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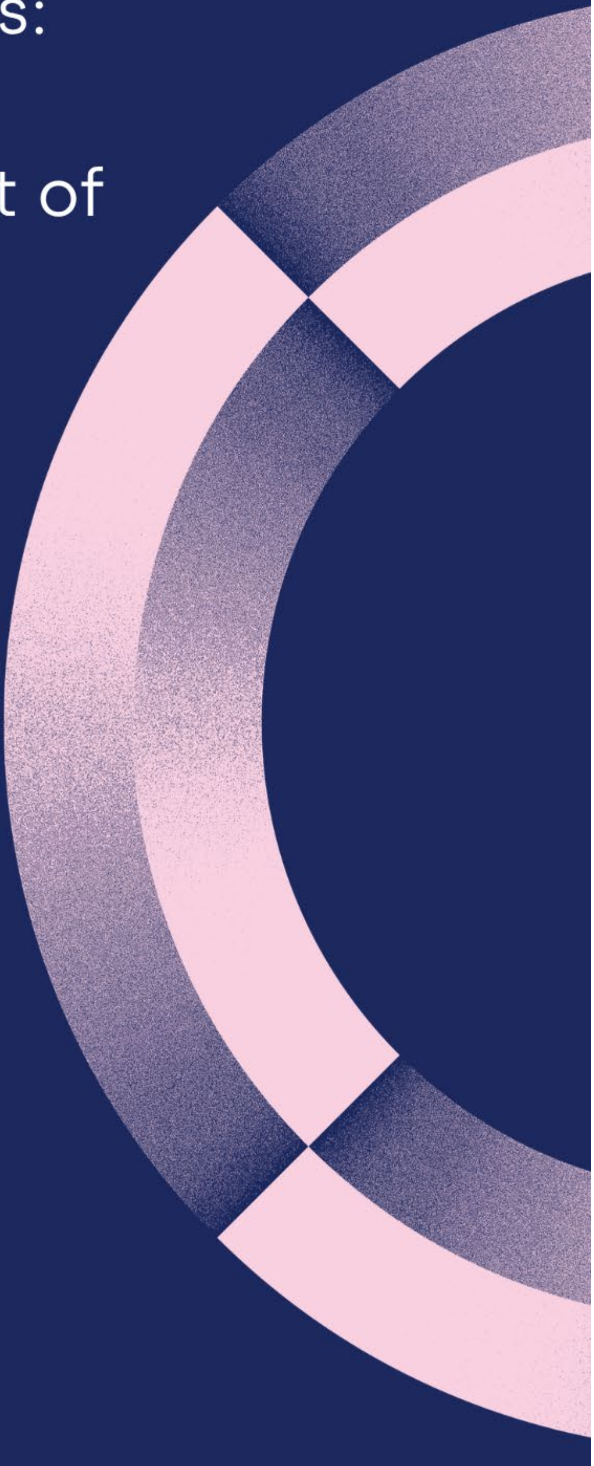
NIHR Policy Research Unit: Quality, Safety and Outcomes of Health and Social Care

Measuring what matters:

Agreeing a standard list of outcomes to assess the benefits of integrated health and social care



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1. Summary

This report presents findings from six interlinked reviews to inform the development of a Core Outcome Set (COS) for evaluating integrated health and social care. Evidence from trials, COS literature, patient and carer perspectives, Integrated Care System (ICS) strategies, safety frameworks, and regulatory indicators was synthesised into 22 outcome domains. These domains reflect what matters most to people with long-term complex health and care needs and system priorities, supporting consistent and person-centred evaluation. The next stage is a Delphi survey with professional and lay stakeholders to achieve consensus on which domains form the minimum set (or COS) for routine measurement.

2. Summary for the public

Key terms are explained in the Terminology section below.

We took a thorough look at current and academic research (e.g. people's experience of health and social care services), and national and local government policy, to agree what should be measured when health and social care work together in a joined-up way (also called integrated care). From this, we created a list of 22 areas, such as quality of life, mental health, and experience of receiving care. We will now ask patients, carers, and health and social care professionals to rate these areas to decide which are most important. Measuring the areas that are rated as most important will help make sure health and social care services are judged on what matters to people with long-term complex health and care needs – many of whom live with one or more long-term conditions - not just on the targets which are set by managers or the health and care organisations.

