

IMPROVING BRAIN TUMOUR CARE SURVEYS

SEPTEMBER 2021

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- **Best Care Everywhere:** We believe everyone should have access to the best treatment and support, personalised to their needs as well as their tumour, everywhere in the UK.
- The **Improving Brain Tumour Care surveys** enable patients and families to identify excellence and gaps in their experience.
- We're **embedding them in neuroscience centres'** pathways as a better mechanism for patient feedback. We're doing this through the Tessa Jowell Centres of Excellence programme.
- This national report (September 2021) gives the results of **1494 responses** from UK adults diagnosed or in treatment in prior 2 years

LIMITATIONS OF THE SURVEY

- This is a **pilot** developed with input from community including clinicians
- In the pilot we have not tested results for **statistical significance**
- Please note there are **differences in sample sizes** throughout.
Results are from 6 surveys for different stages of treatment and support. Where differences by tumour grade or demographic group are quoted, the sample sizes are lower than the total sample because not all respondents disclosed this data.
- Not all **sample sizes** reached the minimum of 383 to be considered sufficiently powered for the population affected by a brain tumour diagnosis.
- The **data set** was limited to people who had been diagnosed or been treated within 2 years of completing the survey and survey responses from the last year have been analysed.
- Contact us **for more information** on methodology
involvement@thebraintumourcharity.org

MAIN GAPS IN PATIENT EXPERIENCE

Experience	Gaps
1. Diagnosis	28% visit GP 3+ times 38% <u>don't</u> understand their prognosis
2. CNS access	41% <u>don't</u> have good access to a CNS
3. Supporting people's needs	74% have unmet needs 41% need more emotional support 68% <u>not</u> connected to benefits 79% don't have a good needs assessment and plan
4. Research participation	35% participate in research
5. Treatment & living with	52% considered & 32% used alternatives 36% had no written info about side effects



**Differences across
30 adult centres**



**Between men
and women**



**Between low and high
grade**

0. SAMPLE & PROFILE

HOW REPRESENTATIVE IS THE SURVEY

We received a large sample size, however certain demographics are underrepresented which may influence findings.

- **Gender:** More respondents were female (59% female vs 41% male) and this skew was more pronounced in respondents with the diagnosis themselves (64% female vs 36% male). *Note: In 2017 UK brain tumour incidence was 51% female 49% male*
- **Grade:** More people were affected by a high grade diagnosis (50% high grade vs 36% low grade). *Note: In 2017 UK brain tumour incidence was 48% 'malignant' or higher grade, 52% 'non-malignant' or lower grade; and estimated prevalence 17% high 83% low grade.*
- **Ethnicity:** Compared with the population fewer respondents were from ethnic minorities (excl white minorities) 7% *Note: We need to find an appropriate national comparison.*
- **Age:** The sample contains only adults respondents (aged 16 years plus)

1. DIAGNOSIS

SUMMARY: DIAGNOSIS EXPERIENCE

Speed and route to diagnosis

- **79% diagnosed within 3 months** of first seeing any HCP, but for 17% it takes over 6mth
- **28% visit the GP 3 or more times** for their symptoms
- **52% diagnosed with something else first** for their tumour symptoms
- **39% don't visit the GP at all**
- **65% diagnosed via A&E** & 33% first told by A&E doctor

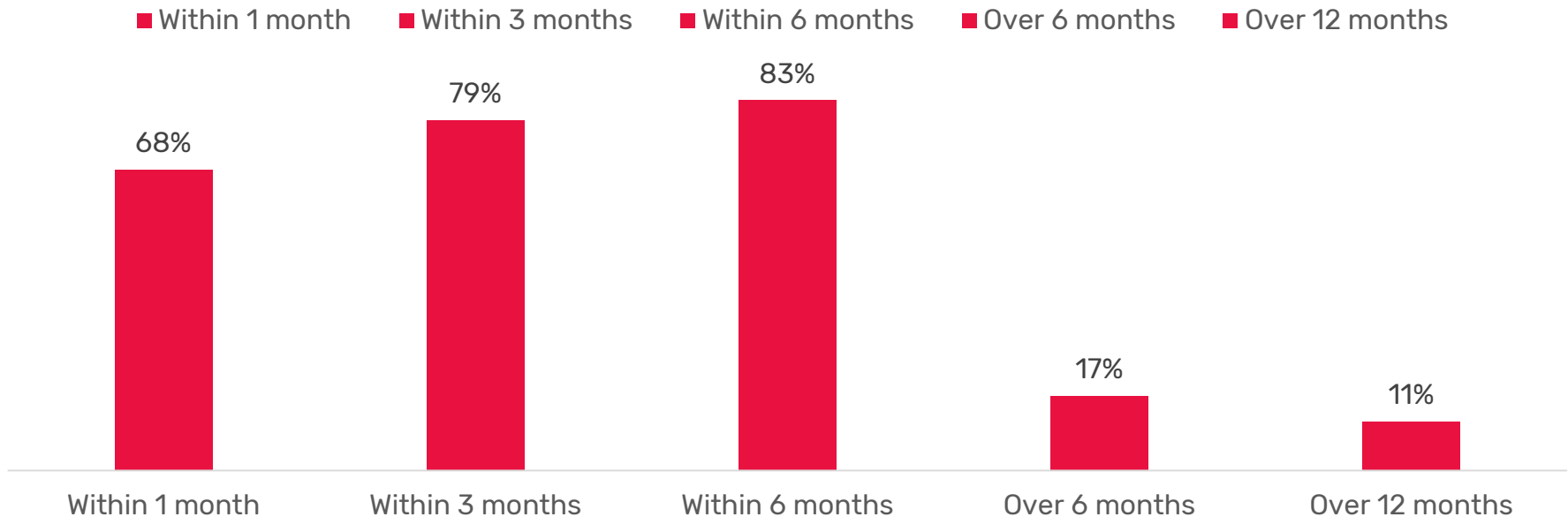
Experience during diagnosis

- **59% first told by a non-specialist in treating brain tumours**
- **16% not told in person**
- **21% not told sensitively**
- 22% not told privately
- 24% not given time to ask questions
- **27% don't understand their tumour**
- **38% don't understand their prognosis**

ESTIMATED SPEED OF DIAGNOSIS

- 79% people are diagnosed in under 3 months
- 17% take over 6 months
- This is an approximation of the 'primary care interval' from presentation to diagnosis. We have not yet surveyed on the 'patient interval' from noticing symptoms to presentation.
- There is a margin of error of 1 month because we are currently analyzing calendar months. This is something we are improving in our methodology.

