

Community Engagement: Recommendations for the NRB

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Community Engagement: Top Recommendations

Jeremy Griffin



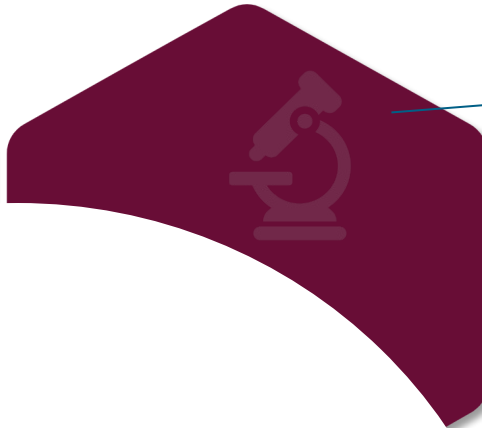
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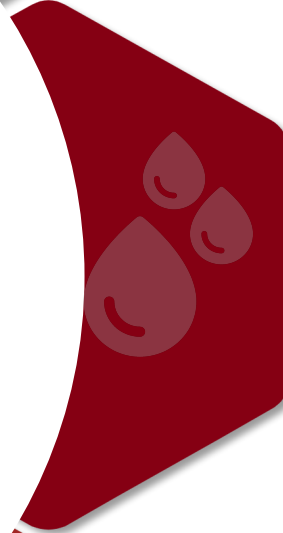
Who is the community?



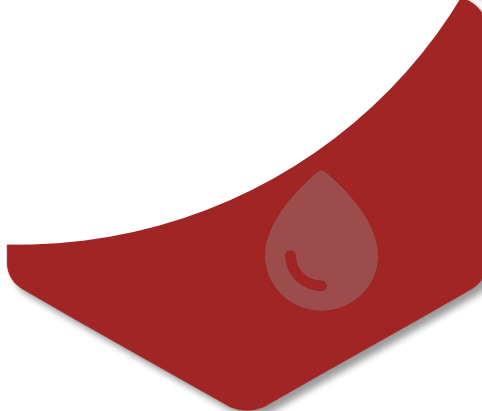
How would we measure success?



How can we ensure ongoing trust and transparency with the community?



What is the level of research literacy?



What is engagement?



What are the current biggest challenges?



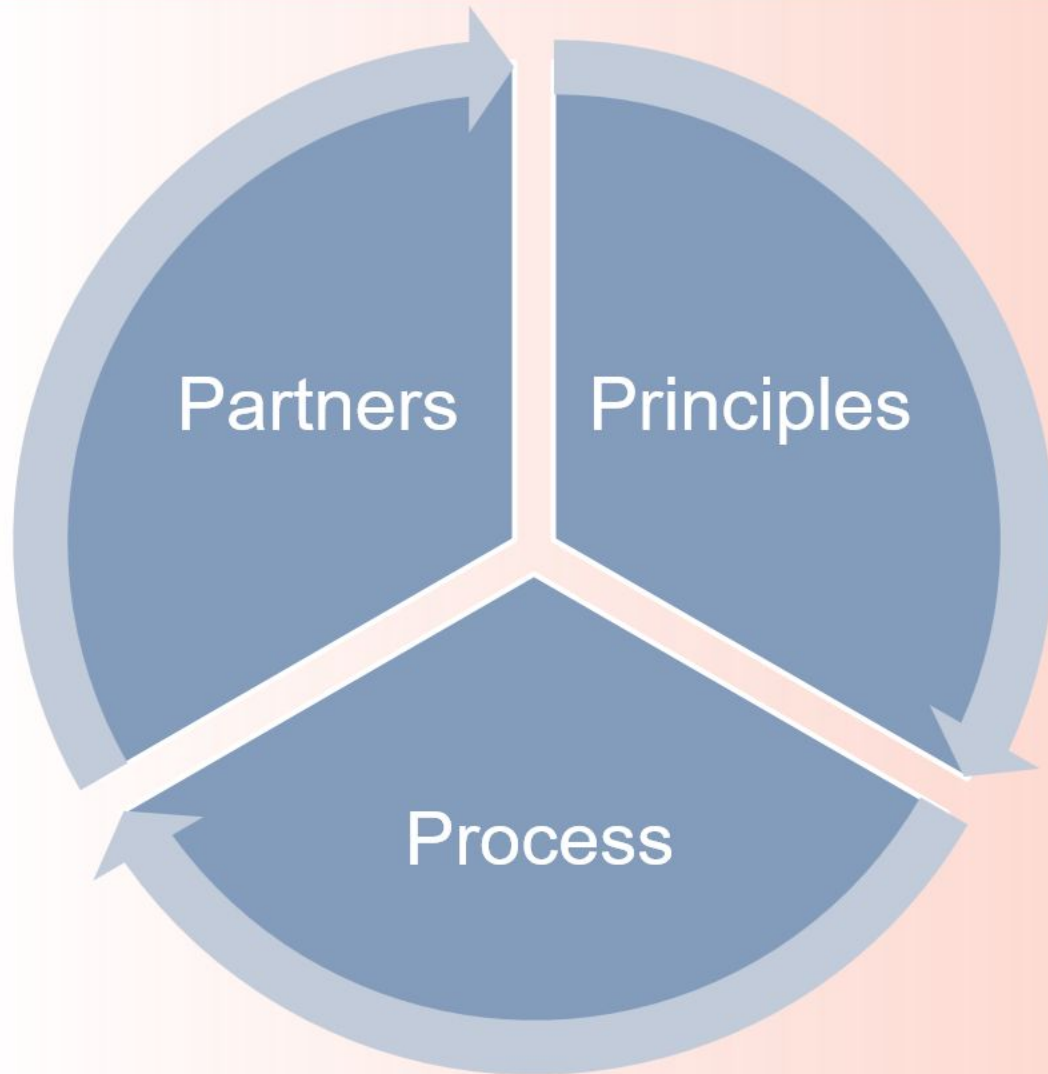
QUESTIONS TO START



Three Priorities for Community Engagement



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Process:

- Leadership expansion
- Focus on LEE values and needs
- Share learnings along the way
- Report final results

Partners:

- LEEs
- Funders
- HTCs
- Advocacy Orgs
- Pharma
- Chapters
- Researchers
- Government Agencies
- Families
- Others

Principles:

- Respect and value lived experience
- Trust and accountability
- Co-Design
- Diversity and Inclusion
- Responsive to need
- Capacity building and support
- Flexibility and adaptability
- Two-way communication



THREE ELEMENTS OF ROLL OUT



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Check

Central Hub

- User-friendly website
- Make connections between all research areas
- Offer training modules
- Engagement recruitment and Continuum Self-Evaluation

Targeted Tactics

- Repurpose content for specific audiences
- Create chapter and HTC toolkits
- Produce video testimonials for LEEs and Research Partners
- Ensure findings and updates are easily accessible and digestible

Two-way Communication

- Ongoing alignment, listening, and reacting to true community needs
- Co-create training modules
- Flexibility that enables us to continually improve



ENGAGEMENT RECOMMENDATIONS

1. Ensure there is a place and role for everyone within the NRB
2. Use co-design principles to design with, not just for
3. Create options for engagement to fit the individual
4. Track and report successes and failures along the way
5. Maintain and build trust in everything we do
6. Understand and actively address barriers to participation
7. Create tailored onboarding processes for partner groups
8. Use pulse surveys and open feedback to maintain alignment
9. Listen deeply
10. Develop toolkits, segmented summaries, and research ambassador program
11. Set our goal to not just engage, but to truly inspire



