

All.Can patient survey 2018 – final questions and answer options – Australia

Q	Question	Response options
1	Are you currently resident in the Australia?	<ul style="list-style-type: none"> • Yes • No
2	Are you filling in this questionnaire for yourself, or on behalf on somebody else?	<ul style="list-style-type: none"> • For myself • On behalf of somebody else
<p>Diagnosing your cancer In this section, we ask about how your cancer was diagnosed, and what could have been improved.</p>		
3	Was your cancer diagnosed as part of a routine screening programme, or as part of a screening programme for an unrelated health problem?	<ul style="list-style-type: none"> • Yes, as part of a routine screening programme • Yes, as part of a screening programme for an unrelated health problem • No, it was not diagnosed as part of any screening programme
4	After first seeing a doctor about the health problem, how long did it take to be diagnosed with cancer?	<ul style="list-style-type: none"> • Less than a month • 1 to 3 months • 3 to 6 months • 6 months to a year • More than a year • Don't know / can't remember • Not applicable
5	Was the diagnosis correct at every point during this time?	<ul style="list-style-type: none"> • Yes, the diagnosis was correct from the start • No, my cancer was initially diagnosed as something different • No, my cancer was diagnosed as something different a number of times • Don't know / can't remember
6	Please think about your cancer diagnosis. Do you have any examples of how this could have been improved? In particular, were there things that you felt were wasting time, money or other resources?	

Your cancer care and treatment		
In this section, we ask about the care and treatment you received for your cancer.		
7	Following your first diagnosis for cancer, did you start some form of cancer treatment (e.g. medicines, surgery, chemotherapy or radiotherapy)?	<ul style="list-style-type: none"> • Yes • No
8	Were you involved as much as you wanted to be in deciding which treatment options were best for you?	<ul style="list-style-type: none"> • Yes, definitely • Yes, to some extent • No, I would have liked to be more involved • There were no different treatment options • Don't know / can't remember
9	Have you always been given enough information about your cancer care and treatment, in a way that you could understand?	<ul style="list-style-type: none"> • Yes • No. I was given information, but could not understand it all • No. I was not given enough information • Don't know / can't remember
10	Did a healthcare professional discuss treatment outcomes with you (i.e. the desired outcome, potential side effects of treatment and reviewing the actual outcome or impact on quality of life) and the impact it would have on your cancer?	<ul style="list-style-type: none"> • Yes, we spoke about this before my treatment started • Yes, we spoke about this before treatment started and during the course of my treatment • Yes, we had a discussion once my treatment finished • No. I didn't have that kind of discussion • Don't know/can't remember
11	Have you always been given enough information, in a way that you could understand, about signs and symptoms to look out for that your cancer might be returning/getting worse?	<ul style="list-style-type: none"> • Yes • No. I was given information, but could not understand it all • No. I was not given enough information • Don't know / can't remember

12	There may be many groups of people involved in your care (e.g. surgeons, oncologists, radiologists, nurses, other specialists). Have you always felt well supported by these people to know when you should seek further care?	<ul style="list-style-type: none"> • Yes, definitely • Yes, to some extent • No, not at all • Don't know/can't remember • Not applicable
13	Did you have access to specialist cancer nurses (i.e. nurses who provide additional support and information about your diagnosis, assists with appointment scheduling and accessing other services) immediately after your diagnosis and/or during treatment?	<ul style="list-style-type: none"> • Yes • No • Not sure/can't remember
14	If you have needed other support (e.g. from dietitians, physiotherapists, or mental health services), is this always available to you when you need it?	<ul style="list-style-type: none"> • Yes, always • Yes, sometimes • No, not at all • Don't know / can't remember • Not applicable
15	Were you offered complementary therapies (e.g. massage, meditation, acupuncture, aromatherapy and/or other non-traditional therapies) as part of your cancer treatment? Did you find them helpful or effective in your cancer care?	<ul style="list-style-type: none"> • Yes, I was offered and found it to be helpful • Yes, but I didn't not think it had any beneficial effects • Yes, but I was not interested in taking complementary therapies • No, but I would have liked to have been offered • No, I'm not interested in complementary therapies • Don't know/can't remember
16	Do you have any ideas of where time or resources could have been more efficiently used by the healthcare system during your cancer care and treatment (e.g. around receiving more/better information)?	

Ongoing support and returning to everyday life

After their initial cancer care, some patients need ongoing support and treatment to return to everyday life. In this section, we ask about your experience of this.

