

## **BRIAN Terms and Conditions of Use ("Agreement")**

**FOR ALL MEDICAL EMERGENCIES, YOU SHOULD CONTACT YOUR HEALTHCARE PROFESSIONAL IMMEDIATELY. DO NOT USE THIS TOOL TO COMMUNICATE MEDICAL EMERGENCIES.**

**"BRIAN"** is the Brain tumouR Information and Analysis Network developed by The Brain Tumour Charity.

**"Data Access Board"** refers to a group established by The Brain Tumour Charity to review applications for access to data from the BRIAN database that has been obtained from sources such as NHS Digital, Public Health England and from BRIAN users. The Board is responsible for the framework for assessing applications for data extracts and the criteria for accepting, accepting with conditions or rejecting requests.

**"GMC"** is the General Medical Council.

**"GMCSI"** is the GMC Services International Limited.

**"Healthcare Professional"** means a member of the Individual's healthcare team, authorised by Individual, who may access portions of the Individual's record through the BRIAN web-app, as well as use any additional functions available to healthcare professionals. Examples of healthcare professionals include clinical nurse specialists, oncologists and general practitioners.

**"Individual"** means the BRIAN account holder.

**"Invitee"** means a user who is invited by "Individual" to access Individual's BRIAN account.

**"LRMP Product"** means the list of registered medical practitioners kept by the GMC pursuant to the Medical Act 1983 (**"LRMP"**).

**"Maintenance"** refers to the modification of the BRIAN web-app to correct faults or to improve performance or other attributes.

**"Research"** refers to an activity undertaken by both clinical and academic scientists at universities or industry partners in the UK or globally. As part of their job they investigate different aspects of brain tumours to try and understand how

they are created, what keeps them growing and how they can be controlled or cured.

1. The *BRIAN* web-app is designed as a secure Internet-based environment through which an Individual may enter certain confidential healthcare information about a brain tumour patient's treatment and care, medication, appointments and quality of life. The *BRIAN* web-app also provides the user with a number of Insights and Tools.
2. Individual is responsible for remembering the *BRIAN* password and for keeping this information confidential and in a safe place for future reference. It is Individual's responsibility to prevent disclosure of Individual's password and to change Individual's password if Individual feels that Individual's security has been compromised. The Brain Tumour Charity shall not be liable for any damages that result from Individual's failure to keep the password secure.
3. It is Individual's responsibility to advise The Brain Tumour Charity if it appears that Individual's account has been compromised in any way.
4. It is Individual's responsibility to advise The Brain Tumour Charity if a device on which Individual has previously logged into *BRIAN* has been lost or stolen.
5. Access to *BRIAN* will be activated once Individual creates an account.
6. It is Individual's responsibility to keep Individual's email address up-to-date in the My account section of the *BRIAN* web-app in order to ensure that Individual receives notification of newly released information and general notices relating to *BRIAN* in a timely manner. The Brain Tumour Charity is not responsible for any damage resulting from Individual's failure to keep up-to-date Individual's email address and account information.
7. If Individual has invited Invitee to have access to Individual's account, Invitee will be notified when Individual requests in the *BRIAN* web-app that an invitation be sent to Invitee.
8. If Individual has invited Invitee to have access to Individual's account, be aware that delays can occur in Invitee's acceptance of the invitation including, but not limited to frequency at which Invitee is able to check or respond to their emails or technology occurrences outside of The Brain Tumour Charity's control.
9. It is possible that Invitee could decide not to accept an invitation from Individual. It is not The Brain Tumour Charity's responsibility to remind Invitee that Invitee has not accepted an invitation from Individual.
10. It is Individual's responsibility to control who Individual invites to have access to Individual's account, what type of access they have, for what duration, and to which sections of the account.
11. **Users of the *BRIAN* web-app should not use it to convey urgent medical matters to a healthcare team. For all urgent medical matters, the relevant healthcare team should be contacted directly and as soon as possible. Never send any messages to The Brain Tumour Charity requiring urgent attention from a healthcare team. Although a healthcare professional may have been given access to a user's account it is highly unlikely that they will be actively viewing the user's account.**
12. By accessing or using *BRIAN* Individual agrees to be bound by all the terms and conditions of this Agreement and The Brain Tumour Charity's Privacy Policy

incorporated herein by reference to this <https://www.thebraintumourcharity.org/about-us/our-policies/privacy-policy/>. It is important to review the Agreement and Privacy Policy periodically as The Brain Tumour Charity may modify this Agreement and the Privacy Policy at any time, and Individual agrees that such modifications are effective and binding upon Individual immediately upon the posting of the modified version.

