

Supplementary Materials File S1

Phase 2 - Brain Tumor Delphi

Participant information and eligibility questions

Please provide your contact details so we can contact you about the future rounds of the study.

- ☐ Preferred name _____
- ☐ Email _____
-

What is currently your main role as it relates to adults with primary brain tumours?

- ☐ Health professional
- ☐ Researcher
- ☐ Consumer (patient/carer/advocate)
-

In which country do you currently live?

- ☐ Australia
- ☐ New Zealand
- ☐ Neither
-

End of Block: Participant information and eligibility questions

Start of Block: Consumer demographics

Please indicate your main background experience with adult primary brain tumours

- ☐ Previously diagnosed with a primary brain tumour
- ☐ Carer for patient with a primary brain tumour
- ☐ Advocate
- ☐ Other, please specify _____
-

What is your postcode?

Please indicate where you live?

- ☐ Major city
- ☐ Regional/Rural
- ☐ Remote
-

Please tell us about your education background?

- ☐ Did not complete high school
- ☐ Completed high school
- ☐ TAFE certificate/ diploma, Business College
- ☐ University degree
- ☐ Higher degree (postgraduate)
-

What is your age?

	18	25	32	40	47	54	61	68	76	83	90
Years											

What is your gender?

- ☐ Male
- ☐ Female
- ☐ Other (please state) _____
- ☐ Prefer not to answer
-

Display This Question:

If Please indicate your main background experience with adult primary brain tumours = Previously diagnosed with a primary brain tumour

The following questions are about the treatment you have received for a brain tumour.

Display This Question:

If Please indicate your main background experience with adult primary brain tumours = Carer for patient with a primary brain tumour

Q84 The following questions are about or the treatment your relative or friend has received for an adult primary brain tumour.

Display This Question:

If Please indicate your main background experience with adult primary brain tumours = Previously diagnosed with a primary brain tumour

Or Please indicate your main background experience with adult primary brain tumours = Carer for patient with a primary brain tumour

Q15 Please indicate the time since you, or your relative or friend, completed treatment?

0 2 4 6 8 10 12 14 16 18 20

Years since treatment completed



Display This Question:

If Please indicate your main background experience with adult primary brain tumours = Previously diagnosed with a primary brain tumour

Or Please indicate your main background experience with adult primary brain tumours = Carer for patient with a primary brain tumour

Q16 In which location did you, or your relative or friend, receive treatment?

- ☐ Major city
- ☐ Regional/Rural
- ☐ Remote

Display This Question:

If Please indicate your main background experience with adult primary brain tumours = Previously diagnosed with a primary brain tumour

Or Please indicate your main background experience with adult primary brain tumours = Carer for patient with a primary brain tumour

Q17 Please indicate if you, or your relative or friend, received treatment in the following settings:

- ☐ Hospital - Public
- ☐ Hospital - Private
- ☐ Private - Practice
- ☐ Both Public and Private
- ☐ Other (please specify) _____
- ☐ Unsure

End of Block: Consumer demographics

Start of Block: Health professional demographics

Q18 What is the postcode of your primary workplace?

Q19 Please indicate the nature of your primary workplace location?

- ☐ Major city
- ☐ Regional/Rural
- ☐ Remote

Q20 Is your main interaction with patients diagnosed with adult primary brain tumours in...?

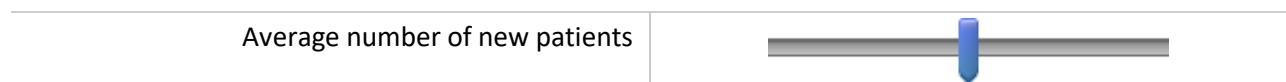
- ☐ Hospital - Public
 - ☐ Hospital - Private
 - ☐ Private - Practice
 - ☐ Both Public and Private
 - ☐ Other, please specify _____
-

Q21 Type of clinical setting

- ☐ Tertiary referral cancer center
 - ☐ District/local hospital
 - ☐ Non-hospital based practice
 - ☐ Other, please specify _____
 - ☐ N/A
-

Q22 On average, approximately how many adult patients with a new diagnosis of primary brain tumour, does your primary site of practice see per year?

0 20 40 60 80 100 120 140 160 180 200



Q23 Which of the following best describes your role in relation to the management of adults with primary brain tumours?

