

Value, benefits and routes to improve brain tumour peer support for non-standard of care treatment

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BACKGROUND

A diagnosis of a brain tumour can lead to patients and caregivers feeling isolated, overwhelmed and quite uncertain of their futures.

Currently Tumor Treating Fields (TTFields) is the only treatment shown in a phase 3 trial to improve survival in addition to the standard of care (SoC) - chemo-radiotherapy with temozolomide is). TTFields is not currently part of SoC nor is many off-label treatments such as immunotherapy, hyperbaric oxygen, and hyperthermia.

Since 2024, we have run a support group and seminars for patients seeking treatment outside of the SoC.

Hearing a patient's voice and peer support may increase their knowledge and use of non SoC treatments, including TTFields.

Here we present the results, impact and what we could do to make it more useful.

METHOD

We set-up a group of patients, caregivers and healthcare professionals to form the HINO, Horizons in Neuro-oncology Group to develop a website and offer seminars and a blog.

We used mixed-methods assessment including questionnaires and focus groups over a 9-month period to obtain unique insights, identify gaps, co-produce improvement strategies, improve the support we offer and produce reliable and useful findings.

A questionnaire was distributed via email and text message to current users of the support group and those who were considering joining. We also held a focus group to provide the basis for further service improvement recommendations.

No personal identifiable information was collected, and any quotes used have been kept anonymous. Names of treatments and quotes have been used as reported by patients and caregivers.

