

Lived Experience Experts: More than just research subjects

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Sammie Valadez
Ray Stanhope



Disclosures

Ray Stanhope

President of the Lone Star Bleeding Disorders Foundation

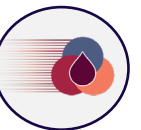
Sammie Valadez

Vice-president of the Bleeding Disorders Alliance Illinois

Top Recommendations



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LEEs As Research Participants Versus LEEs as Research Partners

Research partnership includes research being created, planned and executed for us and with us, the members of the bleeding disorder community who live with a bleeding disorder, rather than research being developed without us to be conducted on us, about us.

Research being created with the members of the bleeding disorder community as active partners in the design, implementation, and dissemination of research insights.



LEE Mission & Vision

Mission:

Improve healthcare outcomes and quality of life for individuals living with bleeding disorders.

Vision:

A research paradigm that includes LEEs as fully engaged partners and valued members of the research team in all phases of the research process. This includes LEE participation in research priorities, study design, recruitment and retention of research participants, grant proposals, implementation, data analysis, communication and dissemination of study results, implementation, and adoption of research findings.



LEE Objectives

- Increase involvement of LEEs in research
 - Awareness
 - Participation in the NRB
 - Participation in research studies
- Increase diversity in research – special focus on under representative population
 - Minoritized populations
 - Women
 - Rare disorders
- Recognize LEEs as valuable partners in research
- Educate and train LEEs for full and meaningful participation in research
- Drive research reflecting the needs and priorities of LEEs
- Make research more meaningful for researchers and the bleeding disorder community



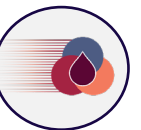


Lived Experience Experts (LEEs)

LEEs are individuals, their caregivers, and family members directly impacted by inheritable bleeding disorders.

Their diverse and personal knowledge gives them the unique ability to translate lived experiences into meaningful system change.

Based on this important perspective, LEEs should, to the best of their abilities, influence and/or drive bleeding disorders research. They should reflect a diversity as vast as those affected by them.



Opportunities for LEE Engagement in Research Efforts

Research Development

- Co-development of study design:
 - research questions,
 - procedures/activities,
 - recruitment plan,
 - outcomes/aims
 - study consent and study materials
- Protocol review



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Research Implementation

- Assist in study
 - recruitment,
 - consenting, and
 - data collection
- Research oversight (Data Safety and Observational Study Monitoring Boards)



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Research Dissemination

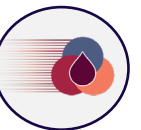
- Participate in data review & manuscript development
- LEE tailored summary of the publication
- Co-develop other dissemination materials
- Help disseminate study results - for example:
 - presentations in educational events



Recruitment of LEEs may be the Biggest Hurdle

Top barriers identified:

- Lack of trust
- Lack of awareness
- Lack of experience and knowledge of the research process
- Prior negative experience with the research process
- Lack of opportunities to participate
- Not being respected or considered a true research partner
- Time and resource constraints
- Lack of compensation for participation



Harmonization with Other WG Recommendations



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Research and Development (R&D)

- LEE WG worked very closely with R&D to fine tune the SOS priorities:
 - LEEs voiced interest in joining the discussions
 - LEE liaison in the group paired with researcher in R&D WG
 - Glossary of terms (common vocabulary and acronyms)
 - LEEs felt included and supported
- Similar process expected in NRB

Infrastructure (IFS)

- NRB's Guiding Principles: collaboration with IFS and Health Equity Diversity and Inclusion (HEDI)
- Need for oversight program for LEE engagement, education, and participation
- Web portal to engage and educate LEEs and HEDI champions
- Processes to ensure LEE participation in all stages of the research enterprise



Community Engagement: The TABLE concept

1. Community Engagement's concept of having everyone at the table was reconsidered in two ways:
 - a. The table to which everyone was invited belonged to the LEEs – an *enhanced LEE-directive concept of LEE participation*
 - b. A picnic organized in the LEE 'neighborhood' to which all partners brought their expertise – an *enhanced partnership-oriented role for LEEs in the research enterprise*
2. DESSERT = rewards of LEE/ community involvement and participation
3. Socialize the term LEE
4. Need for LEE recognition and incentivization, including the possibility of compensation
5. Research Ambassador Program:
 - a. Well versed LEEs going out to communities and teaching peers about research, implications, and benefits
 - b. Help build the “army” of LEEs to participate in the NRB - #jointheLEEmovement



Workforce (WF)

- To become informed participants, LEEs will need to be educated based on their interests and roles
- Educational modules/curriculum and resource development for both LEEs and researchers
- Research Ambassador trainings
 - Individuals who communicate and teach the community about research



Workforce (WF)

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Policy

- Integrate LEEs into Research Advocacy
- Create LEE Network of Research Advocacy Champions (?) Ambassadors – well versed in research, policy
- Involve LEEs in state and local policy discussions as a steppingstone – through NBDF, chapters.
- Focus on engaging marginalized and minoritized populations



