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SCAPE-CH PATIENTS' EXPERIENCES WITH CANCER CARE IN SWITZERLAND

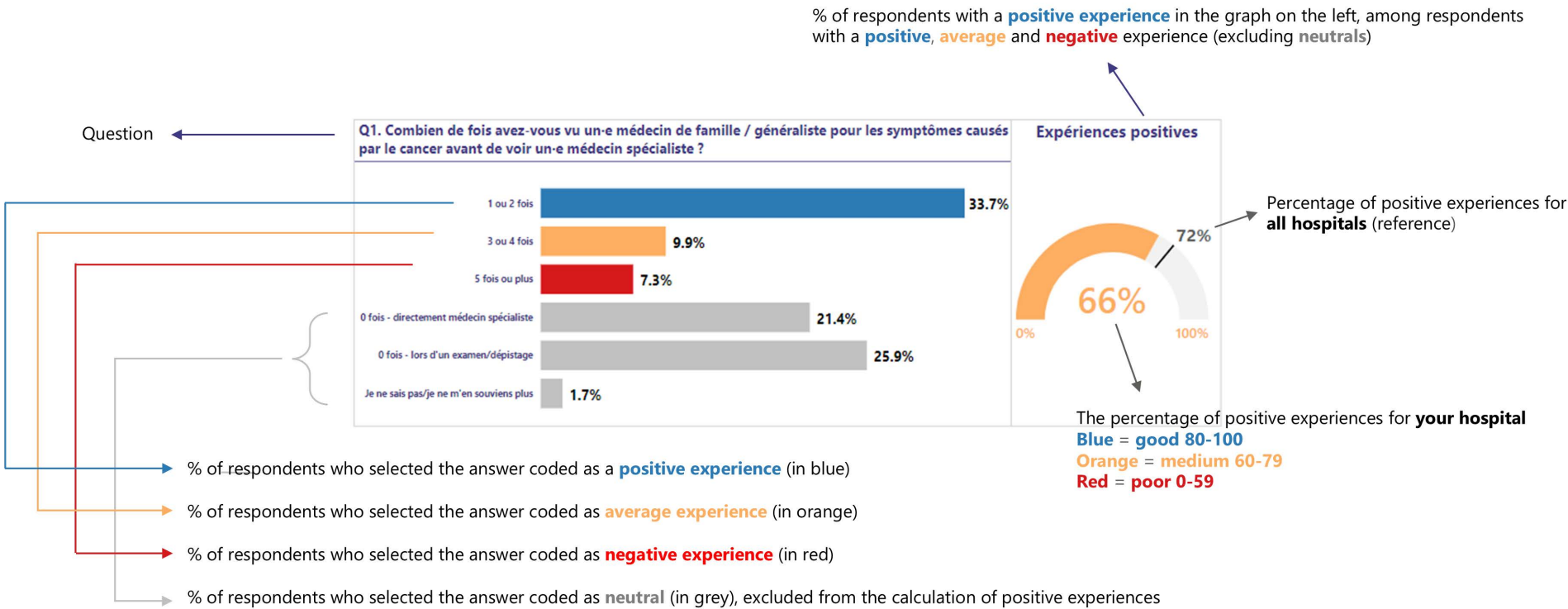
SCAPE-CH is a multicenter, cross-sectional study conducted in 21 oncology centres in French-, German- and Italian-speaking Switzerland. Its aim is to gather information about cancer patients' experiences of care.

The study included adults living in Switzerland who have been diagnosed with cancer and experienced a care episode between January and June 2023.

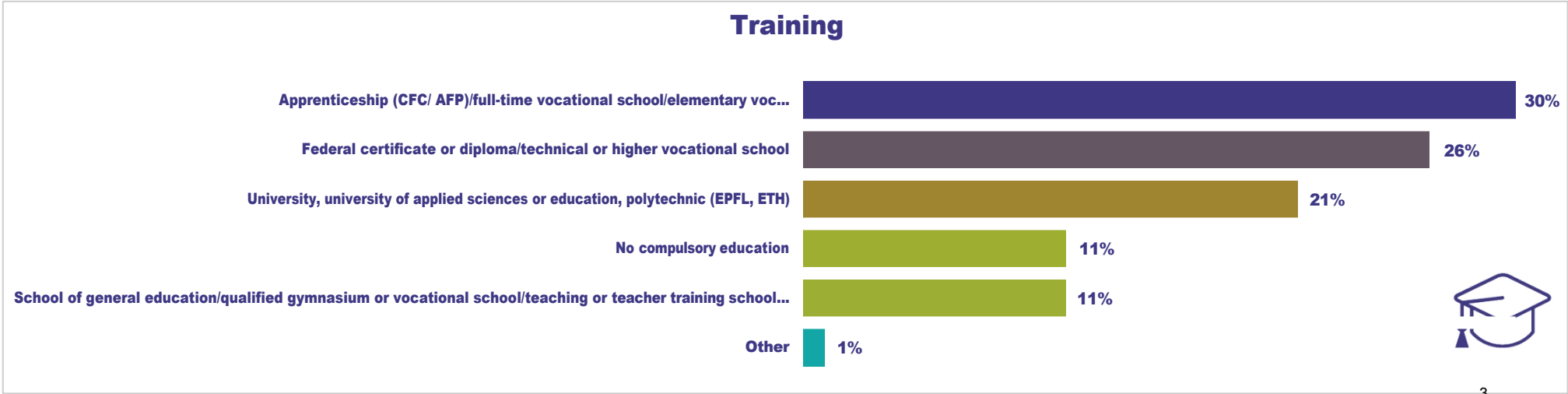
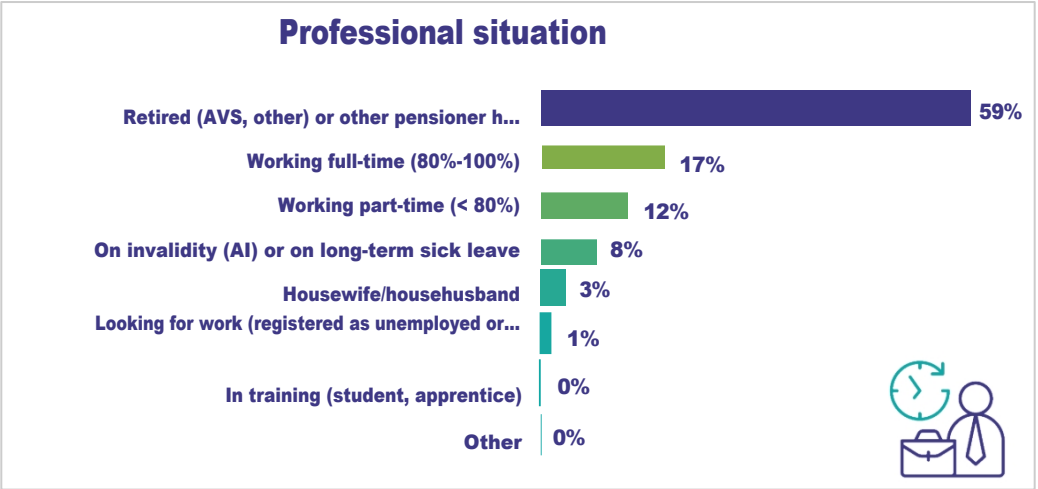
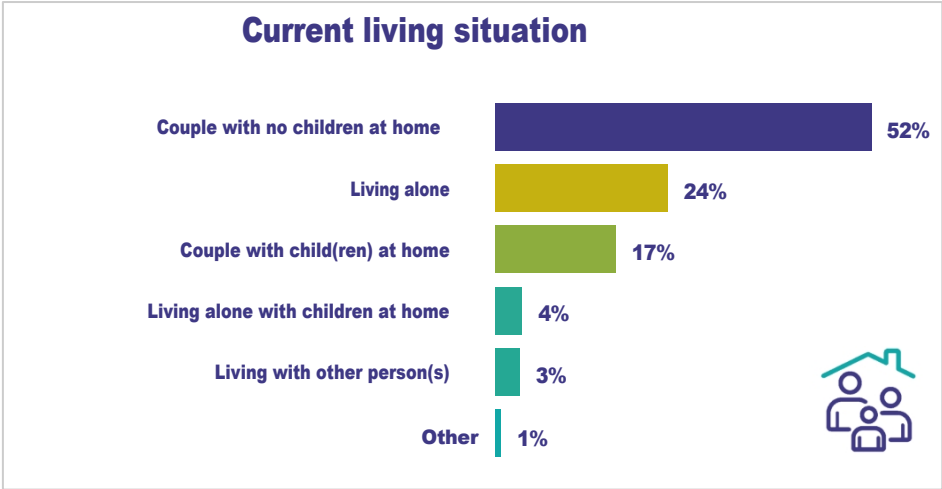
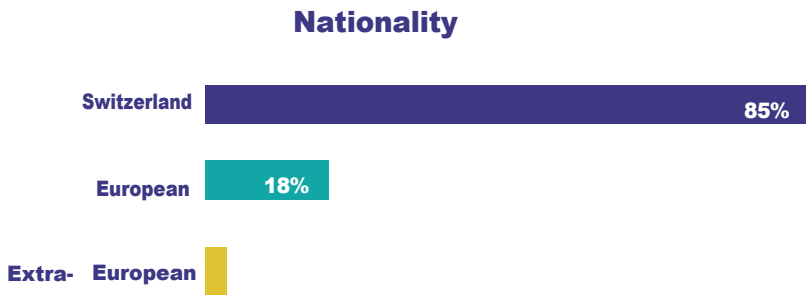
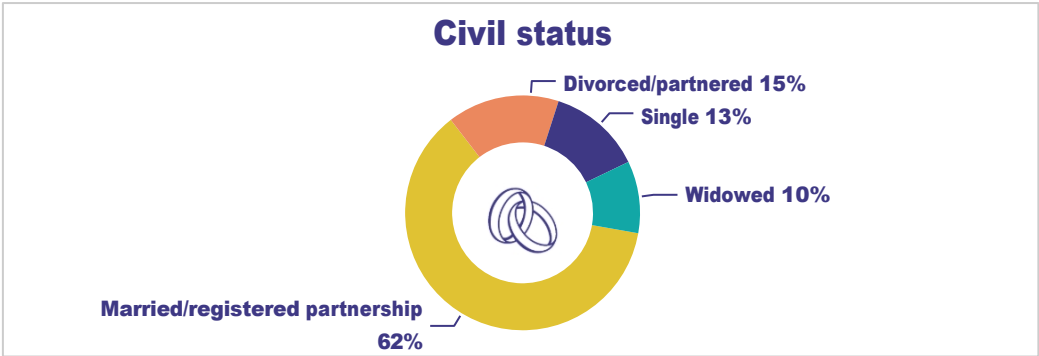
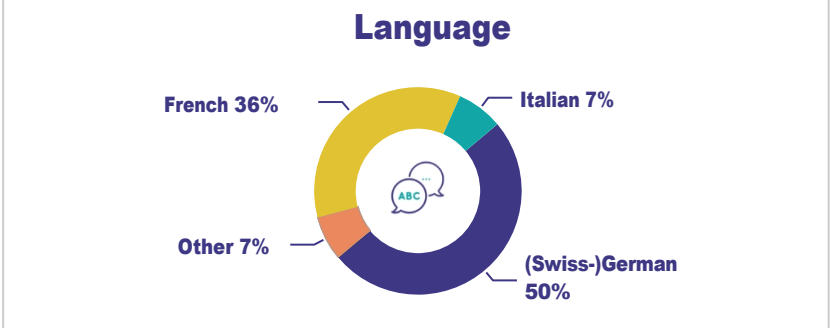
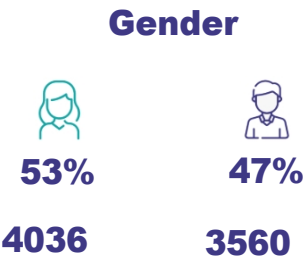
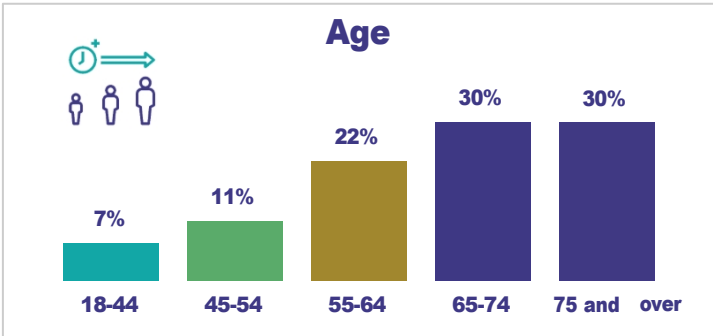
Experiences of care were collected via a self-administered questionnaire, available in German, French, Italian and English, in both paper and online versions. The questionnaire comprised 89 questions: experiences of care (64 questions), cancer and health (12 questions), personal information (13 questions) and three free-text sections.

Of the 16,963 questionnaires sent out, 7,844 were returned (gross participation rate of 46.2%). The adjusted participation rate (by excluding from the denominator people declared dead, those without cancer, duplicates and envelopes not delivered due to address errors) is 48.5%.

GUIDE TO READING THE RESULTS

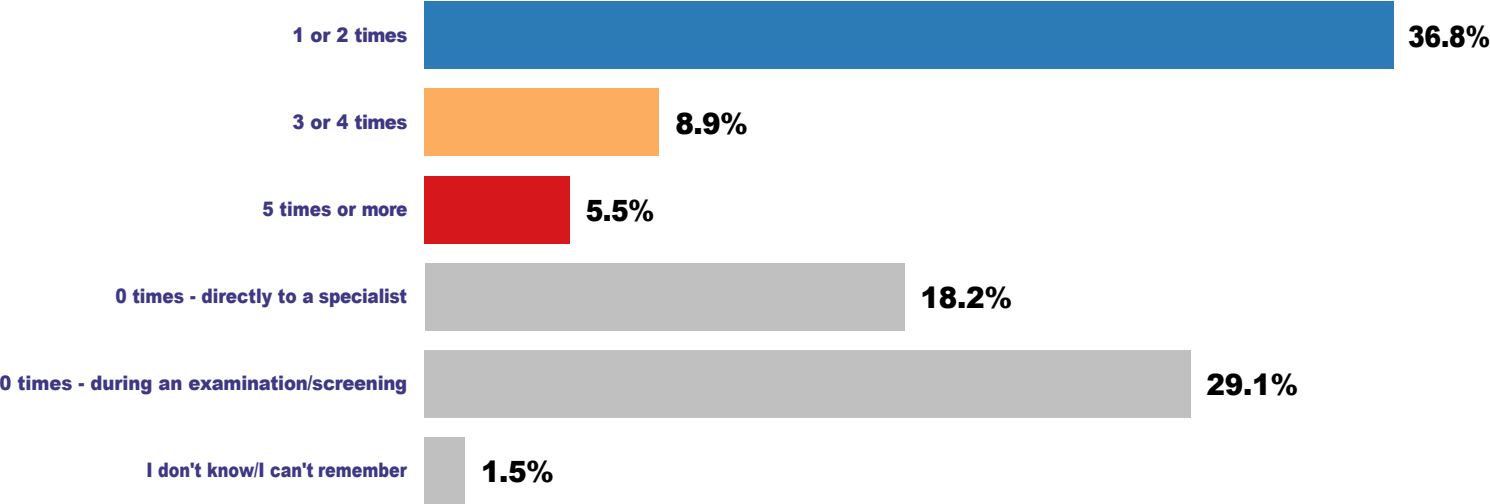


RESPONDENTS' CHARACTERISTICS

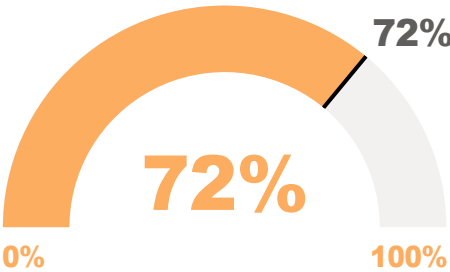


CONSULTATIONS WITH A FAMILY DOCTOR / GENERAL PRACTITIONER before the cancer diagnosis

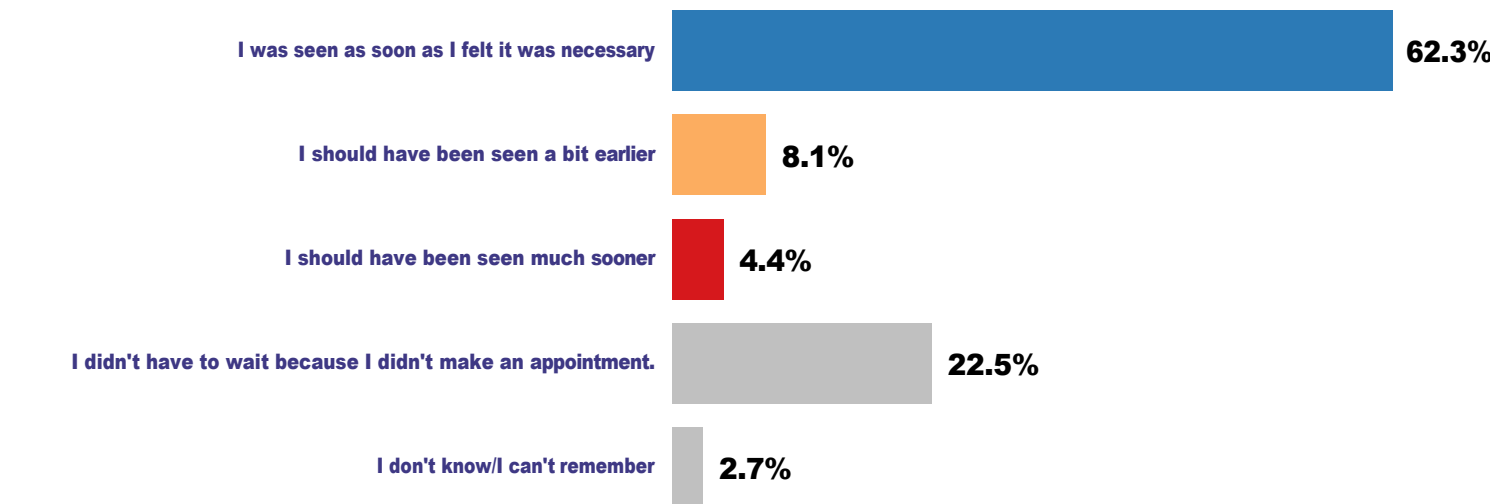
Q1. How many times have you seen a family doctor/general practitioner for symptoms caused by cancer before seeing a specialist?



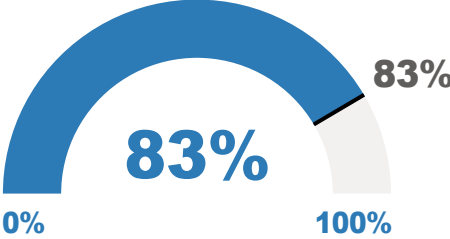
Positive experiences



Q2. How do you feel about the length of time you had to wait before your first appointment with a specialist?



Positive experiences



DIAGNOSTIC TESTS

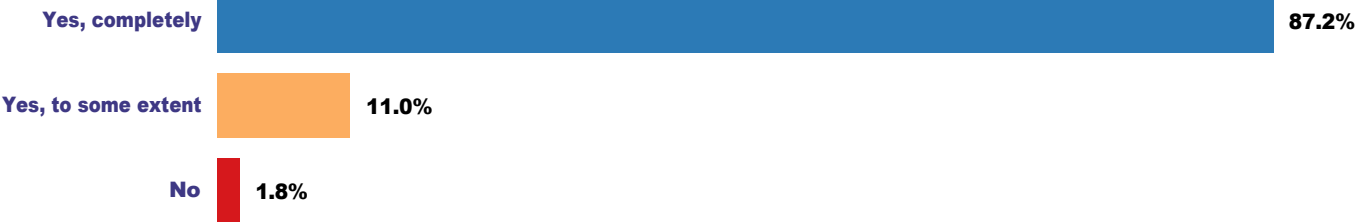
Q3. During the last 12 months, have you had a diagnostic test for cancer, such as endoscopy, mammography or scan, at the hospital?