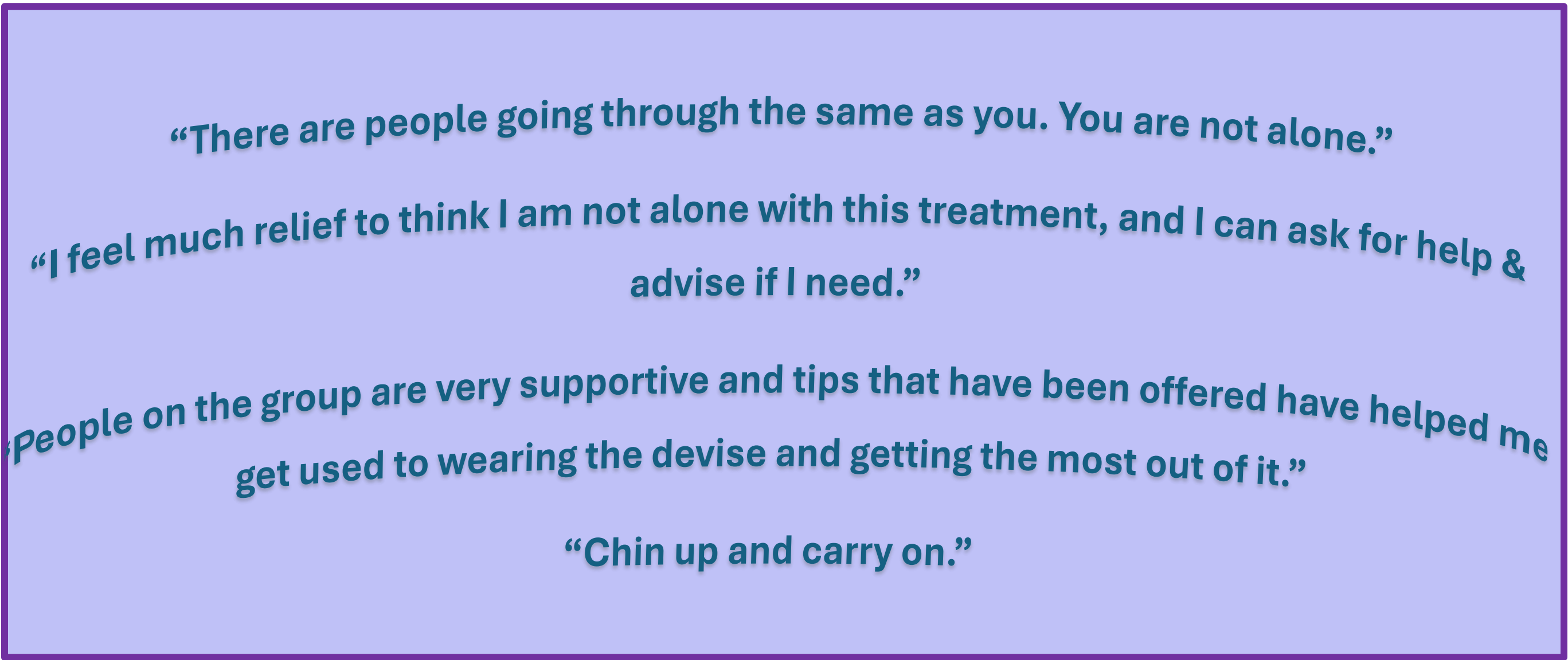


Figure 1: Quotes from users of the Optune Support UK and HINO Support Groups

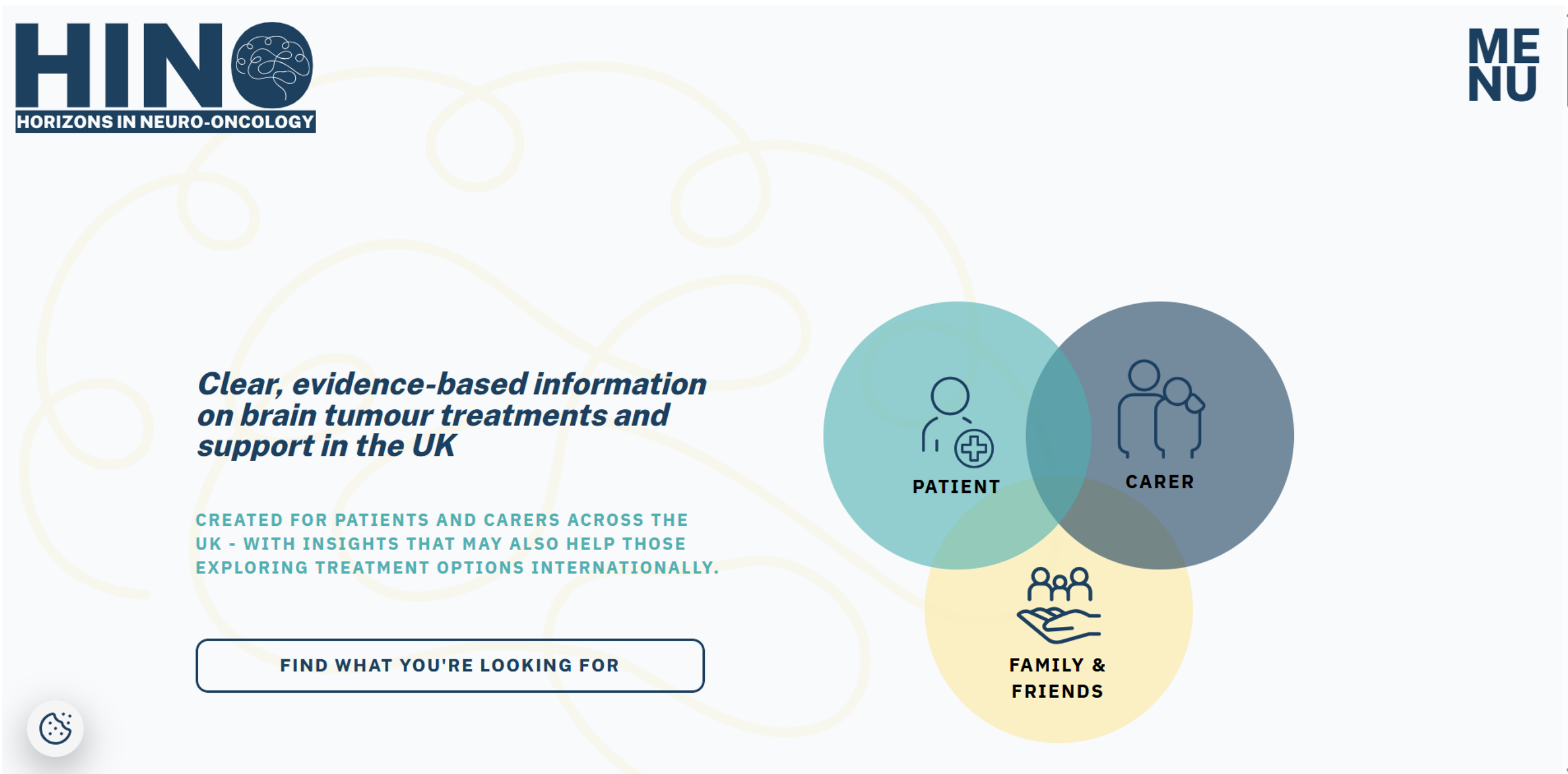


Figure 2: HINO website landing page

RESULTS

We developed and launched our new website www.hino.org.uk in March 2026, supported by the HINO advisory group and a professional website developer ([For The Brave](#)) along with a WhatsApp group.

We received questionnaire responses from 21 patients and caregivers (average age: 62; 4 females; 17 males). Quality of Life scores using EQ-5D with overall VAS were 74.43; TTField wear time was an average of 89% (Figures 3 & 4).