Time between seeing a medical professional for the first time to being diagnosed with a brain tumour

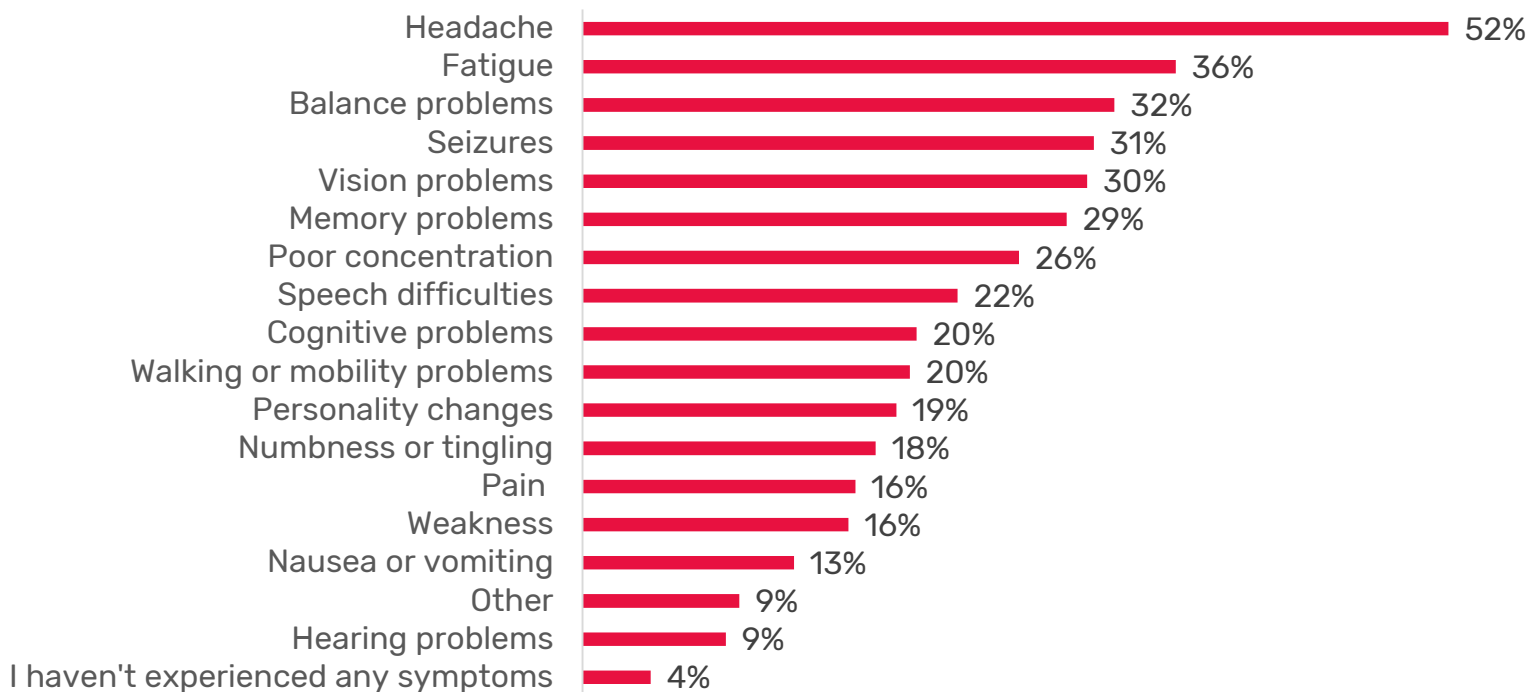


Sample: 245 adults diagnosed with a brain tumour during preceding 2 years. Difference between: Question: When did you first see a healthcare professional (ie any GP, A&E doctor, consultant, or optician) about your symptoms? Answer options: Month & Year. Question: When did you first see a healthcare professional (ie any GP, A&E doctor, consultant, or optician) about your symptoms? Answer options: Month & Year.

SYMPTOMS EXPERIENCED & INITIAL DIAGNOSIS NOT BRAIN TUMOUR

- Top symptoms reported before a brain tumour diagnosis include: headaches (52%), fatigue (36%) balance problems (32%), seizures (31%) and vision problems (30%)
- 52% people say they were diagnosed with something else first for their brain tumour symptoms.

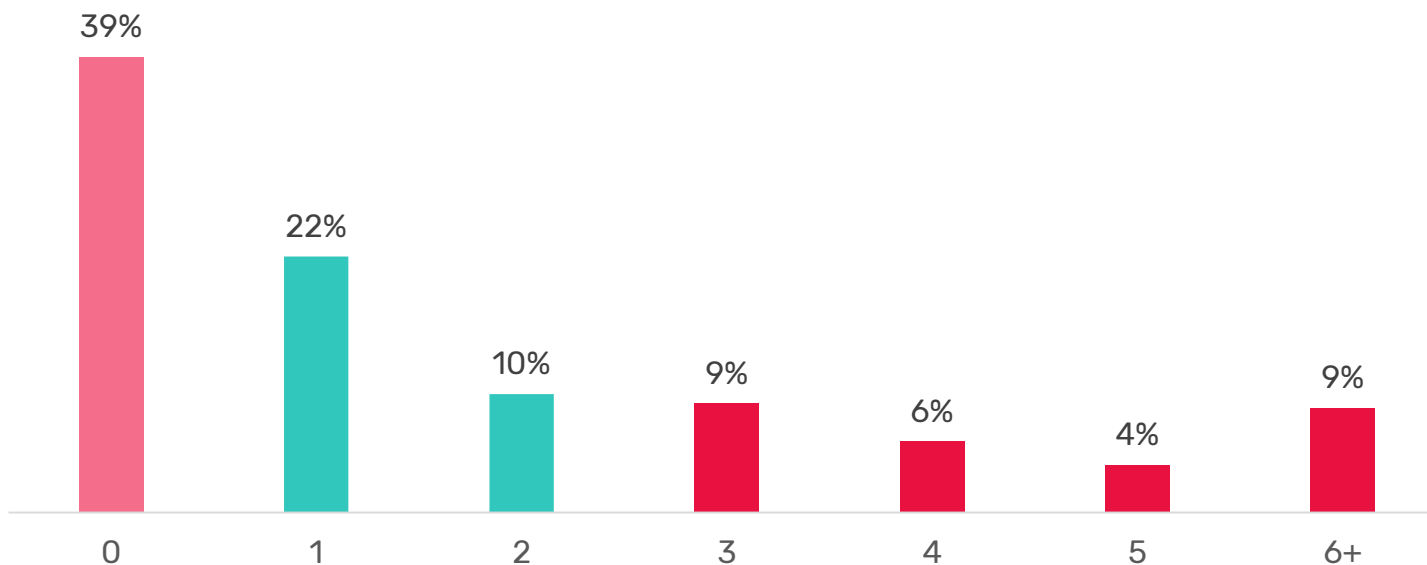
% people who experienced symptoms before being diagnosed



