2020 Survivors' Conference

Bridging the gaps for childhood brain tumour survivors

Conference Feedback



Milly Meadows, Survivor and Conference Presenter, with her Dad

Brighter Futures For Childhood Brain Tumour Survivors



Shakeerah and her mother, Yasmeen

Shakeerah has a tracheostomy and uses a ventilator overnight. She is fed through a little plastic tube in her tummy and bears scars around her head and tummy from the numerous operations, (45 and counting), she has had to date.

And yet she is the fiercest little creature I know, ruling our household with her small yet powerful iron fist.

Her medical issues are complex, but against all odds she has persevered and is meeting most of her milestones like a typical toddler.

She is a survivor.

Yasmeen - Shakeerah's Mum

a truly inspiring event. A big thank you to everyone who has contributed and for sharing your stories so honestly.

Thank you for this wonderful, insightful opportunity, fabulous speakers.

Thanks for everyone involved in the conference, it's been amazing, and I have learned so much.

I've gained knowledge that will help me understand my son's condition much better in the future.

Thank you so much. It was very informative and not overwhelming at all, so easy to understand.

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1. A MESSAGE FROM OUR CHAIRMAN AND FOUNDER

I was delighted to welcome some 280 delegates to the 4th annual Success Charity Survivors' Conference. As a result of Covid-19, this was held virtually. One of the key benefits of the new format was that we were able to welcome twice the number of delegates than has been possible at previous, physical events, and to extend the reach to survivors and families from across the world.

The theme was "**bridging the gaps for survivors of childhood brain tumours**" which reflects one of Success Charity's core aims – to address the unmet rehabilitation and support needs of survivors of brain tumours diagnosed and treated in childhood.

This *Conference Feedback Report* outlines some of the main areas of feedback from the conference, which I hope you will find useful and informative.



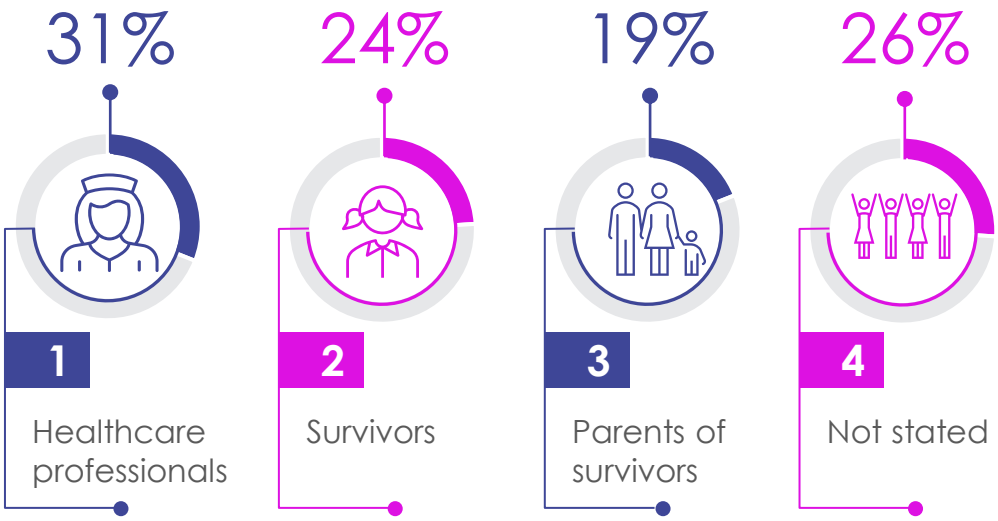
Dr Helen Spoudeas
Success Chairman and Founder

