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## Nick Smallwood: Young cancer patients advocate for improved care

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*For many young cancer survivors, the impact of cancer does not stop when treatment does*



There was a sense of purpose in the air at the [Youth Cancer Europe](#) (YCE) annual meeting in Vilnius last week, as over 100 attendees from 22 countries gathered to discuss the most pressing issues facing young people who have successfully survived treatment for cancer or are currently undergoing treatment for it.

The meeting connected a new generation of patient advocates, providing a platform for people to share experiences and work on a collective action plan to transform the way the medical profession engages with young cancer patients.

YCE was founded in 2014 by [Šarunas Narbutas](#), who underwent treatment for chronic myeloid leukaemia when he was 18 and is president of the Lithuanian Cancer Society, together with [Shajjad](#) and [Katie](#) Rizvi, founders of the Romanian cancer charity [Little People](#). Membership of YCE is open to young cancer patients and survivors aged 18-39 and its founders have set ambitious goals:

- Working towards age appropriate, full, and equal access to effective cancer treatment across Europe;
- Improving long term follow-up and the quality of life of cancer survivors;
- Creating a network of patient advocates to increase the political and regulatory influence of young people with cancer.

The aim of the Vilnius meeting was to shape YCE's agenda for 2018, set targets, and elect people to take responsibility for achieving them. An energetic and friendly group from the [Lithuanian Junior Doctors Association](#) kindly facilitated the meeting, capturing key discussion points and organising evening activities to permit an opportunity to share experiences and forge friendships in a more relaxed setting.

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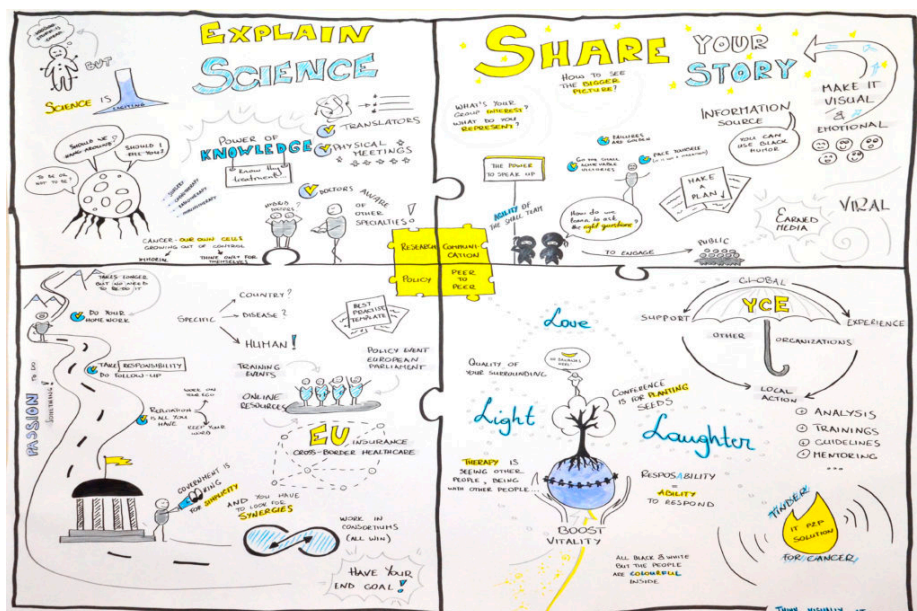
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Material from the meeting

The final day of the meeting was spent outlining YCE's activities for the next 18 months. This included setting up several working groups. One to organise a face to face capacity building session for 25 patient advocates in April 2018, aimed at helping national cancer groups influence health policies in their own countries. A second group will run policy events in the European Parliament in October 2018 and March 2019. A third will create easy to understand information about the latest cancer research/treatment by collaborating with scientists and researchers and promoting this material through platforms such as YouTube, social media, and the YCE website. A fourth will focus on communications, for example, telling YCE's story and working to expand the network. A fifth will focus on fundraising. Five board members were elected to direct these activities and support YCE on the next stage of its journey.

As a carer for a patient with cancer and someone committed to helping young people have a greater influence on health policy and practice, I left the meeting hugely impressed with the courage and commitment of the participants. I have little doubt that they will exemplify the maxim attributed to Margaret Mead: "Never doubt that a small group of committed citizens can change the world. Indeed, it is the only thing that ever has."

**Nick Smallwood** is a lawyer at Cambridge University Press. He is also an occasional journalist covering sport and medicine.

**Competing interests:** I have read and understood BMJ policy on declaration of interests and declare the following interests: None.