- ☐ Medical oncologist
- ☐ Neuro-oncologist
- ☐ Radiation oncologist
- ☐ Neurosurgeon
- ☐ Nurse
- ☐ Cancer Care Coordinator
- ☐ Physiotherapist
- ☐ Occupational therapist
- ☐ Social Worker
- ☐ Psychiatrist
- ☐ Clinical psychologist or psycho-oncologist
- ☐ Palliative care physician
- ☐ Rehabilitation physician
- ☐ Trainee (please specify discipline) _____
- ☐ Other, please specify _____

Q24 Years practising in your discipline?

0 4 8 12 16 20 24 28 32 36 40



Q25 Years practising in your current position?

0 4 8 12 16 20 24 28 32 36 40



Q26 What is your highest level of research training?

- ☐ Completed a Master of Research (or equivalent)
 - ☐ Currently enrolled in a Master of Research (or equivalent)
 - ☐ Completed a Doctor of Philosophy (or equivalent)
 - ☐ Currently enrolled in a Doctor of Philosophy (or equivalent)
 - ☐ None of the above
-

Q27 What experience do you have in relation to adult primary brain tumour research?

- ☐ No experience
 - ☐ Predominantly referral of patients to clinical trials only
 - ☐ Minimal experience (e.g., involvement in a research project)
 - ☐ Some experience (e.g., trial co-investigator)
 - ☐ Substantial experience (e.g., being the chief or principal investigator on a primary brain tumour research study)
 - ☐ Research assistant/research officer
 - ☐ Other, please specify _____
-

Q28 What is your age?

18 25 32 40 47 54 61 68 76 83 90

Age in years

Q29 What is your gender

- ☐ Male
 - ☐ Female
 - ☐ Other (please state) _____
 - ☐ Prefer not to answer
-

End of Block: Health professional demographics

Start of Block: Researchers or others

Q30 What is the postcode of your primary workplace

Q31 Please indicate the nature of your primary workplace location?

- ☐ Major city
- ☐ Regional/Rural
- ☐ Remote

Q32 Please indicate the research setting you work in?

- ☐ University
- ☐ Hospital
- ☐ Both (University and Hospital)
- ☐ Other (please specify) _____

Q33 Please describe the type of research you undertake in relation to adult primary brain tumour research.

Q34 Years practising in your discipline?

0 4 8 12 16 20 24 28 32 36 40

Years in discipline



Q35 Years practising in your current position?

0 4 8 12 16 20 24 28 32 36 40

Years in current position



Q36 What is your highest level of research training?


- ☐ Completed a Master of Research (or equivalent)
 - ☐ Currently enrolled in a Master of Research (or equivalent)
 - ☐ Completed a Doctor of Philosophy (or equivalent)
 - ☐ Currently enrolled in a Doctor of Philosophy (or equivalent)
 - ☐ None of the above
-

Q37 What experience do you have in relation to adult primary brain tumour research?

- ☐ No experience
 - ☐ Minimal experience (e.g., involvement in a primary brain tumour research project)
 - ☐ Some experience (e.g., trial co-investigator)
 - ☐ Substantial experience (e.g., being the chief or principal investigator on a primary brain tumour research study)
 - ☐ Research assistant/research officer
 - ☐ Other (please specify) _____
-

Q38 What is your age?

18 25 32 40 47 54 61 68 76 83 90

Age in years	
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Q39 What is your gender?

- ☐ Male
 - ☐ Female
 - ☐ Other (please state) _____
 - ☐ Prefer not to answer
-

End of Block: Researchers or others

Start of Block: Survey questions - all participants

Q40 The aim of the study is to determine the priorities for adult primary brain tumour research in Australia and New Zealand. Adult primary brain tumours include primary malignant or benign brain tumours diagnosed in people aged 18 years or older. The priorities that have been identified in the list provided focus on research and clinical trials rather than the quality of clinical care per se.

On the next pages you will see a list of research priorities that were generated from Phase 1. Please rate each priority based on the importance you feel it holds for research on adult brain tumours in Australia and New Zealand, on the scale provided.

1. not important; not a priority
2. somewhat important; low priority
3. moderately important; intermediate priority
4. very important; urgent priority

Items may be rated as “very important” if they address one or more of the following aspects:

1. Research is urgently needed in the area.
2. There is a gap in the existing evidence base in that area
3. Research in the area will directly impact the quality of life of patients diagnosed with a primary brain tumour and their carers/families

We have provided definitions for some of the scientific terms and concepts directly beneath each priority where deemed relevant.

Should the meaning still be unclear, we have provided an “unable to score” option, but we ask that you use this sparingly.



Please indicate how important each research priority is to you.

