

MEDICARE CURRENT BENEFICIARY SURVEY (MCBS)

Task 9.30 PaRIS Cognitive Testing Report

HHSM-500-2014-00035I, Task Order # HHSM-500-T0002

APRIL 29, 2021

PRESENTED TO:

William Long, Contracting Officer's
Representative
Centers for Medicare and Medicaid Services
7111 Security Boulevard
Baltimore, MD 21244

PRESENTED BY:

Susan Schechter, Project Director
NORC at the University of Chicago
55 East Monroe Street
30th Floor
Chicago, IL 60603

Table of Contents

Executive Summary	4
Introduction	5
Methods	6
Sampling and Recruitment	6
Data Collection.....	7
Data Analysis Methods.....	8
Findings	8
General Findings on Administration of the PaRIS Survey	8
Terminology: “On the Level” (Q8)	10
<i>Results</i>	10
Terminology: “Health Professional(s)” (Q36, Q37, Q39, Q41, Q42).....	11
<i>Results</i>	12
Terminology: “Single Professional” (Q51, Q52)	12
<i>Results</i>	13
Terminology: “Care Plan” (Q60, Q61, Q62, Q63).....	13
<i>Results</i>	14
Terminology: “Care Records” (Q69)	15
<i>Results</i>	15
Terminology: “Primary Care Centre” (Q59, Q69, Q70, Q71, Q72, Q74, Q75, Q76, Q82, Q93) 16	
<i>Results</i>	17
Demographics Probes (Q99, Q100, Q107, Q108, Q109).....	17
<i>Results on Gender (Q99)</i>	18
<i>Results on Sexual Orientation (Q100)</i>	18
<i>Results on Location of Birth (Q107)</i>	19
<i>Results on Citizenship (Q108)</i>	19
<i>Results on “Hamlet” (Q109)</i>	19
Q50. Health Problems	19

Discussion and Recommendations21

 General Findings on Administration of the PaRIS Survey21

 Discussion of Probed Terminology21

 Considerations for Retaining MCBS Demographic Items23

 Notes on Other Items Identified during Testing.....26

 Conclusion.....27

Appendix A. PaRIS Cognitive Interview Screener.....28

Appendix B. PaRIS Cognitive Interview Questionnaire.....31

Appendix C. PaRIS Cognitive Interview Probes50

List of Exhibits

Exhibit 1.	Distribution of Sex, Ethnicity, Race, and Educational Attainment among Cognitive Interview Respondents.....	7
Exhibit 2.	Questionnaire Specification Errors	9
Exhibit 3.	Q8 Question Text and Response Options	10
Exhibit 4.	“On the Level” Cognition	10
Exhibit 5.	Questions Containing “Health professionals”	11
Exhibit 6.	“Health Professionals” Cognition	12
Exhibit 7.	“Single Professional” Question Text	12
Exhibit 8.	“Single Professional” Cognition	13
Exhibit 9.	“Single Professional” Provider Type Frequency	13
Exhibit 10.	“Care Plan” Question Text.....	14
Exhibit 11.	“Care Plan” Cognition	14
Exhibit 12.	Cross Tabulation of Response to Q60 and Cognition of “Care Plan”	15
Exhibit 13.	“Care Records” Question Text.....	15
Exhibit 14.	“Care Records” Cognition.....	16
Exhibit 15.	“Primary Care Centre” Question Text	16
Exhibit 16.	“Primary Care Centre” Cognition	17
Exhibit 17.	Demographics Items for Probing.....	18
Exhibit 18.	Understanding of “Hamlet” (Q109).....	19
Exhibit 19.	Q50 Question Text and Response Options	20
Exhibit 20.	Demographic Items from PaRIS Compared to MCBS	23
Exhibit 21.	Question Comprehension Issues	26
Exhibit 22.	PaRIS Cognitive Interview Probes.....	50

Executive Summary

The Medicare Current Beneficiary Survey (MCBS) is a longitudinal panel, multi-purpose survey of a nationally representative sample of the Medicare population, conducted by the Centers for Medicare & Medicaid Services (CMS) through a contract with NORC at the University of Chicago.

In 2017, the Organization for Economic Cooperation and Development (OECD) launched the Patient-Reported Indicator Surveys (PaRIS) initiative, a collaborative, innovative effort where countries work together to develop, standardize, and implement indicators that measure outcomes and experiences of health care that matter most to people¹. The Department of Health and Human Services (DHHS) is considering the Medicare Current Beneficiary Survey (MCBS) to potentially be the primary means of implementing the PaRIS Patient Questionnaire (subsequently referred to as the “PaRIS survey”) in the U.S., in the coming years.

NORC conducted nine cognitive interviews on the draft PaRIS instrument to test the ability of Medicare respondents to understand the PaRIS questionnaire in the context of the American health care system. The survey was developed from existing, validated sources. However, some of these sources, such as the European Health Interview Survey and Commonwealth Fund International Health Policy Survey of Older Adults, may include terminology unfamiliar to U.S. respondents.

This report summarizes recommendations on revisions to some PaRIS items when they are administered in the U.S.; in particular, these recommendations would be used to modify PaRIS items if it is administered to MCBS respondents. It also provides recommendations on general revisions to some PaRIS items that should be considered by the OECD Working Group as part of the Field Trial Phase.

¹ For more information, please visit: <https://www.oecd.org/health/paris/>

Introduction

In 2017, the Organization for Economic Cooperation and Development (OECD) launched the Patient-Reported Indicator Surveys (PaRIS) initiative, a collaborative, innovative effort where countries work together to develop, standardize, and implement indicators that measure outcomes and experiences of health care that matter most to people. One of the ways to accomplish this goal is to close critical data gaps that will inform health systems. The PaRIS International Survey of People Living with Chronic Conditions focuses on closing gaps in two areas: Patient Reported Experience Measures (PREMS) which measure how patients experience health care and Patient Reported Outcome Measures (PROMS) which measure how patients assess the results of the care they receive. The PaRIS Patient Questionnaire, administered to patients, includes both PREMS and PROMS items and aims to collect vital information about primary health care, by asking about topics such as the respondent's health, health behaviors, patient activation and confidence in managing their health care, experiences with health care and health providers including access to health care, quality of life, physical functioning, and psychological well-being².

The PaRIS Patient Questionnaire will be conducted internationally with respondents ages 45 and older who receive care in primary care or ambulatory settings. The Department of Health and Human Services (DHHS) is considering the Medicare Current Beneficiary Survey (MCBS) to potentially be the primary means of implementing the PaRIS Patient Questionnaire in the U.S. in the coming years. The MCBS is a continuous, multi-purpose survey of a representative national sample of the Medicare population, including the population of beneficiaries aged 65 and over and beneficiaries aged 64 and below with certain disabling conditions, residing in the U.S. The MCBS is conducted by the Centers for Medicare & Medicaid Services (CMS) through a contract with NORC at the University of Chicago. Given the age and health characteristics of Medicare beneficiaries and the survey's existing operational infrastructure, the MCBS is a natural choice for a one-time implementation of the PaRIS Patient Questionnaire. This report will subsequently refer to the PaRIS Patient Questionnaire as the "PaRIS survey".

The PaRIS survey was drafted by an international consortium of methodological and health care experts who followed a rigorous approach including developing a conceptual framework, conducting an extensive literature review, identifying existing survey items, and mapping existing items to the PaRIS conceptual framework. Examples of existing validated items in the draft PaRIS survey include the Porter-Novelli Scale for measuring patient activation and the World Health Organization Well Being Index (WHO-5) to measure mental health.

² For more information, please visit: <https://www.oecd.org/health/paris/>

- The PaRIS survey is being developed and implemented over the course of three phases:
- Development Phase (Phase 1, Feb 2020-Jan 2021): A consortium of survey experts from participating countries developed the draft PaRIS survey via a comprehensive review of existing, validated sources.
- Field Trial Phase (Phase 2, anticipated February 2021-July 2022): Cognitive testing of the draft PaRIS survey; Pilot test of draft survey in European Union countries.
- Main Survey Phase (Phase 3, anticipated August 2022-December 2023): Full implementation of finalized PaRIS survey in all participating countries, including collection and dissemination of data.

As part of Phase 2, NORC conducted nine cognitive interviews of the draft PaRIS survey instrument to test the ability of Medicare respondents to understand the PaRIS questionnaire in the context of the American health care system. While the survey was developed from existing, validated sources, some of these sources, such as the European Health Interview Survey and Commonwealth Fund International Health Policy Survey of Older Adults, may include terminology unfamiliar to U.S. respondents. Accordingly, the goal of this testing effort was to assess the understanding of some of the healthcare related concepts among Medicare beneficiaries in the U.S. This report summarizes recommendations on revisions to some PaRIS items when they are administered in the U.S.; in particular, these recommendations would be used to modify PaRIS items if it is administered to MCBS respondents. It also provides recommendations on general revisions to some PaRIS items that should be considered by the OECD Working Group as part of the Field Trial Phase.

Methods

The methodological design of the PaRIS cognitive testing was consistent with the design of typical cognitive testing research. This section discusses the methodologies used to conduct the study.

Sampling and Recruitment

NORC recruited potential respondents through personal networking and community outreach. NORC staff made outreach to their networks to identify second- or third-degree contacts who are Medicare eligible and had at least one chronic condition. NORC also engaged with community organizations in the Chicago area serving people who generally qualify as Medicare beneficiaries. These organizations assisted with publicizing the study by disseminating flyers and word-of-mouth. Flyers were also posted on social media groups geared towards people over 65. Community organizations and social media groups were selected specifically with an aim to recruit a diverse group of respondents, with priority placed on respondents who were non-white, Hispanic, or had an education level lower than a college degree. Community organizations were recruited via email and phone outreach to organizational leadership such as directors or other contacts identified on organizational websites.

