

New Research Initiative

Voice hearers and allies are partnering to find out what makes our Hearing Voices groups so useful. Your voice and stories are essential to answering that question. If you are a voice hearer and have been involved in these groups, please consider offering your wisdom.

Instructions: Responses can be submitted on-line at www.ourvoicesraised.org or using this paper form. If you complete this paper form, please return your consent form in one envelope and your survey responses in a second envelope in order to keep your responses anonymous. Mailed responses can be sent to the following address:

Hearing Voices Research & Development Project
Attn: Caroline Mazel-Carlton
187 High Street, Suite 202
Holyoke, MA 01040

Whether you complete the survey on-line or on paper, you may complete as many or as few questions as you choose.

Mount Holyoke College Informed Consent Form

Study: How do Hearing Voices peer-support groups work?

Principal Investigator: Gail Hornstein, Professor of Psychology

Procedures:

The procedures to be followed in the project will be explained to you, and any questions you may have about the aims or methods of the project will be answered. This questionnaire is an invitation to share your story about what Hearing Voices Groups mean in your life. The amount of time you spend telling that story is up to you. You can write as much or as little as you like. You can respond in as much or as little detail as you would like. If you don't want to answer a question, just leave it blank. Hearing your story is very important to us so questions that invite you to reflect on and describe parts of your experience may take more time. The 1st and 2nd sections of this questionnaire have questions like these. We'll also ask some background questions and they can be found in the last section. Some people move quickly through them but others will find that there are stories to be told there, too. Either way, there are always options for you to explain things in your own words if choices offered don't seem right for you.

Risks of Being in the Study:

It is possible that in reflecting on, and describing things that have occurred in your life, you may experience negative emotions and feelings. If you feel yourself becoming overly distressed, we recommend that you stop filling in the questionnaire. If you need additional support, touch base with your group or its membership, if possible, or other people in your support network. You are also welcome to reach out to us at research@OurVoicesRaised.org.

Benefits of Being in the Study:

The questionnaire is part of a research project investigating Hearing Voices Groups in the United States. We're interested in gaining a better understanding of how Hearing Voices groups work and what essential elements of hearing voices groups make them effective for people who hear voices, see visions or have other unusual or extreme experiences. It is an opportunity to amplify your voice and knowledge with respect to the growing work of the Hearing Voices movement and its groups across the nation. Your involvement will inform our understanding about what it is to hear voices, see visions or have other unusual experiences and what works best for those who do. This is the first project in the US that aims to include voice hearers at every stage of the research process. This project is committed to sharing its findings with the community that has generated them (and beyond), and to create opportunities for the hearing voices community to expand its work in new ways.

Confidentiality:

The research team will keep your personal information strictly confidential. The Consent Form will be stored separately from the Questionnaire. Should you offer your name and personal details for a voluntary follow-up interview, they, too, will be stored securely and will not appear in any reports or publications that result from our research. The questionnaires will be seen only by the research team.

The responses you provide may be used in published writings in academic journals, articles, books, conference presentations or other project-related activities. When direct quotations are offered to help illustrate a point or to stimulate discussion, we will ensure that people are not personally identifiable (for example, any identifying names, places and institutions will be changed or edited out).

The final section of the Questionnaire asks whether you'd like to be involved in a follow-up interview that may be carried out with a subset of participants. We would do this by arranging a phone call. If this is something you'd be interested in, please check the box and add your name and email address. Otherwise, just leave it blank. The final section and the Consent Form will be kept separate from the questionnaire and linked only through an anonymous ID number.

Voluntary Nature of the Study:

Participation is voluntary and you are free to stop completing the questionnaire at any time.

Contacts and Questions:

Any inquiries: Please contact martha@westernmassrlc.org or caroline@westernmassrlc.org

In addition, you may contact the Mount Holyoke College Institutional Review Board (institutional-review-board@mtholyoke.edu) for information about the rights of human subjects at Mount Holyoke-approved research.

Statement of Consent:

I have read and understand the above information. I am 18 years of age or older. I consent to participate in the study. I allow my data to be used for research purposes, but I understand that researchers will make sure that I will not be personally identifiable in any presentation or publication.

- By checking this box and signing my full name below, I agree to the above Statement of Consent.

Sign Full Name*

- I would like a report of the group results of this research project upon completion.

QUESTIONNAIRE

Sections:

- A. About your Hearing Voices Group
 - B. Reflect on your relationship with your voices
 - C. How things have changed, if at all, in your life overall
 - D. Demographic information
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A. Please tell us about your Hearing Voices Group:

1. Please tell us about your involvement with the group:

- a) How did you first hear about the group?

- b) How long did you know about the group before you first attended?

- c) How long have you been attending the group?

- d) How frequently do you attend the group?

