

# **University of Arizona**

Artworks
Consent to Participate in Research

Research Project/Study Title: The Music, Health and Wellness Storytelling Project

Principal Investigator (person leading the research project/study): Jennie Gubner, PhD

The Institutional Review Board (IRB) at the University of Arizona is responsible for protecting you in research. The IRB read everything about this project. They decided it is safe for you to join if you choose.

### What is this form?

This is a paper for you to sign if you want to be a part of this research project. \*A research project is a group of people trying to find an answer to a question. In this paper, it is also called a study. This paper has important information about the project that you should read before you agree to be a part of the project. You should ask questions so you understand what will happen during the project.

### **Summary of the Research**

There are many people from different places. They have different ways to live their lives. They can feel lonely and alone. This project is going to ask different kinds of people about the music they like. This project will also ask when those people like to listen to that music.

# Why are we doing this study?

Music is important to many people who share feelings of loneliness. Music also helps those people in their lives. This project wants to tell those stories. There will be short videos and stories about music, health, and feeling better. These stories will be put on the internet.

### What will happen if I take part in this study?

We will ask questions to make a music story about you. We will record your voice or videotape you. You will talk about why music is important to you. You will also talk about how music makes you feel.

### How long will I be in this study?

We want to do at least one recorded discussion with you. You will talk about why music is important to you. We may want to talk to you again.

### How many people will be in this study?



### Can I stop being in this study whenever I want to?

You do not have to be in this project. If you want to be a part of it, you can leave it whenever you want. You will **not** be in trouble for leaving, and you will **not** lose any benefits. Whatever you decide, it will not have any effect on your time at Artworks, or the University of Arizona.

## What am I risking, and what can I gain, from being in this study?

We want health care providers to use music and art as a part of helping people feel better. Health care providers may be doctors, nurses, medical assistants, or other people who support your health. You will have a chance to add to research. This research can better understand how health care providers can use music to support patients. You will be able to share music you are passionate about.

Your only risk is that you might feel bad or remember a time that makes you feel bad. A bad feeling is when you feel a way you do not want to. You might feel bad when you listen to music. You might also feel bad when you talk about music. But you can stop talking or listening whenever you want. You can change what you are listening to. You can change what you are talking about.

For example, imagine a participant listens to music for this study. One song they listen to is a song their grandmother used to sing. They start to feel sad because they no longer see their grandmother. They ask the study team to stop playing the song. They tell the team they would like to talk about something else. The study team agrees and they ask the participant about a different song.

### Will I be paid for being a part of this study, or will I have to pay for anything?

You will not receive anything. You will not have to pay for anything. We will only need your time while you are at Artworks.

### Will the information you get about me be kept secret?

When you sign this form, you are telling us it is okay to use you in the videos we take of you, and what you tell us. If you want to use a fake name so no one knows it is you, we will do that for you. If there is something you do not want us to share about you, we will not share it.

### Will the information I tell you be used again in the future?

We will only use your information in the future if you tell us it is okay to do that.

### Who can answer my questions about this research project?

For questions, concerns, or complaints about the project, you may contact Dr. Jennie Gubner at 521-621-6709 or jgubner@arizona.edu.

For questions about what rights you have in this project or to talk about other things in the project that are worrying you, or complaints with someone who is not part of the research



team, you may contact the Human Subjects Protection Program Director at 520-626-8630 or online at https://research.arizona.edu/compliance/human-subjects-protection- program.

### Now I will ask you some questions about the study

- 1. What will you do if you are part of this study? [Answer for the person who is gaining consent: You will record my voice or videotape me. I will talk about why music is important to me. I will also talk about how music makes me feel. You will make a music story about me.]
- 2. **What are the risks of this study?** [Answer for the person who is gaining consent: I might feel bad or remember a time that makes me feel bad.]
- 3. What do you get for participating in this study? [Answer for the person who is gaining consent: I can talk about music and help health care providers use music to support their patients.]
- 4. What does it mean that the study is "voluntary?" [Answer for the person who is gaining consent: I can join the study or not.]
- 5. What can you do if you want to stop or don't want to participate anymore? [Answer for the person who is gaining consent: I can tell study staff I do not want to be part of the study anymore.]

[Note to person gaining consent: You may have other ways of wording these questions. If the potential participant is unable to answer a question or answers it incorrectly/incompletely, return to that part of the consent form, review it, and then ask that question again. You might also consider asking the relevant question after you cover the corresponding section in the consent form.]

6.	Do you	have	any	questions	for	me?
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7.	For guardian/legal representative (if appropriate): Do you agree for [person's name] to participate in this study? Yes/No Study staff initials Date			
8.	Do you agree to continue with this project?			
	Yes / No			
	Study staff initials			
	Date			

# Individual is unable to consent – read script

Participant ID

Do you have someone who helps you make decisions? [If yes, "Would you like to talk to that person about participating in the study and then contact me again?" If no, read the following:]



### [Plain Language Adapted Version] posting with a permission

Thanks for your interest in the study. We need to make sure you understand what the study is about, and we are not sure you understand what it is about right now. You will not be able to participant in the study and that's ok.

Color meanings:

Yellow – Shorten sentence and paragraph length to focus on one subject per sentence and one topic per paragraph

Green – Use common words or define necessary jargon - Not everyone knows every word, so using common words avoids confusion

Red – Communicate expectations clearly - Not everyone picks up on indirect statements

Blue – Exclude or move less-important information - Too much information can confuse the wrong audience and distract them from the important information

Turquoise – Avoid passive voice and use active voice - Passive voice can be vague and confusing

Dark Red – Use talk-back (teach-back) and comprehension checks - Ask open-ended questions and have participants repeat and rephrase information to check for understanding. Provide instructions for the research team on how to explain information differently if someone is not able to answer the teach-back questions.

\*\*\* NOTICE: Many areas might overlap with multiple colors. Other colors are most likely to happen at the same time as yellow. If this overlap happens, one of two things happen.

One: the section is a mix of both colors in one sentence. This highlights the specific area where the non-yellow color is. Yellow is a full sentence change. If part of a sentence is yellow, the rest is also changed with yellow rules in mind.

Two: The document gives non-yellow colors a priority. Yellow changes happen so often. Showing where those changes happen is less important than showing where the document uses non-yellow rules.