Haematological cancer



A total of 3,981 people completed the <u>All.Can patient survey</u>. Of those, **9% (362 people) indicated they had been diagnosed with haematological cancer.** Overall characteristics of this respondent sub-group are presented in **Table 1**.

Findings presented here are unweighted and therefore represent the actual responses from current and former cancer 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 cancer-specific findings in this profile must be considered independently and cannot be directly compared with those of other cancer types as the respondent characteristics vary considerably between cancer 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/

Table 1. Characteristics of haematological cancer respondents

Country		Age	Sex
Australia 20% (73) Belgium 10% (38)	Spain 1% (4) Sweden 1% (2)	0-24: 8% (28) 25-44: 28% (99)	Female 65% (233) Male 35% (123)
Canada 14% (52) France 1% (3)	UK 7% (25) USA 12% (42)	45–64: 44% (155) 65+: 19% (66)	
Italy 2% (6) Poland 26% (95)	Other 6% (22)	Not specified: 14	Not specified: 6

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?

- Dealing with the ongoing side effects 29% (85)
- My initial cancer diagnosis 22% (67)
- Dealing with the psychological impact 15% (44)



'The side effects are more than just a nuisance and need real recognition.'

Haematological cancer respondent from the UK

Swift, accurate and appropriately delivered diagnosis

- 76% (193) of respondents with haematological cancer were diagnosed outside of a screening programme.
- 20% (60) of respondents whose cancer was detected outside of a screening programme waited more than six months to be diagnosed with cancer
- 37% (80) of respondents whose cancer was detected outside of a screening programme said that their cancer was diagnosed as something different either initially or multiple times

Information, support and shared decision-making

- 52% (129) of respondents with haematological cancer did not feel involved enough in deciding which treatment options were best for them
- 38% (120) were not given enough information (in a way they could understand) about their cancer care and treatment
- 54% (177) did not receive enough support to deal with ongoing symptoms and side effects including beyond the active phase of their treatment
- 37% (95%) did not receive enough information (in a way they could understand) about the signs and symptoms indicating that their cancer might be returning or getting worse
- 36% (83) felt that they lacked adequate information and care for dealing with the pain they experienced
- 51% (173) were not given information about available peer-support groups

Integrated multidisciplinary care

- 64% (169) of respondents with haematological cancer reported that they needed some form of psychological support during/after their cancer care but, of those,
 41% (69) said it was not available
- Of those who received psychological support, 64% (102) said it was 'very' or 'quite' helpful
- 63% (142) said that support from other healthcare professionals (e.g. dietitians, physiotherapists or mental health services) was not always available when they needed it

The financial impact of cancer

- 49% (267) of respondents paid for some part of their cancer care: 21% (76) already had private health insurance, 8% (29) paid for care and treatment not covered by insurance or their country's healthcare system, and 11% (40) paid to avoid delays
- 20% (71) reported a loss of employment, 29% (104) travel costs, 4% (13) childcare costs, and 8% (29) loss of insurance as a financial implication of their cancer care and treatment.