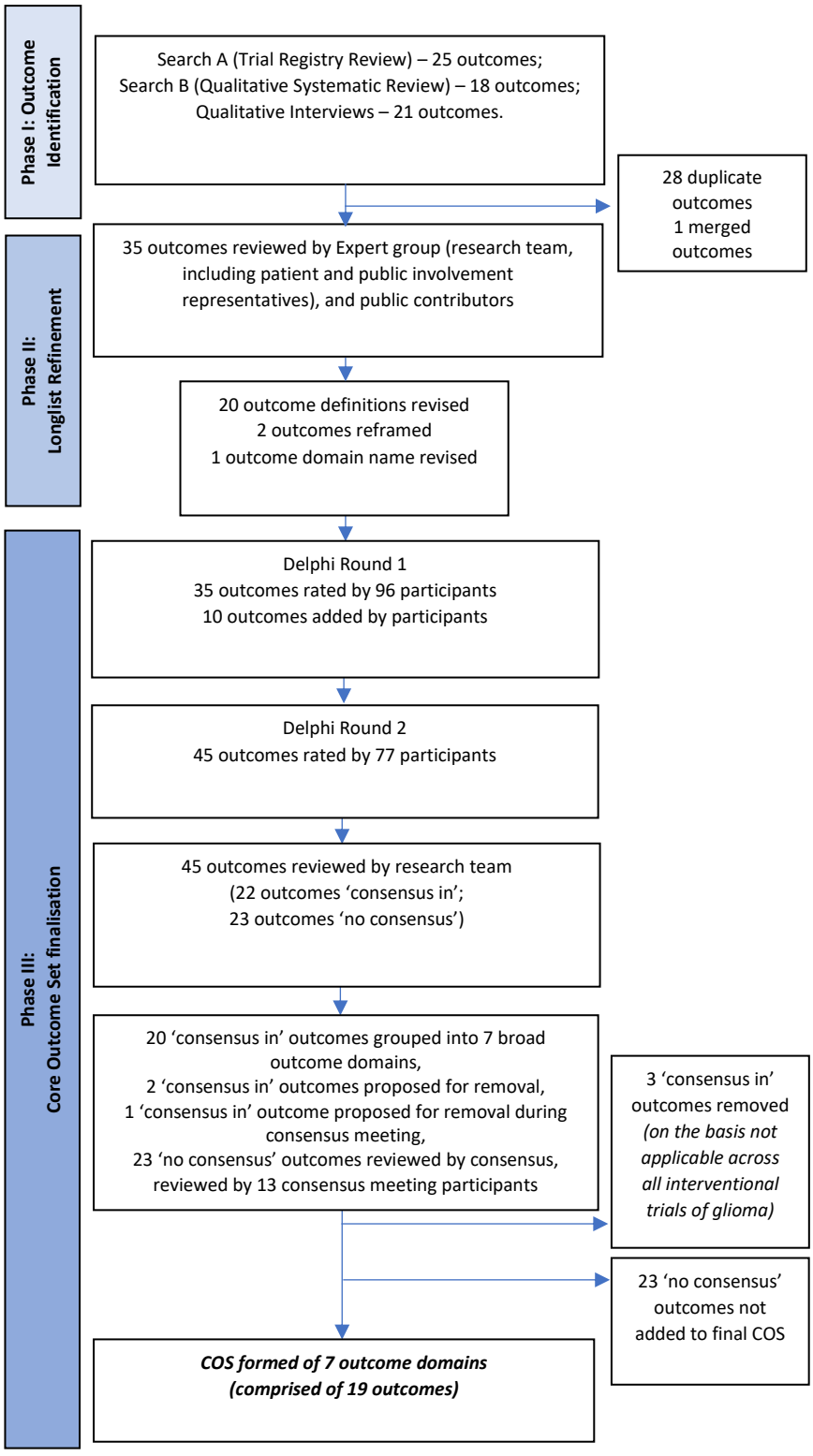

[Figure 1] ILLUSTRATION OF CORE OUTCOME SET DEVELOPMENT PROCESS

Demographics	Patients	Caregivers
TOTAL	19	7
Age (mean, range)	46, 27-66	50, 39-60
Gender		
- Female	7	5
- Male	12	2
Ethnicity		
- White, British	17	6
- Asian/Asian British – [Indian] [Pakistani] [Bangladeshi] [Chinese] [Any other Asian background]	2	0
- Unclear	0	1
Diagnosis	2007-2021	N/A
Glioma type		
- Glioblastoma	6	3
- Astrocytoma	4	1
- Oligodendroglioma	3	1
- Anaplastic astrocytoma	2	0
- Anaplastic pilocytic astrocytoma	1	1
- Anaplastic oligodendroglioma	1	0
- PXA tumour	1	0
- Grade 3 glioma	1	1
Glioma grade		
- Grade 2	8	2
- Grade 3	4	2
- Grade 4	7	3