All interviews were conducted in English. Due to the COVID-19 pandemic, all interviews were conducted remotely. Potential respondents were given the option to do the interview either via phone or Zoom video conference.

All respondents were provided a \$40 incentive for participating. Respondents ranged in age from 66 to 79. Exhibit 1 shows distributions by sex, ethnicity, race, and educational attainment as reported during screening.

Exhibit 1. Distribution of Sex, Ethnicity, Race, and Educational Attainment among Cognitive Interview Respondents

Characteristic	Count
Sex	
<i>Female</i>	5
<i>Male</i>	4
Ethnicity	
<i>Non-Hispanic</i>	9
<i>Hispanic</i>	0
Race	
<i>Black or African American</i>	2
<i>Asian</i>	1
<i>White</i>	6
Education	
<i>High school graduate</i>	2
<i>Some college, but no degree</i>	2
<i>Associate degree</i>	1
<i>Bachelor's degree</i>	1
<i>Master's, professional or doctorate degree</i>	3

Data Collection

Potential respondents were screened over the phone to determine their eligibility for participation. The screener is provided in Appendix A. The screener consisted of items to measure eligibility, such as age, Medicare enrollment status, chronic condition diagnosis, and basic demographics. To be eligible to participate, respondents had to self-report eligibility for Medicare and have at least one chronic condition. Once respondents were determined to be eligible, interviewers scheduled the remote interview. Respondents were asked during screening if they preferred a Zoom or phone interview.

Before starting the interview, respondents were read a series of informed consent questions and were asked for verbal consent. Interviews were recorded with the respondent's permission so that analysts could reference the recording during analysis as needed. Interviewers administered the questionnaire remotely as a paper-and-pencil interview (PAPI). The questionnaire instrument is provided in Appendix B.

The questionnaire was administered in sections and interviewers debriefed with respondents on each section before moving on to the next section. The debriefings consisted of reviewing terminology used by certain pre-selected questionnaire items and probing for information about how the respondent interpreted these terms and arrived at their answers. This cognitive testing effort primarily used retrospective probing techniques, meaning respondents were administered the full questionnaire section and then retrospectively asked questions about the items being tested. The questions were pre-selected for probing based on a comprehensive review of the questionnaire; the corresponding probes are shown in Appendix C. Respondents were also asked for general feedback on the clarity of items in each questionnaire section. After each interview, interviewers wrote notes summarizing the themes and responses.

Data Analysis Methods

Analysts reviewed the interview notes and listened to recordings for additional clarity. Analysts identified themes in the responses and created frequency counts of themes identified. This approach provides insight into the confusion respondents may have experienced in responding to specific survey items. It also serves to identify items that respondents did not answer as intended and provides insight into whether the concepts were understood by U.S. respondents.

Findings

The discussion below outlines general findings on the administration of the PaRIS survey, findings based on the specific terminology used in items that were probed, and findings on other comprehension issues that arose during testing.

General Findings on Administration of the PaRIS Survey

In general, the PaRIS survey flowed well and made sense to respondents. The average cognitive interview duration with probing was 1 hour and 20 minutes. Interviewers had some difficulties administering the PAPI over the phone or via video conference, with some questions harder to administer by an interviewer than would have been as a self-administered survey.

In the course of cognitive testing, interviewers identified a number of issues in the PaRIS specifications relating to skip logic and response option errors. Some of these errors were identified

prior to cognitive interviewing during the pre-interview questionnaire review and are listed here to provide a comprehensive list of all recommended changes. These errors are summarized in Exhibit 2.

Exhibit 2. Questionnaire Specification Errors

Question Number	Error Type	Question Text	Description of Error
9	Mismatched Point of View	9. In the past 7 days, I had a problem with my sleep. 10. In the past 7 days, how would you rate your fatigue on average?	Q9 is written in the first-person, whereas the subsequent items (10-13) are written in the second-person.
73	Question Text	73. How often did you have a health problem but did not seek care, or did take a prescription medicine because of the cost?	The word “not” is missing between “did” and “take.”
75	Routing Error	75. As far as you know, which of the following online services does your primary care centre offer?	If “None of these” is selected at question 75, respondent should skip question 76.
78	Question Text	78. Have you been in a hospital emergency department for your own medical care?	Item has an unspecified reference period. Respondents were unsure if this question referred to “ever” or a specific period of time.
79	Question Text	79. Have you been in the hospital for one night or longer?	Item has an unspecified reference period. Respondents were unsure if this question referred to “ever” or a specific period of time.
80	Response Options	80. What was the purpose of this visit?	Response option “First contact for a new problem” is listed in the code list twice (the first two response options).
101	Response Options	101. Which of these best describes your current work situation?	The eighth response option in the code list says “Answer” which appears to be a placeholder.
107	Response Options	107. Were you born in the United States of America? - Yes - No (if you answered ‘No’, please state what country you are a citizen of: _____)	If you answer no, the text says to enter the country you are a “citizen of” but it should read “what country you were born”. Citizenship and place of birth are not the same and Q108 asks about citizenship.

Terminology: “On the Level” (Q8)

This question was selected for probing based on concerns that the term “on the level” is likely not understood by respondents from the U.S.

Exhibit 3. Q8 Question Text and Response Options

Question Number	Question Text	Response Options*
8	Please select the response that best describes your current situation in relation to your breathing:	<ul style="list-style-type: none"> - I only get breathless with strenuous exercise - I get short of breath when hurrying <u>on the level</u> or up a slight hill - I walk slower than people of the same age <u>on the level</u> because of breathlessness or have to stop for breath when walking at my own pace <u>on the level</u> - I stop for breath after walking 100 yards or after a few minutes <u>on the level</u> - I am too breathless to leave the house

* Underlining added to emphasize the terms being tested; underlining was not part of the actual question.

Results

During probing, it was found that five respondents understood the term while four either did not understand or had questions about it, as shown in Exhibit 4.

Exhibit 4. “On the Level” Cognition

Cognition	Count
Understood	5
Knew two meanings and asked for clarification	1
Did not understand, asked what it meant	2
Interpreted Incorrectly	1

One respondent interpreted the term incorrectly, saying they thought it meant "...as something compared to people my age". Another asked for clarification, noting that there are two definitions of “on the level”, either (1) flat pavement or (2) honest and straight to the point. Cognitive interviewers noted that even respondents who were able to properly describe the term as “on a flat surface”, most gleaned the definition from contextual clues and were not actually familiar with the term.

Terminology: “Health Professional(s)” (Q36, Q37, Q39, Q41, Q42)

Eleven items use the term “health professionals” or “health professional.” Probing was conducted specifically on Q36 to test this term. The term “health professionals” or “health professional” was selected for probing to test whether respondents would include the full scope of health professionals in their understanding of the item as included in the definition provided in the introduction to the section “Managing your health and healthcare”, occurring between Q18 and Q19.

Exhibit 5. Questions Containing “Health professionals”

Question Number	Question Text*
Introduction to “Managing your health and health care” section, between Q18 and Q19	The next few questions ask about your recent physical activity, diet and use of tobacco and alcohol and the support you may have received from <u>health professionals</u> (doctors, nurses, and other <u>health professionals</u>).
20	In the past 12 months, has any <u>health professional</u> talked with you about your physical activity?
23	In the past 12 months, has any <u>health professional</u> talked with you about healthy eating?
26	In the past 12 months, has any <u>health professional</u> talked with you about the health risks of smoking or using tobacco and ways to quit?
28	In the past 12 months, has any <u>health professional</u> talked with you about alcohol use?
29	I rely on <u>health professionals</u> to tell me everything I need to know to manage my health
36	My <u>health professionals</u> and I work together to manage my health
37	When I read or hear something that is relevant to my health care, I bring it up with my <u>health professionals</u>
39	When I think something is wrong with my health care, I raise my concerns with my <u>health professionals</u>
41	How confident are you that you can follow instructions from <u>health professionals</u> about how you should care for yourself at home?
42	How confident are you that you can follow instructions from <u>health professionals</u> about how to change your habits or lifestyle?

* Underlining added to emphasize the terms being tested; underlining was not part of the actual question.

Results

During probing, it was found that three respondents understood the term “health professional” to mean doctors (MDs), three understood it as doctors and physical therapists, and three understood as strictly their primary care doctor.

Exhibit 6. “Health Professionals” Cognition

Cognition	Count
Doctors (MDs)	3
Doctors & Physical Therapists	3
Primary Care Doctor	3

Three respondents interpreted the term in relation to the doctor they see, with one stating, “My primary doctor at the VA; that’s the only health provider I see.” and another stating, “My primary is generally the only person that I see right now.” Cognitive interviews showed that only three respondents interpreted “health professionals” more broadly to include physical therapists and none included other health professionals like nurses or nurse practitioners included in the definition between Q18 and Q19.

Terminology: “Single Professional” (Q51, Q52)

Two items in the PaRIS survey use the term “single professional” (Q51 and Q52). Probing was conducted specifically on Q51, though Q52 shares similar terms. Probing was conducted to test whether the term “single professional” would have meaning to a respondent from the U.S. and whether a respondent from the U.S. understood the concept of care coordination.

Exhibit 7. “Single Professional” Question Text

Question Number	Question Text*
51	Do you have a <u>single professional</u> who takes responsibility for coordinating your care across the services that you use?
52	Is this the same <u>professional</u> that you see for most of your health problems?

* Underlining added to emphasize the terms being tested; underlining was not part of the actual question.

