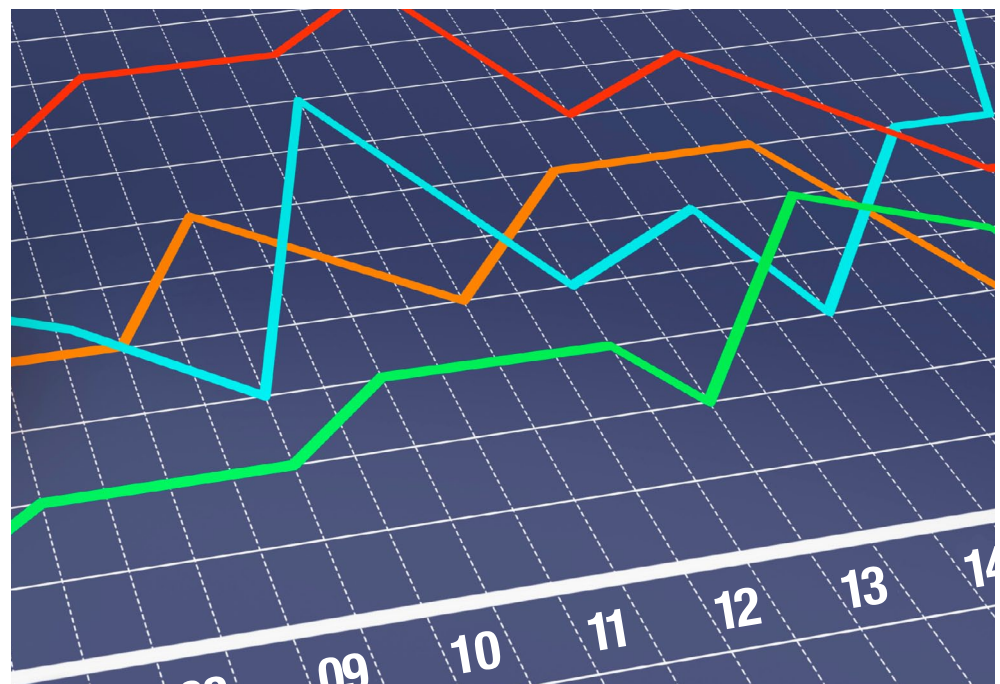

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Final report

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For further details, please contact:

Bob Erens

Policy Research Unit in Policy Innovation Research (PIRU)
Department of Health Services Research & Policy
London School of Hygiene and Tropical Medicine
15–17 Tavistock Place
London WC1H 9SH
Email: Bob.Erens@lshtm.ac.uk
www.piru.ac.uk

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Veena Raleigh¹, Martin Bardsley², Paul Smith², Gerald Wistow³,
Raphael Wittenberg³, Bob Erens⁴ and Nicholas Mays⁴

1 The King's Fund

2 Nuffield Trust

3 Personal Social Services Research Unit, London School of Economics

4 Health Services Research & Policy, London School of Hygiene & Tropical Medicine



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1. Introduction

Improved care coordination and integration of services within the health care sector, and across health, social care and other public services, is a priority for the government. The expectation is that integrated care will lead to more person-centred, coordinated care, improve outcomes for individuals, deliver more effective care and support and provide better value from public spending. Many initiatives are currently underway and planned to bring about better integration of health, social care and other services to meet people's needs more comprehensively and seamlessly. The aim of two recent initiatives in England – the Integrated Care and Support 'Pioneers' and the Better Care Fund (BCF) – is to enable more effective partnership working across the NHS and local government sectors, including the commissioning and provision of public health, health and social care services, together with other Local Authority responsibilities.

The Department of Health (DH) commissioned the Policy Innovation Research Unit (PIRU)¹ to carry out two short-term projects: the first ran from November 2013 to February 2014 and aimed to provide advice on indicators of integrated care for individual and collective progress monitoring using routine data; the second is an early evaluative study of the first 15 months of the Pioneers in the context of the BCF, with a report due in mid-2015. This report relates to the first project on the identification of indicators for measuring integrated care. Some parts of this work build on two earlier reports commissioned by DH: the Picker Institute et al (2013) report on options for measuring patient/user experience of integrated care; and the Picker Institute/Oxford University report (2013) identifying potential survey questions for measuring patient/user experience of integrated care.

This paper outlines the background to our work, the aims of and audiences for the indicators, how the proposed indicators were selected, some general issues relating to the measurement of integrated care, guidance on using the indicators, and some steers on how to use routine quantitative data to measure trends in integrated care. We are very grateful for the feedback received from the Pioneers during two consultation rounds, which has helped inform our final selection of indicators and the commentary in this report. We also acknowledge the valuable work being done by the Pioneer sites themselves to monitor and evaluate the impact of their local interventions to improve care coordination and integration.

¹ The Policy Innovation Research Unit (PIRU) is a collaboration between the London School of Hygiene & Tropical Medicine (LSHTM), the Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science (LSE), and the Health and Care Infrastructure Research and Innovation Centre (HaCIRIC) at Imperial College London Business School plus RAND Europe and the Nuffield Trust. It brings together leading health and social care expertise to improve evidence-based policy-making and its implementation across the National Health Service, social care and public health. The Unit is funded by the Policy Research Programme of the Department of Health.



2. Aim and objectives

The aim of this project is to provide advice on a set of indicators, measurable from existing data sources, that address the elements of integrated care as defined below, and which can be used by local communities, especially the Pioneers, for monitoring, assessing and improving care coordination and other dimensions of local integration. The indicators relate to the areas and causes of fragmentation, such as poor access, poor coordination and capacity constraints for key roles/services. Ideally, their use should also support the alignment of the Public Health Outcomes Framework (PHOF), the NHS Outcomes Framework (NHSOF) and the Adult Social Care Outcomes Framework (ASCOF), and the joint working between local agencies that is essential for improving care coordination and integration. Some of these indicators may also play some part in the evaluation of the Pioneer and BCF programmes.

The objectives of the project were to:

- Provide advice on a generic set of indicators of 'integration' performance drawn from existing routine information and relevant to all Pioneers for individual and collective progress monitoring, and independent evaluation of the Pioneers, and to identify relevant data sources.
- Advise on potential indicators relevant to the specific objectives of particular Pioneers or sub-groups of Pioneers (e.g. focusing on particular client groups, service models, change mechanisms, etc.) and to identify relevant data sources.
- Produce a final report setting out a common indicator set with data sources and, where possible, indicators relevant to sub-sets of the Pioneers.

The primary audiences for this work are the Pioneer communities, including their Clinical Commissioning Groups (CCGs), Local Authorities (LAs), providers of health and social care services, Health and Wellbeing Boards (HWBs) and local branches of Health Watch. The core set of generic indicators can support benchmarking against peers and monitoring against national trends. However, given the differences between Pioneers in their goals, target groups, interventions and time frames, a core set of generic indicators can only be of limited use. The expectation therefore is that individual sites will compile and use their own, bespoke baskets of indicators relating to their objectives and the contexts provided by their care economies (including local trusts and other providers), to supplement a core minimum data set across all the Pioneers.

We also see this work as being potentially relevant and useful for other communities working to improve care coordination and integration. It may be informative for a wider audience including regulators, other national agencies and academic researchers. Further, there is considerable international interest in metrics for measuring integrated care.



3. Time frames and processes

This work took place to a very tight timetable between late November 2013 and early February 2014 with a draft report provided to DH in mid-February 2014. PIRU convened an expert group with representation from LSHTM, Nuffield Trust, The King's Fund and PSSRU/LSE to review existing data sources and advise on possible metrics. We consulted on provisional indicator lists with the Pioneers on two occasions, and also sought feedback from a wider network of stakeholders.

We have been constrained in the amount of developmental work we were able to undertake by (a) the tight deadline for this project, and (b) the requirement of our terms of reference to focus on how existing, routinely collected data could be used to measure an aspect of commissioning and provision as complex and multidimensional as integrated care. We are also aware that many Pioneer communities are well advanced in developing integrated care measurement frameworks and metrics for local use. We have tried to draw on this expertise and resource in the limited time available, and also commented on some of the measurement work underway in the Pioneer sites.