GP VISITS

- 39% people don't visit the GP for their symptoms, which would includes those diagnosed via A&E after a critical incident like a seizure.
- 28% of people have to visit the GP 3 or more times with their symptoms
- 9% visit 6 times or more.

GP visits with symptoms before being referred to a hospital consultant



DIAGNOSIS PATHWAY

- 65% visit A&E and 33% are first told they have a brain tumour by an A&E doctor
- 59% people first learn they have a brain tumour from a non-specialist in treating brain tumours which will mean they may not receive all the information and support they need.
- There are indicative differences by gender: more men (67% v 55%) visit A&E, more women visit the GP 3+ times (36% vs 14%) and have a high street eye exam (36% v 15%)
- More high grade tumours are diagnosed via A&E visits (77% v 52%) but fewer via eye exams (16% v 40%)

HOW WERE YOU FIRST TOLD?

- 16% people are first told by letter or phone not in person, 21% not told sensitively, 22% not told privately
- 25% not given time to ask questions or sufficiently involved in decisions about their treatment
- 43% not able to have family/friends present at diagnosis, potentially exacerbated by COVID
- Indicatively, women scored lower on questions about diagnosis experience e.g. fewer are told in person (76% vs 100%)
- Only 50% had written information about their tumour type, treatment options, side effects or had a written plan of their own proposed treatment
- 27% don't understand their tumour and 38% want to but don't understand their prognosis

OUR ACTIONS TO IMPROVE DIAGNOSIS

- Launching **Headsmart awareness campaign** on signs & symptoms
- Training **optical professionals** on signs & symptoms
- Supporting **trial and scaling of diagnostic tests** e.g. Dxcover blood test
- Sharing our **print and multi-media guides** for tumours & treatment
- Growing insight from **Improving Brain Tumour Care surveys** to track progress and understand gaps in experience by gender, location, ethnicity, tumour type etc
- Developing **diagnosis policy and solutions** using evidence and engagement

2. CNS ACCESS

ACCESS TO A CNS, BY CENTRE

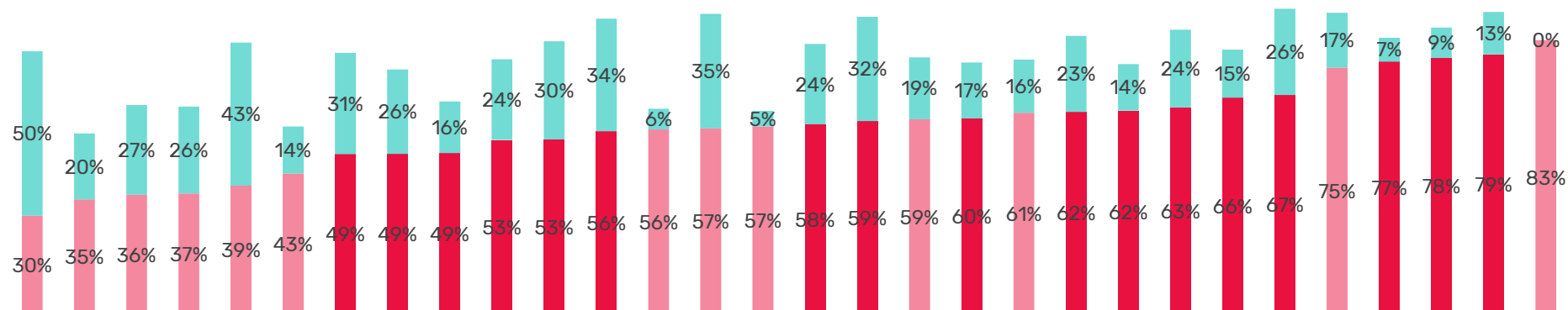
- 79% people were given any access to a CNS or keyworker
- 59% people good access to a CNS, when they needed them
- Good CNS access is higher for high grade (68%) than low grade (53%)
- Good CNS access is higher for men (74%) than women (52%)
- 30 percentage point range (49% to 79%) in having good access to a CNS across centres

% people given a named Clinical Nurse Specialist or key worker who can answer any questions, address worries and fears, and help get support at any time

Centres with over 40 responses

■ Yes I have and can ask them anything anytime

■ Yes I have but I can't always reach them for help



Sample: 1487 UK adult experiences of diagnosis or treatment for a brain tumour in preceding 2 years. Question: Do you have a named Clinical Nurse Specialist or key worker who can answer any questions you have, address your worries and fears, and help you get support at any time?

