# **Develop** a Virtual Participant Support Network to Build Trust

What should I do?

Demonstrate a commitment to building trust and credibility. Sustained efforts to increase diversity and improve equity and inclusivity in clinical trials starts with building trust. Develop a virtual participant support network to demonstrate your commitment to ensuring that your participants are fully supported by your organization or team.

Build Trust & Credibility

Community Partnerships

Representative Clinical Teams

Participant Support Network
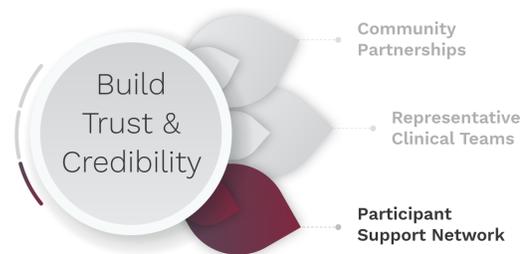
Why should I do it?

➔ Build trust and transparency between participants, Sponsors and clinical trial teams for long term engagement with clinical trials and research.

➔ Increase and improve patient engagement and retention.

➔ Reduce burdens for participants and clinical trial teams by streamlining processes and including participants as partners.

➔ Increase compliance and participant adherence.

➔ Improve outcomes with more robust data collection.

➔ Increase access and awareness for participants to clinical trial participation.

➔ Increase awareness for participants on clinical trial participation value and process.

Ethical Considerations

Trust is hard to build and easy to destroy; therefore, careful and respectful measures are needed. A virtual participant support network is an efficient way to build trusted relationships with participants. However, it will be important to ensure that all populations have adequate knowledge of and access to technology to participate fully, and obtain the most benefit. This will be important for an online support network. Measures will be required to ensure inclusivity. The recommendations provided here should be used as a starting point and then customize it to your support group participants.

The **participant voice** is an essential component for a person-centric approach. While community representatives and diverse clinicians will provide deeper knowledge about participants' community and culture, participants will provide the richest information on their **lived experiences** and how that will **affect** their **participation**. Taking part in a clinical trial can be overwhelming and stressful. Therefore, participants **need a strong support system**. Many times this can be best served by other participants who have gone through or are going through similar experiences. Participants need a support group or network. An online/virtual support group can be more convenient for participants, especially with providing increased accessibility.

Additional resources on **building trust and credibility**

1. Develop Community Partnerships

2. Diversify Clinical Teams to Build Trust

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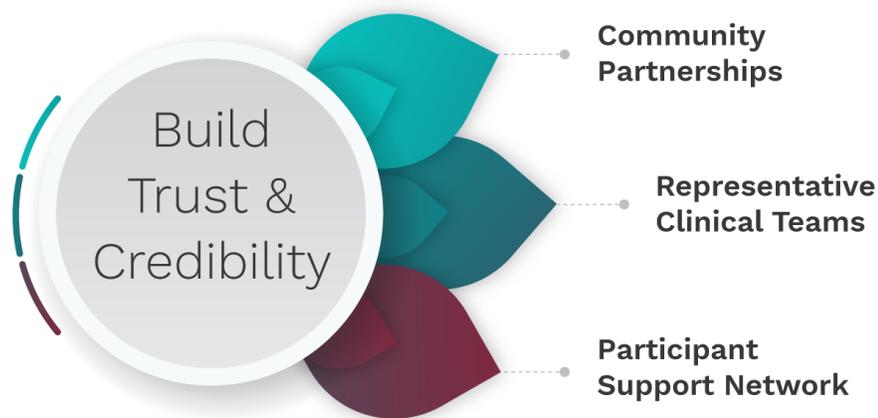
Several digital tools can be used to design, implement, and nurture a support network. Digital solutions/platforms can be used to set up a support network infrastructure that is under your control for security and privacy. Online communities, virtual visits and on demand videos can also be utilized. See the "Elements of a Diverse, Equitable, and Inclusive Digital Clinical Trial" for details on using each of these tools.

Jump to:

- Benefits of a Participant Support Network

- Recommendations for Designing a Virtual Support Network

Benefits of a Participant Support Network

1. Benefits **for participants** in a clinical trial

   a. **Sharing a common experience** (similar concerns, everyday problems, treatment decisions or treatment side effects).

   b. Sharing a **common purpose** or belonging and likely to better understand one another.

   c. Feeling **less lonely**, isolated or judged.

   d. **Reducing distress**, anxiety, or fatigue.

   e. Talking openly and honestly about feelings, in a **safe space**.

   f. Improving **skills to cope** with challenges.

   g. Staying **motivated** and sticking to treatment plans.

   h. Gaining a sense of **empowerment**, self-efficacy, control or hope.

   i. Improving **understanding** of a disease.

   j. Getting practical **feedback** to manage the experience.

   k. **Learning** about health, economic or social resources.

2. Benefits **for clinical trial sponsors** and **clinical sites**

   a. Building trust and credibility which will be valuable for **adherence**, retention and future work.

   b. Demonstrating a genuine interest in participants' **wellbeing**.

   c. Obtaining **qualitative information** (e.g. quality of life), possibly in real-time, about participants' experiences with your clinical trial.

   d. Building **relationships** with participants that can be used to promote your organization, trial, or product.

Recommendations for Designing a Virtual Support Network

1. Consider working with **community partners** or form a collaboration with a patient advisory/engagement organization, clinic, or hospital.

2. Consider **partnering** with a **clinical trial site team** or principal investigator.

3. Build in **security** to protect participants' **privacy** and ensure that bad actors do not join.

4. Partnering with others per items 1-3 will help with ensuring **authenticity** and security of the network.

5. Hosting a virtual support network will allow for more people to join the network, and will provide the **convenience** of not having to travel.

6. Allow participants to join from **different communication** devices, e.g. smartphone or tablet with a digital companion app, or on a computer. A call in via a phone option should also be provided.

7. Utilize **virtual platforms**, along with breakout rooms.

8. The **format** should **vary** from topic focused or guided discussions, to open discussion or presentations from invited guests; or consist of a combination of these.

9. Topics should bring some **value to participants**, and could include: navigating clinical trials, concerns prior to, during or after participating in a trial, or any other topics participants are interested in.

10. Support sessions should occur at **regular intervals**, at a time that is convenient for multiple time zones.

11. Consider who should host or **facilitate** the **sessions**; a clinical research nurse, social worker, a community partner or participant with assistance and support from you.

12. Regardless of who is hosting/leading the sessions, a more experienced person should be present to **assist with any issues** arising from sharing confidential information or misinformation, or any inappropriate or disruptive behaviors.

References & Resources

1. [A Newly Developed Online Peer Support Community for Depression (Depression Connect): Qualitative Study](). Internet support groups allowed the members to learn from each other's knowledge and experiences and explore newly gained insights and coping skills.

2. [Creating and Facilitating Peer Support Groups](). Learn how to bring together and facilitate support and encouragement among a group of people who share common problems and experiences.

3. [Culturally Based Online Peer Support Group Brought Mental Health Benefits During COVID-19; Has Promise for Other Usage](). An online culturally based support program, developed during the COVID-19 pandemic may serve as an effective peer support model beyond.

4. [Online Support Groups: Nuts and Bolts, Benefits, Limitations and Future Directions](). Computer technology is now altering the traditional ways people handle stress, and allowing more people to participate in online support groups.

5. [The Case for Peer Support](). Peer support improves quality of life, increases patient engagement and self-management, and increases overall wellness.