Results

In general, most respondents understood the terminology used in Q51, as shown in Exhibit 8. The respondent who did not understand said “Not sure about the question; everything has to go through our PCP....I guess I don’t really understand the question.”

Exhibit 8. “Single Professional” Cognition

Cognition	Count*
Understood	7
Didn't Understand	1

*One respondent was not probed on this item.

While most respondents generally understood the question, some had a hard time answering because the concept of care coordination is not as established in the U.S. as compared to other countries. Exhibit 9 shows the frequency of the type of providers respondents were thinking of as a “single professional” when responding to Q51.

Exhibit 9. “Single Professional” Provider Type Frequency

Responses to Q51	Count*
Primary care doctor	4
VA	1
Doesn't have one but primary is closest	2
Doesn't have one	1

*One respondent was not probed on this item.

Two respondents said their primary care doctor provides most of their referrals. However, neither respondent considered this as “coordinating” their care because the act of scheduling appointments falls to the patient, and the patient is free to see someone other than the referred provider. One respondent said “When you say ‘coordinating’, she [the doctor] looks at things and she makes a suggestion but it's up to me which doctor I would like to go to...” The respondent who said they didn’t have a single professional coordinating their care understood the question to mean one person who they can call for all of their care, which the respondent does not have. The respondent felt they do all the coordination themselves so answered the question with a response of “No”.

Terminology: “Care Plan” (Q60, Q61, Q62, Q63)

The term “care plan” appears in the introduction to the section titled “Your experiences of health care” (before Q46) and four subsequent questions (Q60, Q61, Q62, and Q63). Probing was conducted specifically on Q60 though the others share similar terms. This item was selected for

probing to test whether the term “care plan” would have meaning to a respondent from the U.S. and whether MCBS respondents would be able to accurately respond to the question.

Exhibit 10. “Care Plan” Question Text

Question Number	Question Text*
Introduction to “Your experience of health care” section, between Q45 and Q46	The following questions concern the care you are receiving from <u>primary care</u> services for your health and wellbeing. <u>Primary care</u> services are usually the first point of contact with the health service for a wide range of new and long-term health problems. They are frequently delivered by teams of health professionals, usually coordinated by a family doctor or a general practitioner working in a <u>primary care</u> centre. In your case this may be also another member of the primary care team, such as a nurse, or another specialist doctor. We also want to ask you in relation to a <u>care plan</u> , which is an agreement between you and your health professionals detailing the type of health care you need and how this care will be given. Not everybody has a care plan.
60	Do you have a <u>care plan</u> that takes into account all your health and wellbeing needs?
61	Is this <u>care plan</u> (or plan of care) available to you?
62	To what extent have you found your <u>care plan</u> (or plan of care) useful for you to manage your health and wellbeing?
63	To what extent do all the professionals involved in your care appear to be following the same <u>care plan</u> ?

* Underlining added to Q60-63 emphasize the terms being tested; underlining was not part of the actual question. Underlining for the introduction to “Your experience of health care” section, between Q45 and Q46, is part of the original instrument.

Results

Five of the nine respondents did not understand the meaning of “care plan,” as shown in Exhibit 11. Respondents who did not understand the term said things such as “I don't know if it's a plan, she [the doctor] looks at everything so I am not sure if that qualifies as a plan...” and “Does doing what my doctor says count as a care plan?” Three respondents referred to their health insurance or Medicare as their “care plan,” which is not the correct interpretation.

Exhibit 11. “Care Plan” Cognition

Cognition	Count
Understood	4
Did not Understand	5

Not only did five respondents not understand the meaning of “care plan” when probed, four of those five responded “Yes” to Q60, saying that they did in fact have a care plan. This suggests measurement error in the question as respondents are saying they have a “care plan” when they don’t know what it is and some are erroneously equating “care plan” with health insurance.

Exhibit 12. Cross Tabulation of Response to Q60 and Cognition of “Care Plan”

Response to Q60	Understood	Did not Understand	Total
Yes	1	4	5
No	2	0	2
Not Sure	1	1	2
Total	4	5	9

Terminology: “Care Records” (Q69)

This item was selected for probing because of the use of the term, “care records,” which is not commonly used in the U.S.

Exhibit 13. “Care Records” Question Text

Question Number	Question Text*
69	The next few questions are about your experience with your primary care centre in the last 12 months. Were there times when you had to repeat information that should have been in your <u>care records</u> ?

* Underlining added to emphasize the terms being tested; underlining was not part of the actual question.

Results

The majority of respondents were able to define “care records” when probed, but there was still some confusion. Most respondents defined “care records” as medical records maintained by their primary care doctor. Two respondents defined “care records” to be their medication list, which is a narrower definition than the question likely intended.

One respondent thought the question was asking if records are shared across physicians in different practices. This is likely a result of not understanding the term “primary care centre,” not “care records.”

Exhibit 14. “Care Records” Cognition

Cognition	Count
Understood	7
Did not Understand	2

Terminology: “Primary Care Centre” (Q59, Q69, Q70, Q71, Q72, Q74, Q75, Q76, Q82, Q93)

The term “primary care centre” appears in ten questions without ever being defined. Probing on this term was conducted specifically on Q70 and Q74 to test whether a respondent from the U.S. would be able to accurately interpret “primary care centre.”

Exhibit 15. “Primary Care Centre” Question Text

Question Number	Question Text*
59	How often does someone at your primary care centre talk to you about specific goals for your health?
69	The next few questions are about your experience with your <u>primary care centre</u> in the last 12 months. Were there times when you had to repeat information that should have been in your care records?
70	How often do you believe you have had any safety problems in your <u>primary care centre</u> (such as not getting an appointment when needed; wrong or delayed diagnosis or treatment; or problems with communications between healthcare professionals)?
71	How often did you feel that the health professionals at your <u>primary care centre</u> encouraged you to talk about any concerns about your healthcare?
72	How often did you have a health problem but did not seek care because of difficulties in travelling to your <u>primary care centre</u> ?
74	The next questions are about the online services that your <u>primary care centre</u> may offer to patients like you, such as a website, smartphone app or video consultations: How easy is it for you to use your <u>primary care centre’s</u> website to look for information or access services?
75	As far as you know, which of the following online services does your <u>primary care centre</u> offer?
76	Which of the following online services of your <u>primary care centre</u> have you used?

Question Number	Question Text*
82	Where was this professional working? - A <u>primary care centre</u> - An outpatient department of a hospital - Other - Not sure
93	In the last 12 months, have you avoided making an appointment at your <u>primary care centre</u> for any reason?

* Underlining added to emphasize the terms being tested; underlining was not part of the actual question.

Results

The term “primary care centre” was understood by most respondents and frequently equated with their primary care doctor’s office. Upon initial probing at Q70 one respondent said she was thinking about a recent appointment with a specialist, suggesting she didn’t really understand the term. However, when asked what “primary care centre” meant to them, she said it meant “taking care of the chronic stuff that is not done by a specialist.”

Exhibit 16. “Primary Care Centre” Cognition

Cognition	Count
Understood	8
Did not Understand	1

In addition to comprehending “primary care centre,” respondents had some trouble understanding Q74, which asked about difficulties accessing the primary care centre’s website. One respondent asked if “website” was referring to the primary care center’s actual website or if it included their patient portal for online records. Many practices in the U.S. have separate websites for the patient portal than for the website with practice information.

Demographics Probes (Q99, Q100, Q107, Q108, Q109)

Five questions in the “About Yourself” section were selected for additional probing. Q99, Q100, Q107, and Q108 were selected for probing because of general sensitivity of these questions. Q109 was selected to test the cognition of the term “hamlet” by respondents in the U.S.

Exhibit 17. Demographics Items for Probing

Question Number	Question Text
99	Are you... - Female - Male - Other - Prefer not to say
100	This question is about your sexual orientation. Do you identify as: - Heterosexual or straight (that is, attracted to the opposite sex) - Homosexual (gay or lesbian, that is, attracted to the same sex) - Bisexual (attracted to both sexes) - Other - Prefer not to say
107	Were you born in the United States of America? - Yes - No (if you answered ‘No’, please state what country you are a citizen of: _____
108	Are you a citizen of the United States of America? - Yes - No (if you answered ‘No’, please state what country you are a citizen of: _____
109	Which of these options best describes the place you live in? - A village, hamlet or rural area (fewer than 3,000 people) - A small town (3,000 to about 15,000 people) - A town (15,000 to about 100,000 people) - A city (100,000 to about 1,000,000 people) - A large city (with over 1,000,000 people) - Don’t know

Results on Gender (Q99)

All respondents understood the question and did not have any concerns with answering it. However, all respondents reported they were either female or male, so this sample did not test the sensitivity of the question with people who do not identify as male or female.

Results on Sexual Orientation (Q100)

All respondents understood the question and did not have any concerns with answering it. However, all respondents responded that they were heterosexual so this sample did not test the sensitivity of the question with respondents of other sexual orientations.

Results on Location of Birth (Q107)

All respondents understood the question and did not have any concerns with answering it. However, all respondents reported they were born in the U.S. so this sample did not test the sensitivity of the question with respondents born in other countries and now living in the U.S.

Results on Citizenship (Q108)

All respondents understood the question and did not have any concerns with answering it. However, all respondents reported they were U.S. citizens so this sample did not test the sensitivity of the question with respondents who are not U.S. citizens.

Results on “Hamlet” (Q109)

All respondents understood Q109 and were able to provide a fairly accurate response. One respondent googled their town’s size in order to accurately respond to the question. Interviewers observed that most respondents were responding based on the population estimates provided in the response options, and not the designation of town, city, etc. For example, one respondent lives in a municipality of 10,000 people that is officially designated as a village. They selected the response option of “A small town (3,000 to about 15,000 people)”, not “A village, hamlet or rural area (fewer than 3,000 people)” even though either could have been accurate.

