

## **Interview Study About Using an Advanced Computer Program for Treating Brain Tumors**

We invite you to participate in a research study being conducted by investigators from Washington University in St. Louis. You are being asked to participate in this research study because you or a loved one have been diagnosed with a glioblastoma brain tumor. The purpose of this study is to explore perspectives about a new advanced computer program that uses artificial intelligence (AI) to inform doctors' treatment decisions for patients with brain tumors. This computer program can help predict prognosis (i.e., projected life expectancy and quality of life) and provide information about likely outcomes of brain tumor removal. The National Institutes of Health (NIH) is funding this study.

If you agree to take part in the study, you will participate in a 1-hour Zoom interview. During the interview, you will be asked questions exploring perceived risks, benefits, and ethical considerations of using this advanced computer program to assist doctors in making treatment decisions. Approximately 60 people will take part in this study at Washington University.

The interview will be audio recorded and transcribed. Your responses will remain confidential. Any identifying information about you will be removed from the interview transcript. Files that contain identifying information will be available only to research staff for purposes of conducting the study. De-identified data may be shared with a data repository. Audio recordings will be stored using a password protected and HIPAA compliant system.

You will receive a \$60 e-gift card for completing the interview. You will need to complete a study payment form including your full name, home address, and phone number as required by Washington University in order for us to provide you with the gift card. You will be asked to provide your social security number (SSN). It is not required to provide your SSN in order to receive the gift card. This is for payment purposes only and will not be retained for research purposes.

Taking part in this study is completely voluntary. You may choose not to take part at all. If you decide to participate in the study, you may stop participating at any time. Any data collected as part of your participation will remain as part of the study records and cannot be removed. If you decide not to complete this study, or if you stop participating at any time, you will not be penalized or lose any benefits for which you otherwise qualify.

### **Privacy Protection**

The funding source for this research may require that we share the data from this study with others to make sure the results are correct and to use for future research. Your information will be shared in a way that cannot directly identify you.

To further protect your privacy, this research is covered by a Certificate of Confidentiality from the federal government. This means that the researchers can refuse to disclose

information that may identify you in any legal or court proceeding or to anyone who is not connected with the research except if:

- there is a law that requires disclosure, such as to report child abuse and neglect, or harm to self or others;
- you give permission to disclose your information, including as described in this consent form; or
- it is used for other scientific research allowed by federal law.

This Certificate may not be effective for information held in foreign countries.

You have the right to share your information or involvement in this study with anyone at any time. You may also give the research team permission to disclose your information to a third party or any other person not connected with the research.

Any report or article that we write will not include information that can directly identify you. The journals that publish these reports or articles require that we share your information that was collected for this study with others to make sure the results of this study are correct and help develop new ideas for research. Your information will be shared in a way that cannot directly identify you. Federal regulatory agencies and Washington University, including the Washington University Institutional Review Board (a committee that reviews and approves research studies) and the Human Research Protection Office may inspect and copy records pertaining to this research.

## **HIPAA**

We would like to tell you about what we will be doing with the information you give us. This research will create Protected Health Information (PHI) that identifies you. Your health information is protected by law under HIPAA (the Health Insurance Portability and Accountability Act). Because of this law, you will need to give the research team permission to use and share your protected health information collected for this research.

When possible, the research team will make sure information cannot be linked to you. Once information doesn't identify you, it may be used and shared for other purposes not discussed in this document. The information collected during the study may be seen by people making sure the research is being done right. This may be people at Washington University and people from the National Institutes of Health.

- If you agree, you are giving permission for us to use your PHI for this research, and your permission will not expire.
- If you do not agree to allow us to use your PHI it will not affect your treatment or the care given by your health provider, insurance payments or enrollment in any health plans, or any benefits to which you are entitled. However, it will not be possible for you to take part in this study.
- Once your health information is shared with someone outside of the research team, it may no longer be protected by HIPAA.
- If you change your mind and do not want the research team use or share your information, you will need to provide a written letter to the research team cancelling

your permission. Please contact the Human Research Protection Office for more information on how to revoke your authorization or contact the research team to request the withdrawal letter. If you do this, the research team may only use and share information already collected for the study. You will not be allowed to continue to participate in the study.

- If you have questions or concerns about your privacy and the use of your protected health information, please contact the University's Privacy Officer at 866-747-4975.

### **Principal Investigator Contact Information**

If you have questions for the research team, please contact the Principal Investigator, Dr. Tristan McIntosh at [t.mcintosh@wustl.edu](mailto:t.mcintosh@wustl.edu) or (314) 286-0042. Or you may contact the Human Research Protection Office at 1-800-438-0445 or [hrpo@wustl.edu](mailto:hrpo@wustl.edu).

Thank you very much for considering participating in this research study.