Advancing Innovation in Measuring Patient Advocacy Outcomes
Progress in Cancer: Measuring Success in Patient Advocacy Initiatives

A Metrics Study Conducted in 2013
Measuring Impact in the Evolving World of Nonprofit Organizations (NPOs)

- Fierce competition for funding
- Increased pressure to measure impact
- Measuring success a daunting challenge
Progress in Cancer Study Overview

Objectives

- Evaluate how diverse NPOs in cancer measure impact against goals to assess trends and best practices

Rx4good Methodology

1. **Primary Research: Group Self-Assessment**
   - 24 NPOs participated in self-assessment of metrics best practices via 8-item Survey Monkey questionnaire

2. **Secondary Research: Assessment of Websites and Annual Reports**
   - 45-question survey evaluated how 35 NPOs report on diverse measures of progress against goals
Websites and annual reports of 35 NPOs assessed:

Self-assessments completed by 24 (69%) of the 35 organizations
Group Demographics

The majority of the 35 assessed organizations have been operating for 20+ years with annual revenue of $1M–$5M.

### Age of Organization

<table>
<thead>
<tr>
<th>Age of Organization</th>
<th>Percentage (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>20+ Years</td>
<td>49% (n=17)</td>
</tr>
<tr>
<td>10-20 Years</td>
<td>43% (n=15)</td>
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<tr>
<td>5-10 Years</td>
<td>6% (n=2)</td>
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<tr>
<td>1-5 Years</td>
<td>2% (n=1)</td>
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### Annual Revenue

<table>
<thead>
<tr>
<th>Revenue Range</th>
<th>Percentage (n)</th>
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<tbody>
<tr>
<td>&lt;$1M</td>
<td>20% (n=7)</td>
</tr>
<tr>
<td>$1M - $5M</td>
<td>31% (n=11)</td>
</tr>
<tr>
<td>$5M – $10M</td>
<td>23% (n=8)</td>
</tr>
<tr>
<td>$10M - $30M</td>
<td>11% (n=4)</td>
</tr>
<tr>
<td>&gt;$30M</td>
<td>11% (n=4)</td>
</tr>
<tr>
<td>N/A</td>
<td>3% (n=1)</td>
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Research Findings

NPO Self-Assessment of Metrics Best Practices and Online Audit of NPOs
Cancer NPOs Have a Strong Commitment to Reporting Results…

- 91% Publish an annual report
- 89% Report annual revenue & operating expenses
- 60% Clearly state organizational goals
- 46% Report progress against each goal
Survey Revealed NPO’s Perspective on Metrics Reporting...

75% of NPOs have changed their view about metrics during last three years

- Increased understanding of value of metrics
- Funder expectations

96% Metrics are essential for evaluating success against goals

33% The work we do is difficult to measure

25% Metrics are important but we don’t have the resources to measure our programs

8% We would rather invest in programs than in measuring results

75% of NPOs have changed their view about metrics during last three years

- Increased understanding of value of metrics
- Funder expectations
Key Obstacles to Measuring Impact

**Lack of Resources**

We have limited time, staff and funding to do all the things we want to do...And it's hard to increase staff size without an increase in funding.

Measuring impact takes so much staff and time that the programs do not get the attention they deserve. It is the wrong way around.

**Determining Outcomes Change**

Not all of our programs are easy to track, especially grassroots and advocacy initiatives.

It can be a challenge to determine the best way to measure impact. It can also be challenging to determine if behavior has really changed due to a program or an event.
NPOs Measure Impact in Many Ways, Led by Progress Achieved Against Goals

- Progress Achieved Against Goals: 96%
- Numbers Reached, Attended Events: 92%
- Actions Taken by Stakeholders as a Result of Programs: 92%
- Social Media or Web Engagement: 92%
- Media Coverage: 79%
- Funding Received: 75%
- Perceptions Changed or Reinforced: 75%
- Sustainability of Programs or Initiatives: 67%
- Message Delivery: 67%
- Funding Given: 54%
NPOs and Funders Aligned on Most Important Metrics

