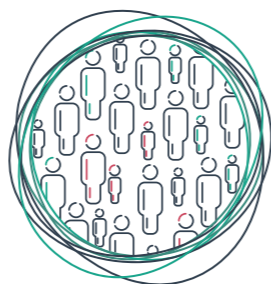


# Brain/CNS tumours



A total of 3,981 people completed the [All.Can patient survey](#). Of those, **2% (97 people)** indicated they had been diagnosed with brain/central nervous system (CNS) tumours. Overall characteristics of this respondent sub-group are presented in **Table 1**. Specific pathologies within brain/CNS tumours were not identified in the survey and responses have not been filtered by type of tumour or grade as we do not have this information.

Findings presented here are unweighted and therefore represent the actual responses from current and former patients and/or caregivers who completed the survey. Percentages were calculated after excluding respondents who did not answer each particular question. Numbers in brackets represent the number of people who responded to that answer option.

**The brain/CNS tumour-specific findings in this profile must be considered independently and cannot be directly compared with those of other tumour types as the respondent characteristics vary considerably between tumour types.**

To find out more about the survey and to view additional materials, see: [www.all-can.org/what-we-do/research/patient-survey/about-the-survey/](http://www.all-can.org/what-we-do/research/patient-survey/about-the-survey/)

**Table 1. Characteristics of brain/CNS tumour respondents**

Country		Age	Sex
Australia <b>26%</b> (25)	Spain <b>1%</b> (1)	0-24: <b>9%</b> (8)	Female <b>52%</b> (49)
Belgium <b>11%</b> (11)	Sweden <b>3%</b> (3)	25-44: <b>38%</b> (36)	Male <b>47%</b> (44)
Canada <b>8%</b> (8)	UK <b>6%</b> (6)	45-64: <b>44%</b> (41)	
France <b>1%</b> (1)	USA <b>5%</b> (5)	65+: <b>10%</b> (9)	
Italy <b>3%</b> (3)	Other <b>6%</b> (6)		
Poland <b>29%</b> (28)		Not specified: 3	Not specified: 4

Note: All percentages are rounded to the nearest whole number, therefore the sum of percentages for all answers to a given question may not total 100%.

## Where did inefficiencies occur most?

- My initial diagnosis: **26%** (20)
- Dealing with ongoing side effects: **16%** (12)
- Dealing with the psychological impact: **16%** (12)



‘Many people will say they are “coping” when, in reality, they need support readily at hand.’  
Brain/CNS tumour respondent from Australia

## Swift, accurate and appropriately delivered diagnosis

- **35%** (21) of respondents said that their brain/CNS tumour was diagnosed as something different – either initially or multiple times
- **18%** (16) of respondents waited more than six months to be diagnosed

## Information, support and shared decision-making

- **42%** (30) of respondents with brain/CNS tumours did not feel involved enough in deciding which treatment options were best for them
- **51%** (45) were not given enough information (in a way they could understand) about their care and treatment
- **51%** (44) did not receive enough support to deal with ongoing symptoms and side effects – including beyond the active phase of their treatment
- **41%** (24) felt that they lacked adequate information and care for dealing with the pain they experienced
- **56%** (36) did not receive enough information (in a way they could understand) about the signs and symptoms indicating that their brain/CNS tumour may be recurring or getting worse
- **58%** (53) were not given information about available peer-support groups
- **75%** (30) of those who did receive information about these groups used them ‘a lot’ or ‘some’ of the time

## Integrated multidisciplinary care

- **62%** (36) said that support from other healthcare professionals (e.g. dietitians, physiotherapists or mental health services) was not always available when they needed it
- **62%** (50) reported that they needed some form of psychological support during or after their care but, of those, **36%** (18) said it was not available to them
- Of those who received psychological support, **88%** (35) said it was ‘very’ or ‘quite’ helpful

## The financial impact

- **64%** (59) of respondents paid for some part of their care: **12%** (12) already had private health insurance, **11%** (11) paid for care and treatment not covered by insurance or their country’s healthcare system, and **19%** (18) paid to avoid delays in their diagnosis, treatment or care.
- **40%** (39) reported a loss of employment and **33%** (32) reported travel costs as a financial implication of their care and treatment