



○ Developing measures of people's self-reported experiences of integrated care

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This report describes findings from qualitative research with patients, service users, and carers who volunteered to give their feedback about their experiences and helped us test questions looking at aspects of integrated or co-ordinated care. We are grateful to them for their time and for the thoughtful, informative discussions they took part in. Thanks are also given to the organisations who helped us recruit volunteers.

1 EXECUTIVE SUMMARY

1.1 Context

The Department of Health commissioned the Picker Institute and the University of Oxford to develop new questions to measure people's experiences of integrated care. The aim of the project was to provide recommendations for a limited set of new questions to be included in up to seven existing national surveys:

- GP Patient Survey.
- NHS Inpatients Survey.
- VOICES national bereavement survey.
- Community Mental Health survey.
- National Cancer survey.
- Personal social services carers survey.
- Personal social services adult social care survey.

The work was carried out in five phases, which are detailed below. In all cases, we have looked at integrated care as defined in the 'narrative for person-centred co-ordinated care'¹. The domains and "I" statements" (developed by National Voices & Think Local Act Personal (TLAP)) accompanying the narrative have been used to investigate components of integrated care. Specifically, we follow the narrative's position that integrated care should impose the perspective of users as its organising principle (c.f. Lloyd and Wait, 2005). This stands in contrast to 'service integration' models and means that we focus on the user's understanding of "person centred co-ordinated care" rather than looking at interactions between or across specific services, such as health and social care.

1.2 Evidence review

The first stage of the project comprised a review of evidence to identify any gaps in the "I statements". This work took an iterative and pragmatic approach to identify relevant articles from academic journals, policy and research papers and grey literature. The review noted some gaps in the evidence-base: there was limited focus outside of secondary care settings, and some international health economies – eg the Netherlands – were overrepresented. Nevertheless, the evidence found provided support for the narrative's domains, and the "I statements" were found to be reflected in a number of publications. Three specific constructs not explicitly identified in the "I statements" were also noted: *self-management support*, *access to care and information*, and *monitoring and responding to change*.

¹A Narrative for Person-Centred Coordinated Care (National Voices, 2013), available online at: <http://www.england.nhs.uk/wp-content/uploads/2013/05/nv-narrative-cc.pdf>

1.3 Focus groups

Four focus groups were conducted, involving more than 20 people from a range of backgrounds. Participants were typically supportive of the narrative's "I" statements" and were able to identify the elements of integrated care that were most important to them from within these. Moreover, there were clear themes in some of the elements of integrated care that were given the highest priority by participants.

Three particular statements (A4, C4, and C6) were chosen more frequently than others, but it should be noted that the focus groups do not provide a quantitative evaluation of the relative importance of different statements. More detailed analysis suggested a number of themes that seemed particularly important, with 19 "I" statements" linked to these.

1.4 Desk review of existing survey questions & survey architecture

Eighteen existing survey instruments and collections were reviewed to identify items relevant to the 19 priority "I" statements" identified from the focus groups. Relevant questions were mapped back to specific "I" statements" and questions unsuitable for use (eg because they were excessively complex, or only distally related to key concepts) were identified and removed. A number of new questions were developed and a short list of recommended questions provided to stakeholders.

In parallel to the abovementioned desk review, the content and approach of the seven existing national surveys was reviewed. This identified two key recommendations: that new items should be as broadly applicable as possible, and that items should be reviewed prior to testing to avoid conflicts in the framing of items in different surveys.

1.5 Owners workshop

The initial shortlist of items developed was presented to stakeholders such as the Care Quality Commission, Department of Health and NHS England. Feedback was sought on coverage and wording of questions with the comments from stakeholders considered before the question set was further refined to a testable set of fewer than twenty survey items.

1.6 Cognitive testing

Cognitive interviews were carried out with 59 participants to test and refine the questions developed in the earlier phases of work. Interviews focussed on participants' comprehension, interpretation, evaluation and response to questions.

Cognitive interviewing revealed a varied level of question appropriateness across the question set. Two questions required no alteration between rounds:

- Do you know who to contact if you need to ask questions about your condition or treatment?
- Do you feel this person understands about you and your condition?

A number of questions required changes to answer text only such as:

- 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?

- Have all your needs been assessed?

Others required substantial changes to question text and answer options such as:

- To what extent do you agree or disagree with the following statement...‘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’

A number of questions were revised for use with carers (to ensure that they covered issues relevant to the ‘person cared for’ rather than the carer), however no differences in question performance between other cohorts (such as mental health service users and those with long term conditions) were found.

1.7 Final question set

The final question set (18 questions) as a result of cognitive testing can be seen in section 8.

A number of these items are considered to be usable for national indicator purposes. The research team acknowledge some flexibility around the specific choice of items that should be used, but recommend minimising the number of questions to ease the process of integrating them into existing surveys.

Ideally the addition of a few of these questions in national surveys will help providers and commissioners to identify, explore, and challenge poorly integrated care locally.

2 INTRODUCTION

2.1 Aims

The aim for this research was the development of a set of questions which could be used in existing vehicles to measure people's experiences of integrated care in health and social care.

2.2 Background

This research builds on previous work by The King's Fund, National Voices, the Nuffield Trust, and the Picker Institute where an options appraisal on the measurement of people's experiences of integrated care was carried out. This study concluded that:

- No single indicator was currently suitable for measuring user experience of integrated care.
- Existing interim measures, whilst useful for immediate quality improvement, are not suitable for longer term use. This is partly because they do not cover a sufficient range of care services, but also as they do not adequately address the concept of "person-centred co-ordinated care".
- Development of a new survey specifically to cover integrated care would not offer value for money, and there were significant barriers associated with more novel potential approaches (such as incorporation of questions into the friends and family test, or the use of data from social media).

One recommendation made by the multi-organisational team was to add a small set of questions on integrated care to a range of existing national survey collections: this was seen as being more timely and cost-effective than bespoke development of a new survey.

And so the aim of this research is the rapid development of a core set of new questions for inclusion in existing survey collections.

2.2.1 Definition of integrated care

As set out in the specification provided by the Department of Health the definition of integrated care adopted in this work is 'person-centred co-ordinated care'. This is based upon the definition given in 'A narrative for person-centred co-ordinated ('integrated') care' by National Voices.

The concept of "person-centred co-ordinated care" is irreducibly complex: it is a singular construct and should not be seen as simply the combination of "person-centred care" and "co-ordinated care" as distinct entities. Whilst this may appear semantic, it is an important point: process and outcome measures designed to assess the quality of integrated care from the user perspective must be mindful of this distinction.

The definition has been developed by users and has the support of key national stakeholders. It focuses on what is important from a user perspective: namely, care that

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”.

The service user statements, termed as “‘I’ statements”, seen in the narrative are based upon the experience of patients, service users, carers, and their representative charities. The statements were initially drawn from consultations with patient organisations and experience indicators: following this they were tested and revised as a result of workshops system leaders, patients, service-users and patient organisations. Further details of the development of the ‘narrative for person-centred co-ordinated care’ can be found in Redding (2013)².

The “‘I’ statements” are grouped into topic headings such as ‘communication’ and ‘shared decisions’. It is these “‘I’ statements”, as seen in Appendix A, that have been used to investigate components of integrated care in this research.

Specifically, we follow the narrative’s position that integrated care should impose the perspective of users as its organising principle (c.f. Lloyd and Wait, 2005). This stands in contrast to ‘service integration’ models and means that we focus on the user’s understanding of “person centred co-ordinated care” rather than looking at interactions between or across specific services, such as health and social care.

2.3 Methods

To meet the objective of developing new measures of people’s experiences of integrated care a five phase approach was adopted:

- Phase 1: Evidence review, focussing on literature describing key domains of integrated care.
- Phase 2: Qualitative research – focus groups. The groups involved a discussion about the nature of integrated care as well as exercises to get user views on the relative importance of different aspects of integrated care.
- Phase 3: Desk review of existing surveys and drafting of questions for testing. The desk review helped identify any additional considerations to inform question development.
- Phase 4: Owners workshop. This was attended by representatives from national survey owners. This helped highlight issues with the developed questions before cognitive testing.
- Phase 5: Cognitive testing. Three rounds of testing were carried out with patients, service-users and carers resulting in a set of recommendations for questions which could be used in existing vehicles being made.

Each of these phases are detailed in this report.

² Redding, D. (2013). The narrative for person-centred coordinated care. *Journal of Integrated Care*, 21(6), 315-325.

3 PHASE 1: EVIDENCE REVIEW

3.1 Aims

The phase 1 evidence review focused on literature describing key domains of integrated care and any information on prioritising these from the user's perspective. The overall aim was to identify any gaps in the "I' statements" developed by National Voices & Think Local Act Personal (TLAP) (2013).

3.2 Methods

The review was iterative and pragmatic in its approach to identifying relevant literature. Several sources and resources were accessed; references were checked and accessed where relevant. Specific literature in relation to conceptual frameworks and patient generated domains considered important for good integrated/co-ordinated care was utilised. The primary aim was to provide supportive evidence for the generic statements and more specific "I' statements". This sought to ascertain whether the statements provided a comprehensive picture of good integrated care as described in other research, but was pragmatic and sought to avoid duplicating the development process that informed the "I' statements". Attempts were made to identify literature that provided additional patient perspectives of integrated care that were not captured by the "I' statements" but that were more important for specific cohorts, including:

- Older people (aged 66 years and above).
- People with a long-term physical condition.
- People with a long term mental condition.
- Adult social care users.
- Carers.

Articles were considered relevant if they:

- a) Described components/domains of integrated/co-ordinated care from a patient/carers perspective.
- b) Evaluated integrated care programmes using patient perspectives.
- c) Provided evidence of patient experiences of integrated care.
- d) Were published from 2000 onwards.
- e) Were published in the English language.
- f) Gave reference to specific cohorts as mentioned above.
- g) Described the development of measures of quality of integrated care

UK based literature was preferred but some studies were included from non-UK contexts if they provided illustrative evidence.

3.1 Results

The following types of literature were retrieved:

- Charity/organisational reports.
- Systematic reviews.
- Conceptual papers.
- Primary research reporting survey results or qualitative interviews of patient experiences with integrated care.

PubMed was searched using broad terminology- “integrated care” OR “co-ordinated care”. The Journal of Integrated Care and International Journal of Integrated Care were accessed to identify relevant literature. Over 2000 articles were identified from the search. It was not within the scope or timelines of this review to adopt a systematic, exhaustive approach; therefore the most relevant and recent publications were included using the criteria detailed above.

The literature is presented under the following headings:

- Existing frameworks.
- UK perspectives of integrated care.
- International perspectives.
- Measurement of integrated/co-ordinated care.

The “I’ Statements” generated from patients (National Voices & Think Local Act Personal., 2013) are supported by the National Collaboration for Integrated Care and Support (May 2013). This makes specific reference to these statements forming the basis of future measurement of integrated care (whilst recommending that in the short term localities could use the Department of Health Interim solutions (2012)).

The “I’ statements” are grouped into the following broad domains (National Voices, 2013):

- My goals/outcomes.
- Care planning.
- Information.
- Communication.
- Decision making (including budgets).
- Transitions.

The full “I’ statements” are detailed in Appendix A. Generally, we found that the literature supports the generic and specific “I’ statements” in each domain. However, for some generic domains, the literature supported some additional specific items (see conclusions).

3.2 Existing frameworks

Several conceptual frameworks have been published; most are derived from other frameworks or defined components of integrated services. Very little evidence is derived from patient's narratives. McDonald et al. (2010) developed a conceptual framework for the measurement of co-ordinated care based on a review of published frameworks and measures. Recommendations of measures for each domain are compiled in a comprehensive atlas. Recommendations are for the measurement of patient, healthcare professionals' and service managers' perspectives. Domains for patients include:

- Communication - interpersonal and information transfer.
- Transitions, both between healthcare professionals and across settings.
- Assessment of needs and goals.
- Care planning.
- Monitoring and responding to change.
- Supporting self-management goals.
- Linking to community resources.

Several overviews of different models of integrated care have been published with some reference to essential elements which are relevant to patients for positive outcomes and experience and for service improvement and development (Minkman, 2012). One important component frequently cited is 'case-management'. Furthermore, Minkman refers to self-management support, and care pathways as important dimensions.

Systematic reviews of outcomes of different integrated care programmes for specific conditions report the following components of integrated care programmes: self-management support and education; clinical follow-up and case-management (Ouwens, 2005).

A systematic review of integrated care interventions and effects for patients with cancer (Ouwens et al., 2009) reported from n=33 studies (13 from the UK) that information, use of decision aids, recordings of consultation, follow-up, and case management had a positive effect on health outcomes and satisfaction with care.

Continuity of care is frequently cited as an important component of integrated care. A large volume of literature was identified which referred specifically to this dimension: two illustrative examples are provided here.

- Freeman et al, (2000) - '*Continuity of care: report of a scoping exercise and subsequent research*' identifies the following dimensions of continuity- information, cross-boundary, team, flexible, longitudinal, and relational-personal. However, these are primarily from professionals' perspectives and are not based on patients' priorities of what is important to them. Continuity of care does not capture all aspects of integrated and co-ordinated care.

- Uijen et al. (2012) conducted a systematic review of measures for continuity of care. Four questionnaires are recommended but developed in Canada and European contexts and focus primarily on the patient-provider relational aspects of care.

Smith & Ross, (2007) conducted a systematic review to ascertain how patients' experiences have been used in the development of integrated care pathways in the UK for cataract care, hip replacement and knee arthroscopy. Whilst these conditions and Integrated Care Pathways are specific to secondary care, the underlying principles are transferable: assessment of patients individual needs, continuity, information, and patient support.

A systematic review to identify attributes of definitions of co-ordinated care and concepts underpinning conceptual definitions (Ehrlich et al., 2009) was found. This review focused on different aspects of co-ordinated care from a service perspective (processes and systems) as well as client level. Person-centred care was reported as fundamental to co-ordinated care delivery with reference to:

- Assessment of patients' needs, goals, & perspectives, ensuring patients had control over their care.
- Self-management and self-efficacy support.
- Care planning, monitoring and review.
- Information, education, and communication.

A comprehensive review of '*Factors that promote and hinder joint and integrated working between health and social care services*' (Cameron et al., 2012) reported that services users value:

- Assessment, review and responsiveness to their needs.
- Relationships and partnerships with named key workers.
- Communication between agencies.
- Information about complex systems.
- Maintenance of independence.
- Care planning.

The review above highlights that what matters to patients and carers may differ from the priorities of service providers and national policy. Patients and carers are less interested in the configuration of services but more how their own needs are addressed: specifically for carers as providers of care but also service users (Cameron et al., 2012).

Most of the publications identified report evaluations of pilots or integrated care programmes using a pre-defined measurement model or survey. Limited published evidence is found regarding patient perspectives.

3.3 UK perspectives of integrated care

National Evaluation of the Department of Health's Integrated Care Pilots (2012, RAND) included one round of patient interviews (n=82) and patient surveys in two rounds at the 11 pilot sites (n=1,650 and n=1,231). The survey was developed for the evaluation and underwent cognitive testing; some items were taken from the GP national survey. Survey domains included:

- Self-efficacy.
- Organisation and co-ordination of care.
- Care planning.
- Communication with doctors/nurses.
- Seeing the same person.
- Involvement in decisions.
- Information about their condition.
- Assessment of care from social services.
- Arrangements following discharge.

Survey results and thematic analysis from interviews evaluating the pilots were generally positive for care planning and better co-ordination of care following discharge but there was less continuity of care, poor communication and less involvement in decisions. These aspects were considered most important to patients.

Pappas et al. (2013) report on the evaluation of North West London national pilot- *Understanding patient and provider experience and communication*. Interviews with patients focused on their views of ideal care, and themes from narratives included: communication, continuity (especially in relation to one person dealing with their care), and clear pathways. Patients in the pilot were older people and those with diabetes.

Tucker & Burgis (2012) report an evaluation of the Norfolk national pilot of integrated care - 'Integrating Care in Norfolk'. This was one of 16 pilot sites in the national programme and focused on providing integrated care for vulnerable older adults. Improvements to integrating services were driven by 'patient pledges' (priorities). Discussions with patient representatives elicited six priorities:

- I want my GP to be the focus of my care.
- I want my care to be better co-ordinated.
- I want fewer repeat assessments.
- I want my care to be local.
- I want a person to be my key worker.
- I want clear and easy to use information.

These statements formed the focus of evaluation of the pilot. These principles continue to provide a framework for service redesign locally.

The Cancer Campaigning Group (2012) conducted a survey of n=358 patients and carers with cancer to understand what 'integrated care' means to patients and what matters. They found that timely treatment, better communication, joined up working, written information, continuity of care, and involvement in decision making were considered important to patients. However, there was a lack of understanding about what integrated care was, and 58% of survey's respondents felt that 'integrated care' was not "the clearest term to describe the co-ordination of care across different care settings" (p4).

The Cancer Campaigning Group presented 19 areas for improvement to patients and they were asked to rank the top five in order of preference. The top five were:

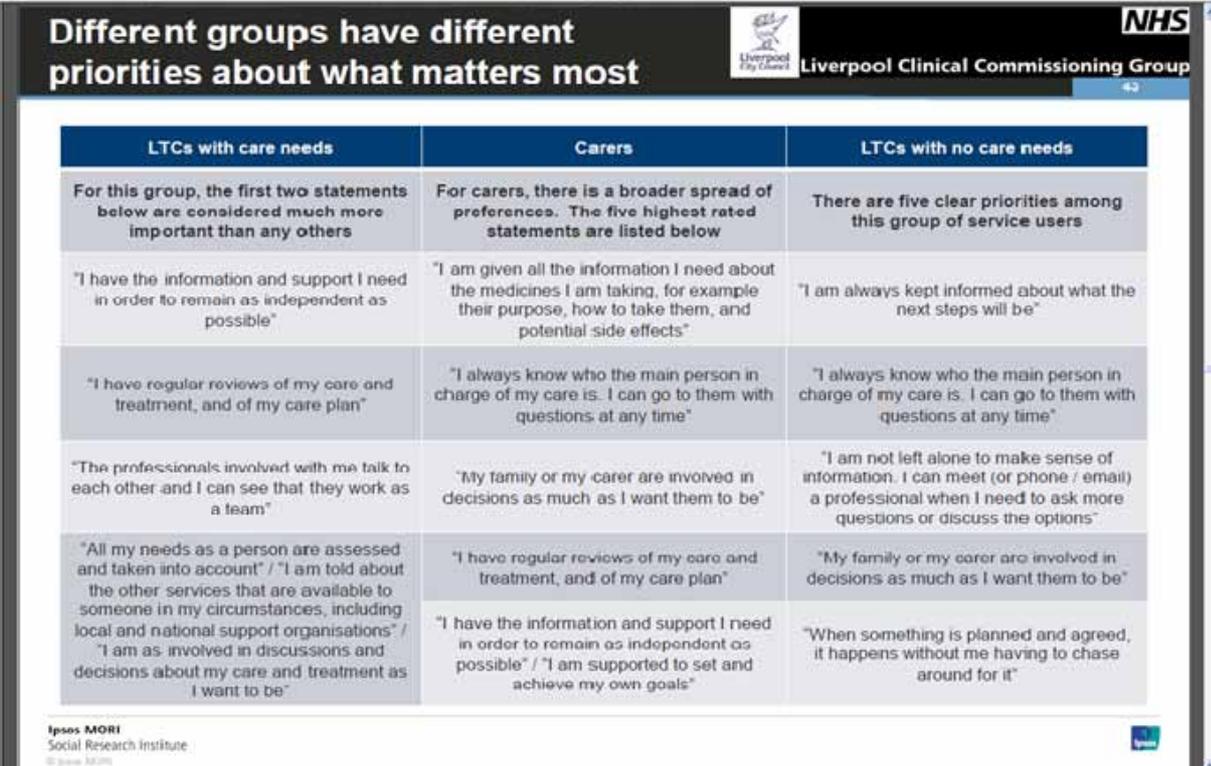
1. Quicker referral from GP to hospital for testing and diagnosis.
2. Finding out the results of tests quicker.
3. Having access to a named cancer nurse specialist or other 'key worker' throughout the pathway.
4. Feeling involved in key decisions about treatment and care.
5. Having records and test results available to all clinicians and staff involved in care.

Other themes from qualitative statements related to more information needed: people wanted written information about their condition, copies of correspondence, information about different services (including financial and social services and charities), and to be listened to. In their recommendations for improving integrated care, the Group advocated systematic use of the Department of Health's *Interim measures for patient experience at the interfaces between NHS services and the National Cancer Patient Experience Survey*.

Beech et al. (2013) evaluated older patients' and carers' experiences of 'closer to home' care following a health crisis, mapping their 'journey'. Experiences were sought within and across organisations (health and social care). Patients reported several challenges and key components of care that were important to them: information and signposting to other services; transition arrangements following discharge from hospital; lack of communication between professionals across organisations. Carers wanted to be included in discharge arrangements.

