

Informed Consent for Studies with Adults

TITLE OF RESEARCH STUDY: What Health Looks Like: Using Graphic Medicine to Bring Underrepresented Voices Forward Through Public Library Health Literacy Programs

RESEARCH TEAM:

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You are being asked to participate in a research study. Taking part in this study is voluntary. The investigators will explain the study to you and will any answer any questions you might have. It is your choice whether or not you take part in this study. If you agree to participate and then choose to withdraw from the study, that is your right, and your decision will not be held against you.

You are being asked to take part in a research study about using the comics format to understand and describe experiences related to health. This research is being funded by the UNT College of Information.

Your participation in this research study involves reading two graphic novels about a person's experiences with illness and health, discussing these two graphic novels with other library patrons in person in the library or online via Zoom, and learning techniques to create a short comic about your own health experience. The time taken to complete the study is about 16 hours over the course of 8 to 12 weeks. More details will be provided in the next section.

You might want to participate in this study if you are interested in reading graphic novels, learning to draw a comic, and/or sharing your health experiences. However, you might not want to participate in this study if you do not have time to participate in the 8 1-hour meetings and to read the graphic novels.

You may choose to participate in this research study if you are 18 years old or older.

The reasonable foreseeable risks or discomforts to you if you choose to take part are a) risks to confidentiality similar to a person's experience in taking a course at the library or online and b) emotional discomfort caused while reading and discussing the selected material. You can compare these risks and discomforts to the possible benefit of learning more about graphic

novels and comics. You will receive compensation for participation in the form of drawing supplies and a \$25 gift card selected from an online catalog of eligible vendors.

DETAILED INFORMATION ABOUT THIS RESEARCH STUDY: The following is more detailed information about this study, in addition to the information listed above.

PURPOSE OF THE STUDY: The purposes of the study are a) to examine how reading and writing comics, also known as graphic novels, can help participants better understand health care experiences for themselves and others, and b) to collect a more diverse range stories about health and wellness in our society. Your participation will influence library programming, as well as education related to health care.

TIME COMMITMENT: Participation in this study will take approximately 16 hours over the course of 8 to 12 weeks.

STUDY PROCEDURES: The study includes the following:

- 1. Completing a brief online survey before the program meetings begin. The survey questions will measure your previous experiences with graphic novels and comics and ideas about health care experiences. You will also be asked basic demographic information, such as your age and ethnicity.
- 2. Visiting your local library branch to borrow the two pre-selected graphic novels and drawing supplies.
- 3. Reading each graphic novel in preparation for discussion.
- 4. Periodic 1 to 2 hour meetings with discussion leaders and other library patrons to discuss the graphic novels and learn how to draw simple comic stories. These discussions will recorded and include your voice and your image. The recordings will be for the researchers to review the discussions.
- 5. Creating a 4-8 panel comic story about a health experience from your life or that of a family member. You will be asked to share a copy of your comic story with the researchers.
- 6. (Optional) Participation in online discussions about the books or drawing comics throughout the 8 weeks.
- 7. Returning the graphic novels to your local library branch.
- 8. Completing a brief online survey after the program meetings finish. The survey questions will ask about your experiences in the program. You will also be asked basic demographic information, such as your age and ethnicity.

AUDIO/VIDEO/PHOTOGRAPHY:

| Participants may choose if they will allow these recordings and photographs to be used in publications or presentations. |
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| <u>I agree</u> to be video recorded and photographed during the research study. |
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| I do not agree that the video recordings and photographs can be used in publications or presentations. |

To participate in the program, participants must agree to be video recorded and photographed.

The recordings and photographs will be kept with other electronic data in a secure UNT OneDrive account for the duration of the study.

POSSIBLE BENEFITS: The study may benefit you by gaining knowledge about graphic novels, the process of drawing comics, and/or a variety of health experiences. It will also help researchers understand how reading and writing comics, also known as graphic novels, can help participants better understand health care for themselves and others. Your comic creation will also help diversify stories about health and wellness in our society. These benefits might continue after the study has ended.

POSSIBLE RISKS/DISCOMFORTS: Participation in this study involves risks to confidentiality similar to a person's experience in taking a course in the library or online and the risk of emotional discomfort caused while reading and discussing the selected material. This research study is not expected to pose any additional risks beyond what you would normally experience in your regular everyday life. However, if you do experience any discomfort, please inform the research team. If you need help after business hours, consider contacting the National Suicide Prevention Hotline at 1-800-273-8255.