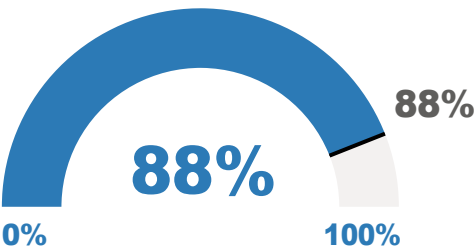
No; Go to Q7

Yes; Go to Q4

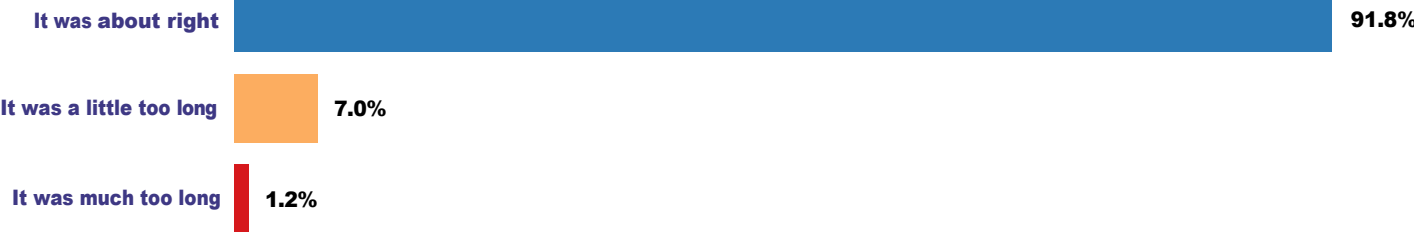
Q4. Before the test, did you have all the information you needed about this test?



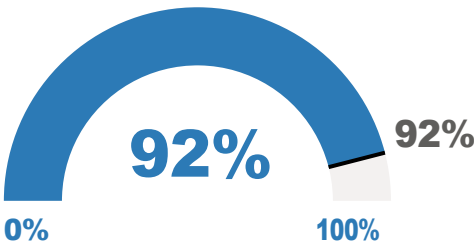
Positive experiences



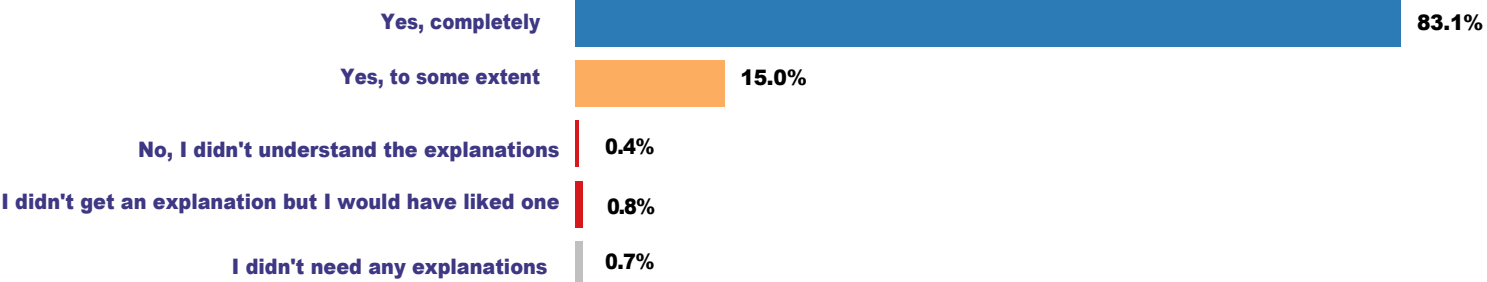
Q5. Overall, how did you feel about the length of time you had to wait between the prescription of the test and its completion?



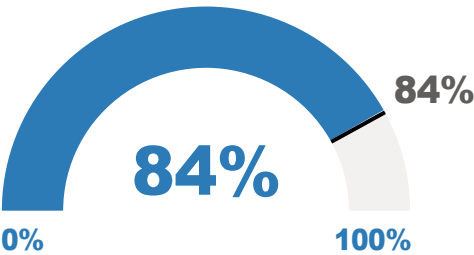
Positive experiences



Q6. Were the results of this test explained in a way you could understand?

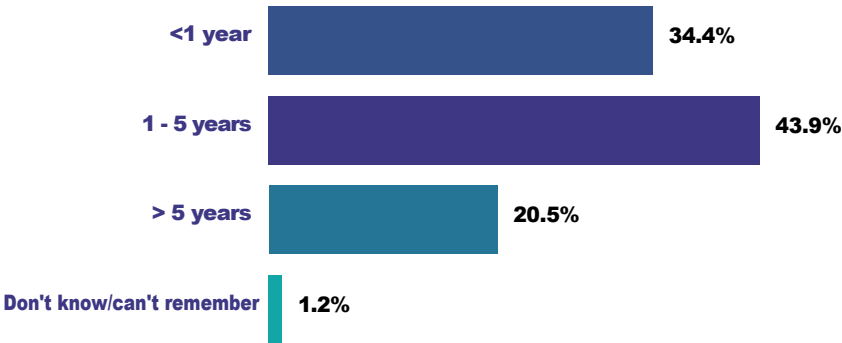


Positive experiences

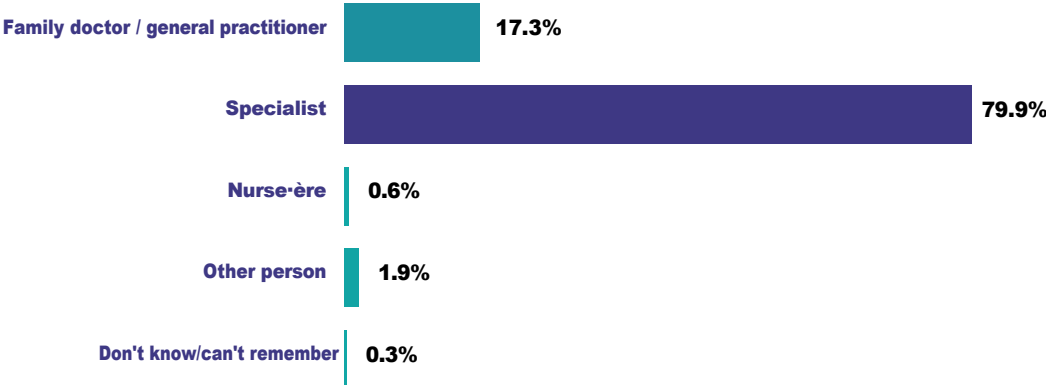


FINDING OUT ABOUT THE CANCER DIAGNOSIS

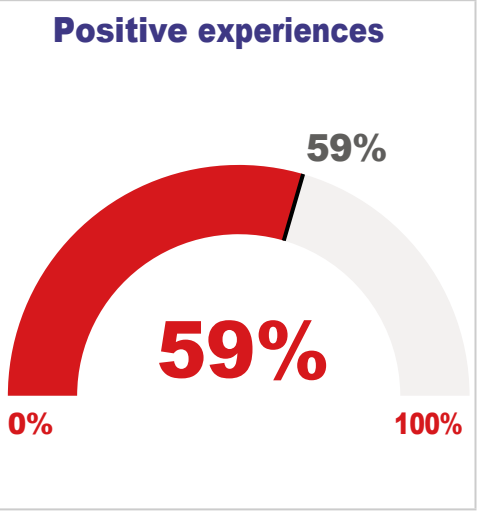
Q7. How long ago were you told you had the cancer for which you were treated or followed up in 2023?



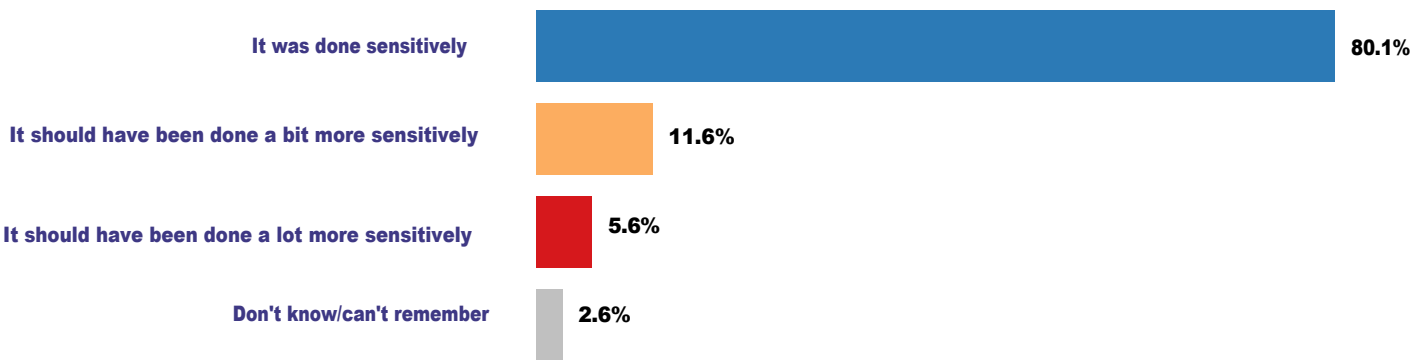
Q8. Who was the first person to tell you that you had cancer?



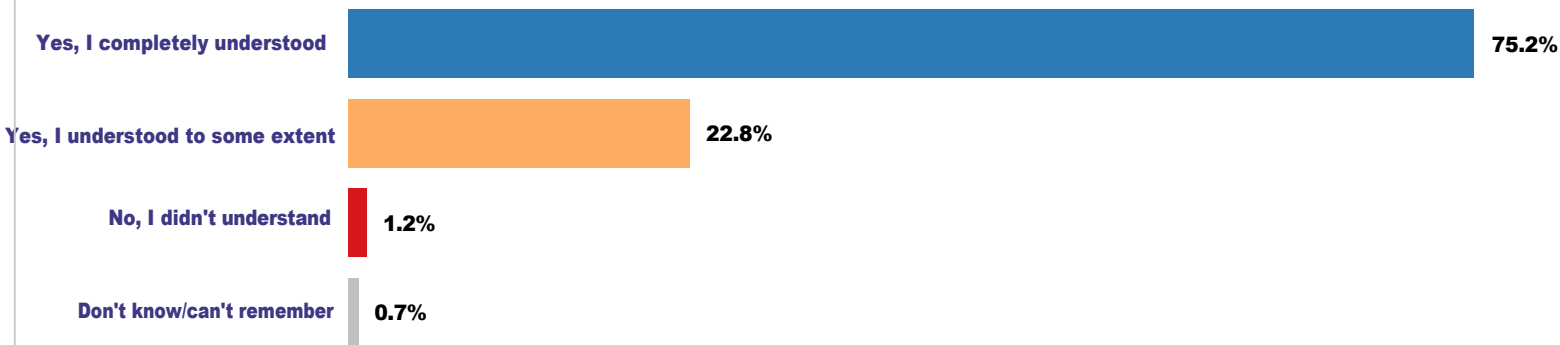
Q9. When you were first told that you had cancer, had you been told you could bring a family member or friend with you?



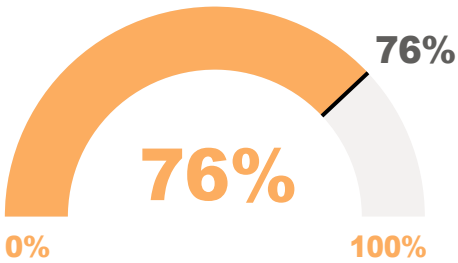
Q10. How do you feel about the way you were told you had cancer?



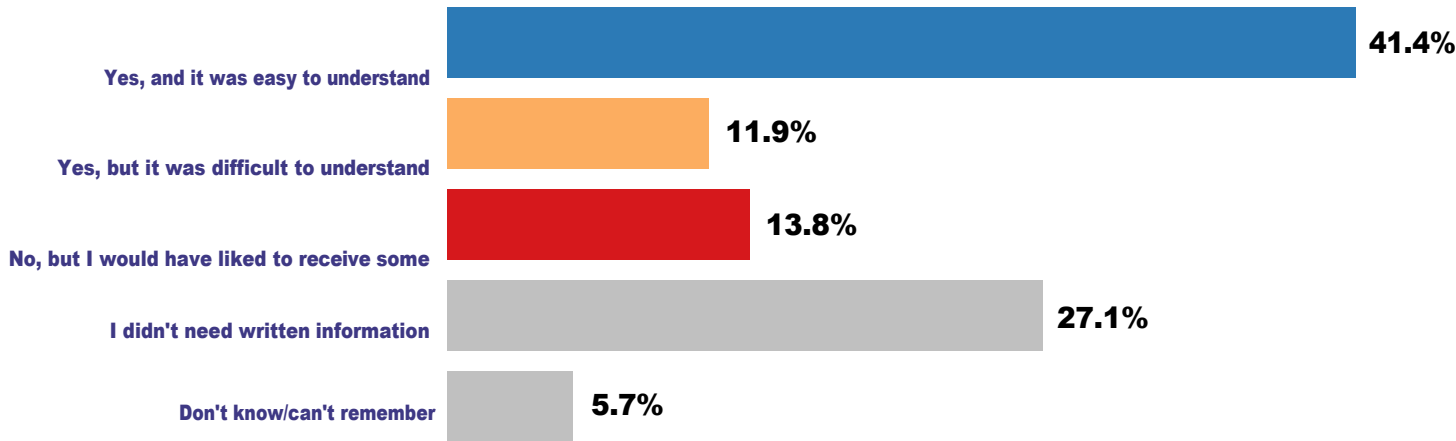
Q11. Did you understand the explanations of what was happening to you?



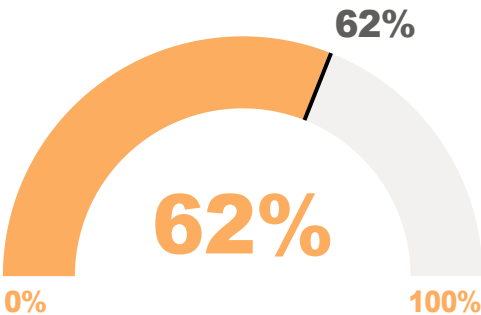
Positive experiences



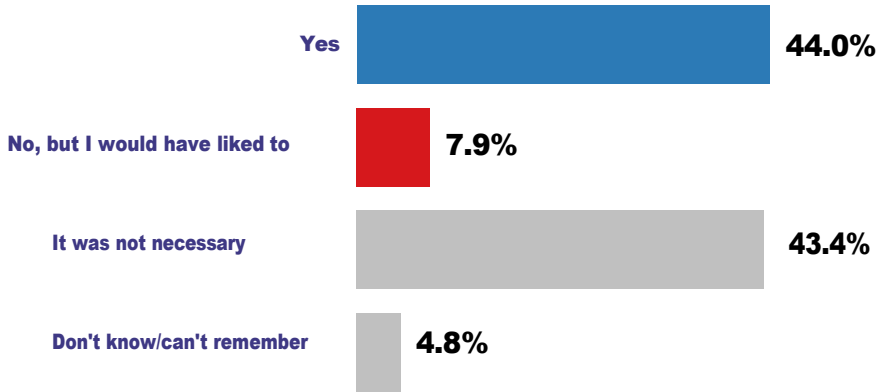
Q12. When you were told you had cancer, were you given any written information about the type of cancer you had?



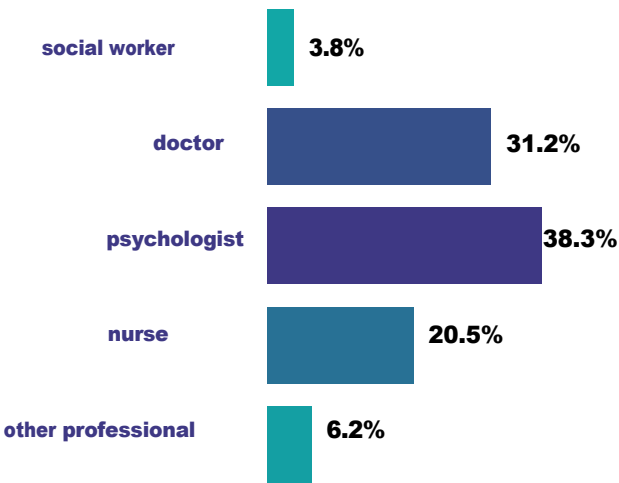
Positive experiences



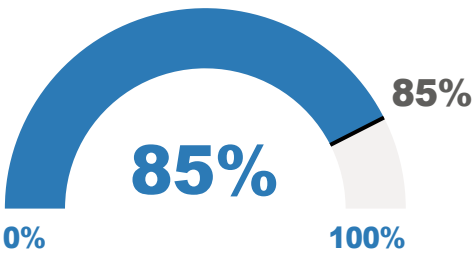
Q13. Have you been offered to see a health professional to address your concerns and fears following the cancer diagnosis?



Q13. Type of professional

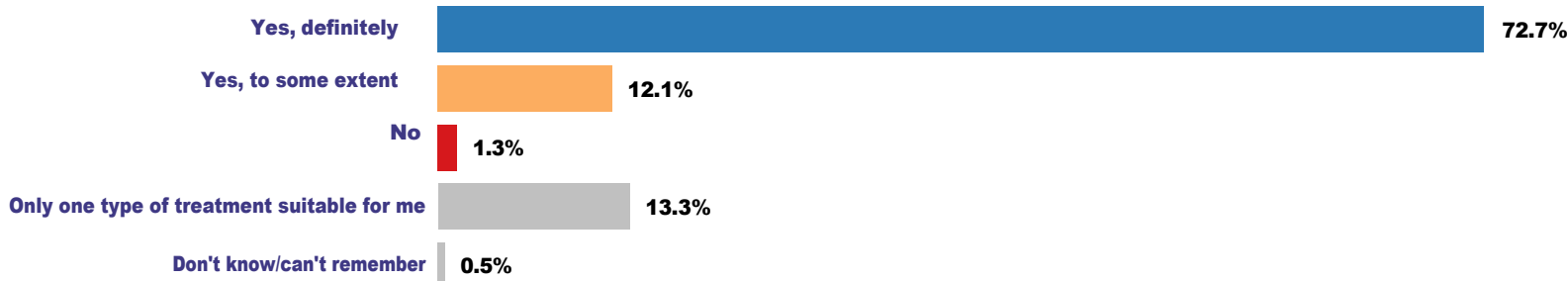


Positive experiences

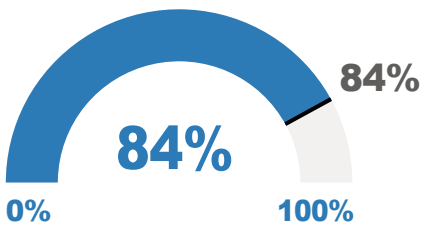


DECIDING THE BEST TREATMENT FOR YOU

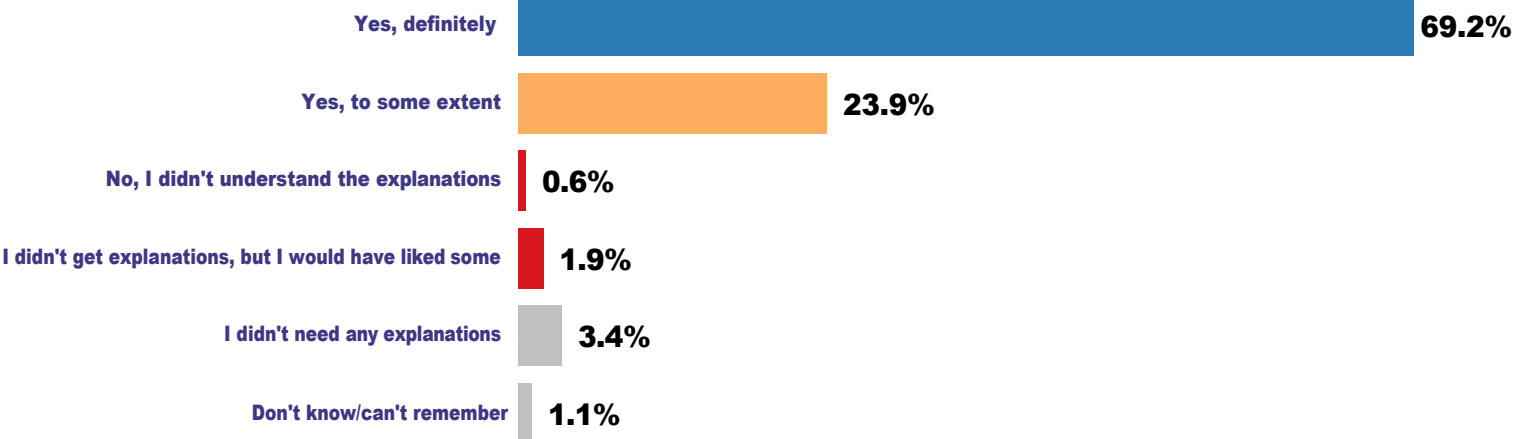
14. Before your cancer treatment started, were your treatment options explained to you?