4. Defining integrated care – policy background

The government has adopted the ‘person-centred coordinated care’ definition of integration developed by National Voices, and an accompanying narrative of ‘I statements’ setting out a user-based perspective of how integrated care should be experienced (National Voices 2013). The government expects this definition of integration as coordinated and personalised care, putting at its centre the individual around whom services should be organised, to be adopted and delivered by all localities through health, social care and other services sharing new or different ways of joint working.

Our rapid review of recent policy statements suggests two primary objectives which the government associates with integration and believes to be mutually reinforcing: (a) securing better outcomes and experiences for individuals, and (b) obtaining better use of resources across health, care and support systems at national and local levels. Two key government initiatives for promoting these goals in England are the 14 Integration and Support Pioneers and the universal BCF. Also relevant in terms of the policy context are the PHOF, NHSOF and ASCOF, which identify national priorities for improved outcomes, with shared indicators across the Frameworks to support integrated care.

The following areas for indicators can be identified from our review of the policy background:

- Transformation of individual outcomes and experience: improvements in health and social care quality of life; improvements in experience of accessing and using services and support based on the definition of integration from the individual user’s perspective and supporting narrative; numbers controlling personal budgets (including joined up health and social care budgets).
- Transformation of local health, care and support systems: fewer avoidable attendances at A&E and fewer unplanned admissions to hospital and to residential/nursing care; reduced lengths of stay in hospital and residential/nursing homes; more services and support options available and taken up in the community; change in ‘balance of care’ and balance of investment including disinvestment in hospital services; higher volume of cashable ‘savings’ realised.
- Change in process including effective engagement of housing and other services in the LA sector, the third sector and for profit sector: in care and commissioning models; whole systems planning and investment; evidence based models of care, commissioning and relationships with providers (contracts, payment models etc.); extension of freedoms and flexibilities; impact of regulation, especially the potential tensions between competition and integration (The King’s Fund 2011), which in the view of the House of Commons Health Committee (2014), for example, are still to be satisfactorily resolved.

The indicators identified by us reflect this policy background; we also drew on the types of indicators used in the Pioneer proposals and by other Integrated Care Pilots; and finally, we reviewed currently available health and social care data sets to develop additional indicators relevant to integrated care.



5. Classification of indicators

Given the many elements of integrated care as defined above and the wide range of services they cover, the indicators have been categorised to ensure that the selection (subject to the constraints of data availability) addresses as many of the key dimensions as possible. Various options were considered for classifying the indicators, such as the domains in the Outcomes Frameworks, the 'I' statements supporting the National Voices definition, and some international frameworks such as the framework for measuring care coordination developed by the US Agency for Healthcare Research and Quality (AHRQ) (2011).

The classification we finally developed to group the indicators is a pragmatic one, reflecting both the elements of care coordination and integration covered by these frameworks, and the 'system' issues referred to above. The topic headings for the indicators are:

- Community wellbeing and population health
- Organisational processes and systems
- Personal outcomes
- Resource use/balance of care
- Service proxies for outcomes
- User/carer experience.

In addition we have identified specific sub-sets of indicators for particular groups of service users. This is in response to the diversity of interests across the Pioneers. We focused, in particular, on indicators relating to mental health and learning disabilities, because this was the most common 'sub-group theme' across Pioneers after older people, and the next biggest sub-group in terms of user numbers. Indicators for the other specific groups listed in Appendix B are intended to be illustrative of the potential uses of available data. Indicators relating to a sub-group of patients or service users can act as a general marker of performance across a wider population with respect to 'integration'.



6. Criteria for selecting indicators

Indicators can be more or less robust and meaningful depending on their characteristics and whether they meet certain criteria. Some generic criteria that indicators should meet if they are to be useful include (see also Association of Public Health Observatories 2008):

- Importance and relevance
- Validity
- Accuracy
- Reliability
- Feasibility
- Meaningfulness
- Implications for action
- Avoidance of perverse incentives.

In the context of this project, some wider considerations also informed the selection of indicators, such as:

- Size of the population covered
- Representation of important aspects of the care system
- (Wholly or partly) within the control of care services i.e. attributability
- Change detectable within suitable time frames
- Unambiguous interpretation
- Likelihood of being meaningful to users, carers and the public
- Likelihood of being meaningful to care professionals, managers and commissioners
- Reflecting the user perspective and/or value for money perspective
- Timeliness
- Ability to assess the impact on inequalities between user groups and areas in terms of access and outcomes of care
- Measurable from routinely collected data.

Given the limited time available, it was not possible to evaluate each indicator systematically against each of these criteria, but they broadly informed our choice of indicators. Our advice is that communities wanting to develop their own indicators for local use should keep these considerations in mind, and identify any additional criteria relevant to their local goals for integration when assessing the value of our candidate indicators for their specific purposes.

In the process of choosing indicators we returned to a number of recurrent themes. The first concerned the extent to which an indicator represented an aspect of 'integration' as a process or an outcome relating to individuals or organisations. This was not always easy given the diversity of forms that integration can take. In general, we erred in favour of being more inclusive due to the significance of the problems for vulnerable people caused by a lack of integration.

Our second most common debate was about the sensitivity of an indicator to change in the short and medium term. For example, measures of life expectancy at a population level are clearly a legitimate long-term goal of service improvement through integration as well as other approaches to health improvement, and something that in the fullness of time could be expected to change as a result of cross agency working. Yet we know that changing life expectancy above trend will take a long time, particularly given that life expectancy has been improving year-on-year and is likely to be the result of a whole set of factors, only some of which may relate to integrated care or integrated working more widely. Hence our indicator lists do not include variables that are unlikely to be amenable to change in 3-5 years.

Finally, we advise that these are indicators, not definitive and unambiguous judgements on performance or quality. They need to be treated with a degree of caution and interpreted in the context of other locally available information to get the best value from them (see section 15).



7. Indicator development (short/medium/long term)

We advise a phased approach to selecting and developing indicators of integrated care as follows:

- **Short-term:** Maximising the potential of currently available data sources. The proposed list of indicators can be derived from routinely available health and social care data.
- **Medium to long term:** There is potential for developing additional indicators from new analyses of currently available data, including the national clinical audits, and through linkage of different data sets. New data sources currently under development (e.g. indicators under development for the Outcomes Frameworks and data sets for community services, child and adolescent mental health services (CAMHS) and learning disabilities) offer further opportunities for developing indicators relevant to integrated care. The potential for measuring integrated care more comprehensively than is feasible currently will be greatly enhanced by information developments now underway, for example, record linkage across health (primary/secondary/community) and social care services.

The commission for the current project restricted us to using current, routinely available data, which inevitably means there will be gaps in the indicators and some dimensions of integrated care will be better covered than others. However, this work should be seen as a foundation for further work that exploits information developments underway. Such developmental work is essential for improving the ability of local agencies to measure the quality of integrated care more holistically and robustly, and for all groups of service users.

There are some general considerations to keep in mind about using national data sources that conform to specified data standards and quality assurance processes, as against collecting bespoke data locally (as proposed by some health and social care communities). Bespoke data collections have their merits, notably in bridging data gaps in national collections and addressing particular, local information needs. The issues about new data collections that should be taken into consideration include cost, burden, challenges in specifying the detailed content and methods of data collection, sustainability, ensuring consistency of interpretation and data recording, logistics of data collection, processing and dissemination, data quality and validation, and wider issues such as not being able to benchmark with others.



8. Proposed indicators

Appendices A and B give our proposed lists of indicators, for generic and for specific sub-groups respectively. They have been categorised as described above. In addition, it should be noted that:

- Given the wide remit of integrated care as defined in section 4, and the diverse approaches to metric development underway locally, our initial indicator lists were long and included indicators from the Pioneers' proposals and other sources. The shorter list of indicators presented here takes into consideration comments received from the Pioneers and other stakeholders.
- While measuring outcomes is ultimately essential, we have also included process measures where they are relevant to, and important for, measuring progress in care coordination and integration. Coordination and integration processes need to be captured so that their link with changes in outcomes can be ascertained.
- Some of the indicators listed can be disaggregated in various ways, as appropriate – for example, to cover specific age, patient or condition groups.
- All indicators will need precise technical specifications before they can be used.
- Some indicators will be available only for specific units of measurement. For example, most patient survey data will be available at trust level and not for specific geographies or populations, while social care indicators will be available at geographical (LA) level only. The intention with this list of indicators is that commissioners, providers and HWBs will use both population- and provider-based data collectively to monitor and assess how effectively their local care economies are delivering integrated care.

