

Options appraisal on the measurement of people's experiences of integrated care

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March 2013



Acknowledgements

This report describes work undertaken by a multi-organisational team based at The King's Fund, National Voices, the Nuffield Trust, and Picker Institute Europe. The work draws both on the experience of the project team and on the views and insight of a broad range of expert stakeholders. In presenting this report we gratefully acknowledge the invaluable contributions of all of the project team—especially Nick Goodwin, Jocelyn Cornwell and James Thompson at The King's Fund—as well as the stakeholders who kindly volunteered their time and thoughts to the project.

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Executive Summary

Background

People who use the NHS and social care want services that are coordinated and centred around their needs. This should include, for example, smooth transitions between services and effective communication between professionals^{1 2}. Consequently, the Health and Social Care Act (2012) places a duty on providers and commissioners to deliver ‘integrated care’. The Department of Health has committed to developing ways of measuring whether care is integrated to support these policy ambitions³.

This report was commissioned by the Department of Health to assist them in developing ways of measuring people’s experiences of integrated care, and specifically to provide:

- An options appraisal to assess the feasibility and cost of a number of strategies for measuring people's experience of integrated care.
- Recommendations on data sources that could be used to produce measures suitable for inclusion in the NHS and Adult Social Care Outcomes Frameworks.

Note that the identification or development of specific indicators was not part of the remit of this project. The work was carried out between January and March 2013 by The King’s Fund, National Voices, the Nuffield Trust, and the Picker Institute. The options appraisal and recommendations are based on a series of consultations with stakeholders and analysis of selected literature and data sources.

The report is organised into four sections:

1. Defining integrated care and understanding the purpose of indicators.
2. Approaches to measuring integrated care.
3. Establishing potential data sources and evaluating their potential for deriving indicators.
4. Recommendations based on this evaluation.

Defining integrated care and purpose of an indicator(s)

Efforts to measure and improve ‘integrated care’ have been hampered by the wide range of definitions of the term. Definitions of ‘integrated care’ often focus on descriptions of what integrated organisations should look like or what they do: in effect, they view integration from the perspective of services. Most of these definitions have come from policy makers, researchers, or health organisations.

This report builds on an alternative, simpler definition of ‘integrated care’ as ‘person-centred coordinated care’. This definition was developed for the NHS Commissioning

¹ <http://healthandcare.dh.gov.uk/forum-report/>

² <http://www.nationalvoices.org.uk/principles-integrated-care>

³ <http://www.dh.gov.uk/health/2012/01/forum-response/>

Board (now known as NHS England) and the Local Government Association by National Voices (a coalition of health and social care charities). The definition – referred to as ‘the Narrative’ - has been developed by users and is supported by key national stakeholders. It focuses on what is important from a user perspective: namely that care is “planned with people who work together to understand me and my carer(s), put me in control, [and] co-ordinate and deliver services to achieve my best outcomes”. Further details of the definition are given in section 1a (page 11) of this report.

To explore this definition and test it against other perspectives from the health and social care systems, we undertook a consultation with a broad range of national stakeholders. These included representatives from local government, the voluntary sector, the NHS, and regulatory bodies. The sessions also probed views on how people’s experiences of integrated care should best be measured, what made a good indicator, who might benefit most from integrated services, and the priorities for service improvement. Further details are included in section 1b (page 17), but we found:

- Support for the National Voices ‘Narrative’, namely that integrated care needs to be viewed from the perspective of the person using services.
- Strong demand for indicator(s) capable of driving or informing service improvement, not just to measure performance from the centre.
- A view that indicator(s) should avoid measuring integrated care just from the perspective of one organisation or service type, but explore transitions where care crosses boundaries, within and between health and social care services.
- A good degree of consensus about what kinds of users/patients might be prioritised, including younger and older people with disabilities and long term conditions.
- Pragmatism around the cost and time constraints involved in developing and introducing a new indicator(s), and realism about likely coverage.

Approaches to measuring integrated care

The second phase of the report looked at how people’s experiences of integrated care might best be measured, drawing on insights from the consultation groups, selected literature, and our knowledge of data sources. The most important distinction is between ‘user-reported’ and ‘service-reported’ measures. ‘User-reported’ measures are those that come directly from what users – including relatives or carers – say about services. ‘Service-reported’ measures, by contrast, come from data collected routinely by NHS and social care: including, for example, information about hospital admissions or the number and type of social care services provided.

The characteristics of the different theoretical approaches are described in detail in section 2a (page 23).

We identified a wide range of existing collections that could potentially provide data to measure people’s experiences of integrated care (see section 2b- page 29). We also identified gaps in data sources currently available, particularly in relation to the

experiences of people as they move across services, from GP to hospital or from hospital to social care. There is no existing survey designed specifically to measure people's experiences of integrated care.

Alongside this, we considered the wider policy context and the views of stakeholders to identify *whose* experiences should be captured. Options ranged from everyone who has contact with health and social care⁴ to just those who have regular contact with services over a period of time, such as people with long term conditions. The potential target groups for inclusion in measures of integrated care are listed in section 2c (page 34).

Finally, we identified a set of criteria for assessing potential data sources, especially for use in the Outcomes Frameworks and/or service improvement. Amongst other considerations, data sources would need to:

- include data that is robust, consistent, and high quality (eg surveys conducted in the same manner across England);
- be detailed enough to capture the experience of our targets groups of users (eg can users with long term conditions be identified?);
- shed light on the performance of more than one service/organisation;
- be suitable for assessing quality locally and supporting service improvement;
- be meaningful to the public and staff, and;
- represent value for money.

The full criteria, listed in section 2d (page 36), were used to evaluate the different options.

Options for an indicator(s)

Based on the consultation and desk research described above, we prepared a list of data sources that could potentially be used for measuring people's experiences of integrated care. We note that some such measures are already in use in the NHS and social care. We also identified key gaps where there was the potential to develop new data collections. Existing and potential new collections were then evaluated with respect to their performance against the key criteria and cohorts identified above.

Having evaluated the data sources available, we conclude that:

- **No single data source or measure is currently suitable for measuring people's experiences of integrated care** comprehensively across and within health and social care settings.

⁴ Since everyone ought to experience seamless, coordinated care, however brief their contact with services.

- A **new, bespoke validated survey** of users of health and social care which captures experiences of care coordination across services would be hard to justify in terms of cost, burden, and time to develop and implement.
- There are nevertheless good opportunities to establish some baseline indicator(s) in a timely and cost-effective way by adding to existing collections. Specifically, we recommend **adding items to some or all of the following annual national surveys**:
 - The Personal Social Services Adult Social Care Survey (ASCS).
 - The Personal Social Services Carers Survey (NB: biennial rather than annual)
 - The National Cancer Survey
 - The Community Mental Health Service Users Survey
 - The GP Patient Survey (GPPS).
 - The NHS Inpatients Survey.
 - The VOICES National Bereavement Survey.
- There is also potential to add questions about coordination and integration to **the Friends and Family Test (FFT)**, but there are barriers to using this as an indicator for integrated care. There are currently no means of attributing this beyond hospital trusts. The timing of the survey, which must be administered within 48 hours of discharge, may also make it difficult for people to reflect on a wider range of services. Additionally, there is variability in how data is collected, which may make comparisons difficult.
- Novel approaches to **understanding experience in near real-time** are emerging, including the use of near real-time local data collections, social media, and dedicated websites such as Patient Opinion and Care Opinion. These options are inherently attractive because of their immediacy, innovativeness, and potential to support service improvement locally. However, these are currently unsuitable for use because they do not provide a consistent, reliable means of systematically collecting information with representative coverage of people using services. Developments in this area should be reviewed in the future.
- The survey data described above could be supplemented by additional **service-reported data**. These data sets describe the actual processes and outcomes of care delivered, rather than direct user feedback, but they can nonetheless be useful in showing where integration can be improved. Some indicators based on existing data sources are already in use or could be identified very quickly: others may require development in the medium-term. There are a several health and social care data sets that can be used for these purposes, such as:
 - Hospital Episode Statistics (HES);

- Mental Health Minimum Dataset (MHMDS); and
 - Social care data.
- In the longer term, there is scope to extend these options, for instance by linking health and social care data sets; developing innovative uses of social media and web-based feedback to capture experiences of care; exploration of patient complaints, and so on.

Recommendations

We recommend that a developmental, ‘twin-track’ approach is taken to indicator design and deployment. This balances the stringent data quality requirements for inclusion in the Outcomes Frameworks with a service improvement perspective and the longer term opportunities. Importantly, our recommendations serve equally to meet the needs of the Outcomes Framework and to deliver information that will support providers and commissioners in improving integrated care locally. We propose a ‘roadmap’ approach to include:

- **Short term** work following a twin-track approach to include the rapid development of:
 - A core set of new questions for inclusion in existing survey collections: data from these questions will meet the requirements of the Outcomes Frameworks at relatively limited cost. Initial indicators – albeit not a comprehensive set – could begin to deliver within the 2013/14 financial year and be incorporated into the 2014/15 Outcomes Frameworks. A basket of indicators on integrated care derived from existing service-reported health and social care datasets to support local service improvements.
- **Medium term** development of a broader array of indicators, including wider use of service reported data in particular to provide a more comprehensive impression of integrated care experiences. This should include, as a priority:
 - Examination of the growing potential to use data linkage approaches to collect person-level data that transcends individual settings and bridges health and social care. Developing information sources that fill gaps within the current Outcomes Frameworks indicators and the wider basket – eg around people with learning difficulties, children, and community services.
- **Longer term** review of developments in new approaches to collecting user-reported information. Some novel methods have not yet reached sufficient levels of maturity or saturation – for example real-time data, or information from social media. This should also include the review of emerging findings from other relevant research.

These recommendations, if adopted, will fulfil the requirements for indicators in the Outcomes Framework via the use of new questions in existing national surveys: this is a highly cost-effective approach but also one that meets all key criteria around indicator quality and robustness. By following this roadmap, it will also be possible to construct

a wider basket of indicators, distinct from the Outcomes Frameworks: this basket will grow to provide comprehensive, actionable, and person-focused information to support local improvements in the standard of integrated health and social care.

The recommended approach to Outcomes Framework indicators and the wider basket share a broad and inclusive approach to collecting data from different sources and settings. By taking data from a variety of sources it will be possible to take a view of integrated care across the breadth of local health and social care economies, and by combining user- and service-reported feedback it should be possible to inform local organisations both of the quality of people's experiences and the system characteristics or processes that drive these. This twin-track approach therefore reconciles the priorities and requirements of national measurement and local improvement.

Phase 1a: defining integrated care

Introduction

The commissioner's requirement for this project is to produce an options appraisal to assess strategies for measuring people's experience of integrated care. The project therefore needs a definition of 'integrated care' that is acceptable to the commissioner and that works with the grain of patient experience measurement – that is, it enables people to make objective reports on specific aspects of their care and treatment.

Background

There is no consistent definition or model for 'integrated care'. The development of integrated care has frequently been hampered by the failure to set clear defining aims, or to resolve the problem of different definitions. One review of research literature identified around 175 different definitions⁵. As a result, defining and delivering integrated care is a challenge for all health and care systems, and has been a preoccupation of the NHS and other care services in the UK for over four decades⁶. The vast majority of these definitions have been generated by policy makers, researchers and health and social care service organisations. They have often taken an 'organisational' perspective focused on 'what we have to do' to bring services together.

These perspectives often bear little relation to the perceptions of service users, or indeed to the question of what benefits and outcomes service users may experience from the 'integrated' care that is delivered. Consequently, many attempts to deliver integrated services have not always been able to demonstrate benefits from the perspective of end users.

Integrated care is a 'hodgepodge' concept⁷. Shaw et al distinguish between 'integration' – the bundle of processes and efforts that are used to try to create better services – and 'integrated care', which is the outcome expressed as improved care for people⁸.

In reviewing the literature, different taxonomies of integrated care have supported this conceptualisation by variously examining (after Nolte and McKee [2]): *types* of integration (e.g. organisational, professional, functional); *breadth* of integration (e.g. vertical, horizontal, virtual); *degree* of integration (i.e. across the continuum: linkage, coordination to full integration); and *processes* of integration (i.e. cultural and social as well as structural and systemic)⁹.

⁵ Armitage, G.D., Suter, E., Oelke, N.D., & Adair, C. (2009). Health systems integration: state of the evidence. *International Journal of Integrated Care* 9(17), 1–11 2009

⁶ Shaw, S., Rosen, R., Rumbold, B. (2011). *What is Integrated Care?* Nuffield Trust: London.

⁷ Kodner, D. (2009). All together now: a conceptual exploration of integrated care. *Healthcare Quarterly* 13(Sp), 6–15.

⁸ Shaw et al (2011). Op cit.. See also Kodner, D.L., & Spreeuwenberg, C. (2002). Integrated care: meaning, logic, applications, and implications – a discussion paper. *International Journal of Integrated Care* 2(e12)

⁹ Nolte E, McKee M. Integration and chronic care: a review. In: Nolte E, McKee M, editors (2008). *Caring for people with chronic conditions. A health system perspective*. Maidenhead: Open University Press; p.64-91.

Some common features of successful integration have been noted as including:

- agreeing common goals;
- interdisciplinary working (especially, in the health context, between primary and secondary care clinicians);
- clarity of roles and responsibilities;
- integrated information systems;
- leadership at the national, regional and local level of care;
- governance and financial systems that enable care providers to collaborate across organizations boundaries;
- intelligent systems for data collection with shared and computerized information to support clinical decision- making;
- care professionals supported and trained to work in partnership;
- care co-ordinators and case managers to support access to appropriate care providers;
- multi-disciplinary teams;
- patient education and empowerment; and
- evidence-based guidelines and care pathways.

However, these ‘ingredients’ do not in themselves help define the ‘recipe’ that brings better integrated care.