OUR ACTIONS TO IMPROVE CNS ACCESS



- Develop **business case** for more CNSs via Tessa Jowell Centres network
- **Best practice** improvement via Tessa Jowell Centres network
- Lobby to improve **CNS provision** (e.g. training, recruitment, division of labour between roles) for brain tumours and in coalition with cancer charities
- Lobby for keyworkers or CNSs **for all patients with low grade** tumours
- Offer portfolio of services which **support CNS, including BRIAN app**

3. SUPPORTING PEOPLE'S NEEDS

SUMMARY: CONNECTING PEOPLE TO SUPPORT FOR THEIR NEEDS

Majority have one or more unmet needs

- **74% people have unmet needs** in one or more area
e.g. **41%** need more **emotional** / psychological support
e.g. **35%** need more help **managing symptoms** & side effects, exploring other **treatment options**, understanding their tumour and **what to expect**

Too few signposted to basic support

- Only **50%** signposted to **emotional** support/counselling, with 61 percentage point range (**from 14% to 75%**) across centres
- Only **55%** connected to support **charities**
- Only **32%** signposted to financial help and **benefits**

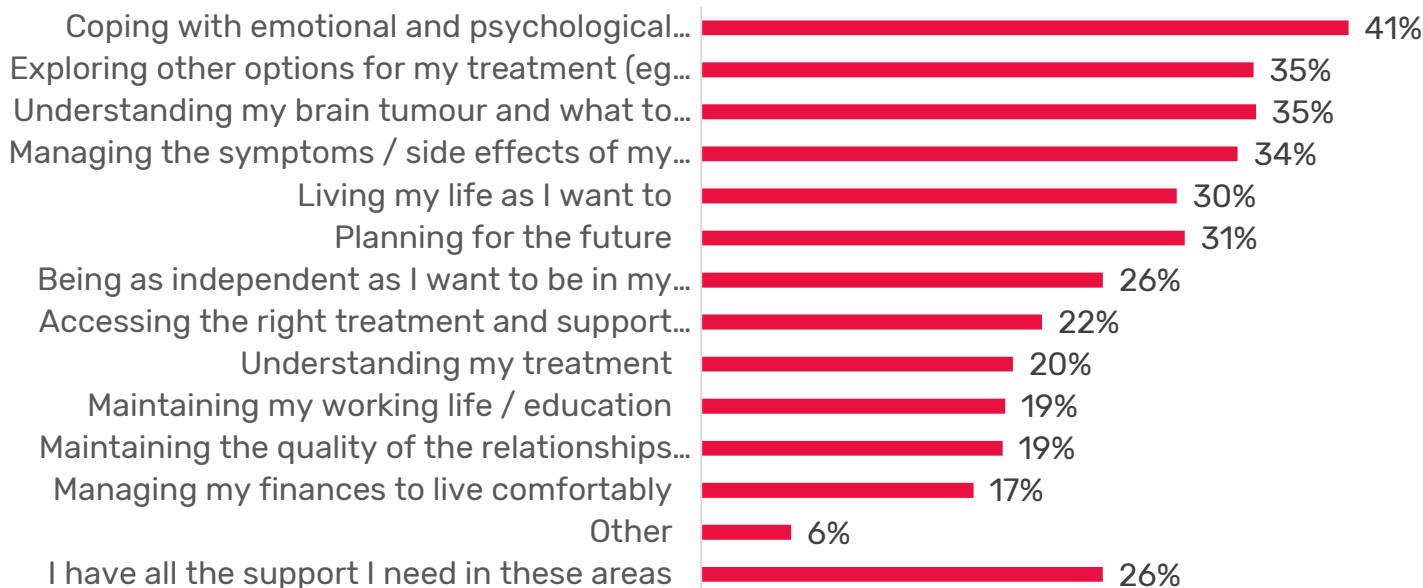
Holistic needs assessments aren't widespread

- **40% offered HNA**, but 55% for those with any CNS access, and 62 percentage point range (**from 12% to 74%**) across centres
- **21%** have a good needs assessment and **good plan**

UNMET NEEDS

- 74% people have unmet needs in one or more areas
- Unmet needs varies by centre- 50 percentage point range (15% to 65%) in needing more emotional support and 43 percentage point range (12% to 55%) in needing more help to manage symptoms and side effects of tumour or treatment

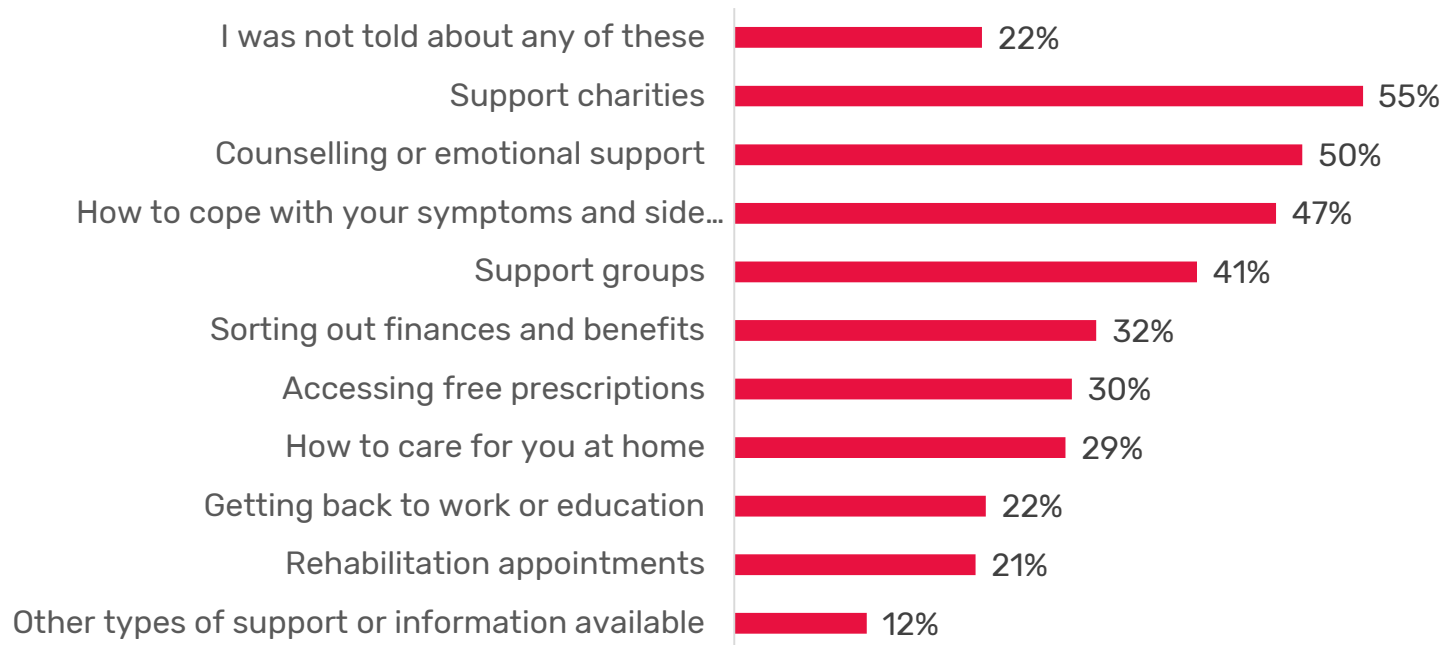
% people who need more support in any of the following areas



SIGNPOSTING

- Too few people told about basic support
- Signposting varies by centre- 61 percentage point range (14% to 75%) in signposting to emotional support and 39 percentage point range (38% to 77%) to charities

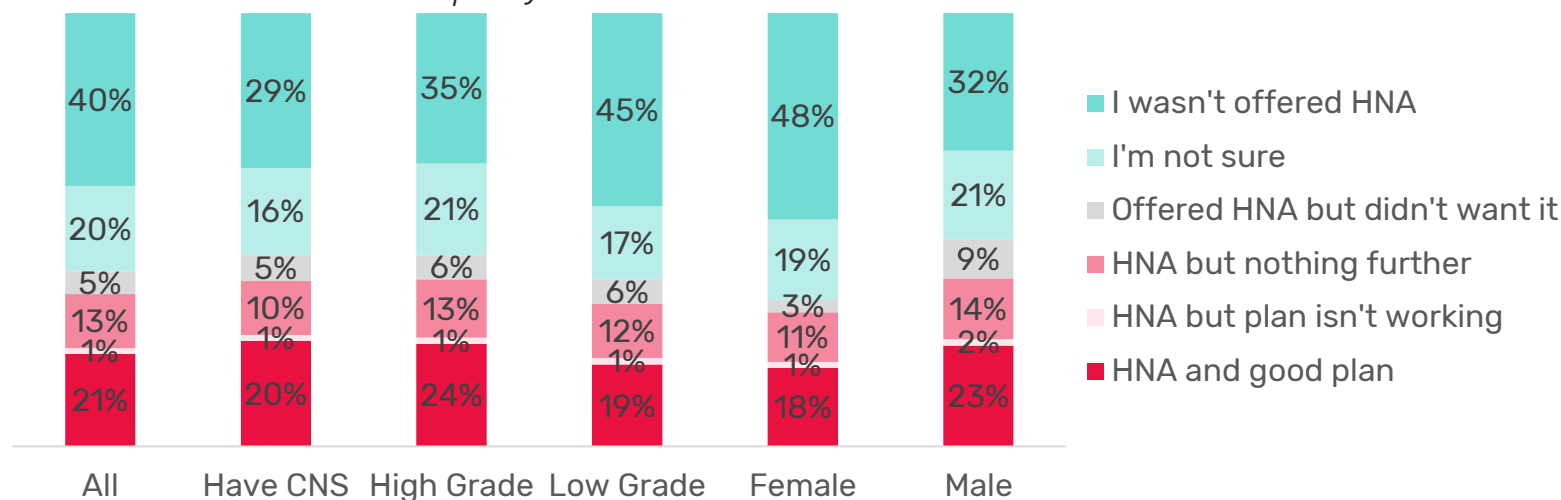
% people signposted to different basic support



HOLISTIC NEEDS ASSESSMENTS (HNA) & CARE PLANS

- 40% offered a needs assessment; 21% people have a good needs assessment and resulting plan.
- Fewer women offered a needs assessment (34% women, 48% men)
- Those who reported good access to a CNS were more likely to report being offered an HNA (55% vs 40% av.)
- 63 percentage point range between centres (11% to 74%) in HNA and care plan being offered & 38% percentage point range (6% to 44%) in having a good HNA and care plan

% people offered assessment of their practical, physical and emotional needs and a written care plan (holistic needs assessment or care plan)



Sample: 1158 adults diagnosed or in active treatment for a brain tumour during the last 2 years. Question: Has your healthcare team offered / done an assessment with you on your practical, physical and emotional needs and made a written plan to help you? (Also known as a holistic needs assessment or care plan.) Answer options: I've had an assessment but nothing further / and have a plan in place which is working well / and have a

OUR ACTIONS TO IMPROVE SUPPORT

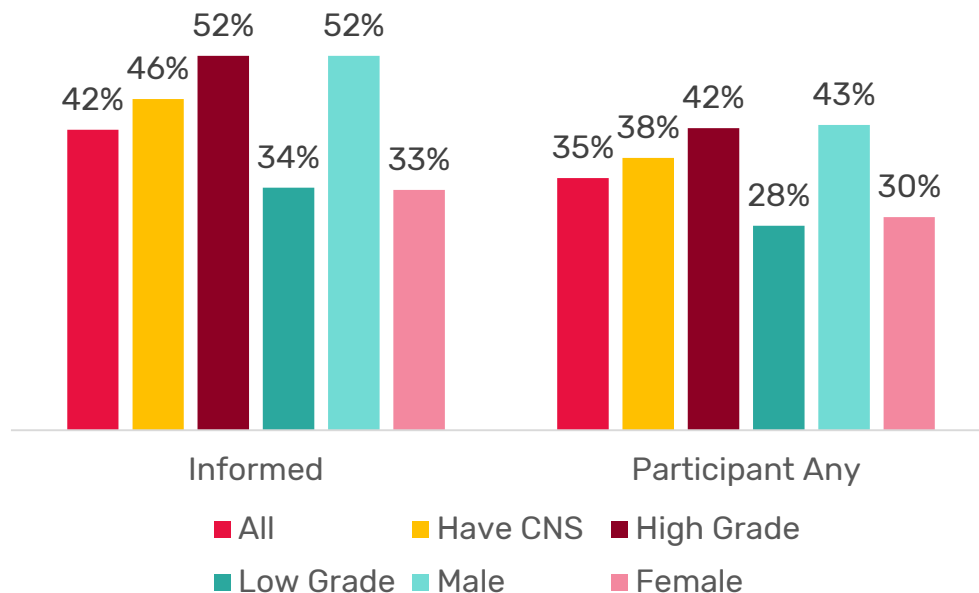
- Develop a **brain tumour digital HNA tool** to analyse needs and shape individual support plans, enable self-assessment and guided conversations with a keyworker, and signpost relevant national and local support.
- **Develop emotional support services** e.g. peer support groups & events, relationship service, support line, counselling, 'buddying'
- Prioritise **signposting** to support charity websites, national and local support.
- **Unite everyone** on a one-page signposting map of national & local support