We would emphasise the importance of monitoring short term process changes as well as outcomes and patient benefits. Many studies have shown the challenges in changing services in areas such as reducing emergency admissions (Steventon et al 2012, Roland et al 2012, Bardsley et al 2013), and the creation of truly integrated services can take time (Shaw et al 2011). It is therefore important to identify the steps along the way, which is very often in the form of monitoring of process measures at local level to ensure that work is going in the right direction. These short-term markers need to be realistic and locally 'owned', especially if they are not based on information that can be put into broad, generalisable indicators.

Because of the multifaceted nature of integrated care, spanning many care dimensions, settings and user groups, it is not possible to specify an optimum number or set of indicators – just as it is not possible to do this easily, say, for public health or hospital care. The number and selection of indicators deemed useful will depend on many factors such as the aims of, and audience for, measurement, local priorities and interventions, target groups, analytical capacity, etc. For example, for quality improvement purposes more rather than fewer indicators are likely to be useful, whereas for performance assessment or pay for performance purposes a more limited set could suffice. Organisations may want to adopt a hierarchical approach, prioritising a limited number of higher volume or higher impact indicators, or those with a stronger evidence base and using a broader set for ongoing monitoring. For these reasons, we see our indicator set as a menu – readers will inevitably find some indicators in the 'core' indicator set more useful than others, and will want to supplement them with their own more locally tailored indicators.

We have deliberately omitted some indicators that are frequently discussed in relation to integrated care, in particular, admissions to residential/nursing care homes. We did not include this indicator because we judged that its interpretation (e.g. whether a rising or falling rate denotes improvement) depends on factors such as the difficulty



of distinguishing between reduced need versus reduced service provision, the local configuration of services and the short-term objectives of integration initiatives in particular contexts. Likewise, we did not include indicators relating to admission to hospital from e.g. residential/nursing care homes, or discharge from hospital to residential/nursing care homes because of concerns about the coding reliability of Hospital Episode Statistics (HES) data on admission source and discharge destination. That said, where reliable data are available locally through this or alternative sources, such indicators could be useful.

A number of indicators of trends in population health have also been omitted because we judged that they would be too insensitive to change related to integrated care initiatives and too likely to be affected by other unrelated factors to be interpretable (see section 6).

Other indicators not included were ones that were relevant to only a few Pioneers (e.g. those relating to children's services and public health).

Finally, we have not included markers for transformational processes which do not lend themselves readily to quantitative measurement in a consistent way, although more qualitative indicators are important locally for ensuring that the capacity development for delivering integrated care is taking place.



9. Gaps in indicators

Any analysis which seeks to identify measures that can be derived from existing data will face the problem of gaps in current information systems. Many of these gaps correspond to the divisions in the current system of care which integration initiatives are trying to overcome. In respect of integration, some of the more noticeable gaps include:

- Information about self-funded social care. Most LAs have very limited information about people who pay for their own social care (home and/or residential care). Such service users are not currently included in the Adult Social Care Survey (although this is due to change in 2014-15), or in statistical returns on national activity and expenditure coordinated by the Health and Social Care Information Centre (HSCIC). As the number and proportion of people whose social care is self-funded is significant and growing, it is vitally important for more data to be collected about this group of social care users if we are to understand the impact of fragmentation and integration on local populations as a whole.
- Information on staff experience was identified as a potentially important area and has been included in previous evaluative work on integrated care based on bespoke data collections (Roland et al 2012). For this project, we reviewed the existing NHS staff surveys to see if they included any questions related to integration, but unfortunately they do not. By their very nature, staff surveys tend to focus on activity within organisations rather than between them. However, we advise that the NHS staff surveys are modified to reflect the priority that health and social care staff are now expected to give to delivering care that is coordinated and integrated across organisational and service boundaries. In addition, it is necessary to collect similar data from social care and other staff if we are to secure a comprehensive perspective on staff attitudes to and experiences of integration and integrated care. We also recognise that local surveys of staff attitudes can be important markers of change that individual Pioneer sites may want to use and conduct themselves.
- There is a dearth of information at national level about services provided in community settings, which is a concern, given the importance of these settings within integration programmes. The number of staff working in community-based integrated care settings was also considered to be a good marker of the speed at which services may be changing, but we were unable to find a reliable and consistent data source on such staff across the country.
- As publicly-funded services become more pluralistic, it becomes increasingly important for information collections to mirror these developments to ensure that data are available to cover all settings and not merely those that are publicly owned. A related point can be made about the evolution of care models and service delivery systems (e.g. personal budgets, extra care housing) which involve greater roles for different sectors and services.
- Patient/user/carer experience measures (see section 10).



10. Measuring patient/user/carer experience

Since the National Voices definition of ‘person-centred coordinated care’ is central to the concept of integrated care, it is essential for any set of indicators on integration to include measures of user experience. Patient/user experience of integrated care has been a placeholder indicator in both the NHSOF and ASCOF. It is also one of the five metrics underpinning the BCF. As no single national measure that meets the current definition of patient/user experience of integration exists currently, new national measures are under development.

In 2013, DH commissioned Picker Institute Europe and Oxford University to develop measures of self-reported patient/user experiences of integrated care (see Appendix C). They developed 18 questions relating to the National Voices ‘I statements’, a sub-set of which are being taken forward and tested potentially for inclusion in seven surveys (included in Appendix C). The DH intends to develop the NHSOF and ASCOF indicators from these survey questions.

As patient/user experience is also one of the 5 metrics underpinning the BCF, NHS England is developing a new national measure to use for this purpose, although it will not be in place in time to measure improvements in 2015/16. Until this new measure is available, local metrics of patient/user experience will be used instead, so there may not be comparability across Pioneers as some of these may be locally developed. However, what is being lost in national comparability may be compensated for by a gain in responsiveness to local service user populations and service improvement goals. Some Pioneers argued for both approaches to be adopted, and it will be appropriate to consider the balance struck between these approaches as the new measure is developed and applied.

Because of the current lack of suitable national measures, and the lack of specificity in existing surveys about integration and priority user groups, some Pioneers are undertaking their own initiatives in measuring user experience. For example, in our January 2014 workshop, the Pioneers in the group on user experience measures were adopting mixed methods approaches to the user dimension. Some Pioneers have emphasised the necessity to adopt approaches which enable longitudinal monitoring of the experiences of specific groups and/or individuals. They also pointed to the potential tension between data quality and usability: e.g. robust high quality national data may be useful for monitoring long-term trends and for comparing sites, but may be less useful for real time service improvement which needs results quickly, even if this is at the expense of some rigour. Local sites tend to be more concerned with the latter and, given limited resources, express concerns that complying with national requirements could be at the expense of (potentially more useful) local activities. We think that there is likely to be value in giving priority to consolidating knowledge of such developments by individual sites and systematising the learning from them in the continuing search for relevant and usable measures locally and nationally.

Appendix A, Section F (on user/carer experience) identifies questions relevant to integration that are already included in a number of existing health and social care surveys (such as the General Practice Patients Survey (GPPS), the Inpatient Survey, the Social Care Users’ Survey). Although these questions do not capture the global user experience of integration, they do capture specific dimensions of integration and could provide useful information where they are relevant to the specific objectives of particular Pioneers.



National Voices are currently developing narratives for integrated care specific to four particular user groups – mental health, children and young people, end of life care and frail older people – which will enable the development of user experience indicators specific to these groups.

Another development in the pipeline is a project to develop a survey tool for measuring user-reported experience of integrated care among older people with a long-term condition, with the aim of supporting health and social care services in England, and more widely in an international context, in measuring and improving the quality of integrated care. Led by the Nuffield Trust in collaboration with the Picker Institute, The King's Fund, National Voices and the International Foundation for Integrated Care, the project is funded by the AETNA Foundation in the US and due for completion in 2015.



11.
**Supplementing
the national
indicator set
with local
metrics**

We are aware that, in order to monitor and study change within an area, the best sources of information will be held within local systems. In some cases these are specific data collection and monitoring systems within an area that may have preceded Pioneer status.