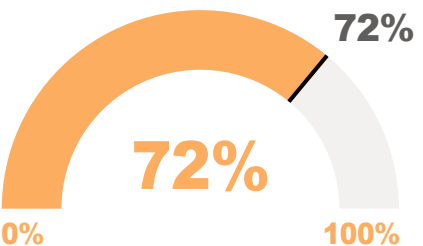
Positive experiences



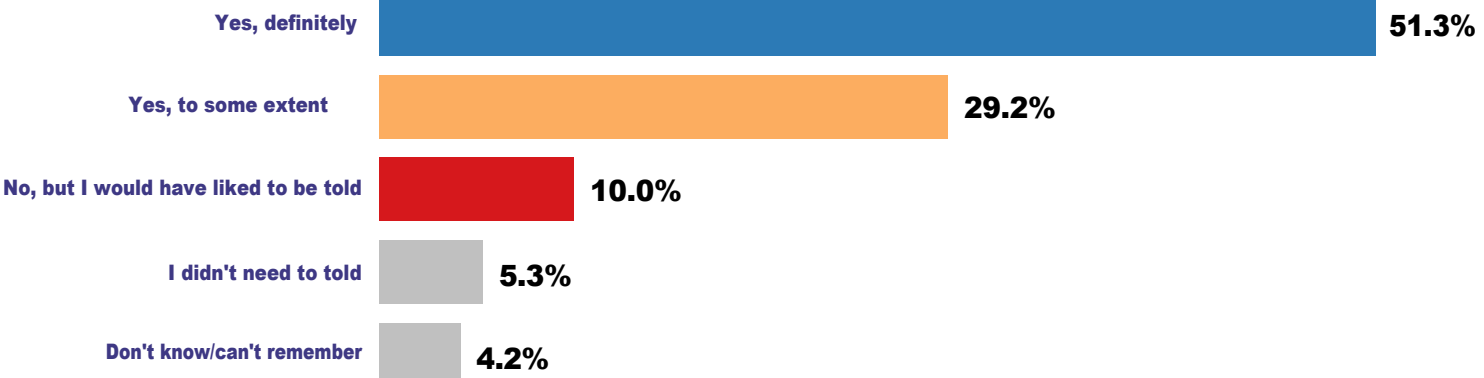
15. Were the possible side effects of treatment(s) explained in a way you could understand?



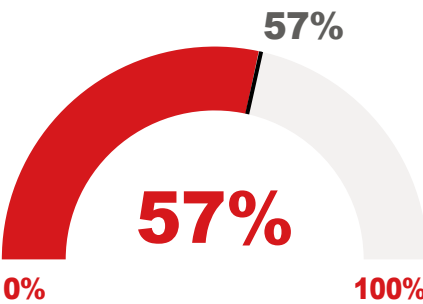
Positive experiences



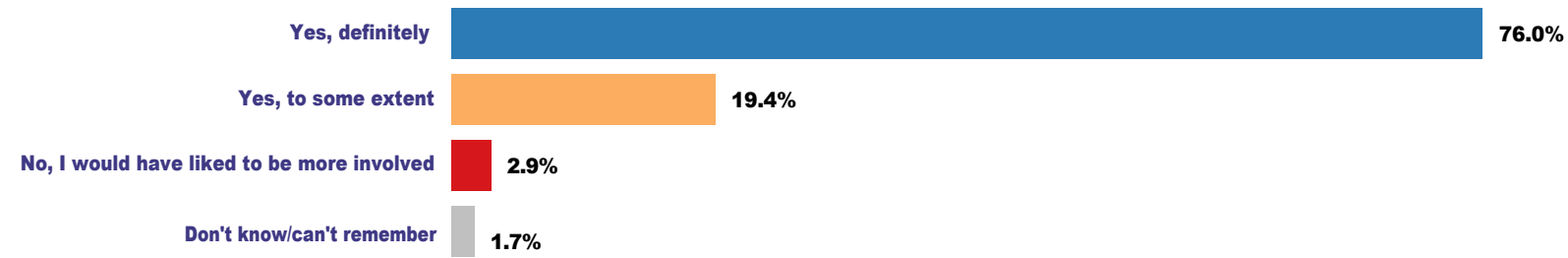
16. Were you also told about any side effects that could occur later rather than straight away?



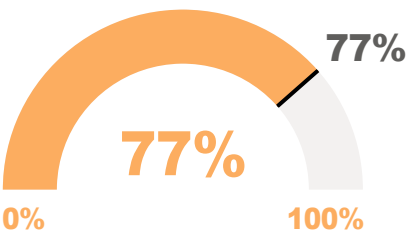
Positive experiences



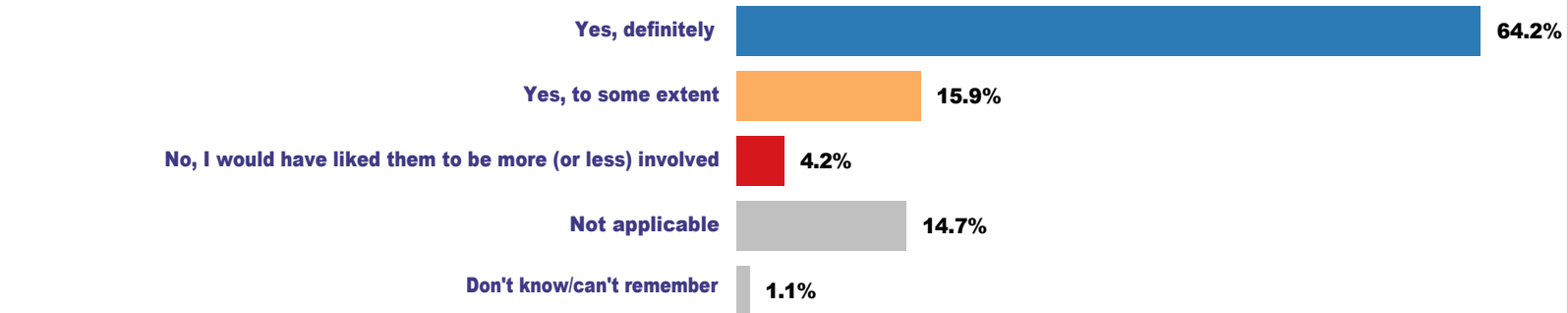
17. Were you involved as much as you wanted to be in decisions about your care and treatment?



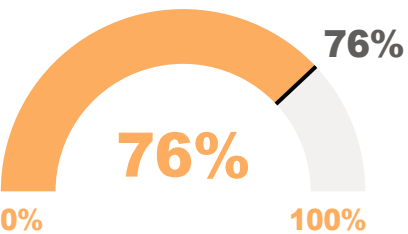
Positive experiences



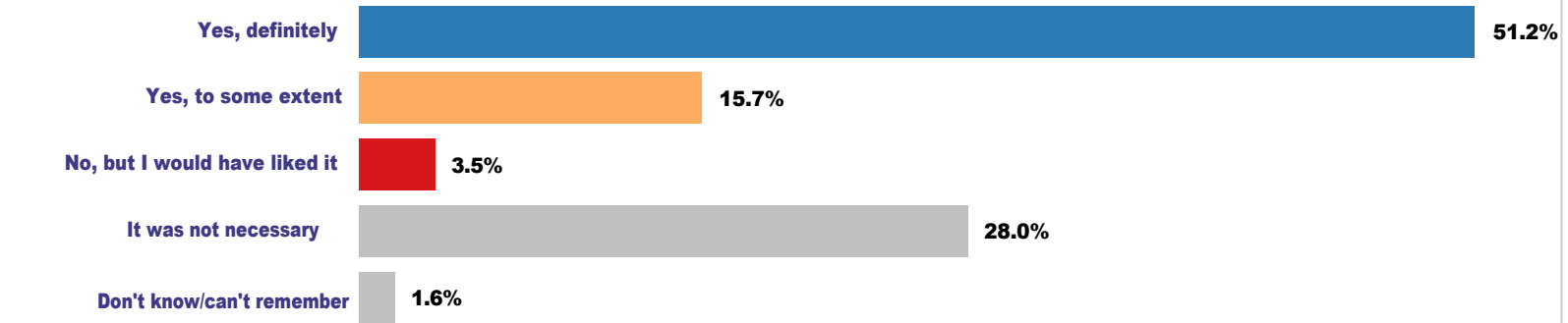
18. Were your family and/or friends able to be involved as much as you wanted them to be in decisions about your care and treatment?



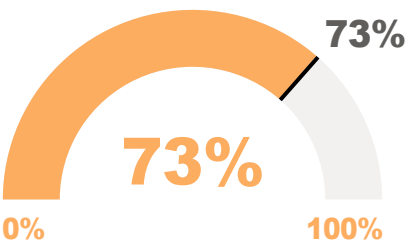
Positive experiences



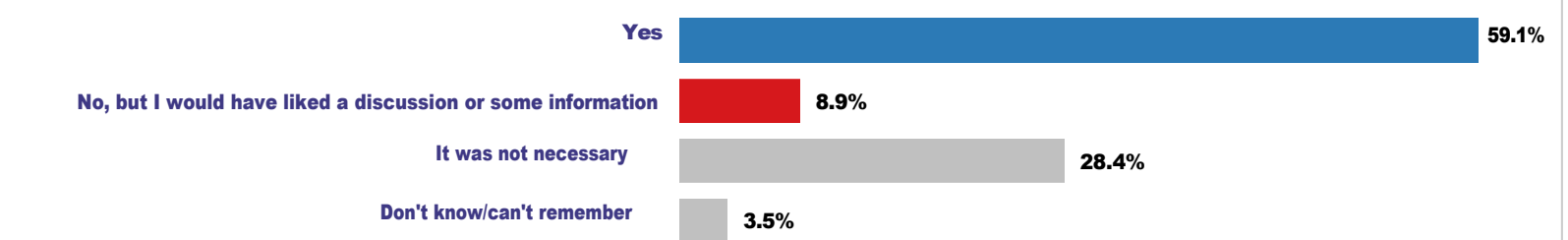
19. Were your lifestyle, family situation, and/or work situation considered in decisions about your care and treatment?



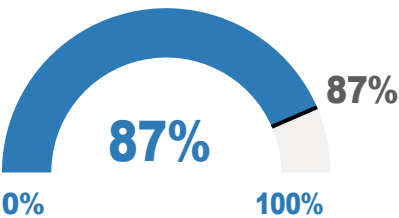
Positive experiences



20. Did anyone discuss with you or give you information about the impact of cancer on your daily activities (for example, work, hobbies)?

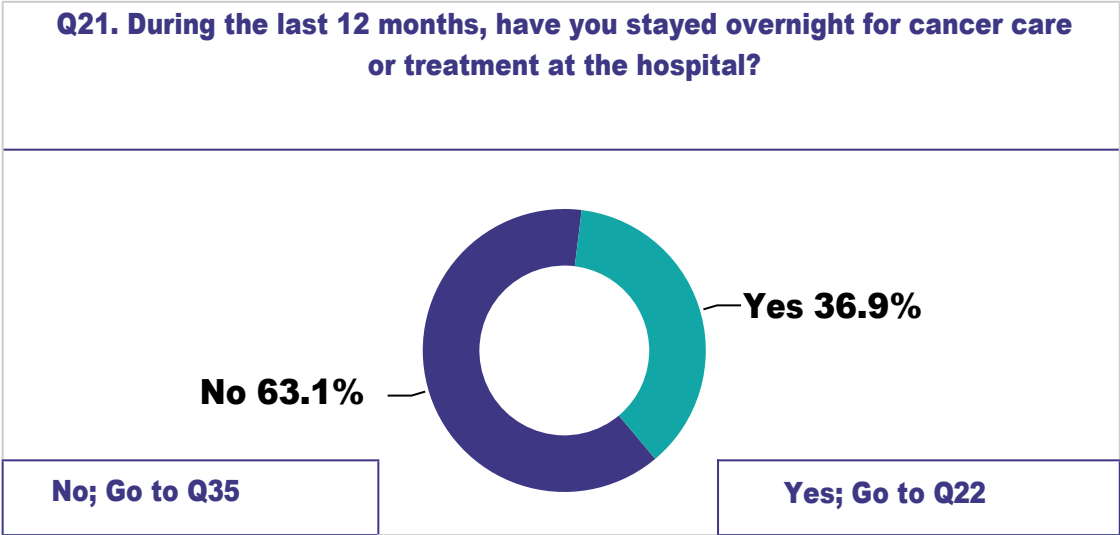


Positive experiences



HOSPITAL CARE AS AN INPATIENT

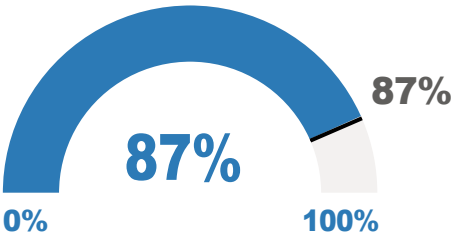
(lasting more than 24 hours)



Q22. Did doctors and nurses talk in front of you as if you were not there?



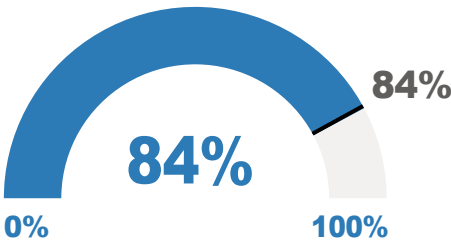
Positive experiences



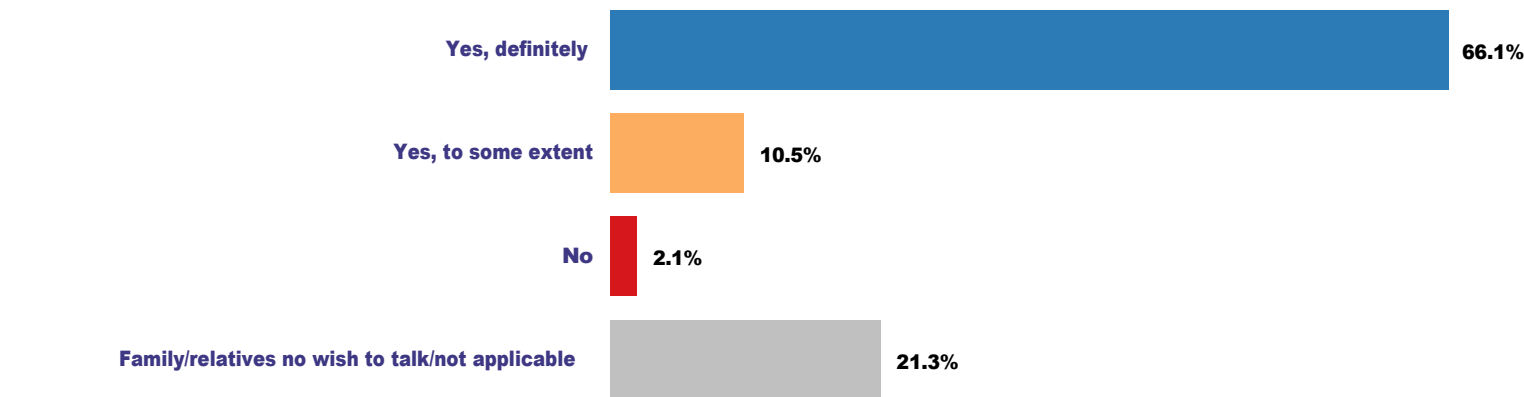
Q23. Did you have confidence and trust in the doctors looking after you?



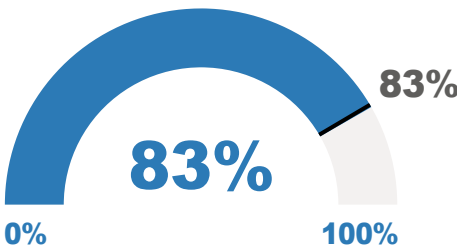
Positive experiences



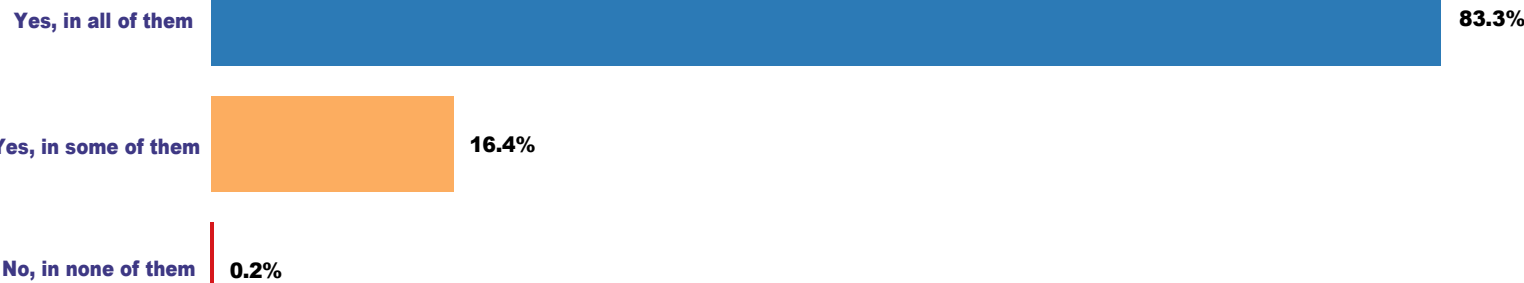
Q24. If a member of your family or friend wanted to talk to a doctor, were they able to?



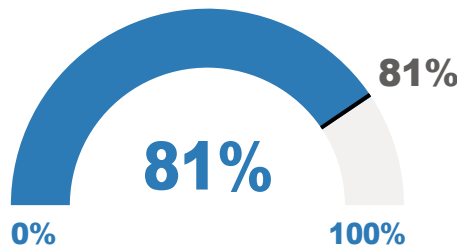
Positive experiences



Q25. Did you have confidence and trust in the nurses looking after you?



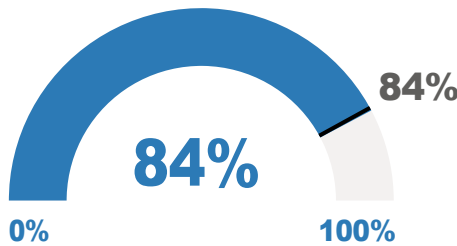
Positive experiences



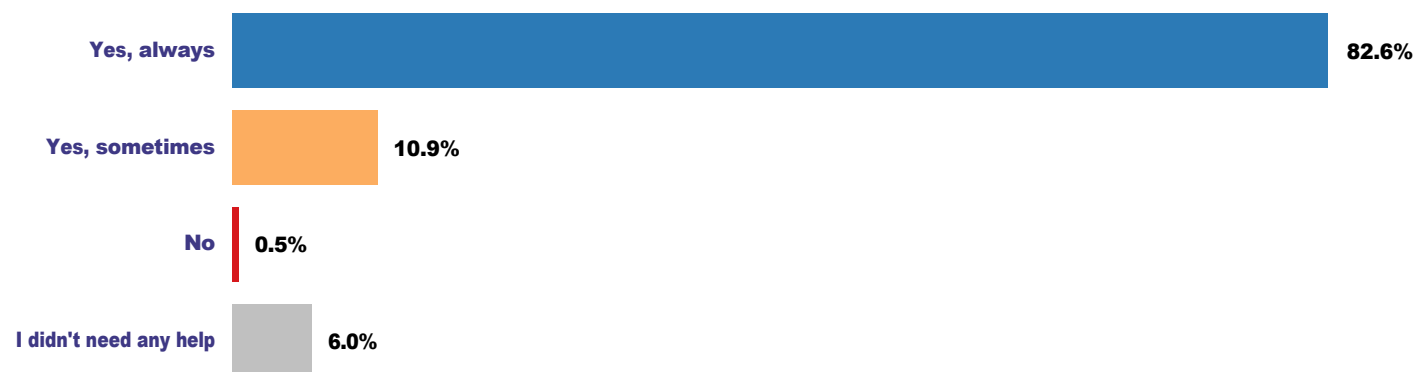
Q26. Were you given enough privacy when discussing your condition or treatment?