Terminology

'Integrated care' refers to joined-up working across health, social care, and the voluntary sector, aiming for joined up, coordinated, seamless support to improve patient and carer's experiences and outcomes.

'Patient' (sometimes in social care, referred to as service user) refers to anyone accessing services, receiving care, treatment or support from health and/or social care services.

'Carer' refers to a family member or friend who provides unpaid support to someone receiving health and/or social care.

'Long-term (longstanding) conditions' are those lasting or expected to last 12 months or more and include physical and mental health conditions. Conditions that reduce a person's ability to carry out day-to-day activities are described as limiting longstanding conditions.

'Complex health and care needs' refer to situations where a person requires ongoing, coordinated support across health and social care due to the intensity, unpredictability, or complexity of their needs. This often involves multiple services and professionals working together. Eligibility for integrated care or specialist support is determined by assessed needs rather than diagnosis, and may include both physical and mental health conditions.

3. Introduction

Integrated care aims to improve patient and carer (family or friends who provide care and support) experiences and outcomes by co-ordinating or joining up services across health, social care, and the voluntary sector. Achieving this – where services work seamlessly, appointments are coordinated and patients, carers and staff are not unduly burdened – can enhance quality and safety in health and social care. Integrated care is likely to be of particular importance to people with long-term conditions and complex health and care needs, who rely on coordinated support from multiple health and/or social care services.

In England, Integrated Care Systems (ICSs) have been introduced to support this approach, but evaluating their impact on people's outcomes and experiences remains challenging. It is unclear what should be measured, which measures should be used and whether existing measures reflect what matters most to people with long-term health conditions (hereafter referred to as patients) and their family members and/or friends who provide them with care and support (hereafter referred to as carers).

This work aligns with the NHS Experience Excellence Framework (NEEF), which prioritises coproduction, health equity, and person-centred care. The NEEF principles underpin several of the domains under consideration for this Core Outcome Set, such as patient experience, information, and holistic care, ensuring evaluation reflects what matters most to people—not just clinical outcomes.

This study aims to develop a Core Outcome Set (COS) – a standardised minimum set of outcomes and recommended measures for assessing integrated care. The COS is agreed by patients, carers and professionals. A COS helps ensure that consistent, meaningful data is collected, enabling comparison and supporting improvements in care. It can include person-centred, system-level and professional outcomes.

The proposed Core Outcome Set (COS) represents the minimum set of outcomes that should be routinely collected. Additional outcomes may be relevant in specific areas of care. In the Delphi survey, participants will be asked to rate which domains are most important to include in the core set.

To inform this work, six interlinked reviews were carried out to identify outcomes that should be considered for this COS.

This report summarises the findings from the scoping reviews (research that helps us map out what information already exists**)** and identifies 22 key domains – such as patient harm, equity and person-centred holistic care – that should be considered for a COS, drawing on both system priorities and lived experience.

4. Methodology

Each review focused on a distinct but related aspect of outcome and stakeholder perspectives on integrated care. Reviews 1, 2, and 5 examined evidence on outcomes and measurement without focusing on any particular stakeholder groups. Reviews 3, 4, and 6 synthesised the views of specific stakeholders — including patients and carers, ICSs, and policymakers and regulators. Across all six reviews, we used structured literature searches (using Google Scholar and PubMed), a clear and consistent process for screening and analysing evidence, document analysis, and thematic synthesis.

Review 1: Outcomes of integrated care interventions

14 studies (2018–2024), organised using Kelly *et al.'s* (2020) framework: structure, process, outcomes

Review 2: Core Outcome Sets (COS)

39 studies across dementia, ageing, mental health; identified common domains and measures

Review 3: Lived experience perspectives

36 articles; priorities include relational care, continuity, feeling safe

Review 4: ICS outcome strategies

9 strategic documents from 4 ICSs; highlighted priorities and gaps (refer to table in **Appendix** for ICS details)

Review 5: Safety in integrated care

Scientific and grey literature; Lalani et al. (2023) as key source

Review 6: Outcomes assessed by policymakers and regulators

Better Care Fund metrics, Care Quality Commission (CQC) Single Assessment Framework; mapped alignment and gaps

All reviews contributed to each of the proposed domains, although to varying degrees and based on a framework developed from outcomes for health and social care integration (Kelly *et al,*2020). An initial draft list of domains and sub-domains emerged from the reviews. Through an iterative process involving consultation with policymakers and public advisors, a list with 22 domains was created, **see below**. Please note the domains are ordered alphabetically.