One of the critical advantages of devising locally based indicators is that it is possible to be specific about the client groups who are the focus of new integrated services. The aim of being able to identify a specific sector of the population, e.g. those at high risk, is common across the Pioneer sites. It follows that the best measures of change will identify care patterns and outcomes for these particular groups. The most sophisticated approaches, discussed by a number of Pioneers, extend this approach to looking at ways to track health and service use over time for a cohort of individual users. These approaches will rely on the use of linked data sets, which put together information about an individual's use of services over time and across care sectors. A number of studies have demonstrated the possibility of such data linkages (Tian et al 2013, Steventon et al 2013, Chitnis et al 2012), but their application nationally has yet to prove feasible.



12. Describing resource use

Many of the suggestions we received revolved around indicators to describe the level of activity or expenditure within a given sector, e.g. care home admission, emergency bed days. While we have included some of these resource indicators in our list, looking at one sector in isolation could be potentially misleading. What is needed is a framework to describe both activity and costs across sectors of care. The table below gives an example of services, described in broad terms, which could be used to track change over time. The emphasis here is on the balance of activity across sectors and how it is changing as a result of more integrated care. It allows monitoring of progress in the shifting of resources into community settings. By using population denominators, there is also some scope for using it to make rough comparisons of relative levels of resourcing between different parts of the country.

Service	Activity	Estimated costs
GP contacts		
Outpatient attendance		
Emergency inpatient care		
Elective inpatient care		
A&E attendance		
Mental health community care		
Mental health secondary/tertiary care		
Other community health care contacts		
Social care – home-based		
Social care – residential & nursing home		
Voluntary sector funded care		
Self-funded care		

The information required for developing this view across a local population can be extracted from locally available data sets, e.g. on community based services. Creating these indicators at a national level, however, is more challenging until such data sets become available nationally in a consistent format.

To apply an accurate costing locally could be difficult if you wish to include accounted expenditure. A simpler approach is to use pre-defined unit costs, such as those published by PSSRU (Personal Social Services Research Unit 2012). By applying these unit costs, the resulting figure may not equate to accounted expenditure, but it does provide a useful way of estimating approximate expenditure on different activities. It is independent of changes in local accounting systems, definitions or financial flows that can make full costing very difficult.

A more sophisticated approach would be one that looks not just at activity but also at real local costs and questions of efficiency. In this case the optimal balance of activity and expenditure locally between different services should reflect not only local needs and preferences but also local relative unit costs. In social care, for example, the relative unit costs of home based care and residential care vary between urban and rural areas. To the extent that they do vary, the 'optimal' (efficient) balance of care is likely to vary between areas.

If the focus is on understanding efficiency of local provision, the use of national unit costs will provide an inaccurate impression of the relative expenditure on different services if relative unit costs locally differ significantly from national average relative unit costs. This issue might appear to be particularly significant in the case of social care, in the absence of national tariffs as there is in hospital care. However, since tariffs are effectively the price set for different aspects of health care, underlying (actual) resource costs may vary between areas in ways that affect the balance of costs for different mixes of health and social care in integrated schemes.



13. Indicator/data production and maintenance processes

In our work, we have made no assumptions about how our suggested indicators might be specified, produced, disseminated and updated. Currently, there is no central source of data on indicators on integrated care. Given the priority that the government attaches to integrated care, and the importance of information in supporting service improvement, this is a clear gap. In particular, we see that there are advantages in having one organisation take the lead for ensuring that these indicators are developed, produced, disseminated and regularly updated nationally, including for the Pioneer sites. This would enable all local care and support economies to benchmark themselves relative to others nationally and over time on the indicators most useful to them locally. Such benchmarking is critically important for supporting quality improvement. Doing this centrally will also significantly reduce the costs, burden and demands on analytical capacity for local organisations, especially as many of the proposed indicators are already available, but in disparate national portals for health and social care indicators. Central indicator production has the potential to ensure the use of quality assured national data sets, consistency of data, technical specifications and analytical methodology, and regular updating. It also does not inhibit local sites from producing their own indicators should they wish to do so.

There are many precedents of national systems for producing indicators and portals for their dissemination. Examples are the HSCIC indicator portal with the Compendium of Population Health Indicators and indicators for the three Outcomes Frameworks and general practices; the Commissioning Outcomes Indicator Set (COIS) and other indicator sets produced by NHSE for CCGs and LAs; and various PHE indicator sets for LAs. In contrast, an equivalent dedicated central portal for integrated care indicators is conspicuously lacking. However, there may be opportunities to exploit some of the existing mechanisms in HSCIC and NHSE for compiling and disseminating local data on integrated care indicators. Since these indicators are primarily a tool to inform local change, the development of such a central resource would benefit from consultation with local users in order to design a system that best supports their needs.

In parallel, development work is needed on innovative approaches to using information and defining new indicators for integrated care, which exploits the potential of information developments nationally and the best of the local work, rather than being constrained by the limitations of existing national data sets. This will require specialist expertise with knowledge of the relevant data developments and experience of using emerging data sets, such as linked records.

In the longer term, the best information to measure integrated care will probably be derived from analysis of linked data sets and records, and it is important that the capability to exploit such data is also promoted locally.



14. Information governance issues

Many Pioneer sites are interested in exploring the use of linked data sets, as a means of risk prediction and case finding or as part of commissioning, evaluation and monitoring. As noted above, such analyses are important but largely beyond the scope of existing indicators. However, such work is critically important for supporting the delivery of integrated care locally. Many Pioneer sites report that the current uncertainty around data sharing and record linkage is a significant barrier to commissioning and delivering integrated care, which has made progress difficult. The feedback we have received also shows that the understanding and practice about such information governance issues, and what is thought to be possible or not, differs locally. We consider that clear, national guidance on data sharing and record linkage, to support a variety of functions such as commissioning, monitoring, risk prediction and care delivery, is urgently needed and should be made available to all local communities including the Pioneer sites.



15. Interpreting the data

Whilst quantitative indicators can be very powerful, they need to be interpreted with care. There are accepted ways to make the most of the information, especially where there may be uncertainty or ambiguity around the data. It is clear that some indicators will be more reliable than others, both in terms of data quality and their ability to measure what they purport to measure. One important aspect is to recognise the natural statistical variability in a measure. When an indicator has a naturally high level of variability and uncertainty, it is important to distinguish between random variation and statistically meaningful differences. The standard way to handle this is to use statistical tests as necessary.

When using such data, it is important to know when a particular indicator is showing something significant, i.e. when it is higher, or lower, than expected. How performance is to be assessed (e.g. absolute or relative values) will vary between individual indicators, depending on the nature of the indicator and how it is to be used. In fact, all indicators will require some understanding of an 'expected value'. This is commonly in the form of a national comparison (e.g. 'we are among the highest in the country'), but it doesn't have to be. It could also be based on the previous year's value, or on values in similar organisations in other parts of the country, as in benchmarking for quality improvement. The expected value could also be based on a minimum performance threshold or value statement, e.g. 'people should not have to wait more than x weeks for this service'. Indicators linked to pay for performance will need precisely defined, absolute performance thresholds. So it is worth considering local performance as something more than just being better or worse than average. We would, however, caution against setting overly ambitious performance targets for indicators that are unlikely to show significant movement in the short-term and without realistic confidence about their achievability.

Listing relevant indicators is just the start. Much will depend on the ability of local organisations to work individually and collectively to understand the data and the relationships within them, and to have the appropriate forums and arrangements locally for doing so. The indicators relate to different units of measurement, e.g. GP practices, acute trusts, social care providers, CCGs, LAs. It will be important that HWBs, CCGs, LAs, providers and others have access to analytical skills which enable them to interpret these different data streams and the patterns within them in order to understand what they show about integration and care coordination in the local care economies that may straddle different geographical and catchment populations. In this respect, integrated care can present unprecedented substantial additional challenges in combining data across multiple geographies, populations and providers.

Another reason for not looking at indicators in isolation is that they have to be interpreted in light of locally planned care models and the inherited pattern of provision in the area, and thus the goals and emphases of local integration initiatives across the spectrum of care. For example, the level and trends in use of residential care in an area may need to be interpreted in relation to whether the area has been well or poorly provided with residential care places in the past and the use made of such facilities, thresholds for access to services, and levels of self-funded care. Indicators about the use of hospital services will need to be interpreted alongside indicators that reduce the risk of hospital admission (e.g. indicators relating to primary and community care) and length of hospital stay (e.g. indicators relating to access to social care and other post-discharge support mechanisms).