	1 Not important; not a priority	2 Somewhat important; low priority	3 Moderately important; intermediate priority	4 Very important; urgent priority	X Unable to score
1. Understanding the causes of adult brain tumour development.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Developing research questions around familial glioma syndromes.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Conducting pre-clinical research to identify actionable drivers (and new molecular targets) for brain tumour therapy. <i>Conducting laboratory research in animals (pre-clinical) to identify genetic changes in brain tumours that will justify use of targeted therapy in patients.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Development of pre-clinical models of gliomas and other primary Central Nervous System malignancies with improved validity and reproducibility. <i>Developing reliable and accurate ways of predicting personalised responses to new drugs in animals (pre-clinical), taking into account personalised tumour characteristics.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Understanding the tumour microenvironment with the aim of reducing immunosuppression and facilitating immunotherapy. <i>Understanding the interaction between tumours and their surrounding tissue (tumour microenvironment) to reduce immunosuppression and facilitate immunotherapy.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Developing pre-clinical models and strategies to enhance Blood Brain Barrier (BBB) penetration for novel drugs. <i>Developing methods to increase penetration of new drugs into the brain.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Developing and testing of novel therapeutic approaches with the ability to specifically target the stem cell-like	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

population. *(Stem cells are special human cells that are able to develop into many different cell types).*

8. Developing cell surface proteomics analysis platforms to better define novel and actionable receptors in brain tumours.

Developing sophisticated ways of analysing proteins expressed on the surface of tumours (proteomics) to allow us to specifically target them.

9. Investigating reasons for treatment resistance.

10. Further development of a network for biobanking for all brain tumours.

Development of infrastructure to enable storage of brain tumour samples (biobanking) for future research.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please provide any comments related to your answers for the items above (1-10).
Comments might include why you rated items as high priority or not a priority. You may also clarify why you have selected "unable to score" for any items.



Please indicate how important each research priority is to you.

	1 Not important; not a priority	2 Somewhat important; low priority	3 Moderately important; intermediate priority	4 Very important; urgent priority	X Unable to score
11. Developing a brain tumour registry to track outcomes for all brain tumours in Australia and New Zealand.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Developing big data repositories/networks for radiation oncology and radiology innovation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Developing national benchmarking and quality indicators and outcomes of care (including surgery) to improve the quality and efficacy of treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Developing systems for genomic and proteomic profiling of brain tumours.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Conducting Phase 0 studies (including imaging, blood and tumour biomarker development to enable neoadjuvant therapy). <i>Conducting drug dosing studies to show drug penetration into the brain (with or without treatment benefit) and then developing ways of measuring treatment response by testing blood or tumour tissue when drugs are given prior to surgery (Phase 0).</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Evaluating the use of liquid biopsies for diagnosis and monitoring treatment and response. <i>(A liquid biopsy is a test done on a sample of blood to look for cancer cells that are circulating in the blood).</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Exploring the effectiveness of precision medicine/personalised treatment based on genomic profiling. <i>Exploring the effectiveness of personalising cancer treatment based on an individual's tumour mutations.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

18. Developing the role of theranostics in guiding treatment. *Developing the role of using a personalised approach which can be used as both a) diagnostic and b) therapy tools (theranostics).*

☐

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19. Conducting clinical trials that include relevant patient reported outcomes (including Quality of Life or unmet supportive care needs).

☐

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20. Implementation research into improving primary care awareness, early diagnosis and investigation of “red flag” symptoms (implementation of optimal care pathway and demonstrating impact of delay).

☐

☐

☐

☐

☐

Q44 Please provide any comments related to your answers for the items above (11-20). Comments might include why you rated items as high priority or not a priority. You may also clarify why you have selected "unable to score" for any items.

X→

Please indicate how important each research priority is to you.

	1 Not important; not a priority	2 Somewhat important; low priority	3 Moderately important; intermediate priority	4 Very important; urgent priority	X Unable to score
21. Exploring support provided to patients pre-diagnosis and the role of care coordinators pre-diagnosis.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Testing devices/techniques to improve extent of surgical resection (e.g. focused ultrasonography).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Development of clinical trials using immunotherapy agents.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Conducting clinical trials using cellular therapies (e.g. CAR T cells, dendritic cells).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Determining the correlation between chemoresistance and drug metabolism (metabolomics). <i>Determining the relationship between tumour resistance (chemoresistance) to chemotherapy/drug therapy and drug metabolism (metabolomics).</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Determining which drugs are radiation sensitisers that are effective in managing brain tumours. <i>Determining which drugs can be used to enhance the effectiveness of radiation (radiation sensitisers) used to treat brain tumours.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. Conducting drug repurposing studies in adult brain tumours. <i>Conducting studies of drugs useful for other conditions to test their effectiveness in brain tumours.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. Conducting clinical trials using viral vectors (e.g. oncolytic viruses, viral gene therapy).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29. Developing and trialling high throughput in vitro drug screening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30. Developing trials to address mitigation of radiation toxicity (acute and late radiation effects) – new techniques, survivorship, improved outcomes.