Domains included in the Delphi survey

- Ability to self-manage
- Carer burden
- Carer experience of integrated care
- Carer health-related Quality of Life
- Carer social care-related Quality of Life
- Cognitive health
- Digital Literacy
- Fair and inclusive access
- Functional ability
- Information
- Life expectancy
- Mental health
- Mortality
- Patient experience of integrated care
- Patient harm
- Patient health-related Quality of Life
- Patient social care-related Quality of Life
- Person-centred holistic care
- Physical health
- Psychological well-being
- Risk of deterioration
- Social well-being

The next step is for Delphi Survey participants to rate the importance of each of these domains to establish agreement on which domains form part of the minimum (or core) set of outcomes.

4.1. Public Advisor Involvement and Engagement

A public advisor is a member of the public with lived experience of health or social care services who contributes to the design, conduct, and interpretation of research or evaluation. Public advisors help ensure that work reflects the priorities, needs, and real-world experiences of patients, carers, and communities.

Public advisors provide oversight and a lay "critical friend" perspective throughout. They contributed to planning, ethical review, domain and instrument selection, shaping Delphi survey stages and will support recruitment, and dissemination (including a lay report). They also ensured domain descriptions are clear. They have also co-authored and reviewed this report.

4.2. Equality, Diversity and Inclusion (EDI)

Integrated Care Systems serve diverse populations with different needs and who face different barriers. When considering outcome domains, participants should assess whether each domain is inclusive, supports fair measurement, and helps reduce inequalities in access, experience, and outcomes. We will also involve diverse stakeholders throughout the process. This ensures the Core Outcome Set is person-centred, equitable, and representative of all populations. Both our research team and our public advisors represent different protected characteristics and diversity.

5. Results

Over the next few pages, a list of 22 outcome domains is presented (in alphabetic and, non-hierarchical order), with descriptions, that are commonly measured in care for adults with long-term conditions and complex health and care needs.

1. **Ability to self-manage** (patient-reported)

The knowledge, skills, ability and confidence to manage one's own health, treatments and care over time. It includes, for example, medication and dietary management, symptom monitoring, treatment adherence, use of digital and supportive health technology, and goal setting. (Bandura, 1977; Barker *et al.* 2017; Deeny *et al*. 2018; NHS England, 2022).

Self-management was included in COS studies as a key domain. Outcomes related to confidence, self-efficacy (e.g. confidence in managing symptoms, ability to stick to treatment plans), and adherence to lifestyle changes were commonly reported (Gangannagaripalli *et al*., 2022; Morbey *et al*., 2019). ICS strategies also prioritise self-management, with systems supporting individuals to tackle poor health behaviours, manage chronic conditions, and navigate services independently (*ICS A*). Review findings described communication challenges and lack of support, which may act as barriers to self-management (Bower *et al*., 2018; Grol *et al.,* 2020). Regulatory frameworks such as the Quality Impact Assessment Framework and the NHS Oversight Framework include references to patient experience and empowerment, but do not consistently measure self-management as a standalone domain (NHS England, 2025). Including self-management in the COS would ensure integrated care is evaluated by its ability to enable people to take an active role in their health and wellbeing.

2. **Carer burden** (carer-reported)

The demands and pressures experienced by carers because of their caregiving role. Carer burden reflects, for example, the strain associated with caregiving tasks, including pressures, practical workload, and direct and indirect financial demands. It captures how challenging and demanding the caring role feels, independent of the carer's personal health or wellbeing. (Zarit *et al.* 1980; Pearlin *et al.* 1990; Schulz & Sherwood, 2008).

Carer burden reflects the cumulative strain associated with responsibilities such as time constraints, practical workload, emotional stress, financial strain, and disruption to personal life. It focuses on the intensity and impact of these demands, rather than overall carer wellbeing (Zarit et al., 1980; Pearlin et al., 1990; Schulz & Sherwood, 2008).

Carer burden was included in COS studies as a distinct domain, with outcomes such as mood, stress, and emotional exhaustion (Gonçalves et al., 2020; Morbey et al., 2019). Despite its significance, carer burden is rarely measured in ICS strategies or regulatory frameworks. Including this domain in the COS would not only reflect the pressures faced by carers but also elevate carer burden as a priority for ICSs, prompting action to reduce strain through better support and resources.