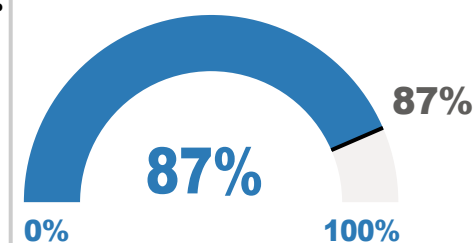
Positive experiences



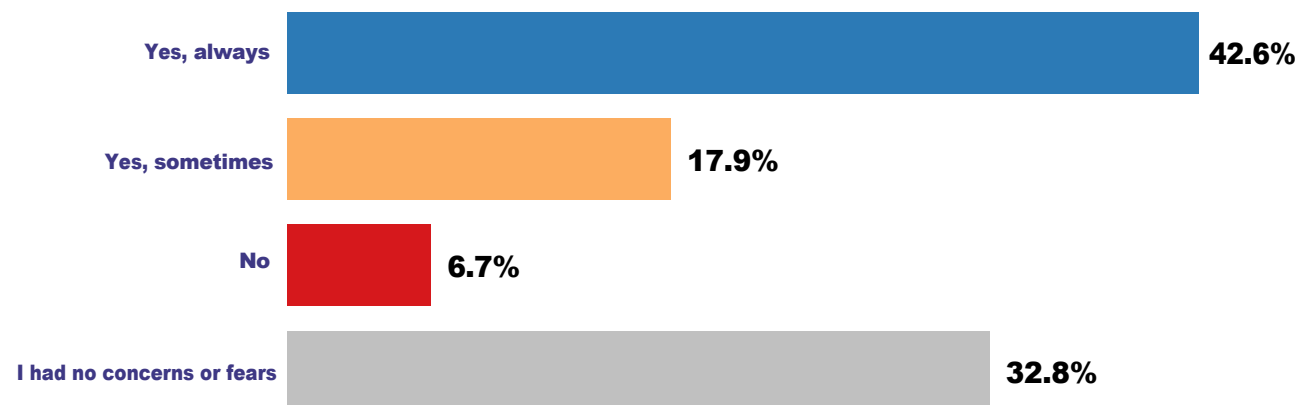
Q27. Was a member of staff available when you needed them?



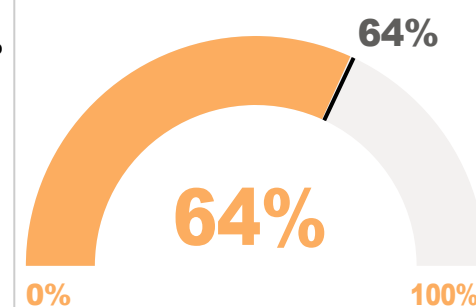
Positive experiences



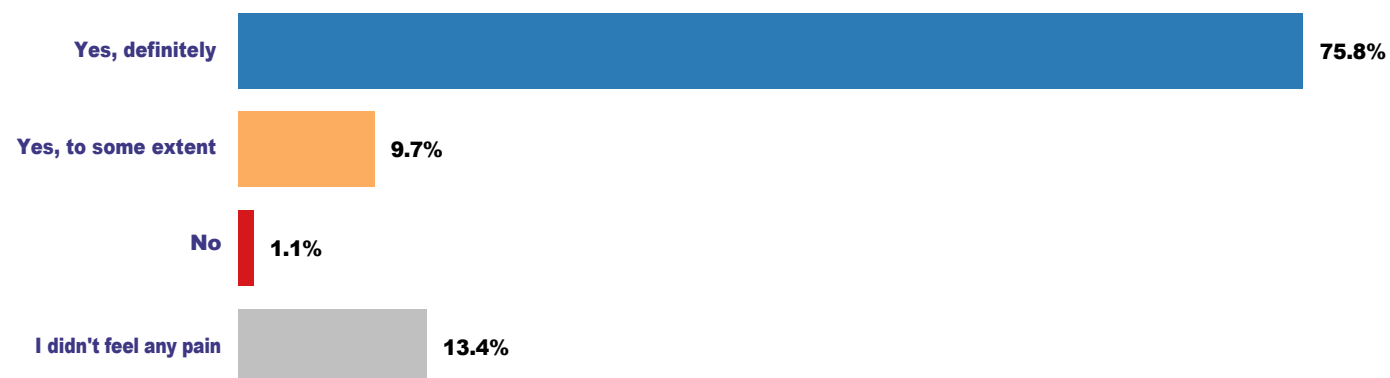
Q28. During your hospital stay, did you find someone on the hospital staff to talk about your worries and fears?



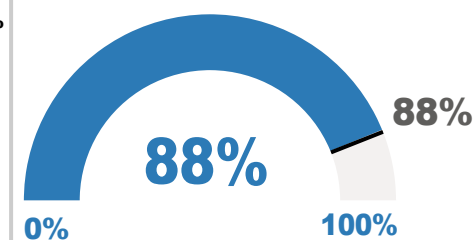
Positive experiences



Q29. Do you think the hospital staff did everything they could to help control your pain?



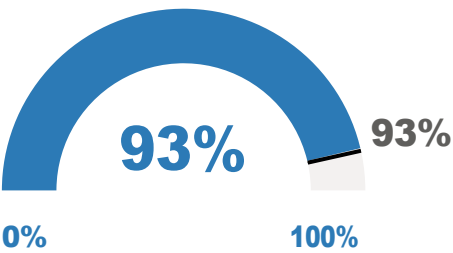
Positive experiences



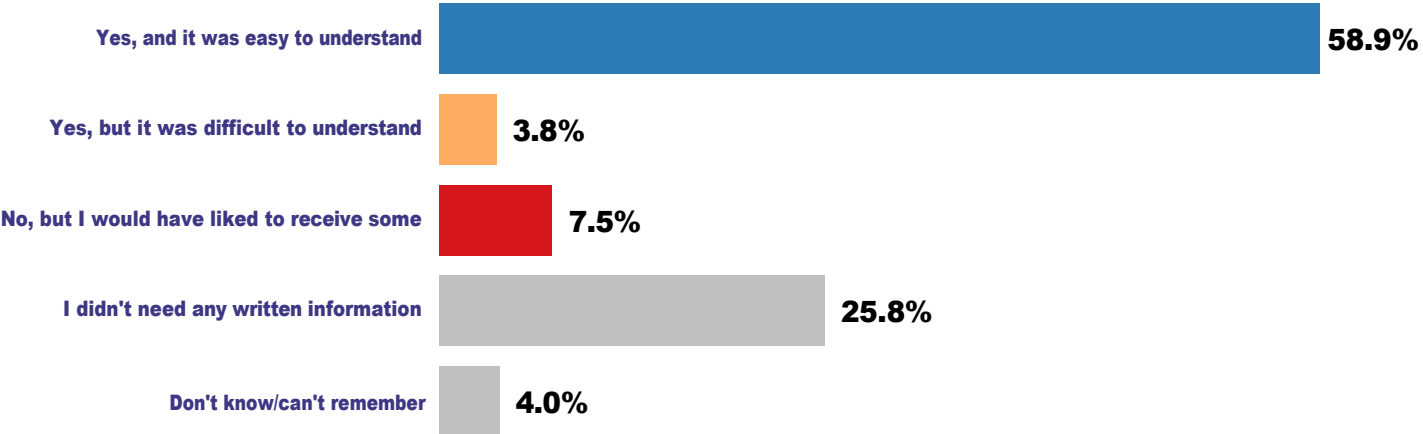
Q30. Overall, did you feel you were treated with respect and dignity during your stay in the hospital?



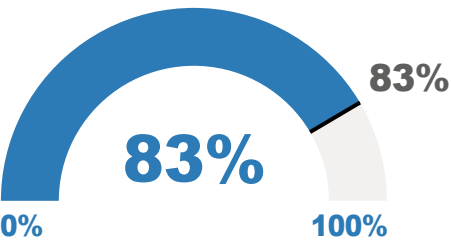
Positive experiences



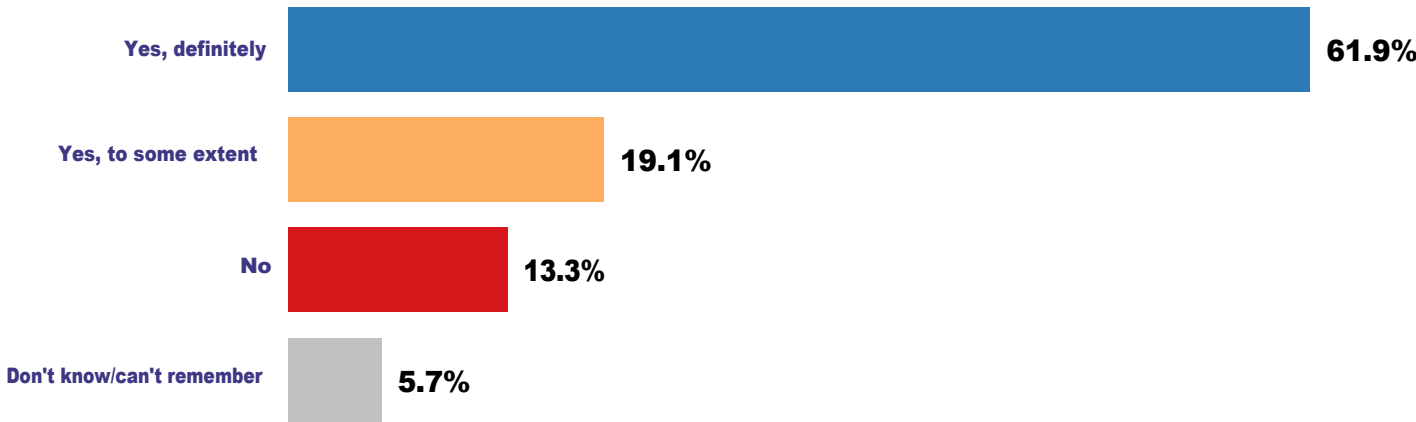
Q31. Were you given written information about what you should or should not do after leaving the hospital?



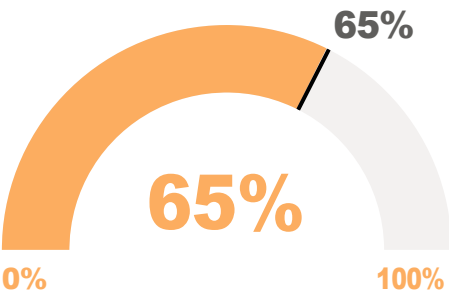
Positive experiences

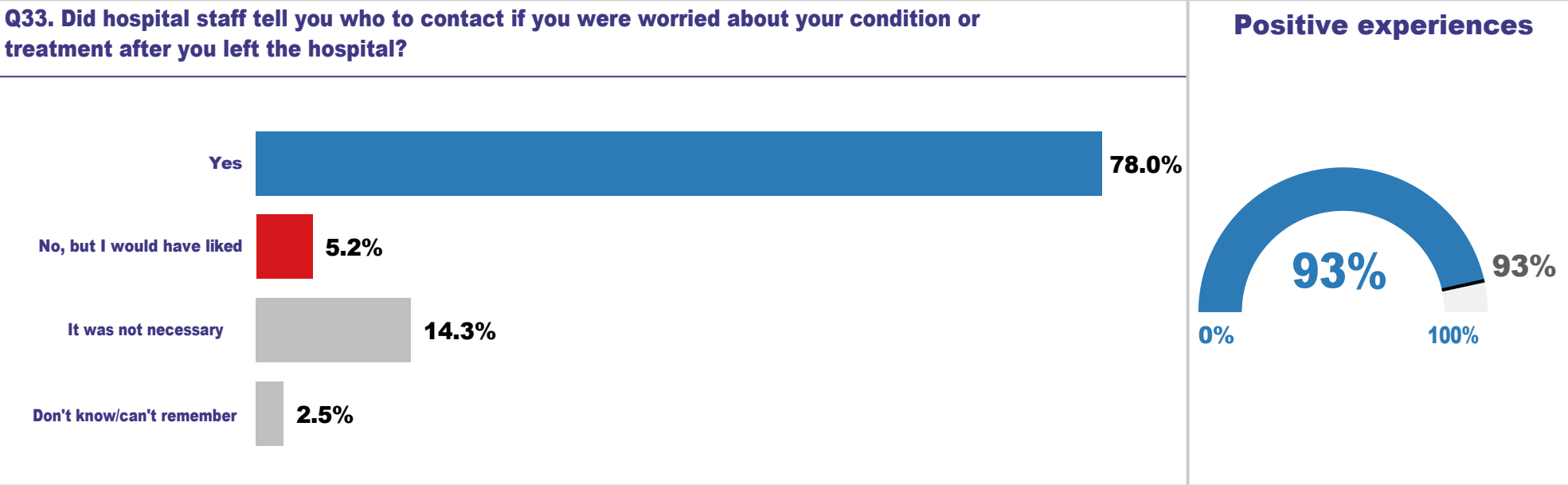


Q32. Did someone from the hospital explain to you the warning signs related to your condition or operation that you should watch for when you got home?

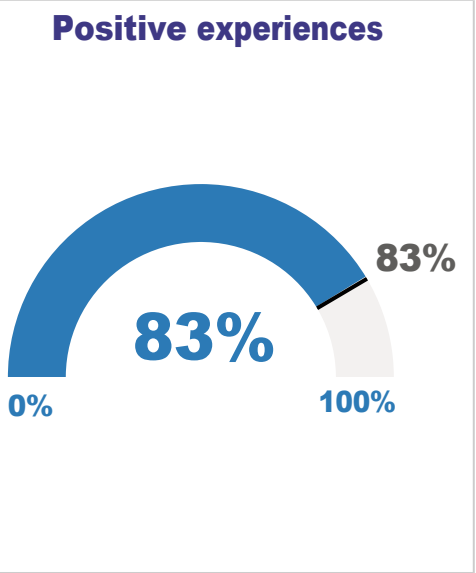
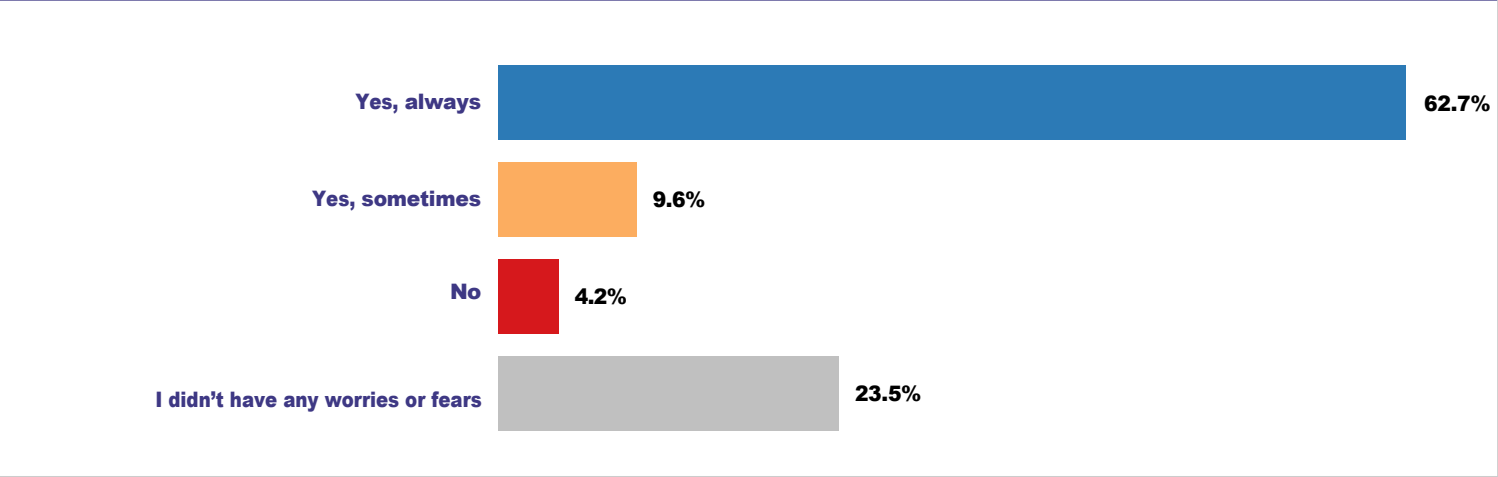


Positive experiences

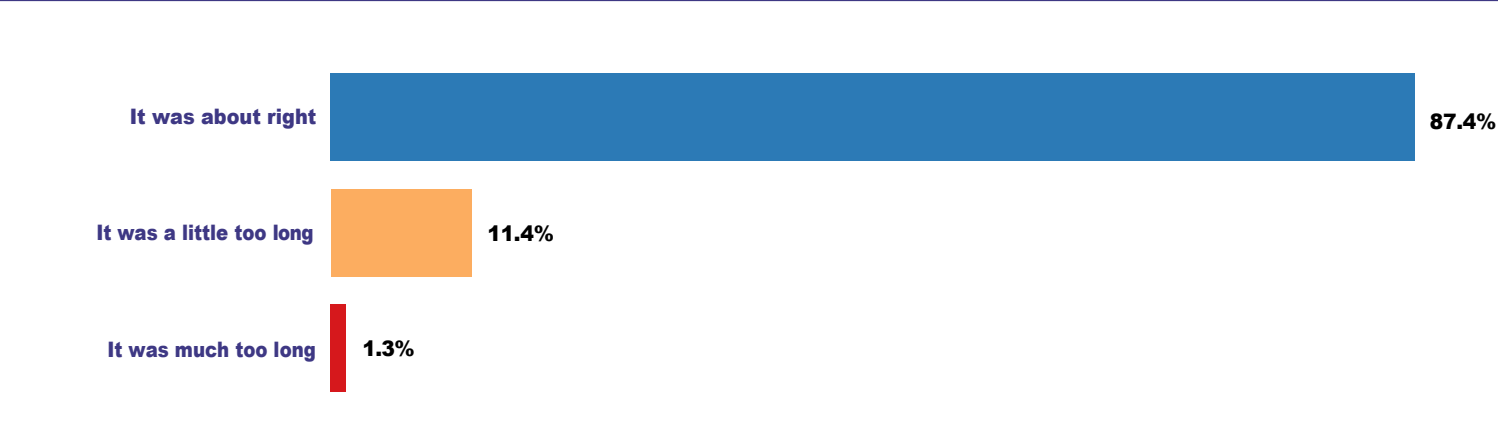




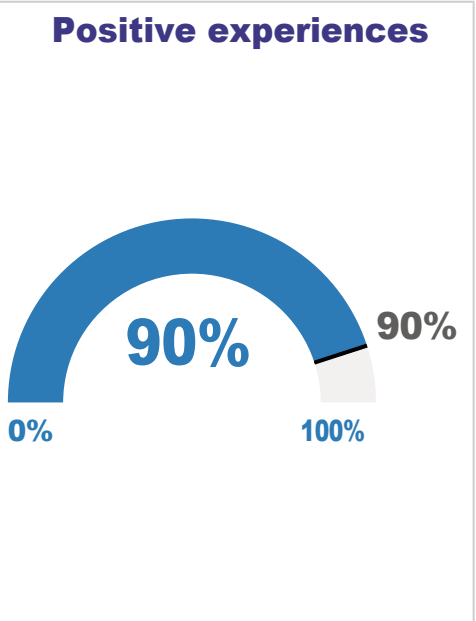
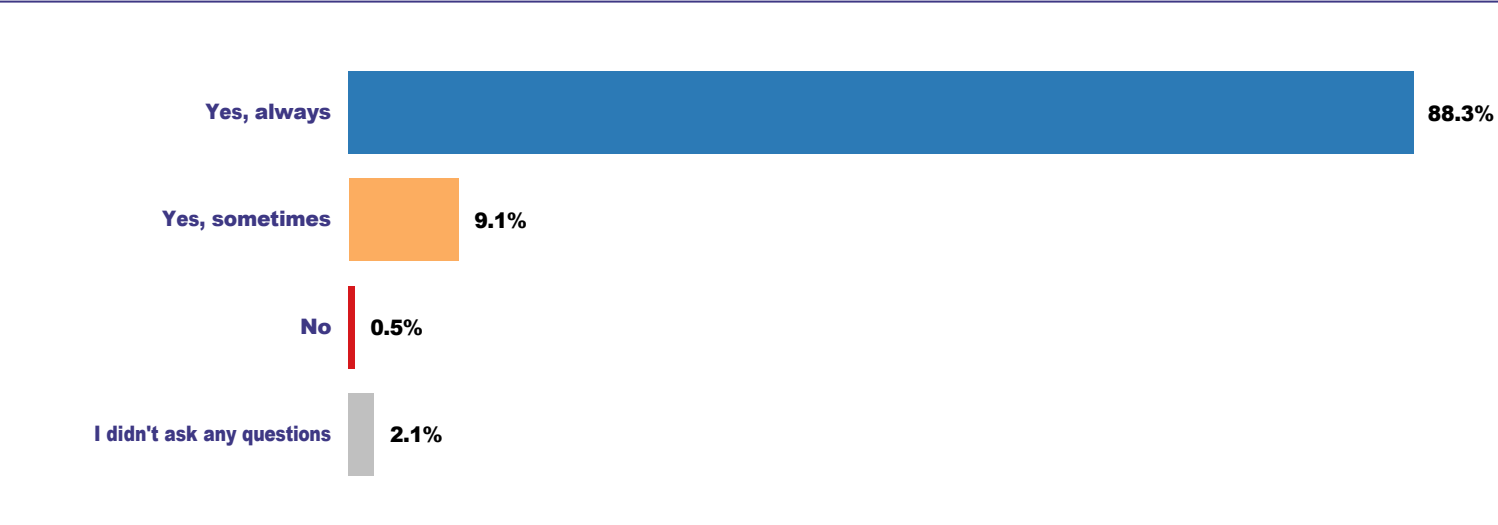
Q36. While you were being treated as an outpatient or day patient, did you find someone on the hospital staff to talk to about your worries or fears?



