

**LEGAL BASIS**

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research.  This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

**INTERNATIONAL TRANSFERS**

There may be a requirement to transfer information to countries outside the European Economic Area (for example, to a research partner). Where this information contains your personal data, Imperial College London will ensure that it is transferred in accordance with data protection legislation. If the data is transferred to a country which is not subject to a European Commission (**EC**) adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient organisation that incorporates EC approved standard contractual clauses that safeguard how your personal data is processed.

**CONTACT US**

If you wish to raise a complaint on how we have handled your personal data or if you want to find out more about how we use your information, please contact Imperial College London’s Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO). The ICO does recommend that you seek to resolve matters with the data controller (us) first before involving the regulator.

Imperial College London will collect information about you for this research study from discharge summaries. This information will be redacted. We will use this information to help improve the quality of discharge summaries.

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research (<https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/>).

Your information could be used for research in any aspect of health or care, and could be combined with information about you from other sources held by researchers, the NHS or government.

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Imperial College London will collect information about you for this research study from discharge summaries. This information will include contact details, and date of birth, and health information, which is regarded as a special category of information. We will use this information to help improve the quality of discharge summaries.

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research (<https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/>).

Your information could be used for research in any aspect of health or care, and could be combined with information about you from other sources held by researchers, the NHS or government.

The information will only be used for the purpose of health and care research, or to contact you about future opportunities to participate in research. It will not be used to make decisions about future services available to you, such as insurance.

Your data will only used in research that has been independently reviewed by an ethics committee.

**Contact for further information**

If you would like any more information about the study, or about the project itself, I am happy to be contacted by email.

We look forward to working with you during this study, and in improving patient safety during the discharge process.

**Lizzy Dobres**

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