

Creating a Patient Engagement Workbook for Research Teams

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POLL Question #1:

- What is your experience with patient engagement in research?
- - I'm a researcher with patients/stakeholders engaged on my team
- - I'm a researcher who wants to engage patients/stakeholders on my team
- - I'm a patient who is a member of a research team
- - I'm a patient who is a member of a patient board that is not study specific
- - I'm something else

HMORN Patient Engagement in Research Scientific Interest Group

- Created the HMO Research Network [HMORN] work group in 2013
 - 12 members representing 8 HMORN member organizations
- Expanded to a Scientific Interest Group in 2014
 - Today: 60 members representing 12 HMORN member organizations
- Mission of the SIG:

Improve the HMORN's capacity to meaningfully engage patients as members of research teams to increase the value and applicability of research findings for patients, and to enable them to make informed healthcare decisions and achieve better health outcomes.

Patient Engagement in Research SIG: Activities and Goals

- Develop a community of engagement practice among HMORN researchers, patients and other stakeholders
- Conduct baseline assessments of engagement resources available in member organizations
- Consult on building engagement infrastructure within member organizations
- Consult on planning for and implementing patient engagement in all phases of research
- Recruit patient partners as members of the SIG
- Identify best practices for measuring the engagement of patient partners
- **Develop tools and resources for research teams**

Looking for best practices in patient engagement

**WE THOUGHT WE WANTED A CHECKLIST -
WE ENDED UP WITH A WORKBOOK.**

STEP 1: PER SIG SURVEY – June 2014

Purposes of Survey:

1. Elicit engagement practices of HMORN research teams
2. Identify best practices in engagement
3. Highlight organizational barriers and/or efficiencies

- Sent to PER SIG members and requested they also share with colleagues engaging patients in research
- 26 electronic respondents from 9 HMORN institutions

Subjects of Survey Questions:

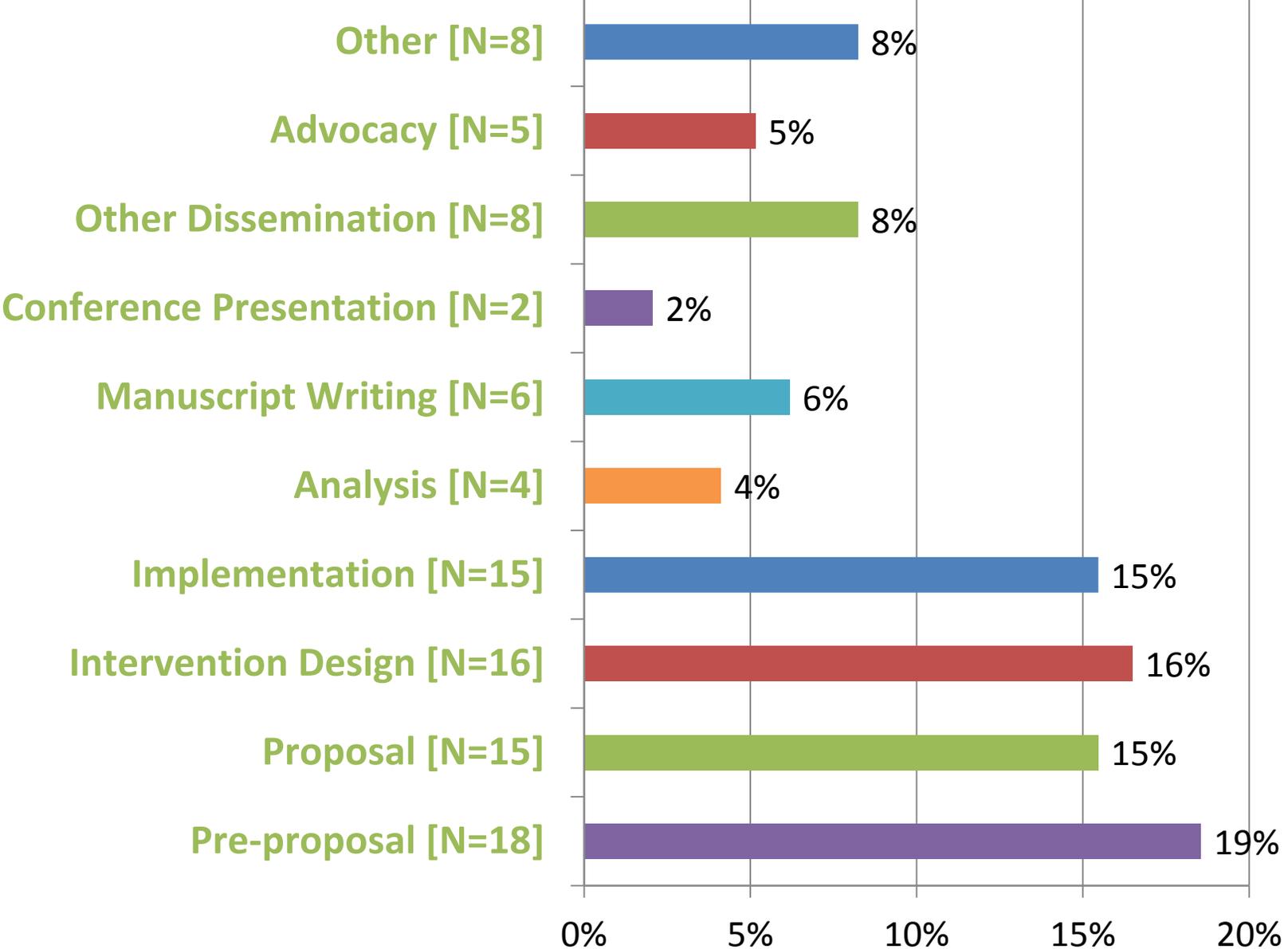
- Roles and Stages of Engagement
- Identification/Recruitment/Screening
- IRB Oversight
- Organizational Support
- Compensation/Contracting/Hiring
- Training – Patient Partners and Research Team
- Data Sharing
- Feedback and Evaluation/Retention