Q46 Please provide any comments related to your answers for the items above (21-30).

Comments might include why you rated items as high priority or not a priority. You may also clarify why you have selected "unable to score" for any items.



Q47 Please indicate how important each research priority is to you.

	1 Not important; not a priority	2 Somewhat important; low priority	3 Moderately important; intermediate priority	4 Very important; urgent priority	X Unable to score
31. Conducting radiation therapy trials to improve outcomes for people with benign brain tumours (e.g. meningiomas).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32. Investigating advanced neuro-oncology imaging (e.g. newer MRI and PET scanning techniques) for diagnosis and treatment response monitoring.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33. Developing new effective therapies against rarer primary Central Nervous System tumours.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34. Developing and testing of pharmacological/other interventions to improve symptom management (including seizures, thromboembolic events (blood clotting events)).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35. Developing actual versus optimal utilisation models for standards of care (for each main treatment modality e.g. surgery/radiotherapy/systemic therapies).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
36. Evaluating optimal treatment and care pathways for people with brain tumours.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
37. Identifying barriers to equitable outcomes for under-served populations (including regional/remote patients, culturally and linguistically diverse populations, and First Nations/ Aboriginal and Torres Strait Islander/Māori and Pasifika people).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
38. Determining the impact and optimal models of care coordination.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

39. Determining the impact and optimal models of telehealth (to allow patients to participate in healthcare appointments virtually).

☐☐☐☐☐

40. Determining the impact and developing optimal models of teletrials (to allow participation and conduct of clinical trials virtually).

☐☐☐☐☐

Q48 Please provide any comments related to your answers for the items above (31-40).

Comments might include why you rated items as high priority or not a priority. You may also clarify why you have selected "unable to score" for any items.



Q49 Please indicate how important each research priority is to you.

	1 Not important; not a priority	2 Somewhat important; low priority	3 Moderately important; intermediate priority	4 Very important; urgent priority	X Unable to score
41. Developing and testing interventions for cognitive, personality and behaviour changes.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
42. Developing and testing interventions for fatigue.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
43. Determining the most effective rehabilitation interventions for patients and carers.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
44. Exploring the impact of neuropsychology interventions in brain tumour care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
45. Exploring patients and carers' barriers and enablers in accessing timely palliative care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46. Exploring and testing palliative care interventions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
47. Evaluating implementation of end-of-life care plans and advance care directives.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
48. Evaluating implementation of increased assessment of patient and carer anxiety, distress, and quality of life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
49. Developing and testing psychosocial interventions to address unmet needs, anxiety, and distress experienced by patients, carers, and families following a brain tumour diagnosis.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
50. Trialling novel technologies for delivering support, monitoring, and follow-up to patients, carers, and their social networks.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q50 Please provide any comments related to your answers for the items above (41-50).

Comments might include why you rated items as high priority or not a priority. You may also clarify why you have selected "unable to score" for any items.

Q51 Please indicate how important each research priority is to you.

	1 Not important; not a priority	2 Somewhat important; low priority	3 Moderately important; intermediate priority	4 Very important; urgent priority	X Unable to score
51. Exploring grief and loss (e.g. loss of independence, loss of the person who once was, loss of the imagined future) for patients, carers and their social networks.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
52. Exploring patients, carers and families survivorship needs following treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
53. Developing and testing survivorship focused interventions to support patients, carers and families following treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
54. Exploring the financial toxicity associated with brain tumour diagnosis, treatment, and follow up care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
55. Exploring the cost-effectiveness of supportive care interventions for patients, carers and their social networks.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
56. Developing and testing decision support tools throughout treatment/care pathway to assist patients and carers/families to communicate with clinicians and decide on treatment and supportive care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
57. Trialling interventions to improve patient, carer and family education about brain tumours, treatment options, disease progression, symptoms and side effects and supportive care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

58. Determining the role of complementary therapies (e.g. meditation; relaxation; aromatherapy; acupuncture; reflexology; massage) in managing adult brain tumours and how these align with conventional therapies being undertaken.