- e) I first started attending the group....
 - as soon as I heard about it
 - within the first year of having heard about it
 - more than a year after having heard about it
 - other (please describe)

f) I support the group by...(please check all that apply and feel free to add more)

- helping with drinks and snacks
- listening to what's going on for others
- staying in touch outside of group time
- sharing parts of my own experience
- facilitating
- other(s) (please describe)

g) My group is located in the following state (write in the US state where your group is held)

h) I consider our group location...

urban suburban rural

other (please describe)

2. Please tell us about how your Hearing Voices Group is structured:

a) Where does your group meet? (To ensure privacy, please use non-specific descriptions like: a mental health agency, community center, local town public space, clinic, library, peer support organization or hospital)

b) Is your group sponsored by someone? If so, please describe: (To ensure privacy, please use non-specific descriptions like: a mental health agency, community center, local town public space, clinic, library, peer support organization or hospital)

c) How often does your group meet?

d) How long has your group been meeting? (If you don't know, just leave blank.)

3. Please tell us about facilitation and group process:

a) How many facilitators usually facilitate your group?

b) What experiences do your facilitator(s) bring to the group? (please check all that apply and feel free to add more)

Mental health professional

Ally (a family/friend of voice hearer(s), who doesn't hear voices themselves)

Voice hearer

I am one of the group's facilitators

Other(s) (please describe)

c) Are there things your facilitators do that you find particularly useful? If so, please describe:

d) Are there things your facilitators do that you find are not useful? If so, please describe:

e) The group adheres to guidelines or agreed-upon values that are...

- Based on the HVN Charter
- Developed by someone else (agency, hospital, NAMI, etc.)
- I'm not sure where our guidelines or values came from
- We have no guidelines that I know of
- Developed by the group itself
- Developed by the facilitator(s)
- Other(s) (please describe)

f) What sorts of topics come up in your group discussions? (please check all that apply and feel free to add more)

- The Hearing Voices Network and our being part of a larger movement
- HVN history and charter and how our group fits in
- What our voices say to us
- Local events and what's going on socially, news, or otherwise
- Good or bad things happening in our lives
- Sharing things that have worked for us
- Navigating our choices around medication use
- How our group might be improved
- How we manage with our voice hearing experience
- Reflecting on the personal strengths we possess
- Reflecting on voice hearing not always being a sign of illness
- Relationships with family, friends, co-workers, etc.
- Other(s) (please describe)

g) Each of us understands our voice hearing experience in unique ways. Is your group curious about, and does it make space for a variety of viewpoints about voice hearing, for example...(please check all that apply and feel free to add more)

- Being highly sensitive
- Related to upsetting and overwhelming events
- Being gifted
- Extra sensory perception
- Feeling possessed
- Having super powers
- The voices are those of aliens
- The voices are of a spiritual nature
- Being subject to government broadcasts
- Being sick and hearing voices as a result
- Other(s) (please describe:

h) How does your group handle conflict or difficulties when they arise? (please check all that apply and feel free to add more)

- Try to address it in the moment
- Look for places where people can agree (commonality)
- Use someone outside the group to settle things
- Make space for differences of opinion/belief
- Ask some people not to attend anymore
- Change the subject
- Use our ground rules to help us through the difficult place
- Shut it down because it is against our guidelines
- Other(s) (please describe)

i) The best thing about attending the Hearing Voices Group is...

j) Something I don't like about my group is...

k) Something that would really improve my Hearing Voices Group is...

The next set of questions are more about you, your voices and your personal experience with your Hearing Voices Group. Questions asked in this section will help us understand more about your group from your unique perspective. As mentioned in the instructions, for the purposes of this questionnaire, "voice hearers" refers to people who hear, see, feel, taste, and/or smell (that is sense) things that others do not.

B. Please tell us a bit more about your voices:

1. What is your voice hearing experience like?

a) I have had this experience since...

b) How often do you hear, see, or otherwise sense things that others do not?

c) I sense them...(please check all that apply and feel free to add more)

Coming from outside my body

Coming from inside my head

Coming from somewhere else in my body

Other(s) (please describe)

2. Do your voices have names? Who are they to you? How do you get along with them? Tell us anything else you'd like us to know about them:

3. In addition to your Hearing Voices Group, have you consulted other resources in order to try to understand your experience? (such as doctors, nurses, mental health professionals, friends, church and other cultural affiliations, books, internet, etc.) If so, please describe who, and your experience with them.

4. For me, voice hearing is...

C. Please tell us about how your involvement in the Hearing Voices Group has touched your life:

D. These questions may or may not have much to do with the Hearing Voices Group but will help us to understand more about people's experiences. As with the previous questions, please feel free to skip any you wish and use language that feels authentic to your identity and experience.

1. What is your age? (in years)
2. How would you describe your gender?
3. How would you describe your race or ethnicity?
4. Have you been given a psychiatric diagnosis? If so, please describe:
5. Have you been hospitalized for a psychiatric reason? If you feel comfortable, please describe:
6. Have you been prescribed medication based on a psychiatric diagnosis? If so, what has your experience been?

Congratulations! You have completed the questionnaire. If you are interested in taking part in a follow-up interview based on your response to this survey, please indicate that by checking the box below and offering us your contact information.

- I would welcome a follow-up call from the research team (please note that due to capacity, the research team may not be able to contact everyone interested.)

Name:

City:

State:

E-mail:

Phone number: