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.

What is this research about?

People with long-term complex health and social care needs (hereafter referred to as patients), and their family or friends (hereafter referred to as carers), are often frequent users of health and social care services. They can be burdened by the frequency of needing to engage with a complex and disjointed health and social care system. This may adversely impact on their health outcomes and experiences of care. Integrated, or better coordinated, care has been proposed as a means to improve outcomes for people with long-term health and social care needs. In England, Integrated Care Systems (ICSs) were introduced in 2022 to provide people with more coordinated health and social care services. Currently it is not known how to assess the benefits (e.g. patient outcomes) of integration delivered by ICSs.

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 COS is an agreed minimum set of outcomes to measure (such as improved health, or care provided), and the best measures to use. Consensus is sought from relevant stakeholders including patients, carers, and health and social care professionals. The COS approach helps make sure that the same minimum outcomes data is collected in different contexts, so results can be compared and used to improve care.

The objectives are:

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

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 using the health and social care systems.

Why have I been asked to take part?

You are invited to take part because you are a professional with experience and / or expertise in adult (18 years+) health and social care in England related to Integrated Care Systems (ICSs). This may be through being a:

- Health or social care professional.
- Policymaker, Regulator, e.g. CQC / NICE etc. Service commissioner, e.g. Local authority.
- ICS system and quality leader such as members of the ICB (integrated care board) or ICP (integrated care partnership).
- Charity representative supporting people with long-term conditions who may have complex health and social care needs (patients), including family members and friends (carers).
- Researcher/academic with an interest in integrated health and social care or outcome measurement.

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

What is involved in taking part?

The study involves two online Delphi surveys and a short demographic questionnaire. A Delphi survey is an iterative process of gathering opinions, summarising and sharing responses with the aim of reaching consensus among those taking part. The purpose of the Delphi survey 1 is to reach consensus on *which* outcome domains should be included in the COS. The outcomes have been identified through literature reviews and consultations with policy makers. Delphi survey 2 aims to reach consensus on *how* to measure (i.e. what outcome measures to use) the outcome domains identified in Delphi survey 1.

You will be invited to complete the first survey, followed by a second survey approximately 6–8 weeks later. Each Delphi survey will consist of up to three rounds. We estimate that each survey will take up to 20 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 improving understanding of how to assess outcomes in integrated care services such as those delivered by ICSs. The findings will inform policy and practice on how to monitor outcomes for people with long-term complex health and social care needs, and their carers. A COS will give ICSs the tools to measure what matters for people with long-term complex health and care needs, and their carers. This will help them monitor and improve, where necessary, quality of health and social care services.

Are there any risks in taking part?

This study is considered to be low risk. We are interested in your views on which outcomes and measures are most important for evaluating 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 or professional 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 nothing you share will be passed on to employers, managers, or regulators, and only researchers who are involved in the study will know who has taken part. The study is not intended to assess or investigate individual services or organisations. Once your responses have been combined

with those of other participants, these 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 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 reminder emails about the survey. You will not be sent more than 2 reminder emails.

Withdrawing will not affect your rights 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 produce an accessible research summary that will be made available on NIHR PRU QSO website (click here) and publish academic papers, as well as present the findings at relevant conferences. Participants will also receive a summary of the study results. The demographics information you share with us will be used to ensure that we hear from people with a varied range of backgrounds and experiences.

Who is responsible for my data?

This study is carried out jointly by the University of Kent and the University of Oxford, and Picker. Both universities act 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 (Delphi survey 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 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 information will be stored securely on University of Kent and University of Oxford servers and used only for the purposes of this study. Where required, data will be shared via a secure Microsoft Teams folder held on the University of Kent secure servers. Researchers from the University of Oxford and Picker have guest access to this folder. Picker will not independently store any of your personal data. Data will not be shared with anyone outside the research team except as required by law.

Your survey responses will be pseudonymised during the study, meaning they will be linked to a unique participant ID rather than your name. This allows us to link your responses across survey rounds. Once data collection is complete, responses will be combined and fully anonymised, so that it is no longer possible to identify you.

Your contact details (such as your name and email address) will only be used to manage your participation in the study (for example, to invite you to take part in follow-up survey rounds or to share study findings with you). Contact details will be kept for up to one year after the end of the study 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 questions or concerns, 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 and been given a favourable opinion by the University of Kent Research Ethics Committee (reference: 1279).

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