Finally, we need to add the reminder that these are only indicators and as such are milestones or markers towards longer-term goals and aspirations. When used well they can help improve understanding of what is happening locally and the extent to which progress is being achieved, but they cannot provide a definitive judgment on the success or failure of integration in any one area.



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Appendix A Generic indicator list

A Community wellbeing and population health

Indicator ID	Indicator description	Data source	Other notes
(1)	Excess winter deaths	Office for National Statistics	
(2)	Proportion of people who use (social care) services and their carers who reported that they have had as much social contact as they would like	Adult Social Care Outcomes Framework indicator 1L; Public Health Outcomes Framework indicator 1.18i	
(3)	Proportion of physically active and inactive adults	Public Health Outcomes Framework indicator 2.13ii	

B Organisational processes and systems

Indicator ID	Indicator description	Data source	Other notes
(4)	Delayed transfers of care from hospital, and those which are attributable to adult social care Delayed transfers of care, days of delay, all ages, all settings, per 100k older pop	Adult Social Care Outcomes Framework indicator 2C	Suggest delays caused by NHS and social care as distinct indicators. The accuracy of these indicators has been questioned and they may have to be subject to some local validity checks.
(5)	Access: Attendances at A&E (separate OoH and 9-5)	Hospital Episode Statistics	Separating 'in hours attendees' has been undertaken by the HSCIC
(6)	Potential indicators linked to changes to GP contracts from April 2014 (for further details, see: http://www.england.nhs.uk/wp-content/uploads/2013/11/gms-contr-let-at113.pdf)	GP contract changes effective from April 2014 – details of measures not yet available but presumably will be measured for payment purposes	Named, accountable GP for people aged 75 and over with overall responsibility for their care. Out of Hours services: new contractual duty to monitor and report on the quality of OoH services and support more integrated care. Reducing unplanned admissions: new enhanced service to improve services for patients with complex health and care needs and to help reduce avoidable emergency admissions.
(7)	Proportion of older people (65 and over) who were offered rehabilitation following discharge from acute or community hospital	NHS Outcomes Framework indicator 3.6ii; Adult Social Care Outcomes Framework indicator 2B(2)	
(8)	Improving access to GPs	GP patient survey; HSCIC: Number of GPs per registered and weighted practice population	



Generic indicator list *continued*

C Personal outcomes

Indicator ID	Indicator description	Data source	Other notes
(9)	Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation services	NHS Outcomes Framework indicator 3.6i; Adult Social Care Outcomes Framework indicator 2B	
(10)	Social care related quality of life	Adult Social Care Outcomes Framework indicator 1A	
(11)	Carer reported quality of life	Adult Social Care Outcomes Framework indicator 1D	
(12)	Injuries due to falls in people aged 65 and over	Public Health Outcomes Framework indicator 2.24i	
(13)	Proportion of people feeling supported to manage their (long term) condition	Better Care Fund local metric, NHS Outcomes Framework indicator 2.1	
(14)	Proportion of patients with fragility fractures recovering to their previous levels of mobility/walking ability at 30/120 days	Better Care Fund local metric, NHS Outcomes Framework indicator 3.5	

D Resource use/balance of care

Indicator ID	Indicator description	Data source	Other notes
(15)	Bed days for selected patient types	Hospital Episode Statistics	
(16)	Hospital use in last 100 days of life	Hospital Episode Statistics; Office for National Statistics	Such an indicator can be generated from analysis of HES data linked to hospital mortality and could be useful in areas that are seeking to promote greater home-based end of life support.
(17)	Gross residential and nursing care expenditure, per 100k older population	PSS EX1 data; Office for National Statistics	PSS EX1 to be replaced by ASC-FR return from April 2014
(18)	Gross residential and nursing care expenditure minus NHS contribution, per 100k older population	PSS EX1 data; Office for National Statistics	PSS EX1 to be replaced by ASC-FR return from April 2014
(19)	Numbers receiving long-term community-based care as a proportion of total numbers receiving long-term care services (by user group)	RAP/CAR returns	RAP/CAR to be replaced by SALT returns from April 2014
(20)	Numbers receiving long-term social care as a proportion of the sum of numbers receiving emergency hospital care and numbers receiving long-term social care (by age group, or just for 65+ group)	RAP/CAR returns; Hospital Episode Statistics	RAP/CAR to be replaced by SALT returns from April 2014

Table continued over page >



Generic indicator list *continued*

D Resource use/balance of care *continued*

Indicator ID	Indicator description	Data source	Other notes
(21)	Numbers of people receiving long-term community-based social care relative to population (by age group, or just for 65+ group)	RAP/CAR returns; Office for National Statistics	RAP/CAR to be replaced by SALT returns from April 2014
(22)	Proportion of gross current social care expenditure funded through income from the NHS (by user group)	PSS EX1 data	PSS EX1 to be replaced by ASC-FR return from April 2014

E Service proxies for outcomes

Indicator ID	Indicator description	Data source	Other notes
(23)	Emergency admissions stratified by age (e.g. young people, over 65s); and risk group	Hospital Episode Statistics; GP data	The selection of age groups can be adapted to particular aims of individual projects or risk.
(24)	Avoidable inpatient activity for people with ACS admissions including LTCS, e.g. lower limb amputations in people with diabetes	Hospital Episode Statistics	There are freely available definitions of these conditions that can be applied to derive time series data to put change in context.
(25)	Patients with multiple admissions per year for specific age groups/prior conditions	Hospital Episode Statistics	This would require bespoke analysis of HES data and we suggest 2-3 variants are tested by age groups and distinguishing emergency care episodes. There will also have to be ways to separate out people that have died during the reporting period.
(26)	Readmissions for selected patient groups e.g. falls	Hospital Episode Statistics	We suggest that readmissions are limited to specific conditions where a readmission is more likely to indicate a problem with prevention or community based care.
(27)	Proportion of people using social care who receive self-directed support, and those receiving direct payments	Adult Social Care Outcomes Framework indicator 1C	New definition for 2014/15
(28)	Persons (65+) discharged for rehabilitation from hospital, per 100k older population		



Generic indicator list *continued*

F User/carer experience

Indicator ID	Indicator description	Data source	Other notes
(29)	Proportion of people dying at home/place of their choosing	National End of Life Care Intelligence Network – End of Life Care Profiles	
(30)	Improving people's experience of integrated care	NHS Outcomes Framework indicator 4.9; Adult Social Care Outcomes Framework indicator 3E	New ASCOF indicator from 2014/15
(31)	Safety: the proportion of people who use services who say that those services have made them feel safe and secure	Adult Social Care Outcomes Framework indicator 4B	
(32)	GP Patient Survey questions	GP Patient Survey	<p>Q32. (For people with LTCs) In the last six months have you had enough support from local services or organisations to help you to manage your long-term health condition(s)? Please think about all services and organisations, not just health services.</p> <p>Q33. How confident are you that you can manage your own health?</p> <p>Q40. Do you know how to contact an out-of-hours GP service when the surgery is closed?</p>
(33)	Inpatient survey questions	Survey of adult inpatients	<p>Q60. Did hospital staff take your family or home situation into account when planning your discharge?</p> <p>Q63. Did hospital staff discuss with you whether you would need any additional equipment in your home, or any adaptations made to your home, after leaving hospital?</p> <p>Q64. Did hospital staff discuss with you whether you may need any further health or social care services after leaving hospital (e.g. services from a GP, physiotherapist or community nurse, or assistance from social services or the voluntary sector)?</p> <p>Q65. Did you receive copies of letters sent between hospital doctors and your family doctor (GP)?</p>

Table continued over page >



Generic indicator list *continued*

F User/carer experience *continued*

Indicator ID	Indicator description	Data source	Other notes
(34)	A&E survey questions	Accident and emergency survey	<p>Q38. Did hospital staff take your family or home situation into account when you were leaving the A&E Department?</p> <p>Q41. As far as you know, was your GP given all the necessary information about the treatment or advice that you received in the A&E Department?</p>
(35)	VOICES national bereavement survey questions	National bereavement survey (VOICES), Office for National Statistics	<p>Q3. When he/she was at home in the last three months of life, did he/she get any help at home from any of the services listed?</p> <p>Q4. When he/she was at home in the last three months of life, did all these services work well together?</p> <p>Q5. Overall, do you feel that you and your family got as much help and support from health and social services as you needed when caring for him/her?</p> <p>Q27. Did the hospital services work well together with his/her GP and other services outside of the hospital?</p> <p>Q44. Do you think he/she had enough choice about where he/she died?</p> <p>Q46. Were you or his/her family given enough help and support by the healthcare team at the actual time of his/her death?</p> <p>Q52. Since he/she died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his/her illness and death?</p>