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Health Equity Diversity Inclusion (HEDI)

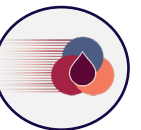
- Strong collaboration with the HEDI WG
- Recruitment of diverse researchers
- Strong focus in engaging the underrepresented disengaged minoritized and marginalized communities
- Participation in research may be a conduit to increase access to care



Integration into the NRB

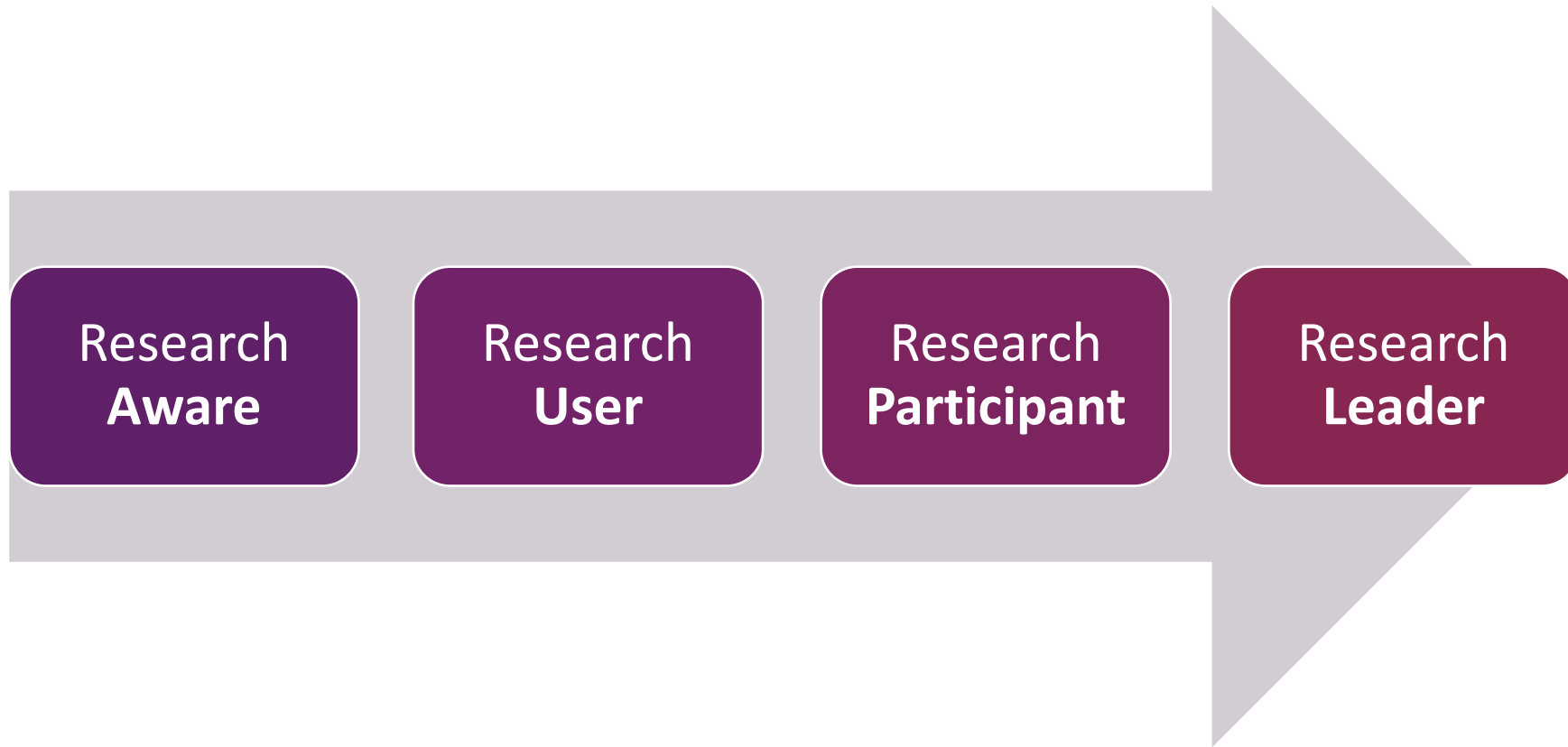


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Training of LEEs

Training should focus on multiple levels of engagement and be tailored based on the LEE's level of interest and comfort



LEE/Researcher Collaboration within the NRB

Web Portal

LEE

- 1 Identify interest
- 2 Participate in education and training



LEE participation in content development, and advisory, review, evaluation, and other committees throughout the research enterprise

3 Connect LEE and researchers based on interest

4 Develop and execute project

5 Disseminate findings

LEE-Centered Research

Researcher

- 2 Participate in education and training
- 1 Identify interest



Mitigating Challenges

- Building trust through complete transparency
- Leverage the role of community engagement to help increase awareness, education, and participation
- Promote research and the NRB through Research Ambassadors
- Evaluation of participants (LEE, researchers, subjects) to improve processes
- Compensate LEEs for time and effort



Q | A



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