2. DELEGATE INFORMATION
EXTENDING THE REACH

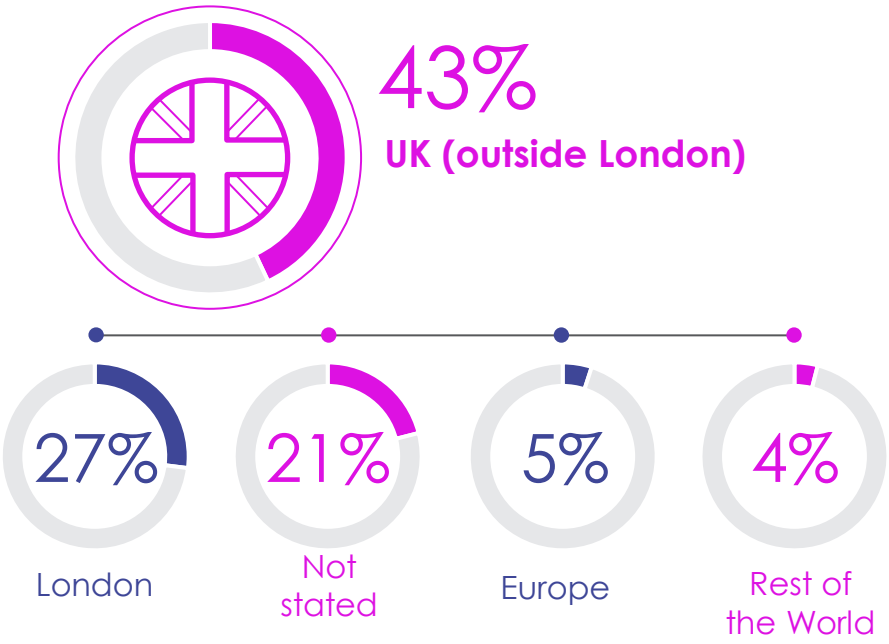
We want to deliver the long-term quality survival that all survivors of childhood brain tumours deserve.

Dr Helen Spoudeas, Success Charity Founder and Chair of Trustees

I am a...



Location of Delegates





At the start of the conference, delegates were asked, using up to **3 words**, to describe the most important thing they would want from brain tumour survivorship support services

3. DELEGATES FEEDBACK

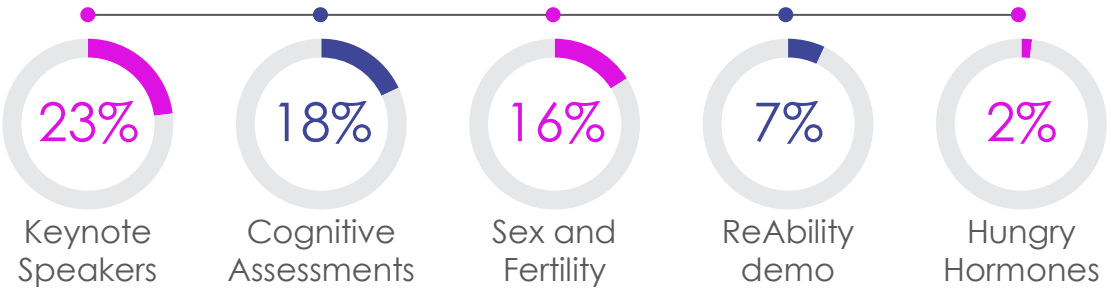
> *Survivors' powerful and inspirational stories are always the highlight of every conference, and they are again this year!*
>
> **Claire Cardy**, Success Charity CEO

Which sessions did you enjoy the most?

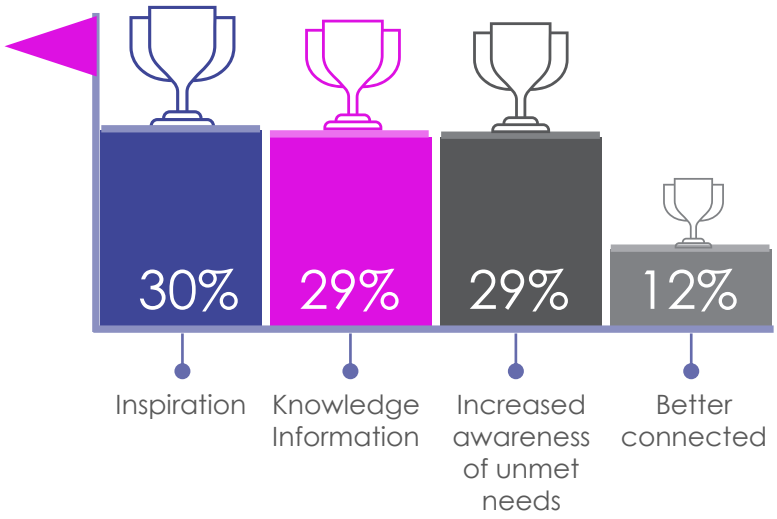


34%

Survivors' talks



What have you gained most from this year's conference?



