ALLO HOPE
FOUNDATION

Stakeholder Engagement Guide for Patient Advocacy Groups

MAY 2024

INTRODUCTION

The resource presented herein is intended as a guide to facilitate effective stakeholder engagement with special consideration to rare disease patient advocacy groups. The engagement tools outlined below stem from the effective engagement of a diverse multi-stakeholder convening to discuss the disease-specific considerations, research needs, and barriers and facilitators to research in the community of patients, caregivers, clinicians, researchers and industry members affected by and interested in red cell alloimmunization/hemolytic disease of the fetus and newborn (HDFN).
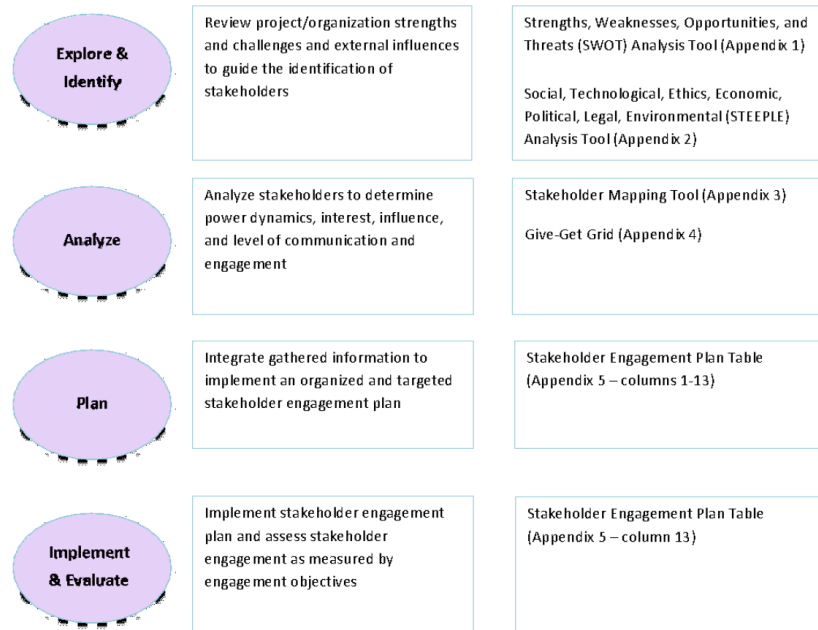
The engagement was led by the Allo Hope Foundation (AHF), a U.S. 501(c)(3) nonprofit whose mission is to prevent harm and stillbirth in families affected by alloimmunization/HDFN. Alloimmunization is a rare disease whereby a woman develops red cell antibodies against foreign blood, either from blood transfusion, intravenous drug use, or exposure to fetal blood during pregnancy. During pregnancy, these antibodies can cross the placenta and destroy fetal red blood cells, resulting in HDFN. HDFN presents as significant and sometimes life-threatening anemia in the fetus and newborn, as well as hyperbilirubinemia in the newborn. If untreated or improperly manage, HDFN can cause fetal/neonatal heart failure, brain damage, and death.

AHF's leadership team is comprised of alloimmunized patients with a background in education, clinical management, and research. AHF oversaw a 21-month stakeholder engagement initiative as part of a contract with the Patient Centered Outcomes Research Institute (PCORI)'s Engagement Awards program. The engagement included outreach and inclusion of a diverse group of patients, caregivers, researchers, clinicians and industry leaders in a series of four listening sessions and additionally a small roundtable convening to finalize a strategic research plan for the organization.

The AHF team utilized targeted and specific engagement methods to reach necessary stakeholders and to continue to engage these stakeholders in long-term partnership with AHF. The guide below is intended as a resource to other organizations seeking to engage a rare disease patient community, with specific attention being given to mental health considerations of rare disease patients.

Figure 1 below depicts the phases of successful stakeholder engagement and suggested tools and resources to proceed through the engagement guide. The patient advocacy group must first explore and identify their own organizational and external strengths and weaknesses to facilitate successful engagement. If for example the advocacy group maintains strong connections with patients but has not yet established trusted partnerships with expert clinicians or relevant industry members, the team must discuss how best to engage these groups and consider additional methods of building trust with other stakeholder groups before engaging them formally in research or other efforts. The group must then analyze the targeted stakeholders to anticipate any difficult power dynamics, their interest and motivation for participating in the engagement initiative, and the most effective means of communication for a given stakeholder or stakeholder group. Next, the group will implement their findings from their exploration and analysis phase to plan an organized stakeholder engagement plan. Such a plan is unique to every organization and project, and the more tailored, the more effective it may be. A stakeholder engagement plan table is provided in Appendix 5. Lastly, the group must implement the stakeholder engagement plan and evaluate the success of the engagement based on the project objectives.