When probed on the meaning of “hamlet”, answers ranged from describing it as a term used in Europe or another country, a literary word, rural area, or not knowing. Respondents answered this question based on other context clues in the question and most did not really know what a hamlet is.

Exhibit 18. Understanding of “Hamlet” (Q109)

Definition of Hamlet	Count
Term used in Europe	3
Literary term	1
Rural area	2
Does not know	2

Q50. Health Problems

This question was not selected for probing, but the cognitive interview analysis indicate that this item was unclear to respondents and warrants further consideration.

Exhibit 19. Q50 Question Text and Response Options

Question Number	Question Text	Response Options
50	<p>Have you ever been told by a doctor that you have any of the following health problems?</p> <p>Please specify which health problem(s):</p>	<ul style="list-style-type: none"> - High blood pressure - Cardiovascular or heart condition - Diabetes (type 1 or 2) - Arthritis or ongoing problem with back or joints - Ongoing depression, anxiety or other mental health conditions (e.g. bipolar disorder or schizophrenia) - Breathing conditions (e.g. asthma or COPD) - Chronic kidney disease/Chronic liver disease - Cancer (diagnosis or treatment in the last 5 years) - Alzheimer’s disease or other cause of dementia Neurological conditions (e.g., epilepsy or migraine) - Other long-term problems: _____ _____ - I have never been told by a doctor that I have any of these problems.....

Results

While respondents generally understood what was being asked at this item, many were unsure of what conditions should be included for each response option. Two respondents asked if borderline diabetes should be included in the diabetes response category. Some conditions that were reported by respondents in the “Other long term problems” option would not be considered chronic conditions by most public health agencies. Responses included taking medication for their thyroid, gallbladder issues, obesity, a motion disorder, and esophageal issues. None of these would be considered chronic conditions under CMS definitions³.

³ “Chronic Conditions”, Centers for Medicare & Medicaid Services. January 15, 2021. https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/CC_Main

Discussion and Recommendations

This section will discuss the findings above and make recommendations for potential modifications to the PaRIS Survey administration to the MCBS audience.

General Findings on Administration of the PaRIS Survey

The PaRIS survey was designed to be a self-administered paper-and-pencil (PAPI) survey. However, the cognitive interviews were administered as a telephone interview to mirror the modes most likely to be used when implemented on the MCBS. Interviewers observed a number of challenges in administering the PaRIS survey verbally. Once a data collection mode is selected the implementation of the PaRIS survey on the MCBS, it is recommended that the survey be reviewed for edits to accommodate the selected mode(s).

Discussion of Probed Terminology

Based on the findings discussed in the previous section, below are recommendations on modifications to make when administering to the MCBS population.

- **“On the Level” (Q8)** - When these items are administered on the MCBS, it would be beneficial to replace “on the level” with a synonym better understood by respondents in the U.S., such as “on a flat surface”.
- **“Health Professional(s)” (Q36, Q37, Q39, Q41, Q42)** - Respondents would benefit from repeating the term’s definition in the question text, as help text, or as an on-screen definition.
- **“Other Long Term Problems” (Q50)** – If the analytic objectives of the PaRIS survey are to measure the experiences of people living with chronic conditions, then it is recommended that the wording for the “Other long term problems” category should be revised to only include chronic conditions and exclude other general health problems.
- **“Single Professional” (Q51, Q52)** - It would be helpful to move or repeat the explanation of coordinated care from the introduction of this series (which occurs before item Q46), making it available as help text or as an on-screen definition so that it is top of mind for respondents when answering Q51 and Q52. If the analytic objective of these items is to measure a respondent’s perception of whether their care is coordinated by a single professional, then migrating and/or repeating the definition currently included before Q46 when the PaRIS survey is administered on the MCBS is likely to be a sufficient revision. Alternatively, if the primary goal is to measure the respondent’s experience of care coordination in the U.S. health system as compared to other countries, then it would be helpful to include a uniform definition and examples of care coordination at these items to assist respondents in the U.S. in answering. In lieu of additional examples at how care is coordinated, respondents living in the U.S. are likely to interpret the

concept of “care coordination” at this item differently than respondents in other countries, particularly those respondents in countries that have national health systems.

- **“Care Plan” (Q60, Q61, Q62, Q63)** - To aid in response, the definition of “care plan” in the introduction to this series (which occurs between items Q45 and Q46) should be moved to immediately precede Q60, which is when the term is first used in a question. If the analytic objective of these items is to measure respondent’s perception of whether they have a care plan, then migrating the definition currently included before Q46 is likely to be a sufficient revision. Alternatively, if the primary goal is to measure the respondent’s experience of care plans in the U.S. health system as compared to other countries then it would be helpful to include a uniform definition and examples of care plans at these items to assist respondents in the U.S. in answering. In lieu of additional examples or parameters around what a care plan is, respondents living in the U.S. are likely to interpret the concept differently than respondents in other countries, particularly those respondents in countries that have more established and standardized care plans in use.
- **“Care Records” (Q69)** - It would be beneficial to replace the term “care records” with “medical records” to be more readily understood by respondents in the U.S. Help text or an on-screen definition defining “care records” or “medical records” to include all types of care, not just medication, may also be useful.
- **“Primary Care Centre” (Q59, Q69, Q70, Q71, Q72, Q74, Q75, Q76, Q82, Q93)** - Given the lack of colloquial use of the term “primary care centre” in the U.S., it would be beneficial to substitute with an alternative term for fielding on the MCBS. Alternatives to be considered include “primary care office,” “primary care practice,” or “primary care doctor’s office”. Additionally, help text or on-screen definitions may be useful at Q74 to explain whether “website” is inclusive of patient portals that may be hosted on other websites but used by the practice or accessed through the practice website.
- **Gender (Q99)** – This item performed satisfactorily. However, the MCBS already collects gender as part of the main MCBS interview so it is recommended that the PaRIS survey use gender as already collected by the MCBS instead of re-asking it during the PaRIS survey.
- **Sexual Orientation (Q100), Place of Birth (Q107), and Citizenship (Q108)** - The items on sexual orientation, place of birth, and citizenship performed satisfactorily and do not require additional changes for inclusion on the MCBS.
- **Type of Municipality (Q109)** - The MCBS has address information for all respondents so it would be less burdensome and more accurate to create this variable during data processing instead of asking it to be self-reported.

Considerations for Retaining MCBS Demographic Items

In addition to the demographic items that were probed on, there are nine other demographic items on the PaRIS survey that obtain information already collected by the MCBS, as shown in Exhibit 20. These nine MCBS items are slightly different when compared to the PaRIS survey due to differences in response options or question framing. Items such as education, weight, and height on the PaRIS survey lack cultural considerations for respondents living in the U.S., as they collect weight in kilos, height in centimeters, and ask about educational attainment in terms not used in the U.S. Items on income, employment status, household size, and activities of daily living, although framed differently on the PaRIS survey, reflect the same analytic objective as their MCBS equivalents. Therefore, it is recommended that the existing MCBS items be used when fielding the PaRIS survey on the MCBS to reduce respondent burden.

Exhibit 20. Demographic Items from PaRIS Compared to MCBS

PaRIS Question Text	PaRIS Response Options	MCBS Question Text	MCBS Response Options
99. How old are you?	<ul style="list-style-type: none"> • 44 years old or younger • 45-49 years old • 50-54 years old • 55-59 years old • 60-64 years old • 65-69 years old • 70-74 years old • 75-79 years old • 80-84 years old • 85 years or older 	That makes [you/(SP)] (AGE) today. Is that correct?	(01) YES (02) NO
98. What is the highest educational level that you have attained?	<ul style="list-style-type: none"> • Early childhood education • Primary education • Lower secondary education • Upper secondary education • Post-secondary non-tertiary education • Short-cycle tertiary education • Bachelor's degree or equivalent level • Master's degree or equivalent level 	<p>What is the highest degree or level of school [you have/(SP) has] completed?</p> <p>[IF THE SAMPLE PERSON ATTENDED SCHOOL IN A FOREIGN COUNTRY, IN AN UNGRADED SCHOOL, HOME SCHOOLING, OR UNDER OTHER UNIQUE CIRCUMSTANCES, REFER THE RESPONDENT TO</p>	<p>(01) NO SCHOOLING COMPLETED</p> <p>(02) NURSERY SCHOOL TO 8TH GRADE</p> <p>(03) 9TH-12TH GRADE, NO DIPLOMA</p> <p>(04) HIGH SCHOOL GRADUATE (HIGH SCHOOL DIPLOMA OR THE EQUIVALENT)</p> <p>(05) VOCATIONAL/TECHNICAL/BUSINESS/TRADE SCHOOL</p>

