

N=1 Collaborative Donated Resource Hub: Guidelines for Publicizing Donations

Purpose

These guidelines encourage collaborative communication between donors and recipients of the Donated Resource Hub, focusing on the best practices for external communications while respecting patient privacy and proprietary information.

Collaboration Between Donors and Recipients

1. **Encourage Collaborative Discussions:**
Donors and recipients are encouraged to work together to scope external communications. Open dialogue will help ensure that shared information aligns with privacy considerations and best practices.
2. **Hold External Communications:**
All external communications regarding donations should be temporarily held until both parties have discussed and agreed upon the messaging.

Best Practices for External Communications

1. **Specific Identifiers:** Do not disclose specific patient information or details that could lead to the identification of individuals without proper permissions (Protected Health Information - PHI).
2. **Protect Proprietary Information:** Avoid sharing any proprietary scientific information related to drug development or clinical trials without proper permissions.

Recognition

1. **Acknowledgment in Publications:**
If recipients issue any press releases or public statements, all publications resulting from the use of donated resources should include the following acknowledgment:
"[Resource] was obtained from [Organization], a donor within The N=1 Donated Resource Center."
2. **Social Media and Informal Communications:**
Donors and recipients are encouraged to recognize each other and The N=1 Collaborative in social media posts and informal communications while adhering to privacy and consent guidelines.
3. **N1C Logo Usage:**
Support from the N1C should be acknowledged by including the N1C logo in any print or online material used for promotional purposes. For online usage, the logo should include a link to www.n1collaborative.org.

Contact Information

For any questions or concerns regarding these guidelines, please contact The N=1 Collaborative communications team at info@n1collaborative.org.