3. **Carer experience of integrated care** (carer-reported)

The carer's perception of how well health and social care services are coordinated and responsive to the needs of both the patient and the carer. This includes, for example, the carer's involvement in communication and care planning; recognition and respect of their caregiving role; person centredness (such as age, gender, culturally appropriate care); and the availability of accessible, timely information, advice, and support (WHO, 2016; NHS England, 2021).

Carer experience of integrated care is often underrepresented in evaluations, despite carers playing a central role in supporting people with complex needs. Carers described being sometimes expected to take on coordination roles without adequate support, and reported feeling excluded from decision-making and uncertain about whether their messages will reach the right team (Pigott *et al*., 2023; Robertshaw and Cross, 2019; Bower *et al.,* 2018). Regulatory frameworks such as the CQC ICS Assessment Framework include statements about involving carers, but implementation remains variable (CQC, 2023). Including carer experience in the COS would help ensure integrated care is evaluated from the perspective of those providing informal support, not just those receiving care.

4. **Carer health-related quality of life** (carer-reported)

The carer's self-perceived and subjective physical, mental, social and material wellbeing. This includes, for example, the impact of caring on the carer's physical and mental health, such as emotional stress, sleep, self-care, social interactions and participation, and their ability to do the activities that matter to them (Brouwer *et al.* 2006; Peasgood *et al.* 2018; Rand *et al.* 2019).

Carer health-related QoL remains underrepresented in evaluations and ICS strategies, despite its critical role in sustaining long-term and complex care. COS literature identified outcomes such as carer mood and overall health-related wellbeing (Gonçalves *et al*., 2020; Morbey *et al*., 2019), yet these are rarely embedded in routine measurement. One ICS included was a notable exception, addressing loneliness and isolation (*ICS C*). Other reviews reported that carers often experience stress, emotional strain, and role ambiguity, compounded by insufficient support and unrealistic expectations to act as care coordinators (Pigott *et al*., 2023; Smith *et al*., 2021). Including Carer health-related QoL in the COS would ensure integrated care reflects the needs of friends and family providing support and recognises their role in sustaining care systems.

5. **Carer social care-related quality of life** (carer-reported)

The aspects of a carer's life that are directly influenced by social care and support services. This reflects, for example, whether carers are supported to have control over their daily lives, feel safe, maintain their own health and wellbeing, participate in social and meaningful activities, maintain personal relationships, and have time and space for themselves alongside caring responsibilities (Rand *et al.* 2015; Rand *et al.* 2019; NHS England, 2024).

Carer social care-related Quality of Life was similarly overlooked in policy frameworks and evaluations, despite its relevance to integrated care. COS literature identified domains such as carer burden and morale (Gonçalves *et al*., 2020; Morbey *et al*., 2019), but again, these were rarely reflected in ICS strategies or regulatory indicators. As noted above, review findings have shown that carers are often expected to take on coordination roles without adequate support from the system (Pigott *et al*., 2023; Robertshaw and Cross, 2019): this may reflect gaps in social care provision that could otherwise assist carers and help to manage their burden.. Including carer social care-related Quality of Life in the COS would help ensure integrated care reflects the relational and emotional dimensions of caregiving.

6. **Cognitive health** (patient-reported, with assistance if the patient is unable to report this themselves)

How well a patient can think, learn, remember, and use reasoning, language, and planning skills. It can be influenced by lifelong differences in learning, education or understanding (for example, learning disabilities) and by changes in thinking or memory over time, such as cognitive decline mild cognitive impairment, or dementia (CDC 2007*;* WHO, 2019).

Cognitive health was another prominent domain in COS studies focused on dementia, ageing, and long-term conditions. Subdomains include memory, attention, and cognitive function, often assessed alongside psychological and functional outcomes (Grycuk *et al.,* 2023; Moniz-Cook *et al*., 2008). ICS strategies also address cognitive health indirectly through their focus on frailty, ageing well, and reducing risk of deterioration (ICS literature). Including cognitive health in the COS would ensure that integrated care reflects the needs of populations at risk of cognitive decline and supports early identification and intervention.