In its literature review and work with stakeholders for Monitor, Frontier Economics sought a definition that would combine the ‘experiential’ perspective of users with issues of cost and quality. They drew on the work of Goodwin and Kodner to suggest three dimensions of integrated care (paraphrased below):

- Improving the quality and cost-effectiveness of care for people and populations by ensuring that services are well co-ordinated around their needs – that is, being both 'patient-centred' and 'population-oriented'.
- Being necessary for anyone for whom a lack of care co-ordination leads to an adverse impact on their care experiences and outcomes.
- Having the patient or users perspective as the organising principle of service delivery.¹⁰

Historically most definitions of integrated care have not met the ‘person centred’ or ‘users’ perspective’ criteria above. Integration has been described from the perspectives of policy makers, system leaders, clinicians and researchers.

These ‘organisational perspectives’ are now perceived, in general, not to have universally succeeded in enabling sufficient progress in producing better co-ordinated care to patients and service users. They tend to emphasise organisational processes

¹⁰ Frontier Economics. (2012). *Enablers and barriers to integrated care and implications for Monitor*. Frontier Economics: London.

(‘integration’) while having insufficient focus on outcomes (‘integrated care’). Their emphasis on ‘joint working’ has tended to mean that ‘success’ has been described as better organisational coordination, or in terms of care plans executed, rather than better care coordination. The Audit Commission has demonstrated this in the English context¹¹.

As a result, what Frontier Economics describe as a new ‘clear consensus’ has developed in England, that “integrated care is not about structures, organisations or pathways – it is about better outcomes for service users”¹².

Influential in this consensus building was the NHS Future Forum and in particular the recommendations drawn from work by The King’s Fund and Nuffield Trust to advise it¹³. A central recommendation was the need to come up with a clear definition of integrated care:

“The most fundamental prerequisite to the development of integrated care at scale is the crafting of a powerful narrative at both a national and local level about how services could and should be delivered for people with complex conditions”

Since it was vital to keep the needs of service users, and their outcomes, at the heart of the discussion, this ‘narrative’ must include ‘a clear articulation of the benefits to patients, service users and carers’.

The report also recommended, citing Lloyd and Wait¹⁴, that those developing integrated care ‘must impose the user’s perspective as the organising principle of service delivery’. Any narrative must be built from a service user perspective.

In 2012 the nascent NHS Commissioning Board and the Local Government Association commissioned National Voices to help them develop such a narrative.

The ‘Narrative’ definition

For the purpose of this project and throughout this project report, we define ‘integration’ as ‘person centred coordinated care’ (coordinated care, for short). This definition is the one used in the draft Narrative commissioned by the NHS Commissioning Board and LGA from National Voices. It is anticipated that a refined version will appear as the definition supported in the forthcoming Common Purpose Framework which will be supported not only by the Department of Health (our commissioner), but by all key system stakeholders at national level.

Advantages of this definition

This definition has the following advantages:

1. Service user perspective

¹¹ Audit Commission, the. (2009). Means to an end: joint financing in health and social care. *Health National Report: London*.

¹² Frontier Economics (2012). Op cit.

¹³ Goodwin, N., Perry, C., Dixon, A., Ham, C., Smith, J., Davies, A., Rosen, R., & Dixon, J. (2012). *Integrated care for patients and populations: Improving outcomes by working together*. King’s Fund and Nuffield Trust, London.

¹⁴ Lloyd, J., & Wait, S. (2005). *Integrated Care: A guide for policymakers*. Alliance for Health and the Future: London.

The definition uses the perspective of people who use services and their carers, and was co-produced with users and service user organisations. This is essential for capturing people's experiences of whether services are 'joined up'.

2. System alignment

The draft Narrative is an attempt to create common goals across the health and social care system. Such narratives have proven to be successful at this at both the local and regional levels, for example in the use of the *Mrs Smith* narrative for integrated care in Torbay¹⁵ or in the *Esther* project to improve older people's care in Sweden¹⁶. Although it is early in the process, the Narrative definition has the provisional support of partners in the national collaborative on integration: the NHS Commissioning Board, the Local Government Association, the Department of Health, Monitor and the Association of Directors of Adult Social Services.

3. Policy alignment

The definition aligns with Department of Health's policies on integration. .

Exploration of the Narrative definition

The Narrative offers two subsidiary explanations of what the headline definition might mean.

Explanation 1

This explains what person- centred, coordinated care means from the point of a view of a service user:

"My care is planned with people who work together to understand me and my carer(s), put me in control, co-ordinate and deliver services to achieve my best outcomes"

Explanation 2

This explains what person- centred, coordinated care means from the point of view of organisations which either commission or provide care:

"Partnering the person to plan, pick and pull together care, support and treatment."

Context

The Narrative has been tested with stakeholders and will be refined and completed during March 2013, in parallel with this project. Beyond that, there will be a process of securing its adoption and use by system leaders and stakeholders including clinical commissioning groups.

¹⁵ Thistlewaite, P. (2011). *Integrating Health and Social Care in Torbay - Improving Care for Mrs Smith; The King's Fund*, London. Retrieved from <http://www.kingsfund.org.uk/publications/integrating-health-and-social-care-torbay>.

¹⁶ Henriks, G. (2012). *The Esther Project, presentation to The King's Fund*. Retrieved from <http://www.kingsfund.org.uk/sites/files/kf/goran-henriks-lessons-from-sweden-esther-project-kings-fund-may12.pdf>

It is possible that aspects of the current draft text will be challenged and amended. However, we are assured by our commissioner that system commitment to the definition of ‘person centred coordinated care’, described from the user perspective, will not change. For the purposes of this project, therefore, we use the headline definition and explanations described above.

Definition at the level of categories and indicators

This project is required to make recommendations on the ‘who’ and the ‘how’, rather than on ‘what’ specific questions people should be asked. However, in order to assess currently available indicators or groups of indicators, and identify gaps, the project needed an understanding of the aspects of care coordination that are most significant for service users and carers and have most impact on the quality of their experience and health outcomes. Since this has not been tested as such, we need a way to draw on lessons learned during the preparation of the draft Narrative. That is, we need more detail beyond the headline definition to help guide the enquiry.

The draft Narrative provides this through a set of statements that service users could make *if* their care was well coordinated (known as the ‘I’ statements)¹⁷. As many of these have been developed with service users and their organisations, it is important for them to shape our thinking. However, taken individually, they are too specific and too numerous for the project’s purposes.

In the draft Narrative the ‘I’ statements are grouped into topic headings such as ‘communication’ and ‘shared decisions’. These topics were chosen and imposed by the project managers rather than service users and may be amended in the light of feedback.

For this project we need a set of categories of the things that are significant to users and about the coordination of their care, and which are based on the ‘I’ statements. Based on what was heard from service users and their organisations in the 18 months leading to the Narrative we propose the following:

- Clear, explicit and consistent contact mechanisms (preferably one point of contact);
- All staff (within and across services) working together as a team around the individual;
- Opportunities to plan my care and treatment, with my preferences respected;
- Shared decisions and as much control and independence as possible;
- Carer and family involvement;
- Information shared between staff and services and with me;
- Transitions work smoothly and emergencies are anticipated and planned for.

¹⁷ Some of these were drawn from existing co-produced statements in the ‘Making it Real’ personalisation initiative pioneered by Think Local Act Personal.

The international perspective

There are a growing number of methods and tools worldwide designed to measure integrated health care, drawing on routine service data and questionnaires aimed at staff, managers and patients¹⁸. Many of these measure processes of care, outcomes and more frequently measure the provider rather than the patient perspective. Through a preliminary literature search and consultation with researchers in the UK and North America, we have identified a number of questionnaires for measuring integration, continuity or coordination of care¹⁹.

Many of these focus on a specific setting (primary care or specialty care) or specific population or disease and/or a particular element of a pathway (such as the transition from hospital) or clinical processes. Surveys designed for patients to respond to at home (ie away from a specific health care setting) are rare (one Dutch only language example is cited in Uijen (2012)²⁰. Interest in measures of people's experiences of integrated care is growing internationally.

Overall, the application of these survey tools to allow providers to use patient experience to support quality improvement in practice is in its infancy internationally. One of the most comprehensive reviews of these tools has been conducted by the US based Agency for Healthcare Research and Quality²¹. This review analysed the content of over 60 surveys, using a matrix of activities/processes that are important for care coordination, as measured from the perspective of either patients/family, health care professionals or 'systems'. AHRQ's analysis of these tools suggests that relatively few really try to capture user experience, and most are disease or client-group specific: they generally do not provide a broader examination of the experiences of people with, for example, complex health and/or social care needs.

Similarly, the OECD's (Organisation for Economic and Cultural Development) healthcare quality measurement group has a subgroup focussing on user experience measures, and one of this subgroup's current priorities is looking at international examples of questions on integrated care. The scope of this work is rather different to the current project, however, in that it looks at specific items for use in patient surveys, and these items typically focus on healthcare only. The work of AHRQ and OECD may therefore be of interest to UK researchers developing specific survey questions on integrated care, but does not directly support the current evaluation.

¹⁸ Strandberg-Larsen, M., & Krasnik, A. (2009). Measurement of integrated healthcare delivery: a systematic review of methods and future research directions. *International Journal of Integrated Care*, 9(1).

¹⁹ Uijen, A.A., Heinst, C.W., Schellevis, F.G., van den Bosch, W.J.H.M., van de Laar, F.A., Terwee, C.B., & Schers, H.J. (2012). Measurement properties of questionnaires measuring continuity of care: a systematic review. *PLoS ONE* 7(7): e42256.

²⁰ Ibid.

²¹ McDonald, K.M, Schultz, E., Albin, L., Pineda, N., Lonhart, J., Sundaram, V., Smith-Spangler, C., Brustrom, J., & Malcom, E. (2010). *Care coordination measures atlas*. Agency for Healthcare Research and Quality: Rockville, MD. <http://www.ahrq.gov/professionals/systems/long-term-care/resources/coordination/atlas/care-coordination-measures-atlas.pdf>

Phase 1b: consultation with stakeholders

Introduction

Three consultative discussion groups with key national stakeholders were held as part of the 'defining' phase of the work. Stakeholders attended one of the three groups, each facilitated by members of the consortium. The topic guide and participant list for the groups are included as Appendix 1 and 2.

The discussion groups explored:

- participants' ideas about and understandings of integration;
- organisational perspectives on measuring and describing integration;
- organisations' information gathering and requirements for measuring and understanding people's experiences of integrated care;
- the nature, purpose and usefulness of potential measures(s) and an indicator(s) of integration; and
- the potential 'audiences' for measures and indicators of integration.

This section of the report outlines the main themes that emerged from the consultation.

Defining integrated care

As outlined previously, the Narrative developed by National Voices was adopted as the working definition of integrated care for this project. Throughout the discussion groups, facilitators sought to understand how closely stakeholder's ideas about and understandings of integrated care matched with the content of the Narrative.

The vast majority of stakeholders agreed that the Narrative would be the most appropriate definition to base potential measures and indicator(s) on in the future.

Stakeholders agreed with the Narrative's core sentiments, with its approach to understanding and describing integration and that it included the right features of integrated care, from their organisational perspectives.

There was very strong concordance between the views expressed during the consultation and the Narrative's emphasis on developing a person-centred understanding of integrated care. Participants agreed entirely with the National Voices position that integration must be seen as coordinated *by the person using services*.

In particular, stakeholders welcomed the 'my best outcomes' phraseology used within the Narrative. They approved of the sense of sovereignty that this accords to patients and service users. Many participants rejected the idea of measuring integrated care solely from the provider, commissioner or 'care process' perspective.

Many participants felt it was important to include carers as beneficiaries or recipients of integrated care in their own right. Participants pointed out that carers may, in some circumstances, bear the costs of services that are neither coordinated nor person-centred as much as - or even more than - the patient or service user. Some specific examples were given, where the patient or service user is a child, or an adult who has a cognitive impairment. Stakeholders also stressed that the definition of carers should include family, relatives and friends who provide informal care.

Data collected and held by stakeholders

In all three discussion groups it was apparent that none of the stakeholder organisations, collected or held data that could be used to adequately measure people's experiences of the integration of health and/or social care.

When asked about data collection, stakeholders discussed a range of different existing data sources that could be seen as proxy measures, although none of these, taken alone or together as composites, would be person centred - i.e. they would not be able to capture integrated care from the patient or service user perspective.

The possible proxies discussed included, for example:

- Delayed discharge data.
- Readmission rates.
- Complaints data.
- Audit data.
- Safeguarding incidents (social care).
- Third sector data (such as Citizen's Advice Bureau contact records).
- General Practice Extraction Service data.
- Inpatient length of stay data.

Stakeholders described the barriers to achieving and measuring integrated care. One key barrier was the absence of timely and appropriate information sharing within, between and across services and sectors.

Other barriers included the lack of a shared language between health and social care, the misalignment of incentives for providers in different services and sectors, and the problems that these cause. Participants felt that a review of incentive frameworks was needed, and that new, clearer and/or more closely aligned incentives would benefit individual services as well as promoting more integrated care.

For social care in particular, participants spoke of tensions between the multiple standards that services must follow and the challenges of delivering high quality and coordinated care. Similar tensions can also be found in health care, where parts of the

acute care system were incentivised to increase admissions and speed up discharges of short stay patients compared to the objectives of integrated care which tries to keep people out of hospitals and cared for in the community.

The nature of potential integrated care indicators

Building on the Narrative, stakeholders' discussions about the nature of potential indicators were focussed on two questions:

- What aspects or elements of integrated care that should be measured.
- Who should be included within 'people's experiences'.

Aspects/ elements of integrated care

Stakeholders discussed a range of approaches to measuring people's experiences of integrated care, ranging from idealistic to pragmatic in scope. At one extreme, stakeholders described an ideal indicator approach, featuring inclusion of all people, across all services, and with comprehensive reporting to different providers and commissioners. More pragmatically, others described a more focused approach, based on a single condition or demographic group, or on a particular service setting, and treating it as an example of the standard of integrated care within an area.