13. All Individual's data stored in *BRIAN* will be treated with utmost confidence by The Brain Tumour Charity.
14. Individual agrees that *BRIAN* is a service offered as an information management tool to users. Individual understands that it provides Individual with online access to Individual's account and any information that Individual has entered into *BRIAN* and that Individual is solely responsible for any sharing of *BRIAN* content that Individual intentionally or unintentionally communicates to others, including to and through any of Individual's authorised Invitee(s).
15. The Brain Tumour Charity seeks to obtain anonymised healthcare information of patients who have been diagnosed with a brain tumour from national healthcare data providers such as NHS Digital and Public Health England and aims to share useful insights derived from this information with Individual.
16. If Individual appoints an Invitee through the *BRIAN* web-app, Individual understands that the Invitee will be able to access whichever sections of Individual's account that Individual has approved, as well as any additional functions available to Invitee's role. In addition, Invitee may take action on behalf of Individual via the *BRIAN* web-app. If Individual chooses an Invitee, it is Individual's responsibility to choose an appropriate Invitee and The Brain Tumour Charity is not responsible for actions taken by Individual's Invitee. If Individual no longer wishes for his/her appointed Invitee to have access to Individual's *BRIAN* account, Individual is responsible for revoking Invitee's access through the *BRIAN* web-app.
17. Individual can discontinue use of *BRIAN* at any time by contacting The Brain Tumour Charity.
18. If Individual decides that Individual no longer wants to share information with *BRIAN*, Individual can contact The Brain Tumour Charity. The Brain Tumour Charity will then delete Individual's information. Deleted information will remain hidden in *BRIAN*'s historical records and would only be accessed for legal reasons or future Data Protection issues.
19. Individual agrees that Individual will not post or send any harassing or offensive material in the *BRIAN* web-app.
20. The Brain Tumour Charity accepts no responsibility for any harassing or offensive material that Individual posts in the *BRIAN* web-app or sends through it. More generally, any views expressed by Individual through the *BRIAN* web-app should not be treated as the views of The Brain Tumour Charity or views that The Brain Tumour Charity would endorse.
21. The Brain Tumour Charity reserves the right, at its sole discretion, to suspend or discontinue Individual's use of *BRIAN* and to discontinue the general use of *BRIAN* itself. Individual will be notified if *BRIAN* is discontinued.
22. The Brain Tumour Charity grants a limited, revocable licence to Individual to make use only of *BRIAN* and the associated services in accordance with these terms and conditions of use. This licence expressly excludes, without limitation, any

reproduction, duplication, sale, resale or other commercial use of *BRIAN* and the associated services or making any derivative of *BRIAN* or the associated services without the express agreement of The Brain Tumour Charity.

23. The *BRIAN* web-app contains links to websites operated by other parties. The links are provided for Individual's convenience only. The Brain Tumour Charity does not control such websites and The Brain Tumour Charity is not responsible for the content and performance of these sites. The inclusion of links to other websites does not imply any endorsement of the material on the websites or any association with their operators. The Brain Tumour Charity does not operate, control, or endorse any information, products, or services provided by third parties through the Internet. Use of other sites is strictly at Individual's own risk, including, but not limited to, any risks associated with destructive viruses. Individual is responsible for viewing and abiding by the terms and conditions of use and the privacy statements of the other websites.
24. The *BRIAN* web-app and all other websites hosted by The Brain Tumour Charity and the content contained on them are provided by The Brain Tumour Charity on an "As Is" basis. The Brain Tumour Charity makes no representations or warranties of any kind, express or implied, as to the operation of its websites, or the content, products and/or services they include. To the fullest extent permissible by applicable law, The Brain Tumour Charity disclaims all warranties, express, or implied, including, but not limited to, implied warranties of merchantability, fitness for a particular purpose, title, and/or infringement.
25. Some of the material in the *BRIAN* web-app is provided by third parties and The Brain Tumour Charity shall not be held responsible for any such third-party material. The Brain Tumour Charity disclaims any responsibility for or liability related to such third-party material and Individual uses of such third-party material. Any questions complaints or claims related to any product should be directed to the appropriate third party.
26. The GMCSI has granted a licence to The Brain Tumour Charity to use the LRMP Product as part of *BRIAN* but is not otherwise endorsing *BRIAN*.
27. Inclusion of the LRMP Product information in *BRIAN* does not imply that the medical practitioners included in this list are registered to practise medicine in the UK.
28. The Brain Tumour Charity will not be liable for any loss, whether such loss is direct, indirect, special or consequential, suffered by any party as a result of their use of the *BRIAN* web-app, its content and functionality.
29. The *BRIAN* web-app is a work-in-progress, and as such has not been fully peer-reviewed. Whilst every effort has been made to ensure the information presented through the web-app is accurate, The Brain Tumour Charity is providing this information without any implied warranty or fitness for purpose or use.
30. *BRIAN's* insights and tools are a work-in-progress, and as such have not been fully peer-reviewed. Whilst every effort has been made to ensure the information presented through the insights and tools is accurate, The Brain Tumour Charity is providing this information without any implied warranty or fitness for purpose or use.
31. In the Insights section of the *BRIAN* web-app, any attribution that Individual makes between a side effect and medication or treatment represents Individual's view and not the view of The Brain Tumour Charity.

32. Individual agrees that any patient reported information that Individual provides to *BRIAN* through the *BRIAN* web-app could be shared by The Brain Tumour Charity with researchers and clinicians should The Brain Tumour Charity consider that this information could be used in valuable research into brain tumours. The Brain Tumour Charity's Data Access Board would have to approve all sharing of anonymised or identifiable data.
33. In line with the principles defined in the Data Protection Act 2018 and the General Data Protection Regulation (GDPR), The Brain Tumour Charity will ensure that personal data in *BRIAN* will be processed in ways that are: (i) Lawful, fair and transparent; (ii) Collected for specific explicit and legitimate purposes; (iii) Adequate, (iv) Relevant and limited; (v) accurate and up-to-date; (vi) not kept for longer than necessary and (vii) secure.
34. The Brain Tumour Charity reserves the right to carry out periodic maintenance and updates to the *BRIAN* web-app. When making these changes, every effort will be taken to minimise the disruption to *BRIAN* users that this may cause.