7. **Digital literacy** (patient-reported, with assistance if patient is unable to report themselves/carer-reported)

A patient's or carer's ability and confidence to access and use digital information and technologies to support health and care. This includes, for example, using online health records or mobile apps, and being able to take part in digital health and care, even when there are limitations such as access to the internet or devices, low digital skills, disability, or poor internet connection (WHO, 2021b; HEE, 2021; NHS England, 2023b).

Digital literacy is referenced in ICS strategies as a means of improving health literacy, independence, and access to services. A number of systems support personalised digital advice and virtual wards and online navigation tools to help individuals manage their care and access services more easily (ICS literature). While review findings described difficulties with communication and uncertainty about whether messages would reach the correct team, they did not explicitly reference digital capability or confidence (Bower *et al*., 2018). If carers cannot access or use digital tools, patients who rely on them may also be disadvantaged. Including digital literacy in the COS would help ensure integrated care is inclusive and responsive to varying levels of digital capability.

8. **Fair and inclusive access** (routinely collected data / patient-reported)

All patients have fair and inclusive (equitable) access to health and social care services and treatments, regardless of their background. Factors influencing access are for example sex, gender, age, people's financial situations, ethnicity, disability, geography (such as travel distance to services). It includes, for example, the absence of unfair or avoidable differences in experiences, outcomes and / or safety between populations (Marmot *et al.* 2020; WHO, 2021c; NHS England, 2023a).

Equity is a core priority in integrated care, particularly in addressing disparities in access, experience, and outcomes. ICS strategies frequently aim to reduce health inequalities, especially in areas with high deprivation or diverse populations (*ICS A, ICS D).* These strategies focus on improving access to care, tailoring services to local needs, and reducing variation in outcomes. National frameworks such as the NHS Oversight Framework and ICB annual assessments also include equity-related indicators (NHS England, 2025). However, equity is rarely measured directly in integrated care evaluations, and few studies disaggregate outcomes by factors such as socioeconomic status or ethnicity. Including equity in the COS would support more consistent monitoring of disparities and ensure integrated care is accountable for addressing structural inequalities.

9. **Functional ability** (patient-reported, with assistance if the patient is unable to report this themselves / clinician-reported)

The actual or potential capacity of a person to perform activities and tasks, taking into account their health conditions, impairments, and personal circumstances. This includes, for example, how well a person can perform activities (such as preparing food, shopping, managing finances, and using the telephone), and is able to self-care (such as eating, bathing, dressing, and toileting independently) (Kirch, 2008; Sugavanam *et al.* 2021).

Functional ability was frequently included in COS studies, particularly in relation to activities of daily living (ADLs), instrumental ADLs (IADLs), mobility, and independence (Dockx *et al*., 2023; Sanchez-Rodriguez, 2023). ICS strategies also reflect this focus, with some ICSs monitoring frailty, falls, and levels of disability as part of their outcome frameworks (*ICS B, ICS C*). However, evaluations of integrated care often fail to capture functional outcomes through patient-reported measures, and these are rarely linked to structural or process indicators such as multidisciplinary team working or shared care records (Round *et al*., 2018). Including functional ability in the COS would ensure that integrated care is assessed in terms of its impact on people's capacity to live independently and maintain daily functioning.

10. **Information** (patient-reported, with assistance if patient is unable to report this themselves / carer-reported)

Information provided to patients and carers about health conditions, treatment and care options, self-management and available health and care services. It includes balanced, clear, timely, easy to understand communication, with appropriate and proportionate adaptations where feasible (such as large print or alternative formats), that support informed decision-making and confidence in care (WHO, 2016; GMC, 2020; NICE, 2021).

Patients and carers described problems with information sharing, breakdowns in communication, and lack of access to medical records, particularly for carers (Grol *et al.,* 2020; Odom Walker *et al*., 2013). These issues were compounded by a lack of mutual understanding of terminology between service users and professionals, contributing to feelings of exclusion (Manthorpe *et al*., 2018). ICS strategies increasingly emphasise the importance of accessible and culturally appropriate information to support personalised care and improve patient confidence (*ICS A, ICS D*). Regulatory frameworks such as the CQC ICS Assessment Framework include quality statements related to communication and information sharing, such as "I only need to tell my story once" (CQC, 2023; SCIE, 2022). Including information in the COS would ensure integrated care is evaluated not only by outcomes, but by how well people are informed and supported throughout their care journey.