For all participants, any measure or indicator must be able to capture experiences of where care crosses boundaries between health and social care, or within each sector itself. Some stakeholders suggested that in an ideal world, the measure would extend beyond health and social care to include education, housing, public health and so forth. For example, ensuring integration of education services would be important for some children and young people, while ensuring integration of housing services might be more relevant for adult acute mental health service users.

Stakeholders emphasised that measures and indicators of integrated care should address the system as a whole, as experienced by the patient or service user, rather than one service. They were very clear that potential measures and indicators should strongly discourage - and (emphatically) should not reinforce - traditional service and sector silos.

Participants felt that some 'transitions' between services were particularly important to measure, for example, the transition from child to adult services, from health to social care, and from curative to palliative to end of life care.

Some stakeholders discussed 'having a care plan' and 'having a named care coordinator' as potential indicators of the 'I' statements in the Narrative. It was however agreed that on their own these would provide only very partial, and not necessarily reliable or comparable, data.

Understanding 'people's experiences'

There was agreement that 'people's experiences' are complex and multi-dimensional, and should not be reduced to single score. Stakeholders did however strongly support the aim of measuring people's experiences of integrated care, and adopted a very realistic approach about 'what and whose experiences' might be measured.

What emerged most strongly from the discussion group is that any future measures and indicator(s) of integrated care will receive broad cross sector support *provided that the approach and the metrics are person centred* (ie that they measure and describe people's experiences of using services, not providers' experiences of delivering them).

Overall, a majority of stakeholders agreed that the indicator(s) of integrated care should ideally be aimed at the general population. They were however very conscious that this may not be achievable and/or cost effective.

When asked to consider what the priorities might be, some stakeholders felt that the focus on particular sub-groups would be decided by both policy priorities and need within the groups. However, the following sub groups were identified for the indicator to focus on. In all cases, the groups include carers as well as patients and service users:

- People living with dementia.
- People living with long term conditions, physical and mental.
- People who have learning difficulties.
- People who are at the end of life.
- Older people.
- Children.

Stakeholders felt that integrated care would be particularly important in meeting the health and social care needs of people in these groups, and in optimising their health and wellbeing. The likelihood of co-morbidities and complex needs was a key factor in these discussions, with a number of stakeholders feeling that focussing on people with complex co-morbidities would be the most appropriate group for the indicator(s) to apply to.

Stakeholders also suggested that, by focussing on a small number of sub groups and ensuring that integrated care was delivered (and measurable), it would shed light on the experience of other sub-groups and the wider population. In other words: 'get it right for these people, and you can get it right for everyone'.

Purpose of the indicator(s)

Stakeholders were clear that the indicator(s) of integrated care must meet generally accepted criteria for 'good' indicators, and, in particular should be useful at local level.

The overarching concerns for all stakeholders were that measures and indicator(s) should:

- be capable of driving improvement at the local level;
- be useful and actionable for commissioners;

- encourage health and social care professionals to start communicating and working together better; and
- benefit the wider health and social care system, for example by creating an enhanced working environment, and/or driving financial and efficiency savings.

Whilst stakeholders accepted that the indicator(s) may not be able to provide a high level of detail, they were very determined that it/they must provide data that is useful and useable at the local level.

Stakeholders argued that:

- a clear 'audience' for the indicator(s) must be set out;
- the purpose of the indicator(s) must be established and communicated; and
- the indicator(s) should, in every sense, be fit for purpose.

Participants' primary concerns were about the tensions between local and national level indicators; if the integrated care indicator(s) is developed for use only as a 'ministerial tool' it will provide a broad overview at the national level but will not be useful locally. Local providers and commissioners require detail in order to identify and attribute the contribution of different local services

Some stakeholders suggested that disaggregated data could feed into regulatory processes and could be published so that potential patients, service users and carers could assess available options and make informed choices. This could, it was argued, extend to joint monitoring and regulation of local health and social care provision.

Stakeholders were very clear that the indicator(s) should have longevity. There was a great deal of concern/suspicion that the indicator(s) would be developed and applied as a 'quick fix', and might not be robust as a result.

Stakeholders also felt that it was important to have measures that could be followed over time, and in the future could describe people's experiences of integration along care pathways and patient journeys.

There was also enthusiasm for a basket of indicators, rather than a single measure, which would allow comprehensive measurement of integrated care due to its multi-faceted nature.

Another key theme that emerged was that measures and indicators should focus on positive outcomes, and allow the identification of good integrated care, to support shared learning across services. This approach would of course also be consistent with designing an indicator(s) whose primary purpose is to drive improvement.

Potential vehicles for the indicator

Discussion around potential vehicles for the indicator(s) elicited interesting ideas from stakeholders, although the general and widely held assumption was that the indicator(s)

data would ideally be derived from an experience-based survey of patients, service users and/or carers (depending on focus).

Some participants suggested using existing experience-based surveys to carry the indicator(s). Indeed, stakeholders typically saw surveys of patients, service users, and their carers as the most likely mechanism for getting feedback on people's experiences of integrated care. Most discussions focussed on statistical sample surveys, and specific suggestions included CQC's national patient survey programme, the GP patient survey, VOICES, and the adult social care survey. One stakeholder suggested that a generic indicator could be included in a number of surveys to cover different sectors and settings. For some stakeholders, using existing patient experience surveys would allow a number of questions covering integrated care to be included, whilst also gathering process measures. This composite approach would provide accountability over providers. Others could see the merit of this suggestion, but pointed out that this might risk missing or excluding key patient, service user and carer groups, including (for example) people receiving only or primarily community-based services. Others raised non-probability survey approaches as an alternative, such as trust's local 'near real-time' collections that may rely on convenience sampling.

An additional suggestion was the Friends and Family Test (FFT) as a potential vehicle for the indicator(s). For some stakeholders, the FFT was not seen as a viable option and should be discounted due to its design as a simple, service specific metric that would not capture the complexity of integrated care.

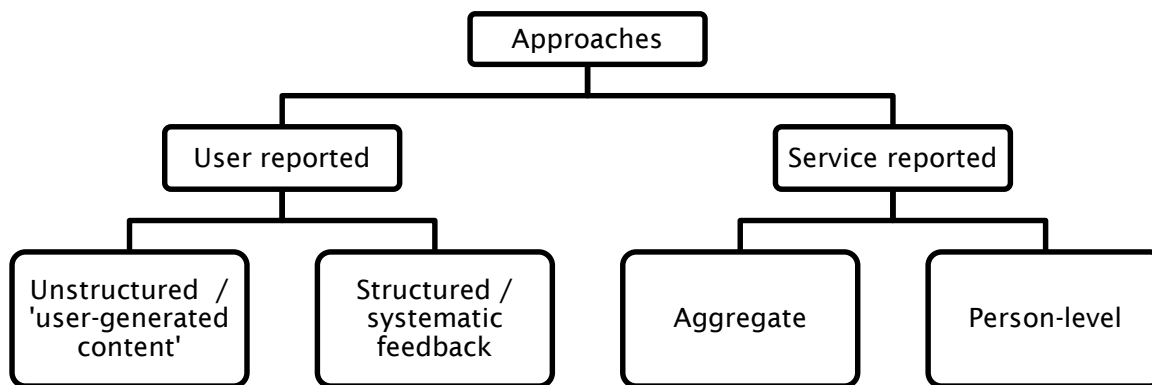
Other suggestions were:

- Detailed analyses of existing data sets (eg Hospital Episode Statistics or the National Minimum Dataset for Social Care) that might function as proxy indicators of integrated care.
- Audits that focus on specific conditions or care sectors including, for example, the national stroke audit.
- Joint inspections (for example, by education, health and social care bodies) to encourage triangulation between the different sectors.
- Thematic analyses of patient/user stories, and use of 'mystery shoppers'.

Phase 2a: Theoretical approaches to measuring people's experiences of integrated care

Introduction

There are broadly four approaches to measuring people's experiences of integrated care, as shown in the following taxonomy tree:



Whilst the definition of integrated care set out earlier considers integrated care specifically from the perspective of users, this does not preclude using other data sources related to the experiences of patients, service users, or carers.

Four key considerations are identified:

- Whether collections are or could be mandated.
- Whether future developments in NHS and social care data – particularly driven by the NHS Information Strategy – might influence options in the near future.
- Whether data would be available in real time or ‘near real time’.
- Whether collections relate to only one or to a range of services or settings.

Distinctions in types of approach

A fundamental distinction is whether information sources provide feedback directly from ‘users’ or come from routine service-reported data.

We consider ‘user-reported’ information to include all data or intelligence explicitly provided by patients, service users, or their friends, relatives, carers, or proxies.

Where the quality of users’ experiences is inferred from other data- be that routine statistics, audit information, or something else- we refer to this collectively as ‘service-reported’ information. For example:

Table X: Examples of information sources by production source

User-reported	Service-reported
Surveys	Audit data – eg from NCAPOP
Complaints & compliments	Routine data – eg HES records
‘Patient stories’ – eg via www.patientopinion.org.uk or www.iwgc.co.uk	

One source of information that is arguably less well captured by this taxonomy is feedback from health and social care staff eg surveys of the experience of staff members. We regard this as ‘user-reported’ information.

User- reported information

User-reported information on integrated care can be split into structured and unstructured collections. Structured collections are those that are centrally designed, administered, and/or co-ordinated with a specified data set collected from a representative sample of people: by contrast, unstructured collections include user feedback that is volunteered and is not structured or standardised.

Surveys are the key structured approach to user-reported data and are already used extensively to collect information on people’s experiences of health and social care²². As noted in phase 1b, stakeholders in the consultation typically saw surveys of patients, service users, and their carers as the most likely mechanism for getting feedback on people’s experiences of integrated care. Most discussions covered **statistical sample surveys**, such as the existing national patient survey programme, the GP patient survey, VOICES, and the adult social care survey. These collections typically contain a range of demographic and health activity items at case-level, meaning that data can often be aggregated and analysed by sub-groups – eg people with long-term conditions, or different age groups. However, most existing collections focus on particular services rather than specifically looking at experiences across different providers.. Some stakeholders therefore felt that a new survey or surveys would be required, specifically to address cross-organisational care experiences. Others felt that existing surveys could provide an efficient vehicle for asking people more broadly about their experiences of integrated care. . As well as statistical sample surveys, it is also possible to gather feedback from **non-probability survey approaches**, and stakeholders noted that, some health and social care providers may have local ‘near real-time’ collections that may rely on convenience sampling. The friends and family test, which operates as a census of certain services, was also mentioned as a possible approach.

Not all people are able to self-report independently due to a physical or mental condition, especially in some key groups where integrated care is particularly salient, such as those with dementia or users of particular social care services. Proxy respondents – such as a relative, carer or close friend – are pivotal for these groups.

²² Graham, C., & Woods, P. (2013). Patient Experience Survey. In Ziebland, S., Coulter, A., Calabrese, J.D., & Lockett, L. (eds). *Understanding and using health experiences: improving patient care*. Oxford University Press: Oxford.

Any user-reported indicators on integrated care that are embedded within structured feedback mechanisms, such as surveys, will need to allow for proxy response data to be collected. This is already common practice in most national surveys: for example, around 16% of responses to the NHS inpatients survey involve a proxy respondent²³, whilst only 31% of questionnaires returned in the adult social care survey 2011 were completed by service users unaided²⁴.

Another source of information is routine **complaints and compliments** submitted to providers by their users. Whilst this information is not currently collated in any way that could support an indicator, it is notable that the final report of the second Francis Inquiry on Mid Staffordshire NHS Foundation Trust recommends much greater use of data on complaints including provision of summary information for CQC's regulatory use. In future, such reports might include information with specific relevance to integrated care.

Another source of primarily qualitative feedback is via **patient/user comments websites** such as www.patientopinion.org, www.iwgc.co.uk, and www.comparecarehomes.com. These sites allow users to leave their stories about accessing services, and all responses are placed in the public domain. More broadly, there may be a role for **social media** – such as the Facebook and Twitter platforms – as potential sources of user-generated content on health experiences.

Service reported information

By contrast, most routine sources of health and social care data are collected by the service itself or by other professional agents, and provide a major source of data for performance indicators. This is well exemplified in the NHS Outcomes Framework, where approximately three fifths of indicators are based on service-reported information.

Using service-reported information as a proxy for people's experiences of integrated care was raised several times in the consultation. Suggestions included both routine health activity data – eg via sources such as HES (Hospital Episode Statistics) – as well as more focussed collections – such as audits of particular conditions. These data sets already contribute to a wide range of indicators. For example, HES data drives numerous indicators within the NHS Outcomes Framework, whilst the stroke sentinel audit and the national neonatal audit programmes contribute to indicators 3.4 and 5.5 respectively.

A useful distinction in service-reported information is between **aggregated** and **patient/user-level data**. Many sources of routine data consist of individual records at a patient or user level, with information extractable from these: examples include HES, MHMDS (mental health minimum data set), and clinical audit data. Such patient/user-level datasets provide flexibility for using data in a variety of ways. For example, it is possible to aggregate results at different geographical levels, adjust for differences in case-mix, look at different patient groups – eg by age or health condition. Using patient identifiers it is also possible to link different patient level data sets (eg inpatient and PROMs) and it would be possible to 'follow' individuals over time or across different

²³ Graham, C. (2013). *Proxy response in a large-scale patient experience survey*. Manuscript submitted for publication (copy on file with author).