Selected Results:

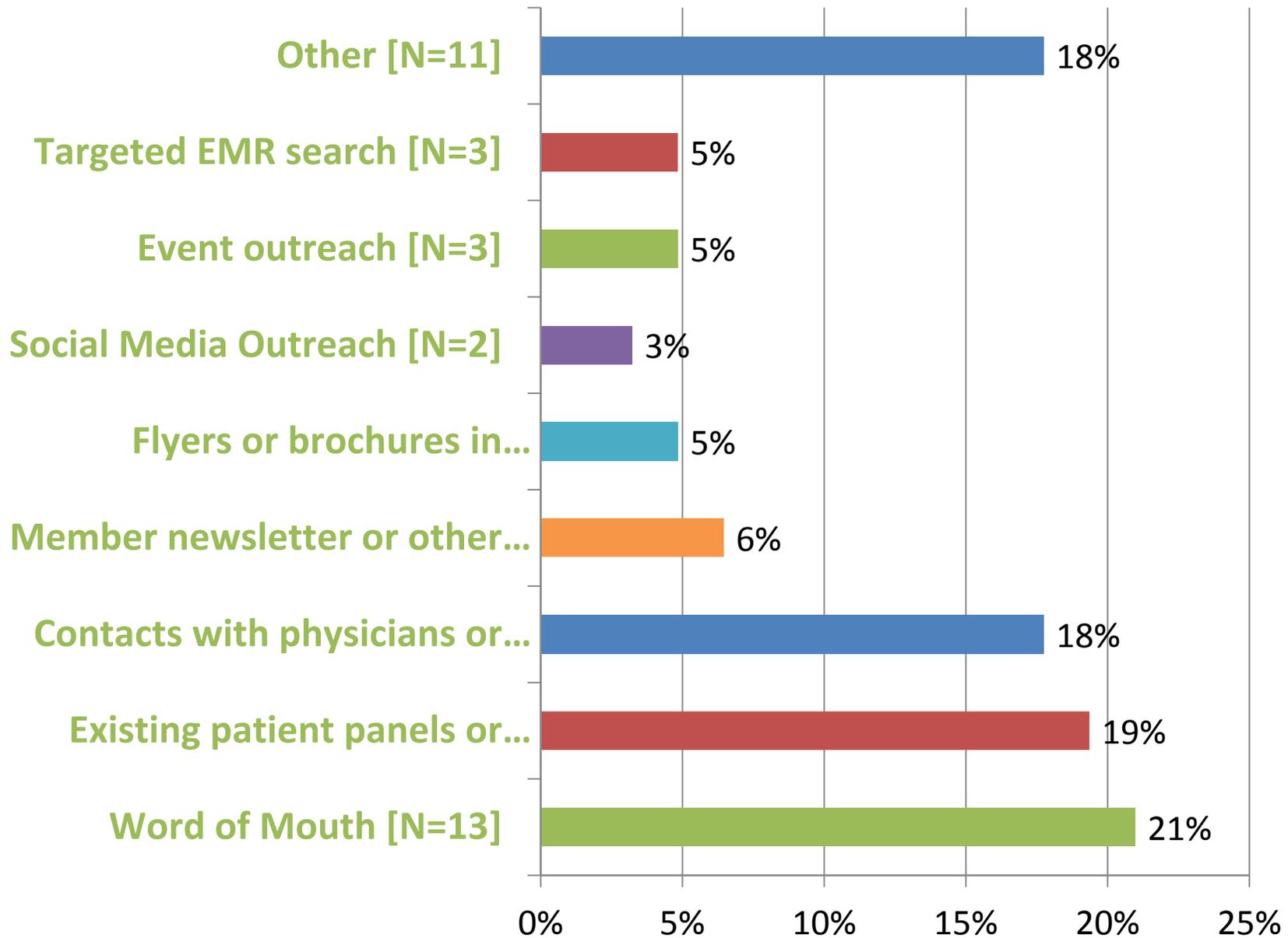
HMORN research teams are engaging patients across the research spectrum.

