

**Drexel University**  
**Permission/Consent to Take Part In a Research Study Conducted at**  
**Drexel University's Center for Public Health Readiness and Communication**

For the purposes of this study, we are asking you to speak on behalf of your experiences with children and youth with special health care needs as a family member, provider, emergency responder, or a health IT expert.

**1. Title of research study: *Effective Communication in Public Health Emergencies - Developing Patient-Centered Tools for Children with Special Health Care Needs and Individuals with Autism Spectrum Disorders***

**2. Researcher:** Dr. Esther Chernak, MD, MPH, Dr. Renee Turchi, Jennifer Plumb

**3. Why you are being invited to take part in a research study**

We invite you to take part in a research study because you have a relationship with a child or youth with special health care needs in the state of Pennsylvania. Participation in this research study is voluntary.

**4. What you should know about a research study**

- Someone will explain this research study to you.
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part now and change your mind later.
- If you decide to not be a part of this research no one will hold it against you.
- Feel free to ask all the questions you want before you decide.

**5. Who can you talk to about this research study?**

If you have questions, concerns, or complaints, or think the research has hurt you, talk to the research team:

Dr. Esther Chernak, MD, MPH  
Dornsife School of Public Health  
Drexel University  
3215 Market Street  
Philadelphia, PA 19104  
Phone: 267-359-6038  
Email: dec48@drexel.edu

Dr. Renee Turchi  
Dornsife School of Public Health  
Drexel University  
3215 Market Street  
Philadelphia, Pa 19104  
Phone: 267-359-6051  
Email: Renee.Turchi@DrexelMed.edu

Jennifer Plumb  
Drexel A.J. Autism Institute  
3020 Market St  
Philadelphia, PA 19104  
Phone: 215-571-3438  
Email: jcp94@drexel.edu

This research has been reviewed and approved by an Institutional Review Board (IRB). An IRB reviews research projects so that steps are taken to protect the rights and welfare of humans subjects taking part in the research. You may talk to them at (215) 762-3944 or email [HRPP@drexel.edu](mailto:HRPP@drexel.edu) for any of the following:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research subject.
- You want to get information or provide input about this research.

### ***6. Why is this research being done?***

Children and youth with special health care needs and individuals of all ages with autism spectrum disorders are at-risk for severe outcomes during disasters. The Center for Public Health Readiness and Communication at the Drexel University's Dornsife School of Public Health (DSPH) will work with partners to study the disaster communication needs of these two understudied populations with unique preparedness and communication challenges. The results of this study will be used to develop tools that can be used for communicating with these at-risk communities during emergencies and disasters.

### ***7. How long will the research last?***

We expect that it will take you 60-90 minutes to complete the qualitative assessment today. The entire study will take approximately 24 months to complete before the results of the study are known.

### ***8. How many people will be studied?***

We expect to interview 150 people directly, including families and caregivers of children and youth with special health care needs, health care providers, other health and social service professionals, emergency response organization representatives, and experts in health information technology.

### ***9. What happens if I say yes, I want to be in this research?***

If you volunteer to participate in this study, the researcher will ask you to do the following tasks today:

1. You will also be asked to complete a short questionnaire providing demographic information.
2. Then, you will be guided through a set of questions regarding your preparedness and communicating needs, as well as your experience during emergencies and disasters. Upon completion of qualitative assessment your participation in this research study will be complete.

### ***10. What are my responsibilities if I take part in this research?***

If you take part in this research, it is very important that you:

- Follow the investigator's or researcher's instructions.
- Tell the investigator or researcher right away if you have a complication or need to stop for any reason.
- Answer all questions as best as you can. You can also skip any questions you are uncomfortable answering.

**11. What happens if I do not want to be in this research?**

You may decide not to take part in the research and it will not be held against you.

**12. What happens if I say yes, but I change my mind later?**

If you agree to take part in the research now, you can stop at any time it will not be held against you.

If you stop taking part in the research, already collected data may not be removed from the study database. If you agree, this data will be handled the same as research data.

**13. Is there any way being in this study could be bad for me?**

Participation in this study should not pose any physical or psychological risks or any type of discomfort. You may choose not to answer any question you do not feel like answering.

**14. Do I have to pay for anything while I am on this study?**

There is no cost to you for participating in this study.

**15. Will being in this study help me in any way?**

There are no immediate benefits for participating in this study. However, the tools developed from the results of this study will help government agencies and health/social service providers learn how to better communicate with at-risk populations, such as families of children with special health care needs, during all phases of emergency response, including long-term recovery and the 'return' to daily living.

**16. What happens to the information we collect?**

Efforts will be made to limit access to your personal information including research study records, to people who have a need to review this information. We cannot promise complete secrecy.

Organizations that may inspect and copy your information include the IRB and other representatives of this organization.

We may publish the results of this research. You may also be asked to test the messages that are developed as a result of this research. However, we will not provide individual information but instead only show results as group results. Your name and other identifying information will not be made available in any results published.

**17. What else do I need to know?**

This research is being done by Drexel University and conducted by the faculty at The Center for Public Health Readiness and Communication who are based at the Dornsife School of Public Health.

You can choose whether or not you want to participate in this study. If you choose to be part of this study, you can stop participation at any time. You can do this without penalty. You are not waiving any legal rights by participating in this study. You may choose not to answer any questions you are not comfortable in answering and still remain in the study.

For families/caregivers/person with special health care needs, including an autism spectrum disorder: If you agree to take part in this research study, you will receive a \$25 gift card for your time and effort.