4. RESEARCH PARTICIPATION

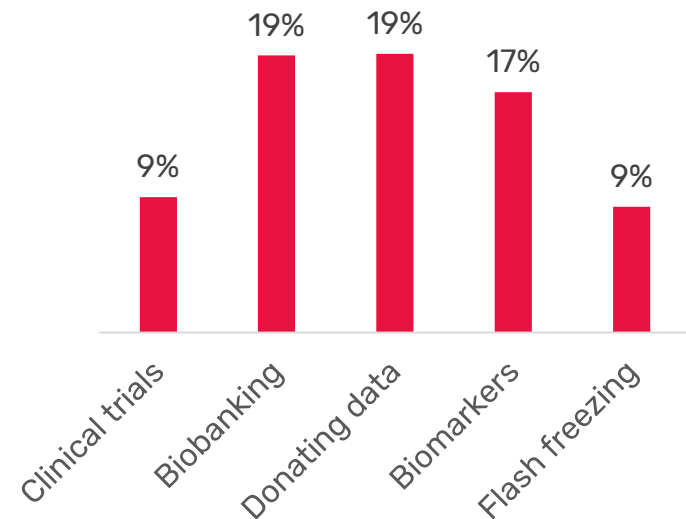
RESEARCH PARTICIPATION

- Only 42% say they are informed about and only 35% say they participated in any research.
- Information and participation is higher for men than women and higher for high grade than low grade.
- 57 percentage point range (4% to 61%) in participation in research across centres

% people informed or participating in one or more forms of research



% people participating in each form of research



OUR ACTIONS TO IMPROVE RESEARCH ACCESS



- Fundraise for **more investment** in research into brain tumours, quality of life and service innovation.
- **Explain research better**, encompassing trials, biomarkers, biobanking, data donation and how they help
- **Signpost research elsewhere** when local opportunities aren't available, eg using BRIAN Clinical trials finder
- Enable **national research initiatives** like BRAIN MATRIX, Spring etc
- Offer **data donation** through our BRIAN app and tracking quality of life.

5. TREATMENT & AFTER

SUMMARY: TREATMENT AND AFTER

COVID impact

- 20% people said their treatment was delayed or cancelled because of COVID

Improving information and understanding

- 19% don't understand their tumour, 24% don't understand their prognosis, 11% don't understand their treatment options
- 38% had no written information about tumour type, 40% about treatment options, 36% about side effects

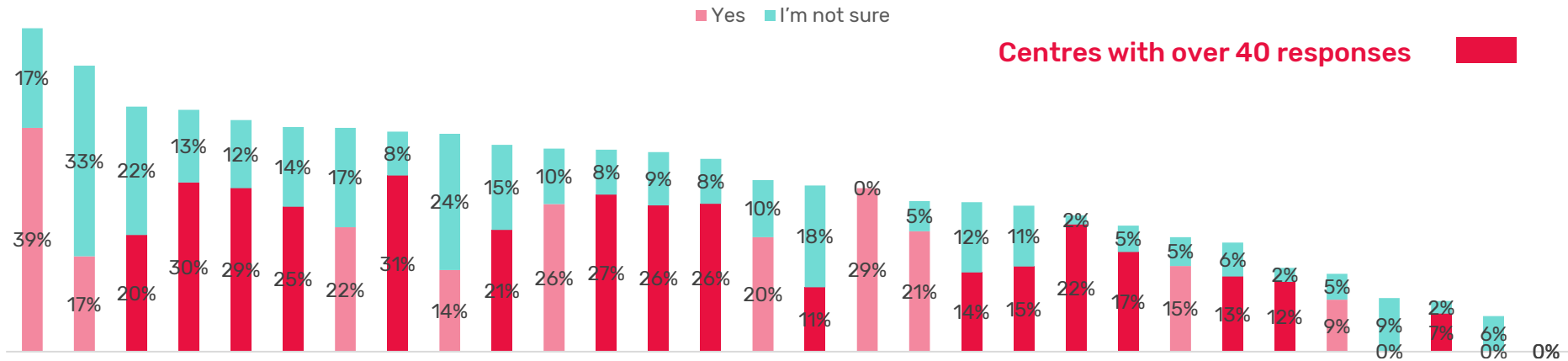
Use of alternative treatments

- 52% people have considered and 32% used one or more alternative treatments alongside or instead of those prescribed by clinicians

DELAYS & CANCELLATIONS DUE TO COVID

- 20% people said their treatment was delayed or cancelled because of Covid
- COVID affected low grade tumours (25%) more than high grade (15%)
- 24 percentage point range (from 7% to 31%) in people experiencing delays or cancellations in treatment due to COVID across centres.

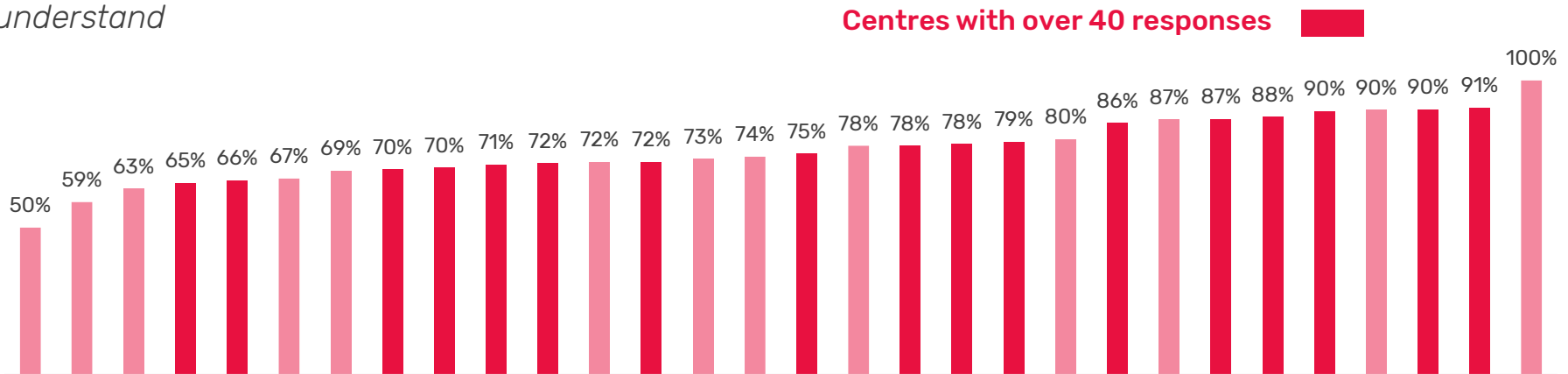
% people whose treatment or care has been delayed or cancelled due to the coronavirus pandemic