11. **Life expectancy** (routinely collected data)

How long, on average, a person is expected to live, based on current age-specific death rates in the population. It is complemented by healthy life expectancy, which represents the average number of years lived in good health, without significant illness or functional limitations (WHO, 2023a; ONS, 2023).

Life expectancy is a key population health outcome and is increasingly prioritised in ICS strategies. Several ICSs explicitly aimed to improve healthy life expectancy and reduce inequalities in premature mortality particularly in areas with high deprivation or chronic disease burden (*ICS A, ICS D*). These strategies focus on helping people live and age well, with targeted interventions for long-term conditions and frailty. While life expectancy was not commonly included in COS literature, it is a core indicator in national performance frameworks and ICB annual assessments (NHS England, 2025). Including life expectancy in the COS would support alignment with system-level priorities and enable evaluation of integrated care's impact on population health.

12. **Mental health** (patient-reported)

A patient's mental health status, including the presence, severity, and impact of psychiatric symptoms or diagnosed mental health conditions such as depression, anxiety, or psychosis. This reflects difficulties in mood, thinking, or behaviour that may impair daily functioning and require clinical support (WHO, 2025).

Mental health was included in several COS studies and common subdomains included psychiatric symptoms, depression and mood (Gonçalves *et al*., 2020; Grycuk *et al*., 2023). ICS strategies also prioritised mental health, with some systems monitoring suicide and self-harm rates, and expanding access to community mental health services (*ICS A, ICS D*). Review findings also identified mental health-related safety risks in community settings, such as delays in care, misdiagnosis, undertreatment, and psychological harm (Averill et al., 2023; Averill et al., 2024). Including mental health in the COS would support more comprehensive evaluation of emotional and psychological needs within integrated care.

13. **Mortality** (routinely collected data)

Death from any cause (all-cause mortality) or a specific cause (e.g. heart disease) during a given time period (CDC, 2023; Wilkinson *et al.* 2025).

Mortality was a commonly used outcome in evaluations of integrated care, typically using administrative data alongside emergency hospital admissions (Kasteridis *et al*., 2021; Morciano *et al*., 2021). While some programmes showed reductions in service use, findings across studies were inconsistent, and mortality outcomes were not consistently linked to integration efforts. COS studies also included mortality-related outcomes such as survival rates, quality of death, and place of death (Gangannagaripalli *et al*., 2022), particularly in populations with long-term or life-limiting conditions. ICS strategies reflect this focus, with several systems tracking avoidable deaths and end-of-life outcomes (*ICS A, ICS D*). Including mortality in the COS ensures alignment with existing evaluation practices while supporting more nuanced, person-centred approaches to end-of-life care.

14. **Patient experience of integrated care** (patient-reported)

A patient's perception of how well health and social care services work together to meet their needs. This includes, for example, effective communication between professionals so patients do not have to repeat their story; inclusive and person-centred (such as age-, gender-, culturally-appropriate) care; efficient transfers between services (such as from hospital to home, referrals); and short waiting times (Singer *et al.* 2011; WHO, 2016).

Patient experience of integrated care is a critical but inconsistently measured domain (Davidson *et al.,* 2021). Evaluations rarely routinely include patient-reported experience measures (Hughes *et al*., 2024), despite their relevance to understanding how integration is perceived. Service users described integrated care as successful when it felt organised, avoided duplication, and centred around their needs, with continuity and trusted coordination being key (National Voices, 2013a; Van Der Feltz-Cornelis *et al*., 2024). ICS strategies increasingly reflect these priorities, with a focus on personalised care, co-designed services, and culturally appropriate communication (*ICS A, ICS D*). Regulatory frameworks such as the Care Quality Commission ICS Assessment Framework embed these principles, linking patient experience to responsiveness, safety, and person-centred care (CQC, 2023; SCIE, 2022). Including patient experience in the COS would ensure integrated care is evaluated not only by outcomes, but by how care is delivered and experienced.

15. **Patient harm** (routinely collected data; also, patient/career/professional-reported)

Any physical, psychological, or emotional harm, injury, suffering, or loss to a patient due to health and care treatment or lack of treatment, care processes, or service delays. This includes preventable and non-preventable harm, for example medication errors or side effects, hospital-acquired infections, or failures in follow-up care (NHS England, 2019; WHO, 2021a; 2023b).

