

The patient perspective on inefficiencies in cancer care: key findings from the global All.Can patient survey

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Full report available here:

www.all-can.org/reports/all-can-patient-survey



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Disclosure of Interests (2005 to date) International Brain Tumour Alliance (IBTA)



I believe I have no real or perceived conflicts of interest in relation to this presentation at the ECCO Summit but for transparency's sake, here is my disclosure of interests.

The IBTA has, since its establishment in 2005, received funding support from AbbVie, Accuray, Antisense Pharma, Apogenix, Archimedes, Ark Therapeutics, Astra Zeneca, Bayer, Boehringer Ingelheim, Brain Tumor Network (USA), Brain Tumor Resource and Information Network (USA), Bristol-Myers Squibb (BMS) Celldex Therapeutics, Crusade, Dijon Designs (UK), Elekta, Eli Lilly, Gerry & Nancy Pencer Brain Trust (Canada), Gosling Foundation (UK), GlaxoSmithKline (GSK), Ivy Foundation (USA), Lilly, Link Pharmaceuticals, MagForce, Medac, Merck Serono, Merck, MGI Pharma, MSD Oncology, NeoPharm, Neuroendoscopy (Australia), Northwest Biotherapeutics, Novartis, Novocure, Pediatric Brain Tumor Foundation (USA), Pfizer, Photonamic, Roche, Schering-Plough (Global), Sontag Foundation (USA), Spink (UK), to-BBB, Vane Percy (UK), VBL Therapeutics and the Wallerstein Foundation (USA).

Patient Advisory Board: Novartis, Bristol-Myers Squibb, AbbVie, GSK, Lilly

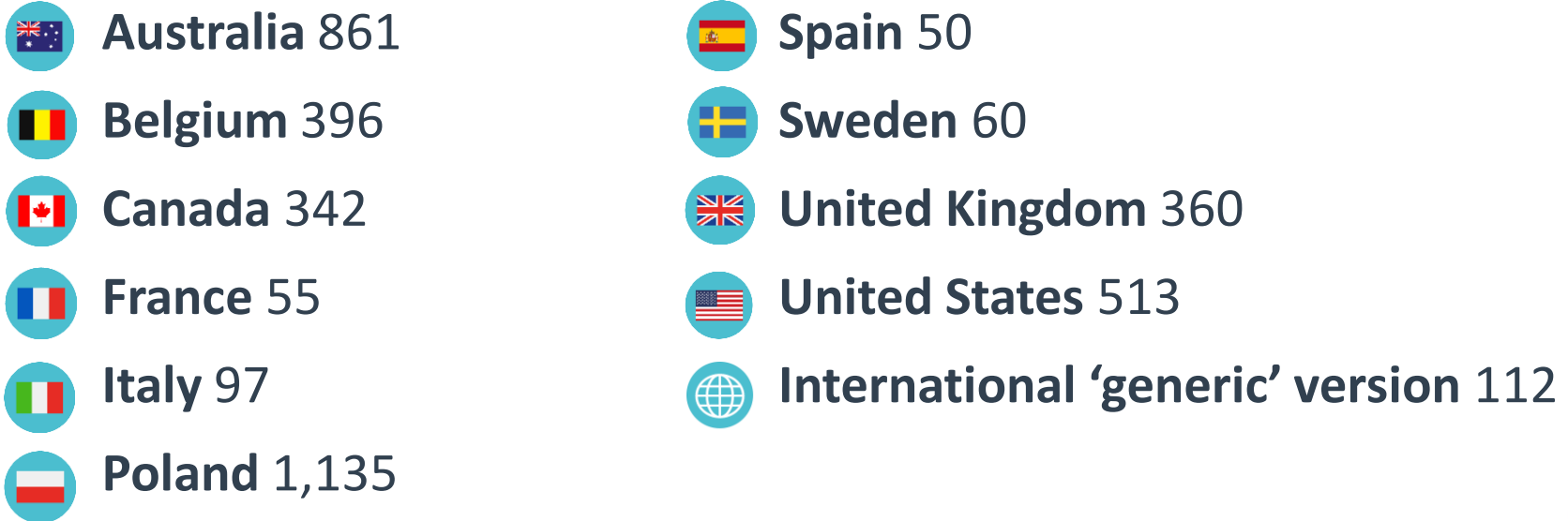
Committees/Projects: EURACAN, All.Can, ECCO Patient Advisory Committee, ESMO Patient Advocacy Working Group, Rare Cancers Europe, GLIOTRAIN, EORTC SISAQOL project, SNO Guidelines Committee, British Neuro-Oncology Society (BNOS), WeCan, INSERT, NCRI Brain Tumour Subgroup on Palliative and Supportive Care, EANO Palliative and Supportive Care Task Force, NCI-Connect