UNDERSTANDING TUMOUR & TREATMENT

- 81% patients' understood their tumour type, with a 22 percentage point range (73% to 95%) across centres
- 76% understood their prognosis, with a 26 percentage point range (65% - 91%)
- 89% understood treatment options, with a 22 percentage point range (76% - 98%)

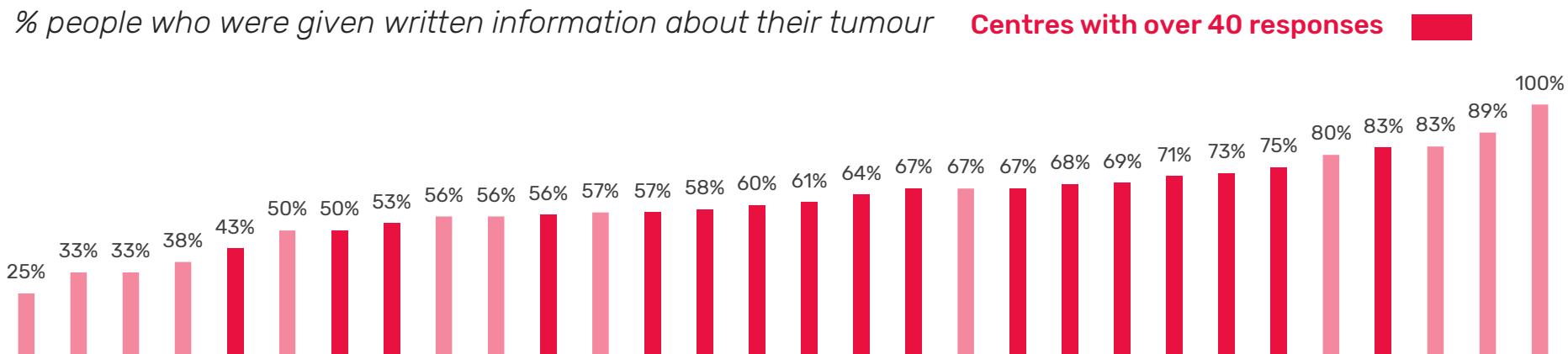
% people told what they might expect of their brain tumour (their prognosis) in a way they could understand



Sample: 1142 UK adult experiences of diagnosis or treatment for a brain tumour in preceding 2 years. Questions: Were you told about your brain tumour (type & grade) / what you might expect of your brain tumour (prognosis) / about your treatment options in a way you could understand? Answer options: Yes, No, I didn't want to know (for prognosis question only)

WRITTEN INFORMATION ABOUT TUMOUR AND TREATMENT, BY CENTRE

- 62% had written information about their tumour type, with a 40 percentage point range (43% to 83%) across centres
- 60% had written information about treatment options, with a 67 percentage point range (22% to 89%) across centres
- 64% had written information about side effects, with a 71 percentage point range (22% to 93%) across centres

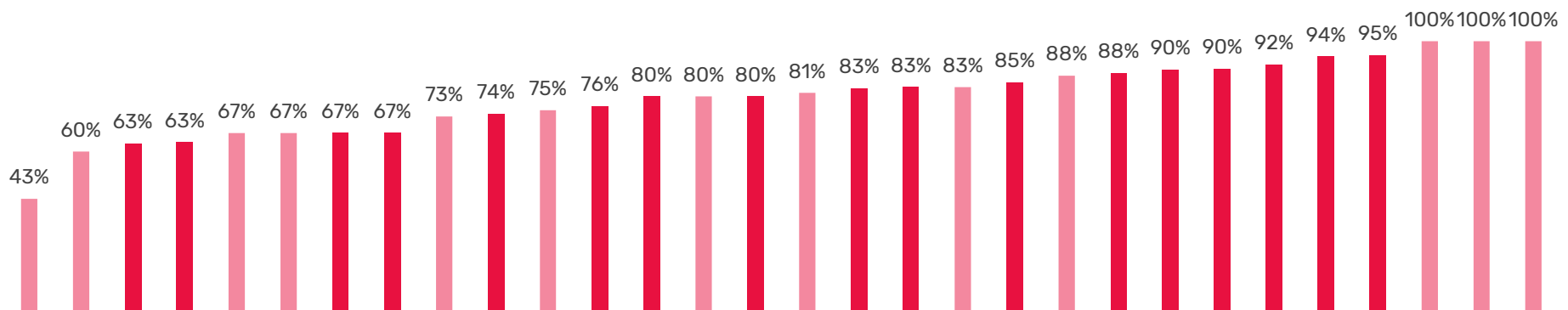


UNDERSTANDING OUTCOMES & RECOVERY

- 93% understand how their treatment has gone. There are no apparent differences by gender, grade or CNS access
- 20% don't understand what they can expect in recovery. Understanding is worse for those with low grade (79%) than high grade (86%) diagnosis.
- Understanding of how treatment went had a 30 percentage point range (70% to 100%) and understanding of recovery had a 32 percentage point range (63% to 95%) across centres

% people who were told about their recovery after treatment in a way they could understand