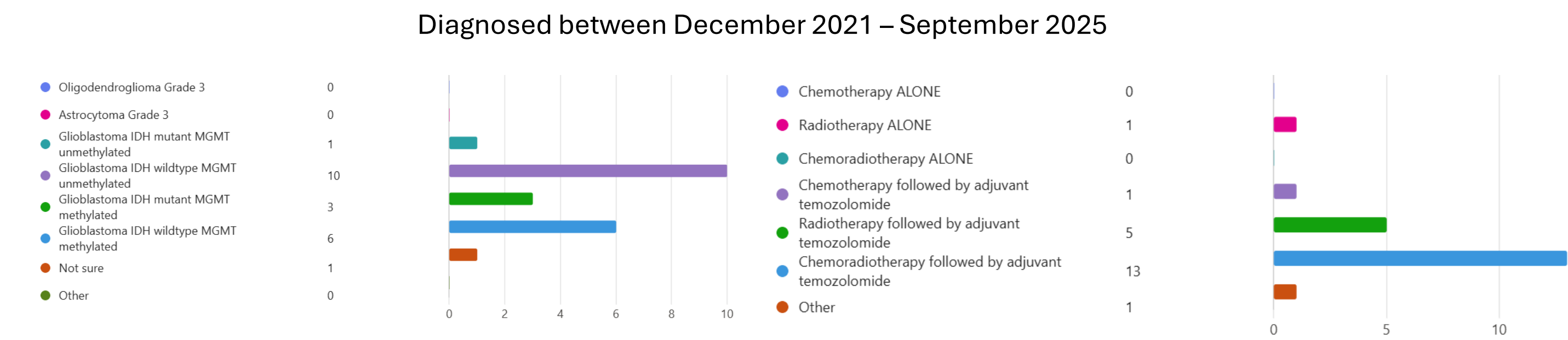


Figure 3: Diagnosis and SoC Treatment

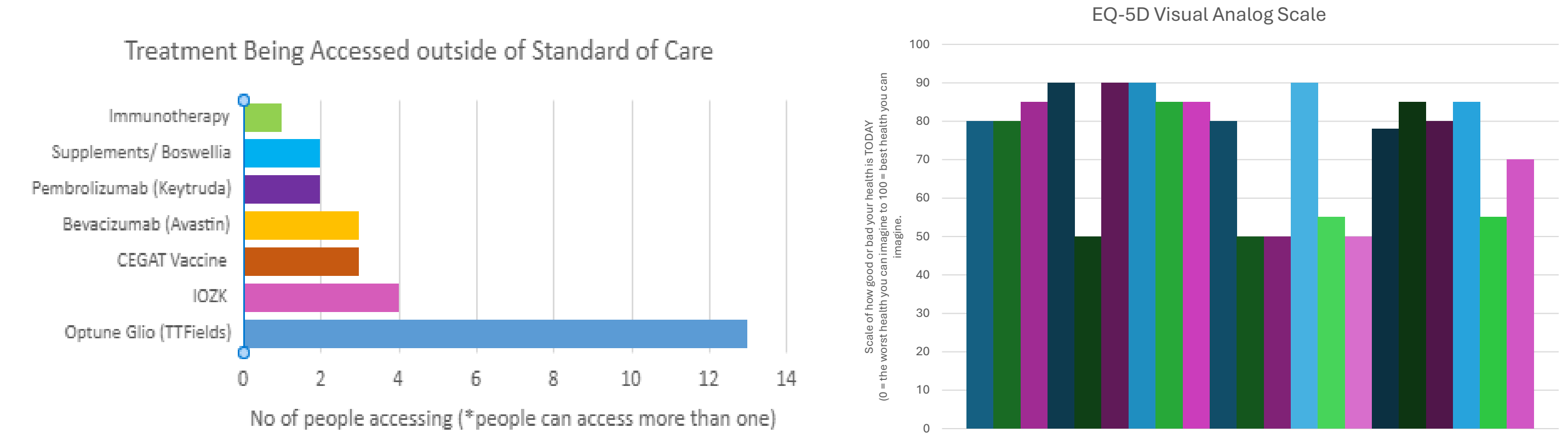


Figure 4: Table showing breakdown of treatments accessed outside of SoC and overall quality of life from 21 respondents between Sept 2025 – July 2026

We delivered more than 12 [HINO Seminars and a HINO day](#) including speakers such as Dr Nader Sanai (Ivy Brain Tumor Centre), Professor Frank Giordano (University of Heidelberg) & Professor Anthony Chalmers (University of Glasgow)

The HINO blog includes [patient inspired stories](#) about accessing non-SoC treatments. The WhatsApp group now has > 100 patients and caregivers and acts as a focus group for patients providing rapid-response peer support.

We now have a much better understanding of the value and effects of peer support and have identified gaps in information in the public domain around treatment options.

“The Support Group has been an **incredible resource**. We’ve learned so much from **others' experiences** and found **comfort** and **hope** in the stories shared. It’s **heartening** to hear good things happening within this **community**.”

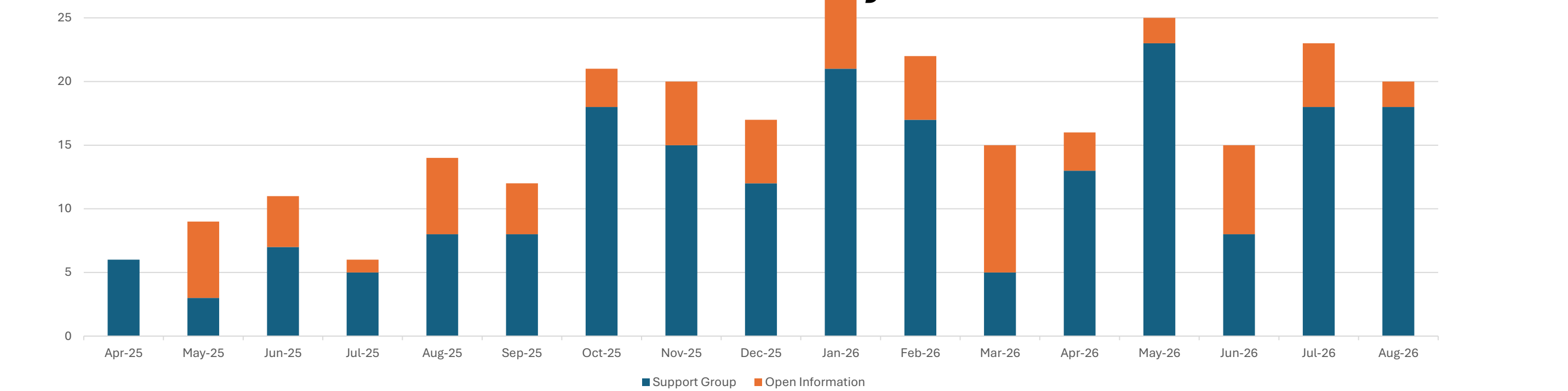


Figure 5: Number of Attendees at the Peer Support Group between April 2025 and August 2026

CONCLUSION

- Support groups and online resources are a vital tool for people living with brain tumours as they provide a “community of togetherness”.
- Peer support helps patients increase their use of TTFields, preserve their quality of life and help access non-SOC treatments.
- Seminars and websites with updated knowledge of the advances of brain tumour treatments and care upskill patients and caregivers.

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