

# Longstanding Health Condition Survey 2019

Development Report

July 2020

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Please note that there is the potential for minor revisions of this report.

Please check the online version at **bhi.nsw.gov.au** for any amendments

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The conclusions in this report are those of BHI and no official endorsement by the NSW Minister for Health, the NSW Ministry of Health or any other NSW public health organisation is intended or should be inferred.

# NSW Patient Survey Program

The New South Wales (NSW) Patient Survey Program was established in 2007. During 2018–19, BHI asked almost 300,000 patients about their experiences of care in the NSW health system, and published the following survey results:

- Adult Admitted Patients 2017
- Admitted Children and Young Patients 2017
- Maternity Care 2017
- BreastScreen NSW Client Experience Survey
- Outpatient Cancer Clinics 2017
- Emergency Department Patient Survey 2017–18.

The results, and more information about these and other surveys, are available on the BHI website at [bhi.nsw.gov.au/nsw\\_patient\\_survey\\_program](https://bhi.nsw.gov.au/nsw_patient_survey_program).

BHI contracts a market research agency to conduct the data collection, while BHI conducts all survey analysis.

The aim of the survey program is to measure and report on patients' experiences in public healthcare facilities in NSW, on behalf of the NSW Ministry of Health and local health districts (LHDs). The survey program is currently being redeveloped to improve the timeliness and usefulness of the data collected under the auspices of the NSW Patient Survey Program Strategy 2019–2022.

## Longstanding Health Condition Survey

In 2019, BHI and the NSW Ministry of Health partnered to develop a survey asking people supported through the NSW Integrated Care Program about their experiences of care.

As few patients interviewed recognised the term 'integrated care' or knew about the program, the questionnaire was called the Longstanding Health Condition Survey 2019.

# Background

This document describes the creation of the Longstanding Health Condition Survey 2019 questionnaire to ask patients with relevant conditions about their experiences of healthcare services in NSW. BHI developed this questionnaire in partnership with the NSW Ministry of Health to help evaluate the NSW Integrated Care Program.

The survey assessed the experiences of care of approximately 25,000 patients enrolled in the NSW Integrated Care Program as of May 2019.

BHI undertakes a rigorous process in the development of new surveys, engaging with patients, clinicians, health managers and policy makers to create and test questionnaires and materials specific to each survey.

BHI also develops the sampling methodology, which details how to identify the population of interest, any exclusion criteria applied on the sample population and the calculations used to determine how many patients should be sampled. For more information on survey methodology, refer to the Longstanding Health Condition Survey 2019 technical supplement at [bhi.nsw.gov.au/nsw\\_patient\\_survey\\_program](http://bhi.nsw.gov.au/nsw_patient_survey_program).

## NSW Integrated Care Program

In March 2014, the NSW Government announced the NSW Integrated Care Strategy. The strategy proposed four strategic objectives aimed at improving patient experience and outcomes:

- organising care to meet the needs of patients and their carers
- designing better connected models of healthcare to meet the needs of smaller rural communities
- improving the flow of information between hospitals, specialists, community and primary care providers
- providing greater access to out-of-hospital community-based care.

The NSW Integrated Care Program is designed to stimulate transformational change in the way health services are planned, organised and delivered in NSW.

The program is designed to support value-based healthcare. It has been a key program for the past six years, aimed at providing the right care, in the right place, at the right time for patients across NSW.

More information about the program and conditions can be found at [health.nsw.gov.au/integratedcare/Pages/default.aspx](http://health.nsw.gov.au/integratedcare/Pages/default.aspx)

## Objectives of the survey

The primary aim of collecting patient-reported measures (PRMs) for the NSW Integrated Care Program is to "enable patients to provide direct, timely feedback about their health-related outcomes and experiences to drive improvement and integration of healthcare across NSW".<sup>1</sup>

The collection of PRMs to complete an evaluation of current integrated care programs is important because:

- delivering integrated care is a major priority for NSW Health
- monitoring and evaluation plans for integrated care programs are based on patient outcomes, the experience of receiving and providing care, efficiency and effectiveness
- the NSW Patient Survey Program is currently the only system in place for collection of PRMs across all of NSW.