Liverpool Public Health insight team commissioned Ipsos MORI (on behalf of Liverpool Clinical Commissioning Group) to conduct research with users, carers and professionals about actions and insights into integrated care for service planning and improvement. Interviews with participants, specifically users of services and carers explored their experiences of services and identified what worked well and difficulties they experienced. The National Voices "I" statements" (Image 1) were ranked in order of priority for people with LTCs with no needs, those with care needs and for carers. The two most important "I" statements" were "*having the information and support they need to remain as independent as possible*" and "*family being involved in care plans and reviews*".

Image 1: Different groups have different priorities about what matters most (p43).



LTCs with care needs	Carers	LTCs with no care needs
For this group, the first two statements below are considered much more important than any others	For carers, there is a broader spread of preferences. The five highest rated statements are listed below	There are five clear priorities among this group of service users
"I have the information and support I need in order to remain as independent as possible"	"I am given all the information I need about the medicines I am taking, for example their purpose, how to take them, and potential side effects"	"I am always kept informed about what the next steps will be"
"I have regular reviews of my care and treatment, and of my care plan"	"I always know who the main person in charge of my care is. I can go to them with questions at any time"	"I always know who the main person in charge of my care is. I can go to them with questions at any time"
"The professionals involved with me talk to each other and I can see that they work as a team"	"My family or my carer are involved in decisions as much as I want them to be"	"I am not left alone to make sense of information. I can meet (or phone / email) a professional when I need to ask more questions or discuss the options"
"All my needs as a person are assessed and taken into account" / "I am told about the other services that are available to someone in my circumstances, including local and national support organisations" / "I am as involved in discussions and decisions about my care and treatment as I want to be"	"I have regular reviews of my care and treatment, and of my care plan" "I have the information and support I need in order to remain as independent as possible" / "I am supported to set and achieve my own goals"	"My family or my carer are involved in decisions as much as I want them to be" "When something is planned and agreed, it happens without me having to chase around for it"

perceptions of integrated care, applying the Singer (2011) conceptual model of integrated care. The findings support the framework proposed by Singer, but cross cutting themes include communication, information, care planning and patient centred care including responsiveness to preferences and needs.

Toscan et al. (2012) interviewed older people treated for hip fractures, informal caregivers, and healthcare providers in Canada to identify factors which were barriers to integrated care and transition between different settings. The main factors related to confusion with communication about care; unclear roles and responsibilities with patients experiencing a lack of involvement in decision making; diluted personal ownership over care-disengagement with self-management and loss of autonomy; and role strain due to system constraints.

A Dutch study by van Eijk-Hustings (2013) explored patient's needs and expectations of rheumatology nursing care during focus groups. The main themes related to communication, self-management support, emotional support and well-organised care.

Care systems may not be the same for these healthcare contexts as the NHS but these are common themes reported across countries.

3.5 Self-reported measures of co-ordinated/integrated care

Several resources are available for selection of patient-reported measures of co-ordinated/integrated care.

The US Agency for Research in Health and Quality compiled an 'Atlas' of indicators on co-ordinated care in 2010 from *patient and family perspective, healthcare professionals and system representative (organisational)*. The Atlas provides definitions, measurement framework and a comprehensive list of measures for specific purposes and contexts – eg generic co-ordination surveys, disease/care pathways of care, and so on. These will be referred to in the next phase of this project. The conceptual framework for measurement includes:

- Assess needs and goals.
- Respond to changes and monitor.
- Self-management goals.
- Care planning.
- Communication, interpersonal and information transfer.
- Link to community services.
- Facilitate transitions.

The Centre for Health Care Strategies (CHCS) (2006) provides a comprehensive profile of measures to evaluate performance of integrated care programmes (Medicaid and Medicare-US). CHCS conducted a workshop including people using these services with wide range of needs (general populations, older adults, chronic diseases, learning disabilities and mental health problems). Stakeholders attended the workshop and, based on discussions, selected five priority domains. They then identified measures that could be recommended within the domains. The domains are: functional status, care co-ordination, care transitions, behavioural health, and safety/nursing home. Several surveys are recommended.

Several integrated care programmes, mainly pathways of care in secondary settings or specific conditions have been evaluated from the patient perspective using newly developed or known patient reported questionnaires. Some have been specifically developed to measure co-ordinated/integrated care – eg. the '*Client Perceptions of Co-ordination Questionnaire*' (McGuiness & Sibthorpe. 2003) and the '*Patient Perceptions of Integrated Care survey*' (Singer et al., 2012). These however have been developed from items from existing patient experience surveys or surveys of chronic disease management (eg. Patient Assessment of Chronic-illness Care - Cramm et al., 2012). These questionnaires will be reviewed for content validity in the next phase of work for this project, which will involve the identification of candidate items.

3.6 Conclusions

This review provides further support of the “I” statement” domains (National Voices, 2013):

- My goals/outcomes.
 - Care planning.
 - Information.
 - Communication.
-

- Decision making (including budgets).
- Transitions.

Within the domains, specific statements are echoed in research presented in this report. Some of the research outlined in this review make reference to the cohorts included in the present study. However, coverage is lacking: many of the publications focus on specific secondary care interventions in hospital, and some international settings – such as the Netherlands – are disproportionately represented.

Conceptual clarity and definitions of components varies across publications. The “I’ statements” are useful in that they describe articulately what patients want from services in their own language. The research evidence is not so explicit and mainly refers to generic domains and components. One exception is the Norfolk integrated care pilot, where patient priorities included:

- I want my GP to be the focus of my care.
- I want my care to be better co-ordinated.
- I want fewer repeat assessments.
- I want my care to be local.
- I want a person to be my key worker.
- I want clear and easy to use information.

Three other constructs referred to in the literature but not explicit in the “I’ statements” relate to:

- **Self-management support.** The “I’ statements” do refer to personal goals and assessment of needs but not specifically to self-management of conditions. However, this may be a consequence rather than an essential ingredient of integrated care.
- **Access to care and information.** This was specific to cancer patients and the CCG evaluation: patients wanted quicker referral and test results.
- **Monitoring and responding to change.** The “I’ statements” do refer to regular reviews but the research evidence is more explicit.

4 PHASE 2: QUALITATIVE RESEARCH: FOCUS GROUPS

4.1 Aims

The aims of the focus groups were to gather patients' perspectives on the different components of integrated care and their relative importance. The framework for discussion was informed in principle by the National Voices "I" statements" and findings from the evidence review in phase one of this study.

4.2 Methods

Four focus groups were held with participants recruited from local media advertising in Oxfordshire and via the National Voices website. A researcher contacted all those who expressed an interest in the discussion groups to assess eligibility. The aim was to ensure a mix of people of different ages, backgrounds, long term physical and mental health conditions, and experiences with social services either as a carer or adult social care user.

Two groups comprised participants with physical health problems (n=6 and n=7); some participants in these groups also had mental health conditions. Two other groups were for participants with mental health conditions (n=3) and a group of carers (n=9). Across the groups almost all participants had some interaction with social care either for themselves or for the person they cared for. There were difficulties recruiting participants with mental health problems during the first recruitment phase. Contact was made with a local mental health charity to identify service-users for focus groups, but they were unable to help on this occasion.

Participants' ages ranged from 21 to 85. Three (11%) were in the 18-24 age group; six (22%) were over 65 years.

Most of the participants didn't have just one health condition but several interrelated or separate comorbidities. Most had experience of a broad range of health and social care services, in some cases including services provided by the private sector. Some also had experience of voluntary sector services. Some of the carers who participated had experiences of health and social care for children with learning disabilities, and their experiences of services included education.

Participants were provided with information sheets, their consent was obtained, and payment of £60 was provided to cover time and expenses.

A pre-defined interview schedule was used to guide discussion and keep to task. An expert facilitator led the discussion and a member of the research group attended taking notes, assisting and engaging in discussion.

In summary, participants were invited to describe their experiences of health and social care with specific reference to 'integrated care' or 'care co-ordination'. They were encouraged to elaborate on components of care that were important to them, either based on good or bad experience.

Participants were then shown the “I’ statements” and invited to comment on them – first generally but then more specifically. The order of presentation of “I’ statements” was rotated for each group to counterbalance for any potential order effects (eg. participants favouring statements presented earlier in the list). They were given time to read through the statements and then invited to choose the five most important statements that reflected what they expected of good integration. A ‘card sort’ methodology was used to enable participants to prioritise “I’ statements”. Each member then explained why they had chosen each statement. The final prioritising exercise was to choose two from the five that were the most important.

Finally, participants were asked if there were any components of care that were not captured by the statements. This provided an informal evaluation of the content validity of the “I’ statements”, and was intended to identify any omissions that would need to be addressed in later stages of this project.

“I’ statements” chosen by participants were accumulated per group and across the groups.

The following sub-sections (4.3~4.6) provide detailed findings from each of the four focus groups conducted. For the overall summary of the focus groups, including the prioritised “I’ statements”, please see page 44.

4.3 Results: Focus group 1: Long-term physical health conditions.

Table 1 outlines participants recruited for this group, of whom six attended (three female, three male). Ages ranged from 34 to 59 (the two participants who failed to attend were aged 26 and 84). All participants were white, British and all had complex health conditions, with the exception of one who had been a formal carer for both parents. Health conditions included endocrine disorders, endometriosis, ulcerative colitis, asthma, spinal problems, arthritis, previous neurological surgery and epilepsy, osteoporosis, and chronic fatigue syndrome (Myalgic Encephalopathy). One participant (Male, aged 44) had experienced a very aggressive form of cancer and had subsequent mobility problems. He had spent one year in hospital and since been at home with little support.

Some had experienced mental health services - psychological therapies – and all had either experienced social care or knew somebody who had.

Table 1: Participant information

Participant	Gender	Age	Long term condition(s)	Social care
1	Female	47	ME, ulcerative colitis, endometriosis, some carer experience	y
2	Female	50	Complex physical conditions	y
3	Female	59	Carer	y
4	Male	34	Type 1 diabetes, hypothyroidism, carer experience	
5	Male	44	Cancer	y
6	Male	48	Asthma, spinal problems	
Did not arrive	Female	26	Chronic fatigue/ME	
Did not arrive	Female	84	Arthritis	y

4.3.1 Themes

The following main concerns were raised during initial discussions about participants’ experiences of integrated/co-ordinated care. These are presented in order of importance to participants based on frequency and impact.

4.3.1.1 Communication and co-ordination

There was general agreement that communication between healthcare professionals and across services, including social care, was very poor. Most of the participants perceived that they were ‘secretaries’ or ‘clerks’ and responsible for co-ordinating their own health and social care; acting as a ‘go between’. Co-ordination of their care was limited and in some cases it was not clear who should be doing this. It was felt that co-ordination did not happen in most cases.

Some reported good care by GPs, including a holistic approach, eliciting patients experiences of ill health, and some ‘pulling together’ of services. However, often healthcare professionals dealt with only one aspect of their health. It was perceived that there was little time to discuss other aspects. One participant felt they were not seen as a person but a ‘condition’ and that their voice didn’t count. People were ‘lost’ and not visible.

Participants described feeling dependent on other people but having to chase them: feeling like they had ‘fallen out of the system’. Some said professionals are ‘gate-keepers’ with a dependent relationship for actions. In addition it was difficult to co-ordinate their own care if weak or vulnerable; it was too tiring.

One participant with complex physical and mental health problems viewed co-ordination of care as 'self-management' but expressed strongly that this was not completely possible, was hard work, tiring and resulted in further fatigue and depression.

One participant felt that there was no co-ordination between health and social care - it was down to the patient to co-ordinate and organise with no linking of communication. They described having to chase people all the time and never speaking to the same person.

4.3.1.2 Access to care

Participants said it was difficult to access physiotherapy. There was conflict between patients' and healthcare professionals' perceptions of need.

Patients knew about their conditions and side effects, but they felt others ignored or did not believe their judgement. It was felt that even when they had knowledge of what care they should receive - eg physiotherapy or if they needed further investigations - this was ignored. They had to push for this and were often correct in their perception. It was felt that people with minor injuries were getting physiotherapy but not those with chronic conditions. Private physiotherapy was thought to be better.

There was a general impression that there was a 'life saving' philosophy to allocation of resources: for example if you have an acute illness, are dying, or elderly more care is given. One participant (44 with cancer) stated that his age was considered a barrier to getting help and care- the assumption was that because he was 'younger' he didn't need it. It was thought that children get good services.

4.3.1.3 Care planning

Most reported that there was little care planning and that there was no continuity of care by a named person; always someone different. One participant had a 'case-manager' who they saw regularly but despite suggesting and planning for interventions, these were not put in place nor followed up. It was felt that they were not 'responsive' to needs.

It was perceived that case/care managers were target driven and had to 'tick boxes' and that effectiveness was measured by the number of reports they had written.

Participants experienced little or no support from professionals. Despite knowing that there are specialist healthcare professionals, participants didn't see them.

One carer did report a good experience with 'fall services' for her father. There was a named person she could contact who co-ordinated related services. However, she reported that there should be carer support and that they shouldn't have to rely on charities.

Generally, discharge planning from secondary care was poor.

4.3.2 "I" statement" prioritisation

Participants were given time to read each statement. The overall impression given was that they were all relevant and important. Participants were then asked to choose the five most important statements in relation to their experiences and what they would consider to be fundamental to a good integration experience. As in all the groups, participants found it challenging to choose five statements. It was felt that some were not relevant to older people, or were specifically for older people: for example it was felt that they need a person who can speak for them.

All participants were able to identify their chosen five statements and to explain their choices. It was clear that some components of care were very important to them. Others took more time and deliberation. Factors that determined their choices were based on the experiences that most agitated them; those they thought were most essential. One person described choosing statements that would be essential for integrated care if he was ‘setting up’ the NHS.

Table 2 outlines participants chosen statements and aggregation of results. **Bold** codes were the two chosen as most important from the original five.

Table 2: Participants’ chosen “I” statements”

Participants	‘I’ statement codes				
	Chosen two main ‘I’ statements				
1	A1	B7	B6	C6	D6
2	A4	C5	D5	E2	B6
3	C4	A4	B8	C2	D5
4	E4	E6	A4	D5	B7
5	A4	B6	C4	B10	B5
6	B8	C1	D5	C6	F2

A: My goals (A1-4)

A1 was identified as important by one participant; A4 was reported as important by four. This was the single most important statement across all domains. Three participants identified it as one of the top two.

(A1) *All my needs as a person are assessed.*

(A4) *Taken together, my care and support help me live the life I want to the best of my ability.*

Overall, participants thought that being treated as an individual was highly important. This reflected the need for ‘tailored care’ as people had different needs within and between conditions. Participants wanted to be listened to so they can do what they want.

It was felt that individualisation was important and to also include the person’s family situation. One participant who was a carer stated clearly that being treated as a person should encompass personal care that was given with dignity and respect.

B: Care planning (B1-10)

B6 was identified as important by three participants, whilst B7 and B8 were each selected by two participants. B10 was selected by one participant.

(B5) *My care plan is clearly entered on my record.*

One participant felt that their care plan should be accessed by other health and social care professionals so that they didn't have to tell their story repeatedly.

(B6) *I have regular reviews of my care and treatment, and of my care and support plan.*

Two participants wanted regular reviews of condition to obtain a clear picture.

(B7) *I have regular, comprehensive reviews of my medicines.*

This was highly emotive to one participant. She had not been assessed for risk of side effects of medications. Others expressed the need for regular medication reviews.

(B8) *When something is planned, it happens.*

It was felt that this did not often happen. Although care may have been planned it was often not implemented.

(B10) *I have systems in place to get help at an early stage to avoid a crisis.*

This was considered important and one participant had an arrangement with the local hospital where she can have direct access to the ward in a crisis to avoid going through A&E.

C: Communication (C1-6)

Of the statements on communication, C4 was selected by two participants, whilst C2, C5, and C6 were selected once each.

(C2) *I am listened to about what works for me, in my life.*

One participant with asthma and other conditions wanted care to be tailored to him as a person: "my asthma is mine".

(C4) *The professionals involved with my care talk to each other. We all work as a team.*

This was considered important by two participants. Both felt that professionals should talk to each other and there should be good communication across teams. Team working was considered an essential ingredient but often patients had to 'project manage' their condition; they were like administrators.

(C5) *I always know who is co-ordinating my care.*

This was a salient concern for one participant. A named person should be accountable if something is not done.

(C6) *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.*

This was considered to be important as a carer- to have a point of contact.

D: Information (D1-6)

D5 was selected by four participants; D6 by one.

(D5) I am told about the other services that are available to someone in my circumstances, including support organisations.

Four participants felt that it was important to have information about all of the services and support organisations but it was difficult to identify which services were relevant.

(D6) I am not left alone to make sense of information. I can meet/phone/email a professional when I need to ask more questions or discuss the options.

This was considered to be important as a carer.

E: Decision making including budgets (E1-6)

(E2) My family or carer is also involved in these decisions as much as I want them to be.

This was highlighted as particularly important- carers and family should know what is happening and be involved.

(E4) I know the amount of money available to me for care and support needs, and I can determine how this is used (whether it's my own money, direct payment, or a 'personal budget' from the council or NHS).

and

(E6) I can get access to the money quickly without over-complicated procedures.

One participant had experienced much difficulty getting money quickly when it was needed. The process was deemed to be exhausting, upsetting and belittling, especially for 'benefits'. Personal healthcare budgets were important but the patient should have some control over how it is spent.

F: Transitions (F1-6)

(F2) When I move between services or settings, there is a plan in place for what happens next.

This was chosen to reflect poor experience of discharge planning.

Table 3: Summary of prioritised “I” statements”.

'I' statement codes	Frequency	Prioritised as top two
A1	1	1
A4	4	3
B5	1	
B6	3	1
B7	2	2
B8	2	1
B10	1	
C2	1	
C4	2	1
C5	1	1
C6	1	
D5	4	
D6	1	
E2	1	
E4	1	1
E6	1	1
F2	1	

4.4 Results: Focus group 2: Mental health conditions.

Table four outlines participants recruited for this group, of whom three attended (two female, one male). Ages ranged from 27 to 50. Two participants were White British and one Black British. One participant failed to attend. All had mental health conditions; one also had a physical health condition.

Some had experienced mental health services (psychological therapies) and all had either experienced social care or knew somebody who had.

Table 4: Participant information

Participant	Gender	Age	Long term condition(s)	Social care
1	Male	50	Severe mental health problems- inpatient	y
2	Female	27	Physical and mental health problems- inpatient	
3	Female	33	Severe mental health problems; inpatient	y
Did not arrive	Female	35	Anxiety and depression	

4.4.1 Themes

One participant had experiences of mental health services and care and treatment from acute surgical services. She had also sought care from the private sector. The level of care provided at the private sector was considered to be more relaxed and there was good communication during handover from private sector to the NHS: information was transferred. The other two participants had experiences of inpatient mental health services and care from community mental health care teams.

4.4.1.1 Communication

All participants reported extreme frustration at having to repeatedly tell their story and history. It was thought that a one page summary or checklist of events so far should be available for all professionals to see: a ‘This is me’ sheet was suggested. The constant explanation was tiring. One participant suggested that healthcare professionals are not aware of surrounding issues; they had a ‘situational focus’ and were not able to view the wider context of the person and their illness.

One participant gave a poignant description of her experiences as an inpatient. She had experienced constant questioning from staff about her reason for admission and some details of her personal life; for example what she had been studying at university prior to her admission. She was puzzled why the staff were repeatedly asking her this information when this would have been written in her notes. She thought that maybe staff were testing her or just making conversation. Constantly telling her history made her feel suspicious and fatigued. She felt that the staff were busy all the time and she had to therefore be clear and concise when giving information. The burden of constantly telling her story resulted in her being defensive and subsequently her medication was reviewed.

There seemed to be a lack of communication between primary and secondary care; in one case, the GP was not aware of a recent hospital admission.

Participants felt they were constantly ‘directing traffic’ and that decision making processes were not clear.

4.4.1.2 Access to care

There was a general consensus that there was a lack of transparency around the process and criteria for referral to mental health services. In addition, there was lack of involvement in decisions about different treatment options. It was felt that there may be some circumstances where transparency was not appropriate but that that this should be the underlying principle.

One participant had experienced both mental health services and healthcare treatment for a medical condition which required surgery. She experienced a long time to diagnosis and referral. She had high expectations of care she should receive but was disappointed. Lack of communication (as described above) was the main feature.

Access to care when needing it was expressed as a concern. Those experiencing mental health crises felt they had to be suicidal (or at least very ill) to get the help they needed.

Others said that once a diagnosis had been made it was then difficult to know what services they needed or where to access them. It was not clear to participants at what point one should get ‘social’ and ‘health’ care. There seemed to be awareness of an ‘absence’ of social care. One participant expressed the need for someone to help get them out of the house; this was considered an important aspect of recovery.

4.4.1.3 Information

There seemed to be a general lack of information made available. Specifically, information was needed about what treatment options were available and what would happen next.

4.4.1.4 Co-ordination of care

It was generally felt that services were more joined up for physical health problems where treatment options and benefits are clear. With mental health, it was less clear about effective treatment options.

4.4.2 “I” statement” prioritisation

All of the statements were considered good and touched on issues that were considered important. It was challenging for participants to rank and prioritise them, but they completed the task in good time and were all able to explain their choices.