Appendix B Indicators for specific conditions or groups of service users

Mental health and learning disability

Indicator ID	Indicator description	Data source	Other notes
(36)	Care Programme Approach (CPA): The proportion of people under adult mental illness specialties on CPA who were followed up within 7 days of discharge from psychiatric in-patient care	UNIFY; Mental Health Minimum Dataset	
(37)	Proportion of admissions to acute wards that were gate kept by the Crisis Resolution Home Treatment teams	NHS Information Centre Omnibus Survey; UNIFY	
(38)	Proportion of adults in contact with secondary mental health services living independently, with or without support	Adult Social Care Outcomes Framework indicator 1H; Public Health Outcomes Framework indicator 1.6ii	
(39)	Proportion of adults with a learning disability who live in their own home or with their family	Adult Social Care Outcomes Framework indicator 1G; Public Health Outcomes Framework indicator 1.6i	
(40)	Proportion of adults with a learning disability in paid employment	NHS Outcomes Framework indicator 2.2; Adult Social Care Outcomes Framework indicator 1E; Public Health Outcomes Framework indicator 1.8ii	
(41)	Proportion of adults in contact with secondary mental health services in paid employment	NHS Outcomes Framework indicator 2.5; Adult Social Care Outcomes Framework indicator 1F; Public Health Outcomes Framework indicator 1.8iii	
(42)	Dementia assessment and referral (new data set from April 2013, see: http://www.england.nhs.uk/statistics/statistical-work-areas/dementia) CQUIN 2013/14 and 2014/15 indicator for acute services, with 3 stages on (a) case-finding (b) assessing and investigating (c) referring, and 3 components	NHS England; UNIFY	60% of funding for: undertaking case finding for at least 90% of patients aged 75 and over admitted as an emergency for >72 hours; ensuring that, where patients are identified as potentially having dementia or delirium, at least 90% are appropriately assessed; and ensuring that, where appropriate, patients with dementia are referred on to specialist services. 10% of funding for ensuring sufficient clinical leadership of dementia within providers and appropriate training of staff. 30% of funding for ensuring carers of people with dementia feel adequately supported.

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Indicators for specific conditions or groups of service users *continued*

Mental health and learning disability *continued*

Indicator ID	Indicator description	Data source	Other notes
(43)	Readmission rates <30 days for those with long-term mental health conditions for mental health diagnosis or for both mental and physical health conditions	Mental Health Minimum Dataset – Hospital Episode Statistics linked data	
(44)	Hospital admissions among users of specialist mental health services – split by elective and emergency admissions	Mental Health Minimum Dataset – Hospital Episode Statistics linked data	
(45)	A&E attendances among users of specialist mental health services	Mental Health Minimum Dataset – Hospital Episode Statistics linked data	
(46)	For those with self-reported mental health problems and/or learning difficulty (GPPS) (sub-set of NHSOF)	GP Patient Survey	<p>Q32. In the last six months have you had enough support from local services or organisations to help you to manage your long-term health condition(s)? Please think about all services and organisations, not just health services.</p> <p>Q33. How confident are you that you can manage your own health?</p>
(47)	Overall satisfaction with services among people with mental health related social care needs	Adult Social Care Outcomes Framework indicator 3A – MH disaggregation	
(48)	User experience of community mental health services (MH service users’ survey)	Survey of people’s experience of community mental health services	<p>Q21. How well does your Care Co-ordinator (or lead professional) organise the care and services you need?</p> <p>Q24. Does your NHS care plan set out your goals? This might include the changes you want to make to your life as your care progresses or the things you want to achieve.</p> <p>Q40. In the last 12 months, have you received support from anyone in NHS mental health services in getting help with your physical health needs?</p> <p>Q41. In the last 12 months, have you received support from anyone in NHS mental health services in getting help with your care responsibilities (including looking after children)?</p> <p>Q42. In the last 12 months, have you received support from anyone in NHS mental health services in getting help with finding or keeping work (e.g. being referred to an employment scheme)?</p>



Indicators for specific conditions or groups of service users *continued*

Mental health and learning disability *continued*

Indicator ID	Indicator description	Data source	Other notes
(48) <i>continued</i>	User experience of community mental health services (MH service users' survey)	Survey of people's experience of community mental health services	<p>Q43. In the last 12 months, have you received support from anyone in NHS mental health services in getting help with finding and/or keeping your accommodation?</p> <p>Q44. In the last 12 months, have you received support from anyone in NHS mental health services in getting help with financial advice or benefits (e.g. Housing Benefit, Income Support, Disability Living Allowance)?</p>
(49)	<p>Planning Guidance Outcome 2, Quality Premium measure: IAPT roll-out:</p> <ul style="list-style-type: none"> • Achieve 15% for CCGs below that level <p>Additional locally set improvement for those over 15% or near 15%</p>	NHS England; UNIFY	
(50)	<p>Planning Guidance Outcome 2, support measures:</p> <ul style="list-style-type: none"> • Increase dementia diagnosis rate to 67% by March 2015 <p>Achieve the IAPT recovery rate of 50%</p>	NHS England; UNIFY	
(51)	<p>Planning Guidance, 2014/15 CQUIN goals:</p> <ul style="list-style-type: none"> • Improving dementia and delirium care, including sustained improvement in Finding people with dementia, Assessing and Investigating their symptoms and Referring for support (FAIR) <p>Improving diagnosis in mental health – providers will be rewarded for better assessing and treating the mental and physical needs of their service users</p>	See http://www.england.nhs.uk/wp-content/uploads/2013/12/5yr-strat-plann-guid-wa.pdf	
(52)	Health-related quality of life measure (based on EQ-5D) for those with self-reported mental health problems and/or learning disabilities (GPPS) (sub-set of NHSOF)	GP Patient Survey	

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Indicators for specific conditions or groups of service users *continued*

Cardiovascular disease

Indicator ID	Indicator description	Data source	Other notes
(53)	Stroke patients discharged or carers given a named person to contact after discharge	SSNAP stroke clinical audit	SSNAP stroke clinical audit – Failure to provide joined up services after discharge raised as an area to improve in stroke patient audit.
(54)	Stroke patients discharged from hospital with a joint health and social care plan	SSNAP stroke clinical audit	
(55)	Stroke patients who receive a follow-up assessment 4-8 months after initial admission	SSNAP stroke clinical audit	
(56)	Referral to cardiac rehabilitation services post-discharge	National Heart Failure Audit provides national comparative data	
(57)	Return to usual place of residence following e.g. stroke, FNOF	Hospital Episode Statistics	

Cancer

Indicator ID	Indicator description	Data source	Other notes
(58)	Cancer patient survey questions	Cancer patient experience survey	<p>Q27. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?</p> <p>Q56. After leaving hospital, were you given enough care and help from health or social services (for example, district nurses, home helps or physiotherapists)?</p> <p>Q63. As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?</p> <p>Q65. Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?</p>

Other

Indicator ID	Indicator description	Data source	Other notes
(59)	Rate of increase of alcohol related hospital admissions	Hospital Episode Statistics	



Appendix C

Developing an indicator on user experience of integrated care for the NHS and Adult Social Care Outcomes Frameworks (Department of Health – January 2014)

Publication of 18 integrated care experience survey questions

On 8 January 2014, the Picker Institute and Oxford University published their report *Developing measures of people's self-reported experiences of integrated care*, commissioned by the Department of Health in May 2013. It provides 18 questions that were derived from the National Voices integrated care 'I statements'² and tested with patients, social care service users and carers.

Following advice from stakeholders through the Integrated Care Question and Indicator Development Group (ICQIDG) – the Department's reference group for this work – and the Adult Social Care Outcomes Framework Reference Group, some of these questions are being taken forward for survey-specific testing and to inform further work to develop questions for seven surveys: Community Mental Health Survey (CMHS); Personal Social Services Carers Survey; Personal Social Services Adult Social Care Survey (ASCS); GP Patient Survey; Cancer Patient Experience Survey; VOICES Bereavement Survey; and NHS Inpatient Survey. Outcome Framework indicators will then be formed from integrated care questions in these surveys.