The NSW Ministry of Health provided the following research and evaluation questions to be informed by the survey results:

- Do patients enrolled in integrated care programs receive well-coordinated care (e.g. whether or not they received conflicting information, how well the health professionals work together, etc.)?
- Are health services patient-centred (e.g. treating patients with respect and dignity, patients and their carers being part of decision-making about their care, patients being given information to help them manage their own care, etc.)?
- What is the quality of life of patients enrolled in the integrated care programs?
- How empowered are patients to manage their own care? What is their health literacy?

## Governance and ethical considerations

The survey was developed and conducted under the governance auspices of the NSW Patient Survey Program.

The NSW Patient Survey Program was reviewed by the Chair of the NSW Population and Health Services Research Ethics Committee in 2007 and again in 2012, and deemed to be surveillance/quality assurance and not research. The advice of this committee was that the survey program does not need to apply to an ethics committee unless required by a superseding ethics committee hierarchy. That is, ethics is only required for data linkage through the Centre for Health Record Linkage (CHeReL) or for release of Aboriginal survey results. The latter requires approval from the Aboriginal Health and Medical Research Council's Research Ethics Committee.

Patient consent to participate in the surveys is implicit in the return of the completed questionnaire. Participants are provided with all survey materials and then make the decision about whether to participate.

1. Agency for Clinical Innovation. Patient Reported Measures – outcomes that matter to patients [website]. Available at <https://www.aci.health.nsw.gov.au/make-it-happen/prms>

# Questionnaire development

BHI worked closely with the NSW Ministry of Health's Patient Experience and System Performance Division and the integrated care program leads in each LHD to develop the survey. The questionnaire went through the following development process:

1. Review of key literature and existing questions including generic health-related quality of life (HRQoL) and self-efficacy modules.
2. Stakeholder engagement about questionnaire structure and core content.
3. Cognitive testing with NSW integrated care program patients.
4. Final questionnaire review and sign-off.

## Review of literature and potential question sets

In 2018, the Agency for Clinical Innovation (ACI) conducted a rapid scoping review on Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs), with a particular focus on the NSW Integrated Care Program. This expert scoping provided information, guidance and recommendations for PRM question sets.

Based on this review and the work of an expert advisory group, ACI developed an initial set of questions to evaluate patient experience with various integrated care projects. BHI considered the appropriateness of these questions for use in the 'Longstanding Health Condition Survey 2019'. BHI also considered existing BHI survey questions with a focus on the themes of coordination and continuity, engagement and participation, and comprehensive and whole-person care.

The NSW Ministry of Health procured a license for BHI to use Insignia Health's Patient Activation Measure (PAM) question set to assess the extent to which patients feel they are receiving the support they need to confidently manage their longstanding health condition. This question set has been internationally validated and provides information on patients' self-efficacy and empowerment, which are critical elements in the assessment of integrated care.

To determine an appropriate set of questions for the assessment of patient outcomes and HRQoL, BHI conducted a rapid literature review for PROMs commonly used in the assessment of patients' ability to undertake activities of daily living and associated quality of life. The review focused on utility and aspects of psychometric and measurement aspects of these PROMs. Due to the large number of available papers, BHI focused on reviews, especially those that looked at integrated care, in the Australian context.

BHI created a shortlist of 10 generic scales, explicitly excluding all condition-specific scales – for example, the Oxford hip and knee scores and the Edmonton Symptom Severity Scale – and narrowly-focused scales, such as the Numeric Pain Rating Scale (NPRS), the Fatigue Severity Scale (FSS) and the Generalised Anxiety Disorder Scale (GAD7).

Table 1 presents the 10 PROMs tools that were assessed for inclusion in this questionnaire. BHI noted the number of questions in each tool and whether these tools required payment of a licence fee. Furthermore, BHI undertook a review to rate these tools on a scale from 0–3 points: zero meaning no evidence or support for the criterion of interest and three meaning high quality evidence for the criterion of interest.

The PROMs tools varied in length from 6–36 items. Most tools were free to use but two (the EQ-5D-5L and the SF-12) required payment of a licence fee. Overall, the Patient Reported Outcome Measurement Information System – 10 item (PROMIS-10) was deemed to have the best trade-off in terms of cost, length and quality, despite having less depth than some of the other tools, and the fact that it cannot be used to determine Quality-Adjusted Life Years (QALYs) at this time (e.g. for an assessment of cost-effectiveness).

of interventions). No questions focused on integration between health services however they had a strong focus on function and quality of life.