> *Thanks for everyone involved in the conference, it's been amazing and I have learned so much. I gained knowledge that will help me understand my son's condition much better.*
>
> **Parent** and delegate

3. FEEDBACK CONT...

100% Delegates
rated their overall experience of the Conference as Good, Very Good or Excellent

100% Delegates
said they would recommend Success Charity's Survivors' Conference to other survivors / families

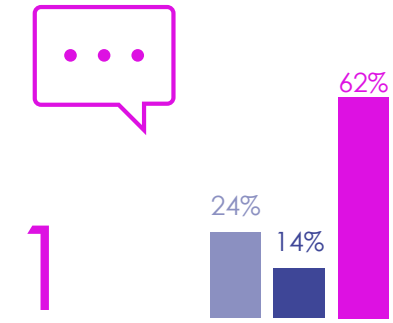
How did you rate the following sessions?

Survivors' talks

1

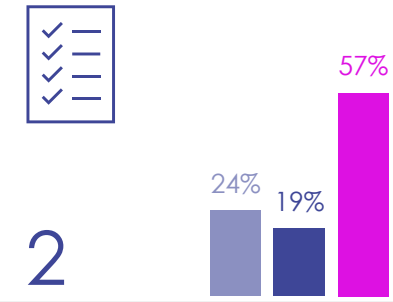






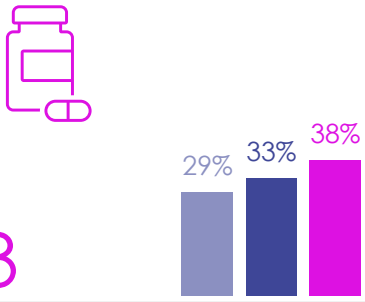
Booking Process

2



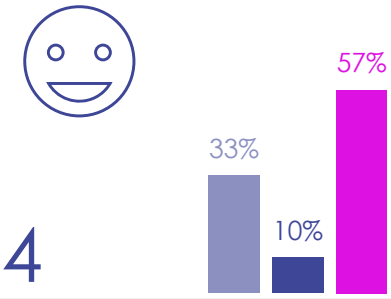
Medical Prof. Speakers

3



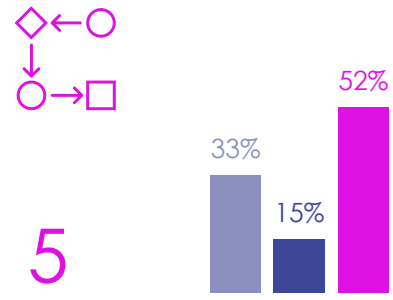
Overall Experience

4



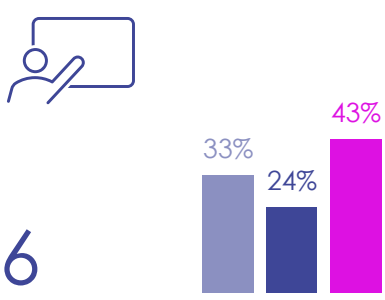
Ease of use

5



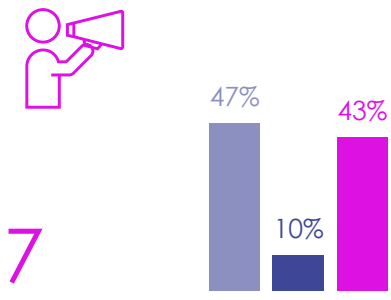
Keynote speakers

6



Pre-event comms.

