Participant Information

Measuring what matters: Agreeing the most important outcomes to assess the benefits of integrated health and social care

You are invited to take part in a research study. Please read this information which will help you to decide whether to take part or not. You do not have to take part if you do not want to. Whether you say yes or no to taking part your care or that of your friend/relative will not be affected in any way.

What is this research about?

People with long-term conditions and their family or friends, are often frequent users of health and social care services, which are often complex and don't always feel joined-up. This may adversely impact health outcomes. Integrated, or better coordinated, care has been proposed as a means to improve outcomes for people with long-term health and social care needs. Integrated care services provide a joined up, seamless experience for people where professionals communicate and work together well to support people's individual needs. In England, the approach to better coordinating health and social care was to introduce what have become known as "Integrated Care Systems (ICSs)" in 2022. All health and social care services in England are now part of an ICS. Currently it is not known how to assess the benefits of integration.

What is the purpose of the research?

The aim of this study is to develop a **Core Outcome Set** (COS) to assess the benefits of integrated health and social care for people with long-term and complex health and social care needs and their families.

A **Core Outcome Set** is a list of the most important things to measure (or domains) and the best way to measure them, as agreed on by people using services, their family members and/or friends who provide them with care and support, and health and social care professionals. It helps make sure that the same key information is collected, so results can be compared and used to improve care.

The objectives are:

- To achieve agreement on the types of outcomes ('what' outcomes) that should be assessed in integrated care
- To achieve agreement on the measures (e.g. surveys, clinical measures) to use to assess each of the agreed outcomes

Who is doing the research?

The research is funded by the National Institute for Health and Care Research (NIHR) Policy Research Unit (PRU) Quality, Safety and Outcomes of health and social care (QSO). It is being carried out by a collaboration of researchers from the University of Kent, University of Oxford, and the Picker Institute Europe. The Principal Investigator is Associate Professor Michele Peters, University of Oxford. Main Collaborators are James Caiels, University of Kent and Chris Graham, Picker. It is supported by three patient and public advisors with lived experience of long-term conditions and the health and social care systems.

Why have I been asked to take part?

You are being invited to take part because you have experience related to Health and or Social Care in England. This may be because you are:

- An adult (18 years+) living with a long-term or complex health condition(s) and / or social care need(s)

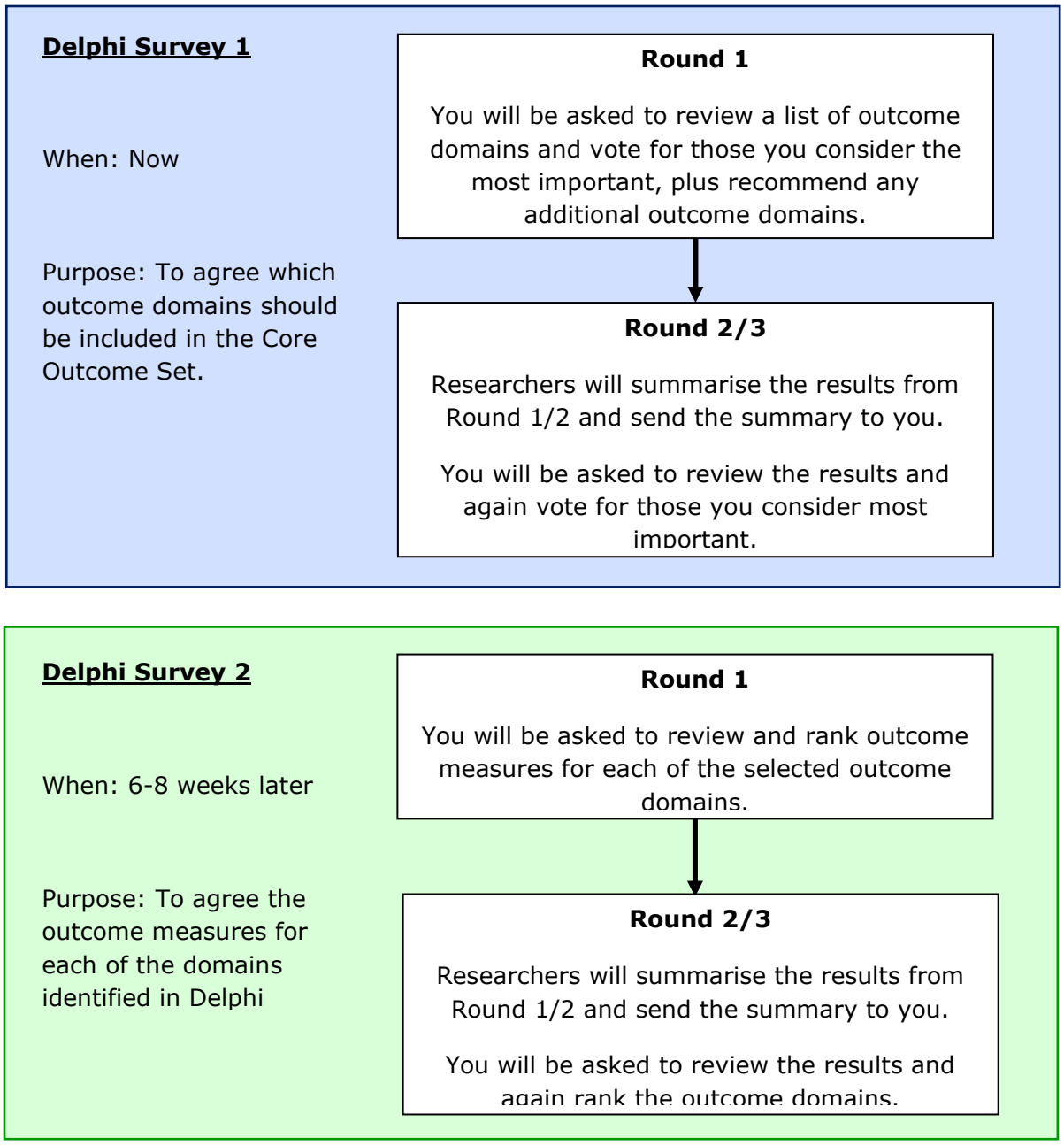
  or

- An adult (18 years+) who is a family member or friend who provides care and support to an adult (18 years+) with long-term or complex health and care needs

Your perspective will help us understand what outcomes matter most and how these outcomes should be assessed to improve quality of care.