Based on the review, BHI recommended that the PROMIS-10 be included as a module within the questionnaire to capture patients' point-in-time assessment of their overall functioning and quality of life. PROMIS measures are publicly available without license, fee or royalty. HealthMeasures granted BHI permission to use the PROMIS-10 question set for this project.

**Table 1 Patient-Reported Outcome Measures (PROMs) commonly used in the assessment of patient functioning**

	Assessment Criteria								
	No. of questions	Licensed	Relevance to integrated care priority topics	Objectivity of questions	Supported written survey response collection	Fit for Quality-Adjusted Life Years (QALY)	Ease of completion	Sensitivity	Reliability
EQ-5D-5L	5+VAS*	Y	1	2	Y*	Y	2	2	3
AQoL-8D	35	N	1	2	Y†	Y	2	3	2
HRQOL-14	14	N	2	2	Y	N	1	2	2
PROMIS-10	10	N	2	3	Y	N	3	2	3
PROMIS-29	29	N	2	3	Y	Y	2	2	3
QOLS	16	N	1	2	Y	N	2	2	2
Short form 12	12	Y	1	2	Y	N	2	2	2
Short form 20	20	N	2	2	Y	N	2	3	3
Short form 36	36	N	2	2	Y	Y	2	3	3
WHOQoL-BREF	26+5	N	2	2	Y	M	2	2	3

\* The Visual Analogue Scale can be difficult to deliver and measure on paper.

† The order of the AQoL-8D is technically randomised for use.

Note: Criteria ratings are provided on a scale from zero to three points: zero meaning no evidence or support for the criterion of interest and three meaning high quality evidence for the criterion of interest.

The findings of this rapid review and associated conversations between the NSW Ministry of Health and BHI informed the questionnaire's structure and subject areas to be covered, as well as the final content of the stakeholder engagement documents.

## Stakeholder engagement

Stakeholder engagement was conducted regarding questionnaire structure and core content. The NSW Ministry of Health engaged integrated care program directors, leads and care coordinators from each of the LHDs to review and comment on the draft survey cover letter and proposed set of questions. BHI asked for feedback on question wording, questionnaire structure, and use of validated question sets, including the:

- terminology used to describe these patients and the integrated care program (e.g. the use of the term 'longstanding health condition' compared with 'chronic condition')
- range and appropriateness of question response options
- use of the PROMIS-10 for assessment of patient outcomes and quality of life
- structure of the questionnaire, including the grouping of questions and section titles
- wording of the two free text questions.

Nine LHDs provided responses and their feedback can be summarised as follows:

- LHDs saw it as important to collect this information and were supportive of a new survey to do so for the purpose of project evaluation.
- Most LHDs supported using the term 'longstanding condition' to replace 'chronic condition' used in the ACI questions but felt that this should be tested with patients. Some stakeholders felt it would be helpful define 'longstanding condition' early in the questionnaire.
- Stakeholders indicated the need for and value of testing questions with patients to look at the impact of low literacy and low levels of education on the ability to respond to the questions.
- Some stakeholders suggested that a short introduction for each section would be useful.
- Consideration should be given to the appropriateness of questions and response options for patients with multiple conditions, multiple care providers or enrolled in multiple programs.
- Approximately half of the questions attracted no specific comments from LHD representatives. The demographic questions and existing BHI patient survey questions were least likely to attract feedback.
- Some LHD representatives felt the survey was too long, especially for older patients and those with multiple health conditions.
- The PROMIS and PAM questions were typically identified as the most complex or difficult to interpret in the survey.
- While PROMIS-10 was seen as a useful set of questions for the assessment of quality of life and care outcomes, some clinical stakeholders felt this tool belonged to the clinical community and should not be used in a PRMs survey.
- The appropriateness of using these questions in a long, one-off postal survey was questioned. Clinicians asked how the PROMIS-10 data would be used to make changes, especially if it was only being reported at higher levels (such as LHD).
- The purpose of including PAM questions was to measure patient activation of those enrolled in the integrated care program. However, some clinicians had concerns that the 'true' purpose of this question set was to improve patient activation over time in the context of discussions between clinician and patient. This raised the issue of how this question set would be used or analysed. It was noted that some of these questions were repetitive in theme to others in the questionnaire.



The survey questions and cover letter were revised based on this input, and the updated questionnaire and cover letter were used for testing with recent patients enrolled in one of the integrated care programs included in the scope.

