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Measuring what matters: agreeing a standard list of outcomes to assess the benefits of integrated health and social care

Submission date 20/05/2026	**Recruitment status** No longer recruiting	[_] Prospectively registered [X] Protocol
Registration date 02/07/2026	**Overall study status** Ongoing	[_] Statistical analysis plan [_] Results
Last Edited 02/07/2026	**Condition category** Other	[_] Individual participant data [X] Record updated in last year

Plain English summary of protocol

Background and study aims
People with long-term complex health and social care needs often use many different services that can be poorly connected. This can negatively affect their health and quality of life and make care difficult to manage. It can also place extra strain on family members and friends who provide care. Integrated care (better coordinated services) aims to improve both health outcomes and care experiences, but it is not yet clear how best to measure its benefits. This study aims to develop a Core Outcome Set - an agreed list of the most important outcomes to measure and the best ways to measure them - for people with complex needs and their carers.

Who can participate?
Adults with long-term and complex health and social care needs, their carers (family members or friends who provide support), and health and social care professionals.

What does the study involve?
The study involves two online surveys. First, participants will rate how important different outcomes (such as quality of life or physical health) are. Outcomes rated as important by most participants will form the core set. Next, researchers will identify possible ways to measure these outcomes. In a second survey, participants will rate which measurement tools are best. The highest-rated measures will be included in the final Core Outcome Set.

What are the possible benefits and risks of participating?
Participants will help shape how integrated care is evaluated in the future, which may improve services. There are no expected clinical risks, but participants may need to spend time completing online surveys.

Where is the study run from?
The study is being run jointly by health and social care research centres based at the University of Oxford, and the University of Kent.

When is the study starting and how long is it expected to run for?
June 2026 to December 2026.

Who is funding the study?
The National Institute for Health and Care Research (NIHR).

Who is the main contact?
1. Michele Peters, Associate Professor, University of Oxford, michele.peters@ndph.ox.ac.uk
2. James Caiels, Senior Research Fellow, University of Kent, J.Caiels@kent.ac.uk

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Principal investigator, Scientific, Public

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Study information

Scientific Title

Developing outcome indicators for integrated care systems

Study objectives
Integrated care intends to join up silos of care across health and care systems, in particular to provide more effective patient-centred support for people with long-term complex health and care needs. In England, 42 Integrated Care Systems (ICSs) were introduced in 2022 to work more effectively on a population-based agenda to improve health and care outcomes. Although ICSs are undergoing changes (i.e., some ICSs are merging), the integration of care remains important to effectively support people. Professional and patient stakeholders believe that a key aim of integration is better outcomes and experiences for patients and service users (Crocker et al., 2020). However, there is no consensus on the indicators or metrics to use for assessing potential benefits of integration to patients and service users. ICS staff have highlighted the need for identifying appropriate measures and metrics, especially those that work across care pathways and address the success of integration (Lalani et al., 2023).

The aim is to develop a Core Outcome Set (COS) to assess the benefits of integrated care for people with long-term complex health and care needs and their families. A COS is a standard list of agreed outcomes, including determining the type of outcomes that should be assessed and the measures to assess each outcome. Consensus or agreement is achieved through Delphi-style surveys with relevant stakeholders.

The objectives are:
1. To achieve consensus on the types of outcomes ('what' outcomes or 'domains') that should be assessed in integrated care.
2. To achieve consensus on the measures ('how') to assess each of the agreed outcomes.

Ethics approval required
Ethics approval required

Ethics approval(s)
Approved 13/05/2026, School of Social Sciences Central Research Advisory Group (CREAG), University of Kent (University of Kent, Canterbury, CT2 7NF, United Kingdom; +44 (0)1227 816639; Lssjethics@kent.ac.uk), ref: 1279

Primary study design
Observational

Secondary study design
Cohort study

Study type(s)

Health condition(s) or problem(s) studied
Integrated health and social care

Interventions
Data collection:
Data will be collected via two online Delphi surveys (administered via JISC surveys), the first in June to July 2026 and the second in September to October 2026. A Delphi survey is an iterative

process of gathering opinions, summarising and sharing responses across multiple rounds with the aim of reaching consensus among those taking part. Our plans are informed by the COMET handbook (Williamson et al., 2017) and the COS-STAD approach (Kirkham et al., 2017).

Recruitment:
Professional participants will be recruited through existing contacts and networks, snowballing and publicly available information (e.g., ICSs, professional associations, voluntary sector organisations). Lay participants will be recruited through existing contacts (e.g. existing PPIE groups), snowballing and research networks such as NIHR Be Part of Research, Join Dementia Research and ENRICH, as well as care and support charities. Where possible for publicly available contact details or existing contacts, an email invitation, together with the relevant Participant Information Sheet (PIS), will be sent from the research team. Potential participants will be invited to register their interest with the research team. Once participants have registered interest and provided contact details (name and email address), the research team will ask participants to confirm eligibility to take part via email. Once confirmed a unique participant ID for each participant will be generated and participants will then be sent a link to the Delphi survey itself (which include an e-consent form to take part). Where direct invitation is not possible, a flyer/poster will be circulated by relevant networks, charities, and posted on social media platforms convened by the respective research team centres. The flyer/poster will include links to the study website and PIS (professional and lay) and invite participants to register their interest in taking part. Once eligibility has been confirmed via email participants will then be sent a link to the Delphi survey. Participants who register their interest to take part but are then deemed ineligible to take part will have their contact details securely deleted.