Table 5: Participants chosen “I” statements”

Participants	‘I’ statement codes				
	Chosen two main ‘I’ statements				
1	A3	E4	A1	B3	B10
2	A3	F3	C3	D6	E3
3	A4	C4	C6	D3	E4/5

A: My goals (A1-4)

Each of the participants selected one of the section A statements in their top two most important items: two chose A3, and one A4. A1 was also selected as important by one participant.

(A1) *All my needs as a person are assessed.*

This was thought to reflect the need for a person-centred agenda rather than doctor-focused. It was about 'them' as individuals. Experiences suggested that participants were not treated holistically and that physical health problems were not taken seriously if the mental health problems were known to healthcare professionals.

(A3) *I am supported to understand my choices and to set and achieve my goals.*
and

(A4) *Taken together, my care and support help me live the life I want to the best of my ability.*

A3 and A4 were prioritised as top two for two and one of the participants respectively. One participant felt for her it was important to have future goals and strategies for achieving them. She wanted to know where she would be going after her inpatient experience. Planning of her future was so important to her. The use of the word 'ability' in A4 was thought to be good, reflecting empowerment and enablement.

B: Care planning (B1-10)

(B3) *I have as much control of planning my care and support as I want.*

The word 'control' was highlighted as important; participants wanted control over their care. It was expressed that mental health patients were the experts: they know when they are getting better.

(B10) *I have systems in place to get help at an early stage to avoid a crisis.*

'Crisis management' was considered an important component of care.

C: Communication (C1-6)

Communication was considered important and had huge impact on their experience if it was not effective. It was felt to not be unreasonable to expect good communication within and across teams and services and there was a belief that this should not be resource intensive.

(C3) *I am always kept informed about what the next steps will be.*

For one participant, knowing what would happen next was essential for recovery. This enabled her to measure her progress.

(C4) *The professionals involved with my care talk to each other. We all work as a team.*
and

(C6) *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.*

This was considered important for vulnerable people – eg. children and older people. One participant selected C4 as one of the two most important "I" statements" for them.

D: Information (D1-6)

D3 and D6 were selected as important by one participant each.

(D3) *I can see my health and care records at any time. I can decide who to share them with. I can correct any mistakes in the information.*

(D6) *I am not left alone to make sense of information. I can meet/phone/email a professional when I need to ask more questions or discuss the options.*

E: Decision making including budgets (E1-6)

(E3) *I have help to make informed choices if I need and want it.*

Making their own choices with support was considered important.

(E4) *I know the amount of money available to me for care and support needs, and I can determine how this is used (whether it's my own money, direct payment, or a 'personal budget' from the council or NHS).*

Some participants had experience of other therapies which were provided by the private sector. Participants felt they should have some control over the personal budget to make choices of what treatments to have.

F: Transitions (F1-6)

(F3) *I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact.*

This overlapped with C3 to some extent for one participant. Good relationships with professionals were considered important for this to happen.

Table 6: Summary of prioritised "I" statements".

'I' statement codes	Frequency	Prioritised as top two
A1	1	
A3	2	2
A4	1	1
B3	1	
B10	1	
C3	1	
C4	1	1
C6	1	
D3	1	
E3	1	
E4	2	1
F3	2	1

4.5 Results: Focus group 3: Long-term physical conditions

Table 7 outlines participants recruited for this group, of whom seven attended (four female, four male). Ages in the group ranged from 33 to 85. One participant, a 21 year old female, was delayed, so an individual interview was conducted. Seven participants were White British and 1 Black Asian. All had physical health conditions; some also had mental health problems. One participant (older person, female) had physical health conditions but was also a formal carer for her husband who had complex health problems. One male participant had both a health condition and experience as a paid carer in the private sector and for the county council. Half of the participants had some interaction with social care, either as a patient, carer or from a professional perspective. Two participants (female) had experiences of services from different counties.

Table 7: Participant information

Participant	Gender	Age	Long term condition(s)	Social care
1	Male	67	Psoriasis. Professional carer in private and public sector	y
2	Female	48	Multiple sclerosis. Formal carer for mother pre-diagnosis	y
3	Male	34	Inpatient for leg serious leg abscess. Community services	
4	Male	75	Diabetes, asthma, detached retina. Wife has complex health problems	
5	Male	33	Road traffic accident- inpatient for surgery.	
6	Female	85	Diabetic, angina. Formal carer for husband with complex health needs. Voluntary and public sector	Y
7	Female	45	Chronic pain. Psychological problems. Registered disabled	y
Individual interview				
8	Female	21	Unwilling to disclose health condition	

4.5.1 Themes

4.5.1.1 Co-ordination

Overall, based on their experiences, participants felt very strongly that services were not co-ordinated at all. This was reported within secondary care services and across all health and social care provision. Inpatient care was described by some as excellent, although one participant had a very bad experience of care. The main problems reported by these

participants were the lack of co-ordination of care from different services within hospitals – eg. surgical services, physiotherapy, counselling, and outpatient appointments.

Discharge planning was also reported to be poor; no assessment of needs was carried out for two participants who had physical functioning problems following surgery. There seemed to be no consideration about whether they would be able to cope with day to day needs at home. They felt that it was assumed that because they were young (33 and 34) they would not need help. Some had to rely on family and friends to get assistance.

One participant wondered if poor co-ordination was due to lack of care or because systems were not in place.

There was consensus amongst the group that as patients they were also ‘project managers’ and, although some were able to do this, it was significantly burdensome to them. One person described being ‘re-traumatised’ by the lack of co-ordination. Constantly and repeatedly having to tell their story was tiring and frustrating and reported by most.

One participant had experience of health and social care in different counties in England. In one county her care was supported by a specialist nurse and GP. Their realistic and pragmatic approach enabled her to understand her condition and tell her what was available, but they did not co-ordinate her care. However, their holistic approach and willingness to get to know her as an individual was appreciated. Care was poor in hospital with no consideration of what she may need on discharge; she had to rely on family for help (she had severe blurred vision). There was a feeling that there was a need for someone to ‘knit’ things together. The participant had also experienced several services for her son who was severely autistic and suffered from ADHD. The most helpful support, though, was given by the head teacher at the son’s school.

4.5.1.2 Access to care

One participant described difficulties getting the right treatment at the time he needed it. There were delays with diagnosis and referral to specialist care. He had accessed several specialist services within secondary care and within each service care was good, but communication and co-ordination across services was described as difficult. He felt he had to ‘look’ for solutions, which required an enormous amount of initiative.

One participant required help from six different services across health and social care. However, she was not able in some cases to receive these services because of strict assessment and selection criteria. This resulted in self-management of her own rehabilitation, by accessing self-funded private therapies. These were extremely helpful and effective but the financial burden resulted in nearly losing her home.

Knowledge of professionals was an issue for one participant, who reported that there seemed to be a general lack of understanding of her condition from professionals. She reported experiencing prejudice and stigma related to opiate use for pain control. There also was also a lack of holistic assessment of her psychological needs or living arrangements and lack of TLC.

One elderly carer described extreme frustration at trying to access care and services. This was compounded by not knowing what help she needed, what help is available, and how to get that help. This was complicated by her not wanting to ask for help and feeling resentment especially when there were different people giving the care. There also was no choice given about the gender of care providers, but it was extremely important to her

that her husband, already 'surrounded by women', should have a male to interact with. Often, she was able to access services 'by chance' – for example, she received a call from social care to ask if she needed anything: this resulted in her getting a stair lift. The Department of Work and Pensions have also helped in providing a 'Severely Disabled Pension Credit' to purchase a mobility scooter to enable her to go out. As well as her caring responsibilities, she has health problems which significantly impact on her life-making it difficult for her to get out of the house without being accompanied. Her needs are often neglected by health and social care professionals until she reaches a crisis. However, she reported that the Carers group and the Red Cross have provided much support and useful information.

4.5.1.3 Care provision

One participant provided a formal carers perspective: he has worked as a carer within the private and public sector for many years. The provision of care from the private sector was, he felt, driven by targets and financial incentives. The visits to service-users were task driven and very limited time was given per visit. This often resulted in long working days for carers and up to 19 service users seen in one day. No background information about the service users was given to the carers. Care provided by Local Authorities (County Council) focused more on gathering background information on service users but less time was spent on delivery of care. Often, discharge planning was poor, especially for the elderly, and there were bureaucratic barriers.

It was generally agreed that patients don't know what services or care they need, which is compounded by the difficulties of health and social care agreeing on what care and services service-users need.

One participant had cared for her dying mother at home but had to wait for three years before she received any help and for 18 months before she had some respite care; this was in response to a crisis.

One significant frustration for some was the conflict between health and social care provision. Health care would say what people needed but social care would disagree. One participant felt like she was failing in her own care and self-management.

There was a general feeling from participants that they wanted to be as 'independent' as possible but that they needed help to do this. One participant suggested that acute services focused on treatable problems, but that along the pathway of care the service-user becomes less visible and that care is 'done to' rather than 'done with'. This shift of focus was perceived to be moving from a 'customer' of services to 'the next job on the list'.

There was agreement that it seemed that care for children and for the elderly was well coordinated but not for working age adults.

Some described having contact with staff that were not trained or skilled enough to help. There was a lack of knowledge of health conditions and treatments they were receiving. Concern was raised about the lack of regulation of healthcare assistants.

4.5.1.4 Communication

All participants reported extreme frustration at having to repeatedly tell their story and history. It seemed to participants that health and social care are not communicating effectively.

One professional carer had some good experience of an electronic record system where all patient records and notes were in one place and health and social care staff could access these. However, this was under-funded and subsequently failed to work effectively.

Discharge planning was considered to be poor for some participants. In one case, errors were made with medications - an incorrect dose was prescribed. The same person reported poor physical functioning assessment prior to discharge; mobility was a problem but no plans were put in place for support or help at home. Care of wounds and dressings was carried out by district nurses which worked well.

4.5.2 “I” statement” prioritisation

All of the statements were considered to capture what good integration might reflect. It was suggested that there were some that were over-invasive. Some participants stated that the “I” statements” were underpinned by ‘power’ but that patients needed to be ‘empowered’.

As with previous groups, it was challenging for participants to rank and prioritise them.

Table 8: Participants chosen “I” statements”

Participants	‘I’ statement codes				
	Chosen two main ‘I’ statements				
1	C4	D4	A4	F3	E1
2	B3	C5	B8	D2	F1
3	B2	F3	B3	C4	E1
4	A4	C6	A3	A2	A1
5	C5	D5	A4	B8	C6
6	C4	E1	D5	E2	E3
7	C2	E4	C6	D3	E1
8	A4	C6	E1	B9	D5

A: My goals (A1-4)

(A1) *All my needs as a person are assessed.*

All participants felt this was extremely important. Some felt that along the pathway of care there was a ‘dehumanising’ process occurring.

(A2) *My carer/family have their needs recognised and are given support to care for me.*

(A3) *I am supported to understand my choices and to set and achieve my goals.*

(A4) *Taken together, my care and support help me live the life I want to the best of my ability.*

A4 was highlighted as important and the ultimate objective of care. Two participants selected this as one of the two most important statements for them, whilst two others included it in their top five.

B: Care planning (B1-10)

(B2) *I know what is in my care and support plan. I know what to do if things change or go wrong.*

(B3) *I have as much control of planning my care and support as I want.*

(B8) *When something is planned, it happens.*

(B9) *I can plan ahead and stay in control in emergencies.*

Care planning was considered fundamental – participants wanted to be involved in planning and be aware of what was going on. Participants wanted as much control over planning and receiving care but that if care was planned that it was implemented.

C: Communication (C1-6)

(C2) *I am listened to about what works for me, in my life.*

Being listened to was expressed as vital to good integration.

(C4) *The professionals involved with my care talk to each other. We all work as a team.*

(C5) *I always know who is co-ordinating my care.*

This was chosen by two people but the group agreed that it was essential that they knew who the person was co-ordinating their care. It was felt that they were always 'pushed' around and that not one person was taking 'ownership' or being responsible. Participants perceived this to be lack of caring. It was thought that this person could be the district nurse or the GP. One point of contact was vital.

(C6) *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.*

D: Information (D1-6)

(D2) *I have information, and support to use it, that helps me manage my condition(s).*

Information was considered empowering: support was needed to gain understanding.

(D3) *I can see my health and care records at any time. I can decide who to share them with. I can correct any mistakes in the information.*

One participant had experiences of incorrect information in notes.

(D4) Information is given to me at the right times. It is appropriate to my condition and circumstances. It is provided in a way that I can understand.

(D5) I am told about the other services that are available to someone in my circumstances, including support organisations.

E: Decision making including budgets (E1-6)

(E1) I am as involved in discussions and decisions about my care, support and treatment as I want to be.

(E2) My family or carer is also involved in these decisions as much as I want them to be.

(E3) I have help to make informed choices if I need and want it.

Participants wanted to be able to make informed choices about care. One participant expressed frustration about having to justify decisions and choices.

(E4) I know the amount of money available to me for care and support needs, and I can determine how this is used (whether it's my own money, direct payment, or a 'personal budget' from the council or NHS).

Participants felt they should have some control over the personal budget to make the best choices for them.

F: Transitions (F1-6)

(F1) When I use a new service, my care plan is known in advance and respected.

(F3) I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact.

This overlapped with C3 to some extent for one participant. Good relationships with professionals was considered important for this to happen.

Table 9: summary of prioritised “I” statements”.

'I' statement codes	Frequency	Prioritised as top two
A1	1	
A2	1	
A3	1	
A4	4	2
B2	1	1
B3	2	1
B8	2	
B9	1	1
C2	1	
C4	3	2
C5	2	2
C6	4	2
D2	1	
D3	1	1
D4	1	1
D5	3	
E1	5	1
E2	1	
E3	1	
E4	1	1
F1	1	
F3	2	1

4.6 Results: Focus group 4: Carers

Table 10 outlines participants recruited for this group. Nine people participated in the focus group (five female, four male), and their ages ranged from 22 to 74. One further participant, a 69 year old female, was delayed so an individual interview was conducted. Eight participants were White British, and two were European. All had experience of caring for family members as formal carers. Some were paid professional carers. All of the participants had some interaction with social care, some with voluntary sector. All but one participant had been recruited through local advertising. The other was recruited via the National Voices website.

Table 10: Participant information

Participant	Gender	Age	Carer experience	Social care
1	Male	31	Cares for mother who is disabled	y
2	Female	22	Paid carer for friend with muscular dystrophy, Nursing student	y
3	Male	22	Cares for family member	y
4	Male	74	Carers for daughter with physical and learning disabilities	y
5	Female	46	Cares for friends disabled daughter	y
6	Male	54	Cares for mother. Nursing background	Y
7	Female	70	Cares for parent and child has severe learning difficulties. Chair of local Community Health Council	y
8	Female	57	Private carer and works for carer organisation	y
9	Female	40	Cares for husband with physical health condition	y
Individual interview				
10	Female	69	Cares for mother and foster son	

4.7 Themes

4.7.1.1 Discharge planning

One participant had experienced good discharge planning for people admitted to a community hospital she had worked in. Patients have a comprehensive assessment prior to discharge and couldn't be transferred until all needs were addressed and support systems in place. It was thought that this worked because the hospital was managed by nurses. Many carers felt that discharge planning should commence as soon as patients are admitted to hospitals.

4.7.1.2 Communication

Several participants described barriers to communication. Staff in hospital would not consult the carers for information about their relatives' conditions, needs etc. In one case, this was because the staff believed that this would break confidentiality.

Constant repeating of history and story was frustrating for many. One carer had developed a care plan for her son so that people knew more about him.

4.7.1.3 Personal budgets

It was generally felt that carers and service-users should have more control over their personal care budgets and be able to make informed choices; the budgets should be more flexible. Some participants expressed frustration at how resources were allocated. It was felt that financial aspects were fundamental in the provision of co-ordinated care.

4.7.1.4 Care provision

Many participants described poor care for relatives, or people they cared for while in hospital. One participant reported immense frustration at having to communicate with staff to have her mother's needs met. It was assumed that her mother didn't need help as she was relatively young.

The people who were cared for by the participants generally had complex physical and/or learning disabilities, requiring specialist knowledge and equipment and making them dependent on carers for activities of daily living (feeding, mobilising, and personal care). In some cases, communication difficulties compounded people's problems. When these people had to be treated as an inpatient there was often a lack of personnel to look after their relative. This in some cases resulted in tensions between carers and staff. In one case, the carer was asked to come to hospital to care for the patient as they didn't have the staff with appropriate skills. Two main examples were given: one of a patient with severe muscular dystrophy who required total care and the other for a daughter with severe learning and physical disabilities. Both carers had detailed knowledge of the care needed and how to communicate with the person they cared for. The staff either relied on the carer to look after them while in hospital or did not seek information from the carer how best to communicate or provide care. Having access to information about their relatives was deemed crucial but often information systems were not in place. It also seemed that staff were not trained to look after people with severe learning disabilities and those with dementia.

One aspect discussed as problematic for a participant was the organisation and provision of transport services by local authorities. It seemed that often, several changes were made to arrangements for collection of service-users to attend schools, appointments, and so on. This resulted in service-users spending several hours in minibuses collecting other people and therefore reducing time spent at school. The constant changes were disruptive and unsettling. There was also a feeling that in some other cases, there was over provision of transport: for example people getting their own specially adapted cars.

One carer suggested that in some cases, community care does not work for people and that residential care enabled care to be fully integrated and co-ordinated, with specialist, trained staff available to care for people with complex needs.

One elderly carer stated that it is difficult for carers as they become isolated. She feels that it is difficult to find joined up care. She noted the social care workers who visit are always stretched for time, meaning that they could not provide a tailored experience, which she feels is important. She said that the services are there but they are not focused on individual needs. She blames the system rather than the actual workers. Information about the different services she could access was provided and helpful. She said she has been kept in the loop but doesn't think that social services understand the amount of support family's need. When there are changes to the way services are operated, family and carers should be listened to.

4.7.1.5 Co-ordination

One participant did describe excellent rehabilitation and reablement for his mother. Integration between health and social care was good. This was experienced in one trust, but more generally structures and systems were not in place for this to happen and strong governance was needed. Also, it seemed that mental health problems were often not addressed and forgotten about by services.

One participant described good co-ordination when he was under the care of child health services. As a child, his paediatrician co-ordinated his care effectively across health, social care, and education but as he moved to adult services this co-ordination was ‘lost’.

4.7.2 “I” statement” prioritisation

All of the statements were considered relevant and salient, both for service users and for carers. As with previous groups, it was challenging for participants to rank and prioritise them.

Table 11: Participants chosen “I” statements”

Participants	‘I’ statement codes				
	Chosen two main ‘I’ statements				
1	A2	D6	A4	C6	E6
2	C2	B8	E4	E2	F3
3	C4	C2	B8	B4	C3
4	D1	C6	C4	B10	A2
5	A4	C6	F6	E4	D5
6	B10	E5	C3	F6	A1
7	C4	A4	F2	D1	A2
8	B4	A4	F2	C2	E5
9	F3	C2	A2	B6	D2
10	A4	A2	F1	C2	F6

A: My goals (A1-4)

(A1) All my needs as a person are assessed.

Being treated as an individual was considered to give people dignity.

(A2) My carer/family have their needs recognised and are given support to care for me.

Several carers identified this as important. They had often had their own needs ignored and subsequently experienced a crisis. Needs were never recognised until it was too late. It was felt that they always had to ‘push’ for something to happen.

(A4) Taken together, my care and support help me live the life I want to the best of my ability.

Four participants chose A4 as one of the most important two items for them.

B: Care planning (B1-10)

(B1) I work with my team to agree a care and support plan.

(B4) I can decide the kind of support I need and how to receive it.

(B6) I have regular reviews of my care and treatment, and of my care and support plan.

One carer described how her husband's condition was not static and constantly changing. It was important that he was not left on one treatment regime.

(B8) When something is planned, it happens.

(B10) I have systems in place to get help at an early stage to avoid a crisis.

For some, there was never a system in place to deal with a crisis.

C: Communication (C1-6)

(C2) I am listened to about what works for me, in my life.

Three participants selected this as one of their two most important statements. There was a prevailing view that the patient and carer are the 'experts' and there is not a text book condition: an individualised approach was highlighted as essential.

(C3) I am always kept informed about what the next steps will be.

(C4) The professionals involved with my care talk to each other. We all work as a team.

Without this, needs cannot be identified. It was important for people to feel part of their care team rather than professionals just meeting up. The sharing of information will help with not feeling like they are in 'limbo'.

(C6) 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.

This was considered fundamental; having to repeat details about the person they care for was described as being burdensome and frustrating.

D: Information (D1-6)

(D1) I have the information, and support to use it, that I need to make decisions and choices about my care and support.

(D2) I have information, and support to use it, that helps me manage my condition(s).

Despite information being made available, it was vital to be able to 'use' the information provided; often, it did not make sense to them.

(D5) *I am told about the other services that are available to someone in my circumstances, including support organisations.*

Carers described how important it was when people look things up on the internet they get information from professionals so they know it is legitimate.