☐☐☐☐☐

59. Investigating the role of diet in improving treatment outcomes and managing symptoms and side effects of treatment.

☐☐☐☐☐

60. Investigating the role of exercise in improving treatment outcomes and managing symptoms and side effects of treatment.

☐☐☐☐☐

Q52 Please provide any comments related to your answers for the items above (51-60).

Comments might include why you rated items as high priority or not a priority. You may also clarify why you have selected "unable to score" for any items.

Q53 Please outline any research priorities for adult brain tumours in Australia and New Zealand that you believe are missing or not adequately covered in this survey:

Q54 Please leave any further comments that you feel may be useful to determining research priorities for adult brain tumours in Australia and New Zealand:

End of Block: Survey questions - all participants

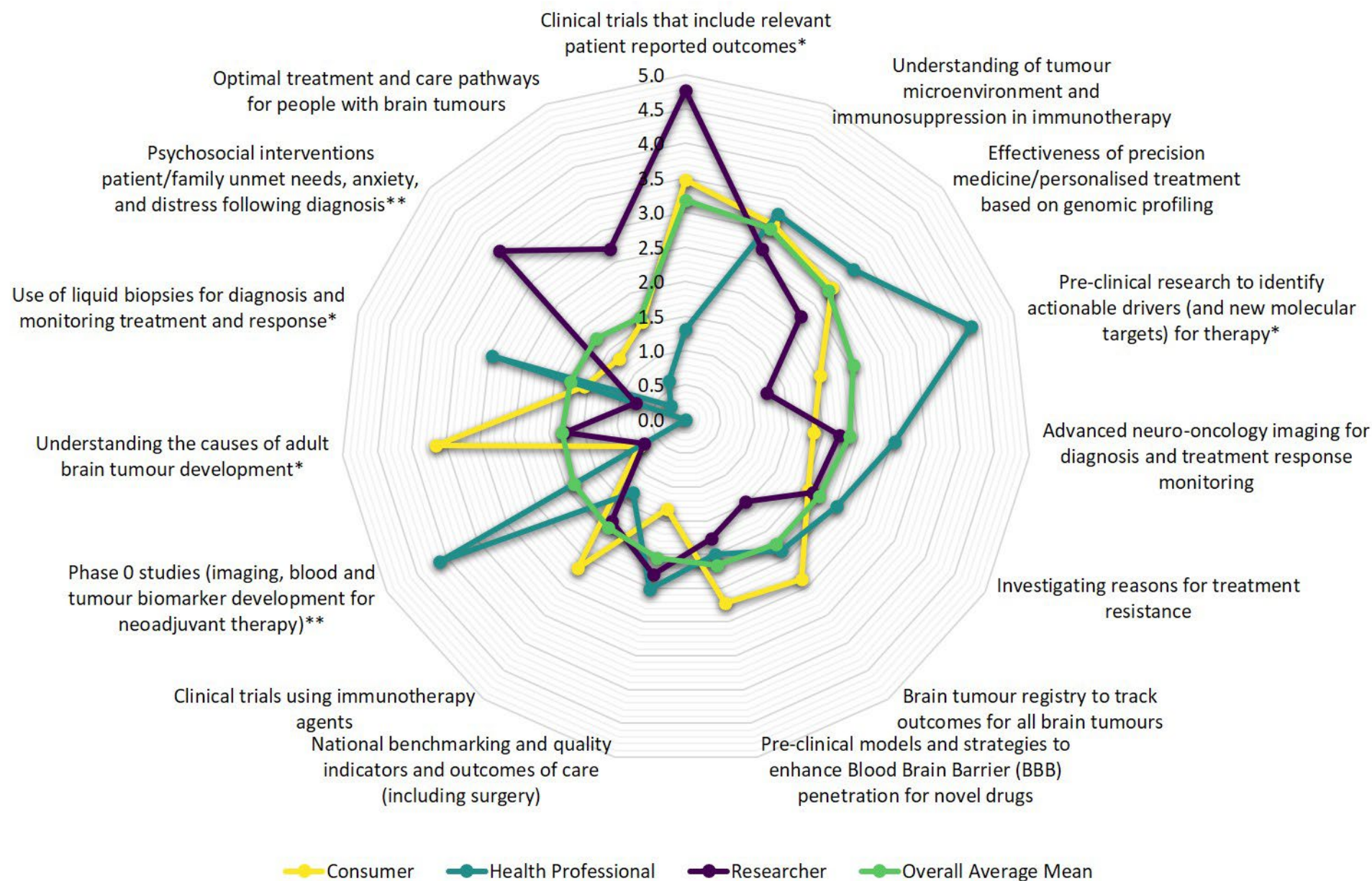


Figure S1. Mean adjusted rankings for top fifteen ranked research priorities by group and overall average mean (higher mean equals higher priority). Priorities are shown from highest to lowest overall mean (from top in clockwise direction). Priorities with notation ($*0.01 \leq p < 0.05$, $**p < 0.01$) have significant inter-group differences.