The study involves two online Delphi surveys of up to three rounds each. A copy of Delphi Survey 1 will be given as an attachment (Delphi Survey 2 can only be developed once Survey 1 has been concluded and analysed). Criteria for achieving consensus are set out below.

Delphi Survey 1 Round 1 :
Participants will complete brief questions on sociodemographic factors (all participants), and either their professional role (professionals only) or condition-related factors (lay people only) as they relate to inclusion criteria in Round 1
Participants will rate each outcome on a 9-point Likert scale (from very relevant to not at all relevant).
A free-text box will invite participants to propose new outcome domains and/or to highlight potential overlaps or duplication of domains.
A second free-text box will invite participants to add any further comments on the domains or study.
Each round of the survey will stay open for three weeks with two reminders sent to participants. One reminder will be sent after 2 weeks, with a final reminder sent 2 days before the round closes, which states there are 48 hours left for participants to complete the survey.
Participants may pause and return to the survey.

Delphi Survey 1 Round 2:
Participants will receive a summary of Round 1 results.
They will be asked to re-rate outcomes that did not reach consensus in Round 1.
Round 2 will be open for 3 weeks with two reminders sent to participants. One reminder will be sent after 2 weeks, with a final reminder sent 2 days before the round closes, which states there are 48 hours left for participants to complete the survey. Delphi Survey 1 Round 3 (if required)
A third round may be conducted if a substantial number of domains fail to reach consensus after Round 2. The same process will be applied as set out in round 2 if this is required.
Outcomes that do not achieve consensus by the final round will be excluded.

Delphi Survey 2:
This will proceed as set out in Delphi survey 1. In this survey participants will be asked to rate outcome measures (i.e., what measure is best to measure the outcome domains that consensus was achieved for in Delphi survey 1). Participants will be given a short report on the literature reviews that identifies the most suitable measures (optional to read), alongside access to each of the outcome measures that they are asked to rate. There will be open text boxes for each domain for participants to give details of other measures that should be considered.

Consensus Criteria:
Outcomes rated 7-9 by ≥70% of participants will be considered to have reached consensus to include and will not be repeated in later rounds.
Outcomes rated 1-3 by ≥70% of participants and fewer than 15% scoring 7-9 will be considered to have reached consensus to exclude and will not be repeated in later rounds.
Outcomes failing to reach consensus to exclude or include will be carried forward to Round 2.
Outcomes that have not reached consensus for inclusion (rated 7-9 by ≥70% of participants) by the end of Round 3 will be excluded.

In Delphi survey 1, if any overlaps or duplications are highlighted in the free text boxes, only one domain (if both reach consensus for inclusion) or a merged domain will be taken forward. Any suggested domains (by at least two participants) that are considered new and relevant will be included in subsequent Delphi rounds.

In Delphi survey 2, if any new measures that are relevant are suggested, these will be included in subsequent rounds.

Intervention Type
Other

Primary outcome(s)
1. Core Outcome Set measured using Delphi consensus at June 2026 - December 2026

Key secondary outcome(s)

Completion date
31/12/2026

Eligibility

Key inclusion criteria
Professional participants:
1. A professional role that is relevant to integrated care and/or outcome measurement such as clinicians and frontline staff (health and social care), ICS staff, policymakers and their arms-length bodies, charities representing relevant conditions or population groups, and researchers with an interest or expertise in outcome measurement, integrated care and/or relevant long-term health conditions
2. Aged 18 years or over
3. Able to complete a survey in English online

Lay participants:
1. Adults with long-term complex health and care needs due to a physical and/or mental health

condition or a carer (family/friends) of such an adult
2. Aged 18 years or older
3. Able to complete a survey in English online
4. Living in England

Healthy volunteers allowed
Yes

Age group
Mixed

Lower age limit
18 Years

Upper age limit
116 Years

Sex
All

Total final enrolment
0

Key exclusion criteria
Professional participants:
1. Working outside of England

Lay participants:
1. People living outside of England
2. People who lack capacity to consent

Date of first enrolment
15/06/2026

Date of final enrolment
30/10/2026

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
-
-

-
England
-

Sponsor information

Organisation
University of Oxford

ROR
https://ror.org/052gg0110

Organisation
University of Kent

ROR
https://ror.org/00xkeyj56

Funder(s)

Funder type

Funder Name
National Institute for Health and Care Research

Alternative Name(s)
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan

IPD sharing plan summary

Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Protocol file			22/05/2026	No	No