²⁴ Health and Social Care Information Centre, the. (2012). *Personal Social Services Adult Social Care Survey, England 2011-12 (Final Release)*. Health and Social Care Information Centre: London. pp146

care settings: this could provide powerful information about people's interactions with a range of services. Data sets comprising individual records generally relate to health care, and are uncommon in social care. Some areas, such as Torbay, are linking records across health and social care and such examples are on the increase. Linkage within health alone – eg across primary care, secondary care, and A&E – is rather more common. The Department of Health's Information Strategy²⁵ highlights the direction of travel towards linked health and social care records.

By contrast, **aggregated** datasets are those where data exists only at a grouped level – for example at the level of organisations or regions – and cannot be disaggregated down to individual service users. Examples include QOF (Quality and Outcomes Framework), and data on waiting times. Such data avoids the confidentiality concerns of case-level data but is less flexible it is not possible to disaggregate or regroup data to look at sub-groups, for example. Some aggregated datasets include aggregates at intermediary levels. For example, social care data often has client group such as physical health, mental health, or learning disability, available as a level of disaggregation.

The distinction between aggregate and person-level information is not restricted to service-reported information. A similar distinction may exist within user-generated content. For the friends and family test, for example, trusts are required to report only aggregate data. As a result case-level responses will not be centrally collated or available for disaggregation. Instances are exceptions rather than common though, and as such, this is not seen as a fundamental structural distinction and is not included in our taxonomy.

Other considerations

Mandatory vs voluntary collections

A new indicator(s) of people's experiences of integrated care would need to provide nationally representative data. This implies comprehensive coverage across different geographical regions. A key determinant of this is whether or not the collection is (or can be) mandated, or whether its return is voluntary. In the consultation, the representatives from local government, noted that there are few nationally mandated data collections in their sector.

Whether or not collections are mandatory is likely to have implications for data collection in a standard, consistent, and systematic way. Voluntary collections are typically associated with patchy coverage and greater local variation. This may encourage local use, but such variability does not permit reliable comparability of data between areas and over time.

Future developments

Given the long-term aims of the NHS Outcomes Framework, it is prudent to consider how information collection may be affected by future developments in policy and practice. The NHS Information Strategy²⁶ is particularly relevant, as it sets out

²⁵ Department of Health (2012). *The power of information: Putting all of us in control of the health and care information we need*. Department of Health: London. Retrieved from http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_134205.pdf

²⁶ *Ibid.*

aspirations for the use of health and social care information with a particular focus on delivering better integration of care. Amongst the recommendations aimed at integrated care are:

- Consistent use of the NHS number.
- Consistent information standards to enable secure, confidential sharing of information across health and social care.
- Increased uptake of electronic care records as a measure of quality.
- Increased linkage of records within health and across health and social care.

These are areas where, at present, limitations or inconsistencies in practice might create obstacles for the use of routine information to create an effective indicator. In order to 'future proof' this review, our options evaluation must take into account the likely future developments as well as current practice. This creates an inevitable degree of risk if anticipated developments in information are not realised. To balance this, our evaluation will:

- Identify specific collections, vehicles, or approaches where current practice may create barriers;
- Briefly describe the best and worst case scenario for improvement in information standards in these areas by 2015 (the end of the period covered by the mandate to the NHS Commissioning Board);
- Determine whether best or worst case changes will affect the feasibility of the approach by 2015.

Real time vs. retrospective data

The timing of data collection is a highly topical issue in health and social care. The Francis Inquiry Report, for example, notes the potential value of information collected and reported in or near to 'real time'. However, the report also highlights a reluctance from users to criticise services at the point of care, suggesting a role for retrospective collections in obtaining more challenging feedback.

We define 'real-time' data as that collected at or originating from the point of care. Retrospective data is termed as data collected after the completion of a care episode. However, there are two issues around 'real-time' versus retrospective data that need further consideration:

- Collection versus reporting. Typically the phrase 'real-time' is applied to collections that also report data very close to its being gathered. There is a question over whether an approach can be meaningfully described as 'real-time' if data collected at the point of care is presented only some time later.
- Defining 'near real time' data. The phrase 'near real time' is often used in place of 'real-time', and some data collections – notably the Friends and Family Test –

allow data from the point of care and within 48 hours of exit to be used interchangeably. There is a question over the point at which a collection moves from being 'real-time' to 'near real-time' to 'retrospective'.

Setting- specific vs. cross- setting data

Information about health and social care services has typically been organised around organisations or services. This has advantages for performance management and quality improvement within settings, but it contrasts with the definition of integrated care as having people's needs as the central organising principle and limits the ability of using data to investigate transitions or integration.

A strong theme from the stakeholder consultation was that a service-specific indicator on integration would have little value, and that any new indicator should address integration across a range of services.

Phase 2b: Existing data collections and vehicles

Introduction

As part of the options appraisal, existing data collections and vehicles are reviewed here, using the theoretical approaches described earlier, namely user-reported (unstructured/structured) and service-reported (aggregate/person-level).

User-reported information

User-reported information provided directly by patients, service users, friends, family, carers, can be both structured (eg surveys) and unstructured (eg patient comments websites).

Unstructured/ 'user generated content'

User generated content may appear in a wide range of forums and via a variety of mechanisms, for example:

- Complaints (both health and social care)
- Social media – especially Twitter and Facebook
- Dedicated user-feedback or 'patient/user stories' websites – eg Patient Opinion and Care Opinion, NHS Choices, I Want Great Care, Your Care Rating, and so on.

Surveys

There are a number of national level or general population surveys that gather data from people on aspects related to health and social care, but they may not be appropriate as potential vehicles for an integrated care indicator(s), because of their sampling approaches, small sample sizes and frequency. These surveys include:

- Understanding Society: a general population household panel survey with a multidisciplinary focus. Data is collected via computer assisted interviews (CAI).
- Public Perceptions of the NHS: a tracker survey of approximately 1000-1100 people collecting data by computer assisted personal interviews (CAPI). The survey focuses on *perceptions* of the NHS and social care rather than specifically on people's experiences of the services. Whilst a question on coordinated care is included on the survey, it does not map particularly well to the Narrative. The survey is conducted up to 3 times within the course of a calendar year.
- National survey of people with diabetes: survey focussing on measuring the experience of people with diabetes, run as part of the Healthcare Commission's national patient experience survey programme. The survey ran in 2006 and has not been repeated since. There are no current plans to conduct the survey again in the next two years.

- Coronary Heart Disease Survey, 1999, 2004: national surveys focussed on the experiences of people with coronary heart disease. The survey formed part of the Healthcare Commission's national patient experience survey programme. There are no current plans to conduct the survey again in the next two years.
- Stroke National Service Framework Survey 2004 and the Stroke Follow up Survey 2005: the first survey focussed on people 6 months after hospital admission for a stroke; the follow up survey focussed on the experiences of stroke patients and the care they received after discharge. Both surveys formed part of the Healthcare Commission's national patient experience survey programme. There are no current plans to conduct the surveys again as there are now National Sentinel Stroke Audits run on a regular basis.

Therefore, the existing surveys covered in this section of the report are deemed to be the most potentially viable. These surveys can be split into three categories according to their topic or population group focus: healthcare surveys, social care surveys, and general population surveys.

Healthcare surveys

These surveys focus on different aspects of 'healthcare' such as particular health settings, conditions, or population groups or have a general health focus. Some surveys also cover multidisciplinary aspects of health and health related behaviour.

- CQC national patient survey programme, including:
 - Inpatients
 - Outpatients
 - Accident & Emergency
 - Community Mental Health
 - Maternity
- General Practice Patient Survey (GPPS)
- National Cancer Survey
- Friends and Family Test
- Health Survey for England (HSE)
- NHS Staff Survey
- VOICES survey (end of life)

Social care surveys

These surveys also focus on particular populations, particular care settings and specific conditions, and are mainly focussed on gathering user experience data:

- Health and Social Care Information Centre Personal Social Services Adult Social Care Survey programme²⁷, including:
 - Personal Social Services Adult Social Care Survey, annual from 2010/11
 - Survey of Adult Carers in England, 2009/10, 2012/13
- CQC Shared Lives Survey
- CQC People who live in care homes (18-65 years old)
- CQC People who live in care homes (older adults)
- CQC People who use domiciliary care services
- Ipsos MORI:
 - Your Care Rating 2012 Survey

General population surveys

These surveys tend to be multidisciplinary in focus, but due to the wide coverage of their target population, they position themselves as potential vehicles for indicator(s) of integrated care:

- English Longitudinal Survey of Aging (ELSA)
- Omnibus surveys (such as the Opinions and Lifestyle Survey, ONS)
- Millennium Cohort Survey (MCS)

Service-reported information

These are national data collections undertaken by health and social care organisations. Within this distinction, there are two types of data collection: aggregate and person level, each with different implications for data analysis.

²⁷ There are a number of social care surveys within this programme that are no longer being conducted, such as Survey of Adults Receiving Community Equipment and Minor Adaptations in England, 2007/8, 2009/10), Home Care Users aged 65 + (2002/3, 2008/9) and Survey of Physically Disabled and Sensory Impaired Users in England, aged 18-64 (2003/4). Whilst they will not be evaluated in this report, they are important to mention due to the changes made for the current programme.

Aggregate level data sources

- Quality and Outcomes Framework (QOF)
- Commissioning Outcomes Indicator set (COIS) 2013/14
- Improving Access to Psychological Therapies (IAPT)
- Mental Health Community Teams Activity Information
- Department of Health datasets including a focus on:
 - Delayed transfers of care
 - Waiting times
 - Bed occupancy statistics
 - Cancelled elective operations/ patients not treated within 28 days
 - Trolley waits (Accident and Emergency)
 - Winter deaths
 - Hospital and community health services complaints
- Community Care Statistics
- Abuse of Vulnerable Adults dataset (IC)
- National Minimum Data set for Social Care (NMDS-SC)

Person level data sources

The data sources included here tend to be held at case level and can be aggregated up to various organisational or geographical levels:

- Hospital Episode Statistics (HES) , covering:
 - Inpatients
 - Outpatients
 - Maternity
 - Accident and Emergency
- Patient Reported Outcome Measures (PROMS)

- Mental Health Minimum Data set
- Child and Adolescent Mental Health Services (CAMHS)
- National End of Life Care Intelligence Network (NEoLCIN)
- ONS Suicide rates
- Confidential Inquiry into suicides and homicides by people with serious mental illness
- National Clinical Audits including for example:
 - Stroke
 - Cancer (bowel, lung, head and neck, oesophago-gastric)
 - Falls and bone health in older people
 - Hip Fracture
 - Continence care
 - Chronic Obstructive Pulmonary Disease (COPD)
- General Practice Extraction Service (GPES), which is a facility for extracting patient level data from GP computer systems

Phase 2c: Identifying key cohorts

To be effective, indicators need to have clear and precise definitions. This poses a challenge when measuring a concept as broad and widely applicable as integrated care.

Effective coordination has long been recognised as a fundamental component of patient-centred care²⁸: All users of health and social care services should routinely experience seamless care from all providers they have contact with. In other words, experiencing effective integrated care should be a common standard for all health and social care users, and it is therefore appropriate to consider the general population as a potential cohort for measurement.

During the consultation, stakeholders were conscious that while a general population indicator would provide a broad, headline measure, it would not be useful at the local level as commissioners and providers would need greater granularity to drive service improvement. Furthermore, it was acknowledged that focussing on the experiences of particular 'target' groups would make it easier to measure and compare the experiences of specific cohorts, as indicative of the standard of integrated care within areas, rather than aiming for universal coverage. Such 'target' groups should reflect those for whom integrated care is particularly salient – for example those with more complex health needs, or who require support from multidisciplinary teams of professionals.

Through discussion with stakeholders and from our own experience, we have identified key cohorts within the wider population that would be suitable as the focus of an integrated care indicator(s). These cohorts reflect both the support needs of different groups and also priority areas for national policy. To best reflect the practical challenges associated with accessing data on or from the different cohorts, we group them within two main categories: **demographic-based** and **condition-based**:

- General population
- Demographic-based:
 - Older people.
 - Families and children – specifically:
 - Families of children with complex needs.
- Condition-based:
 - People with long term physical health conditions.
 - People with long term mental health conditions.

²⁸ Gerteis, M., Edgman-Levitan, S., Daley, J., Delbanco, T.L. (1993). *Through the Patient's Eyes: Understanding and Promoting Patient-Centred Care*. Jossey-Bass Inc., CA. p11.

- People with disabilities, including learning disabilities.
- People living with dementia.
- People who are at end of life.
- NB: experiences of carers should be taken into account alongside each of the above.

We have avoided defining groups by service utilisation (eg hospital inpatients or care home residents), in response to the views of stakeholders that indicator(s) should **not** be tied to a specific service or 'silo'; the clear preference was for indicator(s) to measure quality across different providers.

Phase 2d: Criteria

We used a range of criteria to evaluate the options available. The overarching criterion being that the recommendations should be fit for use within both the NHS and Adult Social Care Outcomes Frameworks. The criteria used are described below and summarised in a table.

- Robustness and quality, including validity, reliability, accuracy, and minimal bias.
 - To be effective and meaningful, any indicator should be robust and of a high standard. This includes considerations of accuracy and consistency – whether the relevant data can be collected with minimal or no variation in methods in different areas, which would undermine data comparability and therefore the integrity of the indicator.
 - As many indicator sources involve estimation and/or user feedback, it is also important to consider their statistical properties: can sufficient data be collected to be reliable, bearing in mind the cost implications of larger collections? This is related to coverage. To avoid or minimise bias, data sources must be as inclusive of the possible target populations as possible so that sampling bias does not reduce data accuracy. Data availability over time is also important for monitoring changes.
 - Finally, it is important to consider how services might respond to any new indicator, in terms of positive, quality-improving behaviours or unintended perverse incentives that encourage unconstructive responses. Measures need to be relevant, actionable by services, and meaningful to clinicians (see below). The potential for gaming (eg by creating or exploiting sampling bias, or manipulating the manner in which data is collected, or by acting in tokenistic ways that address the specific requirements of the indicator without improving integrated care for patients and the public) must be minimised. It is important to note that datasets/indicators in of themselves do not create perverse incentives or lead to unintended consequences - this depends very much on the purposes for which indicators are used and the consequences that depend on their use.
- Relevance to national policies and priorities; meaningful to the public, services, and clinicians; and actionable by health and social care organisations responsible for provision and commissioning.
 - An effective indicator should reflect the efficacy and performance of health and social care services, and help track the system's delivery of national priorities. Given the current policy focus on transparency and delivering choice and control to patients and the public, it is important for this indicator in particular to be meaningful to the public, and presentable in an accessible format that improves public

understanding of health service performance. Whilst these issues are related, they can produce tensions: over-simplifying approaches to suit public presentation can impede their use and acceptance by professionals and policy makers, but overly complex approaches may not be meaningful for the public. The complimentary and competing needs of each audience and purpose must be balanced.

