Tackling Representativeness: A Roadmap and Rubric

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Tackling Representativeness

- What is representativeness in the context of patient engagement?
- Who and how many individuals from the patient community are needed to take part in engagement activities?
- What are the benchmark characteristics desired to engage the right individuals to capture the range of input needed?
- Representativeness versus statistical sampling?
Tackling Representativeness

• Multi-stakeholder Roundtable (May 8, 2017)

• Roadmap and Rubric (September 2017)
  • Intended to guide decision-making on representativeness for a given patient-engagement activity.
Representativeness means a sufficient number of and types of people are included in the engagement activity to ensure that those engaged can speak for the target population. It refers to “who” and “how many” individuals to include in an interaction to, as closely as possible, engage with individuals that represent the broader, targeted patient population.
Representativeness Pyramid

- One Patient
- A Few Patients or Sub-Population Reps
- A Greater Number of Patients or Sub Population Representatives
- Greater Number of Patients Statistically Valid Sample
Guiding Principles

1. Define objective(s) for each engagement effort

2. Understand the full population and subpopulations, and challenges to reaching them

3. Specify minimum target(s) for representativeness for the engagement activity

4. Plan to achieve the minimum target(s) defined.

5. Evaluate to assess progress on achieving target(s) or if they need to be adjusted based on new information.

6. Document how patient representativeness was defined, targeted, achieved, and assessed.
Rubric Example

Understand – Understand as much as possible about the full population and subpopulations, and challenges to reaching them

<table>
<thead>
<tr>
<th>Guiding Questions to Consider</th>
<th>Good Process</th>
<th>Poor Process</th>
</tr>
</thead>
<tbody>
<tr>
<td>• What sources of information about this population are available?</td>
<td>• Patients are engaged in helping describe the full patient population, subgroups, and anticipated challenges and burdens.</td>
<td>• Sources of information on the full population were not tapped or were ignored.</td>
</tr>
<tr>
<td>• Are the sources outdated or inaccurate?</td>
<td>• Issues with feasibility or lack of resources to get to the target are considered</td>
<td>• Patients were not consulted when trying to understand the full and target populations</td>
</tr>
<tr>
<td>• Is the target patient population for the engagement activity the full population or a subpopulation?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Conclusion

- A single target for patient representativeness cannot fit every patient-engagement situation.
- Context, including the objective of the engagement, must influence how patient representativeness is defined for any engagement activity.
- Variability of patient interactions requires that stakeholders address representativeness as a process with a minimum target, rather than a fixed standard.
Resources

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