

	Optimising Management of Patients with Heart Failure with Preserved Ejection Fraction in Primary Care
	COVID-19 IMPACT STUDY

We would like to invite you to take part in a research study to discuss how the COVID-19 pandemic has impacted the way you experience or provide care. It is important that you understand why the project is being carried out and what will be involved. This information sheet will help you decide whether to take part. Please discuss it with your family or carers if you wish. If you have any questions, please contact us using the details provided at the end of this sheet. Your participation is entirely voluntary.

1. What is the purpose of the study?

- The Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), commonly referred to as COVID-19, has resulted in a number of societal and health care provision changes.
- We would like to establish how/if you have been affected by these changes and what this has meant for you.
- We would also like to know your views on any of the new ways of working you may have experienced (e.g. telephone or internet based health consultations rather than face to face consultations) and how/if you think this will change the way healthcare is provided after the pandemic.

2. Why have I been chosen?

We have invited you because you have previously taken part in a research study we conducted and you provided your consent to be contacted about future research we are undertaking.

3. Do I have to take part?

No. It is up to you to decide whether or not to take part. If you decide to take part and then change your mind you may withdraw at any time without giving a reason.

4. What will I need to do if I take part?

We would like to ask you some questions and get your opinions. This can be done face to face at a place that is convenient for you such as your home (if the situation allows for this), or may be done by telephone or via the internet. You may ask a friend or family member to participate with you if you wish. The questions will take around 30 minutes and you may end the conversation at any point. If you are not comfortable speaking with someone, you could opt to complete a paper based questionnaire that can be returned in the post.

5. What are the benefits of taking part in this study?

There is no guarantee that you will benefit personally from taking part. Possible long term benefits of the research are that it will help to improve how we manage future pandemics. Your views on how services have changed are also very important to the National Health Service.

6. Are there any risks?

We do not believe you will be harmed in any way by this research because it only involves discussing or writing down your opinions and experiences and does not involve testing a drug or medical procedure. If you decide to meet one of our researchers you are welcome to have a family member, carer or friend accompany you if you wish. Although we are particularly interested in your answers, your carer may wish to make some additional comments. We may include your carer's comments as part of our study if they provide us with their consent.

7. How will the findings be used?

The results will be used to understand how the COVID-19 pandemic has impacted on your health and what you think of new ways of delivering healthcare that you may have experienced during lockdown. The research will be reported in a way that is confidential and your participation will not be identified in any way. The results may be published on the Cambridge University website and in healthcare journals, presented at conferences and to patient support groups. If you would like to be kept informed of the results please tell the researcher.

8. What will happen to the information I provide?

All information that is collected is strictly confidential. Any information that is stored for the project will have your name and address removed so that you cannot be identified and data will be identified by an identification (ID) number only. Direct quotations may be included in published material but participants will not be identifiable and patients' names will not be used. Only members of the research team will have access to the information. Data will be held in secure storage and destroyed

after ten years. Any information that you give will be used for research purposes only and you may ask to see your personal information at any time.

9. Can I withdraw from the project?

Yes. You may withdraw from the study at any time without giving a reason. This will not affect your treatment or care. If you withdraw we will only retain and use any personal information you have provided up to that point if you give us permission to do so.

10. What if there is a problem or I want to make a complaint?

If you have any concerns please speak to a member of the research team. If you wish to speak to somebody who is independent you can contact:

CAMBRIDGE	
NAME	Cambridge University Hospital's Patient Advice and Liaison Service (PALS)
ADDRESS	Address: Box 53, Cambridge University Hospitals, Cambridge Biomedical Campus, Hills Road, Cambridge, CB2 0QQ
TELEPHONE	Phone: 01223 216756 (Monday to Friday: 9am to 4pm)
EMAIL	Email: pals@addenbrookes.nhs.uk
MANCHESTER	
NAME	
ADDRESS	
TELEPHONE	
EMAIL	
KEELE	
NAME	
ADDRESS	
TELEPHONE	
EMAIL	

11. Who has organised the research?

The Lead Investigator for the study is Professor Christi Deaton, Department of Public Health & Primary Care, University of Cambridge.

12. How has this study been funded?

The research is funded by _____.

13. Further information and contact details

If you would like more information please contact:

CAMBRIDGE	
NAME	
ADDRESS	
TELEPHONE	
EMAIL	
MANCHESTER	
NAME	
ADDRESS	
TELEPHONE	
EMAIL	
KEELE	
NAME	
ADDRESS	
TELEPHONE	
EMAIL	

14. General Data Protection Regulations Transparency Information

Cambridge University Hospitals NHS Foundation Trust and University of Cambridge is the joint sponsor for this study based in England. We will be using information from you and 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. Cambridge University Hospitals NHS Foundation Trust and University of Cambridge will keep identifiable information about you for 10 years after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific 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. You can find out more about how we use your information by emailing research@addenbrookes.nhs.uk

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. 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. Where this information could identify you, the information will be held securely with strict arrangements about who can access the information. 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. Where there is a risk that you can be identified your data will only be used in research that has been independently reviewed by an ethics committee.

Cambridge Specific Information

Cambridge University Hospitals NHS Foundation Trust and University of Cambridge will use your name, NHS number or medical record number and contact details 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. Individuals from Cambridge University Hospitals NHS Foundation Trust and University of Cambridge and regulatory organisations may look at your medical and research records to check the accuracy of the research study. The only people in Cambridge University Hospitals NHS Foundation Trust and University of Cambridge who will have access to information that identifies you will be people who need to contact you to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or medical record number or contact details. Cambridge University Hospitals NHS Foundation Trust and University of Cambridge will keep identifiable information about you from this study for 10 years after the study has finished.