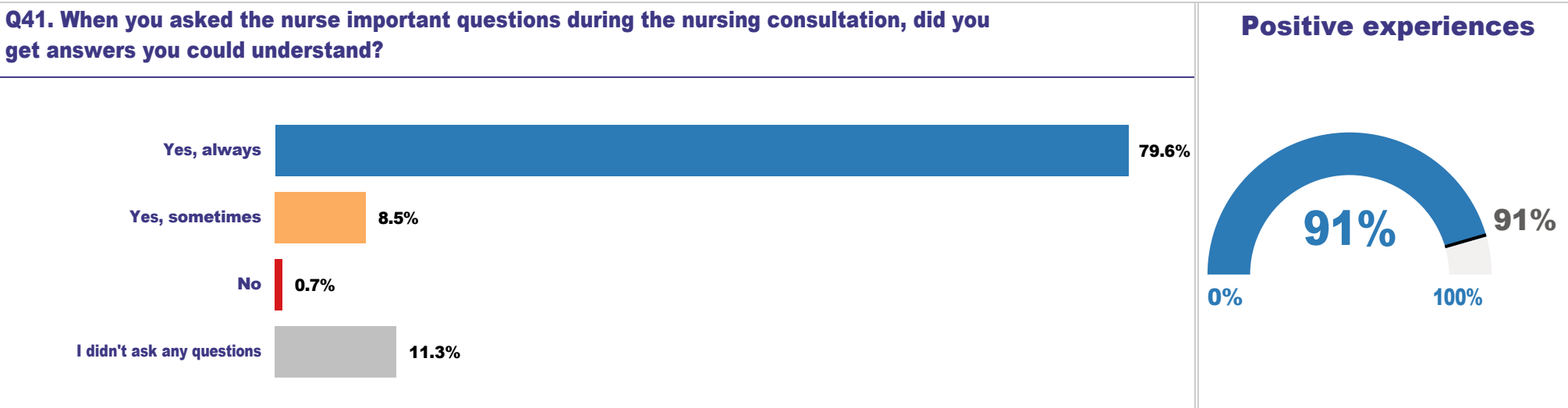
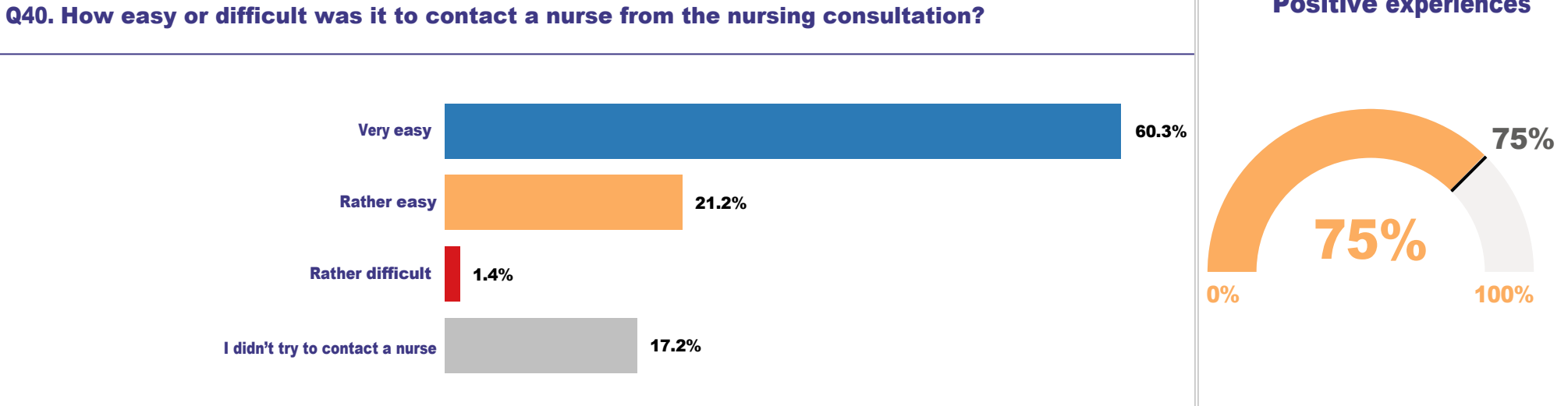
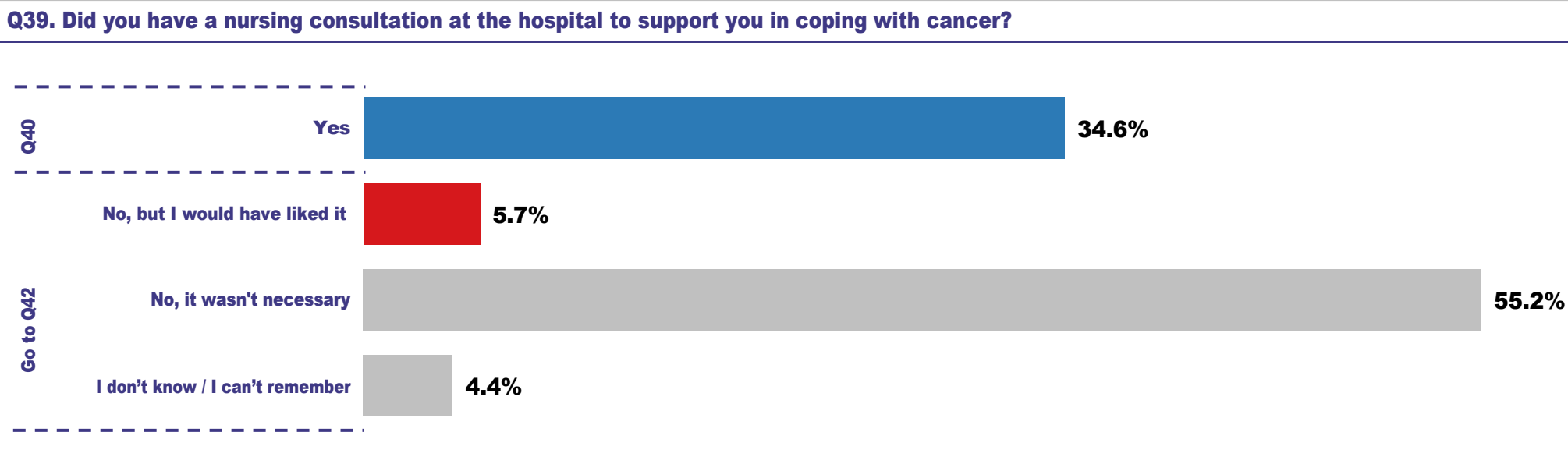
Q37. Overall, how do you feel about the time you spent in the waiting room when you had an appointment for an outpatient cancer consultation or treatment?



Q38. When you asked the doctor important questions during outpatient consultations or treatment, did you get answers you could understand?



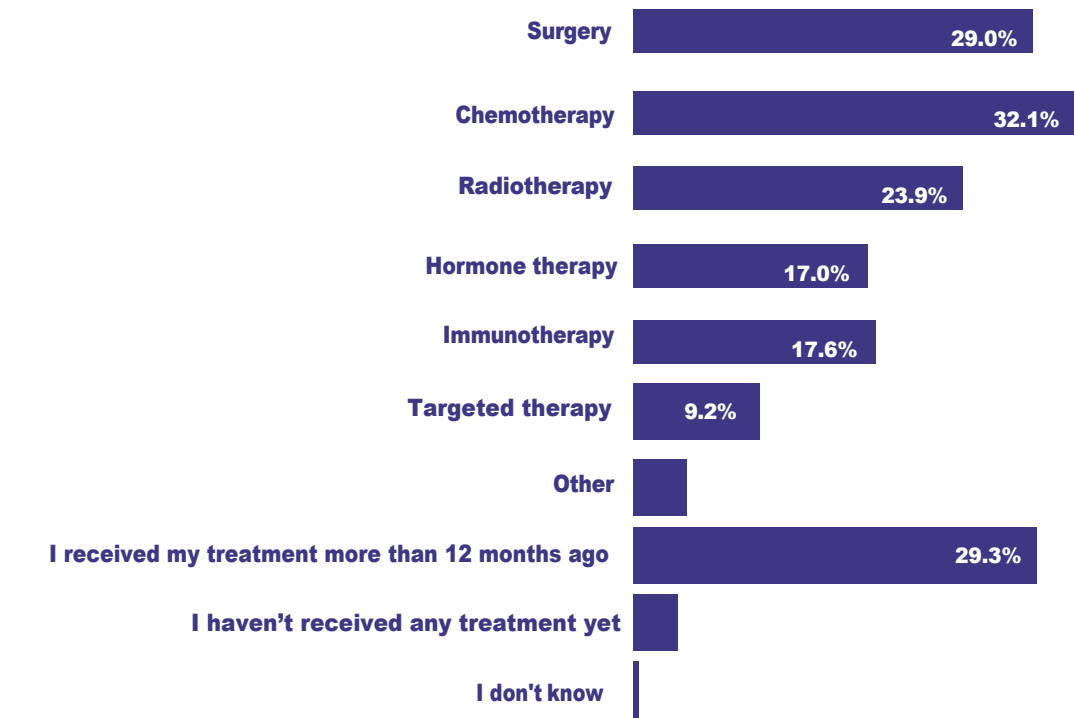
NURSING CONSULTATION



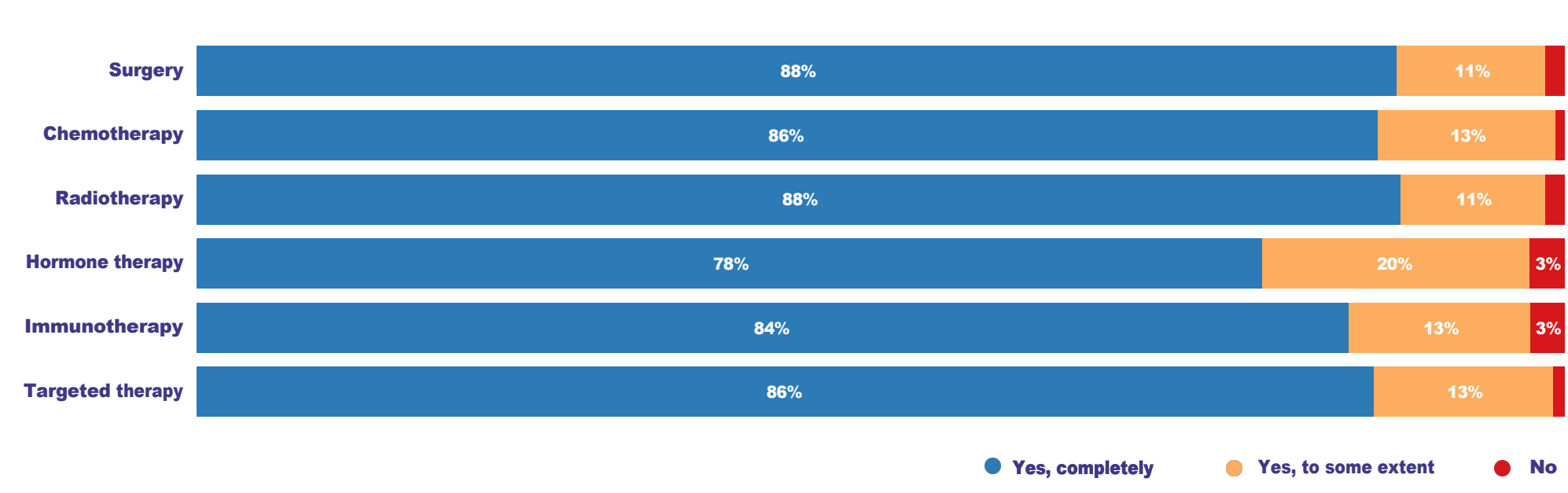


TREATMENTS

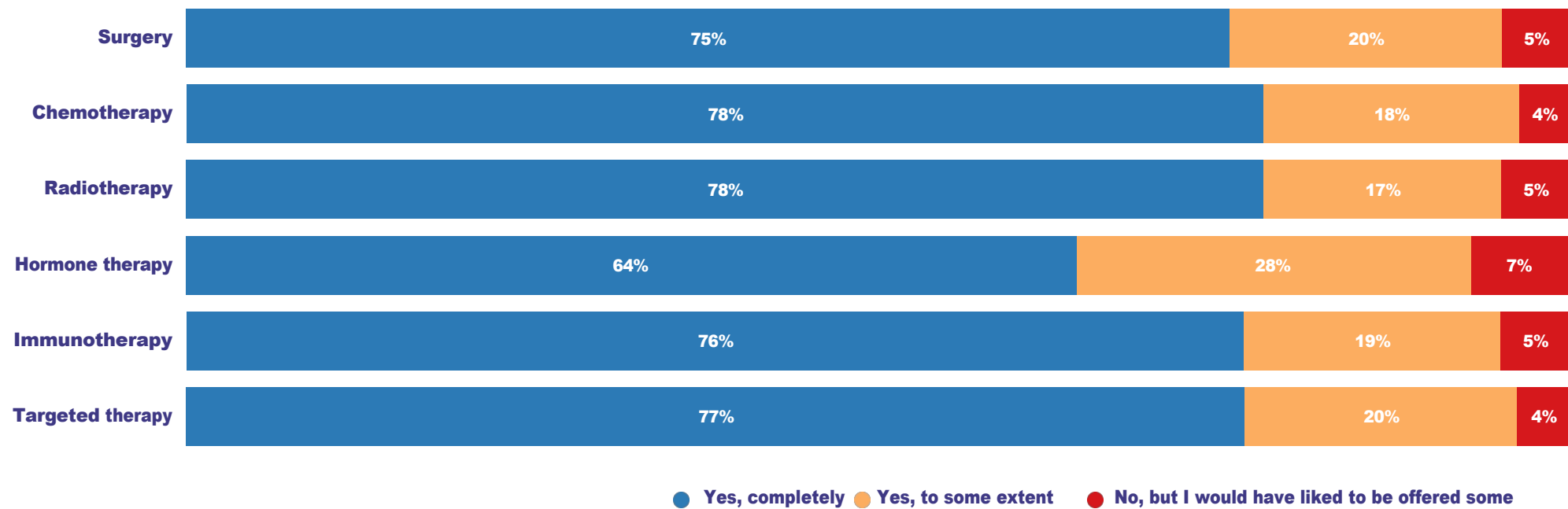
Q42. During the last 12 months, what type(s) of cancer treatment have you received?



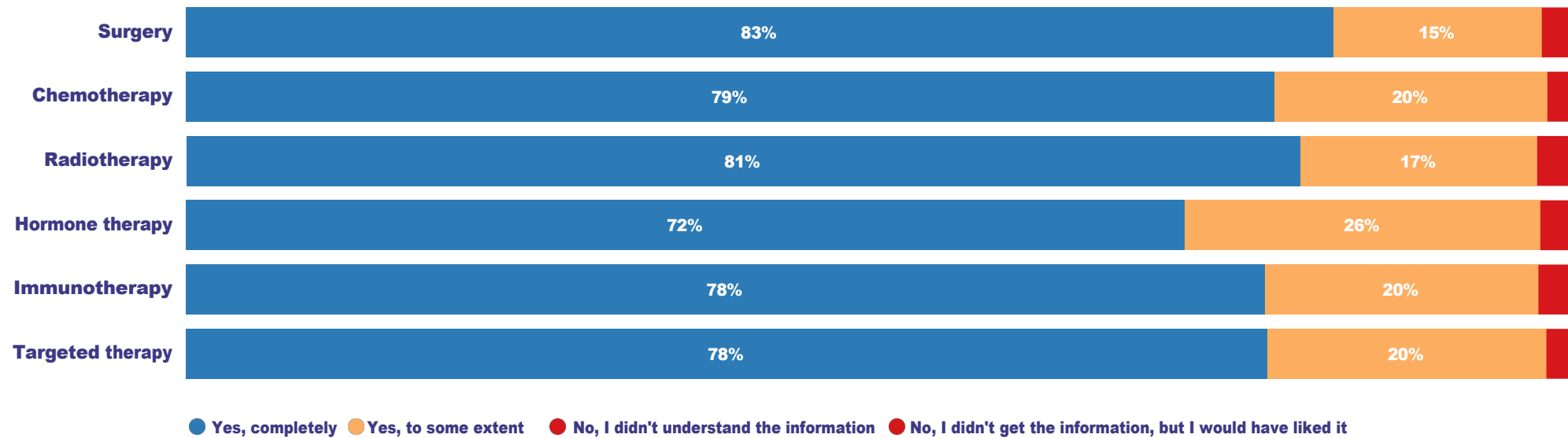
Q43. Before your treatment started, did you have all the information you needed about the treatment?



Q44. Were you offered practical advice and/or support in dealing with the side effects of your treatment?



45. Once your treatment started, were you given information about its results in a way you could understand?

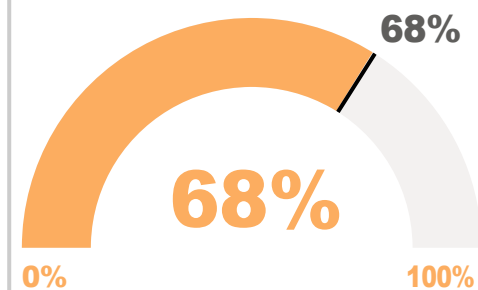


HOME CARE AND SUPPORT

Q46. Did a staff member at the hospital named in the invitation letter ensure that you had the necessary help (for example, home care) and equipment (for example, wheelchair) at home to help you carry out your daily activities?



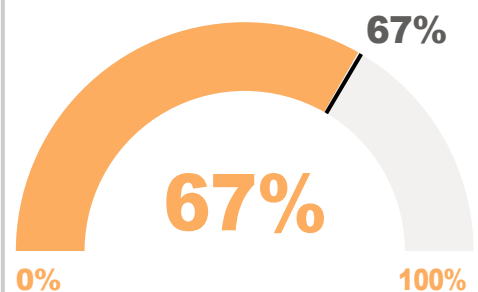
Positive experiences



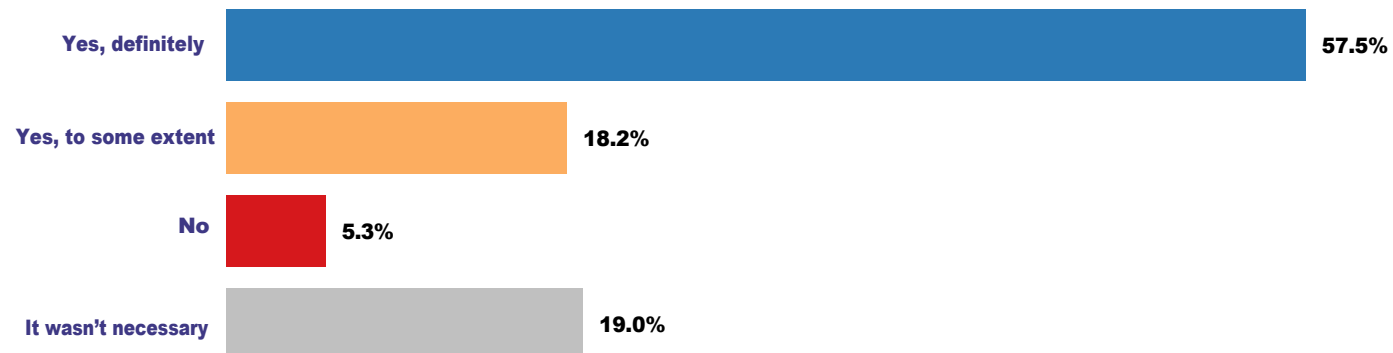
Q47. Were your family or friends given all the information they needed to help care for you at home?