For full details of the IBTA's sponsorship policy, and comprehensive details of our funding organisations, please see our website at www.theibta.org

A total of 3,981 people from over 10 countries completed the survey

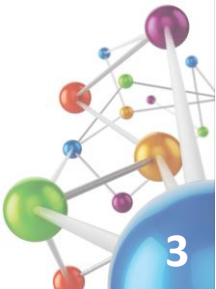


The number of respondents per country:



Reference: All.Can. 2019. Patient insights on cancer care: opportunities for improving efficiency.

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1. Ensure a swift, accurate and appropriately delivered diagnosis

- 26% of respondents said that **their initial diagnosis is where they experienced the greatest inefficiency** – more than any other area of cancer care and treatment
- Respondents reported that the communication of their diagnosis could have been better, in terms of **empathy** from physicians and the **timing** of being told they had cancer
- Among respondents whose cancer was detected outside of a screening programme:
 - Delayed diagnosis (>6 months) was associated with a more **negative respondent view** of all aspects of information, care and support
 - **32%** of respondents reported that their cancer was diagnosed as **something different** once or multiple times
 - **Speed of diagnosis** varied significantly by cancer type

Reference: All.Can. 2019. Patient insights on cancer care: opportunities for improving efficiency.



2.

Improve information sharing, support and shared decision-making

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- Respondents reported that **too much information** being given at once was **overwhelming**, and they would have preferred to receive **relevant information at appropriate points** along the entire care pathway
- **47%** of respondents did not feel **sufficiently involved** in deciding which **treatment option** was best for them
- **39%** of respondents felt they had **inadequate support** to deal with **ongoing symptoms** and **side effects**
- **31%** of respondents felt that they **lacked adequate support** for dealing with **pain**
- **35%** of respondents felt **inadequately informed** about how to recognise whether their cancer might be **returning or getting worse**
- **41%** of respondents were **not given information** at the hospital about **peer-support groups**
- **Gaps in information and support** were more prevalent among people with **advanced cancers**

Reference: All.Can. 2019. Patient insights on cancer care: opportunities for improving efficiency.



Make integrated multidisciplinary care a reality for all patients

- Respondents commented that **specialist cancer nurses** had played a critical role – acting as their **‘navigators’** and helping them **adapt** all aspects of their lives to cancer – both during and after treatment
- **24%** of respondents felt that support from **allied healthcare professionals** (dietitians, physiotherapists etc.) was **not always available when they needed it**
- Respondents wanted **more information** about what they could do to **support their treatment and recovery** in terms of **diet, exercise** and **complementary therapies**
- **69%** of respondents said they needed **psychological support** during or after their cancer care. However, of these, **34%** said it was **not available**
- Respondents frequently expressed concern for the **impact their cancer had on their families**, and wanted psychological support extended to them as well

Reference: All.Can. 2019. Patient insights on cancer care: opportunities for improving efficiency.



Address the financial implications of cancer

- **51%** of respondents **paid for some part of their care**, either out-of-pocket or through private insurance
- **Travel costs (35%)** and **loss of employment income (26%)** were the most frequently reported non-treatment-related costs for respondents
- Cancer had a negative, and often long-term, **impact on productivity** for respondents and their caregivers
- In some cases, a diagnosis of cancer created **lifelong financial insecurity**

‘The running costs of cancer are generally ignored. There are a huge number of hospital visits involved in chemo and oncologist appointments, with travel costs (petrol and parking), as well as the dislocation and stress to the driver/carer's life.’

- Respondent from the United Kingdom

Reference: All.Can. 2019. Patient insights on cancer care: opportunities for improving efficiency.