(D6) *I am not left alone to make sense of information. I can meet/phone/email a professional when I need to ask more questions or discuss the options.*

E: Decision making including budgets (E1-6)

(E2) *My family or carer is also involved in these decisions as much as I want them to be.*

(E4) *I know the amount of money available to me for care and support needs, and I can determine how this is used (whether it's my own money, direct payment, or a 'personal budget' from the council or NHS).*

Participants felt they should have some control over their personal budgets in order to let them make informed choices.

(E5) *I am able to get skilled advice to understand costs and make the best use of my budget.*

(E6) *I can get access to the money quickly without over-complicated procedures.*

One carer stated that if you need money for a service you don't want bureaucracy to negotiate for it.

F: Transitions (F1-6)

(F2) *When I move between services or settings, there is a plan in place for what happens next.*

(F3) *I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact.*

One participant experienced a feeling of 'abandonment'.

(F6) *If I move across geographical boundaries I do not lose my entitlements to care and support.*

Carers had different experiences of care in different counties. One carer said it is like a 'lottery', but if you move you definitely need continuity. It was suggested that an additional statement be added to reflect continuity when moving from child and adult services.

Table 12: Summary of prioritised "I" statements".

'I' statement codes	Frequency	Prioritised as top two
A1	1	
A2	5	2
A4	5	4
B1	2	1
B6	1	
B8	2	1
B10	2	1
C2	5	3
C3	2	
C4	3	2
C6	3	2
D1	2	1
D2	1	
D5	1	
D6	1	1
E2	1	
E4	2	
E5	2	1
E6	1	
F1	1	
F2	2	
F3	2	1
F6	3	

4.8 Results: Overall summary of participants' "I" statement priorities

The list below shows the final "I" statements" to inform next phase of project.

A My goals/outcomes

- (A1) All my needs as a person are assessed.
- (A2) My carer/family have their needs recognised and are given support to care for me.
- (A3) I am supported to understand my choices and to set and achieve my goals.
- (A4) Taken together, my care and support help me live the life I want to the best of my ability.

B Care planning

- (B6) I have regular reviews of my care and treatment, and of my care and support plan.
- (B7) I have regular, comprehensive reviews of my medicines.
- (B8) When something is planned, it happens.

C Communication

- (C4) The professionals involved with my care talk to each other. We all work as a team.
- (C5) I always know who is co-ordinating my care.
- (C6) 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.

D Information

- (D5) I am told about the other services that are available to someone in my circumstances, including support organisations.
- (D6) I am not left alone to make sense of information. I can meet/phone/email a professional when I need to ask more questions or discuss the options.

E Decision making including budgets

- (E1) I am as involved in discussions and decisions about my care, support and treatment as I want to be.
- (E2) My family or carer is also involved in these decisions as much as I want them to be.
- (E4) I know the amount of money available to me for care and support needs, and I can determine how this is used (whether it's my own money, direct payment, or a 'personal budget' from the council or NHS).
- (E5) I am able to get skilled advice to understand costs and make the best use of my budget.
- (E6) I can get access to the money quickly without over-complicated procedures.

F Transitions

- (F2) When I move between services or settings, there is a plan in place for what happens next.
- (F3) I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact.

Overall, participants' choices reflected their personal experiences of health and social care. They typically chose items that reflected the experiences that they had discussed earlier and/or issues and experiences that they had not discussed but that the "I" statements" reminded them of (or perhaps gave them 'permission' to discuss). Few participants, for example, spontaneously mentioned financial issues or budgets, but, taking the three "I" statements" about money/budgets together, ten participants said that financial information and control is important and they gave very clear examples of why.

Participants generally found the task of prioritising the statements somewhat challenging, but all were able to complete it and to explain their choices. Their first impression was that all the statements were relevant and some overlapped with others. Most participants made their choices based on aspects of integrated care that were important to them. Largely, this was based on aspects that did not happen frequently and had significant impact on their lives.

The results from this study supports statements prioritised by the Liverpool Clinical Commissioning Group project referred to in Phase 1: Literature review.

The obvious 'stand-out' "I" statements" were:

- A4 *Taken together, my care and support help me live the life I want to the best of my ability.*
- C6 *I have one first point of contact. They understand me and my condition(s). I can go to them with questions at any time.*
- C4 *The professionals involved with my care talk to each other. We all work as a team.*

Participants who chose A4 generally characterised it (in varying ways and terms) as a good high-level indicator of integration, i.e. care that genuinely helps people to live life to the full really is likely to be person-centred and integrated. Participants also seemed to like the positive and empowering phrasing of this statement, and its focus on the person's 'ability'.

"I" statement" C1 (*I tell my story once*) was chosen as a priority by only one person. This was unexpected, because having to tell one's story to different professionals time and time again was a more or less universal experience for participants. It may be some participants felt that other "I" statements" described processes that would obviate the need to repeat their stories – eg by having professionals "talk to each other" (C4) or by having "one first point of contact... I can go to... with questions at any time" (C6).

Some of the "I" statements" relate to similar, though different, aspects of experience. From the discussions, B6 and B7, for example, are both about regular reviews. Similarly, from the group discussions, statements C5, C6 and D5 also seemed to form a natural group. This clearly led to some vote-splitting, whereby participants with similar ideas about what is important chose slightly different, though obviously related, statements. We would therefore suggest viewing the statement scores individually and in related pairs/groups. Using this approach, the items most likely to be chosen, in A to F "I" statement" order, related to:

- Assessment, recognition of, and response to people's needs – patients/services users and carers/families (A1, A2) .

- People’s choices and goals, and their ability to live their own life (A3, A4).
- Regular reviews – of care, treatment, care plans and medicines (B6, B7).
- Communication between professionals and inclusion/involvement in discussion and decisions i.e. as a ‘member of the team’ (C4, E1, E2).
- A single *and influential* point of contact – who knows what is available, provides information and support, can link and co-ordinate services, follows up, and makes things happen (C5, C6, D5 plus, for some participants, B8 and D6).
- Knowledge about and control over money and how it is spent (E4, E5, E6).
- Transitions – advance planning and information (F2, F3).

These statements and dimensions of integrated care will inform the next phase of the project- identifying items from existing surveys and development of new questions where needed.

Table 13 integrates the results of the prioritisation exercises from the four focus groups and the two individual interviews.

Table 13: “I” statement” priorities (all participants)

'I' statement codes	Physical health problem		Mental health condition		Carer		Total
	Top 2		Top 2		Top 2		
A1	1	1		1		1	4
A2		1			2	4	7
A3		1	2				3
A4	5	3	1		4	1	14
B1							0
B2	1						1
B3	1	1		1			3
B4					1	1	2
B5		1					1
B6	1	2					3
B7	1	1			1	2	5
B8	1	3					4
B9		1					1
B10		1		1	1	1	4

C1	1					1	
C2	1	1			3	2	7
C3		1		1		2	4
C4	3	2	1		2	1	9
C5	3	1					4
C6	2	4		1	2	1	10
D1					1	2	3
D2		1				1	2
D3				1			1
D4	1						1
D5	1	5				1	7
D6		1		1	1		3
E1	1	4					5
E2		2				1	3
E3		1		1			2
E4	2		1	1		2	6
E5					1	1	2
E6	1					1	2
F1		1				1	2
F2		1				3	4
F3	1	1	1		1	1	5
F4							0
F5							0
F6							0

4.8.1 Limitations of the focus groups

The research group acknowledge that all of the participants were recruited in the Oxfordshire area and predominantly – although by no means exclusively – comprised people of white British ethnic origin. Attempt was made to recruit from a wider national network but only one participant was recruited from this. It was difficult to recruit people with mental health problems, and a local specialist charity was unable to help with further recruitment. Some of the limitations to the diversity of participants are attributable to a need to complete recruitment rapidly.

Although the focus groups involved a good number of participants overall, it should be noted that the results are not intended to be generalised to the wider population. Because of this, it is difficult to meaningfully disentangle results for specific cohorts:



further, focussed research would be appropriate if one wished to particularly understand the distinct preferences of a very specific cohort of patients or service users. Also, access to social care was largely experienced across the groups.

5 PHASE 3: DESK REVIEW OF EXISTING SURVEYS AND DRAFTING OF QUESTIONS FOR TESTING

5.1 Aims

The aim of this phase was to take the 19 prioritised “I’ statements” and develop related measures of people’s self-reported experiences to be inserted in to the following survey collections:

- GP Patient Survey.
- NHS Inpatients Survey.
- VOICES national bereavement survey.
- Community Mental Health survey.
- National Cancer survey.
- Personal social services carers survey.
- Personal social services adult social care survey.

In planning the development of such items, it is therefore important to consider the architecture and characteristics of each of the relevant surveys: how the surveys are designed and commissioned; to whom they are sent and via what mechanism; the kinds of questions they contain and their assumptions about frames of reference; and so on. These metadata characteristics will have particular implications for the ways in which questions can be asked, analysed and interpreted.

5.2 Survey architecture

Table 14 below summarises the key architectural characteristics of each of these surveys: this summary builds upon and was helpfully informed by an initial desk review conducted by the Department of Health with input from NHS England. Narrative elements of this section focus on the salient points from the review – the characteristics that have immediate implications for the development of measures of people’s experiences of integrated care.

5.2.1 Sample size and smallest reporting unit

Statistical sample surveys normally work by identifying a population of interest and giving each individual within that population a known (but not necessarily equal) probability of selection. Surveys designed for performance assessment or local improvement information in health and social care typically need to report at several geographical or organisational levels, though: eg both nationally and for individual councils or NHS trusts.

5.2.1.1 Existing architecture and implications

As such, most national surveys of people’s health and social care experiences draw samples at the smallest organisational reporting level before collating these to produce

national results. Of the seven surveys examined here, six drew samples from organisation level records: only the VOICES bereavement survey was designed primarily to produce national level results.

Across the surveys, a range of different reporting geographies are available, as shown in table 14. In most cases, the average number of responses at the local level for surveys covered here is between 300 and 500. This is a good level of response, suitable for generating reliable data with confidence intervals typically in the order of $\pm 5\%$. The average number of responses achieved at the lowest levels of reporting do vary considerably across and within surveys, though. For example, in the adult social care surveys in particular, outlying CASSRs have extremely low numbers of respondents. The implication of this is that if data from new questions on integrated care are to be widely usable then those questions should be applicable to the vast majority of survey respondents. In other words, it will be important to avoid 'filtered' questions, or items that are only relevant to a fraction of all people completing surveys.

5.2.2 Reference period

Surveys of people's experiences of health and social care generally focus on specific reportable events, with an emphasis on whether key events did or did not occur. To avoid ambiguity, it is therefore common for questions to focus on people's most recent relevant experience – eg their latest outpatient appointment or visit from a district nurse.

When it is more appropriate to cover the totality of people's experiences over a period of time, most surveys encourage respondents to think about events only within a limited recent window – eg six months or a year. This is typically intended to reduce 'telescoping' – thinking back to long past events when answering – and to ensure that results reflect current trends, not historic performance. The precise length of this reference period varies from one survey to another, though: sometimes because of the reporting requirements of the survey, and sometimes because of a need to balance the salience of the topic with people's recollections of the subject.

Although there is variance between surveys, most remain internally consistent – so it is unusual for a survey to have a mixture of questions about two different time periods (eg six months for some questions, three months for another). Switching the reference period within a survey is likely to increase the cognitive burden on respondents and reduce data quality.

5.2.2.1 Existing architecture and implications

Analysis of the seven priority surveys shows a range of reference periods in use. Most include questions focussing on a specific recent episode as well as a number looking at a reference period – although this period varies from three months (prior to death, in the case of the VOICES bereavement survey) to six months in the GP patient survey and twelve months in the community mental health, cancer, and both adult social care surveys.

This variance has implications for the development and implementation of generic questions. It is unlikely that questions about a single recent event will be sufficient for the measurement of integrated care: almost by definition, proper assessment of integrated care needs to cover interactions between different individuals or services over time. Consequently the use of a reference period in some items is likely: this requires consideration as to whether a common reference period must be used. If so, care will be needed to ensure that the period(s) chosen will work within each survey, which may

require additional framing to ensure understanding. If not, slight modifications to questions will be required for each survey.

5.2.2.2 Conceptual frame of reference

Just as most surveys seek to establish a particular period of time for respondents to focus on, so do they seek to establish the types of experiences that respondents should refer to when answering. For health and social care surveys, this is typically experiences for a particular condition, with a particular professional or professional group, and so on. To some degree this is linked to the reference period described above, but additionally there is a tendency for survey instructions to encourage people to think about particular eligible events.

5.2.2.3 Existing architecture and implications

Unsurprisingly, the seven surveys reviewed encourage respondents to think about a range of different experiences with a variety of services. Some focus more narrowly on particular services than others, though. The community mental health survey is almost wholly focussed on support from mental health services, even when asking about more holistic aspects of care (such as getting advice on financial support, caring responsibilities, and finding accommodation). Similarly the GP patient survey in particular focuses heavily on experiences with GPs and other practice staff, albeit with some coverage of dental services. By contrast, the carers survey already covers a fairly broad range of topics and services and encourages people to think about these separately and in turn.

The clear implication of this variance is that new integrated care questions will need to be developed to break from the existing framing within surveys: we want respondents to consider the interplay between a range of services, rather than focus on one in particular. This would most readily be achieved with the use of additional framing instructions (eg *“Thinking about all of your experiences with health and social services over the past year...”*) but these will need careful testing as part of the cognitive interviewing stage to ensure that a broadly consistent frame of reference can be used across each of the seven surveys.

There is also a need for care in using phrases that are defined with particular meaning in other parts of existing surveys. A good example is the use of the phrase “care and support services” in the adult social care survey, where it is consistently defined as follows:

“By ‘care and support services’ we mean any equipment or care provided by staff who are paid to help you. The staff could be from [Social Services], an agency, a care home or bought by you using money from [Social Services] through a Direct Payment.”

Because the phrase ‘care and support services’ is established with this meaning in the adult social care survey, it would be difficult to use it as part of new questions intended to cover a wider range of services: the likelihood is that respondents would interpret it more narrowly because of the earlier framing. New questions should be carefully checked to avoid such risks.

5.2.3 Demographic questions

Most large scale surveys include the collection of at least some demographic data about respondents. Firstly, this increases the analytic power and flexibility of data: different

'cuts' can be taken to look at the experiences of different groups (eg men and women, or older and younger people). This is particularly important for public sector surveys, where the Equalities Act (2009) establishes a duty to give due regard to a number of 'protected [demographic] characteristics' such as gender, sexual orientation, and religion.

Secondly, in some cases demographic factors may be linked to systematic differences in responding: in health surveys, for example, it is well established that older people are considerably more likely to give positive responses. This knowledge can be important for comparisons of institutional performance, and demographic data can have an important role in statistically standardising or 'weighting' results to provide a 'level playing field' for performance assessment and comparison.

5.2.3.1 Existing architecture and implications

The demographic information collected in the surveys varies markedly, and this is summarised in table 15. Only three characteristics – age, gender, and ethnicity – are collected in all of the surveys, and for both age and ethnicity there is some variance in the categories used. Other demographics are collected inconsistently – such as religion, sexual orientation, and employment status, which are each included in four of the seven surveys – and/or in a range of formats – such as questions on the relationship of the respondent to the sampled individual.

Whilst there is a lack of consistency in the additional demographic information available from different surveys, we do not consider this a problem for this project. Ultimately the aim of implementing generic questions into different surveys is to cover a range of groups, and this is achieved effectively through both sampling and the diversity of additional information already collected. Adding additional demographic questions to existing surveys would reduce space for other substantive content without significantly expanding the analytic possibilities for integrated care measurement.

Although it is beyond the scope of this project, we note that it may be desirable for organisations leading surveys – NHS England, the Department of Health, and ADASS – to consider reviewing and, where appropriate, harmonising the collection of demographic data across survey collections.

5.2.4 Summary of recommendations

New questions on integrated care should be relevant to the vast majority of respondents within each of the surveys. Additional filtering of questions must be avoided.

Cognitive testing should establish the burden of using a common reference period in surveys that currently refer to different periods of time. If the use of a common period proves too burdensome, agreement should be sought to amend the reference period for items to cover each setting differently.

Items developed should be reviewed prior to testing to ensure that terminology used in framing does not conflict with that in any of the existing surveys.

No additional demographic items are currently required in existing surveys. However, it may be useful in the longer run to consider the extent to which collection of such data can be harmonised across the surveys.

Table 14: Summary of survey characteristics

	GP Patient Survey	NHS Inpatients Survey	VOICES National Bereavement Survey	Community Mental Health Survey	National Cancer Survey	Personal Social Services Carers Survey	Personal Social Services Adult Social Care Survey
Lead	NHS England	NHS England	NHS England	NHS England	NHS England	DH & ADASS	DH & ADASS
Supplier	Ipsos MORI	CQC/Picker Institute	Office for National Statistics (ONS)	CQC/Picker Institute	Quality Health	Health and Social Care Information Centre	Information Centre
Survey mode	Postal Online	Postal	Postal	Postal	Postal	99% postal F2F Telephone	98% postal F2F Telephone
Frequency	Twice annual	Annual	Annual	Annual	Annual	Biannual	Annual
Sampling strategy	Systematic (sex/age sorted) sample within each GP practice	850 consecutive discharges per NHS trust	Stratified sample of deaths in England over three month period	SRS of 850 people using MH services per trust in three month period	People with cancer treated in NHS trusts over three month period	Carers reviewed/assessed by CASSR w/in 12 months, by CASSR	Stratified sample of adults receiving CASSR funded services, by CASSR
Annual sample size	2,700,000	128,000	49,207	45,000	110,000	125,950	173,630
Current response rate	35%	51%	46%	32%	68%	46%	40%
Annual responses	971,232	64,505	22,635	15,000	72,000	57,810	67,755
Smallest reporting units	GP practices	NHS trusts	PCT cluster (n=51)*	NHS mental health trusts	NHS trusts	CASSRs	CASSRs
Average n responses at smallest unit	Varies: aims for $\leq \pm 7\%$ confidence intervals	> 400	> 400	> 250	~ 500	378 (NB: range 10-1,360; IQR=175)	361 (range 25-1,230; IQR=105)
Most recent	13/06/2013	17/03/2013	11/07/2013	10/09/2012	17/08/2012	05/06/2013	10/07/2013



GP Patient Survey	NHS Inpatients Survey	VOICES National Bereavement Survey	Community Mental Health Survey	National Cancer Survey	Personal Social Services Carers Survey	Personal Social Services Adult Social Care Survey
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results							
Link	NHS England	CQC	ONS	CQC	Gov.uk	HSCIC	HSCIC
Coverage (age)	18+	16+	18+	18+	16+	18+	18+
Reference period	Most recent episode / last six months	Most recent episode	Death & last three months of life	Most recent episode / last twelve months	Most recent episode / last twelve month		None** / last year
Alternative questionnaire versions?	Translations	None	Male/female	None	None		Yes – see below***

* Annual data from the VOICES survey is sufficient for reporting down to PCT cluster level, but not to smaller units (eg PCTs or CCGs). The Office for National Statistics' quality and methodology information paper for the survey does note that analysis at more granular levels is possible by combining data from different years of the survey³. Because cases are sampled from registered deaths, samples from different years are necessarily independent – but the limitation of this approach is that data constructed from multiple years will not be truly contemporaneous.

** Most items in the Personal Social Services Adult Social Care Survey do not state a time period to consider when responding but rather ask about current state – eg “Do care and support services help you in feeling safe?”. At least one question asks about experiences in the last year.

*** The Personal Social Services Adult Social Care Survey uses a nested set of model questionnaires with numerous additional options. Firstly, there are separate questionnaires for those resident in the community and for those in residential care. There are separate large print and Easy Read versions of each of those, making six ‘model’ questionnaires. Additionally, there are 11 translated versions, three face-to-face interview scripts, and two telephone interview scripts.

³ Office for National Statistics. (2013 Feb 21). *Quality and methodology information paper: national bereavement survey (VOICES)*. Available at <http://www.ons.gov.uk/ons/guide-method/method-quality/quality/quality-information/health-and-social-care/index.html> (last accessed 20/07/2013). pp2. Copyright 2013 Picker Institute Europe & University of Oxford. All rights reserved.

Table 15: Summary of demographics collected in surveys

	GP Patient Survey	NHS Inpatients Survey	VOICES National Bereavement Survey	Community Mental Health Survey	National Cancer Survey	Personal Social Services Carers Survey	Personal Social Services Adult Social Care Survey
Age in years	○ (categories)	●	○ (categories)	●	●	●	○ (categories)
Gender	●	●	●	●	●	●	●
Ethnicity	●	●	●	●	●	○ (broad categories)	○ (broad categories)
Long-term conditions	○ (checklist)	●	○ (cause of death)		●	●	
Limiting conditions	○	●					●
Religion	●	●	●	●			
Sexual orientation	●	●		●	●		
Relationship of respondent / use of proxy		●	●	●		○ (use of proxy)	● + type of help
EQ-5D	●						○ (partial)
Employment status	●			●	●	●	
Smoking status	●						
Use of sign language	●						

Parent/ guardian living with children aged <16 years	●						
Unpaid caring responsibilities	●					N/A (survey of carers)	
Consent for recontact					●		●
Other Including relevant, but not exhaustive, examples.	● Last seen a GP Last seen a nurse Duration of journey from home to work. Able to see doctor during working house	● Emergency/ planned admission Had operations/ procedures Had tests Travelled in ambulance	● Illness prior to death Contact with health/social care professionals (eg district nurse, social worker, OT, Macmillan nurse, GP, etc) Residence – home/care home Hospital & hospice admissions Place of death	● Mental health inpatient admission Self-reported mental health status Most recent contact with health/social care Time in receipt of mental health services	● Duration of cancer treatment Cancer prognosis Contacts with GP Consent for recontact	● Tenure as a carer Hours/week caring Caring duties Use of services	● Self funding Informal support

5.3 Mapping existing questions to the 19 “I” statements”

After reviewing survey architecture a desk review of patient experience surveys was undertaken to explore whether any existing questions capture, and could be used to measure, the themes seen in the “I” statements”.