Patient harm is conceptualised differently across health and social care. Health services tend to focus on clinical safety, including medication errors, infections, and falls, while social care emphasises safeguarding and individual risk (Scott *et al*., 2017; Lalani *et al*., 2023). ICS strategies include safety-related indicators such as reducing avoidable admissions and harm from inappropriate care settings (*ICS A, ICS C*). However, patient-reported experiences of harm - such as psychological distress or feeling unsafe - are rarely captured in routine evaluation (Barrow *et al*., 2022; Averill *et al*., 2024). Including patient harm in the COS would support a more comprehensive and person-centred approach to safety across integrated services, helping to bridge differences in framing of safety across health and social care.

16. **Patient health-related quality of life** (patient-reported, with assistance if the patient is unable to report this themselves)

A patient's own view of their health, and how health conditions or symptoms affect their day-to-day life. This includes, for example, physical, mental, emotional and social functioning, and the impact of these on daily life, feelings about health, and social support (Crocker *et al.* 2022).

Patient health-related Quality of Life was one of the most consistently included domains across COS studies, alongside measures such as life satisfaction, symptom burden, and functional ability (Reynish *et al*., 2017; Gangannagaripalli *et al*., 2022). ICS strategies prioritised helping people live and age well, with indicators related to frailty, falls, and chronic disease management *(ICS A, ICS B*). However, evaluations of integrated care often rely on system-level indicators, rather than domains that reflect patient experience) (Hughes *et al*., 2024; Davidson *et al*., 2021). Including Patient health-related Quality of Life in the COS would support more consistent, person-centred outcome measurement across services.

17. **Patient social care-related quality of life** (patient-reported, with assistance if the patient is unable to report this themselves)

The aspects of a patient's life that are directly influenced by social care and support services. It includes, for example, how well social care meets needs for dignity, safety, control over daily life, social participation, meaningful activities (such as hobbies, volunteering, or daily routines), comfort, and personal care. Patient social care-related quality of life reflects how effectively social care supports independence, wellbeing, and the ability to live a meaningful daily life (Malley *et al.* 2012; Netten *et al* 2012).

COS studies and ICS strategies highlighted domains such as empowerment, self-management, and meaningful engagement (ICS literature, Gangannagaripalli *et al.,* 2022). Review findings showed that patients value relational continuity, trusted coordination and not having to repeat their story across services (Van Der Feltz-Cornelis *et al*., 2024; Byng, 2005; *ICS A, ICS B, ICS C, ICS D*). Regulatory frameworks like the CQC ICS Assessment Framework embed these priorities, linking patient social care-related quality of life (PSCQoL) to responsiveness and person-centred care (CQC, 2023; NHS England, 2025). Including PSCQoL in the COS would help ensure integrated care supports broader wellbeing and autonomy, not just clinical outcomes.

18. **Person centred holistic care** (patient-reported, with assistance if the patient is unable to report this themselves)

Care that is tailored to the individual patient and meets their physical and emotional health and care needs. It is guided by the patient's values, preferences, beliefs, identity, and circumstances. It involves, for example, shared decision-making, co-produced care plans, continuity of relationships with health professionals, and communication that ensures dignity, respect, and compassion (WHO, 2016; Health Foundation, 2016; Sugavanam *et al*. 2018; NICE, 2021).

Person centred holistic care was consistently emphasised by patients and carers as a marker of successful integration. They described good integrated care as organised, relational, and centred around their needs, with continuity, trusted relationships, and not having to repeat their story across services being key features (National Voices, 2013a; Davidson et al., 2021). Care was seen as more effective when individuals were treated as equal partners, with clear communication and coordination across settings (Holden et al., 2018; Brooks et al., 2021). ICS strategies and regulatory frameworks increasingly reflect these priorities, embedding personalised care and responsiveness into system-level evaluation (CQC, 2023; SCIE, 2022). Despite this, person-centred holistic care outcomes are rarely captured systematically in evaluations. Including person-centred holistic care in the COS would ensure integrated care is evaluated not only by clinical and health outcomes, but by how well it supports dignity, autonomy, and meaningful involvement in decisions about care.

19. **Physical health** (patient-reported / routinely collected data)

Overall health of the body which may relate to the absence, presence and / or severity of disease, symptoms and normal body functions such as mobility, endurance and energy levels. It includes, for example, diagnosed health conditions, other co-existing conditions, and symptoms like pain, fatigue or breathlessness (American thoracic society, 2002; Blackwood & Bindra, 2009).