FIGURE 1. PHASES OF SUCCESSFUL STAKEHOLDER ENGAGEMENT AND RELEVANT ENGAGEMENT TOOLS

Explore & Identify	Review project/organization strengths and challenges and external influences to guide the identification of stakeholders	Strengths, Weaknesses, Opportunities, and Threats (SWOT) Analysis Tool (Appendix 1) Social, Technological, Ethics, Economic, Political, Legal, Environmental (STEEPLE) Analysis Tool (Appendix 2)
Analyze	Analyze stakeholders to determine power dynamics, interest, influence, and level of communication and engagement	Stakeholder Mapping Tool (Appendix 3) Give-Get Grid (Appendix 4)
Plan	Integrate gathered information to implement an organized and targeted stakeholder engagement plan	Stakeholder Engagement Plan Table (Appendix 5 – columns 1-13)
Implement & Evaluate	Implement stakeholder engagement plan and assess stakeholder engagement as measured by engagement objectives	Stakeholder Engagement Plan Table (Appendix 5 – column 13)

Evaluation of the program's success can be achieved in a multitude of ways. Program evaluation science is a discipline dedicated to the examination of these outcomes. Many program evaluation logic models exist in the literature. For implementation science programs, the Implementation Research Logic Model (IRLM) has recently emerged as a popular option and may be a reasonable option for advocacy groups who are evaluating the success if the implementation of a stakeholder engagement program,[1] or the implementation of an initiative or program in their target population. Many logic models exist for program evaluation and they should be considered for the specific initiative at hand. More information is provided through the University of Wisconsin-Madison online module.[2]

SPECIAL CONSIDERATIONS FOR RARE DISEASE ENGAGEMENT INITIATIVES

Rare disease is a unique subgroup of patient advocacy and research. Additional consideration must be given to the fact that identifying stakeholders can be particularly challenging in rare disease, as few clinicians manage the disease with learned expertise, few industry organizations will be developing pharmaceutical or diagnostic assets for the disease, and patients are difficult to capture and not often localized to a particular region.

Some special considerations apply when planning for engagement in rare disease:
- Physical, mental, emotional demands on caregivers as barriers to participation
- Patient mistrust of medical system after missed diagnoses or preventable negative disease outcomes
- Limited funding specific to disease
- Competition among rare disease populations for funding
- Critical need for social support in an otherwise isolating experience
- Nuanced power dynamics among stakeholders
- Stakeholders may be geographically distant limiting in-person participation

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[1] Smith JD, Li DH, Rafferty MR. The implementation research logic model: a method for planning, executing, reporting, and synthesizing implementation projects. Implementation Science. 2020 Dec;15:1-2.

[2] Available at: https://logicmodel.extension.wisc.edu/introduction-overview/section-7-using-logic-models-in-evaluation-indicators-and-measures/

Solutions to these challenges may include:

- Integrating links and introductions to relevant mental health resources or dedicated peer support groups to patients
- Offering a variety of communication and feedback methods such that various stakeholders have an engagement option that feels safe
- Prioritizing dissemination of findings for stakeholders to see project impacts (communication of findings may be harder to find given rarity of research in the field)
- Offer virtual engagement options to offset geographic challenges
- Limiting group size to facilitate feelings of trust and partnership
- Allowing opportunities for patients to share their story as rare disease patient journeys and outcomes often vary significantly
- Include patients in program leadership

APPENDIX 1: SWOT ANALYSIS TOOL TEMPLATE

Purpose: Identify the potential strengths and challenges within the organization and/or project[3][4][5]

	HELPFUL (for project)	HARMFUL (for project)
INTERNAL (within organization)	**Strengths:** Evaluate organization strengths relevant to project **Examples:** successful initiatives, strong relationships	**Weaknesses:** Evaluate organization weaknesses relevant to project **Examples:** gaps in resources or funding, lack of required technology
EXTERNAL (outside organization)	**Opportunities:** Identify potential opportunities to the organization and/or project **Examples:** new funding sources, new collaborations with outside organizations	**Threats:** Identify potential threats to the organization and/or project **Examples:** legislative barriers, public perception