A list of reviewed questionnaires can be seen in table 16 below.

Table 16: Surveys reviewed as part of desk research

Survey
Adult Inpatient Survey 2013 (England)
Community Mental Health Survey 2013 (England)
Maternity Survey 2013 (England)
Outpatient Department Survey 2011 (England)
National Cancer Patient Experience Survey 2013 (England)
RAND evaluation of National IC pilots questionnaire (England)
OECD Healthcare Quality Index Indicators
Client perceptions of integrated care
Consumer Assessment of Healthcare Providers and Systems (CAHPS) (USA)
Ambulatory Care Experiences Survey (USA)
Integrated Care Program: Performance Measures recommendations (CHCS 2006) Suggested measures (USA)
Patient Assessment of Care for Chronic Conditions (USA)
GP Patient Survey 2013 (England)
Personal Social Services Survey of Adult Carers (England)
National Bereavement Survey (VOICES) (England)
Personal Social Services Adult Social Care Survey (England)
CAHE Post-Discharge Patient Questionnaire (Australia) (identified from the ‘Care Co-ordination Measures Atlas’)
Care Transitions Measure (USA) (identified from the ‘Care Co-ordination Measures Atlas’)

Each questionnaire was reviewed in turn and questions mapped to the “I” statements”. In some cases, where themes overlapped, questions were mapped to multiple “I” statements”. For example there is a degree of overlap in the two “I” statements” ‘I have one point of contact. They understand me and my conditions. I can go to them with questions at any time’ and ‘I always know who is co-ordinating my care’. The question ‘Do you know who your Care Co-ordinator (or lead professional) is?’ fits under both statements.

The long list of questions identified were reviewed and assessed by the research team using the criteria seen below. Using this criteria, any questions which the research team deemed unfit for purpose were removed from the list.

Exclusion criteria for “I’ statements”

- (1) the stem of the item was disease specific, reducing general applicability of the item; and
- (2) question was satisfaction rather than based on experience
- (3) yes no answers, unless it is a good question and we change response options
- (4) item content was inconsistent with the “I’ statement” definition;
- (5) the item content was too narrow to have universal applicability;
- (6) the item was confusing.
- Complexity of “I’ statements” and whether one question could encompass the “I’ statement” or whether multiple questions would be required. Multiple questions for one “I’ statement” was seen as undesirable. “I’ statement” A3 is an example of this.
- Crossover in coverage of “I’ statements”. As would be expected there are a couple of “I’ statements” which cover similar themes, such as C6 and D6, in addition D6 is complex and would require multiple questions and so D6 was excluded.
- Complexity of question and whether a new question would be more suitable as a starting point (and then adapting the stem for carers and bereaved etc) rather than taking an existing question and moulding it to fit other surveys. For example there were five questions from the Community Mental Health Survey under the “I’ statement” D5 ‘I am told about the other services that are available to someone in my circumstances, including support organisations’. Having five questions inserted into a questionnaire to cover just one “I’ statement” is not practical and so the research team developed a new question.

It should also be noted that the three “I’ statements” most commonly selected as being of high importance by focus group participants were protected from exclusion. These were:

- A4 Taken together, my care and support help me live the life I want to the best of my ability.
- C6 I have one first point of contact. They understand me and my condition(s). I can go to them with questions at any time.
- C4 The professionals involved with my care talk to each other. We all work as a team.

Once any unsuitable questions were excluded the research team again reviewed the question set to see if any questions needed to be revised or new questions developed. The question set seen in Appendix B was presented to survey owners and stakeholders at a workshop for their feedback.

6 PHASE 4: OWNERS WORKSHOP

6.1 Aims

To have a key discussion with survey owners and stakeholders about suitability of questions, as developed in phase 3, for particular surveys.

6.2 Methods and results

After the review process in phase 3 the question set seen in Appendix B was presented to a core set of survey owners and stakeholders for their feedback. The question set was also distributed to a wider group of stakeholders, parties to comment on the question set were:

- Care Quality Commission
- Local Government Associations
- Mandate, NHS Outcomes Framework & Analysis Team, Department of Health
- NHS Outcomes Analysis Team, NHS England and Department of Health
- NHS Policy and Strategy Unit, Department of Health
- Patients and Information Directorate, NHS England
- Personal Social Services Research Unit / Quality and Outcomes of person-centred care policy Research Unit, London School of Economics and Political Science
- Social Care, Local Government and Care Partnerships, Department of Health

6.2.1 Attribution

Stakeholders touched on the topic of attribution and accountability. The suggestion made was that if questions are intended to measure integrated care provided across services, then is it fair to attribute results to specific providers or challenge them on their performance? For example if a question asking about experience of all health and social care services is inserted in the NHS Inpatients Survey is it fair to attribute results to the specific acute trusts taking part?

Our view is that this question, whilst understandable, is itself rooted in a traditional, 'siloed' approach to health and social care. Conversely, the point of integrated care is that organisations must accept a shared role in people's experiences. Aspects of this may be out of the control of individual providers, but integrated care cannot be achieved if providers dismiss their responsibility once users exit their doors.

Results from the measures developed in this work should therefore be seen to reflect local health and social care economies as much as individual providers. One implication of this is that results should be particularly useful to commissioners to help them identify, explore, and challenge poorly integrated care locally.

6.2.2 Comments on the question set

The list below provides examples of feedback received from these groups.

- Multiple constructs being measured. For example asking participants if a review is both regular and comprehensive in the same question.
- Questions could be more specific. For example when asking if a person’s needs have been assessed should an example of an assessment be given.
- Scales were queried. This relates to the answer options and whether in some cases they are suitable.
- Questions could be more user-friendly. For example is the term ‘first point of contact’ easily understood? In addition is the term ‘social services’ recognised by people.

The development of questions for the “‘I’ statements” focussed on finances and budgets was discussed at the owners workshop. Concerns were raised around how relevant questions on budgets are to the majority of the population and the suggestion that data on budgets could be collected elsewhere was made. As a result the following three “‘I’ statements” were excluded.

- E4 *I know the amount of money available to me for care and support needs, and I can determine how this is used (whether it’s my own money, direct payment, or a ‘personal budget’ from the council or NHS).*
- E5 *I am able to get skilled advice to understand costs and make the best use of my budget.*
- E6 *I can get access to the money quickly without over-complicated procedures.*

The research team reviewed all feedback and the 17 questions below were those chosen to be tested in the phase 5 ‘cognitive interviews’. Questions are presented by “‘I’ statement” with the name of the survey highlighted if they had been pulled from an existing questionnaire.

Table 17: Questions for cognitive testing

'I' statement and related questions	New question or seen in existing survey?
A My goals/outcomes	
(A1) All my needs as a person are assessed.	
Have all of your needs been assessed?	New Question
Yes, definitely	
Yes, to some extent	
No	
Don't know	

<p>(A2) My carer/family have their needs recognised and are given support to care for me.</p>	
<p>Overall, do you feel that your carer/family has had as much support from health and social services as they needed?</p>	<p>New Question</p>
<p>Yes, they have as much support as they needed</p>	
<p>Yes, they have some support but not as much as they needed</p>	
<p>No, although they tried to get more support</p>	
<p>No, but they did not ask for more support</p>	
<p>They did not need support</p>	
<p>There are no family members or carers to support</p>	
<p>(A4) Taken together, my care and support help me live the life I want to the best of my ability.</p>	
<p>Do all of the services help you live the life you want as far as possible?</p>	<p>New Question</p>
<p>Yes, definitely</p>	
<p>Yes, to some extent</p>	
<p>No</p>	
<p>B Care planning</p>	<p>New question or seen in existing survey?</p>
<p>(B6) I have regular reviews of my care and treatment, and of my care and support plan.</p>	

Is your care and treatment regularly reviewed?	New Question
Yes	
No	
(B7) I have regular, comprehensive reviews of my medicines.	
Do you have regular, comprehensive reviews of your medicines?	New Question
Yes	
No	
Don't know	
Not applicable	
(B8) When something is planned, it happens.	
When health or social care staff plan care or treatment for me, it happens?	New Question
Yes, all of the time	
Yes, most of the time	
Yes, some of the time	
No, never	
C Communication	New question or seen in existing survey?
(C4) The professionals involved with my care talk to each other. We all work as a team.	
Do all the different people treating and caring for you work well together to give you the best possible care and support?	New Question
Yes, all of the time	

Yes, most of the time	
Yes, some of the time	
No, never	
Don't know	
(C5) I always know who is co-ordinating my care.	
To what extent do you agree or disagree with the following statement...	
'I always know who is co-ordinating my care and support'	
Strongly agree	New Question
Agree	
Neither agree nor disagree	
Disagree	
Strongly Disagree	
Do you know who to contact if you need to ask questions about your condition or treatment?	
Yes	New Question
No	
Don't know / can't remember	
(C6) a) I have one first point of contact. b) They understand both me and my condition(s). C) I can go to them with questions at any time.	
Do you have a 'first point of contact'?	New Question
Yes – please go to next question	

No	
Can you go to this person with questions at any time?	
Yes, all of the time	New question
Yes, most of the time	
Yes, some of the time	
No, never	
I have not needed to ask any questions	
Do you feel this person understands about you and your condition?	
Yes, definitely	New Question
Yes, to some extent	
No	
D Information	
(D5) I am told about the other services that are available to someone in my circumstances, including support organisations.	
In the past 12 months, have you found it easy or difficult to find information and advice about support, services or benefits? Please include information and advice from different sources such as voluntary organisations and private agencies as well as social services	Carers survey
I have not tried to find information	
Very easy to find	

Fairly easy to find	
Fairly difficult to find	
Very difficult to find	
E Decision making including budgets	
(E1) I am as involved in discussions and decisions about my care, support and treatment as I want to be.	
Were you involved as much as you wanted to be in decisions about your care, support and treatment?	Inpatient Survey 2013
Yes, definitely	
Yes, to some extent	
No	
(E2) My family or carer is also involved in these decisions as much as I want them to be.	
Were your family or carer involved in decisions about your care, support and treatment as much as you wanted them to be?	New question
Yes, definitely	
Yes, to some extent	
No	
There were no family members or carers available to be involved	
I didn't want my family or carer to be involved in decisions about my care and treatment	

F Transitions	
(F3) I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact.	
Thinking about all the health and social care services you have used over the last (insert time frame used in relevant survey)...I am always told what will happen next	New question
Strongly agree	
Agree	
Neither agree nor disagree	
Disagree	
Strongly Disagree	
Do health and social care services work together to coordinate your care effectively?	New question
Yes, definitely	
Yes, to some extent	
No	
Don't know	

7 PHASE 5: COGNITIVE INTERVIEWS

7.1 Aims

The aim of phase 5 was to test and develop the measures of integrated care identified in phases 3 (desk review) and 4 (owners workshop) of this project.

7.2 Recruitment

59 cognitive interviews were held in total. The researchers carried out interviews until saturation point; this is the point at which no new themes or changes to questions were observed from the interviews.

The cognitive interviews were conducted by staff from the Picker Institute and University of Oxford. Interviews were conducted face-to-face and by telephone. Two focus groups were also conducted.

Researchers explored a number of avenues for recruitment and these are listed below:

- Carers Voice Oxfordshire
- Daventry Mind
- Daily Info: local Oxfordshire paper
- Friday-Ad
- Gumtree
- Involve: People in Research
- Lancashire Telegraph: local paper to Blackburn and Preston
- National Voices
- Northampton Volunteering Centre
- Patient Opinion Facebook page
- Patient Voices
- Picker Institute Europe twitter account
- Phase 2 focus group participants
- Snowballing

A researcher contacted all those who expressed an interest in the cognitive interviews to assess eligibility. The aim was to ensure a mix of people of different ages, backgrounds, long term physical and mental health conditions, and experiences with social services either as a carer or adult social care user.

7.3 Interview schedule

Participants were given a brief background to the study their consent was obtained and payment of £20 provided to cover their time.

Participants received one of four questionnaire types. In order to put the questions for testing in context and so that respondents had reflected on their own health and/or social care experience prior to answering, the questions for testing were inserted into abridged versions of four questionnaires each of which contained introductory text to set the scene.

The introductory text for each questionnaire are presented below. Section 7.4, below, gives the additional preamble text used to introduce questions covering integrated care.

7.3.1 Introductory text seen in the questionnaire for those with a long term mental health condition

What is the survey about?

This survey is about the health and social care you receive through NHS mental health services. This might include contact with psychiatrists or psychiatric nurses, social workers, mental health support workers, occupational therapists, psychologists, psychotherapists or other mental health or social care workers, including those helping people with dementia, depression or other types of mental health problem.

Completing the questionnaire

For each question please tick clearly inside one box using a black or blue pen. If you prefer not to answer a question, simply leave it blank.

Sometimes you will find the box you have ticked has an instruction to go to another question. By following the instructions carefully you will only answer the questions that apply to you.

Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

Please do not write your name or address anywhere on the questionnaire. All your answers will be kept confidential. It will not be possible to identify you in any report of the results.

7.3.2 Introductory text seen in the questionnaire for those with a long term physical health condition

What is the survey about?

This survey is about your experiences of health and social care. Your views are very important in helping us to find out how well our services work and how they can be improved. This is part of the NHS commitment to deliver care shaped around you.

Completing the questionnaire

For each question please tick clearly inside one box using a black or blue pen. If you prefer not to answer a question, simply leave it blank.

Sometimes you will find the box you have ticked has an instruction to go to another question. By following the instructions carefully you will only answer the questions that apply to you.

Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

Please do not write your name or address anywhere on the questionnaire. All your answers will be kept confidential. It will not be possible to identify you in any report of the results.

7.3.3 Introductory text seen in the questionnaire for adult social care users

What is the survey about?

We are asking you to complete this questionnaire because you receive, or have received, care and support services that are paid for (at least in part) by your local Social Services Department.

By care and support services we mean you may be living in a care home, receiving a Personal Budget, home care, equipment, meals services, Direct Payments, or attending a day centre.

We want to improve and develop our services so we want to get your views on the services you receive. In particular, we want to hear about your quality of life and how services have affected the quality of your life.

Completing the questionnaire

For each question please tick clearly inside one box using a black or blue pen. If you prefer not to answer a question, simply leave it blank.

Sometimes you will find the box you have ticked has an instruction to go to another question. By following the instructions carefully you will only answer the questions that apply to you.

Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

Please do not write your name or address anywhere on the questionnaire. All your answers will be kept confidential. It will not be possible to identify you in any report of the results.

7.3.4 Introductory text seen in the questionnaire for carers

What is this survey about?

This survey is about you, the person you care for, and your experiences of health and social care services.

If you look after a family member, partner or friend in need of support or services because of their age, physical or learning disability or illness, including mental illness, we would like you to complete this questionnaire.

Completing the questionnaire

For each question please tick clearly inside one box using a black or blue pen. If you prefer not to answer a question, simply leave it blank.

Sometimes you will find the box you have ticked has an instruction to go to another question. By following the instructions carefully you will only answer the questions that apply to you.

Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

Please do not write your name or address anywhere on the questionnaire. All your answers will be kept confidential. It will not be possible to identify you in any report of the results.

7.4 Use of a lead statement

In each questionnaire the questions for testing followed a lead statement specifying a time frame of reference. Table 18 details the time frames of reference used in each questionnaire type.

The use of a lead statement to provide context was important to ensure that participants thinking was focused on their experiences of all health and social care services accessed in the last year. As such, when considering the insertion of one of our tested questions into an existing national survey, survey owners should bear in mind that using a different lead statement or no lead statement at all could lead to the measurement of a different construct or the poor performance of a question. In such cases it would be advisable for survey owners to conduct their own testing of the question.

Section 5.2.2 of this report provides further information around the use of a reference period to establish the types of experiences that people should refer to when answering.

Table 18: Time frame of reference

Questionnaire type	Time Frame	
Questionnaire for those with a long term mental health condition	Last 12 months	Thinking about all the health and social care services you have used over the last 12 months...
Questionnaire for those with a long term physical health condition	Last 12 months	Thinking about all the health and social care services you have used over the last 12 months...
Questionnaire for adult social care users	Last year	Thinking about all the health and social care services you have used over the last year...
Questionnaire for carers	Last year	Thinking about all the health and social care services you have used over the last year... Thinking about all the health and social care services the person you care for has used over the last year...

A pre-defined interview schedule, containing probes for each question, was used to guide the interviews and keep to task. Interviews lasted on average 45 minutes. We used cognitive interviewing methods to test the questions. Cognitive testing followed an iterative process, with three rounds of testing undertaken. Participants were asked to complete the questionnaire to confirm that their understanding of the questions was as intended and therefore to demonstrate, non-statistically, the content and construct validity of the items. In doing this, we considered the cognitive process of responding in terms of the model described by Tourangeau (1984)⁴, seeking to establish consistency in:

- **Comprehension** – people understand what the question is asking in a consistent way that matches the intended research question.
- **Retrieval** – people are able to retrieve from memory the information necessary to evaluate their response to the question.
- **Evaluation** – people are able to use retrieved information to evaluate the question meaningfully, and do this in an unbiased manner (eg, not simply acquiescing or providing socially desirable responses).
- **Response** – people are able to match their evaluation to one of the available responses in a meaningful and appropriate way; the response selected adequately reflects the person's experience.

After each round the research team reviewed findings and made changes to the questions as required.

7.5 Participant details

Details of interviews completed by gender and age group are provided in table 19. Table 20 provides a list of the types of services accessed by participants, in many cases participants had accessed multiple services.

⁴ Tourangeau, R., *Cognitive sciences and survey methods*. In T. Jabine, M. Straf, J. Tanur, & R. Tourangeau (Eds.), *Cognitive Aspects of Survey Methodology: Building a Bridge Between Disciplines*, pp. 73-100. Washington, DC: National Academy Press

Table 19: Interviews conducted by age and gender of interviewees

Gender	Age group	Physical Health Condition	Mental Health Condition	Adult Social Care User	Carer	Total
Female	18-24	1		2		3
	25-34	4	2		2	8
	35-54	4	4	2		10
	55-65	2	1	1	1	5
	66+	2	2		7	11
Male	18-24	2	4	2		8
	25-34	1				1
	35-54	3	1	1		5
	55-65	1	1	1		3
	66+	3	1		1	5
Total		23	16	9	11	59

Table 20: Services accessed

Service	Total	Service	Total
Community	1	Mental Health and Social Services	3
Community and Voluntary	3	Mental Health and voluntary	1
GP	3	Outpatient	4
GP and community	2	Outpatient and Emergency	1
GP and Hospital	2	Outpatient and Social Services	2
GP and outpatient	2	Outpatient and voluntary	1
GP and Tropical medicine	1	Social Care	4
GP and voluntary	2	Social services and GP	1
Inpatient	6		
Inpatient and community services	1		
Inpatient and Mental Health	2		
Inpatient and Outpatient	8		
Inpatient and Social services	3		
Mental Health	2		
Mental Health and GP	1		

See Appendix C for further details on participants.

7.6 Results

Interviews were conducted in three rounds and items were reviewed and revised between rounds. Because the iterative design process used a number of questions were substantially changed between rounds. For convenience, this report summarises findings by question.

A number of the questions were amended for use with carers. This was required to ensure that they covered issues relevant to the 'person cared for' rather than the carer.

Throughout the results specific examples of comments from interviewees are used to illustrate key themes. To add context, each comment is prefixed with a two or three character code to indicate the cohort the comment was from. These codes are as follows:

- MH Long term mental-health condition
- PHY Long term physical-health condition
- CAR Carer
- ASC Adult Social Care User

Time frame

As mentioned in the methods section the time frames 'last 12 months' and 'last year' were used in the lead statements (Thinking about all the health and social care services you have used over the <insert time frame>) and in a number of the tested questions.

Overall participants considered the time frame as appropriate with no one indicating that it was a struggle to think about the whole time period.

- MH *Totally reasonable*
- PHY *12 months is a good time frame*
- PHY *Easy to think last 12 months, I have got other things that have gone on longer than 12 months so could widen it but last 12 months is pretty easy to think about*
- MH *Fine, because I am a student and I think in years*

It should be noted that a few participants highlighted the importance of having a reminder about the time period every so often as they forgot to think about the full 12 months. The tendency was to think about the last interaction with health and social care services *"just think of the last experience, how you felt on the day"* (MH).

No changes were made to the time frames in either the lead statements or tested questions.