## Cognitive testing with current integrated care program patients

Listening to the experiences of patients is essential for developing a questionnaire that respondents feel is important and pertinent to them. In order to gain the patient perspective, BHI undertook cognitive testing with five patients at each of three LHDs (15 patients in total), with iterative changes being made to the questionnaire between the sessions.

Cognitive testing ensures that people completing the questionnaire understand what each question means and how to answer it. It involves interviewing patients as they complete the questionnaire, and probing how each answer is developed. This highlights questions that are being misinterpreted or difficult to understand, and those that are missing response options or have other issues.

BHI can then assess both the construct validity of questions and the effectiveness of the questionnaire layout. The testing process also identifies questions that pose a high cognitive burden for the respondent, providing direction on how the questionnaire can be enhanced for delivery to a wider audience.

A total of 15 face-to-face interviews were conducted with patients who were currently enrolled in an LHD integrated care program. Interviews were held at the following three locations with the permission and support of staff from those sites:

- Macquarie Hospital, Northern Sydney LHD
- Nepean Hospital, Nepean Blue Mountains LHD
- Bathurst Base Hospital, Western NSW LHD.

Patients provided the following feedback during cognitive interviews:

- Overall, patients felt that the questionnaire worked well.
- Some patients felt the questionnaire was too long. While they thought most questions were relevant, they thought others were repetitive.
- Almost all patients did not completely understand some terminology, such as 'coordinated care' and 'integrated care'.
- Patients were able to differentiate between similar words such as 'kind', 'caring', 'polite' and 'considerate', and to suggest the most appropriate/important words to include in the context of 'coordinated care'.
- the role of 'care coordinator' was not well understood and patients had trouble identifying the profession of staff who helped them manage their care.
- There is variation in how often care planning occurs and the degree to which it occurs. Written plans are relatively rare.
- Five-item frequency response scales (always to never) could be truncated as these provided too much variation in reflecting patients' experiences.
- Patients felt the PROMIS-10 and PAM questions were repetitive of other questions and were more difficult to read. Some patients were confused by the grid format, and many missed the instructions for these two validated tools.
- While particular attention was paid to comments provided by Aboriginal patients, no cultural issues were identified with the questionnaire. Aboriginal care coordinator was included as an important care provider in the response options.

## Final questionnaire review

BHI and NSW Ministry of Health staff reviewed the cognitive interview feedback in the context of the purpose of the survey. Although some patients had more difficulty completing the PROMIS-10 and PAM questions, almost all patients were able to do so. Due to the importance of self-efficacy and outcomes to this work, representatives from BHI and the NSW Ministry of Health agreed that these questions would remain within the questionnaire.

The survey questions and their origin are presented in Appendix 1.

Due to the length of the final questionnaire, BHI's usual format of a 12-page booklet with 10 pages of questions and a detachable cover/information sheet was not appropriate. Instead, the cover letter was removed from the booklet, resulting in a separate double-sided invitation letter and an eight-page questionnaire booklet. This is presented in Appendix 2.

Following the BHI and NSW Ministry of Health project teams' review of the final questionnaire, it was submitted to BHI's Chief Executive and the Ministry's Executive Director, Performance Support Branch who provided final approval of the questionnaire and cover letters.

# Appendix 1: Question development notes

The following table outlines the source of each question in the Longstanding Health Condition Survey 2019 and any relevant development notes. The following acronyms are used for questions which were developed for other surveys:

- **Original** – question designed for the Longstanding Health Condition Survey 2019 and not knowingly sourced from any other questionnaire or survey
- **AAPS** – sourced from the BHI Adult Admitted Patient Survey
- **OCCS** – sourced from the BHI Outpatient Cancer Clinics Survey
- **PAM** – sourced from the Patient Activation Measure (Insignia Health)
- **PROMIS-10** – sourced from the Patient Reported Outcome Measurement Information System
- **ACI IC** – sourced from ACI's Integrated Care Survey.