7

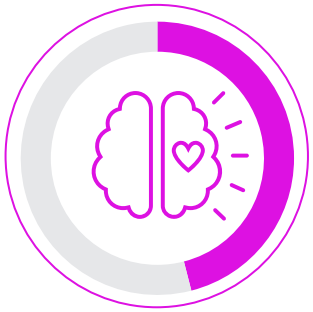


4. SERVICE AND SUPPORT
ADDRESSING THE GAPS

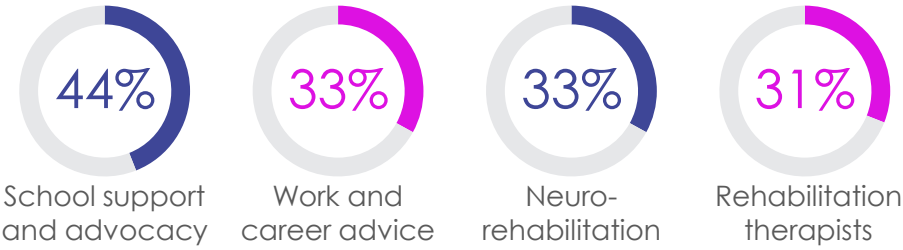
We asked each delegate to identify what they felt were the *biggest gaps in service and support provision* for children and young people with brain tumours.

Support with mental health issues, particularly as young survivors grow older and hit puberty, plus the need for far greater support in school, to enable young survivors to achieve their full educational potential, were identified as areas where families are most struggling.

What do you think are the biggest gaps in services for children with brain tumours? Top 2 picked.



46%
Mental Health Services

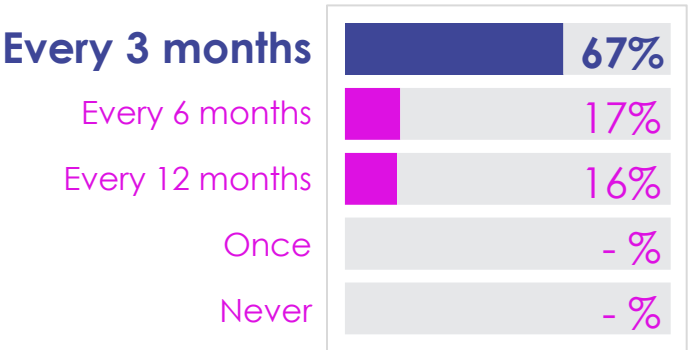


This valuable input from the people we exist to support and advocate for will continue to help inform Success Charity's strategic and operational planning, as we grow our service provision to better meet the needs of survivors and families.

How often would you want to be seen in a BT survivorship clinic?

We also asked delegates often they would like to be seen within the context of a dedicated brain tumour survivorship service.

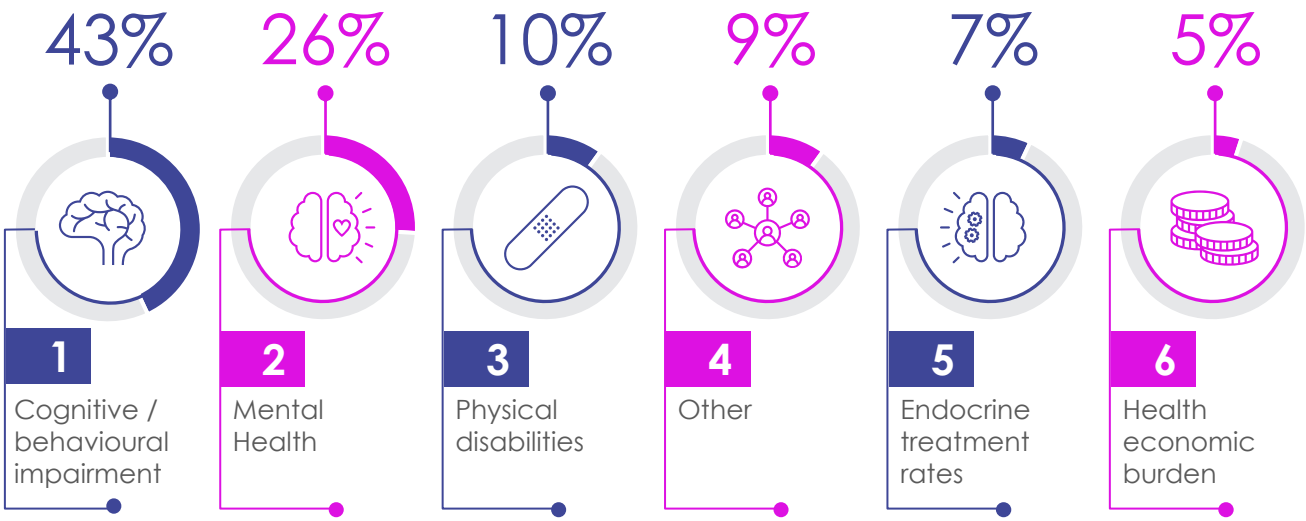
Over **two thirds** of delegates indicated that face to face support every 3 months would be their preference.



