National Cancer Research Institute questionnaire: to be completed by the patient and/or carer as an outpatient

Our remit:

- To assess the concerns of patients, and their carers, with newly diagnosed Glioblastoma who are clinically vulnerable.
- To develop a national guideline for care amongst this patient group.

Please circle as appropriate.				
Your Role:	Patient	Carer		
Gender:	Male	Female	Non-Binary	Prefer not to say

Age (years) at diagnosis:	

Thinking about your initial diagnosis:

How did you first hear you had a brain tumour? Please circle as appropriate.			
Face-to-face	Telephone call	Letter	Other – give details:

Please indicate answers in the relevant box. The symbols are just there to help you.				
In your first cancer medical appointment:	*Yes* ✓	*Partially*	*No* ✗	*Don't know* ?
1. Did you understand what the medical team told you?				
2. Were treatment options discussed with you?				
3. Did options include having 'no treatment'?				
4. Did the medical team listen to you?				
5. Did the medical team answer your questions?				
6. Did you remember the information when you got home?				
7. Were you given written information about your tumour?				
8. Were you given written information about your treatment?				

Thinking about treatment options:	*Yes* ✓	*No* ✗	*Don't know* ?
9. Were you offered treatment?			
10. What treatment did you have? (tick all that apply)	*Yes* ✓	*No* ✗	*Don't know* ?
No treatment			
Surgery			
Radiotherapy			
Chemotherapy			
Non NHS treatment			
If you ticked 'Non NHS treatment', please list them here:			

11. Did any of the following impact your treatment decision? *(tick all that apply)*	*Yes* ✓	*No* ✘	*Don't know* ?
Number of hospital visits needed			
Travel and parking			
Side effects			
Doctor's recommendation			
Nurse's recommendation			
Amount of increased survival time			
Family/carer's wishes			
Ability to look after myself			
Other reason, please provide it here:			

Throughout all your care

Co-ordination of care:	*Yes* ✓	*No* ✘	*Don't know* ?
12. Did you have a key worker (1 person co-ordinating your care)?			
13. If so was this key worker a nurse (or other professional)? (Leave blank if no key worker)			
14. If you had a key worker were you able to contact them when you needed to? (Leave blank if no key worker)			

Symptoms: 15. Did you **want** help with?	*Yes* ✓	*No* ✘	*Don't know* ?
Fatigue			
Seizures			
Headaches			
Memory changes			
Personality changes			
Vision			
Mobility			
Understanding			
Speech			
Swallowing			
16. Did you **get** help with?	*Yes* ✓	*No* ✘	*Don't know* ?
Fatigue			
Seizures			
Headaches			
Memory changes			
Personality changes			
Vision			
Mobility			
Understanding			
Speech			
Swallowing			

17. Did you **want to see** any of these specialist teams?	*Yes* ✓	*No* ✘	*Don't know* ?
Physiotherapy			
Social worker			
Speech and language			
Occupational therapy			
Neuropsychology (not counselling)			
Palliative/Best Supportive Care team			
18. Did you **see** any of these specialist teams?	*Yes* ✓	*No* ✘	*Don't know* ?
Physiotherapy			
Social worker			
Speech and language			
Occupational therapy			
Neuropsychology (not counselling)			
Palliative/Best Supportive Care team			
19. Did you **have concerns** about:	*Yes* ✓	*No* ✘	*Don't know* ?
Money			
Eating and drinking			
Your mental health			
Emotional support			
Life expectancy			
End of life planning			
Power of Attorney/Wills			
20. Did you **receive support** for:	*Yes* ✓	*No* ✘	*Don't know* ?
Money			
Eating and drinking			
Mental health			
Emotional support			
Life expectancy			
End of life planning			
Power of Attorney/Wills			
21. Were you told about other sources of support e.g charities?			

22. Please give any extra information about your experience.