



Improving Access to & Experiences of Transgender & Non-Binary Patients in Clinical Research



**Your Questions Answered by Panelists
from the webinar of October 13, 2021**

Thank you to our collaborators on this webinar.



[Access the webinar recording here.](#)

What are some ways to encourage the trans community to participate in clinical research especially if there is a justified fear of discrimination in receiving healthcare?

- Raise awareness of clinical research in partnership with trusted community advocates
- Utilise inclusive language and visuals in patient education materials
- Deploy trial awareness activities using media accessed by the trans and non-binary community
- Put time and effort into building long-term, meaningful relationships with the trans and non-binary community to build trust
- Provide cultural sensitivity training to site staff to educate them on respectful interactions with transgender and non-binary patients

How can intake forms be updated to be inclusive and still protect the patient from the risk of being accidentally outed?

Provide optionality on intake for patients to detail information on current gender, sex assigned at birth, personal pronouns and sexual orientation if they choose to do so. An additional box could also be added for those wishing to keep their gender identity private to check, in addition to a providing a private space for patient/site staff discussions.

You brought up gendering in lab results, and I'm not sure how that gets changed, but my question is in line with that, we do some studies that collect RNA/DNA samples, how do we include transgender participants in situations like this, do we not need to list their gender at birth?

There are currently no clear medical and scientific guidelines in place in clinical research to guide collection of RNA/DNA samples and how they should be gendered. Parexel is working on this topic and would be happy to share our findings if you would like to provide your contact details via CISC RP.

Do you have any suggestions on Patient Advocacy groups for sponsors to work with to ensure inclusion of transgender participants?

There are local LGBTQ+ (some specifically for transgender and nonbinary individuals) in every state and nearly every county. Some places like the Dana-Farber Cancer Institute have Employee Resource Groups who focus on advocating for their LGBTQ+ patients, supporting LGBTQ+ organizations, etc.

Additional resources:

- [HRC Transgender Patient Services and Support](#)
- [Transgender Advocacy at the State Level](#)
- [How Can Female, LGBTQ, and BIPOC Clinical Trial Disparities Be Improved?](#)
- [Fenway Health – Transgender Health](#) – Excellent resource and Fenway Health does a significant amount of research/studies. Their site is constantly updated and includes:
 - Frequently Asked Questions (FAQs)
 - Trans/Non-Binary Focused Groups
 - Suicide Prevention & Other Support Resources
 - Consent Forms
 - Self-Injection Guidance and Needle & Syringe Disposal
 - Transgender Youth Clinic
 - Trans Health Research Studies
 - Provider Support
 - Additional Trans and Gender Diversity Resources
 - [Making Clinical Research Inclusive: Strategies to Include the LGBTQIA+ Community in Research Trials](#)

Can EMRs also be changed so the gender options are non binary? When accessing a patient's record in an EMR, there are typically only 2 choices.

Yes, they can. [AthenaHealth](#) has been doing a lot of work in this area, since at least 2018. Excellent article on [Health Records Adapting to Meet Transgender Needs](#)

What can be used in healthcare facility to confirm someone's Identity while the person is in the process of getting the correct ID document to avoid many questions. e.g. when making payment.

Patients must show their legal ID in order to be seen at a medical facility/participate in a clinical trial. However, the facility should also include a question on intake forms to ask someone both their preferred and legal name. That way, they can be identified within an EHR but also treated with respect.

Best Practices for Medical Providers and Staff re: Transgender Patients

- Treat transgender individuals with respect.
- Refer to transgender people by the name and pronoun associated with their gender identity.
- Ask politely how they would like to be addressed if you are unsure about a person's gender identity.
- Never reveal a person's transgender status unless it is absolutely necessary for the patient's health care.
- Set a high standard for inclusive care.
- Concentrate on care, not curiosity. For example: it is inappropriate to ask about genital status if it is unrelated to care.
- Avoid negative or shocked facial reactions and offensive language.
- Remember: Treat only the ailment: When providing basic medical care, understand that a person's gender identity is often irrelevant. For example: If a patient comes in with a broken arm, you don't need to know whether they have had gender-affirming top surgery. You don't need to know about their surgical status. Focus on the central concern and treat them.
- Educate yourself and others about transgender health care and issues.