- Coverage of the target groups identified in section 2c.
 - Good coverage is vital to the quality of any indicator. Indicators that do not deliver total or near total coverage of key populations are at significant risk of sampling bias, reducing their reliability as estimators of performance.
- Cost and value for money
 - In the current economic climate, it is imperative that any new indicator(s) should represent good value for money. As new costs need to be justified, it is important to consider the development and implementation costs of different approaches. In particular, we will consider whether existing methods or vehicles will be sufficient or whether new data collections will be required, which has implications for both cost and burden of data collection.

Summary

The full set of criteria to be used in assessing each the data sources is listed overleaf. **PLEASE NOTE** that full assessment details are to be added.

Statistical validity

Validity - measures what it says it measures accurately and consistently*

Reliability - can be tracked reliably over time

Accuracy - data is collected in a consistent and robust way*

Avoids bias and perverse incentives

* **IMPORTANT:** Requires both good data and a robust indicator construction methodology.

Data considerations

Sourced from (a) existing data sources, (b) amendment to existing data sources, or (c) requires new data collection **

Data source

Sample or full population

Unit of assessment: national/regional/CCG/LA/provider***

Groups covered eg older people, people with LTCs, children and families

Can the data be reliably disaggregated for population sub-groups at local level? (small number, statistical power issues)

Patient/user-reported or indirect measure

Covers (a) health care only, (b) social care only or (c) health and social care

Any relevant caveats re the data eg sampling bias, incomplete data coverage, poor data quality

Other considerations

Significantly influenced by health and/ or social care activity

Likely to be meaningful to the public

Likely to be clinically credible

Has the potential for quality improvement

Cost and value for money

** The source of the potential option will determine both the feasibility and timing of implementing an indicator(s) of integrated care.

*** The DH scoping paper notes that: *Indicators have to meet certain criteria to be included in the outcomes frameworks. For the NHSOF, indicators need to be broken down by CCG and to LA level for the ASCOF. Therefore any survey vehicle must provide data to CCG/LA/HWB level.*

NB: To foster joint working by local organisations, the DH scoping paper notes that: *We*

recommend developing a measure for integrated care that is not designed to be attributable to a particular provider. We are in any case developing integration aspects of existing organisation-based patient experience surveys.

Phase 3: Evaluation

Each data option identified during phase 2b was evaluated against the assessment criteria detailed in section 2d. The options we evaluated can be found in Appendix 3; more details can be found in Appendices 4, 5, 6 and 7.

Summary of user-reported mechanisms

The relative infancy of unstructured feedback mechanisms has meant that these tools will not be of use in the short term as potential options. These should be monitored for developments and subsequently considered for future potential options.

In relation to the structured mechanisms, there is a clear trade-off between certain assessment criteria. It is evident that there are a number of vehicles that would not be suitable for contributing data to the Outcomes Framework, namely the FFT, HSE, and the general population surveys (ELSA, Omnibus and MCS). Two social care surveys stand out as viable options: the ASCS and Carers Survey are based on robust and standardised approaches and provide data that can be disaggregated from a national to local level. However, only ASCS reports annually. The remaining surveys deemed as viable options for potential indicators are the CQC national survey programme- in particular the annual surveys within that collection- the GPPS, the National Cancer Survey and VOICES.

Summary of service-reported mechanisms

Existing data sets offer a rich terrain for developing indicators of the quality of integrated care. Many such indicators are already in use, and there is potential for developing others. Although no single data set or indicator provides a "magic bullet" for measuring what is inherently a complex concept to measure, we strongly believe that it is possible to draw on these data sets to develop indicators of the quality of integrated care that will be meaningful for both patients/service users and the local agencies responsible for improving care coordination and integration. Unlike the user-reported data sources, such as patient surveys, these data sets don't measure feedback directly from users. But they can provide tangible measures of the processes and outcomes of care as users move through the health and social care system; how seamless and user-focussed that care is; where it falls below expected standards or peer performance, and what needs to be done by whom to improve care coordination and integration. Critically, such indicators measure aspects of care that commissioners and providers can influence and act on, for example, whether hospital discharge was delayed or whether provision of home care services is weak. They can be monitored over time to measure progress and support quality improvement and offer a valuable supplement to user-reported feedback.

Options

Introduction

It is clear that there are a number of options that could be shortlisted to provide evidence on people's experiences of integrated care. Within these, some options lend themselves well to including indicator(s) of integrated care that would contribute to the Outcomes Frameworks (NHS, Adult Social Care and Public Health) as they meet the required criteria of being robust, reliable and statically valid. Other options, which themselves would not be suitable as vehicles for potential indicator(s), could be used or adapted for local service improvement.

User-reported mechanisms

User-reported mechanisms can be split into structured and unstructured feedback. Within the category of structured feedback the project has identified a number of potential vehicles: healthcare surveys, social care surveys and general population surveys. During the evaluation it has become apparent that not all the surveys considered would be suitable to carry indicators for the Outcomes Frameworks. This section of the report will discuss each of the shortlisted options and outline the advantages and disadvantages of each vehicle.

Developing a new survey

There is no existing national survey collection focused specifically on people's experiences of integrated health and/or social care. Designing a new survey provides an opportunity to develop a vehicle that is, as far as is possible, specifically tailored to measure experiences of integrated care.

As integrated care is a complex and multi-faceted concept, developing a new survey with a questionnaire specifically tailored to different aspects of integrated care would be ideal. This would allow the concept to be measured in full detail, ensuring comprehensive coverage of the range of issues that determine people's experiences of integrated care, and could align well with the 'I' statements featured in the Narrative. Careful development, including full cognitive testing and piloting of the data collection instrument, would result in reliable and statistically valid data.

Methods for a new survey could also be designed specifically to meet the inherent challenges of measuring integrated care. Sampling, for example, could be based on any of a number of criteria to reflect any of the cohorts identified as important. Alternatively, a larger sample with comprehensive background data on individual respondents could allow complex disaggregation to a range of different populations. In addition, it would also be possible to disaggregate the data in ways that will be meaningful not only at a national level but also to providers, commissioners, Health and Wellbeing Boards, and so on.

Developing a new survey, however, does have significant disadvantages. In particular, there are substantial barriers in terms of time, cost of implementation, and added burden of data collection. By following a robust, best practice approach – necessary for the survey to provide data to the standard required for an indicator – it is likely that the survey will take at least one year to develop. Data for the Outcomes Frameworks would

therefore not be available until 2014/15 at the earliest, and existing indicators would have to remain as placeholders for the duration of 2013/14.

Designing, planning, and implementing a new survey from scratch is also a costly exercise. As rough estimates, development costs would be expected to be in the region of £100k. The cost to implement a national survey would then depend on the sampling approach taken and the methods of administration – but in all cases costs are likely to be considerable. There are two main variables:

- **Survey method.** Interviewer administered survey methods – telephone and face-to-face – are the most costly, with self-completion methods – postal and particularly online – proving more economical²⁹. Given limited online access for key groups (eg older people), though, it is likely that the best balance of coverage and cost would be achieved with a postal survey.
- **Sample size.** Sample size would be jointly determined by the population of interest and the required granularity of reporting. Reporting at the levels of local authorities, CCGs, and acute hospital trusts is likely to be most appropriate, and suggests sample size requirements in the order of 100,000-200,000. Smaller samples – as low as around 1,000 – could produce representative national estimates but would not allow for local reporting or service improvement. There may also be a risk of doubling up on specific individuals with increasing numbers of surveys.

Based on the assumption of a postal survey with a sample size of between 100,000-200,000, we estimate an overall annual cost of anywhere in the region of £500k to £1m, depending on whether centralised or devolved administration was used and the detailed approach to the survey. This cost might be reasonable in terms of the likely value of the data return, but there is a risk that a new collection would be seen to duplicate the range of existing surveys of health and social care users. Moreover, this sample size would not cover **all** of the populations of interest in sufficient numbers and it's unclear what the sampling frame would be. Inevitably, sampling would have to be narrowed to select groups. In addition to central development costs, there will be the added costs and burden of new data collection locally. For these reasons, and because of the long time to data availability, we do not recommend the development of a new survey on integrated care.

Existing surveys

Using existing surveys means accepting a limited scope in terms of the questions that can be asked, and also compromising around the choice of cohorts.

The disadvantages of using existing surveys include the lack of flexibility to dictate survey design considerations such as population coverage, ie how inclusive the sampling approach and sample size is, and how quickly data would be reported. Furthermore, questionnaire space should be considered to be 'at a premium' in any existing surveys, especially those already used to populate other indicators. There is scope to only include a small set of questions at most, and this would come at the cost of removing some existing items. This precludes the possibility of a very broad and

²⁹ Graham, C., & Woods, P. (in press). Patient experience surveys. In Ziebland, S., Coulter, A., Calabrese, J., & Locock, L. (Eds.) *Understanding and using experiences of health and illness*. Oxford: Oxford University Press.

detailed focus on people's experiences of integrated care, which is an important compromise in terms of how fully the definition from the Narrative can be explored.

However the cost, burden and timeliness in relation to development and data collection are considerably reduced. Unlike the development of a new survey, the costs of amending the content of an existing questionnaire(s) by the addition of a few questions would be minimal. A number of the existing surveys covered in the evaluation already have robust methodological approaches that produce reliable and statistically valid data, which could be disaggregated to a level that would allow commissioners and providers to identify where improvement in services is needed. At the simplest level, questions for a new indicator could be added via an expert-led design process and cognitive testing of new items. This could be completed, even if testing questions with a number of separate cohorts, at relatively low cost. Based on comparable prior work, we would estimate the development cost for designing and testing a new question or small set of questions to be in the region of £30-40k: this assumes testing across three to four distinct cohorts with 70-90 cognitive interviews, and costs would be lower still with a narrower development focus.

The testing and development process described above could be completed relatively quickly – three months should be sufficient from start to finish. Some notice is typically required for questions to be added to surveys, especially if they require ethical approval, and it should be assumed that questions would need to be decided two to three months before the launch of any survey. Even so, and considering the planned timings of existing surveys, this should mean that an indicator based on some of the candidate surveys could be included in time for the 2013/2014 outcomes frameworks, which we would argue is highly desirable both nationally and locally.

Existing surveys have already had considerable developmental work, including cognitive testing, and represent a good foundation on which to build. Collectively, they cover a wide range of our target groups- for example hospital patients, MH service users, ASCS users, GPPS, EoL - covering between them some 3-4 million users of health and social care services. Profiling the results of the various surveys for each local health and social care economy would give a very rich local picture of user-reported feedback, covering different patient/population groups and care settings. This would be invaluable for local quality improvement by enabling local commissioners and care providers to see where things aren't working locally. This approach can also enable profiling of local "pathways", since GP/primary care could be seen alongside community care, secondary care, MH care, social care, EoL care etc. Finally, some of the existing surveys considered already contribute to the NHS and Adult Social Care Outcomes Frameworks making them highly efficient vehicles for an indicator.

We therefore consider there are several strong pragmatic and quality-related reasons for building on the current health and social care surveys.

General population surveys

Whilst these surveys are methodologically robust and produce reliable and statistically valid data, which makes them suitable as vehicles for an indicator, the main disadvantage of this group is the limited population coverage and the frequency with which they are conducted. Both the English Longitudinal Study of Aging (ELSA) and Millennium Cohort Study (MCS) focus on sub- groups where integrated care is

paramount, older people and children, however this may produce data that is narrowly focussed in particular demographic groups. These two surveys are also only run every 2-4 years which means that they would not provide data in a timely fashion for the outcomes frameworks. Their relative infrequency and national level reporting also makes it unlikely that they will be suitable for local improvement. Similarly, omnibus surveys would not be suitable for either local improvement or carrying an outcomes framework indicator. These surveys tend to have very small sample sizes, approximately 1,000 respondents per survey, and are used as mechanisms for piloting questions for inclusion in larger scale, complex surveys.

CQC National patient survey programme

As a collective these surveys have been shortlisted as potential options for carrying an integrated care indicator that would feed into the NHS Outcomes Framework. The surveys are reliable, methodologically robust, produce both national and local level data and cover a wide population.

The disadvantage to this collection of surveys is that not all of them within the national programme are conducted on a regular basis³⁰: Surveys of hospital outpatients, A&E attendees, and recent mothers are conducted on a rolling three-year cycle. Furthermore, individual surveys tend to focus on specific settings or services resulting in potential silos: care would be needed, if adding questions, to ensure that these were capable of getting respondents to think more widely about their experiences of integrated care.

Two surveys within the national programme are currently undertaken on an annual basis: adult inpatients and community mental health service users, both of which are likely to be of the most value for measuring people's experiences of integrated care. The inpatient survey covers in the region of 130,000 people, whilst community mental health covers 50,000 people. Both surveys include a range of person-level background data that can be used for alternative aggregations and attribution of survey data (including to CCGs).