Table 2 Question source and notes on development, Longstanding Health Condition Survey 2019

Question	Question source	Licensed question	Development notes
Q1 Which of the following longstanding health conditions do you have?	ACI IC	No	Heavily modified for use. Changed 'chronic health conditions' to 'longstanding health conditions' – this change was made throughout the questionnaire. Added 'chronic kidney disease' and 'mental health'. Re-sorted list in order of frequency of condition in NSW. Modified some category headings.
Q2 Is there someone who helps you arrange and plan care for your longstanding health condition?	Original	No	Question acted as a filter to Q3 to identify people other than the patient who helped coordinate their care.
Q3 Who is mostly responsible for helping you arrange and plan your care?	Original	No	Identified primary care coordinator or assistant to allow for targeted questions on access to and communication with this individual.
Q4 Over the past six months, was there ever a time when you were not able to speak to your healthcare professional(s) when you needed to?	Original	No	Question identified whether the patient had ready access to their care coordinator.
Q5 When you had important questions to ask your healthcare professional(s), did they answer in a way you could understand?	AAPS	No	Question reflected the quality of information provided to the patient.
Q6 Did healthcare professionals help you to identify the most important things you need to do to manage your longstanding health condition?	ACI IC	No	Question reflected on whether healthcare professionals worked with the patient to identify important things in the management of their condition.
Q7 Did healthcare professionals help you get access to services you needed at home to manage your longstanding health condition?	ACI IC	No	Minimal changes to ACI question.
Q8 Do you feel that your care is well coordinated?	Original	No	Summary question on whether people felt their entire care was well coordinated.
Q9 Do you have a written care plan designed to arrange and plan your care?	OCCS	No	Modified question from the Outpatient Cancer Clinics Survey regarding the development of a written care plan.
Q10 Were you asked about your preferences for care and treatment when developing this plan?	OCCS	No	Question reflected on whether the patient had been engaged in what they felt was important in their care plan.
Q11 Did you feel your care plan covered everything that needed to be covered?	ACI IC	No	Unmodified.
Q12 Over the past six months, how much of the planned treatment in your care plan, including ongoing treatment, occurred?	ACI IC	No	Unmodified.



Question	Question source	Licensed question	Development notes
Q13 Over the past six months, have you received all the care you feel you needed for your longstanding health condition?	ACI IC	No	Unmodified.
Q14 Over the past six months, how easy has it been for you to manage your longstanding health condition?	ACI IC	No	Unmodified.
Q15 Patient activation measure – 13 items	PAM	Yes	The NSW Ministry of Health procured a license for BHI to use Insignia Health's Patient Activation Measure (PAM) question set (UK version).
Q16 Over the past six months, which of the following healthcare professionals have provided you with care or treatment?	Original	No	This question was added because the NSW Ministry of Health needed to understand who was providing the care and treatment.
Q17 In your opinion, did the healthcare professionals seem to know the important information about your medical history?	Original	No	Discussions with consumers identified this as an important question.
Q18 How often have healthcare professionals asked about personal or emotional issues that affect your health?	ACI IC	No	Slightly modified response options.
Q19 How often have healthcare professionals asked about physical or medical issues that affect your health?	ACI IC	No	Slightly modified response options.
Q20 Did the healthcare professionals explain things in a way you could understand?	AAPS	No	Unmodified.
Q21 Did you ever receive conflicting information about your condition or treatment from the healthcare professionals?	OCCS	No	Unmodified.
Q22. Were you involved, as much as you wanted to be, in decisions about your care and treatment?	AAPS	Yes	Unmodified.
Q23 How much information about your condition or treatment was given to your family, carer or someone close to you?	AAPS	Yes	Unmodified.
Q24 Did you have confidence and trust in the healthcare professionals treating you?	AAPS	No	Unmodified.
Q25 Were the healthcare professionals kind and caring towards you?	AAPS	No	Unmodified.