PaRIS Question Text	PaRIS Response Options	MCBS Question Text	MCBS Response Options
	<ul style="list-style-type: none"> • Doctoral or equivalent level 	THE SHOWCARD AND ASK FOR THE NEAREST EQUIVALENT.]	CERTIFICATE OR DIPLOMA (BEYOND THE HIGH SCHOOL LEVEL) (06) SOME COLLEGE, BUT NO DEGREE (07) ASSOCIATE DEGREE (08) BACHELOR'S DEGREE (09) MASTER'S, PROFESSIONAL OR DOCTORATE DEGREE (-8) Don't Know (-9) Refused
97. How tall are you?	<ul style="list-style-type: none"> • ___centimetres • Prefer not to answer • Don't know 	How tall [are you/is (SP)]?	(01) continuous answer (-8) DON'T KNOW (-9) REFUSED
96. How much do you weigh?	<ul style="list-style-type: none"> • ___kilos • Prefer not to answer • Don't know 	How much [do you/does (SP)] weigh? [WEIGHT SHOULD BE RECORDED IN POUNDS]	(01) continuous answer (-8) DON'T KNOW (-9) REFUSED
102. Which of these categories does your household income usually fall into?	<ul style="list-style-type: none"> • Up to \$X a month [LOW INCOME (X=\$75% OF MEDIAN HOUSEHOLD INCOME)] • Between \$X and \$Y a month [MEDIAN INCOME] • \$Y or more a month [HIGH INCOME (Y=\$125% OF MEDIAN HOUSEHOLD INCOME)] • Don't know 	Now thinking about all of last year, that is calendar year [CURRENT YEAR – 1], how much income did [you/(SP)] and [(SP FIRSTNAME LASTNAME)/(SPOUSE FIRSTNAME LASTNAME)/(PARTNER FIRSTNAME LASTNAME)] receive from these businesses or property before any federal or state taxes were taken out?	(1) [continuous response] (-8) DON'T KNOW (-9) REFUSED
103. In the past 12 months, did you have problems paying or	<ul style="list-style-type: none"> • Yes • No • Not applicable 	Since (LAST HF MONTH YEAR) [have you/has (SP)] had	(01) YES (02) NO (-8) Don't Know

PaRIS Question Text	PaRIS Response Options	MCBS Question Text	MCBS Response Options
were unable to pay any medical bills?		problems paying or were unable to pay any medical bills?	(-9) Refused
110. How many children under the age of 18 live with you, in your household?	_____ children under the age of 18	<p>[At the time of the last interview, [you were living by yourself/(SP) was living by [himself/herself]]].</p> <p>[Besides [you/(SP)], [is/was] there anyone else living or staying in the household [as of (DATE OF DEATH/DATE OF INSTITUTIONALIZATION)]? Remember to include people who [are/were] temporarily absent and any children who [may live/may have lived] in the household.</p>	(01) YES (02) NO (-8) Don't Know (-9) Refused
111. How many people aged 18 and over live with you, in your household? Please do not count yourself.	_____ people aged 18 and over	<p>[At the time of the last interview, [you were living by yourself/(SP) was living by [himself/herself]]].</p> <p>[Besides [you/(SP)], [is/was] there anyone else living or staying in the household [as of (DATE OF DEATH/DATE OF INSTITUTIONALIZATION)]? Remember to include people who [are/were] temporarily absent and any children who [may live/may have lived] in the household.</p>	(01) YES (02) NO (-8) Don't Know (-9) Refused

PaRIS Question Text	PaRIS Response Options	MCBS Question Text	MCBS Response Options
114. Do you need physical care or support, such as help with eating, dressing, bathing, moving around the house or assistance outside the house such as for using transportation?	<ul style="list-style-type: none"> • Yes • No 	Because of a physical, mental, emotional, or memory problem, [do you/does (SP)] have any difficulty... ...bathing or showering? ...dressing? ... eating? ... getting in or out of bed or chairs? ... walking? ... using the toilet, including getting up and down?	(01) YES (02) NO (-8) Don't Know (-9) Refused

Notes on Other Items Identified during Testing

In addition to the findings above on the items that were probed on, interviewers noted a number of comprehension issues on other questions, outlined in Exhibit 21.

These issues should be shared with the OECD Working Group to help improve the survey for all respondents.

Exhibit 21. Question Comprehension Issues

Question Number	Question Text	Interviewer Observations
19	In the past week, on how many days did you do at least 30 mins of either vigorous or moderate activity (such as running, swimming, riding a bike, brisk walking, or dancing)?	Respondent interpreted “vigorous” as “rigorous” leading to great confusion. For example, they did not consider “walking” to be rigorous for them personally.
35	I have difficulty understanding a lot of the health information that I read.	The term “health information” is incredibly broad. One respondent interpreted it as anything from reading and understanding lab results (which they do not understand) to findings from nutrition research (which they do).

Question Number	Question Text	Interviewer Observations
45	How confident are you in using information from the Internet to make health decisions?	Respondent was unclear if the question was asking about a) their ability to decide whether a site/article was a legitimate source of information, or b) if overall what is on the internet is reliable. Respondent did note that if the source is legitimate, they may use it.
56	Are you offered regular follow-up for any of your health problems?	Some respondents were unsure if this question referred to a medical provider or another person, such as a spouse.
58	Are you considered as a ‘whole person’ rather than just a disease/condition in relation to your care?	Some respondents were unclear what was being asked at this item- specifically they were unfamiliar with the phrase "whole being."
80	<p>The next questions are about the last time that you had a consultation with a primary care doctor, nurse or other health professional to get care for yourself (this may have been with your main health professional or another health professional and includes consultations over the phone or in a doctor’s office, a clinic, or the outpatient department of a hospital. Do not include care you got when you stayed overnight in a hospital, dental care visits or accident and emergency care.</p> <p>What was the purpose of this visit?</p>	Respondent was very specifically focused on the word “consultation” from the section introduction preceding this question. Question had to be repeated.
81	Who did you see?	Respondent was unsure on how to answer this question if the primary care doctor had referred them to a specialist.
102	Which of these categories does your household income usually fall into?	Multiple respondents were unsure of their monthly income, but were aware of their annual income.

Conclusion

In general, the PaRIS survey performed well during cognitive testing. Clearly some wording changes should be made if the survey is administered to MCBS respondents. In addition, there are other findings that should be shared with the OECD Working Group as part of the Field Trial Phase (Phase 2).

Appendix A. PaRIS Cognitive Interview Screener

PARTICIPANT NUMERIC IDENTIFIER: _____

1. BENEFICIARY SEX [CODE WITHOUT ASKING IF POSSIBLE.]

- a) MALE
- b) FEMALE

2. How old are you?

_____ years

3. Medicare is the federal health insurance program for people who are 65 or older, certain younger people with disabilities, and people with End-Stage Renal Disease. I need to confirm, do you receive health insurance through Medicare?

- a) YES
- b) NO → I am sorry, but only people who receive insurance through Medicare are eligible for this study.

READ IF NECESSARY: Do you have a Medicare card? Medicare Part A includes coverage for hospital stays and Part B includes coverage for doctor’s services. Part C, Medicare Advantage Plans, is offered through private insurance companies under contract with Medicare. Some people opt to add on Part D, which is prescription drug coverage.

4. I am going to read you a list of medical conditions. Have you ever been told by a doctor that you have any of the following health problems? For each condition, please respond yes or no.

INTERVIEWER: READ EACH CONDITION SLOWLY AND CIRCLE YES OR NO FOR EACH CONDITION.

High blood pressure	YES / NO
Cardiovascular or heart condition	YES / NO
Diabetes (type 1 or 2)	YES / NO
Arthritis or ongoing problems with back or joints	YES / NO
Ongoing depression, anxiety, or other mental health condition (e.g. bipolar disorder or schizophrenia)	YES / NO
Breathing condition (e.g. asthma or COPD)	YES / NO
Chronic kidney disease / Chronic liver disease	YES / NO
Cancer (diagnosis or treatment in the last 5 years)	YES / NO
Alzheimer’s disease or other cause of dementia	YES / NO
Neurological condition (e. g. epilepsy or migraine)	YES / NO

IF RESPONDENT HAS NONE OF THE ABOVE CONDITIONS THANK THEM USING THIS SCRIPT:

Thank you for volunteering for this study. Unfortunately, you do not meet the criteria for this study. I appreciate the time you took to speak with me today.

5. What is the highest degree or level of school you have completed?
 - a) NO SCHOOLING COMPLETED
 - b) NURSERY SCHOOL TO 8TH GRADE
 - c) 9TH-12TH GRADE, NO DIPLOMA
 - d) HIGH SCHOOL GRADUATE (HIGH SCHOOL DIPLOMA OR THE EQUIVALENT)
 - e) VOCATIONAL/TECHNICAL/BUSINESS/TRADE SCHOOL CERTIFICATE OR DIPLOMA (BEYOND THE HIGH SCHOOL LEVEL)
 - f) SOME COLLEGE, BUT NO DEGREE
 - g) ASSOCIATE DEGREE
 - h) BACHELOR'S DEGREE
 - i) MASTER'S, PROFESSIONAL OR DOCTORATE DEGREE

6. Are you of Hispanic, Latino, or Spanish origin?
 - a) YES
 - b) NO

7. What is your race? [SELECT ALL THAT APPLY. READ RESPONSE OPTIONS IF NEEDED.]
 - a) American Indian or Alaska Native
 - b) Asian
 - c) Black or African American
 - d) Native Hawaiian or other Pacific Islander
 - e) White

8. Would you prefer to conduct the interview over the phone or over video, using Zoom?
 - a) PHONE
 - b) ZOOM

9. CONFIRM CONTACT INFORMATION AND SCHEDULE APPOINTMENT:

Ok, let's schedule an appointment to do the interview.

[TAKE INFORMATION]

IF PHONE:

10. Can you confirm that [PHONE NUMBER] is the best number to contact you on [DATE] for the interview?

[TAKE INFORMATION]

IF ZOOM:

11. Could you please provide an email address to send you the Zoom link information to for the interview?

[TAKE INFORMATION]

Thank you for volunteering to participate. We will speak with you on [REPEAT DATE AND TIME OF APPOINTMENT] by [REPEAT MODE]. I will reach out the day before the interview to remind you of the appointment and to confirm the name [and phone number] of the interviewer who will be contacting you.