[Table 1] DEMOGRAPHIC TABLE LIVED EXPERIENCE PARTICIPANTS – PATIENTS AND CARERS

Delphi Survey demographics (both round participants)				
Demographics	Stakeholder			
	Patients	Caregivers	Clinicians/ other healthcare professionals	Other
Stakeholder group	34	14	19	Researchers – 4 Third Sector – 4 Regulator – 2 Pharmaceutical - 1
Age (Range)	22-67	27-70	26-59	25-55
Gender - Female - Male	 16 (47%) 18 (53%)	 8 (57%) 6 (43%)	 6 (32%) 13 (68%)	 7 (70%) 3 (30%)
Ethnicity - White, British - Asian/Asian British - Black/Black British - Other ethnic group - Prefer not to say	 33 (97%) 1 (3%) 0 (0%) 0 (0%) 0 (0%)	 14 (100%) 0 (0%) (0%) (0%) (0%)	 14 (74%) 3 (16%) 1 (5%) 1 (5%) 0 (0%)	 8 (80%) 0 (0%) 0 (0%) 1 (10%) 1 (10%)
Region - England - Northern Ireland - Scotland - Wales - Prefer not to say	 27 (79%) 1 (3%) 4 12%) 1 (3%) 1 (3%)	 13 (93%) 0 (0%) 1 (7%) 0 (0%) 0 (0%)	 12 (63%) 0 (0%) 6 (32%) 1 (5%) 0 (0%)	 6 (60%) 0 (0%) 2 (20%) 1 (10%) 1 (10%)
Participated in a trial - Yes - No	 8 (24%) 26 (76%)			
Relationship to patient - Spouse - Parent - Child - Other (Sibling)		 9 (64%) 1 (7%) 3 (21%) 1 (7%)		
Self-reported glioma diagnosis - Astrocytoma - Anaplastic astrocytoma - Glioblastoma - Oligodendroglioma - Anaplastic oligodendroglioma - Diffuse astrocytoma - Neuroectodermal tumour - Optic nerve glioma - Unknown/Unclear	 6 (18%) 4 (12%) 11 (32%) 7 (21%) 2 (6%) 1 (3%) 1 (3%) 0 (0%) 2 (6%)	 1 (7%) 1 (7%) 6 (43%) 2 (14%) 0 (0%) 0 (0%) 0 (0%) 1 (7%) 3 (21%)		
Self-reported glioma grade - Grade 2				

- Grade 2/3 - Grade 3 - Grade 3/4 - Grade 4 - Unknown/Unclear	12 (35%) 4 (12%) 6 (18%) 1 (3%) 10 (29%) 1 (3%)	2 (14%) 1 (7%) 0 (0%) 1 (7%) 7 (50%) 3 (21%)		
Professional role - Neurosurgery - Neurooncologist - Nurse - Radiographer - Researcher - Third Sector - Regulator - Pharmaceutical - Other			10 5 2 1 0 0 0 0 1	0 0 0 0 3 4 2 1 0
Secondary Roles				
- Caregiver - Clinician/ other healthcare professional - Researcher - Policymaker				1 3 8 1
Round 1 demographics – attrition between Round 1 to Round 2				
Patients	7 – 1 Glioblastoma, 1 Oligodendroglioma, 1 PXA tumour, 1 Low grade glioma, 1 Diffuse midline glioma, 1 Anaplastic oligodendroglioma, 1 Diffuse astrocytoma*			
Caregivers	7 - 4 carers of Glioblastoma, 2 carers of Oligodendroglioma, 1 unknown/unclear*			
Clinicians/Researchers	5 – 3 neurosurgeons, 1 oncologist, 1 researcher			
	*self-reported diagnoses			

[Table 2] DEMOGRAPHIC TABLE FOR DELPHI PARTICIPANTS FOR EACH ROUND

Participant Stakeholder group	**No**	**Representation**
Patients	3	3 Glioblastoma
Caregivers	2	1 Glioblastoma 1 Astrocytoma
Healthcare Professional	5	1 Consultant neurosurgeon 1 Neurosurgeon and researcher 1 Neurosurgery and Neuro-oncology PhD candidate 1 Manager of neuro-oncology network 1 Consultant Psychiatrist
Researcher	1	1 Clinical researcher
Third Sector	1	1 Third Sector
Regulator	1	1 Regulator
Policymaker	1* –	[See healthcare professionals – secondary role of working in 'Health Policy'] *duplicate role, not included in final number count
TOTAL	13	