Question	Question source	Licensed question	Development notes
Q26 Did you feel you were treated with respect and dignity by healthcare professionals?	AAPS	No	Unmodified.
Q27 Overall, how would you rate the care you have received related to your longstanding health condition over the past six months?	Original	No	Modified version of standard BHI overall rating of care question from other program surveys.
Q28 Over the past six months, have you been admitted to hospital?	Original	No	Question used to assess outcomes of avoiding hospital admission through intervention of the integrated care program.
Q29 Was your most recent hospital stay related to your longstanding health condition?	Original	No	Question used to assess outcomes of avoiding hospital admission through intervention of the integrated care program.
Q30 Did hospital staff take your family and home situation into account when planning your discharge?	AAPS	Yes	Unmodified.
Q31 Thinking about when you left hospital, were adequate arrangements made by the hospital for any services you needed?	AAPS	No	Unmodified.
Q32 Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	AAPS	Yes	Unmodified.
Q33 Did the hospital provide you with a document summarising the care you received in hospital (e.g. a copy of the letter to your GP, a discharge summary)?	AAPS	No	Unmodified.
Q34–43 Patient Reported Outcome Measurement Information System – 10 item	PROMIS-10	No	PROMIS measures are publicly available without license, fee or royalty. HealthMeasures granted BHI permission to use the PROMIS-10 question set for this project..
Q44 Who completed this survey?	AAPS	No	Unmodified.
Q45 What is the highest level of education you have completed?	AAPS	No	Unmodified. Key standardisation question.
Q46 Which language do you mainly speak at home?	AAPS	No	Original question for the NSW Patient Survey Program. Records languages other than English, included free-text box. Key standardisation question.

Question	Question source	Licensed question	Development notes
Q47 Are you of Aboriginal origin, Torres Strait Islander origin, or both?	AAPS	No	Unmodified.
Q48 Are you a participant of the National Disability Insurance Scheme (NDIS) or My Aged Care (MAC)?	OCCS	No	Unmodified.
Q49 Do you give permission for the Bureau of Health Information to link your answers from this survey to health records related to you (the patient)?	AAPS	No	Unmodified.
Q50 What has been the best part of the care you received for your longstanding health condition in the past six months?	AAPS	No	Unmodified.
Q51 What has made managing your longstanding health condition difficult?	ACI IC	No	Based on multiple choice question from ACI's Integrated Care Survey.

# Appendix 2: Longstanding Health Condition Survey questionnaire 2019 (final)

NSW Patient Survey

## CARE AND MANAGEMENT OF YOUR LONGSTANDING HEALTH CONDITION

NSW Health is changing the way it provides care to people who have longstanding health conditions. We want to hear from you about the care you have been receiving so that more supportive and patient-centred healthcare services can be provided.

Sometimes you will find the box you have crossed has an instruction to go to another question. By following the instructions carefully you will miss out questions that do not apply to you.

For each question, please cross  clearly inside one box using a black or blue pen. Some questions will ask you to cross more than one box.

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

Please do not write your name or address anywhere on the questionnaire. ■

**MANAGING YOUR CARE**

**Q1** Which of the following longstanding health conditions do you have?

Please  all the boxes that apply to you

- Diabetes
- Lung or respiratory (e.g. asthma, COPD or emphysema)
- Heart or cardiac
- Arthritis/osteoarthritis
- Osteoporosis
- Chronic kidney disease
- Mental health (e.g. anxiety/depression)
- Back pain
- Other longstanding health condition (please specify)

**Q3** Who is mostly responsible for helping you arrange and plan your care?

- One main healthcare professional
- A team of healthcare professionals
- A family member or carer .....Go to Q6
- Someone else .....Go to Q6
- Don't know .....Go to Q6

**Q4** Over the past six months, was there ever a time when you were not able to speak to your healthcare professional(s) when you needed to?

- Yes
- No

**Q5** When you had important questions to ask your healthcare professional(s), did they answer in a way you could understand?

- Yes, always
- Yes, sometimes
- No, I didn't get answers I could understand
- I didn't ask any questions

||| PAGE 1 ||| Please turn over ↻





- Q6** Did healthcare professionals help you to identify the most important things you need to do to manage your longstanding health condition?
- Yes, completely
  - Yes, to some extent
  - No
  - Not applicable; I didn't need help
  - Don't know

- Q7** Did healthcare professionals help you get access to services you needed at home to manage your longstanding health condition?
- Yes, completely
  - Yes, to some extent
  - No
  - Not applicable; I didn't need services at home
  - Don't know

- Q8** Do you feel that your care is well coordinated?
- Yes, always
  - Yes, sometimes
  - No
  - Don't know/can't remember

### YOUR CARE PLAN

The following questions ask about care plans. Care plans are written documents that outline the steps and goals in managing your longstanding health condition(s).