Our ambition has always been twofold – both to develop indicators for inclusion in the Outcomes Frameworks and to support local measurement and improvement. Therefore, whilst work continues on developing national survey questions, we hope that the 18 questions that have been developed will be of use to local areas, including the integrated care pioneers, in their local experience measures. The questions are listed below with comments reflecting the advice from ICQIDG. The numbering of the questions is as used in the Picker/Oxford report.

Background

1. In January 2012 the NHS Future Forum recommended that new experience measures should be developed to evaluate people's experiences across whole journeys of care. The Government accepted the recommendation, and the Care and Support White Paper committed DH to develop a measure of people's experience of integrated care for use in the Outcomes Frameworks. A placeholder was included within both the NHS and Adult Social Care Outcomes Frameworks (ASCOF) when they were refreshed in November 2012, and we also highlighted the development of this measure in the Public Health Outcomes Framework. The ASCOF indicator became a live measure in the November 2013 refresh.
2. The Department of Health carried out its own analysis of the various approaches to measuring integrated care. In order to help determine the most appropriate and cost-effective approach, in January 2013 the Department commissioned an options appraisal for the development of new measures of integrated care from a collaboration of the Picker Institute, National Voices, King's Fund and the Nuffield Trust. They explored:
 - what integrated care means to NHS, local government, voluntary sector and regulatory organisations;
 - how integrated care can best be measured, and from whose perspective;
 - local and national data requirements;
 - the surveys and data sets already in place; and
 - the gaps and priorities for the future.

² Person centred co-ordinated care was developed in the National Voices and Think Local Act Personal (TLAP) narrative. (<http://www.england.nhs.uk/wp-content/uploads/2013/05/nv-narrative-cc.pdf>)



3. The report recommended that integrated care should be measured in a way that combines information from existing national health and social care data sets with feedback directly from patients, service users and carers. It concluded that 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.
4. Instead, the research team recommended a cost-effective and streamlined approach – developing a set of questions specifically about the focus and coordination of care, and including these in established surveys of patients, users, and carers, from which Outcome Framework indicators could be formed. They recommended using seven of the existing surveys: Community Mental Health Survey; Personal social services carers survey; Personal social services adult social care users survey; GP Patient Survey; Cancer Patient Experience Survey; VOICES Bereavement Survey; and NHS Inpatient Survey.
5. Ministers accepted this recommendation, so in May 2013 the Department of Health commissioned Picker Institute and Oxford University researchers to develop new survey questions based on the definition of integrated care provided by the National Voices' and Think Local Act Personal 'I statements'.
6. Patient, service user, and carer focus groups were conducted to review and prioritise the 'I' statements, and questions were developed based on the six domains of the 'I statements': my goals/outcomes; care planning; information; communication decision making (including budgets); and transitions. Individual interviews with people from a wide range of backgrounds and with experience of using different health and social care services were used to test and refine potential questions.
7. The Department of Health has received the report from Picker Institute and Oxford University, which includes 18 developed questions, and was published on 8 January 2014. The earlier options appraisal has also been published. Both can be found at <http://www.pickereurope.org/integrated-care>.
8. ICQIDG has been the reference group for the Picker/Oxford work, and is comprised of representatives of NHS England, Care Quality Commission, Local Government Association, Association of Directors of Adult Social Care, and the Department of Health. It considered the set of 18 developed questions, and recommended a subset to survey owners for survey-specific cognitive testing and further development. The seven survey owners are now considering their options for inserting new questions into their respective surveys.
9. Testing or piloting questions within the context of each survey takes time, as questions will only work well where they are appropriately positioned within each survey and where the need for any preamble or filter questions has been considered. Furthermore, each survey operates on a different cycle and timeline for surveying and publishing data. Therefore the earliest that we expect baseline data from a survey is December 2014, and others will take until December 2015 to provide baseline data.



The questions

Question	Carer version	'I' statement	Notes
<p>Q3.1 Have all your needs been assessed?</p> <p>1 <input type="checkbox"/> All of my needs have been assessed</p> <p>2 <input type="checkbox"/> Some of my needs have been assessed</p> <p>3 <input type="checkbox"/> None of my needs have been assessed</p> <p>4 <input type="checkbox"/> Don't know/can't remember</p>	<p>Q3.1 Have all your needs been assessed?</p> <p>1 <input type="checkbox"/> All of my needs have been assessed</p> <p>2 <input type="checkbox"/> Some of my needs have been assessed</p> <p>3 <input type="checkbox"/> None of my needs have been assessed</p> <p>4 <input type="checkbox"/> Don't know/can't remember</p>	All my needs as a person are assessed	Q3.1 is being taken forward for further testing for potential inclusion in the Inpatient Survey and ASCS
<p>Q3.2a Were you involved as much as you wanted to be in decisions about your care and support?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p>	<p>Q3.2a Were you involved as much as you wanted to be in decisions about your care and support?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p>	I am as involved in discussions and decisions about my care, support and treatment as I want to be	Q3.2a is being taken forward for further testing for potential inclusion in the Inpatient survey and ASCS, but not the Carers Survey (instead Q3.3a (carers version) will be tested)
<p>Q3.2b Were you involved as much as you wanted to be in decisions about your treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p>	The researchers did not recommend using this question in a survey of carers.	I am as involved in discussions and decisions about my care, support and treatment as I want to be	This question relates to 'treatment', so could be seen as quite health-centric. ICQIDG therefore recommended that survey owners use Q3.2a.
<p>Q3.3a Were your family or carer involved in decisions about your care and support as much as you wanted them to be?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> There were no family or carers available to be involved</p> <p>5 <input type="checkbox"/> I didn't want my family or carer to be involved in decisions about my care and support</p>	<p>Q3.3a Were you involved as much as you wanted to be in decisions about the care and support of the person you care for?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>3 <input type="checkbox"/> I didn't want to be involved in decisions about care</p>	My family or carer is also involved in these decisions as much as I want them to be	Q3.3a (carers version) has been put forward for further testing for potential inclusion in the Carers Survey
<p>Q3.3b Were your family or carer involved in decisions about your treatment as much as you wanted them to be?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> There were no family or carers available to be involved</p> <p>5 <input type="checkbox"/> I didn't want my family or carer to be involved in decisions about my treatment and support</p>	<p>Q3.3b Were you involved as much as you wanted to be in decisions about treatment of the person you care for?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>3 <input type="checkbox"/> I didn't want to be involved in decisions about treatment</p>	My family or carer is also involved in these decisions as much as I want them to be	



The questions *continued*

Question	Carer version	'I' statement	Notes
<p>Q3.4 Overall, do you feel that your carer/family has had as much support from health and social services as they needed?</p> <p>1 <input type="checkbox"/> Yes, they have had as much support as they needed</p> <p>2 <input type="checkbox"/> They have had some support but not as much as they needed</p> <p>3 <input type="checkbox"/> No, they have had little or no support</p> <p>4 <input type="checkbox"/> They did not want/need support</p> <p>5 <input type="checkbox"/> There are no family members or carers to support</p>	<p>Q3.4 Overall, do you feel that you have had as much support from health and social services as you needed?</p> <p>1 <input type="checkbox"/> Yes, I have had as much support as they needed</p> <p>2 <input type="checkbox"/> Yes, I have had some support but not as much as I needed</p> <p>3 <input type="checkbox"/> No, I have had little or no support</p> <p>4 <input type="checkbox"/> I did not want/need support</p>	<p>My carer/family have their needs recognised and are given support to care for me</p>	<p>Q3.4 is being taken forward for further testing for potential inclusion in the ASCS and the Inpatient Survey</p>
<p>Q3.5 To what extent do you agree or disagree with the following statement: <i>“Health and social care staff always tell me what will happen next”</i></p> <p>1 <input type="checkbox"/> Strongly agree</p> <p>2 <input type="checkbox"/> Agree</p> <p>3 <input type="checkbox"/> Neither agree nor disagree</p> <p>4 <input type="checkbox"/> Disagree</p> <p>5 <input type="checkbox"/> Strongly disagree</p>	<p>Q3.5 To what extent do you agree or disagree with the following statement: <i>“Health and social care staff always tell me what will happen next”</i></p> <p>1 <input type="checkbox"/> Strongly agree</p> <p>2 <input type="checkbox"/> Agree</p> <p>3 <input type="checkbox"/> Neither agree nor disagree</p> <p>4 <input type="checkbox"/> Disagree</p> <p>5 <input type="checkbox"/> Strongly disagree</p>	<p>I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact</p>	<p>This question has been put forward for further testing for potential inclusion in the ASCS, Carers Survey and CMHS.*</p> <p>Responding to concerns raised over the notion of health and social care staff <i>telling</i> people what will happen next, ICQIDG has recommended that a variant should be tested as well or instead of Q3.5:</p> <p>“Q3.5a To what extent do you agree or disagree with the following statement: <i>“Health and social care staff always ensure I know what will happen next”</i></p> <p>1 <input type="checkbox"/> Strongly agree</p> <p>2 <input type="checkbox"/> Agree</p> <p>3 <input type="checkbox"/> Neither agree nor disagree</p> <p>4 <input type="checkbox"/> Disagree</p> <p>5 <input type="checkbox"/> Strongly disagree”</p> <p>The variant of Q3.5 is being tested for the ASCS, Carers Survey, CMHS and Inpatient Survey.*</p>