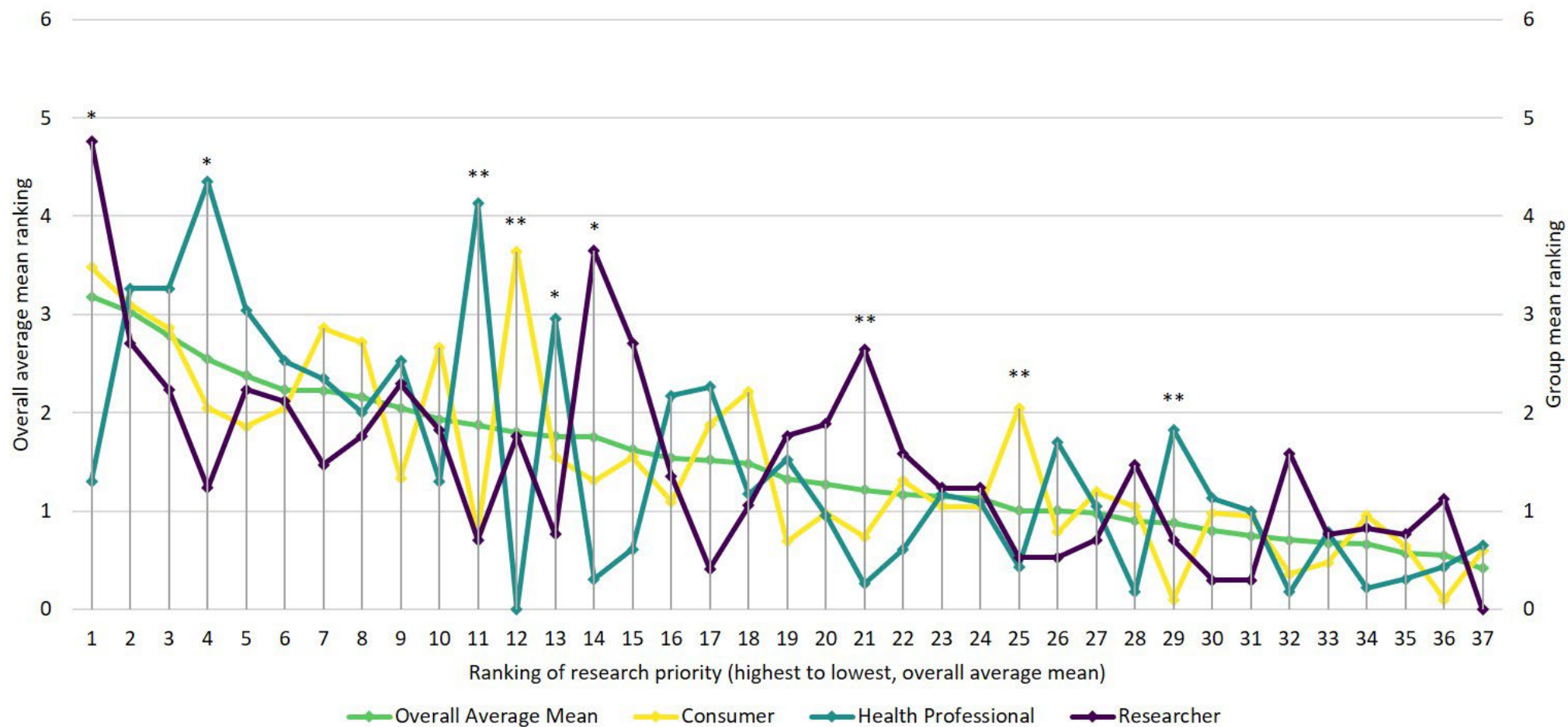


Figure S2. Mean adjusted rankings for all 37 research priorities in phase 2, step 2 by overall average mean (left axis) and by group mean (right axis). Higher mean equals higher priority. Refer to rank position column in table 5 for wording of each priority. Priorities with notation (* $0.01 \leq p < 0.05$, ** $p < 0.01$) have significant inter-group differences.