AFTER HANGING UP, ENTER THE INFORMATION FROM THIS SCREENER INTO THE RECRUITMENT SPREADSHEET ALONG WITH THE DATE, TIME, AND MODE OF THE APPOINTMENT.

Appendix B. PaRIS Cognitive Interview Questionnaire

MATERIALS NEEDED FOR INTERVIEW

- | |
|---|
| <input type="checkbox"/> INTERVIEWER PROTOCOL BOOKLET (THIS BOOKLET) AND SHOWCARD
<input type="checkbox"/> PaRIS QUESTIONNAIRE |
|---|

STEP 1: PREPARE THE RESPONDENT

LOG ONTO THE ZOOM OR PHONE CALL WITH THE RESPONDENT, INTRODUCE YOURSELF, AND MAKE SURE THEY'RE READY TO START.

EXAMPLE SCRIPTS:

- “Hello, my name is [NAME] from NORC at the University of Chicago. Is [RESPONDENT NAME] available?”
- “I’ll explain a little more about what we’re doing and then if you don’t have any questions we can get started. The interview will take about an hour. After the interview is done I’ll take your information and we’ll mail you a check for \$40 to thank you for participating.”

STEP 2: COMPLETION OF THE QUESTIONNAIRE

COMPLETE THE FOLLOWING QUESTIONS AND THEN ADMINISTER THE PARIS QUESTIONNAIRE.

INT1. The Medicare Current Beneficiary Survey (MCBS) asks Medicare beneficiaries about their health status, sources of health care, satisfaction with care, and health care expenditures. In today’s interview I will be asking you about your experiences with health care providers.

Periodically during the interview, I will ask you some questions about how you decided to answer some of the survey questions. If at any point, we ask a question or use a word that you do not understand, please let me know so we can discuss it further. Getting your feedback on the questions can help make the questions better.

[CONTINUE]

INT2. All survey information will be kept private to the extent permitted by law, as prescribed by the Privacy Act of 1974. Medicare benefits will not be affected in any way by survey responses or participation. You may skip questions or end the interview at any time and you will still receive the \$40 payment.

Do you agree to participate in this interview?

- YES -> GO TO NEXT QUESTION
- NO -> STOP INTERVIEW AND THANK THEM FOR THEIR TIME.

INT3. In order to have a complete record of your comments, with your permission, your interview session will be recorded. The recording will be stored electronically on NORC's secure servers. We plan to use the recording to ensure that we capture all of the feedback you provide us. Only staff directly involved in this research project will have access to the recording. Any quotes used in presentations and publications will not include any names or any information that could identify any participant.

Is it okay for me to proceed with the recording on?

- a. YES -> TURN RECORDING ON
- b. NO -> PROCEED WITHOUT RECORDING

4 | DELSA/HEA/PARIS(2021)2

Your health

The first few questions are about your health.

01 In general, would you say your health is:

- Excellent
- Very good
- Good
- Fair
- Poor

02 In general, would you say your quality of life is:

- Excellent
- Very good
- Good
- Fair
- Poor

03 In general, how would you rate your physical health?

- Excellent
- Very good
- Good
- Fair
- Poor

04 In general, how would you rate your mental health, including your mood and your ability to think?

- Excellent
- Very good
- Good
- Fair
- Poor

05 In general, how would you rate your satisfaction with your social activities and relationships?

- Excellent
- Very good
- Good
- Fair
- Poor

06 In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)

- Excellent
- Very good
- Good
- Fair
- Poor

07 To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?

- Completely
- Almost
- Moderately
- A little
- Not at all

The next few questions are about any specific symptoms you may have recently experienced.

08 Please select the response that best describes your current situation in relation to your breathing:

1. I only get breathless with strenuous exercise
2. I get short of breath when hurrying on the level or up a slight hill
3. I walk slower than people of the same age on the level because of breathlessness or have to stop for breath when walking at my own pace on the level
4. I stop for breath after walking 100 yards or after a few minutes on the level
5. I am too breathless to leave the house

09 In the past 7 days, I had a problem with my sleep

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

10 In the past 7 days, how would you rate your fatigue on average?

- None
- Mild
- Moderate
- Severe
- Very severe

11 In the past 7 days, how much did pain interfere with your day to day activities?

- Not at all
- A little bit
- Somewhat

- Quite a bit
- Very much

12 In the past 7 days, how would you rate your pain on average?

- 0 – no pain
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 –Worst imaginable

13 In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?

- Never
- Rarely
- Sometimes
- Often
- Always

For the next few questions please think about how you have been feeling over the last two weeks.

14 I have felt cheerful and in good spirits

1. All of the time
2. Most of the time
3. More than half of the time
4. Less than half of the time
5. Some of the time
6. At no time

6 | DELSA/HEA/PARIS(2021)2

15 I have felt calm and relaxed

1. All of the time
2. Most of the time
3. More than half of the time
4. Less than half of the time
5. Some of the time
6. At no time

16 I have felt active and vigorous

1. All of the time
2. Most of the time
3. More than half of the time
4. Less than half of the time
5. Some of the time
6. At no time

17 My daily life has been filled with things that interest me

1. All of the time
2. Most of the time
3. More than half of the time
4. Less than half of the time
5. Some of the time
6. At no time

18 I woke up feeling fresh and rested

1. All of the time
2. Most of the time
3. More than half of the time
4. Less than half of the time
5. Some of the time
6. At no time

Managing your health and health care

The next few questions ask about your recent physical activity, diet and use of tobacco and alcohol and the support you may have received from health professionals (doctors, nurses, and other health professionals).

19 In the past week, on how many days did you do at least 30 mins of either vigorous or moderate activity (such as running, swimming, riding a bike, brisk walking, or dancing)?

- Every day
- 5 to 6 days
- 3 to 4 days
- 1 to 2 days
- I did not do any vigorous or moderate activity in the past week
- Not sure

20 In the past 12 months, has any health professional talked with you about your physical activity?

- Yes
- No
- Not sure

21 How often do you eat fruits (excluding juice)?

1. Twice or more a day
2. Once a day
3. Less than once a day but at least 4 times a week
4. Less than 4 times a week, but at least once a week
5. Less than once a week
6. Never
7. Not sure

22 How often do you eat vegetables or salad (excluding juice and potatoes)?

- 1. Twice or more a day
- 2. Once a day
- 3. Less than once a day but at least 4 times a week
- 4. Less than 4 times a week, but at least once a week
- 5. Less than once a week
- 6. Never
- 7. Not sure

23 In the past 12 months, has any health professional talked with you about healthy eating?

- Yes
- No
- Not sure

24 Do you smoke at all nowadays?

- Yes, daily..... [Go to Q26](#)
- Yes, occasionally..... [Go to Q26](#)
- Not at all



25 Have you ever smoked daily, or almost daily, for at least one year?

- Yes..... [Go to Q26](#)
- No[Go to Q27](#)



26 In the past 12 months, has any health professional talked with you about the health risks of smoking or using tobacco and ways to quit?

- Yes
- No
- Not sure

27 During the past 12 months, how often have you had an alcoholic drink of any kind (that is beer, wine, spirits, liqueurs or other alcoholic beverages)?

- Never..... [Go to Q29](#)
- Monthly or less
- 2-4 times a month
- 2-3 times a week
- 4-6 times a week
- Every day
- Not sure

28 In the past 12 months, has any health professional talked with you about alcohol use?

- Yes
- No
- Not sure

The next few questions about how you and the health professionals that you usually see support your health and health care.

29 I rely on health professionals to tell me everything I need to know to manage my health

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

30 Most health issues are too complex for me to understand

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

31 I actively try to prevent diseases and illnesses

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

32 I leave it to health professionals to make the right decisions about my health

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

33 It is important to me to be informed about health issues

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

34 I need to know about health issues so I can keep myself and my family healthy

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

35 I have difficulty understanding a lot of the health information that I read

- Strongly disagree
- Disagree

- Neither agree nor disagree
- Agree
- Strongly agree

36 My health professionals and I work together to manage my health

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

37 When I read or hear something that is relevant to my health care, I bring it up with health professionals

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

38 I try to understand my personal health risks

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

39 When I think something is wrong with my health care, I raise my concerns with my health professionals

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

RESPONSE OPTIONS CONTINUE

40 How confident are you that you can manage your own health and wellbeing?

- Very confident
 Confident
 Somewhat confident
 Not confident at all

41 How confident are you that you can follow instructions from health professionals about how you should care for yourself at home?

- Very confident
 Confident
 Somewhat confident
 Not confident at all

42 How confident are you that you can follow instructions from health professionals about how to change your habits or lifestyle?

- Very confident
 Confident
 Somewhat confident
 Not confident at all

43 How confident are you that you can identify when it is necessary for you to get medical care?

- Very confident
 Confident
 Somewhat confident
 Not confident at all

44 How confident are you that you can identify when you are having side effects from your medications?

- Very confident
 Confident
 Somewhat confident
 Not confident at all

45 How confident are you in using information from the Internet to make health decisions?

- Very confident
 Confident
 Somewhat confident
 Not confident at all

Your experience of health care

The following questions concern the care you are receiving from primary care services for your health and wellbeing. Primary care services are usually the first point of contact with the health service for a wide range of new and long-term health problems. They are frequently delivered by teams of health professionals, usually coordinated by a family doctor or a general practitioner working in a primary care centre. In your case this may be also another member of the primary care team, such as a nurse, or another specialist doctor. We also want to ask you in relation to a care plan, which is an agreement between you and your health professionals detailing the type of health care you need and how this care will be given. Not everybody has a care plan.