General Practice Patient Survey (GPPS)

The GPPS is currently administered twice per year and is distributed to a sample of nearly three million people annually. Out of all the surveys considered in this report, only the Friends and Family Test has a larger sample, but it does not have the same degree of methodological consistency as the GPPS. The GPPS is methodologically robust, producing reliable and accurate data that can be aggregated meaningfully at General Medical Practice level. The focus of the survey itself covers experience of general practice, management of long term conditions and dentistry (to some extent). The GPPS also asks about quality of life (using the EQ5D tool) and the existence of specific chronic conditions. The survey is, therefore, a suitable vehicle for an indicator that would feature in the outcomes frameworks. The survey could also be used for local improvement, due to the level to which data can be disaggregated, which will be useful for providers and commissioners.

³⁰ It should be noted that the national surveys within the CQC programme are accompanied by freely available 'local' survey tools, which allow individual organisations and providers locally to complete comparable surveys outside of the programme for use in service improvement and management.

VOICES National Bereavement Survey

This survey is a national survey producing robust, reliable and accurate data on bereaved relatives' experiences of the end of life. The survey covers a number of aspects of end of life care, specifically around care at home, the involvement of different health and social care agencies and coordination of care. The survey covers a large sample size (circa 49,000 people) and draws on bereaved carers to complete the survey. The data can be disaggregated to PCT cluster and analysis can be undertaken for particular population sub-groups. This survey would be a viable option to carry an indicator of integrated care due to its robust approach and large sample size, as well as care coordination already featuring in the survey itself.

National Cancer Survey

As per a number of the other healthcare surveys, the national cancer survey follows a standardised and robust methodological approach, with a large sample size, producing reliable data. The data can be disaggregated to provider level and can provide analysis on specific conditions. The survey is also run on an annual basis meaning that amendment of the survey could be achieved in time for the 2014/2015 outcomes frameworks. This survey would also provide data that could be used for local improvement. AS this survey primarily covers use of healthcare services by people with cancer, it does not currently shed light on integration with social care.

Health Survey for England (HSE)

This survey would not be a suitable vehicle for either an integrated care indicator or as a tool for local improvement. Whilst the survey is reliable and methodologically robust, the focus is on health behaviours rather than quality of care or people's experience. Whilst the survey is conducted annually, it has a limited sample size and will only provide data at the national level which could not be disaggregated to a level that would be useful for providers, commissioners or Health and Wellbeing Boards.

Friends and Family Test (FFT)

This survey would be a suitable tool for providing data for local improvement: data is collected, produced and analysed very rapidly and the level of granularity, ie department or ward, is relevant to front line staff. The qualitative comments that accompany the key FFT question should be particularly important, as these provide the opportunity to establish the reasons for people's low or high willingness to recommend.

Although the FFT may be useful for creating awareness of and enthusiasm for improving people's experiences locally, it would not be a feasible option for Outcomes Frameworks indicators. Due to the degree of variability in how the FFT is administered across different NHS organisations, there is no standardised approach meaning that there are potential concerns around reliability and statistical validity. To be a suitable vehicle for an indicator(s) to be carried in the outcomes frameworks, a standardised method will need to be developed so all organisations are measuring experience in a consistent and comparable way.

The FFT also currently only surveys patients in specific health settings, ie: Inpatients and Accident and Emergency attendees. Whilst the FFT will be rolled out across other services and settings in the future, there are no plans as yet to focus on social care services which would be paramount to measuring integrated care. The focus on gathering people's views at very close to the point of care also limits the scope for

effectively measuring integration, especially around transitions – if people are responding to the FFT within 48 hours of a hospital discharge, say, then their care transition back to other services may not be fully in place and any gaps may not yet be evident.

NHS Staff Survey

Specifically focussing on NHS staff, this survey is robust, produces reliable and accurate data that can be disaggregated from national to locality level. The data from this survey is likely to be meaningful and engaging to staff and could potentially be used to change culture and environment within organisations. The survey currently only focuses on NHS staff and is conducted on an annual basis.

Although the survey could potentially carry questions on integrated care, both for the outcome frameworks and to help drive local improvement, the measure would not be about people's experiences of integrated care from a user point of view. This would inevitably require a different set of questions to be developed than for use in surveys of service users or patients, which would require an increase development overhead and could arguably detract from the focus of an indicator based on multiple surveys of users. We therefore believe that the NHS staff survey, although providing very useful contextual data, should not be a priority for use in measures of people's experiences of integrated care.

Interim measures of integrated care

Whilst it is out of the scope of the project to evaluate particular measures of integrated care, it is important to acknowledge that a collection of 7 core questions currently asked in existing surveys³¹ have been identified by the Department as interim measures of integrated care. Although the core questions that the interim measures are based on demonstrate a high degree of construct validity, due to the thorough cognitive testing and development of the surveys on which they appear, it is recognised that they are proxies for elements of integrated care rather than direct measures. If a series of user reported measures are to be developed for use in the outcomes frameworks, and implemented on existing surveys, then it would be prudent to align the measures with the Narrative and, potentially, the individual 'I' statements. The interim measures, however, do provide valuable and robust data at a local level that NHS trusts can use to identify where service delivery and quality of care can be improved for people.

Local Surveys

It is worth briefly noting that many health and social care organisations undertake their own local surveys, often using near real-time feedback approaches and frequently utilising technology driven solutions (eg surveying via tablet computers or kiosks). Such collections have every potential to provide extremely useful data for local service improvement initiatives, particularly where feedback can be reported in a very rapid and timely fashion that is likely to appeal to staff. Despite their utility for service improvement, however, we rule out the use of local collections to drive any national indicators. No data standards exist for local surveys and there is extensive variation in the methodologies employed, the cohorts surveyed, and, indeed, the quality of approaches. This means that local surveys, en masse, fail to meet a majority of the criteria for effective indicators.

³¹ The surveys include the national NHS Inpatients Survey, GPPS, VOICES, the National Cancer Survey and the national NHS Community Mental Health Service Users Survey

Social care surveys

Since 2010/11, surveys in the Personal Social Services Adult Social Care programme have been mandated for implementation by CASSRs and use robust, high-quality methods to deliver reliable data at a local level. There are two surveys in the programme, covering adult social care and carers respectively:

Personal Social Services Adult Social Care Survey (ASCS)

This survey is a strong candidate for carrying an integrated care measure for inclusion in the ASCOF. Administered in a standardised way across all councils nationally, the data collected is robust and statistically valid. Data can be disaggregated to council level enabling performance management and local improvement initiatives to be developed. Sub-group analysis is possible both demographically and for particular service user groups. This survey also currently contributes to the ASCOF on a number of indicators.

Carers Survey

Introduced as a mandatory collection in 2012/13 following a previous voluntary survey in 2009/10, this survey specifically focuses on carers and their experiences in their caring role. Like ASCS, this survey is conducted nationally via a robust and reliable methodological approach. Data can be disaggregated to council level, but the subgroup analysis opportunities are mainly limited to demography. As per ASCS, this survey contributes to the ASCOF on a number of indicators. However, whilst the population of interest is a key policy focus for the Department of Health and CQC, focussing on this group alone would not support the focus on the service user element within the Narrative. More significantly, the survey is to be conducted biennially and, at the time of writing, the most recent survey has just been completed: adding questions to the next edition of the survey would not produce data until 2015. Our view, therefore, is that the Carers Survey should not be prioritised for immediate development but that the feasibility of including questions on carers' experiences of integrated care should be reviewed ahead of the 2014/15 survey.

Unstructured feedback

The availability of unstructured feedback about health and social care is growing, both across services designed to solicit this type of information and more general services such as social media. Two specific options present themselves, and the opportunities and challenges afforded by these are similar.

Firstly, there are a number of 'user feedback websites' that encourage people to provide ratings or stories about their experiences of health and social care. The most well-known of these are Patient Opinion, Care Opinion, and I Want Great Care. Of these, the first two focus on gathering narratives and facilitating discussions between users and health and social care staff: there is a direct and visible focus on service improvement and the site is clearly not intended to provide indicators per se. The latter, I Want Great Care, is focussed on ratings, and displays a combination of data received from the Friends and Family Test and from self-submitted reviews.

Secondly, the use of social media by which we in particular mean social networks, such as Facebook, and the micro-blogging site Twitter. Both are very widely used in the UK and provide a forum for a near limitless range of discussions including, sometimes, health and social care.

At present, three main factors mean that unstructured online feedback is not viable for producing data for indicators:

- **Coverage** is extremely skewed towards certain demographic groups. For example internet access amongst older people is limited: 30% of those aged 65-74 and 61% of those aged 75 or over have *never* accessed the internet. Similarly, people with disabilities (as defined under the Disabilities Discrimination Act) are much less likely to use the internet, with 33% of this group having never been online³². As these groups are amongst those identified as key cohorts for integrated care, their underrepresentation is a serious limitation to online data collection approaches.
- **Content** is typically not designed in a way that could provide a quantitative assessment of people's experiences of integrated care. For unstructured feedback, emerging analytical approaches like natural language processing and machine learning can help to identify relevant comments and code them as positive or negative but these approaches may not be robust enough to produce reliable results. Even user-feedback websites are unlikely to be able to drive an indicator. Patient & Care Opinion are geared towards discussions rather than metrics, whilst I Want Great Care includes only a small set of rating items.
- **Quantity** of feedback is too limited. Even the most frequently used outlets currently produce only a limited volume of feedback derived from most existing surveys. They are therefore limited in their ability to produce reliable quantitative data for individual providers or commissioners. Patient Opinion, for example, has collected around 50,000 stories since 2006³³: This is a significant quantity in terms of stories for engagement and response, but not sufficient for regular, quantitative assessment of health and social care services. The ASCS, by way of contrast, received over 65,000 responses in 2011/12 alone.

These concerns effectively rule out the use of unstructured feedback for indicators at the present time, although future developments should be monitored and kept under review. This should not prevent or undermine their value for service improvement locally and we would certainly recommend that local organisations take advantage of feedback already available and appearing via these mechanisms. Using these tools, which are already available, alongside standardised indicators could form a useful part of a comprehensive improvement strategy combining rich, qualitative feedback, direct engagement with users (both through sites like Patient & Care Opinion and through social media), and 'milestone' comparisons to other providers.

³² Office for National Statistics. (2013 February 20). *Internet Access Quarterly Updated, Q4 2012*. Retrieved from <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcn%3A77-294263>

³³ <https://www.patientopinion.org.uk/>

Service-reported mechanisms

Our review of data sources has identified a wide range of existing collections that could, potentially, provide useful information on integrated care.

The key challenge for any service-reported measures is the extent to which they can truly deliver evidence of *people's experiences* of integrated care. Routine data sets describe what actually happened to people in the care process, for example whether their discharges were delayed or whether they received reablement services, but they don't give the user perspective directly. This concern was reflected in consultation with stakeholders, who typically had an a priori expectation that measures of people's experiences would need to include information provided by patients and service users themselves – most likely via surveys. However, measuring what actually happens to people in the care process was also considered important for targeting improvement activity, hence it is a useful adjunct.

Health related data sources

The majority of the data sources assessed as part of this options appraisal are national data sources in widespread use and therefore can be considered as valid and reliable. These national data sources provide a robust basis for deriving indicators of integrated care. Some of the data sources are currently undergoing development, for example the General Practice Extraction Service (GPES), Community Information Dataset and the Child and Adolescent Mental Health Services (CAMHS), and they should be considered as potential future options for service reported indicators.

Hospital Episode Statistics (HES)

This national data source provides person level data across a number of different healthcare settings, such as Inpatients, Outpatients, Accident and Emergency, and Maternity. The data covers all patients using these services, and can be aggregated up to cover demography (eg age groups), specific conditions, medical procedures and so on. HES is an existing data source, hence trend data is available to monitor progress and could be used by local agencies to assess interventions around coordinated care and integration. As a reliable, robust and valid data source, many HES-based indicators appear in the Outcomes Frameworks, and HES would be a suitable option for developing integrated care indicator(s). Indicator development will need to be based on the variables related to integrated care. HES data can be analysed by CCG/PCT/LA/provider/referring GP. Many HES-based indicators are already used to measure aspects of integrated care, for example, the reason for admission (primary diagnosis), length of stay, discharge destination, readmission rates.

Quality Outcomes Framework (QOF)

QOF is a national, aggregate level data source focussing on General Practice. QOF data is considered to be reliable, robust, accurate and valid, and is used for pay-for-performance. QOF includes indicators that have a bearing on integrated care, for example, indicators relating to reducing hospital admissions, and to physical health checks for people with serious mental illness. Data is available at General Practice and CCG level. Whilst data is available for patient groups with select conditions, the data cannot be disaggregated or reanalysed by age or other variables in the way patient level data sources, such as HES can. QOF also provides trend data to monitor progress over

time. QOF includes indicators relating to several long-term conditions, and revisions to QOF include measures relating to secondary care. Some of these indicators can be considered for inclusion in a wider set of indicators of integrated care to support local improvement.

National End of Life Care Intelligence Network (NEoLCIN)

NEoLCIN is a national data source producing reliable and accurate data on end of life care, such as the volume, cost and quality of care provided by the NHS, social care and third sector to adults nearing end of life. The data can be disaggregated to local authority level and some population sub-groups. This group of people has been identified as requiring coordinated care, and the data can provide indicators of integrated care that would fit among a wider set of measures.

Patient Reported Outcomes Measures (PROMS)

PROMS data is available for patients undergoing 4 elective procedures (hip and knee replacements, hernia repairs and varicose veins surgery). It is reliable and robust person level data that can be aggregated to CCG/ provider level. PROMS can also provide trend data making it a useful option for local improvement. Questionnaires are given to all patients undergoing the selected procedures, although not all patients respond. The data focuses on pre- and post- operative health and quality of life, and can reflect on integrated care from the perspective of health service users.