[3] Hollmann, S., Regierer, B., Bechis, J., Tobin, L., & D'Elia, D. (2022, October 13). Ten simple rules on how to develop a stakeholder engagement plan. PLoS computational biology. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9560496/

[4] Arshad, A., Fauzan, M., & Bint, R. (2017). A synthesis on SWOT analysis of Public Sector Healthcare Knowledge Management Information Systems in Pakistan. International Journal of Advanced Computer Science and Applications, 8(8). https://doi.org/10.14569/ijacsa.2017.080817

[5] Public health programs SWOT analysis template. Template by ClickUpTM. (n.d.). https://clickup.com/templates/swot-analysis/public-health-programs

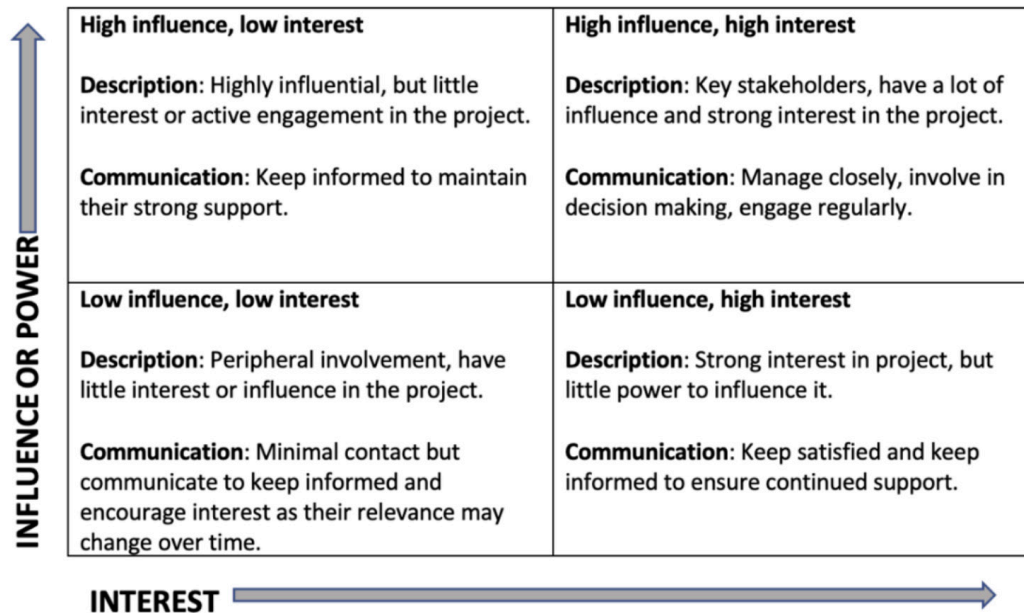# APPENDIX 2: STEEPLE ANALYSIS TOOL TEMPLATE

Purpose: identify the external elements that may influence the project outcomes[6] [7]

Social	Example: providing patient education
	Example: cultural norms
Technological	Example: real-time access to data organization collects
	Example: communication across electronic medical records
Ethics	Example: increasing access to resources within vulnerable populations
	Example: structural racism within healthcare system
Economic	Example: availability of low-cost resources for patients
	Example: economic status of patients
Political	Example: relationships with elected officials
	Example: federal regulations
Legal	Example: data sharing agreements
	Example: healthcare regulations
Environmental	Example: increasing access to telehealth resources
	Example: geographic location of patients

Color Legend: orange=within organization's control/influence, purple=outside organization's control/influence (note, categories could be further divided into those within organization's control, those within organization's influence, and those outside organization's control/influence)

APPENDIX 3: STAKEHOLDER MAPPING TEMPLATE

Purpose: identify influence/power, interest, and level of communication/engagement[8] [9]

INFLUENCE OR POWER ↑	
High influence, low interest **Description**: Highly influential, but little interest or active engagement in the project. **Communication**: Keep informed to maintain their strong support.	**High influence, high interest** **Description**: Key stakeholders, have a lot of influence and strong interest in the project. **Communication**: Manage closely, involve in decision making, engage regularly.
Low influence, low interest **Description**: Peripheral involvement, have little interest or influence in the project. **Communication**: Minimal contact but communicate to keep informed and encourage interest as their relevance may change over time.	**Low influence, high interest** **Description**: Strong interest in project, but little power to influence it. **Communication**: Keep satisfied and keep informed to ensure continued support.