Participating in research may involve a loss of privacy and the potential for a breach in confidentiality. Study data will be physically and electronically secured by the research team. As with any use of electronic means to store data, there is a risk of breach of data security.

If you experience excessive discomfort when completing the research activity, you may choose to stop participating at any time without penalty. The researchers will try to prevent any problem that could happen, but the study may involve risks to the participant, which are currently unforeseeable. UNT does not provide medical services, or financial assistance for emotional distress or injuries that might happen from participating in this research. If you need to discuss your discomfort further, please contact a mental health provider, or you may contact

the researcher who will refer you to appropriate services. If your need is urgent, helpful resources include the National Suicide Prevention Hotline at 1-800-273-8255.

COMPENSATION: To thank you for participation, you may receive drawing supplies and a \$25 gift card. The drawing supplies will be available at your local library before the first meeting. After using them for the study, you may keep them for personal use. Upon completion of the post-meetings survey, you will be emailed a link to a website where you can select a vendor for the gift card.

Internal Revenue Service (IRS) considers all payments made to research subjects to be taxable income. Your personal information, including your name, address, and social security number may be acquired from you and provided to UNT System Tax Office for the purpose of payment. If you are an employee, we will be collecting your employee ID. If your total payments for the year exceed \$600.00, UNT will report this information to the IRS as income and you will receive a Form 1099 at the end of the year. If you receive less than \$600.00 total payments in a year, you are personally responsible for reporting the payments to the IRS.

If you choose not to complete all study procedures, you will still receive the drawing supplies.

There are no alternative activities offered for this study.

CONFIDENTIALITY: Efforts will be made by the research team to keep your personal information private, including research study records, and disclosure will be limited to people who have a need to review this information. All paper and electronic data collected from this study will be stored in a secure location on the UNT campus and/or a secure UNT server for at least three (3) years past the end of this research in a password protected computer in the PI's campus office. Research records will be labeled with a pseudonym and the master key linking names with codes will be maintained in a separate and secure location.

Please be advised that although the researchers will take these steps to maintain confidentiality of the data, the nature of a course prevents the researchers from guaranteeing confidentiality. The researchers would like to remind participants to respect the privacy of your fellow participants and not repeat what is said in the group to others.

Participation in this online study involves the potential for the loss of confidentiality similar to a person's participation in a course at the library or online.

The results of this study may be published and/or presented without naming you as a participant. The data collected about you for this study may be used for future research studies that are not described in this consent form. If that occurs, an IRB would first evaluate the use of any information that is identifiable to you, and confidentiality protection would be maintained.

While absolute confidentiality cannot be guaranteed, the research team will make every effort to protect the confidentiality of your records, as described here and to the extent permitted by law. In addition to the research team, the following entities may have access to your records, but only on a need-to-know basis: the U.S. Department of Health and Human Services, the FDA (federal regulating agencies), the reviewing IRB, and sponsors of the study.

This research uses third party software called Zoom and Qualtrics and is subject to the privacy policies of these software noted here: https://zoom.us/privacy and https://www.qualtrics.com/privacy-statement/

This study uses Tango Card, Inc. ("Tango Card") for your compensation. Tango Card provides that use of www.tangocard.com, www.rewardlink.io and www.rewardsgenius.com (the "Sites") are subject to the Terms Of Service (TOS) posted on their website, which may be updated from time to time. In the event these TOS conflict with the Privacy Notice, the Privacy Notice shall govern as to the conflicting terms. If you have any questions regarding these TOS, please contact cs@tangocard.com.

CONTACT INFORMATION FOR QUESTIONS ABOUT THE STUDY: If you have any questions about the study you may contact Dr. Sarah A. Evans at 940-369-8102, or by email at sarah.evans@unt.edu. Any questions you have regarding your rights as a research subject, or complaints about the research may be directed to the Office of Research Integrity and Compliance at 940-565-4643, or by email at untirb@unt.edu.

CONSENT:

- Your signature below indicates that you have read, or have had read to you all of the above.
- You confirm that you have been told the possible benefits, risks, and/or discomforts of the study.
- You understand that you do not have to take part in this study and your refusal to participate or your decision to withdraw will involve no penalty or loss of rights or benefits.
- You understand your rights as a research participant and you voluntarily consent to participate in this study; you also understand that the study personnel may choose to stop your participation at any time.
- By signing, you are not waiving any of your legal rights.

Please sign below if you are at least 18 years of age and voluntarily agree to participate in this study.

SIGNATURE OF PARTICIPANT

DATE

*If you agree to participate, please provide a signed copy of this form to the researcher team by clicking "Submit." They will provide you with a digital copy to keep for your records.