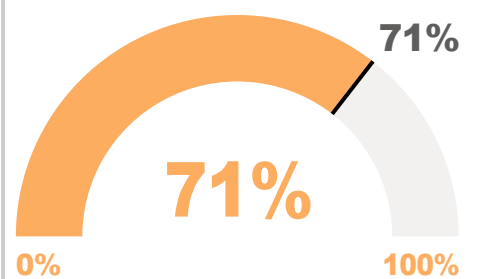
Positive experiences



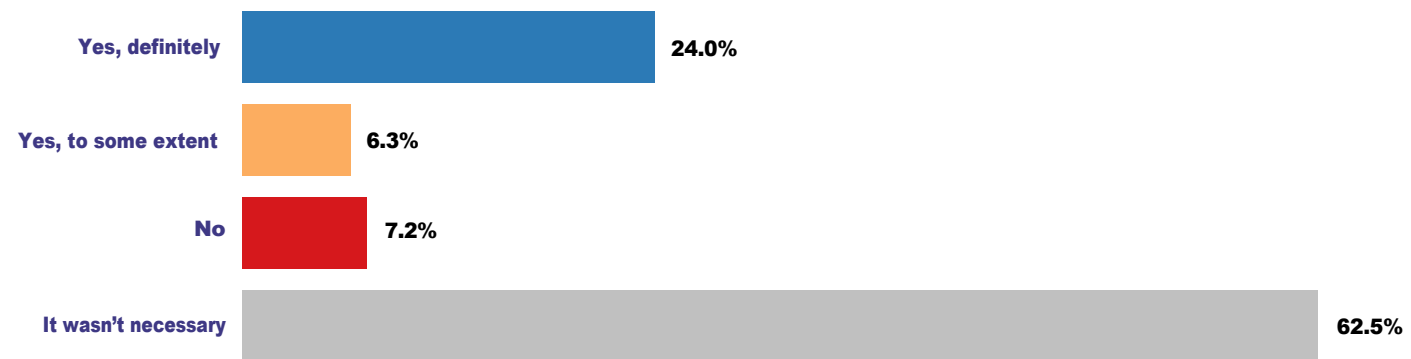
Q48. Were you offered enough practical advice and/or support in dealing with your symptoms (such as pain, nausea, fatigue, anxiety)?



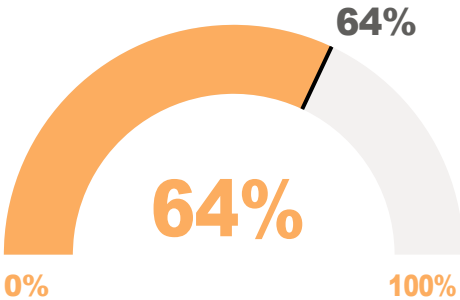
Positive experiences



Q49. Were you given enough care and support from health or social services (for example, home nurse, social worker)?

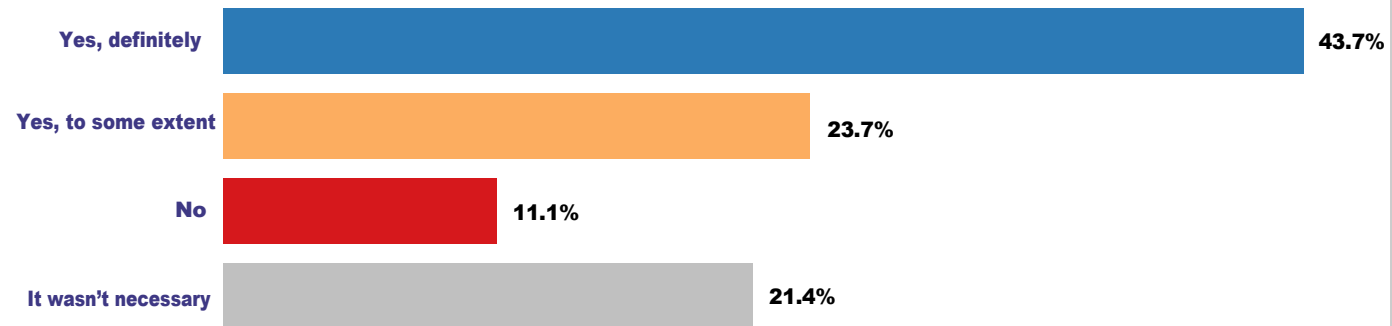


Positive experiences

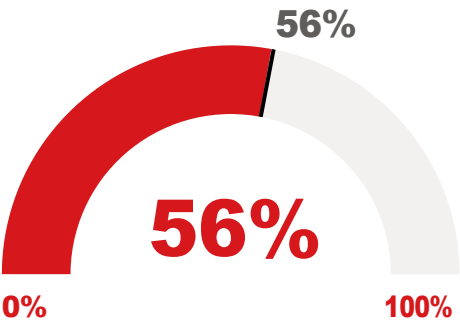


LIVING WITH AND BEYOND CANCER

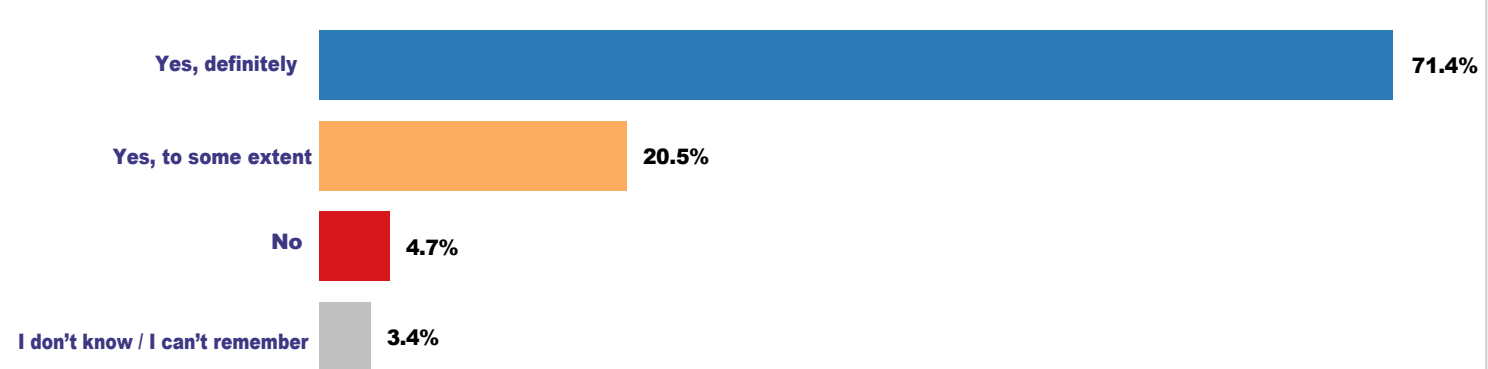
Q50. Were you offered enough practical advice and/or support in dealing with the long-term effects of cancer or treatment (such as fatigue, pain, anxiety)?



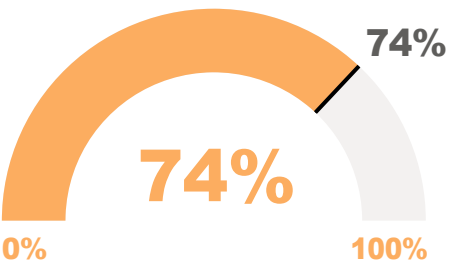
Positive experiences



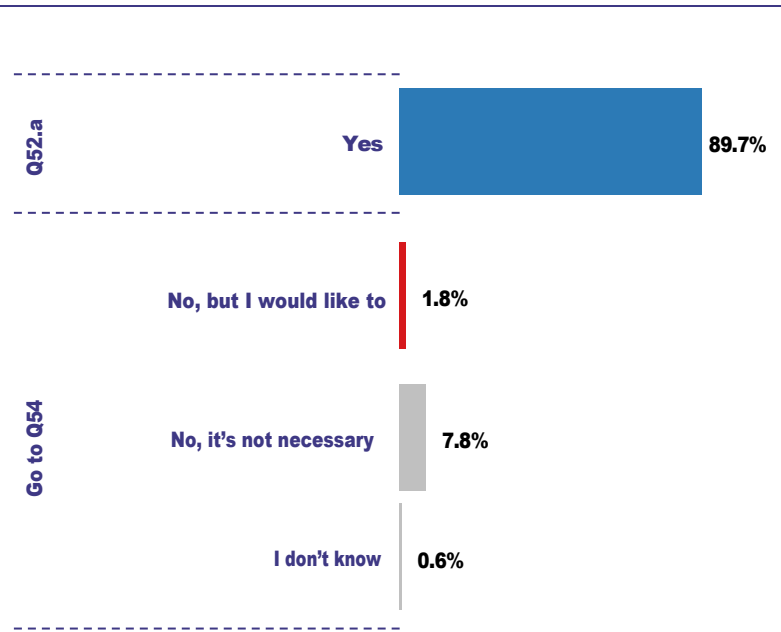
Q51. At the end of the treatments, did you have all the information you needed about follow-up care?



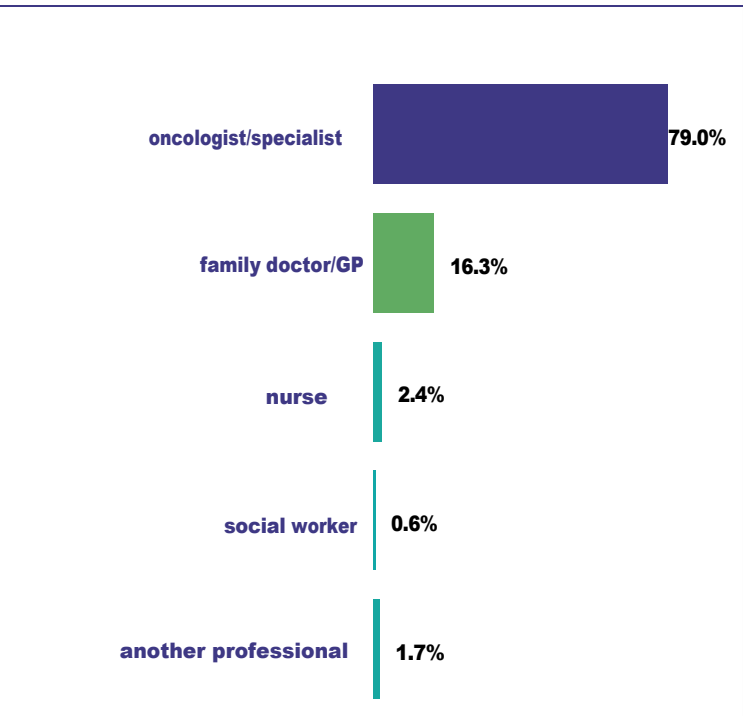
Positive experiences



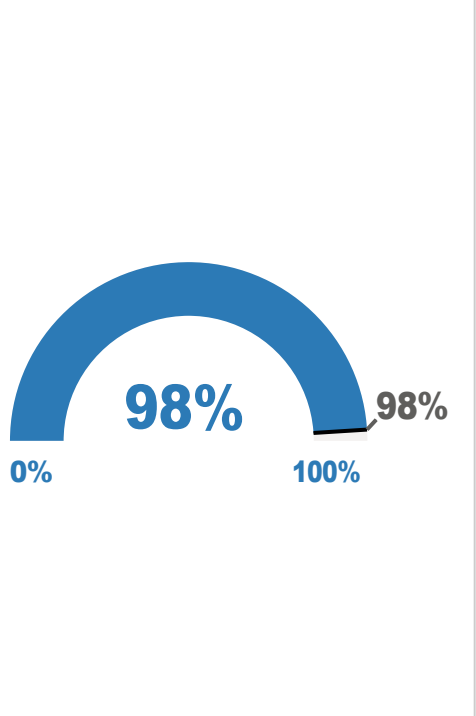
Q52. Are you in regular contact with a reference person (such as a doctor, nurse, social worker) for follow-up care?



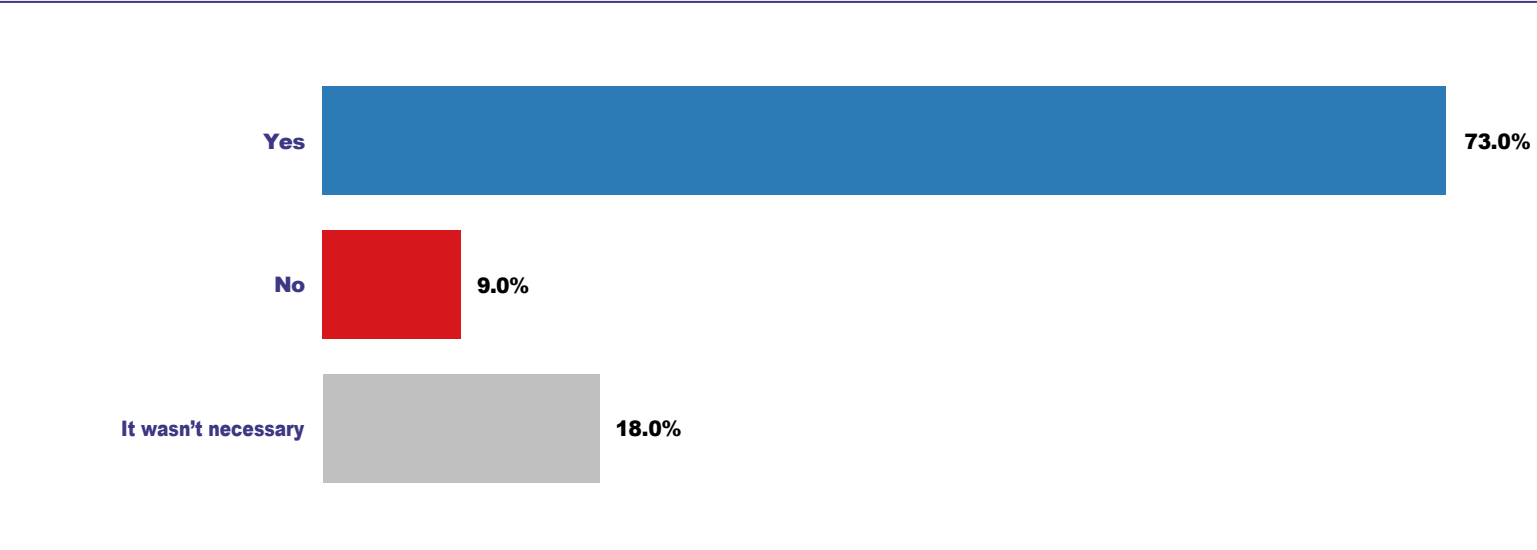
Q52.a Who is this person now?



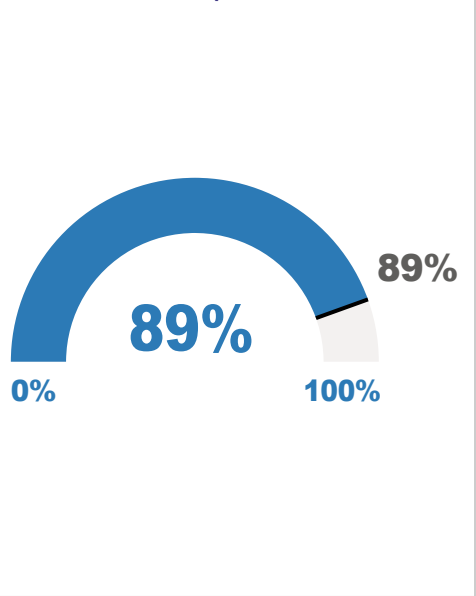
Positive experiences



Q53. Did this reference person provide you with a follow-up plan that outlines your needs and solutions and sets up regular appointments to reassess them?

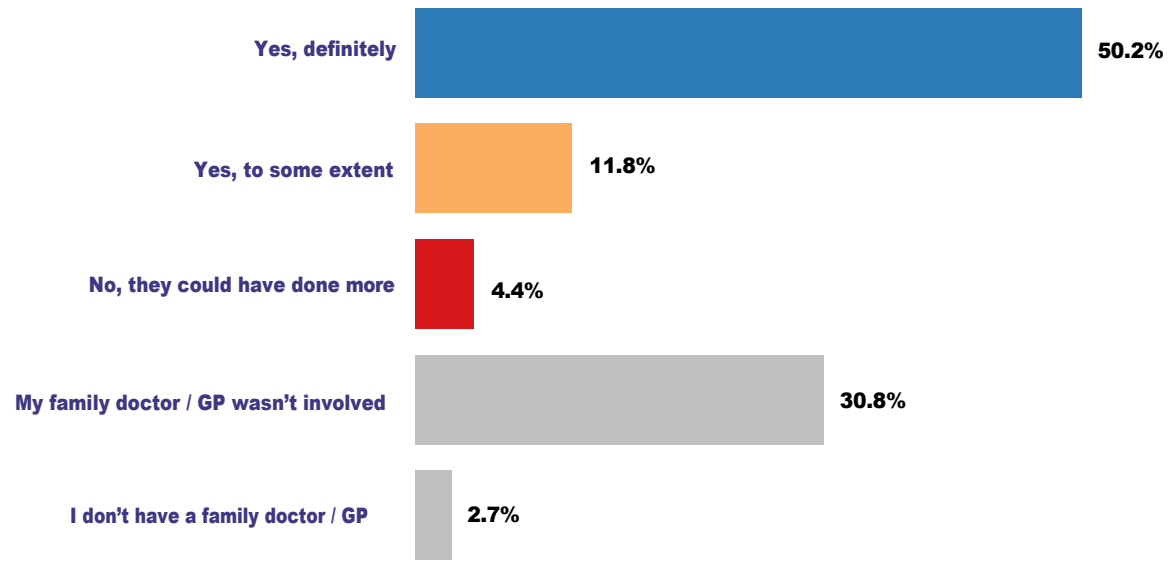


Positive experiences

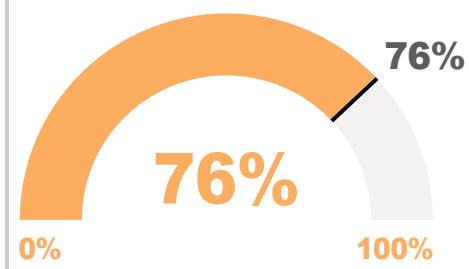


CARE FROM YOUR FAMILY DOCTOR / GP OFFICE

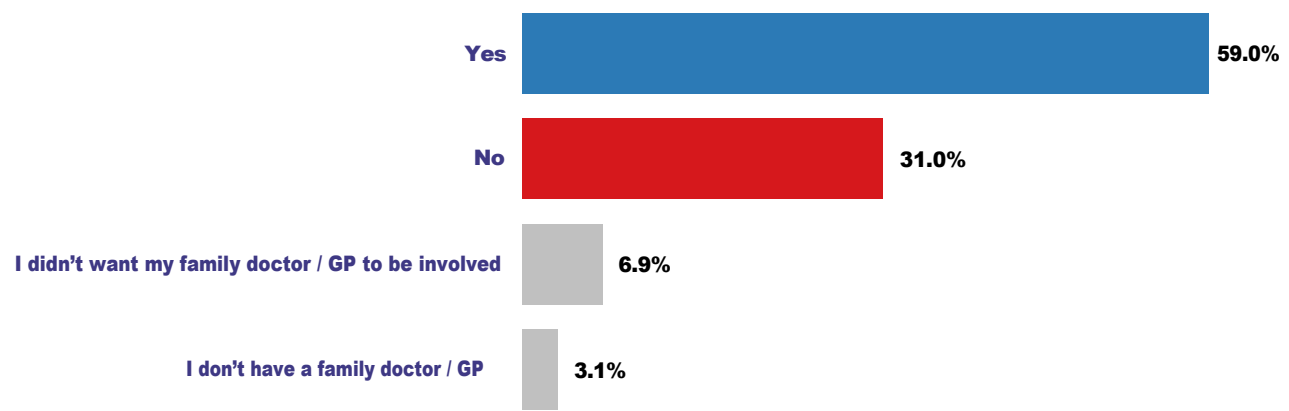
Q54. Do you think that your family doctor / GP and their team did everything they could to support you during your cancer treatment?



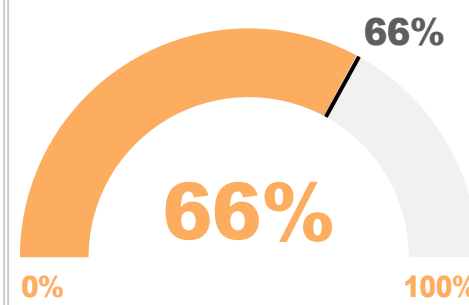
Positive experiences



Q55. Did your family doctor / GP discuss your cancer treatment with you?

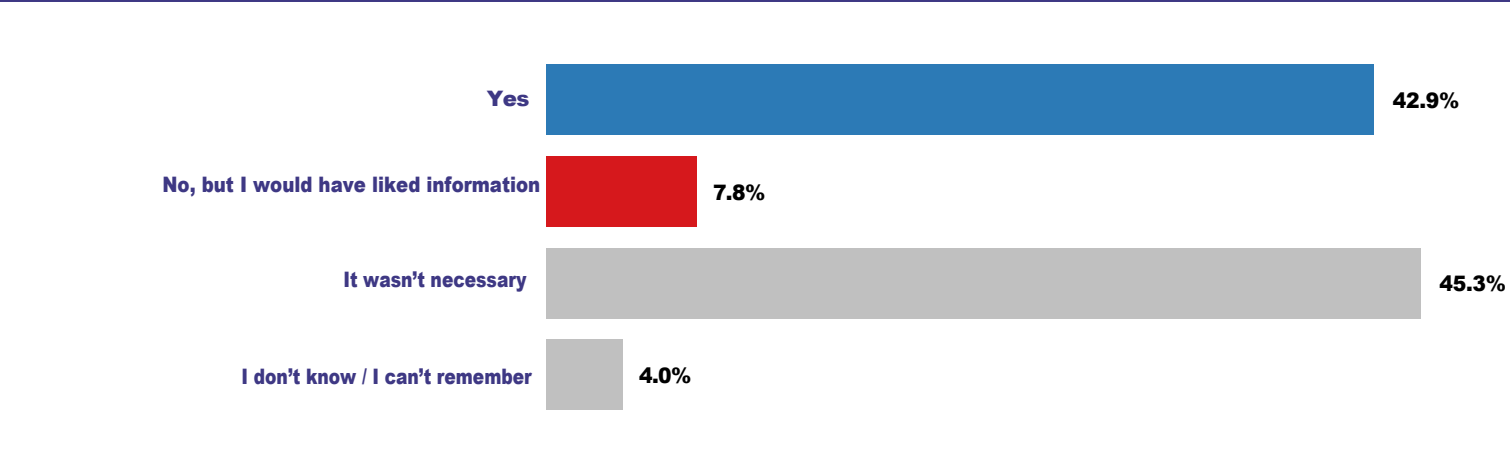


Positive experiences

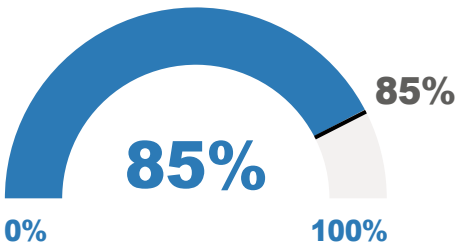


SUPPORT FOR CANCER PATIENTS

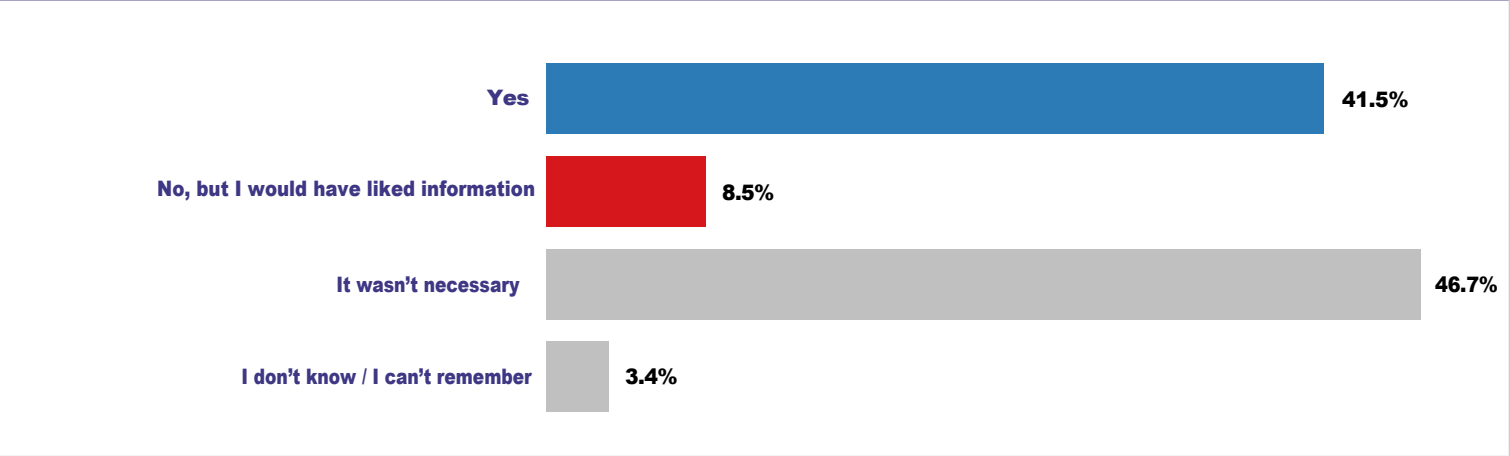
Q56. Were you given information about support or self-help groups for people with cancer?



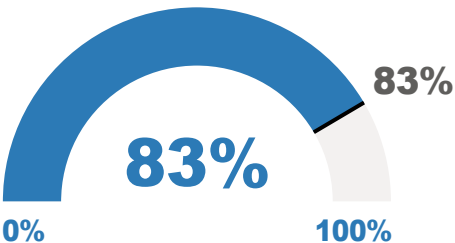
Positive experiences



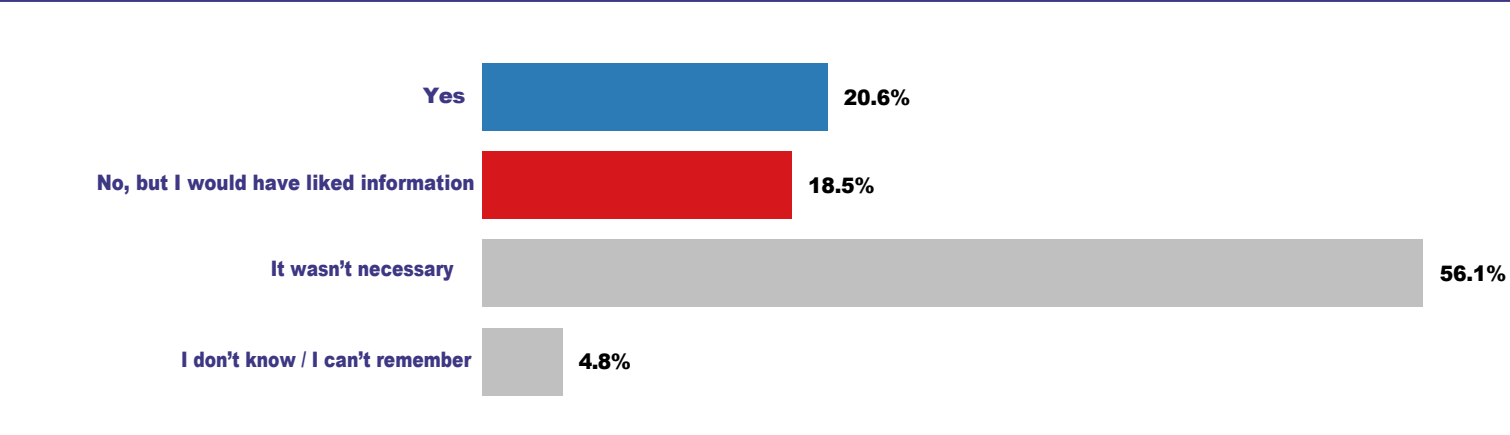
Q57. Were you given information about help and support to help you deal with your emotions (for example, stress, anxiety, sadness)?



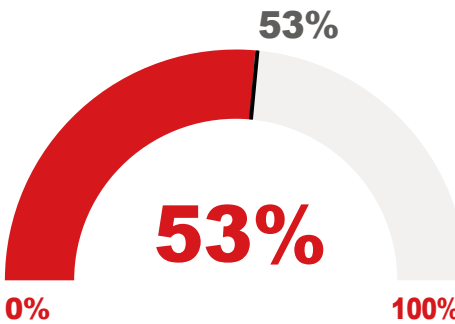
Positive experiences



Q58. Were you given information about how to get financial help or any benefits you might be entitled to?

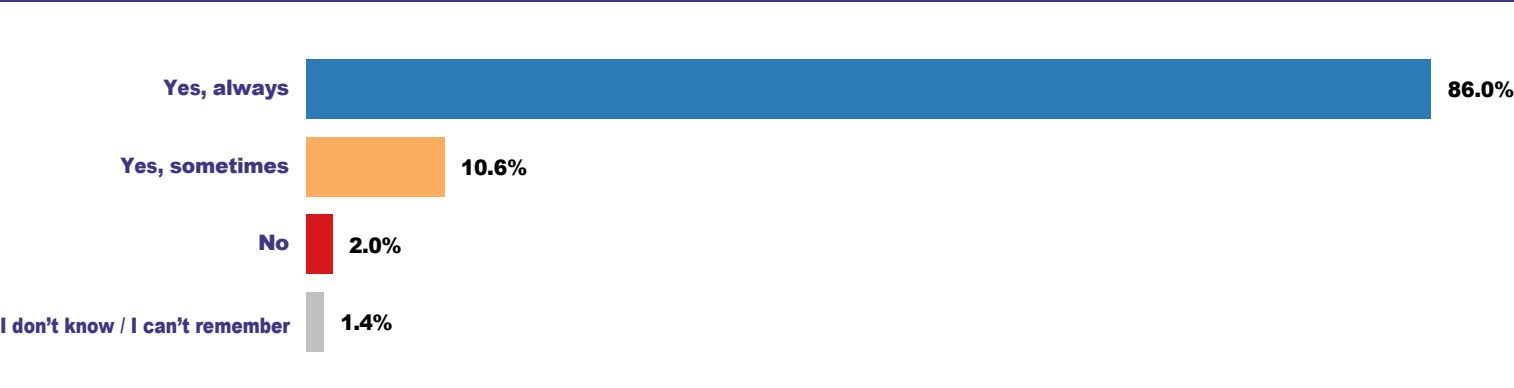


Positive experiences

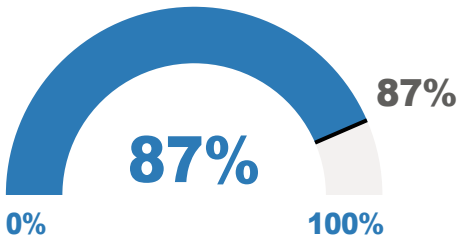


YOUR OVERALL CARE

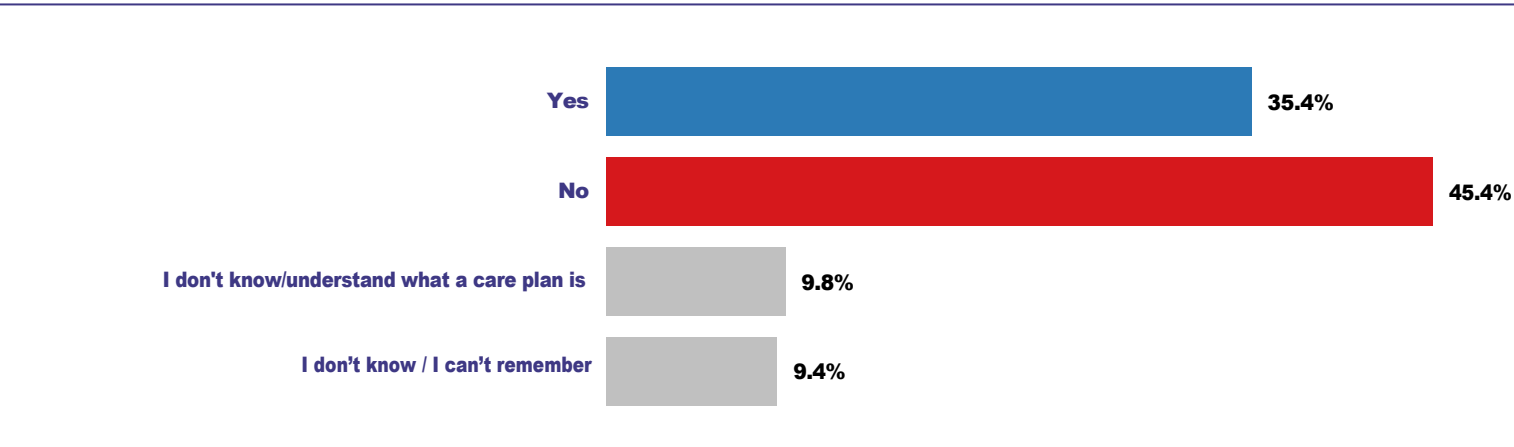
Q59. Did the different people treating and caring for you (such as your family doctor / GP, oncologist, hospital doctors and nurses, home care) work well together to give you the best possible care?



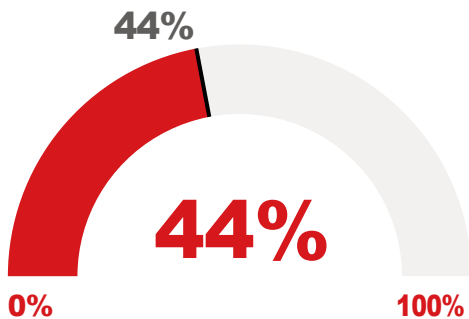
Positive experiences



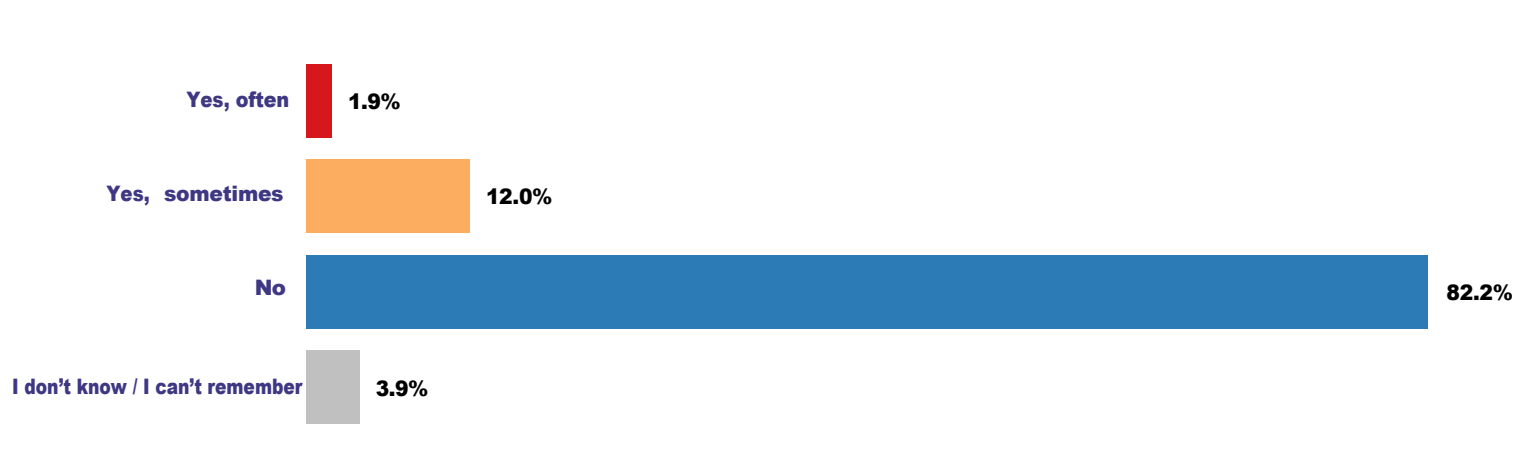
Q60. Were you given a care plan? (A care plan is a written document that sets out your needs and goals for caring for your cancer. It is an agreement or plan between you and your health professional(s) to help meet those goals.)



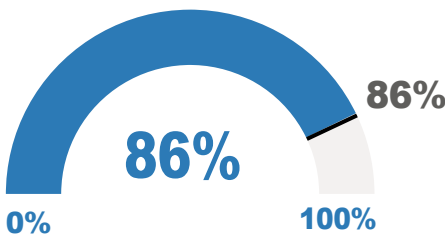
Positive experiences



Q61. During your care, have test results or medical records ever been unavailable at the time of your care appointment?

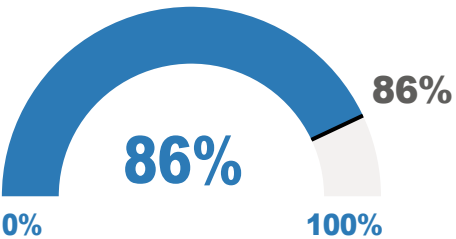


Positive experiences



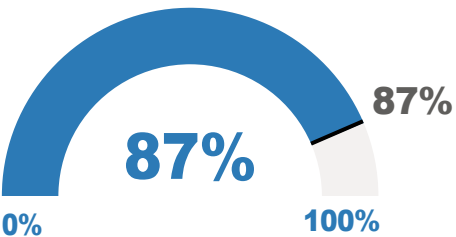
Q62. During your care pathway, have you ever been given confusing or conflicting information about your health condition or treatment?

Positive experiences

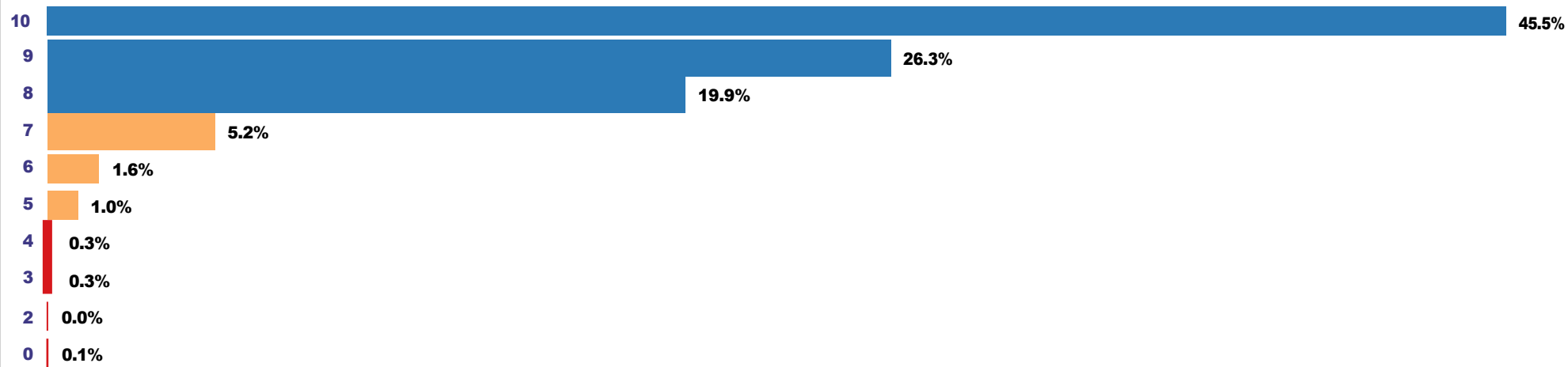


Q63. During your care, was there a time when you felt that tests or other assessments were repeated unnecessarily?

Positive experiences

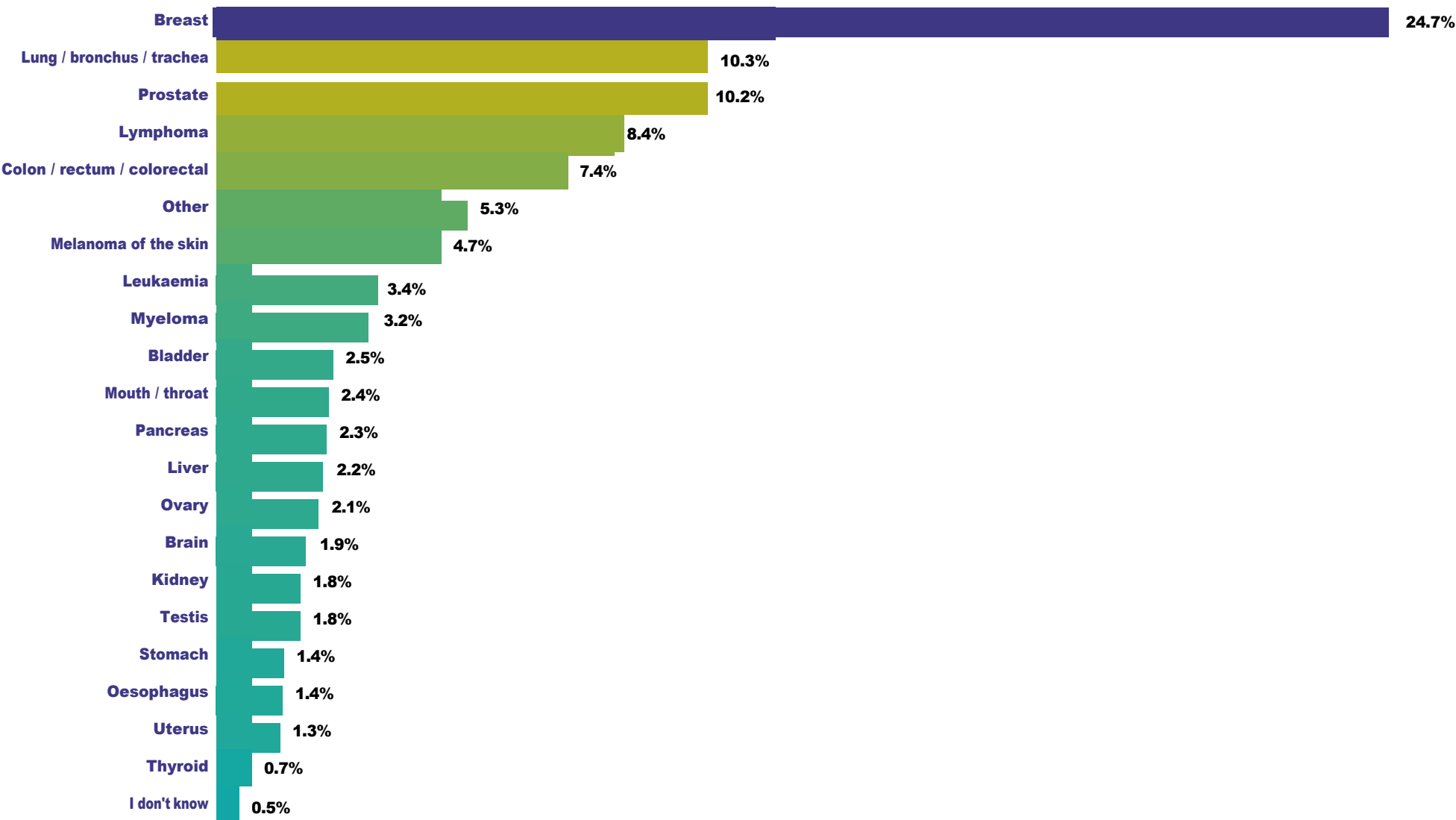


Q64. Overall, how would you rate your care?