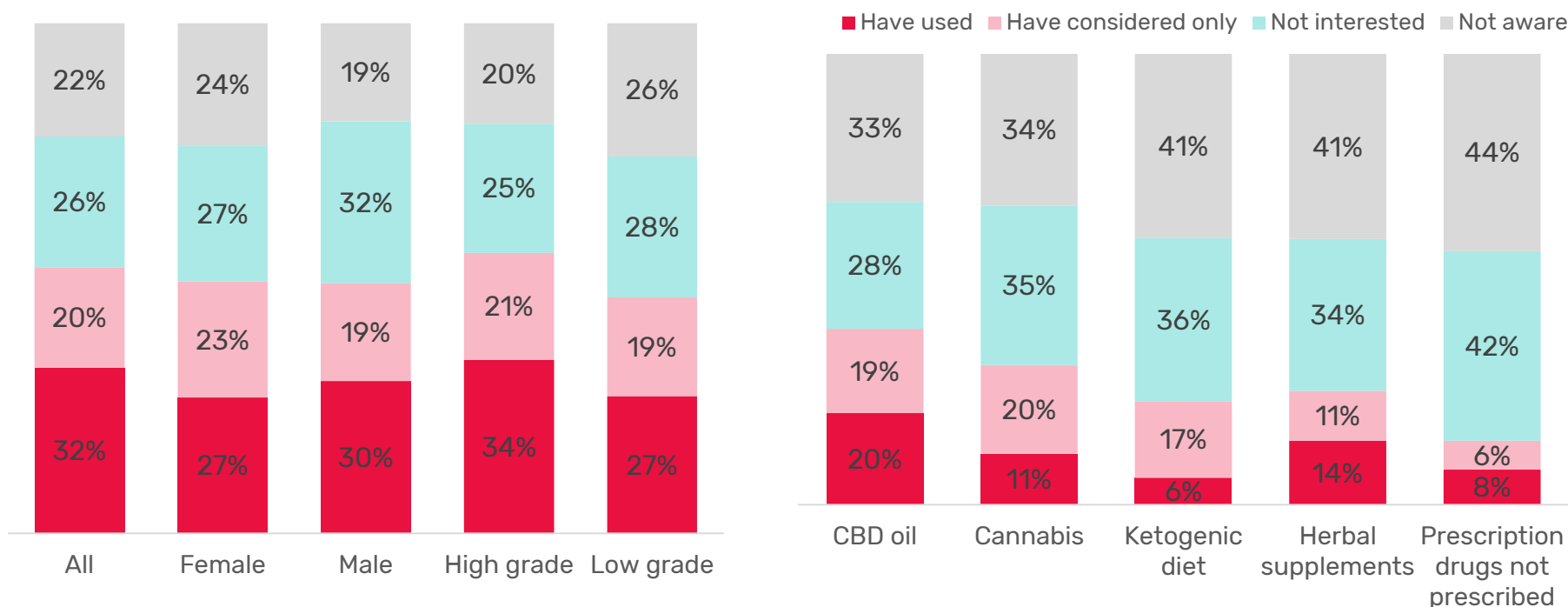
Centres with over 40 responses



ALTERNATIVE TREATMENTS

- 52% considered and 32% used one or more alternative treatments alongside or instead of the treatments prescribed by clinicians
- More people with high grade tumours (55%) than low grade (46%) have considered or used alternatives

% people who have used or considered any alternative therapies or treatments



Sample: 487 UK adult experiences of diagnosis or treatment for a brain tumour in preceding 2 years. Question: have you used or considered any alternative therapies or treatments? CBD oil or product / Cannabis product / Ketogenic diet / Herbal medicines / Prescription drugs not prescribed by a healthcare professional. Answer options: Have considered / have used / Not aware / Not interested.

OUR ACTIONS TO IMPROVE TREATMENT & LIVING WITH

- Define Excellence clinical standards by developing detailed **adult and paediatric pathways**
- Track and **long term patient outcomes** eg quality of life to inform better pathways.
- Research **emerging & complementary therapies** and meet demand for information
- Develop **best practice information library** of written and multi-media information about tumour types, side effects, treatment options, what to expect in treatment and recovery, eg TBTC site

6. DIFFERENCES BY GROUP

DIFFERENCES BETWEEN HIGH AND LOW GRADE

People with a low grade diagnosis score more poorly across support questions

For example,

- Less access to a **Clinical Nurse Specialist**
53% with low grade diagnosis have good access to CNS vs 68% with high grade
- Signposted to **less emotional support**, support charities and benefits support.
36% with low grade diagnosis signposted to emotional support vs 69% with high grade
- Given **less written information** on tumour, treatment and side effects
54% with low grade diagnosis given written information about their tumour vs 71% high grade

DIFFERENCES BETWEEN CENTRES

There are large differences in every aspect of experience between centres

For example,

- Good **CNS access**
ranges from 49% to 79% depending on the centre
- Patient **participation in research**
ranges from 4% to 61% depending on the centre
- Being **offered a holistic needs assessment** and care plan
ranges from 11% to 74% depending on the centre
- Having unmet needs with **managing symptoms and side effects**
ranges from 55% to 12% people depending on the centre
- Signposting to **emotional support**
ranges from 14% to 75% people depending on the centre

DIFFERENCES BETWEEN WOMEN AND MEN

**Men and women have very different experiences;
women tend to score lower across support questions**

For example,

- Less access to a **Clinical Nurse Specialist**
52% female respondents vs 74% male had good CNS access
- Higher **unmet needs** including for **emotional support**
79% female respondents vs 64% male had one or more unmet needs
49% female respondents vs 25% male needed more emotional support
- Offered **holistic needs assessments** less
34% female respondents vs 48% male
- Given less **written information**
55% female respondents vs 70% male given written information about their tumour

OUR ACTIONS TO IMPROVE DIFFERENCES BETWEEN GROUPS



- Support centres via **Improving Brain Tumour Care surveys** and **Tessa Jowell Centres of Excellence** to identify gaps and spread excellence
- **Track progress** on offering support with Improving Brain Tumour Care surveys
- **Understand gaps** with involvement network input.
- **Policy development and engagement** to highlight the gaps by grade, centre and gender

MORE INFORMATION

FOR MORE INFORMATION



- Next release of the Improving Brain Tumour Care survey findings due in Summer 2022
- For further information about the Improving Brain Tumour Care Surveys, email involvement@thebraintumourcharity.org
- [Join our Involvement network](#) to share your experience and create change
- For information and support, please see the [10 Ways We Can Help](#), email support@thebraintumourcharity.org or call us on 0800 800 0004
- For external affairs, email policy@thebraintumourcharity.org