**Participant Information Sheet**

**Project: Patient Expertise**

***Describing the expertise of highly-motivated patients with chronic respiratory disease***

We would like to invite you to take part in a research study. Before you decide whether or not to participate it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

**Project summary:**

This study will consist of questionnaires organised in a three-round Delphi consensus-building process. This means that the questionnaire will be administered three times to the same participants, with small adjustments. The purpose of a Delphi process is to identify points of consensus, disagreement, and priorities of experts in a particular field.

The principle objective of this study has been raised in a previous interview study. The primary objectives will be addressed by answering the following research questions:

1. How should patient expertise be assessed? On which domains, and in which format?
2. What is the threshold level of knowledge/skills for a patient to be considered 'expert'?

The study is part of a PhD research project.

**What is the purpose of the study?**

The objective of this study is to achieve consensus on the patient knowledge, skills, attitudes, and behaviours that lead to effective self-management. Secondarily, the study will address the barriers, and self-management opportunities that patients face in self-managing their care, both from an individual and an organisational perspective.

**Why have I been chosen?**

You have been identified as a patient with bronchiectasis who has expertise and motivation to manage your condition, based on your membership in a patient advocacy organisation, your social media presence, and/or you have been nominated by someone in your network as a person with valuable expertise on this important topic.

**Do I have to take part?**

Participation in this study is purely voluntary.

**What will happen if I decide to take part?**

If you decide to participate, you will be offered an opportunity to provide individual informed consent to participate in **three standardised questionnaires** about the knowledge, skills, and behaviours of respiratory patients who successfully self-manage. These will be disseminated via email (on three separate occasions) and will take approximately 20 minutes to complete.

If you consent, you will be contacted via email with further instructions on how to participate.

**Are there any risks involved with taking part?**

We do not anticipate any risks to staff or patients as a result of the study being conducted.

**What are the possible benefits of taking part?**

This project will examine patient expertise and self-management of chronic respiratory diseases. It will provide you with an opportunity to discuss your perceptions and concerns about behaviours, knowledge, and skills of ‘expert’ patients, and to discuss ways to facilitate patients engaging in these activities more successfully.

This study will also examine the commonalities and differences in attitudes toward patient expertise and autonomy across different stakeholder groups (patients, clinicians, and policymakers). This will shed new light on the dynamics between patients and their healthcare providers, with an eye toward improving the quality of care.

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential, and personal details will be removed so that they cannot be recognised from it. Your identity and data will be anonymised via numeric code system. Your information will be held according to the GDPR, the principles of the NHS Confidentiality Code of Practice and Imperial College's Data Protection Policy.

All data collected will be held electronically and stored using GPG encryption tools (http://gnupg.org/) in a password locked computer only accessed by the researchers and the Big data and analytical unit (BDAU). The identities of the researchers are stated on this ethical application form.

**Transparency Notice**

Imperial College London is the sponsor for this study based in the United Kingdom. We will be using information from you 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. 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>.

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.

**Who will have access to my information?**

The Patient Safety Translational Research Centre (PSTRC) will collect information from you for this research study in accordance with our instructions. The PSTRC will keep your name and contact details confidential and will not pass this information to Imperial College London. The PSTRC will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from Imperial College London and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Imperial College London will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

The PSTRC will keep identifiable information about you from this study for 10 years after the study has finished.

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

The overarching findings of the study will be disseminated locally through engagement events with hospital staff working within the participating trusts. The findings will also be disseminated at national and international healthcare conferences and peer reviewed journals. A copy of any publications will be disseminated directly to participants in the study once published, upon request.

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

This study is funded by the National Institute for Health Research (NIHR), as part of the Imperial Patient Safety Translational Research Centre (PSTRC) funding.

**Who has reviewed the study?**

This study has been given favourable ethical opinion for conduct in the NHS by a Health Research Authority.

**Contact for Further Information**

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