Drivers for change

Delegates were also asked to also 'vote' for a series of '*drivers for change*' which they felt should be adopted nationally, to promote improvements in support for the growing numbers of childhood brain tumour survivors.

They expressed a strong need for recognition of the impact of brain tumours and established treatments on cognitive function.





"Defining the right drivers is important because such measures are a powerful way to generate change, something we at SUCCESS are very keen to do.

Dr Jenny Limond, Senior Lecturer and Research Director Exeter University – Success Charity Trustee

5. SURVIVORS PRESENTATIONS

Our annual conference provides a platform for survivors to lay bare their fears, frustrations, challenges and successes. Our survivors' stories inspire us as a charity, to push harder and do better for the people we represent. But we know they also inspire other survivors, and parents, many of whom are struggling with the debilitating and often unrecognised impact of their tumour and treatment.



Tom Cadle
Survivor

"My best piece of advice for survivors would be: don't be afraid to ask for help.



Milly Meadows
Survivor

"I'm sure I'm not the only one who has to deal with side effects and it would be great to hear from others and what they do to cope.



Nigel Thacker, presenter and parent of **Ollie Thacker** (pictured)

"There is no funding and no clear path to help. An enormous gulf exists between provision for adult mental health and those for children.



"It has not been easy, but I am so excited to see what lies ahead and what the future will bring me.

Lucy Ronson Allalouf
Survivor



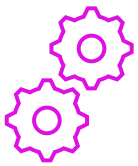
"If I had one wish it would be for more people to recognise that not every disability is visible and better understand needs of survivors.

Zainab Islam Survivor

This year's presenters bravely shared experiences with a wide range of issues including memory loss, anxiety, hypothalamic damage and the impact of this on appetite and weight gain, problems experienced at school and how to better educate teachers on the hidden disabilities many survivors have to deal with every day.

6. WORKSHOP PROGRAMMES

This year we held a series of workshops separate from the main conference event. Hosted online and led by health professionals, survivors and families, these creative, practical and interactive sessions included art therapy, yoga, managing weight gain, a practical demonstration of a new online rehabilitation tool, and guidance on how to make best use of cognitive assessments.



6 No. of workshops held



44 Total registered attendees



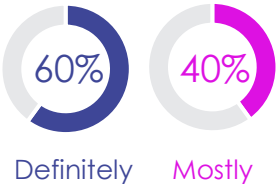
9 Overall score out of 10 !

80%

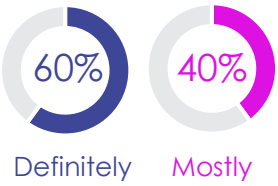
% of attendees who felt better informed at the end

70%

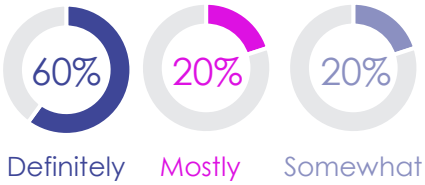
% of attendees who felt more connected



Were they interesting and entertaining?



Did you find them relevant?



Did you find them inspiring?



100% YES !

Were you happy with the booking process?

THANK YOU!

We would like to thank all our presenters, including survivors, parents, medical and care professionals, for providing such inspiring testimony, advice, support and hope.

THANK YOU to our Patron, Dominic Grieve QC and Derek Thomas MP, Chair of the All Party Parliamentary Group on Brain Tumours for their invaluable contribution.

THANK YOU to our sponsors, without whom this conference would not have been possible; Sandoz, Novo Nordisk and Ferring Pharmaceuticals.

THANK YOU to Make Events, for staging and producing the conference.

THANK YOU to our delegates, for attending and being part of a growing community of brain tumour survivors that recognise the need for better; Better rehabilitation. Better information. Better support. Better lives. Together, we are stronger.

To join the community online please visit:
www.healthunlocked.com/childhood-brain-tumours-survivors

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