Balancing stakeholder expectations

HEALTH RESEARCH ALLIANCE
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Agenda

- Non-profit Organization stakeholders
- Stakeholder drivers
- Case studies
- Summary
Stakeholder Universe

- Founders
- Board
- Patients
- Charity Raters
- Public
- Staff
- Research teams
- Donors
- Fund-raisers
- Corp Partners
Stakeholder Drivers

Mission Drivers “My NPO’s focused on”
- Patients, Education, Research, Treatments
- Financial Support and Sustainability

Reputational Drivers “I’m with”
- Leading non-profit
- Great researchers
- Strong community
- Industry leaders
- Winners

Cures

Personal Drivers “I want work with my”
- Condition
- Doctor
- Favorite institution
- Local city
- Idea

While well-intentioned, sometimes NPOs are driven to programs that don’t work out as expected.
Donor-driven funding to a favorite clinician at a specific institution (2 NPOs)
- After ~2 years, the projects did not advance
  - Funding was withdrawn

Disappointment and embarrassment
- Institutional leadership and researcher
- Donors/fundraisers and NPO

Key Takeaways
- Be honest about the risk when accepting $ and making awards
- Can you mitigate risk by adding a second project to increase PTS
CoMMpass: A Matter of Balance

MMRF study of >1,000 newly diagnosed patients. Relied on $MM from multiple pharma partners; institutional enrolment, sample collection and genomic research

- Critical need to offer companies equal access and a level playing field
- Academic researchers wanted option to see data & publish before industry
- Intellectual Property had to be addressed

Solutions arose after internal & external consideration

- Created Pre-competitive Consortium of companies with equal access
- Researchers had time-limited, first access to data
- Agreement that IP directly from study was dedicated to public domain

https://themmrf.org/finding-a-cure/our-work/the-mmrf-commpass-study/
In 2017, the Foundation for Sarcoidosis Research (FSR) was funded by a Celgene Impact Award to identify multidisciplinary centers of excellence for sarcoidosis. Launched in 2018.

- Institutions apply for recognition
- Leading KOLs/clinicians of WASOG review and qualify centers
- One of three FSR programs to help patients find physicians

Work in-progress with future-looking questions

- Managing collaboration and ratings
- Clarifying three offerings: Physician vs Clinic vs Centers of Excellence
- Translating offerings to fundraising for FSR

https://www.stopsarcoaidosis.org/sarc-id/
https://www.stopsarcoaidosis.org/sarc-id/sarcoidosis-clinics/
https://www.stopsarcoaidosis.org/physician-finder/
Summary

All NPOs have stakeholders with various drivers and expectations

- Founders, Board, Donors and Fundraisers, Corporate Partners, Researchers, Patients/Caregivers, Government Officials, Staff, Public

- Programming should harness stakeholder resources and enthusiasm; align with the mission; and protect NPO reputation

- Sharing experiences via HRA and developing novel approaches can make for success for NPOs and their supporters