ONS Suicide rates

Data is provided annually by the Office for National Statistics (ONS), based on death registration data, and used by a number of organisations and agencies, such as the Department of Health, Public Health England, and also mental health support services for policy planning and effective focus of resources. Being based on death certification, the data is statistically valid and accurate. Suicide rates are available at the national level and can be disaggregated to CCG or LA level. The data covers the general population (ie all deaths defined as suicide within a given time period), and analysis for sub-groups is limited to demographic characteristics (gender, age).

The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness

This data source provides information on suicide, homicide and sudden unexplained death by people with serious mental illness, derived from linking ONS mortality data to the Mental Health Minimum Data set (MHMDS). The Inquiry data is reliable and statistically valid, and is available at national and regional level but not down to local level eg CCGs, LAs. However, local data on premature mortality among people with serious mental illness, also based on linked MHMDS and ONS records, is available as part of the NHS Outcomes Framework data set produced by the HSCIC. The data can be tracked over time and covers a key group of interest identified during the consultation phase.

Department of Health datasources

A number of data sources produced by the Department of Health could be viable options for service reported indicator(s) on integrated care. These sources tend to be national, robust and reliable, and focus on particular aspects of healthcare such as waiting times, delayed transfers of care, bed occupancy statistics, trolley waits

(Accident and Emergency), Winter deaths and Hospital and Community health services complaints. Trend data is available and the data is available at national, commissioner and/or provider level. Many DH data sources, for example delayed transfers of care, are already in use for measuring integrated care.

Improving Access to Psychological Therapies (IAPT)

This data source is not patient level, but provides reliable data at national and commissioner level, and trend data is also available. The data set focuses on access to psychological therapies for people with mental illness, and also captures some data on recovery, for example return to employment. This data set could be very useful in the context of integrated care for people with mental illness, a key cohort identified for this work.

Mental Health Minimum Data set (MHMDS)

The MHMDS is a person level data set covering the care of adults using specialist mental health services. The data set contains a number of fields that could reflect on integrated care, such as how long people spend in hospital, numbers of admissions and discharges, employment, and information about types of clinical teams coordinating patient care. The data is statistically valid, accurate, reliable, can be aggregated to organisation/ provider, and can be tracked over time. The data is also likely to be clinically credible and meaningful to the public. Although its focus is on the measurement of health care services, the data reflects on the quality of integrated care, for example by recording hospital admissions.

Clinical Commissioning Group Outcomes Indicator Set (CCGOIS) 2013/14

The CCGOIS's, formerly known as the Commissioning Outcomes Framework (COF), primary aim is to provide information to enable CCGs to benchmark the health services that they commission. The CCGOIS is also in place to provide relevant and unambiguous information to the public about the quality of health services in their area. Many indicators in the CCGOIS are taken directly from the NHSOF, broken down to CCG level, and other indicators are intended to support achievement of the NHS Outcomes Framework's goals. The CCGOIS provides statistically valid and reliable data in a detailed format for commissioners to action and drive forward local improvement, and is used by the NHS Commissioning Board to benchmark CCG performance.

Mental Health Community Teams Activity Information

The Mental Health Community Teams Activity return collects data on new cases taken on in the year by Early Intervention (EI) in psychosis services, the number of patients on Care Programme Approach (CPA) followed up within seven days of discharge from psychiatric inpatient care, and gate keeping inpatient admissions by Crisis Resolution Home Treatment (CRHT) teams. The data is available at regional, commissioner or provider organisation level. The data is statistically valid and robust, and can be tracked over time. Although the data relates to the work of community MH teams, follow-up after hospital discharge and gatekeeping admissions reflect on key aspects of integrated care for people with serious mental illness and will be meaningful to the public and clinically credible.

Child and Adolescent Mental Health Services (CAMHS)

Similar to the MHMDS, the CAMHS Secondary Uses Data Set sets out national definitions for the extraction of data from providers of NHS-funded child and adolescent mental

health services. The CAMHS Secondary Uses Data Set captures data at each stage of the service care pathway such as background, referrals to CAMH services, care planning and so on. Some of these data fields could map to integrated care and particular 'I' statements within the Narrative. The CAMHS dataset can also be linked to both the Maternity Services Secondary Uses Data Set and the Child and Young People's Health Services (CYPHS) Secondary Uses Data Set. CAMHS data is relatively new and cannot be tracked over time, but it covers a vulnerable group of children and provides a useful data source for development of indicators in the future. The data can be aggregated to national, regional, commissioner or provider level.

Waiting times

There are a number of different aggregated sources of data on waiting times. Of particular relevance to integrated care would be the 'referral to treatment' waiting time statistics, cancer waiting times, and the Accident and Emergency waiting time statistics. Whilst waiting times are by no means a direct measure of the quality of people's experiences of integrated care, they could potentially act as proxies for poor care co-ordination, for example where diagnostic and other tests are included in the measured waiting times. Waiting time statistics overall are reliable, robust and statistically valid. The data is available at national level and can be disaggregated to provider and, in some cases, specialty. The data is clinically credible, meaningful to the public, and a useful tool for local improvement initiatives.

Integrated Performance measures monitoring (previously Vital Signs)

This data source used to support the monitoring of PCT performance against measures relating to diabetes, NHS health checks, older people (delayed discharge), access to midwifery, and stroke. Since 2011, these measures have replaced the Vital Signs data (the coverage is similar but not identical) and are covered by the 2011-12 NHS Operating Framework.³⁴

General Practice Extraction Service (GPES)

The General Practice Extraction Service (GPES) is a new development that will centrally manage primary care data extraction for the Quality Outcomes Framework from April 2013. It is intended to provide a standardised record of information from GP clinical systems across England and simplify the data extraction process by replacing QMAS (Quality Management and Analysis System) as the primary extraction method. It will also be used to support payments to GPs calculated by the Calculating Quality Reporting Service (CQRS). GPES opens rich possibilities for data extraction from GP computer systems, and is to be used by a wide range of national users including the NHS Commissioning Board. GPES data will also be linked with hospital data by the HSCIC. While GPES has the potential to facilitate integrated care throughout the NHS, it is a data extraction mechanism and relevant indicators will need to be developed. Bespoke applications for data or indicators need to be submitted to and approved by the HSCIC. Thus while GPES offers possibilities, development of indicators relating to integrated care would have to be a medium term option. Linkage of GPES records to person level

³⁴ UK National Statistics (2013): [http://www.statistics.gov.uk/hub/release-calendar/index.html?newquery=*&uday=0&umonth=0&uyear=0&title=Integrated+Performance+Measures+Monitoring&pagetype=calendar-entry&lday=&lmonth=&lyear=](http://www.statistics.gov.uk/hub/release-calendar/index.html?newquery=*%&uday=0&umonth=0&uyear=0&title=Integrated+Performance+Measures+Monitoring&pagetype=calendar-entry&lday=&lmonth=&lyear=)

social care records (system wise) is a potential future possibility and one that would build on the NHS Information Strategy and support better technical integration.

Clinical audit data

The national clinical audits provide a potentially rich source of evidence-based data on the quality of care provided for people with selected conditions and for selected groups of patients. Several audits relate to the target groups prioritised in this review, for example children, older people, and people with long term conditions. They also cover aspects of care, such as the use of multidisciplinary teams and agreed care plans, which reflect on coordinated, person centred care and which align well with the headline message of the Narrative, even if they do not measure integrated care directly. However, provider participation in the audits and data completeness varies significantly between the audits, and while it is relatively good for some, for example the stroke audit, it is less comprehensive for others. There are also issues around ownership of the data, which lies between various overseeing organisations. The use of clinical audit data in the context of measuring integrated care requires detailed consideration of each of several clinical audits, in discussion with the various organisations associated with the audits, such as HQIP, the HSCIC, and the respective Royal Colleges. It will be necessary to establish which data sets are most pertinent to integrated care, have complete and reliable data quality, are available at sub-national level (specifically CCGs/LAs), on an ongoing basis, and are appropriate for use in the context of the Outcomes Frameworks. Such a review was beyond the scope of this project.

Social care data sources

A number of social care data sources could be used as the basis for indicator(s) of integrated care, as they are national level sources that can provide reliable and valid data.

Community Care Statistics

This report provides statistics and information about CASSRs obtained from their administrative systems which record the process of assessing eligibility to state funded social care. The data is gathered from the Referrals, Assessments and Packages of Care (RAP) and the Adult Social Care Combined Activity Return (ASC-CAR). The dataset meets the requirements for validity, reliability and accuracy. The data is aggregated but broken down into two bands: 18-64 and 65+, and then by client group such as learning disabled, physically disabled, substance abuse service user, mental health service user and 'other vulnerable group.' The data is available at Local Authority level. This data set has relevance to integrated care because of its multi-source input and its reliability. From 2013/14 the AVA will be replaced by the Safeguarding Adults Return, and the new activity collection (both Short and Long Term Support) will replace the RAP and ASC-CAR from 2014/15 (subject to final agreement from local government and the Department of Health). Whilst the AVA, RAP and ASC-CAR are being discontinued, these new data collections will directly replace them. As the new data is not yet available, we cannot evaluate it against the assessment criteria. However, as the Community Care Statistics contribute to the ASCOF, it is likely that the new data collections will be of a similar quality standard and able to contribute data to future refreshes of the ASCOF.

Abuse of Vulnerable Adults dataset (IC)

This data set comprises information from the Abuse of Vulnerable Adults (AVA) data submitted by all 152 CASSRs in 2012. Some councils were unable to submit all data

items before the deadline and therefore some totals do not provide a complete picture of the data across England. Where complete, this data set provides information by age, gender, primary client group and ethnicity. The AVA dataset offers unique information in terms of integrated care; however, the missing data presents a barrier to its use as a data source on integrated care.

National Minimum Dataset for Social Care (NMDS-SC)

The national minimum data set for social care (NMDS-SC) is a nationally aggregated data set that gathers online information about the social care workforce, specifically providers and their employees. Statistically it is reliable, valid, accurate, and can be tracked over time. However, it only provides approximately 50% coverage across both the provider and voluntary sectors. Local authority coverage is much higher and includes some data for each of the 152 Councils with Councils with Social Services Responsibilities (CASSRs). The data can be disaggregated to provider and local authority level. This data set could offer valuable information to an indicator of integrated care, as it specifically provides workforce information across the care sector including staff turnover, which could have a bearing on people's experiences of continuity of care. However, the partial coverage currently limits the scope of the results.

Personal Social Services: Staff of Social Services Departments (2011)

This report is based on data pertaining to staff employed (both directly and indirectly) by adult social services departments in England. The data will be of interest for policy development, monitoring and workforce planning by central government, and performance measurement by local government. The data set does not include information on staff employed by children's social services departments. The report uses data that is collected by the NMDS-SC (see above).

Measures from the Adult Social Care Outcomes Framework (ASCOF)

The ASCOF uses data from a couple of different sources- the Adult Social Care Survey (ASCS) and Community Care Statistics. As reviewed above, both these sources are reliable and provide statistically valid data. The ASCOF data is available at national level and disaggregated to local authority level; it can also be disaggregated to different sub-group populations at the local level. The ASCOF indicators are amenable to influence by health and social care activity, and will be credible to clinicians and meaningful to the public.

Recommendations

Following evaluation of the various data sources identified, the project team arrived at a set of recommendations that would meet the requirements of:

- The Department of Health in creating suitably robust and high quality indicators for inclusion in the NHS, Adult Social Care, and Public Health Outcomes Frameworks - the key output specified for the project.³⁵
- The wider audience of stakeholders and front-line providers and commissioners. The key priority for these audiences is meaningful information to support service improvement.

Given the wide range of target groups, and the complexity of measuring integrated care, it is not possible to adequately cover the totality of people's experiences of integrated care within a single or a few measure/s. Consequently, we recommend that (a) the requirements of the Outcomes Frameworks are met by data from a set of questions added to specific patient/user surveys (whether or not these are composited is for later consideration), and (b) in addition, a basket of indicators is developed to support local quality improvement and provide a fuller local profile of delivery and people's experiences of integrated care.

The Outcomes Frameworks would utilise a small set of high level indicator(s) from user feedback surveys, while the indicator basket would be designed for local use, and contain supplementary indicators based on both user- and service-reported data. The indicator basket should be owned and managed nationally by relevant agencies involved in the common purpose framework (NHS Commissioning Board, LGA, ADASS, PHE etc). The core set of indicators compiled for the basket could be presented as a dashboard for providers and commissioners, who could supplement the basket with other local data as needed. Thus the use of the basket would support delivery of the Outcomes Frameworks indicators thereby also meeting stakeholders' demand for actionable information for service improvement.

A basket with a range of core indicators will have numerous advantages for local quality improvement purposes:

- Firstly, indicators can cover a range of different target groups.
- Secondly, different elements of integrated care can be addressed: this limits the risk of perverse incentives because no single process or outcome will be seen as the sole marker of whether care is well integrated.
- Thirdly, different services and settings can be considered without the need for taking an unduly narrow perspective.

³⁵ Specifically, we consider who should be covered by (an) indicator(s) – the cohorts for inclusion – and how their experiences will be measured. The detail of what should be asked – eg specific survey questions or data variables – is beyond the scope of this project.

- Fourthly, this approach will have clinical and public credibility because indicators covering a range of target groups and services will reflect the real-life complexity of integrated care. By contrast, attempting to shoehorn the experience of disparate groups of people with differing requirements into a single or narrow set of measures will lack face validity with users, service providers, and commissioners.
- Fifthly, the indicator basket can be used by a range of local organisations to benchmark themselves against others and monitor improvements over time.

In considering our recommendations, we recognise the importance of practical considerations and steps to implementation. Ensuring that relevant indicators can be included in the NHS, Adult Social Care, and Public Health Outcomes Frameworks within a reasonable timeframe is of paramount importance. At the same time, hastily assembled indicators focussed on immediacy may fail to take advantage of upcoming information developments, or fail to have long-term utility.

