



<Barcode>
<Title> <First Name> <Last Name>
<Address Line 1>
<SUBURB> <STATE> <POSTCODE>

Date


Dear <First Name> <Last Name>,

Tell us about the healthcare you have received

NSW Health is working to improve the care provided to people who have longstanding health conditions.

Hearing about your experiences is the only way to understand how well this care worked for you. Your feedback will help health professionals and patients work together to provide more supportive and person-centred healthcare services.

The questionnaire is easiest to complete online. Once you start the online questionnaire, it is possible to return later to complete it. Please visit the web address below and log in with the following unique username and password.

	Visit survey.ipsos.com.au/patientsurvey	Username [INS_UNAME]
		Password [INS_PWORD]

If you prefer to complete the attached paper questionnaire, please remove this covering letter before placing the completed copy in the enclosed reply paid envelope.

Your information will be treated confidentially. The healthcare professionals involved with your care will not know whether you have completed the questionnaire and will not be able to see your responses.

If you have any questions or need help filling in the questionnaire, please contact the toll-free Patient Survey Helpline on **1800 220 936** (Monday to Friday, 9am–8pm), or email your questions to **NSWPatientSurvey@ipsos.com** (include your username [INS_UNAME] in the subject line).

For information about the survey program and to see how your local health services are performing, visit the Bureau of Health Information website at **bhi.nsw.gov.au**

Thank you very much for taking the time to help improve NSW Health services.

Yours sincerely

Dr Diane Watson
Chief Executive
Bureau of Health Information

HOW TO COMPLETE THE PAPER QUESTIONNAIRE

Please use a blue or black pen to mark an **X** in the box next to the answer you choose.

Sometimes the box you have marked has a 'Go to...' instruction. By following the 'Go to...' instruction you will be able to move past any questions that do not apply to you.

Q2 **Is there someone who helps you arrange and plan care for your longstanding health condition?**

- YesGo to Q3
- No, but I do want or need someone.....Go to Q6
- No, I don't want or need someone.....Go to Q6

If you make a mistake or wish to change a response, simply fill in that box and mark the correct box:

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

- Yes, always
- Yes, sometimes
- No

If you prefer not to answer a question, leave it blank and continue to the next question.

If someone is helping you to complete the questionnaire, please ensure the answers given are from your point of view, and not the opinion of the person helping you.

PRIVACY INFORMATION

Your privacy is protected by legislation

The Bureau of Health Information (BHI) works with Ipsos Social Research Institute to manage the NSW Patient Survey Program on behalf of NSW Health. Your name and address is provided to Ipsos for the purpose of sending you this questionnaire only. Ipsos will keep your contact details confidential.

Your questionnaire responses will be treated in the strictest confidence. Once you have completed the questionnaire, your contact details are removed from the survey results. No identifying information will be given to your doctor or any other health professionals unless required by law.

Your answers will be analysed along with the responses from other people who completed the questionnaire. The results will be provided to your local hospital and to NSW Health to help improve services.

You can find more information about privacy and confidentiality at bhi.nsw.gov.au/nsw_patient_survey_program/privacy

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.

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.

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.

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)

Q2 Is there someone who helps you arrange and plan care for your longstanding health condition?

- YesGo to Q3
- No, but I do want or need someoneGo to Q6
- No, I don't want or need someoneGo to Q6

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 carerGo to Q6
- Someone elseGo 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

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: Hibbard J, Stockard J, Mahoney E, et al. Development of the Patient Activation Measure (PAM): Conceptualizing and Measuring Activation in Patients and Consumers. Health Services Research. 2004; 39(4 Pt 1), 1005-1026.

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?

- YesGo 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						
Q34	In general, would you say your health is:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>						
Q35	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"/>						
Q36	In general, how would you rate your physical health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>						
Q37	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"/>						
Q38	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"/>						
Q39	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						
Q40	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						
Q41	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						
Q42	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					Worst pain imaginable					
Q43	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

Source: Hays R, Bjorner J, Revicki R, et al. Development of physical and mental health summary scores from the Patient Reported Outcomes Measurement Information System (PROMIS) global items. Quality of Life Research. 2009;18(7):873-80.

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?

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

Some of the questions asked in this survey are sourced from the NHS Patient Survey Programme (courtesy of the NHS Care Quality Commission), the National Research Corporation (USA) and the Agency for Clinical Innovation (ACI). Questions are used with the permission of each organisation. The questions in the Views On Your Health And Condition section comprise the Patient Activation Measure (PAM). This tool is used with the permission of Insignia Health. The questions in the About Your Health section comprise the Patient-Reported Outcomes Measurement Information System – Global Health (PROMIS Scale v1.2 – Global Health). This tool is used with the permission of HealthMeasures.

Barcode