Health and social care services

The lead statements and a number of the tested questions referred to both health and social care services. The researchers explored what participants understood by the terms 'health services' and 'social care services'; it was important to understand whether

participants were familiar with the terms and what kind of services they were thinking about. It was also key to finding out whether participants viewed them as separate services or indeed whether they saw them as overlapping.

'Health services'

Participants were asked what they considered to be a health service. The majority of participants gave their GP or a hospital as an example. Other examples are seen below.

- PHY *Purely medical*
- MH *Those provided by GPs, health staff*
- PHY *Hospitals, physio, drs, nurses*
- PHY *Tropical medicine clinic at hospital*
- MH *CPN*
- ASC *Psychiatrist*

'Social care services'

Participants spoke about a number of different services and kinds of support received under the heading of 'social care'. Examples of what participants considered to fall under social care are seen below.

- MH *Education and housing*
- PHY *Social welfare*
- MH *Social workers and things which are delivered by county council and funded*
- PHY *Are you able to get to shops...are you able to feed yourself...can you get into work...are you stuck at home*
- CAR *Meals on wheels*
- ASC *Local authority and disability allowance*
- PHY *It means having a carer if you are not mobile*
- CAR *Supported Housing*
- PHY *From local authority, provision of equipment and adaptations, personal support*

The majority were familiar with social care and on the whole participants felt it to be different to health services however a few indicated that there should be an overlap between services and that it is important to ask about both.

Many of the participants interviewed had experienced some interaction with voluntary organisations and although not considered to be an example of a social care service they were considered to be a support service.

Q1.1. Have all your needs been assessed?

Have all your needs been assessed?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Don't know

Overall this question performed quite well, it was understood by most participants. A number of participants indicated that the question was quite broad with 'needs' covering a lot of different things and that these would be specific to the person.

When thinking about needs interviewees said:

- PHY *Physical health problem*
- PHY *Refers to health and if I am coping*
- MH *Support required to be able to enjoy a wide range of activities*
- PHY *Best management of condition as can be*
- CAR *Whether I had respite care*
- ASC *Health, housing, that I had meaningful uses of my time*
- PHY *It is specific to the condition as to what the needs are.*
- CAR *Considerations about health condition and her position as a carer*
- PHY *Clean bed in hospital, quiet ward which was needed to recuperate. Being checked regularly.*
- MH *Seeing what counselling options there are available and what medications there are available for my condition.*

Participants were also asked what they understood by 'assessed'. All participants understood the term but the type of assessment was dependent on the type of need.

When thinking about being assessed participants said:

- PHY *Refers to identifying what care will help people with that need*
- MH *Needs taken into consideration*
- PHY *Whether or not I need a particular service*
- PHY *Clinical side is assessing condition and the human side is how comfortable you are*
- CAR *Formal word, so it is like going to an appointment*
- PHY *Not just thinking about appointments but any discussions with staff*

The question was understood and seen as important by all cohorts and despite participants indicating that the question was quite broad, the text fits with the equally broad “‘I’ statement” (A1) **All my needs as a person are assessed**. Because of this no revisions were made to the question text during testing. However, the answer options were amended between round 1 and 2 as a number of participants commented on the bias towards the positive. The question in its final form is seen below.

Have all your needs been assessed?

- 1 All of my needs have been assessed
- 2 Some of my needs have been assessed
- 3 None of my needs have been assessed
- 4 Don't know / can't remember

Q1.2. Were you involved as much as you wanted to be in decisions about your care, support and treatment?

Were you involved as much as you wanted to be in decisions about your care, support and treatment?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

This question relates to the “‘I’ statement” (E1) **I am as involved in discussions and decisions about my care, support and treatment as I want to be** with a number of participants indicating that the question covers everything you might receive from health and social care services “*Overlap between care, support and treatment. Covers all bases*” (MH). However, researchers probed further to explore ‘care’, ‘support’ and ‘treatment’ separately. When participants were asked about each it became apparent that ‘treatment’ was seen as very different to care and support.

‘Care’ and ‘support’

- MH *Support- more for social aspects and not medicines*
- PHY *Care means being treated with decency and respect*
- PHY *Care and support- making sure I was able to cook, wash and get help I need*
- PHY *‘the people thing’ – what you might need in order to be able to do the things you need to do*

'Treatment'

- PHY *Medicines mainly*
- PHY *Medical or health condition*
- PHY *Medical side, technical, medicines*
- CAR *Drugs eg. CBT*
- PHY *Medications, physiotherapy*

The question text remained the same for round 2 as the researchers wanted to continue to explore the idea that 'care' and 'support' are different to 'treatment'. Round 2 confirmed this:

- PHY *'Care and support' and 'treatment' are very distinct.*
- PHY *Care and support would be the same, anything I need such as help I want. I just think of medication with treatment.*

Findings from round 1 and 2 indicate that people see treatment as being about medical aspects of care whereas 'care and support' covers the more social aspects of care. A number of participants indicated that if they were asked separately about 'care and support' and 'treatment' their answers would be different and this was a theme seen across cohorts.

The same version of the question was tested with carers. A number of carers struggled with the question because of its mention of treatment. One participant noted that it was a little odd to be asking about involvement in decisions about treatment as it assumes we think they have a health condition *"hopefully I don't need any treatment; I'm not ill"*. Another when talking about treatment switched to talking about the treatment of the person they care for as they hadn't received any themselves.

With all this in mind the researchers felt it important to split the question in two so that separate feedback about involvement in decisions about care and support and involvement in decisions about treatment could be gathered.

Seen below are the final versions of the questions as tested in round 3. In round 3 the two questions tested well with all groups apart from the carers. Again, a number of carers queried whether the question was about their treatment or the treatment of the person they care for. Taking all feedback into account, we would not recommend inserting the question 'Were you involved as much as you wanted to be decisions about your treatment' into a survey of carers.

Were you involved as much as you wanted to be in decisions about your care and support?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

Were you involved as much as you wanted to be in decisions about your treatment?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

Q1.3. Were your family or carer involved in decisions about your care, support and treatment as much as you wanted them to be?

Were your family or carer involved in decisions about your care, support and treatment as much as you wanted them to be?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 There were no family or carers available to be involved
- 5 I didn't want my family or carer to be involved in decisions about my care and treatment

This question relates to the “‘I’ statement” (E2) **My family or carer is also involved in these decisions as much as I want them to be.** By ‘these decisions’ it is referring to those made in answer to the “‘I’ statement” (E1) **I am as involved in discussions and decisions about my care, support and treatment as I want to be.**

No issues were found with the response options presented. Again discussion was had around the differences, if any, between care, support and treatment and participants confirmed that with this question there is again a difference between ‘care and support’ and ‘treatment’.

As with Q1.2 the decision was made to split this question in two. The two questions seen below were tested in round 3 and are the final versions.

Were your family or carer involved in decisions about your care and support as much as you wanted them to be?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 There were no family or carers available to be involved
- 5 I didn't want my family or carer to be involved in decisions about my care and support

Were your family or carer involved in decisions about your treatment as much as you wanted them to be?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 There were no family or carers available to be involved
- 5 I didn't want my family or carer to be involved in decisions about my treatment

These questions tested well in round 3, and as with the previous rounds and with Q1.2 participants indicated 'care and support' as being one construct and 'treatment' as another.

Carer version

This question was rephrased for use with carers so that it focused on their involvement in the care, support and treatment of the person they care for. See the question below:

Were you involved as much as you wanted to be in decisions about the care, support and treatment of the person you care for?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 I didn't want to be involved in decisions about care and treatment

Comments mirrored those from the other cohorts and so the question was split out for testing in round 3.

- CAR *This might be more challenging to answer because you might have been involved in decisions about care but not about treatment*
- CAR *The care that is coming from outside, the support care. Treatment could be different – medical/psychiatric treatment*
- CAR *Thinking about the day services and being with others (care and support the same). Treatment, I was not thinking about this because he is not ill. There is no treatment.*

Were you involved as much as you wanted to be in decisions about the care and support of the person you care for?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 I didn't want to be involved in decisions about care

Were you involved as much as you wanted to be in decisions about treatment of the person you care for?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 I didn't want to be involved in decisions about treatment

The two questions above tested well with carers in round 3, these are the final versions.

Q1.4. Overall, do you feel that your carer/family has had as much support from health and social services as they needed?

Overall, do you feel that your carer/family has had as much support from health and social services as they needed?

- 1 Yes, they had as much support as they needed
- 2 Yes, they have had some support but not as much as they needed
- 3 No, although they tried to get more support
- 4 No, but they did not ask for more support
- 5 They did not need support
- 6 There are no family members or carers to support

This question relates to the “I” statement” **(A2) My carer/family have their needs recognised and are given support to care for me.** No problems were encountered with the question text however a number of issues were raised with regards to the response options. The use of the word ‘yes’ in answer option 2 was found to be problematic, one participant indicated that it made the answer seem positive when in fact more support was required. The difference between response options 2 ‘Yes, they have had some support but not as much as they needed’ and 3 ‘No, although they tried to get some support’ was also questioned.

The researchers changed the response options, with the question below tested in round 2.

Overall, do you feel that your carer/family has had as much support from health and social services as they needed?

- 1 Yes, they have had as much support as they needed
- 2 They have had some support but not as much as they needed
- 3 No, they have had little or no support
- 4 They did not need support
- 5 There are no family members or carers to support

The question performed well in round 2 with no issues being found with the answer options. Only one change to answer option 4, the addition of the word 'want', was made for round 3. The question below is the final version of the question as tested in round 3.

Overall, do you feel that your carer/family has had as much support from health and social services as they needed?

- 1 Yes, they have had as much support as they needed
- 2 They have had some support but not as much as they needed
- 3 No, they have had little or no support
- 4 They did not want / need support
- 5 There are no family members or carers to support

Carer version

The carer version of this question can be seen below.

Overall, do you feel that you have had as much support from health and social services as you needed?

- 1 Yes, I have had as much support as I needed
- 2 Yes, I have had some support but not as much as I needed
- 3 No, although I tried to get more support
- 4 No, but I did not ask for more support
- 5 I did not need support

Again, in line with the version used with other cohorts the question text was amended and the final version of the question for use with carers, as tested in round 3, can be seen below.

Overall, do you feel that you have had as much support from health and social services as you needed?

- 1 Yes, I have had as much support as I needed
- 2 Yes, I have had some support but not as much as I needed
- 3 No, I have had little or no support
- 5 I did not want / need support

Q1.5. Thinking about all the health and social care services you have used over the last 12 months, to what extent do you agree or disagree with the following statement...I am always told what will happen next

Thinking about all the health and social care services you have used over the last 12 months, to what extent do you agree or disagree with the following statement...

'I am always told what will happen next'

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

This question relates to the "I" statement" (F3) **I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact.** The same version of this question was tested with carers. The question tested well with the majority, with researchers exploring 'what will happen next' with participants.

- MH *Things such as appointments*
- MH *Thinking about during counselling when you would have your last appointment with the counsellor and they wouldn't really explain what you do next*
- PHY *Next phase of treatment, possible side effects. What will happen after specific treatment*
- PHY *With medications staff are very good at saying what they would try next.*

A few participants had concerns over the word 'told' "*told is a bit strong, perhaps rephrase*" (MH) with one participant indicating that it could sound like an order and "*no one can tell me what I will do next*" (PHY). After round 1 the researchers discussed the findings and felt that the word 'told' could bring with it connotations of being told off or directed.

With these comments in mind the researchers wanted to test the question with softer wording. The question tested in rounds 2 and 3 can be seen below.

To what extent do you agree or disagree with the following statement...

'Health and social care staff always tell me what will happen next'

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

This version, which is the final version of the question, tested well with all cohorts with no participants providing negative comment on the phrasing. Similar examples to round 1 were given with regards to 'what will happen next'.

- MH *Any follow up care and letting you know what the future holds with treatment*
- ASC *Giving advice about equipment and what would be installed*

Q1.6. When health or social care staff plan care or treatment for you, does it happen?

When health or social care staff plan care or treatment for you, does it happen?

- 1 Yes, all of the time
- 2 Yes, most of the time
- 3 Yes, some of the time
- 4 No, never

This question relates to the "'I' statement" (B8) **When something is planned, it happens.** In round 1 like with Q1.1 a few participants indicated that the response options were biased towards the positive "*not happy with the yes/no balance*" (MH). No issues were found with the question text. The answer options were amended, with the question used in rounds 2 and 3 seen below. No issues were found with these new answer options and so this is the final version of the question.

When health or social care staff plan care or treatment for you, does it happen?

- 1 Yes, it happens all of the time
- 2 It happens most of the time
- 3 It happens some of the time
- 4 No

Carer version

A different version of the question, with the focus on the care and treatment provided to the person being cared for, was tested with carers.

Thinking about the person you care for, when health or social care staff plan care or treatment for them does it happen?

- 1 Yes, all of the time
- 2 Yes, most of the time
- 3 Yes, some of the time
- 4 No, never

Although no carers raised issue with the answer options, the researchers wanted to keep the question in line with that used with the other cohorts. The question below is the final version of the question for use with carers.

Thinking about the person you care for, when health or social care staff plan care or treatment for them does it happen?

- 1 Yes, it happens all of the time
- 2 It happens most of the time
- 3 It happens some of the time
- 4 No

It should be noted that when discussing whether care or treatment happens a couple of participants spoke about having to wait a long period of time for it. Although this was only mentioned by a minority, and the question matches the “I” statement” (B8) **When something is planned, it happens** moving forward consideration could be given to whether follow up questions are required to explore the time waited or why care and treatment hasn’t happened if someone ticks answer option 4.

Q1.7. Is your care and treatment regularly reviewed?

Is your care and treatment regularly reviewed?

- 1 Yes
2 No

This question which relates to the “I” statement” (B6) **I have regular reviews of my care and treatment, and of my care and support plan** was understood by the majority of participants. However, when researchers asked participants what they considered ‘regular’ to be many indicated that it would be dependent on condition and severity with one participant saying “*depends on the situation, if critically ill they would want it on a weekly basis*” (PHY). Opinions varied from weekly to just being on an ad-hoc basis.

- MH *How long is a piece of string...anything up to every six months. If your condition is unstable then may need more regular reviews.*
- PHY *At least once per year. Some illness may need more constant monitoring*
- MH *If you think of 6 monthly reviews by psychiatrists then that's ok but if in hospital will be every four hours.*
- MH *How would I know what to think if the question does not tell me what regular means*
- ASC *A process maybe every month or could be ad hoc*

Based on this feedback the researchers wanted to move away from the word regular and focus on whether participants regarded their care and support as being reviewed as often as it ought to be. The question below, tested in round 2, provided a more meaningful response than just knowing about the frequency of reviews.

To what extent do you agree or disagree with the following statement...

‘My care and treatment is reviewed as often as it should be’

- 1 Strongly agree
2 Agree
3 Neither agree nor disagree
4 Disagree
5 Strongly disagree

For round 3, in line with previous comments about the differences between care and treatment, the question was split in two. The questions tested in round 3 can be seen below. These are the final versions of the questions.

To what extent do you agree or disagree with the following statement...

'My care and support is reviewed as often as it should be'

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

To what extent do you agree or disagree with the following statement...

'My treatment is reviewed as often as it should be'

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

Carer version

A slightly different version of the question, was used for carers. Again, the comments from carers regarding 'regular' were as varied as those from the other cohorts.

- CAR *Regular-this could mean every five years or more frequently*
- CAR *Every 3 months or when the GP thought it was time*
- CAR *3 months*

For round 3 this question was split with 'care and support' and 'treatment covered in two separate questions.

Thinking about the person you care for, to what extent do you agree or disagree with the following statement...

‘Their care and support is reviewed as often as it should be’

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

Thinking about the person you care for, to what extent do you agree or disagree with the following statement...

‘Their treatment is reviewed as often as it should be’

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

Across all cohorts, having a question to cover reviews of treatment and a question to cover reviews of care and support worked well. When asked if treatment, care and support could appear in one question the consensus from participants in round 3 was that they should remain separate.

Q1.8. Do you have regular, comprehensive reviews of your medicines?

Do you have regular, comprehensive reviews of your medicines?

- 1 Yes
- 2 No
- 3 Don't know

This question relates the “I’ statement” (B7) **I have regular, comprehensive reviews of my medicines**. It soon became apparent during testing that participants felt the question covered two quite different constructs, ‘regular’ and ‘comprehensive’. And in addition, as with Q1.7, what was considered to be regular varied considerably.

'Regular'

- MH *3 months or whenever I think I require a review*
- PHY *Depends on situation*
- MH *Variable, depending on how long been on meds, how stable*

'Comprehensive'

- MH *More exhaustive- embracing, considering all options*
- MH *Holistic, and my review is never holistic*
- MH *Looking at all the details of my situation*
- PHY *What you are on, and why and what your medical problems are. Looking at new medicines that are more suitable. Looking at side effects*
- PHY *This means that they are looking over everything*

Participants felt that if 'regular' and 'comprehensive' were asked about in two questions then the answers could be quite different. Someone could have a regular review of their medicines but they might not be comprehensive or someone may feel that when their medicines are reviewed it is comprehensive but that they just don't have them often.

- MH *The reviews are regular, but they never look into every medication they prescribe me*
- PHY *Comprehensive reviews could happen once or twice a year and regular basic ones could happen every three months.*
- MH *Regular and comprehensive are different*

With these findings in mind the researchers amended the question text after round 1. The question tested in rounds 2 and 3 which is the final version of the question can be seen below.

To what extent do you agree or disagree with the following statement...

'My medicines are thoroughly reviewed as often as they should be'

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

This question performed well with its revised format fitting with the structure of Q1.7. Similar examples to those found in round 1 of what makes a thorough review were given.

- MH *Going through all the possible side effects*
- PHY *Looking at dosage and whether on right tablets and seeing if things needs changing.*

Carer version

Again a slightly different version was tested with carers.

Does the person you care for have regular, comprehensive reviews of their medicines?

- 1 Yes
- 2 No
- 3 Don't know

Carers were also of the opinion that 'comprehensive' and 'regular' are two different constructs and based on these findings, the researchers amended the question text to fit with the version tested with the other cohorts. The final version of the question for use with carers can be seen below.

Thinking about the person you care for, to what extent do you agree or disagree with the following statement...

'Their medicines are thoroughly reviewed as often as they should be'

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

When inserting this question into an existing survey consideration should be given to using a filter question so that if the respondent or person cared for does not take medication then this question can be skipped. The inclusion of another answer option that allows people to indicate that no medicines are being taken would also be a good approach.

Q1.9. To what extent do you agree or disagree with the following statement...I always know who is coordinating care and support

To what extent do you agree or disagree with the following statement...

'I always know who is coordinating my care and support'

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

This question relates to the "'I' statement" (C5) I always know who is coordinating my care. The same version of this question was tested with carers. The researchers explored what participants understood by 'coordinating'.

'Co-ordinating'

- MH *Someone, who is my direct port of call, has an overall view of what is supposed to happen, and when it is supposed to happen, and is in touch with me*
- PHY *A go-to person that you can ring up and they will be able to answer/find out anything and everything*
- PHY *Implies someone has a case file on you and is making things happen for you.*
- ASC *Person who oversees all aspects of my care*
- CAR *The whole team working with the person, including home visits, helping people to get benefits*

Whilst the term 'co-ordinating' was understood by participants, 'I always know' was found to be a source of confusion. One participant was unsure over the difference between 'strongly agreeing' and 'agreeing' to the question saying "surely if you know, you know, so it is a yes" (PHY). For round 2 revisions were made to both the question text and answer options.

Do you have a named health or social care professional co-ordinating your care and support?

- 1 Yes
- 2 No
- 3 I co-ordinate my own care and support
- 4 Don't know / not sure

For round 3 further revisions were made to the question as participants indicated an overlap between answer option 2 and 3. The final version of the question can be seen below.

Do you have a named health or social care professional who co-ordinates your care and support?

- 1 Yes
- 2 No, I co-ordinate my own care and support
- 3 Don't know / not sure

Q1.10. Do you know who to contact if you need to ask questions about your condition or treatment?

Do you know who to contact if you need to ask questions about your condition or treatment?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Don't know / can't remember

This question falls under the "I" statement" (C5) **I always know who is coordinating my care.** A slightly different version was tested with carers:

Do you know who to contact if you need to ask questions about the condition or treatment of the person you care for?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Don't know / can't remember

Both versions performed well, no changes were made to this question between rounds. The majority of participants felt that the question was clear, no participants indicated that they would not know who to contact.

- MH *You know who to contact but will often get referred to someone else*
- ASC *Common sense, you would contact the hospital or GP*
- PHY *I know who to contact but I never know if I will hear back from them or if anything will happen*
- CAR *Question reads very well. Knows who to contact*
- PHY *Same person as is co-ordinating care*

When asked about 'condition' participants tended to speak about their diagnosis or the condition they were suffering from. The inclusion of the word 'treatment' alongside 'condition' caused no problem to participants with some indicating a direct relationship between the two.