Physical health outcomes were commonly included in COS studies, particularly in relation to symptom burden, comorbidity, and physiological status (Gangannagaripalli *et al*., 2022; Ellison *et al*., 2024). ICS strategies also prioritise physical health, with indicators focused on managing long-term conditions such as diabetes and hypertension, reducing frailty and falls, and monitoring clinical measures like BMI and blood pressure (*ICS A, ICS B*). However, evaluations of integrated care often rely on system-level indicators rather than domains that reflect individual health status (Hughes et al., 224; Davidson et al., 2021). Including physical health in the COS would ensure that integrated care is evaluated not only by service use but also by its impact on individuals' health status.

20. **Psychological wellbeing** (patient-reported)

The positive mental and emotional aspects of life, including, for example, mood, life satisfaction, sense of purpose, perceived control, emotional resilience, hopefulness, and the ability to cope with everyday stresses. This reflects how well a person feels psychologically or emotionally, regardless of whether or not they have a mental health condition (Sugavanam *et al*. 2021; Jacobsen *et al*. 2024).

Psychological wellbeing was included in several COS studies, often as part of broader quality of life domains. Common outcomes included emotional wellbeing, mood, and life satisfaction (Gonçalves *et al*., 2020; Morbey *et al*., 2019). ICS strategies also reference psychological wellbeing, with systems aiming to improve happiness, life purpose and emotional health (*ICS A, ICS C*). Patient perspectives highlight that feeling safe and supported is central to wellbeing, and that psychological harm is associated with poor communication, delayed care, or coercive practices (Barrow *et al*., 2022; Averill *et al*., 2024). Including psychological wellbeing in the COS would ensure integrated care reflects the emotional and subjective experiences of those receiving support.

21. **Risk of deterioration** (Routinely collected data / clinician-reported)

The likelihood that a patient's physical, mental or functional health will decline over time (for example, due to frailty, chronic disease progression, relapse of a mental health condition or acute events such as falls or infections), potentially resulting in hospitalisation, increased care needs or loss of independence (Hodge *et al*. 2023; Chung & Jung, 2024).

Risk of deterioration - such as declining health, increased frailty, or avoidable escalation of care - is addressed in ICS strategies through efforts to reduce unplanned hospital admissions, improve access to community services, and support early intervention (*ICS A, ICS C*). Safety-related risks such as falls, medication harm, and functional decline are commonly monitored using system-level indicators like emergency admissions and length of stay (Lalani *et al*., 2023). However, these risks were not consistently framed as deterioration outcomes in COS studies or integrated care evaluations. Including risk of deterioration in the COS would support proactive care and help identify when integrated services are successfully maintaining stability and preventing decline.

22. **Social wellbeing** (patient-reported, with assistance if the patient is unable to report this themselves)

The quality and extent of a patient's social connections and networks, participation in meaningful activities and supportive relationships, which reduce loneliness or isolation and contribute to a sense of belonging and engagement in life (Levasseur *et al*. 2010; Sugavanam *et al*. 2021).

Social wellbeing was included in COS studies, particularly in relation to social functioning, loneliness, and participation in community life (Gonçalves *et al*., 2020; Morbey *et al*., 2019). ICS strategies also reflect this focus, with some systems addressing loneliness and social isolation as part of their outcome frameworks (ICS C). Patients and carers describe integrated care as successful when it felt organised and inclusive, and when they did not fall through the gaps between services (Clifton *et al.,* 2016; Bower *et al*., 2018). Including social wellbeing in the COS would ensure integrated care is evaluated not only for clinical effectiveness but also for its role in fostering connection, inclusion, and quality of life.

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7. Appendix

Table of descriptions of the ICSs used in Review 4

ICS	Organisations
A	One of the most deprived ICS in England, with 1.2 million people. It serves an urban population with high levels of chronic illness, e.g. obesity, diabetes, and health inequalities.
B	A coastal ICS and serves a population of 800,000 people. It is more affluent with low deprivation but has a high proportion of older adults aged 65 or over (30% vs 19% nationally) with high frailty and emergency admission rates.
C	Predominantly rural with mid-deprivation levels and a population of 1.1 million people. It serves an ageing population with issues around access to health services.
D	One of the largest and most diverse ICSs with a population of over 2.1 million people. It is an urban ICS, characterised by significant inequalities in health, access to care, care experiences and outcomes.

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