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The questions *continued*

Question	Carer version	'I' statement	Notes
<p>Q3.6 When health or social care staff plan care or treatment for you, does it happen?</p> <p>1 <input type="checkbox"/> Yes, it happens all of the time 2 <input type="checkbox"/> It happens most of the time 3 <input type="checkbox"/> It happens some of the time 4 <input type="checkbox"/> No</p>	<p>Q3.6 Thinking about the person you care for, when health or social care staff plan care or treatment for them does it happen?</p> <p>1 <input type="checkbox"/> Yes, it happens all of the time 2 <input type="checkbox"/> It happens most of the time 3 <input type="checkbox"/> It happens some of the time 4 <input type="checkbox"/> No</p>	When something is planned, it happens	This question has been put forward for further testing for potential inclusion in the Carers Survey
<p>Q3.7a To what extent do you agree or disagree with the following statement: <i>“My care and support is reviewed as often as it should be”</i></p> <p>1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree</p>	<p>Q3.7a Thinking about the person you care for, to what extent do you agree or disagree with the following statement: <i>“Their care and support is reviewed as often as it should be”</i></p> <p>1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree</p>	I have regular reviews of my care and treatment, and of my care and support plan	The carers version of this question has been put forward for further testing for potential inclusion in the Carers Survey
<p>Q3.7b To what extent do you agree or disagree with the following statement: <i>“My treatment is reviewed as often as it should be”</i></p> <p>1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree</p>	<p>Q3.7b Thinking about the person you care for, to what extent do you agree or disagree with the following statement: <i>“Their treatment is reviewed as often as it should be”</i></p> <p>1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree</p>	I have regular reviews of my care and treatment, and of my care and support plan	
<p>Q3.8 To what extent do you agree or disagree with the following statement: <i>“My medicines are thoroughly reviewed as often as they should be”</i></p> <p>1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree</p>	<p>Q3.8 Thinking about the person you care for, to what extent do you agree or disagree with the following statement: <i>“Their medicines are thoroughly reviewed as often as they should be”</i></p> <p>1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree</p>	I have regular, comprehensive reviews of my medicines	



The questions *continued*

Question	Carer version	'I' statement	Notes
<p>Q3.9 Do you have a named health or social care professional who co-ordinates your care and support?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No, I co-ordinate my own care and support</p> <p>3 <input type="checkbox"/> Don't know/not sure</p>	<p>Q3.9 Do you have a named health or social care professional who co-ordinates your care and support?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No, I co-ordinate my own care and support</p> <p>3 <input type="checkbox"/> Don't know/not sure</p>	<p>I always know who is co-ordinating my care</p>	<p>Q3.9 is being taken forward for the Inpatient Survey and for further testing for potential inclusion in the ASCS, where the following additional answers will be included as Q3.9a:</p> <p>No – I need and/or would like someone to coordinate my care and support</p> <p>No – I don't have multiple needs so my care and support does not need co-ordinating</p> <p>No – For other reasons</p>
<p>Q3.12 If you have questions, when can you contact the people treating and caring for you? Please tick ALL that apply</p> <p>1 <input type="checkbox"/> During normal working hours</p> <p>2 <input type="checkbox"/> During the evening</p> <p>3 <input type="checkbox"/> During the night</p> <p>4 <input type="checkbox"/> Weekends</p> <p>5 <input type="checkbox"/> Don't know/not sure</p>	<p>Q3.12 If you have questions, when can you contact the people treating and caring for the person you care for? Please tick ALL that apply</p> <p>1 <input type="checkbox"/> During normal working hours</p> <p>2 <input type="checkbox"/> During the evening</p> <p>3 <input type="checkbox"/> During the night</p> <p>4 <input type="checkbox"/> Weekends</p> <p>5 <input type="checkbox"/> Don't know/not sure</p>	<p>I have one first point of contact. They understand both me and my condition(s). I can go to them with questions at any time.</p>	
<p>Q3.13 Do you feel this person understands about you and your condition?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p>	<p>Q3.13 Do you feel this person understands about the person you care for and their condition?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p>	<p>I have one first point of contact. They understand both me and my condition(s). I can go to them with questions at any time.</p>	
<p>Q3.14 Do all the different people treating and caring for you work well together to give you the best possible care and support?</p> <p>1 <input type="checkbox"/> Yes, all of them work well together</p> <p>2 <input type="checkbox"/> Most of them work well together</p> <p>3 <input type="checkbox"/> Some of them work well together</p> <p>4 <input type="checkbox"/> No, they do not work well together</p> <p>5 <input type="checkbox"/> Don't know/not sure</p>	<p>Q3.14 Thinking about the person you care for, do all the different people treating and caring for them work well together to give the best possible care and support?</p> <p>1 <input type="checkbox"/> Yes, all of them work well together</p> <p>2 <input type="checkbox"/> Most of them work well together</p> <p>3 <input type="checkbox"/> Some of them work well together</p> <p>4 <input type="checkbox"/> No, they do not work well together</p> <p>5 <input type="checkbox"/> Don't know/not sure</p>	<p>The professionals involved with my care talk to each other. We all work as a team.</p>	<p>Q3.14 (carers version) has been put forward for further testing for potential inclusion in the CMHS, Inpatient Survey, ASCS and Carers Survey*</p>

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The questions *continued*

Question	Carer version	'I' statement	Notes
<p>Q3.15 Do health and social care services help you live the life you want as far as possible? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No</p>	<p>Q3.15 Do health and social care services help you live the life you want as far as possible? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No</p>	<p>Taken together, my care and support help me live the life I want to the best of my ability</p>	<p>Q3.15 is being taken forward for further testing for potential inclusion in the ASCS and Inpatient Survey</p>
<p>Q3.17 To what extent do you agree or disagree with the following statement: <i>"In the last 12 months, health and social care staff have given me information about other services that are available to someone in my circumstances, including support organisations"</i> 1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree</p>	<p>Q3.17 To what extent do you agree or disagree with the following statement: <i>"In the last 12 months, health and social care staff have given me information about other services that are available to someone in my circumstances, including support organisations"</i> 1 <input type="checkbox"/> Strongly agree 2 <input type="checkbox"/> Agree 3 <input type="checkbox"/> Neither agree nor disagree 4 <input type="checkbox"/> Disagree 5 <input type="checkbox"/> Strongly disagree</p>	<p>I am told about the other services that are available to someone in my circumstances, including support organisations.</p>	<p>This question has been put forward for further testing for potential inclusion in the Carers Survey</p>

* Cognitive testing of Q3.5, Q3.5a and Q3.14 for use in the CMHS found that the cohort did not fully understand that they were being asked about their experience of a range of health and social care services, including services for both mental and physical health. The questions have therefore not been included in the 2013/14 survey; further work is planned for the 2014/15 survey in order to ensure that if included the questions are framed so as to collect the intended inform.

The Policy Innovation Research Unit (PIRU) brings together leading health and social care expertise to improve evidence-based policy-making and its implementation across the National Health Service, social care and public health.

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Policy Innovation Research Unit

Department of Health Services Research & Policy
London School of Hygiene & Tropical Medicine
15–17 Tavistock Place, London WC1H 9SH

Tel: +44 (0)20 7927 2784
www.piru.ac.uk