- PHY *The chronic fatigue- much better word than illness*
- MH *My diagnosis*
- PHY *Everything involved with what is wrong with you*
- PHY *My heart, my stomach and if I were feeling ill I could contact gp*
- PHY *If you were to just ask about condition it might be about new symptoms but would be related to treatment anyway*
- PHY *Makes sense...condition and treatment are both medical*

The use of 'don't know' and 'can't remember' as one answer option was queried with participants. Combining the two responses was seen as appropriate by participants.

- CAR *Someone may not want to be honest about not remembering*
- MH *OK to keep together, better than just 'don't know'...a bit of a saving grace*
- MH *Would keep them together because they are pretty much the same*

Q1.11. Do you have a 'first point of contact'?

Do you have a 'first point of contact'?

1 Yes

2 No

This question relates to part a of the "I" statement" C6) a) I have one first point of contact. b) They understand both me and my condition(s). C) I can go to them with questions at any time. The same version of the question was tested with carers.

'First point of contact'

The researchers, with a concern that the term could be considered jargon, explored what participants understood by 'first point of contact'.

- PHY *Not sure what a first point of contact is*
- MH *You have to define what you mean by point of first contact. I have different people depending on what happens.*
- CAR *First point of contact for what? It is unlikely you will have*
- PHY *Is this the same as 16? Superfluous*
- MH *Depends where I am...in hospital- community setting, GP*

- PHY *Could be someone different depending on setting- consultant, community district nurse.*
- ASC *There needs to be more explanation around the term 'first point of contact'*
- MH *Similar to co-ordinator question, is it a co-ordinator?*

Overall the term 'first point of contact' caused confusion, it was found to be a term not widely used or familiar to participants. Q1.9 and Q1.10 cover a similar topic (knowing which professional to contact to ask questions) and in comparison to Q1.11 caused little trouble for participants.

With this in mind the researchers took the decision to remove the question from testing after round 1.

Q1.12. Can you go to this person with questions at any time?

Can you go to this person with questions at any time?

- 1 Yes, all of the time
- 2 Yes, most of the time
- 3 Yes, some of the time
- 4 No, never
- 5 I have not needed to ask any questions

This question follows on from Q1.11 and relates to part c of the "I" statement" C6) a) I have one first point of contact. b) They understand both me and my condition(s). C) I can go to them with questions at any time.

'At any time'

The researchers explored what participants understood by 'at any time.'

- CAR *I was only thinking about during the day. There needs to be a specification that this question includes weekends and evenings. We did have someone out of hours to contact, but that is not normal*
- CAR *Reasonable question assuming there is someone. But won't be able to all of the time. Nor would you expect there to be. There won't be any professional you could contact at weekends unless you had built up a relationship with someone*
- PHY *Reasonable to expect to speak to someone during office hours. It is not reasonable to expect to speak to someone immediately*
- MH *Can't go any time of night. But with mental health might need to contact someone at any time of night*

It soon became apparent that when answering the question most participants were thinking of during the week, day time only, rather than weekends and nights. Consequently, 'yes, all of the time' presented itself as an unreasonable response option.

In addition one participant said *“go is not a good word, suggests you can physically go and see someone” (PHY).*

As a result of this feedback the question changed between round 1 and round 2 however it should be noted that it was quite a struggle for the researchers to come up with what they felt was an improved question. There were still concerns that the round 2 version would not test well and if implemented in a national survey would fail to provide useful results. In addition, the removal of Q1.11 due to its poor performance meant that for round 2 the focus was shifted away from ‘first point of contact’ to ‘people treating and caring you’.

If you have questions, when can you contact the people treating and caring for you? Please tick ALL that apply

- 1 During normal working hours
- 2 During the evening
- 3 During the night
- 4 Weekends
- 5 Don't know / not sure

The majority of participants selected answer option 1 ‘during normal working hours’ as their response which was not unexpected. Those few participants that did select other options said they were thinking about out of hour’s services or an emergency situation. With this in mind there is still concern over the usefulness of this question if added to an existing national survey needs to be considered.

Q1.13. Do you feel this person understands about you and your condition?

Do you feel this person understands about you and your condition?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

The question follows on from Q1.12 and relates to part b of the “I” statement” (C6) a) I have one first point of contact. b) They understand both me and my condition(s). C) I can go to them with questions at any time. A slightly different version was tested with carers:

Do you feel this person understands about the person you care for and their condition?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

Many participants liked this question and it performed well during testing.

'About you' and 'about your condition'

Participants were asked whether understanding about you was the same thing as understanding about your condition. The majority of participants noted that 'about you' and 'about your condition' were different.

- PHY *'You' and 'your condition' quite different. 'You' it is everything else and other impacts of condition*
- MH *May be gemmed up about condition but wouldn't know about other things in my life-personal circumstances*
- MH *How does my condition influence how I live and maintain my life*
- PHY *Understanding about you comes with relationship building*
- ASC *There is a difference between you and your condition. Some people might want lots of advice but others would only want some advice and it is about the person knowing that*
- PHY *You aren't defined by your condition. The person might have in-depth knowledge about your condition but no about you, these are different things*
- MH *About condition "Is my diagnosis"*

Despite many participants noting the difference, when asked if 'about you' and 'about your condition' should be asked in two questions, many indicated that they didn't need to be. Understanding about the person as a whole was seen as important.

- ASC *So different but very much important to consider both together*
- CAR *Can't separate 'you' and 'your condition' as you can't meet the person I care for and have his condition as separate as it influences who he is. There are parts of him that relate to his condition*

This is different to the view about 'care and support' and 'treatment' which the majority of participants felt should be separated out.

No changes were made to either version of the question between rounds.

It should be noted that in round 1 this question followed on from Q1.11. Do you have a 'first point of contact'? However because Q1.11 was removed from testing in round 1, in rounds 2 and 3 this question followed on from Q1.9 'Do you have a named health or social care professional co-ordinating your care and support?'. Inserting this question into an existing survey would require it to have a similar lead question.

Q1.14. Do all the different people treating and caring for you work well together to give you the best possible care and support?

Do all the different people treating and caring for you work well together to give you the best possible care and support?

- 1 Yes, all of the time
- 2 Yes, most of the time
- 3 Yes, some of the time
- 4 No, never
- 5 Don't know

This question relates to the “I” statement” (C4) **The professionals involved with my care talk to each other. We all work as a team.** The researchers probed what participants thought counted as ‘working well together’ and what would be the ‘best possible care and support’

‘Work well together’

As can be seen below, working well together was considered by the majority of participants as being about good communication between professionals.

- MH *Knowing what the other people are doing*
- PHY *Discussing things if you talk to a consultant, tell him you need something then it should go back to whoever needs to know*
- PHY *Communication and co-ordinating so they are not working against each other*
- PHY *From my knowledge they write letters to each other and communicate back to my GP with results so I am guessing that is how well they work together*

‘Best possible care and support’

The researchers also probed what participants felt to be the ‘best possible care and support’ they could receive.

- PHY *To provide exactly what you need when you need it*
- PHY *Dealing with my condition and getting it sorted and offering me ways to minimise its effect on me and my life*
- ASC *Communication is a priority so they know if there is a change in your condition*
- PHY *Not just about treating me but making sure my appointments are booked and understanding about side effects*

The question text remained the same between rounds however the answer options were amended to move the focus away from how often the professionals work well together to whether they all work well together. The final version of the question can be seen below.

Do all the different people treating and caring for you work well together to give you the best possible care and support?

- 1 Yes, all of them work well together
- 2 Most of them work well together
- 3 Some of them work well together
- 4 No, they do not work well together
- 5 Don't know / not sure

It should be noted that while the question tested well over the rounds overall, a couple of participants indicated that they could just assume that professionals work well together as they get a good outcome. This indicates that if not witness to the interactions between staff, but the outcome is good, respondents could just assume the staff have worked well together. This highlights the importance of having a 'Don't know / not sure' answer options.

Carer version

Again a different version was tested with carers. The round 1 question can be seen below.

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?

- 1 Yes, all of the time
- 2 Yes, most of the time
- 3 Yes, some of the time
- 4 No, never
- 5 Don't know

In line with the other cohorts the answer text was revised between round 1 and round 2. Similar examples of 'working well together' and 'best possible care and support' to those from the other cohorts were provided by the carers.

'Work well together'

- CAR *Keeping the person and each other informed*
- CAR *Meeting regularly and me getting a summary of that meeting*

'Best possible care and support'

- CAR *Health and social care working hand in glove*

No further changes were made to the question with the final version seen below.

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?

- 1 Yes, all of them work well together
- 2 Most of them work well together
- 3 Some of them work well together
- 4 No, they do not work well together
- 5 Don't know / not sure

Q1.15. Do all the services help you live the life you want as far as possible?

Do all of the services help you live the life you want as far as possible?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

This question looks at the “‘I’ statement” (A4) **Taken together, my care and support help me live the life I want to the best of my ability.** The same version of this question was tested with all cohorts.

The researchers explored ‘live the life you want’ to understand what participants thought about and while the examples given were varied on the whole they related to being able to work and do everyday activities and hobbies.

‘Live the life you want’

- ASC *About doing various interests as well as working a full time job*
- CAR *I was thinking about time for me, handling stress better and being a better carer. Also looking after myself*
- PHY *Being able to work and do everything that I want to do, I am not restricted in any way*
- PHY *They still haven't cured me. Like to be able to go out for meals but can't, like to go up to high altitude but can't. So everyday things and activities*
- MH *Everything you are capable of doing*
- CAR *Can I have a life of my own apart from looking after husband?*

The question performed well and no changes were made between round 1 and 2. However, for round 3 with the aim of slotting the question into existing surveys in mind the researchers felt it important to clearly state the services as ‘health and social care services’. The question tested in round 3 can be seen below.

Do health and social care services help you live the life you want as far as possible?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

This question again tested well in round 3, with the addition of 'health and social care services' helping give focus to the question. The question tested in round 3 is the final version of the question.

Q1.16. Do health and social care services work together to coordinate your care effectively?

Do health and social care services work together to coordinate your care effectively?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Don't know

The researchers wanted to include a question which looked at opinion of how well care is co-ordinated by health and social services. And so whilst not directly related to one specific "I" statement" it could fall under (C5) I always know who is coordinating my care and (F3) I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact.

When asked about co-ordination participants gave similar examples to those given to Q1.9.

'Co-ordinating'

- PHY *Do all services gel together*
- MH *Joined up thinking*
- PHY *Effective co-ordination...would look like heaven!*
- CAR *Being aware what's happening, knowing what others are doing*

A few participants noted this question's overlap with Q1.14 'Do all the different people treating and caring for you work well together to give you the best possible care and support?' and Q1.15 'Do all of the services help you live the life you want as far as possible?'. One participant after commenting on its similarity then noted that *"it doesn't add anything that hasn't already been covered"* (MH). Another had to re-read the question to figure out how it differed from asking about 'all the different people'. One participant preferred Q1.14 because it was easier to think about staff rather than a service.

In addition one participant said that they “wouldn’t know if they worked together at all” (PHY) and when asked why they said it was like making a judgement on the whole system which they found difficult.

With this feedback in mind, weighing up its performance against Q1.14 and Q1.15, the researchers took the decision to remove the question from testing after round 1.

Q1.17. In the last 12 months, have you found it easy or difficult to find information and advice about support, services, and benefits? Please include information about advice from different sources such as voluntary organisations and private agencies as well as social services?

In the last 12 months, have you found it easy or difficult to find information and advice about support, services, or benefits? Please include information and advice from different sources such as voluntary organisations and private agencies as well as social services?

- 1 I have not tried to find information
- 2 Very easy to find
- 3 Fairly easy to find
- 4 Fairly difficult to find
- 5 Very difficult to find

This question tested relates to the “I’ statement” (D5) **I am told about the other services that are available to someone in my circumstances, including support organisations** and appears in the Personal Social Services Carers Survey. The same version of this question was tested with all cohorts.

Many participants in round 1 indicated that it was important to cover the provision of information and advice.

‘Information and advice’

Types of information and advice thought about by participants can be seen below.

- PHY *Information given to me by specialist about what was wrong with me and how I can improve*
- MH *Benefits such as sickness and housing*
- ASC *Services might include day centre*
- CAR *Equipment, occupational therapy, money and finance*
- MH *Getting information about care services like podiatrists*
- MH *Mind support centres, charities that can help with day to day things*

Despite many participants indicating the question’s importance, it performed poorly during round 1 testing. A number of participants had to read the question a couple of

times before being able to answer. One interviewee said *"it makes sense but is quite long"* (MH) and another said *"it covers too many constructs"* (CAR). In addition one participant asked about the difference between information being 'fairly easy to find' and 'fairly difficult to find'.

The researchers broke the question down in to its three key elements (Easy or difficult / Information and advice / Support, services, or benefits) and felt that it would need changing drastically with the possibility of multiple questions being required to ensure that each key element was covered adequately. The researchers decided that the best option would be to trial a variation of the "I" statement" in round 2.

To what extent do you agree or disagree with the following statement...

'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'

- 1 Strongly agree
- 2 Agree
- 3 Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

The question performed well in round 2 and 3. Unlike in round 1 no participant's struggled with the length or number of constructs presented in the question. This simpler question was also found to elicit similar examples of information and advice as seen in round 1. This is the final version of the question.

7.6.1 Versions tested with carers: a consideration

As mentioned throughout this section for a number of the questions a different version was tested with carers. See table 21 for a table showing the carer version of the questions against those tested with the other cohorts.

During round 1 the questions for carers were tested in the same order as those tested with other cohorts. The researchers soon found that this order meant frequently switching between questions that asked 'about you' and 'about the person you care for' which was a cause of confusion for participants.

In rounds 2 and 3 the researchers re-ordered the question set to ensure the grouping of all questions that asked the carer about themselves and all questions which asked about the person they care for. The lead statements (seen in table 1) were also used to focus participants. These changes gave the question set a better flow.

When inserting any of our tested questions into an existing survey of carers consideration should be given to question order and use of leading statements to eliminate the type of confusion found in round 1 of our testing.

7.6.2 Differences between cohorts

As mentioned above, a few of the questions tested were found to be not as relevant or suitable to carers as the other cohorts. For example, 'were you involved as much as you wanted to be in decisions about your treatment?' is an example of a question which didn't test well with carers.

No other real differences were apparent between cohorts, which is a good indication of the question set's generalisability. However, it should be noted that there are some questions in the set which will not always be relevant to all respondents within a national survey. For example, the question which asks if treatment is reviewed as often as it should be is not applicable to those not receiving treatment. It is not clear what proportion of respondents to the personal social services adult social care survey this would be relevant to.

No differences in comprehension or relevance of questions were found between participants in different geographic regions. As would be expected, when discussing the types of services accessed, the voluntary and support services accessed by participants varied. For example, some mental health service users in Oxford cited a particular charity as a support group whereas mental health service users in Daventry cited accessing other types of support. Whilst this did not have an influence on the performance of questions it does reflect an expected variation in the voluntary and support services available across regions.

8 FINAL QUESTION SET

This section details the final set of eighteen questions cognitively tested with people from a range of backgrounds and with experience of using different health and social care services.

A number of these items are considered to be usable for national indicator purposes. The research team acknowledge some flexibility around the specific choice of items that should be used, but recommend minimising the number of questions to ease adoption into existing surveys.

It is hoped that by the addition of a few of these questions in national surveys it will help providers and commissioners to identify, explore, and challenge poorly integrated care locally.

Table 21 below provides details on the final set of questions. For each question the table shows:

- Final question and answer text
- Related “I’ statement”
- Summary of changes between rounds
- If the question requires a filter
- If the question covers a similar theme to another question in the set

Table 21: Final question set

Question	Carer version	‘I’ statement	Revisions made between rounds?	Filter required?	Similar question in set?
<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>	<p>(A1) All my needs as a person are assessed.</p>	<p>Yes, revision to answer text after round 1</p>	<p>No</p>	<p>Unique</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>	<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>(E1) I am as involved in discussions and decisions about my care, support and treatment as I want to be.</p>	<p>Yes, revision to question text after round 2</p>	<p>No</p>	<p>Similar to Q3.2b</p>
<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>	<p>The researchers do not recommend using this question in a survey of carers.</p>	<p>(E1) I am as involved in discussions and decisions about my care, support and treatment as I want to be.</p>	<p>Yes, revision to question text after round 2</p>	<p>No</p>	<p>Similar to Q3.2a</p>
<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>4 <input type="checkbox"/> I didn't want to be involved in decisions about care</p>	<p>(E2) My family or carer is also involved in these decisions as much as I want them to be.</p>	<p>Yes, revision to question text after round 2</p>	<p>No</p>	<p>Similar to Q3.3b</p>
<p>Q3.3b Were your</p>	<p>Q3.3b Were you</p>	<p>(E2) My family</p>	<p>Yes, revision</p>	<p>No</p>	<p>Similar to</p>

<p>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</p>	<p>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>4 <input type="checkbox"/> I didn't want to be involved in decisions about treatment</p>	<p>or carer is also involved in these decisions as much as I want them to be.</p>	<p>to question text after round 2</p>		<p>Q3.3a</p>
<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 I 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>5 <input type="checkbox"/> I did not want / need support</p>	<p>(A2) My carer/family have their needs recognised and are given support to care for me.</p>	<p>Yes, revision to answer text after round 1 and after round 2.</p>	<p>No</p>	<p>Unique</p>
<p>Q3.5 To what extent</p>	<p>Q3.5 To what extent</p>	<p>(F3) I know in</p>	<p>Yes, revision</p>	<p>No</p>	<p>Unique</p>

<p>do you agree or disagree with the following statement...</p> <p>'Health and social care staff always tell me what will happen next'</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>do you agree or disagree with the following statement...</p> <p>'Health and social care staff always tell me what will happen next'</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>advance where I am going, what I will be provided with, and who will be my main point of professional contact.</p>	<p>to question text after round 1</p>		
<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</p> <p>2 <input type="checkbox"/> It happens most of the time</p> <p>3 <input type="checkbox"/> It happens some of the time</p> <p>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</p> <p>2 <input type="checkbox"/> It happens most of the time</p> <p>3 <input type="checkbox"/> It happens some of the time</p> <p>4 <input type="checkbox"/> No</p>	<p>(B8) When something is planned, it happens.</p>	<p>Yes, revision to question text and answer options after round 1.</p>	<p>No</p>	<p>Unique</p>
<p>Q3.7a To what extent do you agree or</p>	<p>Q3.7a Thinking about the person you</p>	<p>(B6) I have regular reviews</p>	<p>Yes, revision to question</p>	<p>No</p>	<p>Similar to Q3.7b</p>

<p>disagree with the following statement...</p> <p>'My care and support is reviewed as often as it should be'</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>care for, to what extent do you agree or disagree with the following statement...</p> <p>'Their care and support is reviewed as often as it should be'</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>of my care and treatment, and of my care and support plan.</p>	<p>text and answer options after round 1 and round 2.</p>		<p>and Q3.8</p>
<p>Q3.7b To what extent do you agree or disagree with the following statement...</p> <p>'My treatment is reviewed as often as it should be'</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>Q3.7b Thinking about the person you care for, to what extent do you agree or disagree with the following statement...</p> <p>'Their treatment is reviewed as often as it should be'</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>(B6) I have regular reviews of my care and treatment, and of my care and support plan</p>	<p>Yes, revision to question text and answer options after round 1 and round 2.</p>	<p>No</p>	<p>Similar to Q3.7a and Q3.8</p>
<p>Q3.8 To what extent do you agree or disagree with the</p>	<p>Q3.8 Thinking about the person you care for, to what extent</p>	<p>(B7) I have regular, comprehensive</p>	<p>Yes, revision to question text and</p>	<p>Yes – to filter out those who</p>	<p>Unique</p>

<p>following statement...</p> <p>'My medicines are thoroughly reviewed as often as they should be'</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>do you agree or disagree with the following statement...</p> <p>'Their medicines are thoroughly reviewed as often as they should be'</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>reviews of my medicines.</p>	<p>answer options after round 1.</p>	<p>do not take medicines</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>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>(C5) I always know who is co-ordinating my care.</p>	<p>Yes, revision to question text and answer options after round 1 and round 2.</p>	<p>No</p>	<p>Similar to Q3.10</p>
<p>Q3.10 Do you know who to contact if you need to ask questions</p>	<p>Q3.10 Do you know who to contact if you need to ask</p>	<p>(C5) I always know who is coordinating</p>	<p>No changes to this question.</p>	<p>No</p>	<p>Similar to Q3.9</p>

<p>about your condition or 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> <p>4 <input type="checkbox"/> Don't know / can't remember</p>	<p>questions about the condition or 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>4 <input type="checkbox"/> Don't know / can't remember</p>	<p>my care.</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?</p> <p>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>(C6) a) I have one first point of contact. b) They understand both me and my condition(s). C) I can go to them with questions at any time.</p>	<p>Yes, revision to question text and answer options after round 1.</p>	<p>No</p>	<p>Unique</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>(C6) a) I have one first point of contact. b) They understand both me and my condition(s). C) I can go to them with questions at any time.</p>	<p>No changes to this question.</p>	<p>Yes – Q3.9</p>	<p>Unique</p>
<p>Q3.14 Do all the different people treating and caring for you work well together</p>	<p>Q3.14 Thinking about the person you care for, do all the different people</p>	<p>(C4) The professionals involved with my care talk to</p>	<p>Yes, revision to answer text after round 1.</p>	<p>No</p>	<p>Similar to Q3.15</p>