[Table 3] TABLE OF DEMOGRAPHIC CHARACTERISTICS OF CONSENSUS MEETING PARTICIPANTS

Outcome domains, outcomes, and definitions	Final voting results [Consensus meeting]	
	Retain	Remove
Survival - Overall Survival *In a clinical trial, the time to a person's death from any cause, starting from the time they joined the trial.* - Survival Rate *In a clinical trial, the time from when a person starts a trial, to when their disease worsens or they die.* - Survival without neurocognitive deterioration *The time from when a person starts a clinical trial to when their neurocognitive symptoms (e.g., memory) become worse or they die due to any cause, whichever occurs first.*	75%	25%
Adverse Events - Frequency of adverse events *How often a person experiences any unfavourable, unexpected symptoms or signs that may be related to the treatment, including neurological adverse events (e.g., seizure activity), in a given time period.* - Severity of adverse events *The severity of any unfavourable, unexpected symptoms or signs a person experiences that may be related to the treatment, including neurological adverse events (e.g., seizure activity).* - Interference of adverse events *How unfavourable, unexpected symptoms or signs a person experiences, interferes with their daily activities. These may be related to the treatment, including neurological adverse events (e.g., seizure activity).* - Overall Tolerability *The degree to which adverse events (symptoms or signs) of the intervention (e.g., chemotherapy or peer support), can be tolerated by a person, overall.* - Evaluation of late adverse events *The assessment of unfavourable, unexpected late symptoms or signs of an intervention (e.g., chemotherapy or peer support), experienced by a person after the intervention period has finished.*	83%	17%
Activities of Daily Living - Activities of daily living – basic *A person's daily functioning including feeding, personal toileting, bathing, dressing and undressing, getting on and off a toilet, controlling bladder, controlling bowel, moving from wheelchair to bed and returning, walking on level surface (or propelling a wheelchair if unable to walk) and ascending and descending stairs.* - Activities of daily living – instrumental *A person's ability to undertake activities which allow them to live independently and participate in the community (including driving/ transportation, work, shopping, cooking meals, participating in social activities).* - Performance Status *A measurement of a person's overall function, including mobility, self-care and work.*	92%	8%
Health-related Quality of Life - Health-Related Quality of Life *A person's assessment how their physical, emotional, social or other types of well-being are affected by glioma or its treatment.*	92%	8%
Seizure Activity		

- Seizure Activity *An overall measure of how often a person experiences seizures and their severity.*	83%	17%
Neurocognitive Function - Neurocognitive Function *An overall assessment of a person's neurocognitive function.* - Higher Executive Function *A person's ability to plan, execute and monitor their goals.* - Memory *A person's ability to register and store information, and retrieve it as needed.* - Dysphasia *A person's experience of difficulty in comprehending or expressing language in its written or spoken form, sometimes described as aphasia.*	83%	17%
Physical Function - Hemiparesis *A person's experience of difficulty or inability to intentionally move parts of the body or to coordinate movements.* - Vision *A person's experience of partial and/or double vision.*	92%	8%

Table 4] FINAL CORE OUTCOME SET, NUMBER OF VOTING ROUNDS AND SCORES.

Core Outcome Set domains	Survival	Adverse Events	Activities of Daily Living	Health-related Quality of Life	Seizure Activity	Cognitive Function	Physical Function
Registry Review – patient-reported outcome measures (PROM)	-			EQ-5D-5L EORTC QLQ-BN20 EORTC QLQ-C30 MDASI-BT FACT-Br LASA (Linear Analogue Self Assessment)			
Registry Review – Quality of life PROM overlap with COS domains	-	FACT-Br - Overall Tolerability: GP5 [definition of GP5 below – encompassing frequency, severity and interference of adverse events]	FACT-Br - Activities of daily living (ADL) (instrumental): Physical, social and Functional well-being – work, enjoying life, usual activities; Additional concerns (driving, independence, basic activities) LASA (writing, mobility, self-care, physical activity, recreation, social life, housework, family relations MDASI-BT ADL (basic and instrumental): B: general activity, walking I: work, enjoyment of life EORTC QLQ-C30 ADL (basic and instrumental) B: carrying shopping, walking, eating, dressing, washing, using toilet; I: work, hobbies, leisure time activities, social and family interference due to symptoms EQ-5D-5L ADL (basic and instrumental)		FACT-Br - Seizure Activity: Br2, Br5 MDASI-BT - Seizures EORTC QLQ-BN20 - Seizure (‘did you have seizures’)	FACT-Br - Memory Br3 Dysphasia Br8, Br9 - Cognitive and Executive Function Br1, Br11, Br13, Br15, Br16, Br17 LASA - Speech MDASI-BT - Memory: difficulty remembering - Dysphasia (difficulty speaking) - Cognitive Function, Executive function – difficulty understanding, difficulty concentrating EORTC QLQ-BN20 - Dysphasia EORTC QLQ-C30 - Memory - Cognitive Function (concentrating, reading, watching TV)	FACT-Br - Hemiparesis: Br19, 20, 21 - Vision: Br6 LASA - Mobility MDASI-BT - Hemiparesis (weakness on one side) - Vision (problems with vision) EORTC QLQ-BN20 - Vision - Hemiparesis

[Table 5] TRIAL REGISTRY REVIEW PATIENT-REPORTED OUTCOME MEASURES MAPPED TO FINAL CORE OUTCOME SET DOMAINS.