INTEREST →

[6] Hollmann, S., Regierer, B., Bechis, J., Tobin, L., & D'Elia, D. (2022). Ten simple rules on how to develop a stakeholder engagement plan. PLoS computational biology. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9560496/

[7] Moran, J.W. & Meadows, A. (2016). PESTLE Chart. Public Health Foundation. https://www.phf.org/resourcestools/Documents/PESTLE_Chart.pdf

[8] Lopez, A. (2021). Stakeholder Mapping 101: A Quick Guide to Stakeholder Maps. https://www.projectmanager.com/blog/stakeholder-mapping-guide

[9] Stakeholder Analysis. (2022). https://www.groupmap.com/portfolio/stakeholder-analysis

APPENDIX 4: GIVE-GET GRID TEMPLATE

Purpose: identify stakeholders' differences in perceptions of the value of investment and benefits; helps identify resources, anticipate outcomes, and promotes expectations for agendas[10]

Stakeholder	Stakeholder Contributions	Stakeholder Benefits
Example: Obstetricians with experience managing alloimmunized patients	Example: Provide expertise for development of guidelines for management of alloimmunization	Example: Potential publishing opportunity of guidelines, standardized protocols for practice, professional networking/connections

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[10] Southerland, J. B. (2013). Using the give-get grid to understand potential expectations of engagement in a community-academic partnership. Health Promot Pract 14(6), 909-17.

APPENDIX 5: STAKEHOLDER ENGAGEMENT TABLE TEMPLATE

Purpose: identify internal and external stakeholders and establish a clear communication and engagement plan for the project[11] [12] [13]

Stakeholder Information				Communication		Engagement						Evaluate
Stakeholder Name/Title	Stakeholder Influence	Stakeholder Interest	Stakeholder commitment [1]	Communication Method	Communication Frequency	Level of Engagement[2]	Potential Barriers to Engagement	Potential Facilitators of Engagement	Engagement Method(s)[3]	Project phase of engagement	Project Staff Responsible for Communication and Engagement	Engagement Objective(s)[4]
Joe Smith/ Obstetrician	High	High	Leading	Zoom Meeting	Weekly	Collaborate	Work schedule	Department funding for research	Focus groups, surveys, meetings	Planning, data collection, data analysis	Jane Doe	Survey responses, meeting attendance

[1] Commitment levels: unaware (unaware of project), resistant (aware of project, resists change), neutral (aware of project, neither resist nor supports change), supportive (aware of project, supports change), leading (aware of project, supports change, actively engaged in project) [10]

[2] Levels of engagement: none, inform (inform stakeholders of work), consult (ask stakeholders for feedback), involve (ask stakeholders to identify areas of change), collaborate (ask stakeholders to identify areas of change and develop strategies, participate in shared decision making), co-create (stakeholders impacted by project though not often included in decision making take the lead in making decisions/implementing actions) [1]

[3] Examples of stakeholder engagement methods: surveys, focus groups, interviews, meetings, events, workshops, advisory panels, letters, emails, text messages, social media, online chats

[4] Examples of objectives to assess engagement: survey responses, meeting attendance, number of stakeholders contributing feedback, new stakeholder contacts throughout project, growth of social medial engagement

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[11] Eby, K. (2023). Free Stakeholder Engagement Plan Templates With Examples and Full How-Tos. https://www.smartsheet.com/content/stakeholder-engagement-plan-template

[12] Stakeholder engagement process (n.d.). https://nirn.fpg.unc.edu/sites/nirn.fpg.unc.edu/files/resources/Stakeholder%20Engagement%20Process%20Handout.pdf

[13] Kimberley (2021). How to Develop a Stakeholder Engagement Plan in 5 Easy Steps. https://swiftdigital.com.au/blog/stakeholder-engagement-plan/#levels-stakeholder

[14] Stakeholder engagement process (n.d.). https://nirn.fpg.unc.edu/sites/nirn.fpg.unc.edu/files/resources/Stakeholder%20Engagement%20Process%20Handout.pdf