- Q9** Do you have a written care plan designed to arrange and plan your care?
- Yes
  - No ..... Go to Q13
  - I don't need one. .... Go to Q13
  - Don't know/can't remember .. Go to Q13

- Q10** Were you asked about your preferences for care and treatment when developing this plan?
- Yes
  - No
  - Don't know/can't remember

- Q11** Did you feel your care plan covered everything that needed to be covered?
- All aspects of care were covered
  - Most, but not all aspects of care were covered
  - Some aspects of care were covered
  - Very few or no aspects of care were covered
  - Don't know

- Q12** Over the past six months, how much of the planned treatment in your care plan, including ongoing treatment, occurred?
- All
  - Most
  - Some
  - Very little or none
  - It is too early to say
  - Don't know

- Q13** Over the past six months, have you received all the care you feel you needed for your longstanding health condition?
- Yes, completely
  - Yes, to some extent
  - No
  - Not applicable – I didn't need any care
  - Don't know

- Q14** Over the past six months, how easy has it been for you to manage your longstanding health condition?
- Very easy
  - Easy
  - Neither easy nor difficult
  - Difficult
  - Very difficult



## VIEWS ON YOUR HEALTH AND CONDITION

**Q15**

Below are some statements that people sometimes make when they talk about their health.

Please indicate how much you agree or disagree with each statement as it applies to you personally by crossing the box that suits you. There are no right or wrong answers, just what is true for you. If the statement does not apply to you, cross "Not applicable".

	Disagree strongly	Disagree	Agree	Agree strongly	Not applicable
I am the person who is responsible for taking care of my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking an active role in my own healthcare is the most important thing that affects my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident I can help prevent or reduce problems associated with my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what each of my prescribed medications do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident that I can tell a doctor or nurse concerns I have even when he or she does not ask	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident that I can carry out medical treatments I may need to do at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand my health problems and what causes them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what treatments are available for my health problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have been able to maintain lifestyle changes, like healthy eating or exercising	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to prevent problems with my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident I can work out solutions when new problems arise with my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident that I can maintain lifestyle changes, like healthy eating and exercising, even during times of stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Disagree strongly	Disagree	Agree	Agree strongly	Not applicable

Source: Insignia Health. Patient Activation Measure, Copyright 2003-2019 University of Oregon, all rights reserved.

## YOUR HEALTHCARE PROFESSIONALS

**Q16** Over the past six months, which of the following healthcare professionals have provided you with care or treatment?

Please  all the boxes that apply to you

- GP/family doctor
- Medical specialist
- Nurse
- Allied health worker  
(e.g. physiotherapist, dietician, speech language therapist, health educator)
- Social worker
- Aboriginal Health Worker
- Other

(please specify)

- I have not seen a healthcare professional in the past six months . . . . . Go to Q28

**Q17** In your opinion, did the healthcare professionals seem to know the important information about your medical history?

- Always
- Mostly
- Sometimes
- Rarely
- Never
- Don't know/can't remember

**Q18** How often have healthcare professionals asked about personal or emotional issues that affect your health?

- Always
- Mostly
- Sometimes
- Rarely
- Never

**Q19** How often have healthcare professionals asked about physical or medical issues that affect your health?

- Always
- Mostly
- Sometimes
- Rarely
- Never

**Q20** Did the healthcare professionals explain things in a way you could understand?

- Yes, always
- Yes, sometimes
- No

**Q21** Did you ever receive conflicting information about your condition or treatment from the healthcare professionals?

- Yes
- No

**Q22** Were you involved, as much as you wanted to be, in decisions about your care and treatment?

- Yes, definitely
- Yes, to some extent
- No
- I wasn't well enough
- I didn't want or need to be involved

**Q23** How much information about your condition or treatment was given to your family, carer or someone close to you?

- Not enough
- The right amount
- Too much
- It was not necessary to provide information to any family or friends
- Don't know/can't say

**Q24** Did you have confidence and trust in the healthcare professionals treating you?

- Yes, always
- Yes, sometimes
- No

**Q25** Were the healthcare professionals kind and caring towards you?

- Yes, always
- Yes, sometimes
- No

**Q26** Did you feel you were treated with respect and dignity by healthcare professionals?

- Yes, always
- Yes, sometimes
- No

**Q27** Overall, how would you rate the care you have received related to your longstanding health condition over the past six months?

