



Research Participation Guidelines

Things to think about before agreeing to participate in research:

Research helps bring the stories of our families into the minds and lives of people who otherwise might not know about the unique joys and struggles our families face. It can be empowering to engage in efforts to change public opinion, policy, and mental health and health care delivery and policy. At the same time, when considering an interview that carries the risk of exposing your child or family's story to others, we encourage you to ask questions and always act in the **best interest of your child and family**. In our quest to educate others it is sometimes easy to be swept up into something that we may later regret. Take the time up front to really think through your participation and what implications it may have for your child and your family. Play through the worst case scenarios in your head. Check out the people asking you for your time, thoughts and stories. Above all, if the project doesn't "feel right", even if you can't put your finger on anything specific, **DON'T DO IT**.

What kind of research do you want to participate in? There are basically three types of requests:

1. Academic/Medical Research
2. Grassroots Community and Organizational Research
3. Media Research

Each of these types has different target audiences and different standards and procedures.

Academic and Medical Research:

This includes studies by doctors, mental health professionals and academic researchers in the social sciences (primarily sociology and political science). All academic, medical and psychological research is conducted by individuals or teams of researchers who are affiliated with institutions such as universities or hospital-based clinics. The one exception might be individual clinicians in private practice publishing on their own clientele.

If a researcher approaches you to participate in academic or medical research, consider the following:

- Is the researcher(s) affiliated with an institution I trust? It is more than OK to check out an institution's credibility and research history.
- Do the researcher(s) have the appropriate credentials? By this, we mean an advanced degree. You can also ask around about the reputation of the researcher(s) and connection to the community, etc.
- Have the researcher(s) secured the appropriate institutional approval for their work? This is crucial. ALL research conducted with other human beings requires approval by an institutional review board (IRB). NEVER agree to participate in academic research that does not bear a seal from the university IRB. These boards ensure that the research will in no way harm the participants (you), and take specific steps to protect your confidentiality. It also ensures that you're being told everything you need to know about what you're agreeing to do, and what will be done with the results. **There are NO exceptions to this rule.**
- What is the researcher trying to find out? What are the basic assumptions underlying the research? Are these compatible with your values and how you wish to see your family participate?
- Who is the study aimed at? Who does the research mean to be in conversation with? Is the research going to support efforts to improve policy or the lives of youth, or is it merely an academic exercise?
- Do I want to contribute my time and energy to this sort of project?
- Have all of my personal concerns been addressed **in writing** by the researcher? For example, if you feel strongly that you do not want your name or identifying details used, do you have a written contract that states that this will be the case?
- How do you feel about the researcher? Do you feel comfortable, listened to, respected?
- If, at ANY time, even AFTER you've finished the research, you decide that you don't want to participate, you have the right to let the researcher(s) know that, and to ask that your data be destroyed.

Grassroots Community and Organizational Research:

This includes research done by organizations that provide services to individual communities- it could be anything from counseling to political advocacy and legal services. Organizations will typically conduct research for a few reasons: to help them understand the needs of a particular community, or to evaluate the efficacy of their services or programs.

Sometimes this research will concentrate on people affiliated with individual organizations or programs, but often, it will include others from outside the community. Some things to think about:

- Do I believe in the mission of this organization?
- Do I want to contribute my time and energy to this sort of project?
- Do I feel like I fully understand what the research is for and how it will be used? (These organizations typically have no requirements for institutional review, so you want to be extra sure you're comfortable with everything they say about the purpose of the research and the way your "data" will be handled, who will see it, etc. Always keep in mind that the risks for inadvertent mishandling of the data or "outing" of participants' responses, or having your data associated with your name in a small community are much greater with this type of research.)
- Does this researcher or organization have a relationship to other people or organizations that I already know and trust? (It's always a red flag when nobody you know has ever heard of an individual or group or seem unwilling to endorse a project.)
- Are there trained researchers associated with the project? (Often, organizations will contract with researchers to help them ensure that they are using widely accepted methods. This is important, because incompetently conducted research isn't very convincing to funders or policymakers.)
- When and how will the results be published? Who will have access to the results?
- When will the study be concluded?
- Who will evaluate the responses and how will it be compiled?

Media (TV, Radio, Print) Research

While media portrayals of transgender people help to educate the public they are often not done in the best interest of the participants. Please refer to this link for more in-depth advice: <http://imatyfa.org/educators/tyfamediamanualforparents.pdf>

- What is the reputation of the media outlet? The reporter? The interviewer?
- Have they ever dealt with the topic of transgender and gender variant children before?
- Who else will be interviewed?
- What is the angle of the story?
- What is the time requirement?
- Will they protect identities?
- Will they require "before" and "after" photos and birth names?
- Have you evaluated the physical and emotional health and resilience of your entire family and their readiness to be so public? Are you prepared to handle the outcome if things do not go as planned?

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