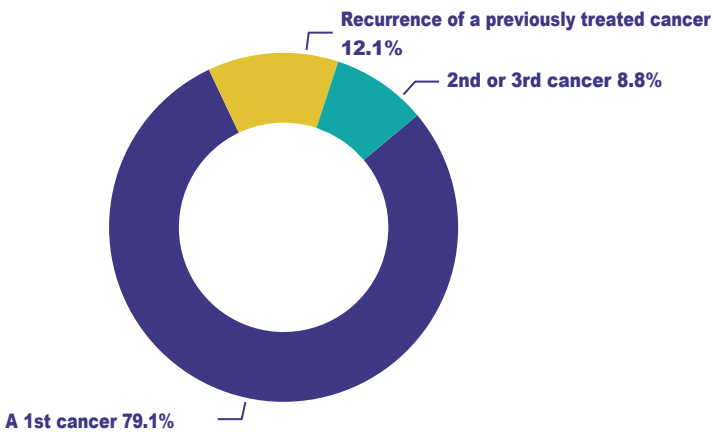


HEALTH CONDITION

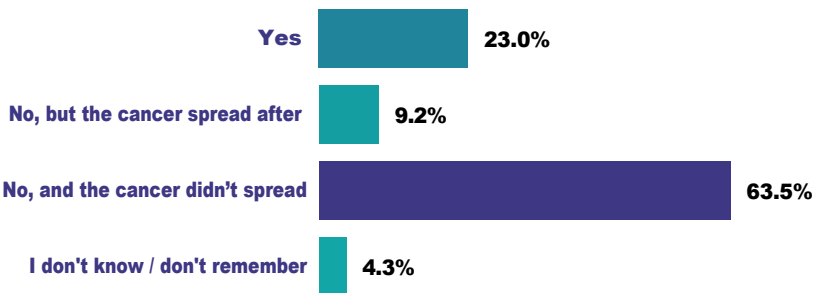
Q65. What is the main type of cancer for which you have been treated or monitored in the last 12 months?



Q66. The cancer reported above is :

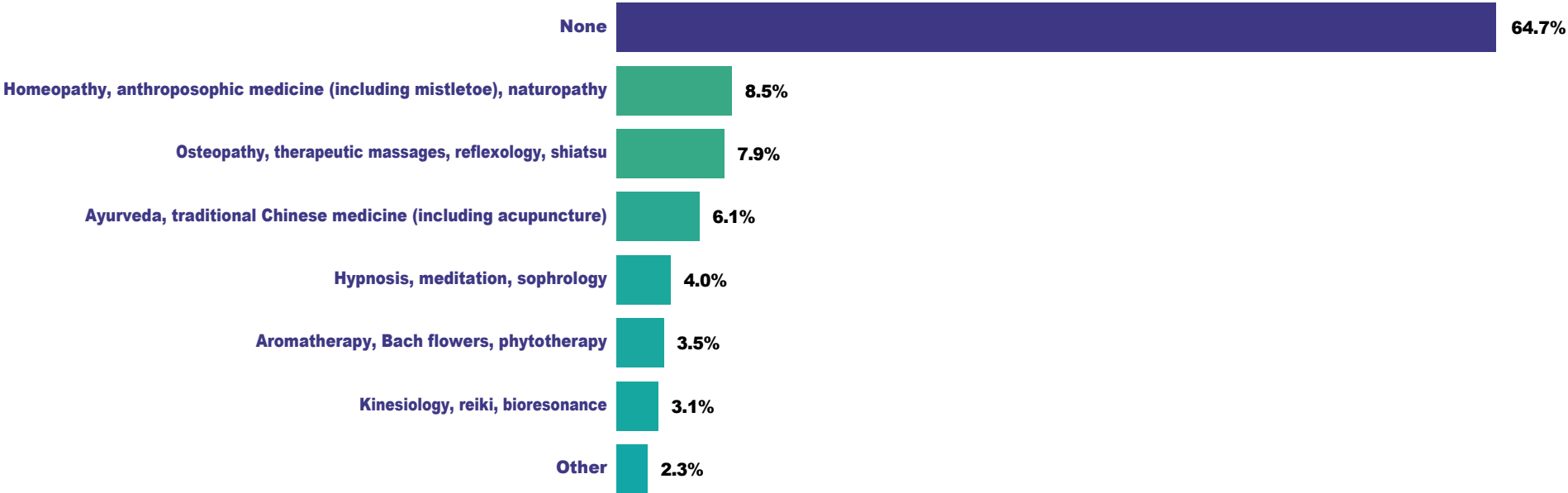


Q67. Had your cancer spread to other organs or parts of your body (metastatic cancer) at the time you were first told you had cancer?





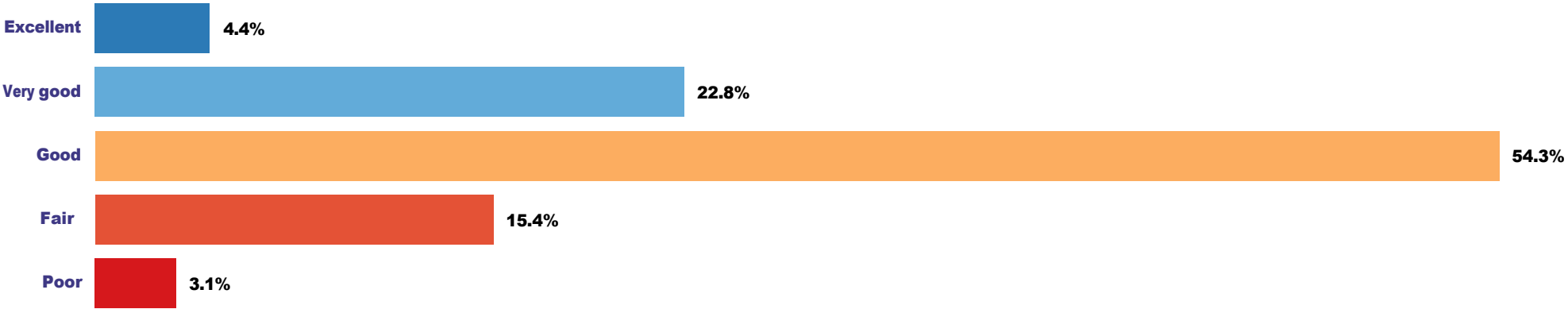
Q68. Have you received one or more complementary medicine therapies for cancer treatment or symptom management?



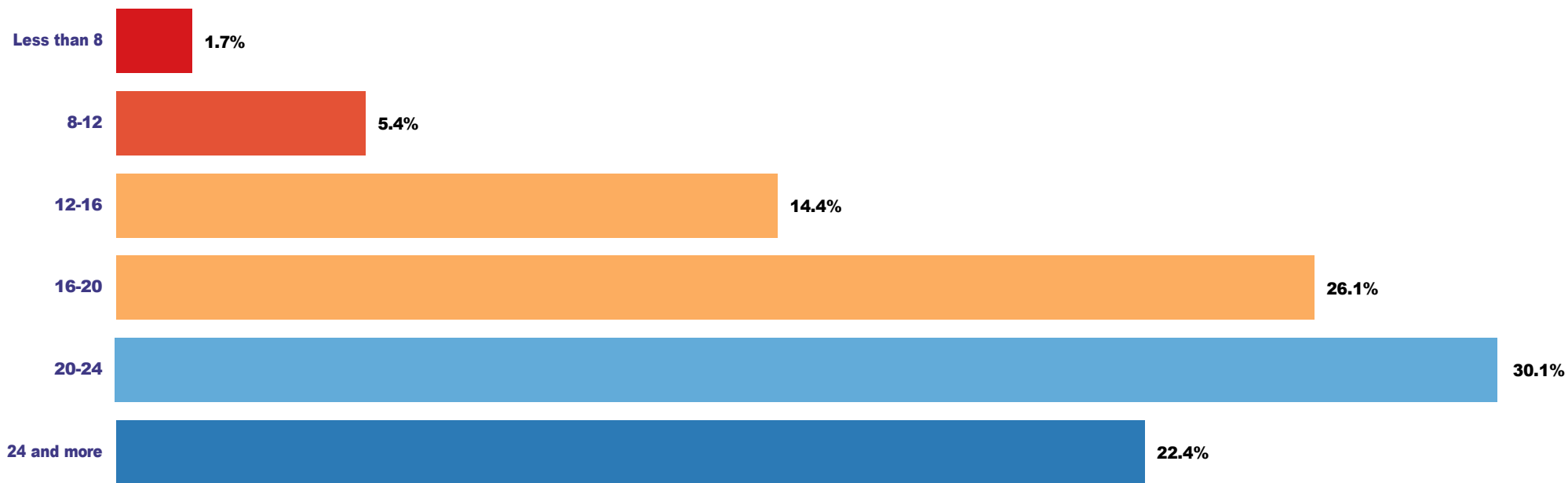
Q69. Have you received any medical treatment in the last 12 months or are you currently being treated for a chronic health problem other than cancer?



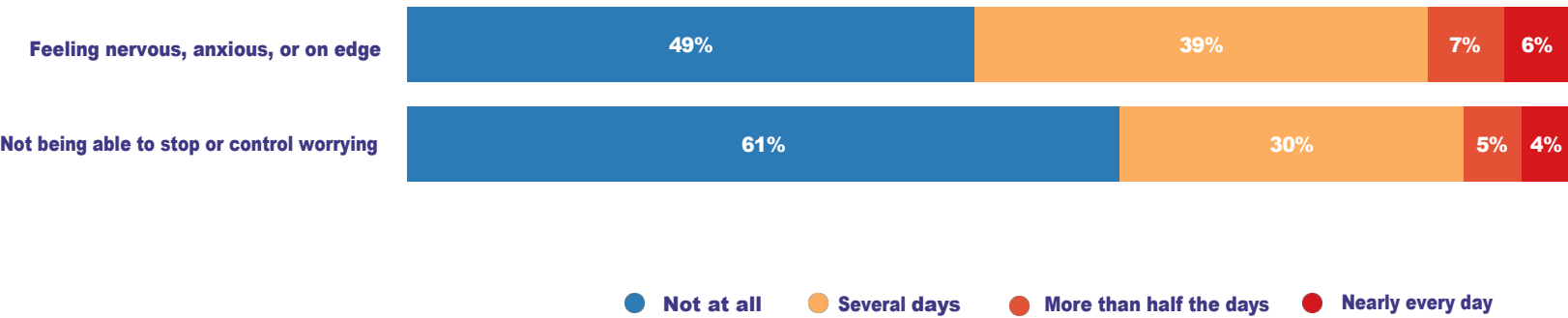
Q70. In general, would you say your health is:



Q71. Quality of life scale (from 0 low to 28 high)



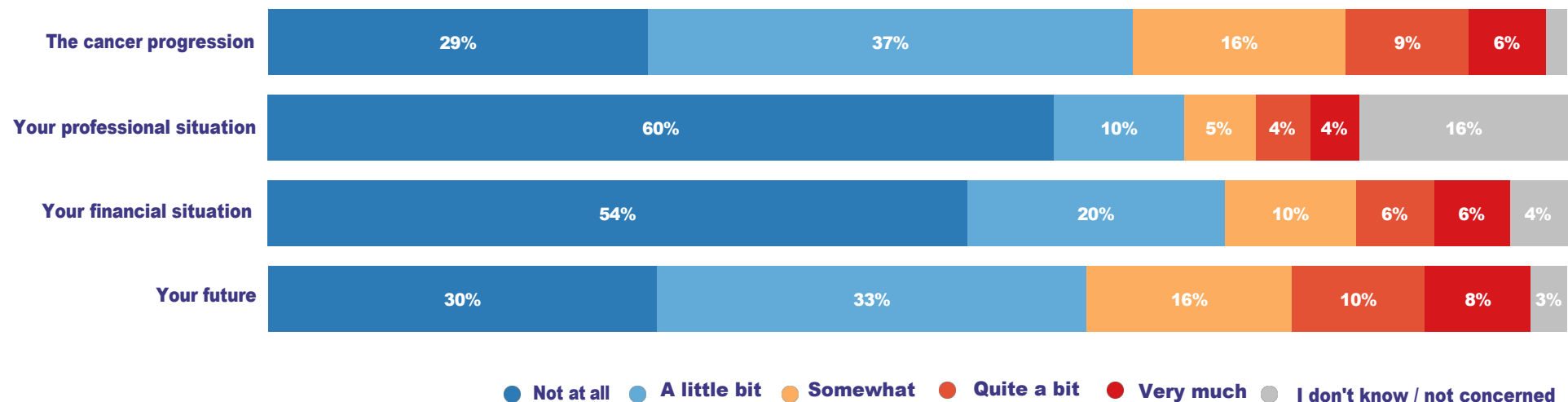
Q72. Over the last 2 weeks, how often have you been bothered by the following problems?



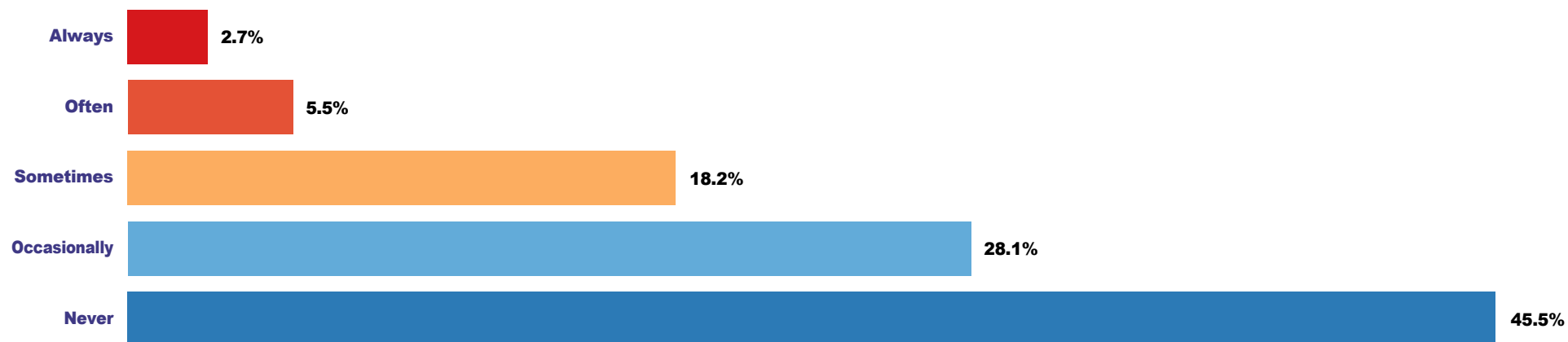
Q73. During the past month, ...



Q74. To what extent are you currently concerned about...



Q75. When you get written information about a medical treatment or your health condition, do you have any problems understanding it?

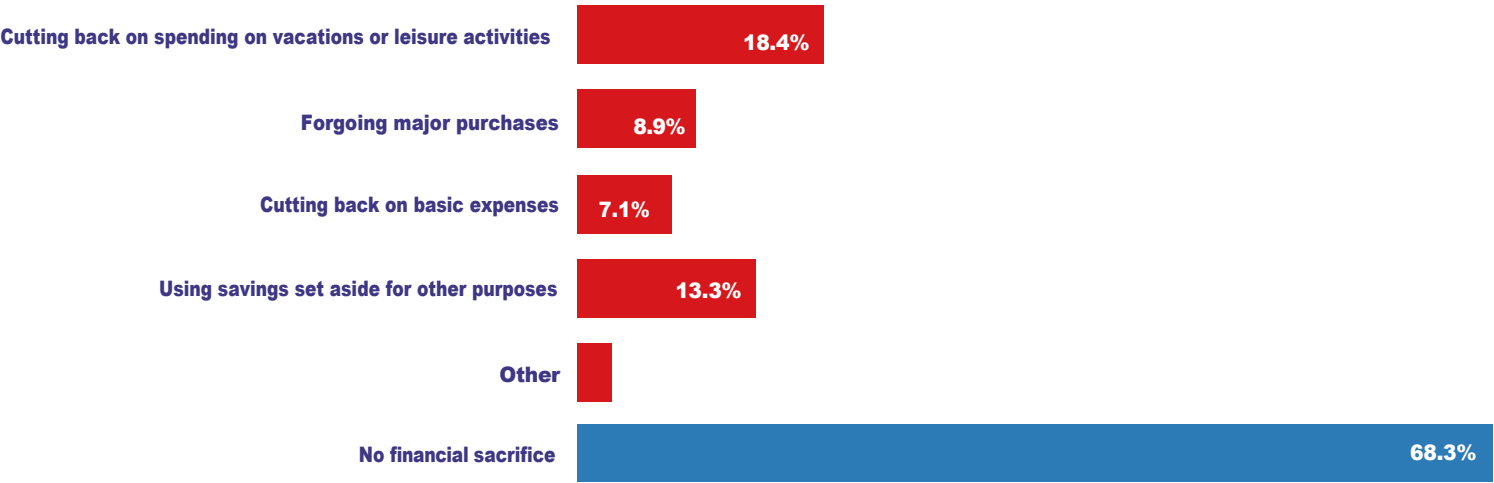


Q76. In general, how do you prefer to make medical decisions about cancer?

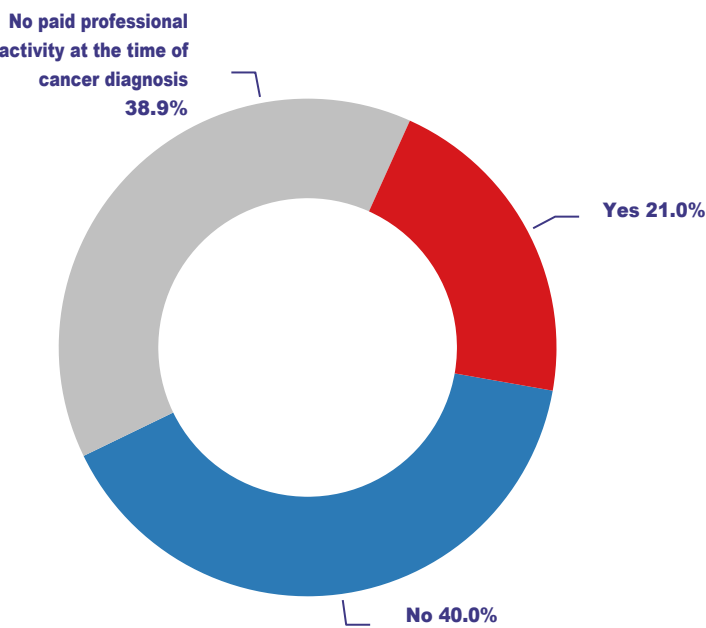


FINANCIAL IMPACT OF CANCER

Q87. Have you or your family had to make financial sacrifices because of cancer, cancer treatment(s), or related long-term effects?



Q88. Have you ever been afraid of losing your job and income, or having your income limited in the future because of cancer?



Q89. Has a family member or friend ever taken unpaid leave or reduced work hours to support you?