46 **Is there one doctor you usually go to for most of your health problems?**

Yes, I have one regular doctor

Yes, I have more than one regular doctor..... **Go to Q50**

No, I do not have a regular doctor **Go to Q50**

Not sure **Go to Q50**

47 **Who is this doctor?**

Primary care doctor

Specialist doctor

Other doctor

Not sure

48 **How long have you been seeing this doctor?**

1. 1 year or less

2. more than 1 year but no more than 3 years

3. more than 3 years but not more than 5 years

4. more than 5 years but no more than 10 years

5. 10 years or more

6. Not sure

49 **How often have you been to this doctor's office in the past 12 months?**

I have not visited in the past 12 months

1 time

2-4 times

5 times or more

Not sure

50 **Have you ever been told by a doctor that you have any of the following health problems?**

Please specify which health problem(s):

- High blood pressure
- Cardiovascular or heart condition
- Diabetes (type 1 or 2)
- Arthritis or ongoing problem with back or joints
- Ongoing depression, anxiety or other mental health condition (e.g., bipolar disorder or schizophrenia)
- Breathing condition (e.g., asthma or COPD)
- Chronic kidney disease/ Chronic liver disease
- Cancer (diagnosis or treatment in the last 5 years)
- Alzheimer's disease or other cause of dementia
- Neurological condition (e.g., epilepsy or migraine)

Other long-term problem(s):
.....
.....

99. I have never been told by a doctor that I have any these problems.....
Go to Q69

The next few questions are about the care you may have received for these health conditions.

51 **Do you have a single professional who takes responsibility for coordinating your care across the services that you use?**

Yes

No..... **Go to Q54**

Not sure..... **Go to Q54**

52 **Is this the same professional that you see for most of your health problems?**

Yes..... **Go to Q54**

No

RESPONSE OPTIONS CONTINUE

Not sure

53 Who is this professional?

- 1. A primary care doctor
- 2. A specialist doctor
- 3. A primary care nurse
- 4. A hospital nurse
- 5. Other doctor
- 6. Other nurse
- 7. Other health professional
- 8. Not sure

54 Is your healthcare organized in a way that works for you?

- Not at all
- To some extent
- More often than not
- I only use one healthcare service (e.g. primary care)
- Not sure

55 Are you offered regular follow-up for any of your health problems?

- 1. Yes, every 3 months or more often
- 2. Yes, every 6 months
- 3. Yes, every 12 months
- 4. Yes, over longer periods of time
- 5. No
- 6. Not sure

56 Do you discuss what is most important for you in managing your own health and wellbeing?

- Not at all
- To some extent
- More often than not
- Always
- Not relevant

57 Are you involved as much as you wanted to be in decisions about your care?

- Not at all
- To some extent
- More often than not
- Always
- Not relevant

58 Are you considered as a 'whole person' rather than just a disease/condition in relation to your care?

- Not at all
- To some extent
- More often than not
- Always
- Not relevant

59 How often does someone at your primary care centre talk to you about specific goals for your health?

- 1. Always
- 2. Often
- 3. Sometimes
- 4. Rarely
- 5. Never
- 6. Not sure
- 7. Not applicable

60 Do you have a care plan that takes into account all your health and wellbeing needs?

- Yes
- No..... [Go to Q64](#)
- Not sure..... [Go to Q64](#)

12 | DELSA/HEA/PARIS(2021)2

61 Is this care plan (or plan of care) available to you?

- Yes
- No
- Not sure

62 To what extent have you found your care plan (or plan of care) useful for you to manage your health and wellbeing?

- Not at all
- To some extent
- More often than not
- Not sure

63 To what extent do all the professionals involved in your care appear to be following the same care plan?

- Not at all
- To some extent
- More often than not
- Not sure

64 Do you have enough support from the health care professionals to help you to manage your own health and wellbeing?

- 1. I do not need support
- 2. I have had no support
- 3. I sometimes have enough support
- 4. I often have enough support
- 5. I always have enough support
- 6. Not relevant
- 7. Not sure

65 To what extent do you receive useful information at the time you need it to help you manage your health and wellbeing?

- 1. I do not receive any information
- 2. I sometimes receive enough information

- 3. I often receive enough information
- 4. I always receive enough information/ I receive too much information
- 5. Not relevant
- 6. Not sure

66 Are your family, friends and/or carers involved as much as you wanted them to be in decisions about your care?

- 1. Not at all
- 2. To some extent
- 3. More often than not
- 4. I did not want my family, friends or carers to be involved
- 5. My family, friends or carers did not want to be involved
- 6. I have no family, friends or carers

67 How many different medications as prescribed by a doctor or a nurse are you taking on a regular or ongoing basis?

- No medication.....Go to Q69
- 1-4 different medications
- 5-9 medications
- 10-15 medications
- 16 or more medications

68 In the past 12 months, has a health professional reviewed with you the medications you take?

- Yes
- No
- Not sure

RESPONSE OPTIONS CONTINUE

The next few questions are about your experience with your primary care centre in the last 12 months.

69 Were there times when you had to repeat information that should have been in your care records?

- Yes, definitely
- Yes, to some extent
- No, not really
- No, definitely not
- Not sure

70 How often do you believe you have had any safety problems in your primary care centre (such as not getting an appointment when needed; wrong or delayed diagnosis or treatment; or problems with communications between healthcare professionals)?

- 1. Always
- 2. Often
- 3. Sometimes
- 4. Rarely
- 5. Never
- 6. Not applicable

71 How often did you feel that the health professionals at your primary care centre encouraged you to talk about any concerns about your healthcare?

- 1. Always
- 2. Often
- 3. Sometimes
- 4. Rarely
- 5. Never
- 6. Not applicable

72 How often did you have a health problem but did not seek care because of difficulties in travelling to your primary care centre?

- 1. Always
- 2. Often
- 3. Sometimes
- 4. Rarely
- 5. Never
- 6. Not applicable

73 How often did you have a health problem but did not seek care, or did take a prescription medicine because of the cost?

- 1. Always
- 2. Often
- 3. Sometimes
- 4. Rarely
- 5. Never
- 6. Not applicable

The next questions are about the online services that your primary care centre may offer to patients like you, such as a website, smartphone app or video consultations:

74 How easy is it for you to use your primary care centre's website to look for information or access services?

- 1. Very easy
- 2. Fairly easy
- 3. Not very easy
- 4. Not at all easy
- 5. I haven't tried
- 6. My primary care centre does not have a website
- 7. Not sure

14 | DELSA/HEA/PARIS(2021)2

75 As far as you know, which of the following online services does your primary care centre offer?

1. Booking appointments online
2. Ordering repeat prescriptions online
3. Accessing my medical records online
4. Video consultations
5. None of these
6. Don't know

76 Which of the following online services of your primary care centre have you used?

1. Booking appointments online
2. Ordering repeat prescriptions online
3. Accessing my medical records online
4. Video consultations
5. None of these
6. Don't know

When taking all things into consideration in relation to the care you have received...

77 Overall, how do rate the medical care that you have received in the past 12 months from your primary care centre?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor
6. Have not received medical care in the last 12 months
7. Not sure

Other health services

78 Have you been in a hospital emergency department for your own medical care?

- No
- Yes, once
- Yes, twice
- Yes, 3 or more times
- Not sure

79 Have you been in the hospital for one night or longer?

- No
- Yes, once
- Yes, twice
- Yes, 3 or more times
- Not sure

The next questions are about the **last time** that you had a consultation with a **primary care doctor, nurse or other health professional** to get care for yourself (this may have been with your main health professional or another health professional and includes consultations over the phone or in a doctor's office, a clinic, or the outpatient department of a hospital. Do not include care you got when you stayed overnight in a hospital, dental care visits or accident and emergency care.

80 What was the purpose of this visit?

1. First contact for a new problem
2. Routine care for a long-term problem
3. Non-routine care for a long-term problem
4. General preventive care
5. Not sure

81 Who did you see?

1. A primary care doctor
2. Another specialist doctor
3. A nurse
4. An allied health professional, such as a physiotherapist, dietician, or podiatrist
5. Another health professional
6. Not sure

82 Where was this professional working?

- A primary care centre
- An outpatient department of a hospital
- Other
- Not sure

83 Which of the following best describes the type of care you received?

1. Face to face consultation
2. Telephone consultation
3. Video consultation
4. Home visit
5. Other
6. Not sure

84 How quickly did you get an appointment to see this health care professional?

- Same day
- Next day
- 2-5 days
- 6-7 days
- 8-14 days
- 15-30 days
- 31-60 days
- 61-90 days
- More than 90 days
- Not sure

85 Was the time you waited a problem for you?

- Yes
- No
- Not sure

86 Did this health professional spend enough time with you?

- Yes, definitely
- Yes, to some extent
- No, not really
- No, definitely not
- Not sure

87 Did this health professional explain things in a way that was easy to understand?

- Yes, definitely
- Yes, to some extent
- No, not really
- No, definitely not
- Not sure

88 Did this health professional give you an opportunity to ask questions or raise concerns about recommended treatment?

- Yes, definitely
- Yes, to some extent
- No, not really
- No, definitely not
- Not sure

89 Did you have confidence and trust in the healthcare professional you saw or spoke to?

- Not at all
- To some extent
- More often than not
- Always
- Not relevant

90 Overall, how would you rate the quality of this consultation?

- Excellent
- Very good
- Good
- Fair
- Poor
- Not sure

The next questions are about your experience of care in relation to the COVID/coronavirus pandemic.