We therefore recommend a developmental approach that balances urgent requirements with the longer term opportunities and needs within the health and social care system. This should involve:

- In the short-term a twin-track approach:
 - (a) A rapid development of a focussed and tightly related set of indicators based on new questions to be added to a number of existing health and social care survey collections. Some content could also be rapidly identified and implemented based on service reported datasets. Initial indicators – albeit not a comprehensive set – could begin to deliver within the 2013/14 financial year and be incorporated in the 2014/15 Outcomes Frameworks.
 - (b) This could be supplemented by the identification of a wider basket of indicators derived from service-reported health and social care data sets, which could serve as a toolkit for commissioners, providers and health and wellbeing boards to support benchmarking and local service improvements. Comprehensive, actionable, and person-focussed data drawn from a range of different sources, and covering different cohorts and sectors, will provide a kaleidoscopic view of care integration spanning local health and social care economies. The intention is that the basket of indicators will be developed over time.
- In the medium- term, extend the use of new questions to a wider range of annual surveys. Work should also identify and address gaps in routinely available health and social care data sets, to provide a more comprehensive profile of people’s experiences of integrated care to meet the service planning and development needs of frontline providers and commissioners. For example, data relating to people with learning disabilities and children.
- Additionally, in the medium- term, a priority should be to hasten progress in linking data and records across health and social care. Linkage is already underway in some areas, but if it was undertaken routinely at a national level, it would greatly enhance measurement of the quality of integrated care.

- In the long-term, maintain a ‘horizon-scanning’ approach to information developments – for example technology based tools, real-time data, information from social media, or information from person level social care records. Findings from other research – such as the Picker Institute and University of Oxford led policy research programme project on developing new models of addressing people’s experiences along pathways – should also be reviewed to assess whether they provide opportunities for adding to national and local measurement, understanding, and improvement of integrated care.

Further detail on each of these elements is provided below.

Short term

We strongly recommend the development of a set of indicators based on existing survey collections, supplemented by service-reported data. This is an expedient, proportionate, cost-effective and feasible way of providing robust, meaningful information in the short term for monitoring progress on the Outcomes Frameworks, and for dissemination to providers, commissioners, and the public.

Following our evaluation, we have identified some key surveys where the inclusion of an item or items on integrated care should be prioritised. The surveys are, in alphabetical order:

- The Personal Social Services Adult Social Care Survey (ASCS), conducted by the Health and Social Care Information Centre on behalf of the Department of Health.
- The Personal Social Services Adult Social Care Carers Survey (ASCCS), conducted by the Health and Social Care Information Centre on behalf of the Department of Health.
- The national Cancer Survey, conducted by Quality Health on behalf of the Department of Health.
- The Community Mental Health Service Users Survey (CMHSUS), co-ordinated by the Picker Institute on behalf of the Care Quality Commission.
 - The CMHSUS is typically undertaken in Spring each year, covering people’s experiences in the previous financial year. This suggests that it should be possible to incorporate questions into the 2014 survey, reporting retrospectively on the 2013/14 financial year, providing items are development in time.
- The GP Patient Survey (GPPS), conducted by Ipsos MORI on behalf of the Department of Health.
- The NHS Inpatients Survey, coordinated by the Picker Institute on behalf of the Care Quality Commission (CQC).
 - As mentioned previously, the NHS Inpatients Survey runs annually and whilst there are other surveys within the CQC national programme, such as Outpatients, Accident and Emergency, and Maternity, these

run on a rotation schedule, ie each conducted every three years, meaning that Inpatients is currently the most suitable survey within this collective in the short-term.

- The VOICES National Bereavement Survey, administered by the Office for National Statistics (ONS) on behalf of the Department of Health.
- The surveys above do not include the experiences of children and young people. However, domain four of the NHS Outcomes Framework includes a placeholder indicator on children's experiences of care: we anticipate that this will be delivered via a new survey collection and, if so, the feasibility of including suitable questions on integrated care within that collection should be investigated.
- The surveys above do not include community services, aside from the community mental health survey. At present, there is no national experience based survey of community services. Whilst work has been done locally by some organisations, recent feasibility work has identified several potential challenges to conducting a national community services survey. Until these challenges are resolved, we suggest that providers of community services continue to undertake local surveys to focus on quality improvement.

These surveys provide robust and reliable data, attributable to different organisations and geographies, and a firm basis for future collections. Although the individual surveys typically focus on specific user groups or services, rather than the interaction between services, there is scope to add items to each survey to specifically address transitions and people's wider experiences of integrated care. Testing would be required to establish the feasibility of asking people for a broader view of the range of services that they use.

Data from the inclusion of identical (or similar) questions in this broad spectrum of surveys would provide good coverage of the diverse groups for whom integrated care is relevant, and hence an indicator that was greater than the sum of its parts. Including similar or identical questions across surveys would provide a measure of the quality of integrated care across local areas, helping to identify 'pressure points' in local systems. The range of surveys identified as priority candidates also means that the Outcomes Frameworks, taken together, could provide closely related coverage of people's experiences of integrated care at the level of CASSRs, GP practices, and NHS acute and mental health trusts. Linking data back to CCGs, as is possible with at least two of the surveys described above, would also make this intelligence highly valuable to commissioners.

A crucial advantage to our recommendation of using existing surveys is cost efficiency. Each of the surveys described above uses best practice methods and large sample sizes. The cost of developing and implementing a new survey to a similar standard and scale would be significant – in the order of six figures for the inpatients or VOICES surveys, and as high as seven to eight figures for GPPS. Adding new questions to existing collections avoids such costs and reaches large numbers of the key groups. Questionnaire space is always at a premium, hence a tight focus will be needed in setting the scope of initial questions. It may be possible to revisit the approach of

developing, through cognitive testing, a single question for use in the surveys³⁶. This will need to be balanced against the agreed definition of integrated care, which does not lend itself to a single question as it covers multiple domains of care: hence it may become necessary to develop a small set of questions.

There are two main challenges with recommending the use of survey data. Firstly, the Department will need to gain the support of relevant stakeholders to add questions to the surveys. This will require negotiation especially if existing items are to be removed and where surveys involve a degree of co-production with other stakeholders. For example, the adult social care survey is effectively co-produced with local government, and the Department could not unilaterally make changes. Given the broad support for new measures of integrated care expressed in our stakeholder consultation, we are optimistic about the prospects of gaining their support.

A second challenge relates to the pace at which new questions could be developed and adopted. We would anticipate a minimum of three months for the development and testing of new items. Realistically, this means that it is likely to be mid to late Q2 of 2013/14 before new items are ready for use. The lead times associated with development and agreement of questionnaires for some national surveys might prevent immediate adoption in 2013/14: this could, for example, be a likely issue for the adult social care survey and the adult inpatient survey. However, if development work can be planned and completed in time, then it should be possible to begin collecting data from at least some of the 2013/14 surveys. This would give an initial read-out on people's experiences of integrated care, with further detail to be added by other surveys adopting the questions in 2014/15. Providing development of the questions could be completed by mid-2013/14, giving sufficient lead-time for inclusion of a new indicator in the relevant Outcomes Frameworks for 2014/15. A delay to this process will have knock-on implications for the timetable.

While existing surveys have potential for developing indicators on user experience of integrated care, this option will have to be targeted and it will not be feasible to cover people's experiences of integrated care in great detail. This approach will not fully meet the expressed needs of stakeholders for actionable, local data that will support monitoring and improvement of integrated care. This provides the justification for our additional recommendation that work be undertaken alongside the survey development, to identify a broader basket of indicators for use specifically in supporting local service improvements. This can be done relatively quickly, given that many such indicators are already in use in various contexts, and the routinely available data can be exploited to develop more indicators. There are already notable examples where baskets of indicators have been developed specifically to support local quality improvement, for example, the Commissioning Outcomes Indicator Set and the support packs for CCGs and LAs produced by the NHS Commissioning Board. PHE is also set to produce public health intelligence to supplement what's already available. Integration plays a key role in the Mandate for the NHS Commissioning Board and in Monitor's new role, and was a priority highlighted by the Future Forum. A basket of indicators, as a dashboard, can play a valuable role in local care needs assessments, planning and delivery of integrated

³⁶ As has previously been trialled, unsuccessfully, in the context of the GP Patient Survey. This proved problematic largely because of the use of the word 'integration' in the question: this was poorly understood by respondents, but given the agreed definition a new approach may be taken going forward (eg focusing on whether care was 'co-ordinated').

services by supporting joint working between local organisations, and can also be used by Health and Wellbeing Boards to oversee delivery of integrated care. It will provide valuable information about actionable aspects of service provision – ie what services are provided, for whom, to how many, their quality relative to services provided by comparators, and whether and how they need to be improved. The data is statistically robust and allows for flexibility as it can often be spliced for different user groups and geographies. Such a basket can also support the work of national bodies such as CQC, Monitor, the LGA, and Healthwatch. Based on routinely available data sets, it is a pragmatic, expedient and low-cost option for providing intelligence on integrated care.

An exercise similar to the survey development work will be needed to develop the indicator basket, which would entail:

- identifying indicators in current use,
- how they align with the definition of integrated care and identified groups,
- how they rate against the criteria, and
- what support they have from various stakeholders and agencies.

However, this need not be a protracted process, as it is imperative to not only make this information available early to support quality improvement but we see this as the starting point of a set of indicators that will evolve over time and could offer learning internationally.

Medium term

We recommend prioritising the development of user reported feedback, which is the most direct way of assessing standards from the point of view of people using services, and is consistent with the operationalisation of integrated care set out in work on definitions and consultation with stakeholders. Existing service-reported data should, however, perform a highly complementary role – particularly in allowing organisations to identify where systems are producing good or bad experiences of integrated care, and where interventions are needed to improve quality. Several available data sources contain information relevant to people’s experiences of integrated care, providing valuable complementary information that could be useful for service improvement or commissioning information locally.

We also recommend that, as a priority, the potential for data linkage approaches are fully explored. Data linkage of records both within and between different sectors, such as health and social care, would allow for the collection of person-level data that would go beyond individual settings and sectors. This would provide a powerful and flexible analytic resource to comprehensively investigate and evaluate the standard of integrated care in different areas.

Longer term

In the longer term, we recommend that the Department maintain a ‘horizon-scanning’ approach to reviewing and updating the feasibility of using new and emerging data streams on integrated care.

This longer term recommendation is important because of the developing landscape around patient experience measurement. Whilst there are a number of well established, gold-standard surveys in place – and recommended for immediate use around integrated care – there are a range of emerging approaches that may offer potential in the future. Typically these offer advantages in terms of the cost and/or timeliness of data collection and reporting. Two main streams of information particularly worth watching are user generated content, eg via social media websites such as Twitter and Facebook, and ‘real-time’ data:

- **Social media** of all kinds is increasing in popularity and utilisation. However, there are still significant limitations to the coverage of these sources, and considerable bias in the demographic characteristics of those who are represented. Whilst these services may serve as valuable communications or community engagement tools for health and social care providers and commissioners, they cannot offer sufficiently robust data to support indicators and measures at the present time. This should be reviewed in the future to assess change and growth.
- **‘Real-time’** or ‘near real-time’ feedback is increasingly prevalent in health and (to a lesser extent) social care settings. This is most visible in acute hospital care, where most providers routinely collect at least some feedback in near real-time – eg via tablet computers, kiosk terminals, or other methods.

As detailed in our evaluation, concerns around variation in administration and collection methods mean that we do not currently recommend near real-time feedback as viable for national indicators on integrated care – although we encourage organisations to use their existing near-real time collections as part of their work on integrated care. Developments in this area should be monitored in case the barriers to use reduce.

Roadmap

The roadmap below shows the likely timescales for our recommended developmental approach to producing indicators of integrated care. The roadmap focuses on what we consider to be national actions: local service improvement work can and should commence (or continue) immediately based on data available locally.

2013/14

- Q1/Q2: Commission development of common questions for adoption in national surveys.
- Q1/Q2: Identify initial set of existing service-reported indicators to supplement user experience measures.
- Q3: Announce detailed definitions of new experience survey indicators for 2013/14.
- Q3/Q4: Begin to implement new questions and establish baseline measures from key national surveys, including GPPS, community mental health, and, development time permitting, adult inpatients.

- Q1-Q4: Commission development of a broader toolkit of indicators, with a particular focus on meeting local monitoring and improvement needs.

2014/15

- Q1: Begin adding wider 'toolkit' indicators to the developing basket of indicators on people's experiences of integrated care.
- Q1/Q2: Baseline data from initial surveys available for use.
- Q3/Q4: Trend data from repeat surveys becomes available. Collection work extends to broader range surveys.
- Q1-Q4: Iterative development of further indicators to support local use.

2015/16

- Q1/Q2: Further expand and complete range of 'toolkit' indicators in supplementary basket.
- Q1-Q4: Continue to monitor developments in new collection and emerging collection approaches and data sources.

A note on service improvement

The steps listed above form a 'roadmap' to developing a national and local indicator approach for measuring people's experiences of integrated care. Necessarily, they prioritise the rapid development of robust indicators suitable for use in the Outcomes Frameworks. Other service-reported data can supplement indicators on user experience of integrated care, and will have utility locally for service improvement. A range of data sources is already being used locally to understand and improve people's experiences of integrated care.

Social media, local surveys, and rating and stories websites provide valuable supplementary information. Although such information will vary locally, most providers should already have access to some direct sources of intelligence on people's experiences of integrated care. Similarly, the interim measures of integrated care identified by the Department of Health, provide acute trusts in particular with robust data that is largely comparable over time and against other trusts. This should be a valuable resource for local service improvement, and trusts and commissioners should not await the publication of Outcomes Frameworks indicators to identify and act on areas for improvement. Providers and commissioners should exercise judgment to make the best use of available information to improve people's experiences of integrated care, and should be encouraged to experiment with collecting local data on integrated care.

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