What is involved in taking part?

You will take part in two online Delphi surveys and a short questionnaire about you that lets us know a little about the different people taking part. This will include things like your age, sex, and roughly where you live in the country. A Delphi survey is a type of survey that asks people's opinion over one, two or three rounds to gain agreement. After each round responses are summarised and shared to refine the agreement. The purpose of the Delphi survey 1 is to reach agreement on *which* outcome domains (or types of measures) should be



included in the Core Outcome Set. The outcomes have been identified through literature reviews and consultations with policy makers. Delphi survey 2 aims to reach agreement on *how* to measure (i.e. what outcome measures to use) the outcome domains identified in Delphi survey 1. The process is shown in the diagram below.

You will be invited to complete the first survey, followed by a second survey approximately 6–8 weeks later. We estimate that each survey will take up to 30 minutes to complete.

What are the benefits of taking part?

While there are no direct benefits to you, by taking part in this study, you will contribute to important research that aims to improve our understanding of how integration of health and social care systems affect the experiences and outcomes of patients, carers, and communities.

The findings will help inform policy and practice, helping health and social care services to work together more effectively to deliver better, more coordinated care.

Are there any risks in taking part?

This study is considered to be low risk. We are interested in your views on what is most important for assessing integrated care systems, rather than asking you to describe personal experiences of health or social care, or specific workplace situations.

We do recognise that people may sometimes share personal experiences when giving their views. If this happens, we will not ask you to provide further details.

All responses will be kept confidential and pseudonymised. This means that your responses will be linked to a unique participant ID number rather than your name or identifying details, and only members of the research team will have access to the information linking your identity to this ID. The study is not intended to assess or investigate individual services or organisations. Once your responses have been combined with those of other participants, the data will be fully anonymised and it will no longer be possible to identify individual responses.

If anything you share suggests that someone may be at immediate risk of harm, the research team will follow university safeguarding procedures and will advise you on appropriate sources of support or reporting.

If you find any questions difficult or upsetting, you are free to skip any questions you do not feel comfortable answering. You can also take a break or stop participating at any time.

What if I want to stop taking part in the study?

If you decide to take part, you are free to withdraw from the study, without giving a reason, at any time by contacting a member of the research team using the contact details below, or not completing any further surveys. If you stop completing surveys without telling us that you are withdrawing, we may send you reminder emails about the survey. You will not be sent more than 2 reminder emails.

If you decide you do not want to continue being part of this project this will not affect your rights or those of your relative/friend in any way. If you decide to withdraw from the study, we will continue to use the information you have already provided unless you tell us that you would like it removed. You can request withdrawal of your data up to one week after completing your last survey. After this point, your responses will be anonymised and combined with those of other participants, and it will no longer be possible to identify or remove your individual data.

What will you do with information from the study?

The findings from this study will be included in a report for the Department of Health and Social Care (DHSC). We will also produce an accessible research summary that will be made available on the QSO website and publish academic articles, as well as present the findings at conferences. Participants will also receive a summary of the study results. The information you share with us about you will help us make sure we hear from people with different backgrounds and a wide range of experiences.

Who is responsible for looking after the information I give?

This study is being carried out jointly by the University of Kent and the University of Oxford, and Picker - an international charity working across health and social care. Both universities act together as joint data controllers for the information you provide. This means they have agreed jointly on how and why your personal data (your contact details and your demographic data) and your research data (questionnaire responses) will be used for the purposes of this research.

The universities have agreed that the University of Kent will act as the main contact point for participants who wish to exercise their data protection rights (such as accessing, correcting, or withdrawing your data). However, you may contact either university, and your request will be dealt with appropriately.

In addition, Picker is supporting this study as a data processor. This means Picker will process your data securely and only on the instructions of the University of Kent and the University of Oxford. Picker does not make any independent decisions about how your data is used.

Your responses to the Delphi surveys will be pseudonymised, meaning they will be associated with your unique participant ID number. We do this so we can tell who has taken part in the survey and to invite you to take part in follow-up survey rounds. Your information will be kept securely on University of Kent and University of Oxford servers, and used only

for the purposes of this study. It will not be shared with anyone outside the research team except as required by law.

Your contact details will be kept for up to one year after the end of the study so that we can share findings with you after the study has ended and will then be securely deleted.

The legal basis for processing your personal data is that this research is a task carried out in the public interest.

Who can I contact?

You can find out more about how we use your information by viewing the University of Kent's research privacy notice at: Privacy Notice for Research Participants.

If you have any further questions or would like to discuss any aspect of the research, please contact the research team.

- Michele Peters : michele.peters@ndph.ox.ac.uk
- James Caiels: J.Caiels@kent.ac.uk

If you would like to speak to someone independent from the research team, please contact **Tegan Coleman**, who is the Senior Research Ethics and Governance Officer, at the University of Kent (email: t.coleman-581@kent.ac.uk).

Has the research been reviewed?

Yes, the project has been reviewed by the University of Kent Research Ethics Committee (reference: 1279).

Thank you for taking the time to read this information sheet and for considering the possibility of participating in our research.