- Very good
- Good
- Neither good nor poor
- Poor
- Very poor

### YOUR HOSPITAL ADMISSION AND DISCHARGE

**Q28** Over the past six months, have you been admitted to hospital?

- Yes ..... Go to Q29
- No ..... Go to Q34
- Can't remember ..... Go to Q34

### FOR QUESTIONS 29-33, PLEASE REFLECT ON YOUR MOST RECENT ADMISSION TO HOSPITAL

**Q29** Was your most recent hospital stay related to your longstanding health condition?

- Yes
- No

**Q30** Did hospital staff take your family and home situation into account when planning your discharge?

- Yes, completely
- Yes, to some extent
- No, staff did not take my situation into account
- It was not necessary
- Don't know/can't remember

**Q31** Thinking about when you left hospital, were adequate arrangements made by the hospital for any services you needed?

- Yes, completely
- Yes, to some extent
- No, arrangements were not adequate
- It was not necessary

**Q32** Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?

- Yes
- No
- Don't know/can't remember

**Q33** Did the hospital provide you with a document summarising the care you received in hospital (e.g. a copy of the letter to your GP, a discharge summary)?

- Yes
- No
- Don't know/can't remember

## ABOUT YOUR HEALTH

Please respond to each question or statement by marking one box per row.

		Excellent	Very good	Good	Fair	Poor						
<b>Q34</b>	In general, would you say your health is:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>						
<b>Q35</b>	In general, would you say your quality of life is:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>						
<b>Q36</b>	In general, how would you rate your physical health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>						
<b>Q37</b>	In general, how would you rate your mental health, including your mood and your ability to think?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>						
<b>Q38</b>	In general, how would you rate your satisfaction with your social activities and relationships?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>						
<b>Q39</b>	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).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>						
		Completely	Mostly	Moderately	A little	Not at all						
<b>Q40</b>	To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>						
		Never	Rarely	Sometimes	Often	Always						
<b>Q41</b>	In the past seven days, how often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>						
		None	Mild	Moderate	Severe	Very severe						
<b>Q42</b>	In the past seven days, how would you rate your fatigue (tiredness) on average?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>						
	No pain <span style="font-size: 2em;">→</span> Worst pain imaginable											
<b>Q43</b>	In the past seven days, how would you rate your pain on average?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
		0	1	2	3	4	5	6	7	8	9	10

## ABOUT YOU

**Q44** Who completed this survey?

- Me (the patient)
- Me (the patient) with help from family or carer
- Me (the patient) with help from healthcare staff
- Someone on behalf of me (the patient)

**Q45** What is the highest level of education you have completed?

- Less than Year 12 or equivalent
- Completed Year 12 or equivalent
- Trade or technical certificate or diploma
- University degree
- Post graduate/higher degree

**Q46** Which language do you mainly speak at home?

- English
- A language other than English

What is that language? Please write below

**Q47** Are you of Aboriginal origin, Torres Strait Islander origin, or both?

- Yes, Aboriginal
- Yes, Torres Strait Islander
- Yes, both Aboriginal and Torres Strait Islander
- No

**Q48** Are you a participant of the National Disability Insurance Scheme (NDIS) or My Aged Care (MAC)?

- Yes, the National Disability Insurance Scheme
- Yes, My Aged Care
- Neither of these
- Don't know

**Q49** The Bureau of Health Information would like your permission to link your survey answers to other information from health records relating to you which are maintained by various NSW and Commonwealth agencies (including your hospitalisations, medical visits, ambulance transportation, medication or health registry information). Linking to your healthcare information will allow us to better understand how different aspects of the care provided by health facilities are related to the health of, and use of health services by, their patients.

**Your information will be treated in the strictest confidence.** We will receive the linked information after your name and address have been removed. We will not report any results which may identify you as an individual and your responses will not be accessible to the people who looked after you.

Do you give permission for the Bureau of Health Information to link your answers from this survey to health records related to you (the patient)?

- Yes
- No

## YOUR COMMENTS

Q50

What has been the best part of the care you received for your longstanding health condition in the past six months?


< INSERT BARCODE NUMBER HERE >

Q51

What has made managing your longstanding health condition difficult?


## THANK YOU FOR YOUR TIME

Please return the questionnaire in the reply paid envelope provided or send it in an envelope addressed to our survey processing centre (no stamp needed):

NSW Patient Survey, Ipsos Social Research Institute

Reply Paid 91752, Port Melbourne VIC 3207

The questions in the About Your Health section comprise the Patient-Reported Outcomes Measurement Information System-Global Health (PROMIS-GH; 10 questions). This tool is used with the permission of HealthMeasures.

Barcode