Community Engagement: Harmonizing with Working Groups

Nathan Mermilliod



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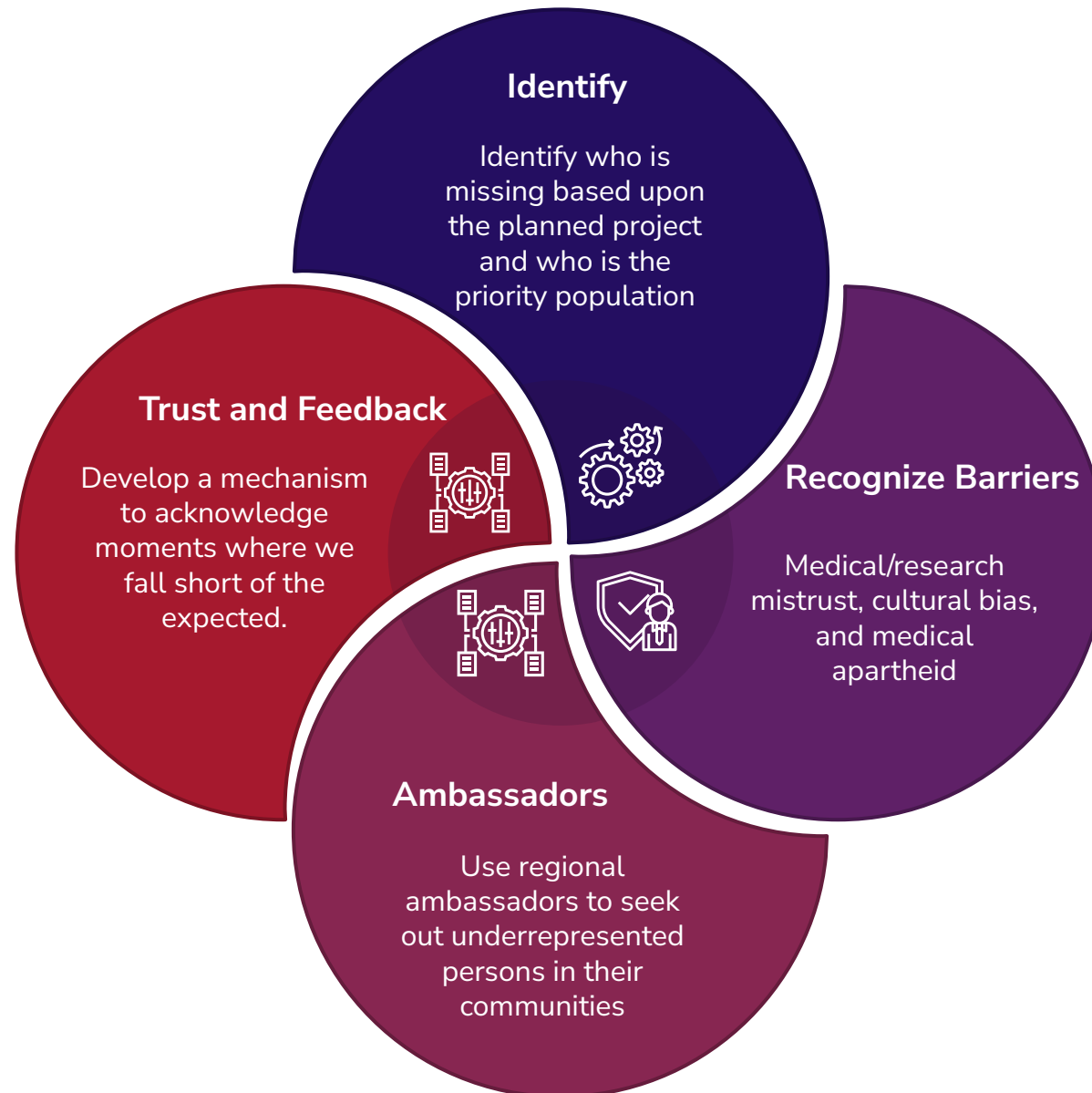


LEE Engagement Concept

- LEE Engagement is a priority
- The LEE's Table



HEDI - Engaging Underrepresented Individuals



R&D

- Aligned Value: Public Input
 - Develop web-based portal
 - Bring expertise
 - Train community members
 - Create system for On-Ramping



IFS

- Aligned Value: Public Trust
 - Oversight program for CE and outreach
 - Dynamic Governance Model
 - Training should level the playing field