91 In the last 12 months has a health care professional confirmed that you have had COVID-19?

- Yes
- No
- Not sure

92 In the last 12 months have you been vaccinated for COVID-19?

- Yes
- No
- Not sure

93 In the last 12 months, have you avoided making an appointment at your primary care centre for any reasons?

1. Yes, because I did not have time
2. Yes, because I was worried about the risk of catching COVID-19
3. Yes, because I was worried about the burden to the health system
4. Yes, because I found it too difficult
5. Yes, for another reason
6. I didn't need an appointment
7. No
8. Not sure

94 In the last 12 months, how often have you been concerned that you may not be receiving the care you needed because services were focusing on the response to the COVID-19 pandemic?

- Always
- Often
- Sometimes
- Rarely
- Never
- Not applicable

About yourself

Finally, we would like to ask you about some information about yourself. It is important to collect this information to understand whether there are any differences in the quality of services experienced by different groups of people.

95 How old are you?

- 44 years old or younger
- 45-49 years old
- 50-54 years old
- 55-59 years old
- 60-64 years old
- 65-69 years old
- 70-74 years old
- 75-79 years old
- 80-84 years old
- 85 years or older

96 How much do you weigh?

_____ lbs

- Prefer not to answer
- Don't know

97 How tall are you?

_____ feet _____ inches

- Prefer not to answer
- Don't know

-
-
-
-
- -
- -
-
-
-

99 Are you...?

- Female
- Male
- Other
- Prefer not to say

100 This question is about your sexual orientation. Do you identify as:

1. Heterosexual or straight (that is, attracted to the opposite sex)
2. Homosexual (gay or lesbian, that is, attracted to the same sex)
3. Bisexual (attracted to both sexes)
4. Other
5. Prefer not to say

101 Which of these best describes your current work situation?

1. Self-employed [work for yourself]
2. In paid employment [work for someone else]
3. Looking for work
4. Looking after the home
5. Unable to work due to sickness or ill-health
6. Retired
7. Student
8. Answer
9. Not working and not looking for work
10. Apprentice
11. Other
12. Don't know

102 Which of these categories does your household income usually fall into?

- Up to \$4,020 a month
- Between \$4,020 and \$6,700 a month
- \$6,700 or more a month
- Don't know

103 In the past 12 months, did you have problems paying or were unable to pay any medical bills?

- Yes
- No
- Not applicable

How often in the past 12 months would you say you were worried or stressed about the following things?

104 Having enough money to buy nutritious meals?

- Always
- Usually
- Sometimes
- Rarely
- Never

105 Having enough money to pay your rent or mortgage?

- Always
- Usually
- Sometimes
- Rarely
- Never

106 Having enough money to pay for other monthly bills, like electricity, heat, and your telephone?

- Always
- Usually
- Sometimes
- Rarely
- Never

107 Were you born in the United States of America?

- Yes
- No (if you answered 'No', please state what country you are citizen of:

108 Are you a citizen of the United States of America?

- Yes
- No (if you answered 'No', please state what country you are citizen of:

109 Which of these options best describes the place you live in?

1. A village, hamlet or rural area (fewer than 3 000 people)
2. A small town (3 000 to about 15 000 people)
3. A town (15 000 to about 100 000 people)
4. A city (100 000 to about 1 000 000 people)
5. A large city (with over 1 000 000 people)
6. Don't know

110 How many children under the age of 18 live with you, in your household?

_____ children under the age of 18

111 How many people aged 18 and over live with you, in your household? Please do not count yourself.

_____ people aged 18 and over

112 Should you need help, how easy is it for you to get help from a close family member (including your partner)?

- Very easy
 Easy
 Neither easy nor difficult
 Difficult
 Very difficult

113 Should you need help, how easy is it for you to get help from friends, neighbours and co-workers?

- Very easy
 Easy
 Neither easy nor difficult
 Difficult
 Very difficult

114 Do you need physical care or support, such as help with eating, dressing, bathing, moving around the house or assistance outside the house such as for using transportation?

- Yes
 No

115 Do you need emotional care or support, such as comfort, advice or counseling?

- Yes
 No

116 Do you need support for health care, such as administering medicines, changing bandages or arranging for appointments with primary care providers?

- Yes
 No

117 How strongly do you agree or disagree that the health care system can be trusted?

- Strongly disagree
 Disagree
 Neither agree nor disagree
 Agree
 Strongly agree

118 Who was the main person or people that filled in this questionnaire?

- The patient invited to complete the survey
 A friend or relative of the patient
 Both patient and a friend or relative together
 The patient invited to complete the survey with the help of a health professional or care worker

Thank you for taking the time to complete this questionnaire.

Thank you for participating in the interview today. To thank you for your time, we'd like to send you a check for \$40. Could you please provide me with an address to mail the check to?

NAME: _____

STREET: _____

CITY: _____

STATE: _____ ZIP: _____

GENERAL PROBES: Suggested general neutral probing for issues that arise.

- How did you decide on that answer?
- Can you tell me more about that?
- Can you give me an example of that?
- Tell me what you are thinking.
- What did you think about when I asked that question?
- What did you think about in deciding on your answer?
- What doctors did you include when you answered this question?
- What does [QUESTION/TERM] mean to you?

SEXUAL ORIENTATION AND GENDER IDENTIFY PROBES: Suggested general neutral probing specifically for the SOGI items.

- Did you have any trouble deciding on that answer?
 - If YES, What were you concerned about?
- Were there any words that you were uncertain about?
 - Which ones?
 - How did this affect your answer?
- What does Bisexual mean to you?
- [IF R ANSWERED: OTHER IN RESPECT TO GENDER IDENTITY:]
 - What else would best represent how you think about yourself?
- [IF R ANSWERED: I don't know how to answer:]
 - What makes it difficult for you to answer this question?

Appendix C. PaRIS Cognitive Interview Probes

Exhibit 22. PaRIS Cognitive Interview Probes

Survey Section	Question Text	Probes
Your Health	<p>8. Please select the response that best describes your current situation in relation to your breathing:</p> <ul style="list-style-type: none"> - I only get breathless with strenuous exercise - I get short of breath when hurrying on the level of up a slight hill - I walk slower than people of the same age on the level because of breathlessness or have to stop for breath when walking at my own pace on the level - I stop for breath after walking 100 yards or after a few minutes on the level - I am too breathless to leave the house 	<p>What were you thinking about when you responded to this question?</p> <p>What does "on the level" mean to you?</p>
Your Health	n/a	<p>Before I move on to the next section, were there any questions or concepts in this section that you found to be confusing?</p>
Managing your health and healthcare	36. My health professionals and I work together to manage my health	<p>What were you thinking about when you responded to this question?</p> <p>Who do you consider to be "health professionals"?</p>
Managing your health and healthcare	n/a	<p>Were there any (other) questions or concepts in this section that you found to be confusing?</p>
Your experience of health care	51. Do you have a single professional who takes responsibility for coordinating your care across the services that you use?	<p>What were you thinking about when you responded to this question?</p> <p>How did you decide on your answer?</p> <p>If answer was yes, who is the person you were thinking of?</p>
Your experience of health care	60. Do you have a care plan that takes into account all your health and wellbeing needs?	<p>What were you thinking about when you responded to this question?</p> <p>How did you decide on your answer?</p> <p>What does the term "care plan" mean to you?</p>

Survey Section	Question Text	Probes
Your experience of health care	69. The next few questions are about your experience with your primary care centre in the last 12 months. Were there times when you had to repeat information that should have been in your care records?	What were you thinking about when you responded to this question? How did you decide on your answer? What does the term "care records" mean to you?
Your experience of health care	69. Were there times when you had to repeat information that should have been in your care records?	What were you thinking about when you responded to this question? How did you decide on your answer? What does the term "care records" mean to you?
Your experience of health care	70. How often do you believe you have had any safety problems in your primary care centre (such as not getting an appointment when needed; wrong or delayed diagnosis or treatment; or problems with communications between healthcare professionals)?	What were you thinking about when you responded to these questions? How did you decide on your answer? What does the term "primary care centre" mean to you?
Your experience of health care	74. The next questions are about the online services that your primary care centre may offer to patients like you, such as a website, smartphone app or video consultations: How easy is it for you to use your primary care centre's website to look for information or access services?	What were you thinking about when you responded to these questions? How did you decide on your answer? What does the term "primary care centre" mean to you in this question?
Your experience of health care	n/a	Were there any (other) questions or concepts in this section that you found to be confusing?
Other health services	n/a	Were there any questions or concepts in this section that you found to be confusing?
About yourself	99. Are you...? - Female - Male - Other - Prefer not to say	What did you think about when I asked this question? How did you decide on your answer?

Survey Section	Question Text	Probes
About yourself	100. This question is about your sexual orientation. Do you identify as: <ul style="list-style-type: none"> - Heterosexual or straight (that is, attracted to the opposite sex) - Homosexual (gay or lesbian, that is, attracted to the same sex) - Bisexual (attracted to both sexes) - Other - Prefer not to say 	What did you think about when I asked this question? How did you decide on your answer? Were there any terms that you were uncertain about? Which ones?
About yourself	107. Were you born in the United States of America?	What did you think about when I asked this question? How did you decide on your answer?
About yourself	108. Are you a citizen of the United States of America?	What did you think about when I asked this question? How did you decide on your answer?
About yourself	109. Which of these options best describes the place you live in? <ul style="list-style-type: none"> - A village, hamlet or rural area (fewer than 3,000 people) - A small town (3,000 to about 15,000 people) - A town (15,000 to about 100,000 people) - A city (100,000 to about 1,000,000 people) - A large city (with over 1,000,000 people) - Don't know 	What were you thinking about when you responded to these questions? How did you decide on your answer? What does "hamlet" mean to you?
About yourself	n/a	Were there any questions or concepts in this section that you found to be confusing?