### Most Important

<table>
<thead>
<tr>
<th>NPO</th>
<th>Both</th>
<th>Funders</th>
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</thead>
<tbody>
<tr>
<td>Numbers Reached, Attended Events</td>
<td>✔️</td>
<td>✔️ Perceptions Changed or Reinforced</td>
</tr>
<tr>
<td>Actions Taken By Stakeholders as a Result of Programs</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Progress Achieved Against Goals</td>
<td>✔️</td>
<td></td>
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</tbody>
</table>

*Ranked 1 or 2 as “most important” by the majority of survey respondents

### Least Important

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<thead>
<tr>
<th>NPO</th>
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<th>Funders</th>
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<tbody>
<tr>
<td>Message Delivery</td>
<td>✔️</td>
<td>✔️ Funding Given</td>
</tr>
<tr>
<td>Media Coverage</td>
<td>✔️</td>
<td>✔️ Funding Received</td>
</tr>
<tr>
<td></td>
<td></td>
<td>✔️ Sustainability of Programs</td>
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*Ranked 9 or 10 as “least important” by the majority of survey respondents

Q: Please rank the following metrics options in order of importance to your ORGANIZATION/FUNDERS, with one being the most important, 10 least important.
NPO Metrics Best Practices

- Ongoing review of progress against goals
- Digital reporting
- Broad program evaluation & follow-up
- Tracking research advances
Website Research Shed Light on NPO Priority Metrics

<table>
<thead>
<tr>
<th>MORE COMMON</th>
<th>LESS COMMON</th>
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<tbody>
<tr>
<td>Audience reach/ event attendance</td>
<td>Survey patients about impact of programs</td>
</tr>
<tr>
<td>(91%)</td>
<td>(23%)</td>
</tr>
<tr>
<td>Legislative/ policy work</td>
<td>Media coverage</td>
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<tr>
<td>(74%)</td>
<td>Message delivery</td>
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<tr>
<td>Scientific progress</td>
<td>Website hits</td>
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<tr>
<td>(63%)</td>
<td>Unique visitors</td>
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<tr>
<td></td>
<td>(31%)</td>
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Key Takeaways and Study Implications

Metrics increasingly valued by NPOs, driven largely by funder expectations
– Tasked with finding more immediate measures of success
– Limited resources and knowledge on how to best convey impact

Variety of reporting techniques; more “outputs” than “outcomes”
– Funders and NPOs largely aligned in metrics they deem most/least important
– More focused on reporting results than websites/annual reports indicate

NPO demographics have marginal bearing on metrics activities
– Effective metrics reporting not necessarily linked to size or revenues

Diverse stakeholders and funding obstacles will continue to challenge metrics reporting, but best practices and cost-effective strategies exist to showcase impact
Cancer Nonprofit Metrics Sponsorship
Amgen & Center for Social Sector Leadership, Berkeley-Haas
Establishing meaningful metrics is critical for nonprofits to improve their impact on the lives of those they serve and demonstrate results to funders," - Colin Boyle, Lecturer, Haas School of Business
The Initiative

- Two-year partnership with Center for Social Sector Leadership, Berkeley-Haas

- New graduate-level 15-week course on “Social Impact Metrics”
  - Dedicated to solving metrics challenges of four winning oncology patient advocacy organizations

- Share course outcomes/best practices with industry, nonprofit cancer and philanthropic community through webcast and co-authored social sector publication
The Metrics Challenges of the Four Nonprofits

Chris4Life
Colon Cancer Foundation
We’re here for you.

Clinical Trial Recruiting Database for Colorectal Cancer

Critical Mass
The Young Adult Cancer Alliance

Young Adult Cancer Search Engine

B CAN
Bladder Cancer Advocacy Network

Webinar Series on Bladder Cancer

Cancer Support Community

Volunteer Hotline for People with Diverse Cancers
What We Hope to Achieve

• Meaningful, executable solutions to the metrics challenges of four nonprofit partners
• Best practices in measuring impact that can be shared across nonprofit patient communities
• Greater understanding among funders and nonprofits of challenges of measuring impact
• Future support for this initiative so it can continue and help even more nonprofits