17	Many cancer patients say that they need ongoing psychological support throughout their care, and maybe even afterwards. If you have needed this, has it always been available to you?	<ul style="list-style-type: none">• Yes, always• Yes, sometimes• No, not at all• Don't know / can't remember• I didn't need it• Not applicable
18	How helpful has this psychological support been?	<ul style="list-style-type: none">• Very helpful• Quite helpful• Neither helpful nor unhelpful• Quite unhelpful• Very unhelpful• Don't know / can't remember
19	Do you feel you have always been given enough support to deal with any ongoing symptoms and side effects, even beyond the phase of 'active' treatment (if applicable)?	<ul style="list-style-type: none">• Yes, always• Yes, most of the time• Yes, some of the time• No, never• Don't know / can't remember• Not applicable
20	Looking specifically at pain, do you feel that you have always been given sufficient information and care to deal with the pain you may have experienced?	<ul style="list-style-type: none">• Yes, always• Yes, most of the time• Yes, some of the time• No, never• Don't know / can't remember• Not applicable

21	Do you have any examples of where things could have been done more efficiently, and more focused on your needs, in your ongoing support and help in returning to everyday life?	
22	Once you started your cancer treatment, what impact did this have on your everyday life?	<ul style="list-style-type: none"> • My home and family life was negatively affected by my treatment needs, making relationships more difficult • My family and friends were supportive during my treatment and it made us closer • My work life was affected due to my treatment needs and appointments. Colleagues and managers treated me differently • My work life was affected, but my colleagues were supportive during my treatment • My work life was affected, but my employers made adaptations to ensure my return to work after treatment was made easier • I was made to feel isolated with limited access to support as I lived far away from my specialists and where I was receiving treatment • Other (please specify)
23	How far did you have to travel to attend appointments and/or treatment?	<ul style="list-style-type: none"> • I travel less than 30 minutes for treatment/appointments • I travel 30 minutes to 1 hour for treatment/appointments • I travel 1 to 2 hours for treatment/appointments • I travel more than 2 hours for treatment/appointments • Travel for treatment/appointments requires an overnight stay as my appointments were too far from home • I receive treatment and care at home • I have used or have been offered telehealth services instead of face-to-face appointments

Financial implications of your cancer		
In this section, we ask about some of the financial implications of your cancer care and treatment.		
24	Did you incur out-of-pocket costs (i.e. costs you had to find money for that were not covered by the public hospital system or by your private health insurance. Such as costs for medicines, cost of doctors and specialists, physiotherapy, diagnostic tests) and how did you cover these costs?	<p><i>Please tick all that apply</i></p> <ul style="list-style-type: none"> • No, I did not have any out-of-pocket costs. All my costs were covered by the public hospital or private health insurer (exclude known excess). • Yes, I had out-of-pocket costs because the medication I need is not listed on the Government funded PBS • Yes, I had out-of-pocket costs and I had to find extra money out of my own pocket • Yes, I had out-of-pocket costs and I had to rely on income protection/superannuation to support costs associated with my treatment • Yes, I had out-of-pocket costs and I had to rely on Veterans Affairs to cover the costs • Yes, I had out-of-pocket costs and I relied on friends, family or engaged in fundraising to cover the costs • Other (please specify)
25	Were there any other financial implications of your cancer care and treatment?	<p><i>Please tick all that apply</i></p> <ul style="list-style-type: none"> • Loss of employment • Travel costs • Childcare costs • Loss of insurance • Other • Not applicable
Patient support groups		
In this section, we ask about patient support groups that you may have been in contact with.		
26	Were you given information about patient groups, charities and other organisations that might be able to support you through your diagnosis and care?	<ul style="list-style-type: none"> • Yes • No • Don't know / can't remember

27	How did you find out about these groups?	<p><i>Please tick all that apply</i></p> <ul style="list-style-type: none"> • From my healthcare professional(s) • Through family and friends • Searching on the internet or through social media • Other • Don't know / can't remember
	If other, please specify below.	
28	What made you contact a patient support group following your cancer diagnosis?	<p><i>Please tick all that apply</i></p> <ul style="list-style-type: none"> • I wanted to speak to someone who has had a similar experience • I wanted to access the services offered by the patient support group • I felt I wasn't receiving enough information from my specialists and/or hospital staff • I needed help understanding some technical information about my diagnosis and treatment • I wanted the opportunity to speak to someone beyond my family and friends • I wanted to help others who may be going through a similar situation • Other (please specify below)
29	To what extent did you use these groups?	<ul style="list-style-type: none"> • A lot of the time • Some of the time • Not at all
<p>Taking part in clinical trials In this section, we ask about clinical trials.</p>		
30	Have you been involved in clinical trials related to your cancer?	<ul style="list-style-type: none"> • Yes • No. I was asked to participate, but didn't want to • No. I wasn't asked • There were no clinical trials available • Don't know / can't remember