Public Input and Trust in LEE Oversight Program

Web Portal

01 Set up Toolkits and Research Papers in Layman's Terms

02 Dynamic Governance model for building trust

C1 Orient and Educate

C2 Engage in research

C3 Feedback system

GOAL

Engagement helps sustain and expand NRB

Ambassador Program (outreach)

01 Engage community member and identify their place on continuum

02 Engaged regional ambassador training



Inspiring Motivation



Community Engagement Integration into proposed NRB Schema

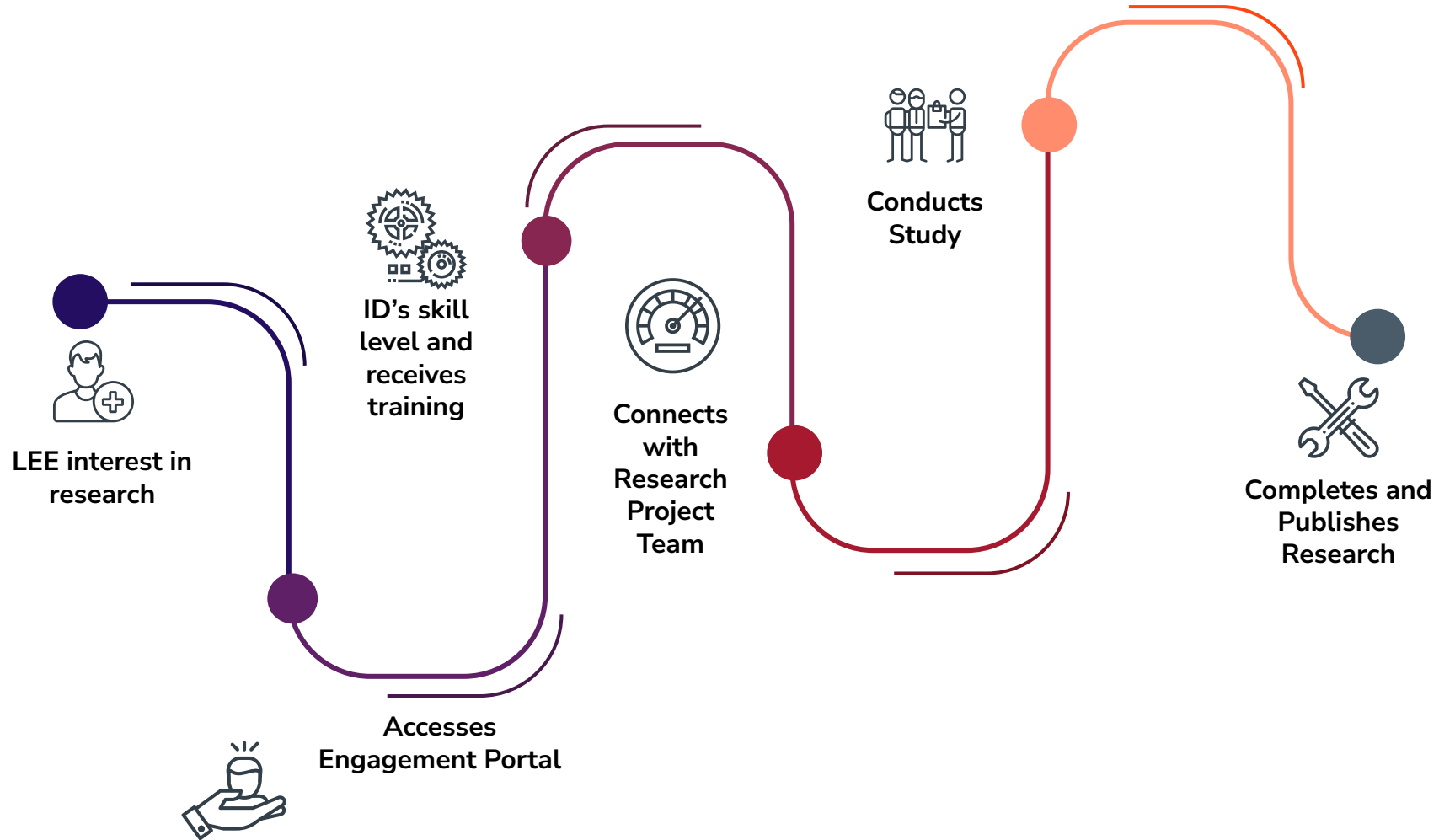
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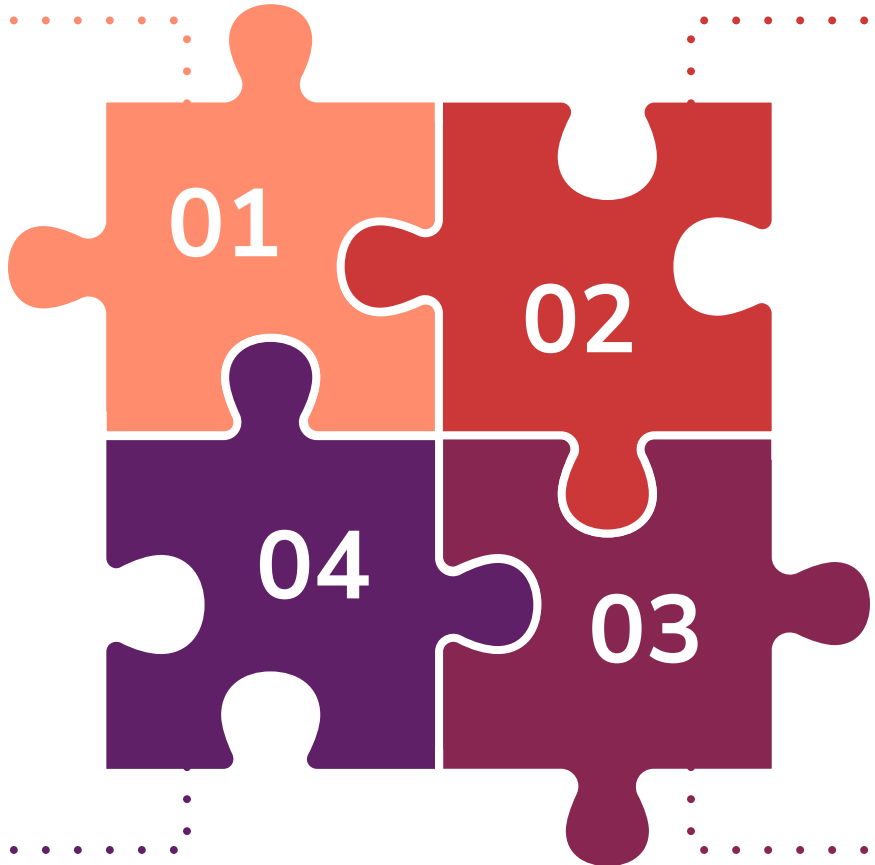
Community Engagement: Ideal State



Meeting the Call: Centering of LEE's

Governance Structure
LEE membership at every level

Community Prioritized
Research Themes



NRB Resource Website

LEE Research
Ambassador Program



Questions That Remain



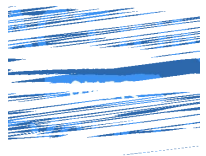
Are power imbalances recognized and counterbalanced?



Does portal include 2-way communication? What is ease of process?



Is information on research progress continuously provided to community?



Is NRB responsive to feedback with actionable changes?



Potential Pitfalls

LEE's finding the NRB

Though Chapter and Research Ambassador Programs will reach some LEE's, it is still a somewhat passive approach to getting people involved.

Ability to monitor portal

The NRB will have to make sure portal is monitored regularly to ensure feedback and questions are responded to in a timely manner.

Connecting with Research Team

There are practical barriers to collaboration including geographic and time issues. We will need to be creative to circumvent these.

Updating Research Progress

It will be important to communicate not just results of studies but current status of ongoing projects in a clear and concise way.



Q | A



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