<p>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>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>each other. We all work as a team.</p>			
<p>Q3.15 Do health and social care services help you live the life you want as far as possible?</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>Q3.15 Do health and social care services help you live the life you want as far as possible?</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>(A4) Taken together, my care and support help me live the life I want to the best of my ability.</p>	<p>Yes, revision to question text after round 2.</p>	<p>No</p>	<p>Similar to Q3.14</p>
<p>Q3.17 To what extent do you agree or disagree with the following statement...</p>	<p>Q3.17 To what extent do you agree or disagree with the following</p>	<p>(D5) I am told about the other services that are available to</p>	<p>Yes, revision to question text and answer text</p>	<p>No</p>	<p>Unique</p>

	statement...	someone in my circumstances, including support organisations.	after round 1.
'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'	'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'		
1 <input type="checkbox"/> Strongly agree	1 <input type="checkbox"/> Strongly agree		
2 <input type="checkbox"/> Agree	2 <input type="checkbox"/> Agree		
3 <input type="checkbox"/> Neither agree nor disagree	3 <input type="checkbox"/> Neither agree nor disagree		
4 <input type="checkbox"/> Disagree	4 <input type="checkbox"/> Disagree		
5 <input type="checkbox"/> Strongly disagree	5 <input type="checkbox"/> Strongly disagree		

9 Appendix A: Person-centred, coordinated care: National Voices “I” statements”

- A** **My goals/outcomes**
- (A1) All my needs as a person are assessed.
 - (A2) My carer/family have their needs recognised and are given support to care for me.
 - (A3) I am supported to understand my choices and to set and achieve my goals.
 - (A4) Taken together, my care and support help me live the life I want to the best of my ability.
- B** **Care planning**
- (B1) I work with my team to agree a care and support plan.
 - (B2) I know what is in my care and support plan. I know what to do if things change or go wrong.
 - (B3) I have as much control of planning my care and support as I want.
 - (B4) I can decide the kind of support I need and how to receive it.
 - (B5) My care plan is clearly entered on my record.
 - (B6) I have regular reviews of my care and treatment, and of my care and support plan.
 - (B7) I have regular, comprehensive reviews of my medicines.
 - (B8) When something is planned, it happens.
 - (B9) I can plan ahead and stay in control in emergencies.
 - (B10) I have systems in place to get help at an early stage to avoid a crisis.
- C** **Communication**
- (C1) I tell my story once.
 - (C2) I am listened to about what works for me, in my life.
 - (C3) I am always kept informed about what the next steps will be.
 - (C4) The professionals involved with my care talk to each other. We all work as a team.
 - (C5) I always know who is coordinating my care.
 - (C6) 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.
- D** **Information**
- (D1) I have the information, and support to use it, that I need to make decisions and choices about my care and support.
 - (D2) I have information, and support to use it, that helps me manage my condition(s).
 - (D3) I can see my health and care records at any time. I can decide who to share them with. I can correct any mistakes in the information.
 - (D4) Information is given to me at the right times. It is appropriate to my condition and circumstances. It is provided in a way that I can understand.
 - (D5) I am told about the other services that are available to someone in my circumstances, including support organisations.

(D6) I am not left alone to make sense of information. I can meet/phone/email a professional when I need to ask more questions or discuss the options.

E Decision making including budgets

(E1) I am as involved in discussions and decisions about my care, support and treatment as I want to be.

(E2) My family or carer is also involved in these decisions as much as I want them to be.

(E3) I have help to make informed choices if I need and want it.

(E4) I know the amount of money available to me for care and support needs, and I can determine how this is used (whether it's my own money, direct payment, or a 'personal budget' from the council or NHS).

(E5) I am able to get skilled advice to understand costs and make the best use of my budget.

(E6) I can get access to the money quickly without over-complicated procedures.

F Transitions

(F1) When I use a new service, my care plan is known in advance and respected.

(F2) When I move between services or settings, there is a plan in place for what happens next.

(F3) I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact.

(F4) I am given information about any medicines I take with me – their purpose, how to take them, potential side effects.

(F5) If I still need contact with previous services/professionals, this is made possible.

(F6) If I move across geographical boundaries I do not lose my entitlements to care and support.

10 Appendix B: Questions presented at owners workshop

A My goals/outcomes	Survey
(A1) All my needs as a person are assessed.	
<p>Patient Perceptions of Integrated Care survey</p> <p>Thinking back about the care you received in the last [6 months], how often do you think your [doctor] understood the things that really mattered to you?</p> <p>Always Usually Sometimes Never</p>	<p>Patient Perceptions of Integrated Care survey</p>
<p>New Question</p> <p>Thinking about all the care you received in the last 6 months from health and social care services...</p> <p>Have all of your needs been assessed?</p> <p>Yes, definitely Yes, to some extent No</p>	<p>New Question</p>
(A2) My carer/family have their needs recognised and are given support to care for me.	
<p>National voices survey of bereaved people</p> <p>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]?</p> <p>Yes, we got as much support as we wanted Yes, we got some support but not as much as we wanted No, although we tried to get more help No, but we did not ask for more help We did not need help</p>	<p>National voices survey of bereaved people</p>
<p>New Question</p>	<p>New Question</p>

<p>Overall, do you feel that your carer/family has had as much help and support from health and social services as they needed?</p> <p>Yes, they have as much support as wanted Yes, they have some support but not as much as we wanted No, although they tried to get more help No, but they did not ask for more help They did not need help</p>	
<p>(A3) I am supported to understand my choices and to set and achieve my goals.</p>	
<p>New Questions</p> <p>Have you been supported to understand your choices? and to set and achieve your goals?</p> <p>Yes, definitely Yes, to some extent No</p> <p>Have you been supported to set any goals?</p> <p>Yes, definitely Yes, to some extent No</p> <p>If you have set any goals, do you think they have been achieved?</p> <p>Yes, definitely Yes, to some extent No</p>	<p>New Questions</p>
<p>Mental Health Community Survey (2013):</p> <p>Do you understand what is in your NHS care plan?</p> <p>Yes, definitely Yes, to some extent No, I don't understand it I don't know/can't remember what is in my care plan I do not have a care plan</p>	<p>Mental Health Survey</p>
<p>Mental Health Community Survey (2013):</p> <p>Do you think your views were taken into account when deciding what was in your NHS care plan?</p> <p>Yes, definitely</p>	<p>Mental Health Survey</p>

Yes, to some extent No	
<p>Mental Health Community Survey (2013):</p> <p>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>Yes, definitely Yes, to some extent No</p>	Mental Health Survey
<p>Mental Health Community Survey (2013):</p> <p>Have NHS mental health services helped you start achieving these goals?</p> <p>Yes, definitely Yes, to some extent No</p>	Mental Health Survey
<p>(A4) Taken together, my care and support help me live the life I want to the best of my ability.</p>	
<p>Adult social care survey</p> <p>Do care and support services help you in having control over your daily life?</p> <p>Yes No</p>	Adult social care survey
<p>New Question</p> <p>Thinking about all of the health and social care you have accessed...</p> <p>Do care and support services help you live the life you want as far as possible?</p> <p>Yes, definitely Yes, to some extent No</p>	New Question
<p>B Care planning</p>	
<p>(B6) I have regular reviews of my care and treatment, and of my care and support plan.</p>	
GPPS	GPPS

<p>Does your GP, nurse or other health professional review your written care plan with you regularly</p> <p>Yes No Don't know</p>	
<p>Mental Health Community Survey (2013):</p> <p>In the last 12 months have you had a care review meeting to discuss your care?</p> <p>Yes, I have had more than one Yes, I have had one No, I have not had a care review in the last 12 months Don't know / Can't remember</p>	<p>Mental Health Survey</p>
<p>(B7) I have regular, comprehensive reviews of my medicines.</p>	
<p>Mental Health Community Survey (2013):</p> <p>In the last 12 months, has an NHS mental health worker or social care worker checked with you about how you are getting on with your medication - i.e. have your medicines been reviewed? (Please do not include reviews by your GP.)</p> <p>Yes No</p>	<p>Mental Health Survey</p>
<p>New Question</p> <p>Do you have regular, comprehensive reviews of your medicines?</p> <p>Yes No Don't know</p>	<p>New Question</p>
<p>(B8) When something is planned, it happens.</p>	
<p>New Question</p> <p>How much do you agree or disagree with the following statement...</p> <p>When health or social services plan care or treatment for me, it</p>	<p>New Question</p>

<p>happens'?</p> <p>Strongly agree Agree Neither agree nor disagree Disagree Strongly Disagree</p>	
<p>C Communication</p>	
<p>(C4) The professionals involved with my care talk to each other. We all work as a team.</p>	
<p>National voices survey of bereaved people</p> <p>Did the hospital services work well together with (his) GP and other services outside the hospital?</p> <p>Yes, definitely Yes, to some extent No they didn't work well together Don't know</p>	<p>National voices survey of bereaved people</p>
<p>National voices survey of bereaved people</p> <p>When (he) was at home in the last three months of life, did all (these-health and social services) work well together?</p> <p>Yes, definitely Yes, to some extent No they didn't work well together He did not receive any care Don't know</p>	<p>National voices survey of bereaved people</p>
<p>National Cancer Patient Survey (2012/2013):</p> <p>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> <p>Yes, always Yes, most of the time Yes, some of the time No, never Don't know</p>	<p>National Cancer Patient Survey</p> <p>Re-frame for Carers</p>
<p>(C5) I always know who is coordinating my care.</p>	
<p>Mental Health Community Survey (2013):</p> <p>Do you know who your Care Co-ordinator (or lead professional) is?</p>	<p>Mental Health Survey</p>

<p>Yes No Not sure</p>	
<p>National Cancer Patient Survey (2012/2013):</p> <p>Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?</p> <p>Yes No Don't know / not sure</p>	<p>National Cancer Patient Survey</p>
<p>New Question</p> <p>To what extent do you agree or disagree with the following statement...</p> <p>'I always know who is responsible for my care'</p> <p>Strongly agree Agree Neither agree nor disagree Disagree Strongly Disagree</p>	<p>New Question</p>
<p>(C6) a) I have one first point of contact. b) They understand both me and my condition(s). c) I can go to them with questions at any time.</p>	
<p>Mental Health Community Survey (2013):</p> <p>Can you contact your Care Co-ordinator (or lead professional) if you have a problem?</p> <p>Yes, always Yes, sometimes No</p>	<p>Mental Health Survey</p>
<p>National Cancer Patient Survey (2012/2013):</p> <p>How easy is it for you to contact your Clinical Nurse Specialist?</p> <p>Easy Sometimes easy, sometimes difficult Difficult</p>	<p>National Cancer Patient Survey</p>

I have not tried to contact her/him	
<p>New Question</p> <p>Do you have a 'first point of contact'</p> <p>Yes No</p> <p>Do you feel this person understands about you and your condition?</p> <p>Yes, definitely Yes, to some extent No</p>	New Questions
<p>D Information</p>	
<p>(D5) I am told about the other services that are available to someone in my circumstances, including support organisations.</p>	
<p>Inpatient Survey (2013):</p> <p>Did hospital staff discuss with you whether you may need any further health or social care services after leaving hospital? (eg. services from a GP, physiotherapist or community nurse, or assistance from social services or the voluntary sector)</p> <p>Yes No, but I would have liked them to No, it was not necessary to discuss it</p>	Inpatient survey
<p>National Cancer Patient Survey (2012/2013):</p> <p>Did hospital staff give you information about support or self-help groups for people with cancer</p> <p>Yes, No, but I would have liked information It was not necessary Don't know/cant remember</p>	National Cancer Patient Survey
<p>Mental Health Community Survey (2013):</p> <p>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>Yes, definitely Yes, to some extent</p>	Mental Health Survey

<p>No, but I would have liked support I did not need any support I do not have any physical health needs</p> <p>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>Yes, definitely Yes, to some extent No, but I would have liked support I did not need any support I do not have any caring responsibilities</p> <p>In the last 12 months, have you received support from anyone in NHS mental health services in getting help with finding or keeping work (eg. being referred to an employment scheme)?</p> <p>Yes, definitely Yes, to some extent No, but I would have liked support I did not need any support I am unable to work because of my mental health problems</p> <p>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>Yes, definitely Yes, to some extent No, but I would have liked support I did not need any support</p> <p>In the last 12 months, have you received support from anyone in NHS mental health services in getting help with financial advice or benefits (eg. Housing Benefit, Income Support, Disability Living Allowance)?</p> <p>Yes, definitely Yes, to some extent No, but I would have liked support I did not need any support</p>	
<p>Adult social care survey</p>	<p>Adult social care survey</p>

<p>In the past year, have you generally found it easy or difficult to find information and advice about support, services or benefits</p> <p>Very easy to find Fairly easy to find Fairly difficult to find Very difficult to find</p>	
<p>Carers survey</p> <p>In the past 12 months, have you found it easy or difficult to find information and advice about support, services or benefits? Please include information and advice from different sources such as voluntary organisations and private agencies as well as social services</p> <p>I have not tried to find information Very easy to find Fairly easy to find Fairly difficult to find Very difficult to find</p>	<p>Carers survey</p>
<p>(D6) I am not left alone to make sense of information. I can meet/phone/email a professional when I need to ask more questions or discuss the options.</p>	<p>Captured by C6, part c</p>
<p>National Cancer Patient Survey (2012/2013):</p> <p>Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?</p> <p>Yes, No Don't know/cant remember</p>	<p>National Cancer Patient Survey</p>
<p>Inpatient Survey (2013):</p> <p>Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?</p> <p>Yes No Don't know / can't remember</p>	<p>Inpatient Survey (2013)</p>
<p>New Question</p> <p>Do you know who to contact if you need to ask questions about your condition or treatment?</p> <p>Yes No</p>	<p>New Question</p>

Don't know / can't remember	
E Decision making including budgets	
(E1) I am as involved in discussions and decisions about my care, support and treatment as I want to be.	
Inpatient Survey (2013): Were you involved as much as you wanted to be in decisions about your care and treatment? Yes, definitely Yes, to some extent No	Inpatient Survey (2013)
(E2) My family or carer is also involved in these decisions as much as I want them to be.	
Carers survey In the last 2 months do you feel you have been involved or consulted as much as you wanted to be in discussions about the support or services provided to the person you care for? There have been no discussions that I am aware of I always felt involved or consulted I usually felt involved or consulted I sometimes felt involved or consulted I never felt involved or consulted	Carers survey
PEQ Did the healthcare staff offer your family, carers or friends the opportunity to be involved in decisions about your condition and treatment? Yes, always Yes, sometimes No, never There were no family members, carers or friends available to be involved I didn't want my family, carers or friends to be involved in decisions about my care and treatment	PEQ
(E4) I know the amount of money available to me for care and support needs, and I can determine how this is used (whether it's my own money, direct payment, or a 'personal budget' from the council or NHS).	

For discussion	
(E5) I am able to get skilled advice to understand costs and make the best use of my budget.	
For discussion	
(E6) I can get access to the money quickly without over-complicated procedures.	
For discussion	
F Transitions	
(F2) When I move between services or settings, there is a plan in place for what happens next.	
Captured in A, B	
(F3) I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact.	
Inpatient Survey (2013): Were you given enough notice about when you were going to be discharged? Yes, definitely Yes, to some extent No	Inpatient Survey (2013)
New Question If you have moved between services has there been a plan in place for what happens next? Yes, definitely Yes, to some extent No Don't know	New Question
New Question Thinking about the health and social care services you have accessed... Do the services work together to co-ordinate your care effectively?	New Question

Strongly agree Agree Neither agree nor disagree Disagree Strongly Disagree	
--	--

11 Appendix C: Cognitive interviews, all participant details

No.	Gender	Ethnicity	Age	Carer	Condition	Examples of services accessed in last year	Employment	Q version
1	Female	White British	70	Yes	Arthritis		Voluntary work	Carer
2	Male	White British	69	No	Diabetes	Outpatient		Physical
3	Male	White British	73	No	Stroke	Inpatient	Retired, voluntary work	Physical
4	Male	White British	45	No	Mental health condition	Mental Health and voluntary	Voluntary work	Mental Health
5	Male	White British	48	No	Cervical Spondylitis	Inpatient and Mental Health		Physical
6	Female	White British	37	No	Anxiety and depression	Mental Health and Social Services	Full time student	Social Care
7	Male	White British	45	No	Aortic regurgitation	Inpatient and Outpatient	Unemployed	Physical
8	Female	White French	69	No		Inpatient and Outpatient	Retired, voluntary work	Physical
9	Female	White British	56	Yes			Working 16+ hours a week	Carer
10	Female	White Italian	48	Yes			Unemployed	Carer
11	Female	White British	49	No	PTSD and Asthma	Mental Health and GP	Self-employed	Mental Health
12	Female	White English	33	No		Mental Health and Inpatient		Mental Health
13	Female	White British	69	Yes		Social Care		Carer
14	Female	White British	47	No	Endometriosis	Outpatient and Social Services	Working 16+ hours a week	Physical

15	Male	White British	66	No	Barrett's oesophagus	Inpatient		Physical
16	Female	White British	28	No	Chronic pelvic and back condition	GP and outpatient	Working 16+ hours a week	Physical
17	Male	White British	50	No		Social Care		Social Care
18	Female	White British	26	No	Chronic fatigue	GP and Hospital	Working 1-15 hours a week	Physical
19	Female	White British	41	No	Depression, borderline personality disorder	Mental Health and Social Services	Unemployed	Social Care
20	Female	White British	49	No	Parkinson's	GP and Hospital	Working 16+ hours a week	Mental Health
21	Male	White British	22	No		Inpatient	Self-employed	Mental Health
22	Female	White British	68	Yes		Outpatient and Emergency	Voluntary work	Carer
23	Male	White British	21	No	diagnosis of Schizophrenia	Community	Voluntary work	Mental Health
24	Male	White British	22	Yes	Depression	Mental Health	Student	Mental Health
25	Female	White British	38	No		Community and Voluntary	Unemployed	Physical Health
26	Female	White British	66	Yes		GP	Retired	Carer
27	Female	White British	57	No	Cluster Headaches	Inpatient	Retired	Physical Health
28	Male	Indian	21	No	Depression	Mental Health		Mental Health
29	Female	Asian	19	No		Social care		Social Care
30	Male	White British	30	No	Coeliac disease	Inpatient	Working 16+ hours a week	Physical Health
31	Female	White British	27	No	Polycystic ovary	GP and Tropical medicine	Working 16+ hours a week	Physical Health

32	Male	White British	59	No	Diabetes, heart disease	Inpatient and Outpatient	Working 1-15 hours a week	Physical Health
33	Female	White British	59	No	Rheumatoid arthritis	Inpatient and Outpatient	Working 1-15 hours a week	Physical Health
34	Female	White British	68	Yes	Diabetes	Inpatient and Social services	Retired	Carer
35	Female	White British	66	Yes		Social Services	Retired	Carer
36	Male	White English	58	No	Glycogen storage disorder	Inpatient and Social services	Working 16+ hours a week	Social Care
37	Female	White English	66	Yes	Atypical facial pain	Inpatient and Outpatient		Physical Health
38	Female	White British	20		Chronic Pain Condition	Outpatient and Social Services	Voluntary work	Physical Health
39	Female	Black African	47	Yes		GP and voluntary	Working 1-15 hours a week	Carer
40	Male	Black African	22			GP and outpatient		Physical Health
41	Male	White English	22	No	Asperger's	Community services and voluntary	Unemployed	Social Care
42	Female	White British	45	No	Personality Disorder	Community services and voluntary	Unemployed	Mental Health
43	Female	White British	54	No	Bipolar	Inpatient and community services	Unemployed	Mental Health
44	Male	White British	72	No		Outpatient	Retired	Mental Health
45	Male	White British	57	No	Bipolar	GP and voluntary services	Unemployed	Mental Health
46	Female	White British	63	No	Bipolar and Diabetes	Outpatient	Retired	Mental Health
47	Female	White British	23	No		Inpatient and social services	Unemployed	Social Care
48	Female	White British	66	No		Outpatient and voluntary	Retired	Mental Health

49	Female	White British	31	No	Cystic fibrosis	Inpatient and outpatient	Working 1-15 hours a week	Physical Health
50	Male	Black Caribbean	22			Outpatient		Social Care
51	Female	White Welsh	30	No		Inpatient and outpatient	Student and working	Mental Health
52	Female	White British	67	Yes	Heart Disease	Inpatient and outpatient	Retired	Carer
53	Male	White British	24	No	Asthma	GP	Unemployed	Physical Health
54	Female	Roman Saxon	54	No	Heart Attack	Inpatient	Working 1-15 hours a week	Physical Health
55	Female	White British	60	No	Arthritis	Mental Health and Social services	Retired	Social Care
56	Male	White British	38	No		GP		Physical Health
57	Female	Indo - Caribbean	52	No	Diabetes	GP and community	Working 16+ hours a week	Physical Health
58	Male	White Irish	71	Yes		Social services and GP	Retired	Carer
59	Female	White British	74	No		GP and community	Unemployed	Mental Health

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