31	Would you like to have been asked?	<ul style="list-style-type: none"> • Yes • No • Not sure
Your overall experience		
In this section, we ask some general questions about your overall cancer care.		
32	During the whole of your care and treatment for cancer, did you have to miss or cancel appointments at short notice?	<ul style="list-style-type: none"> • Not at all • Once or twice • Three or more times • Don't know / can't remember
	If so, for what reasons?	
33	During the whole of your care and treatment for cancer, how often were appointments cancelled by the hospital or clinic you were due to attend?	<ul style="list-style-type: none"> • Not at all • Once or twice, with clear explanations given about why • Once or twice, with no clear explanations given about why • Three or more times • Don't know / can't remember
34	At the end of your cancer treatment, were you left with any excess medications that you didn't need?	<ul style="list-style-type: none"> • Yes, because I was given too much • Yes, because I didn't take the medications I was supposed to • No • Don't know / can't remember • Not applicable
35	During the whole of your cancer care and treatment, where do you feel there was most inefficiency?	<ul style="list-style-type: none"> • My initial cancer diagnosis • Getting the right treatment for my cancer • Dealing with ongoing side effects • Dealing with the financial implications • Dealing with the psychological impacts • Access to patient support groups • The opportunity to take part in clinical trials • Other • Don't know / can't remember

	If other, please specify below.	
36	Many cancer patients talk about the emotional burden on them and their families, as they go through cancer care. Have you come across any examples of how the healthcare system could have worked differently, or did work, to reduce this?	
37	Was communication between you and your specialists, nurses, general practitioner and other hospital staff clear during your cancer care?	<ul style="list-style-type: none"> • Yes completely • Yes to some extent • No, not at all • Don't know / can't remember
<p>About your condition In this section, we ask some details about your cancer, so we can understand the views of different groups of patients.</p>		
38	With what type of cancer were you first diagnosed?	<ul style="list-style-type: none"> • Brain/central nervous system • Breast • Colorectal/bowel • Ovarian • Prostate cancer • Skin cancers/melanoma • Gynaecological • Lymphoma • Leukaemia • Myeloma • Mesothelioma • Rare cancer • Digestive (e.g. Oesophageal, Stomach, Bile Duct) • Endocrine • Head and neck • Lung • Other

	If other, please specify below.	
39	At what stage is/was your cancer at?	<ul style="list-style-type: none"> • Stage 0 • Stage 1 • Stage 2 • Stage 3 • Stage 4 • Don't know/can't remember
40	How long is it since you were first treated for this cancer?	<ul style="list-style-type: none"> • Less than 1 year • 1 to 5 years • More than 5 years • Don't know / can't remember
41	Had your cancer spread to other organs or parts of your body at the time you were first told you had cancer?	<ul style="list-style-type: none"> • Yes • No • Don't know • Does not apply to my type of cancer
42	Which of the following applies?	<ul style="list-style-type: none"> • My cancer has been removed/treated, without any sign of further problem • My cancer was removed/treated without any sign of further problem, but has since come back / spread to other parts of my body • None of the above options apply to my type of cancer • I would prefer not to say • I don't know
<p>About you In this section, we ask some details about you, so we can understand the views of different groups of patients.</p>		
43	In what year were you born?	
44	What is your gender?	<ul style="list-style-type: none"> • Male • Female • Other

45	What is your postcode?	
46	Which best describes where you live?	<ul style="list-style-type: none"> • I live in an urban area – i.e. within a major city • I live in a regional area – i.e. within a major regional city • I live in a rural area – i.e. outside a town or city
Keeping in touch		
47	Where did you hear about this survey?	<ul style="list-style-type: none"> • I saw a link to it online • From family / friends • Direct contact from a patient organisation • From a healthcare professional • Other
	If other, please specify below.	
48	We may be interested in following up some of your answers in more detail. If you are happy for us to contact you again, please tick the box below.	Yes, I would be interested in following up some of my answers in more detail
49	<p>If you wish to receive the results of the survey, and to follow All.Can's related policy engagement activities, please tick the box below.</p> <p>If you agree to give your email address to All.Can, Quality Health will pass that information on to the All.Can secretariat so that they can send you the results of the survey and keep you up to date with All.Can's related policy engagement activities. You have the choice of opting out of All.Can's mailing list at any point in the future.</p>	Yes, I wish to receive the results of the survey and to follow All.Can's policy engagement activities

50	If you have ticked at least one of the boxes above, please confirm your choice by typing your email address in the box below.	
	Many thanks for your assistance. Please click the 'Complete' button below to save your responses and exit the survey.	