Stages of Patient Engagement in Research

N = 87



Recruitment Strategies to Identify Patient Team Members N = 62



Where do we find our patient partners?

Being embedded in our health systems helps... a lot.

POLL Question #2:

How do you identify potential patient partners for your research teams?

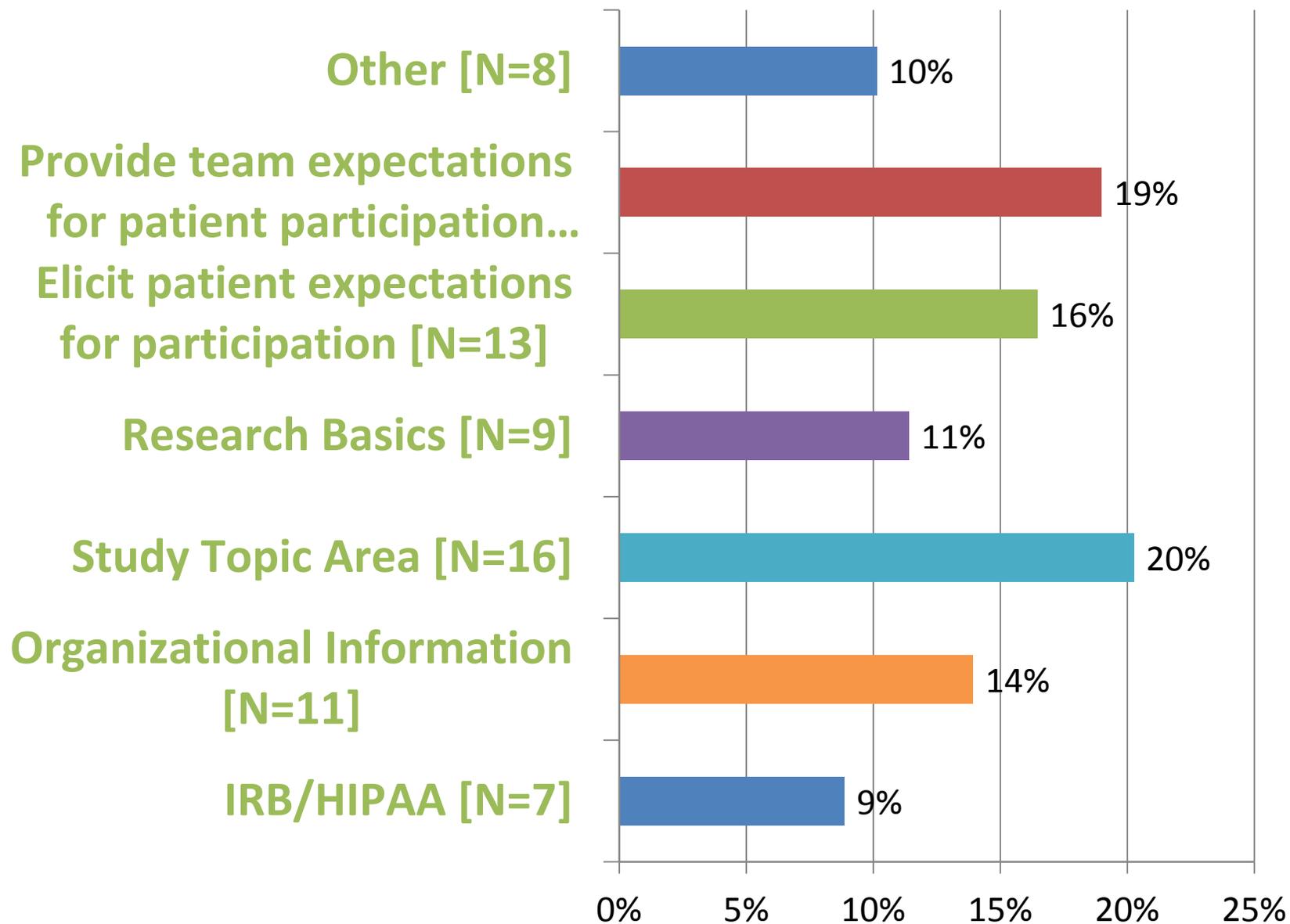
- Outreach at events, through newsletters, brochures or flyers
- Clinic waiting rooms or physician contacts
- Patient partners in other studies
- Social media
- Word of mouth
- Other

How do we prepare our patient partners?

We provide a broad base of information, i.e., most respondents addressed more than one topic in their trainings

Training Topics for Patient Team Members

N = 79

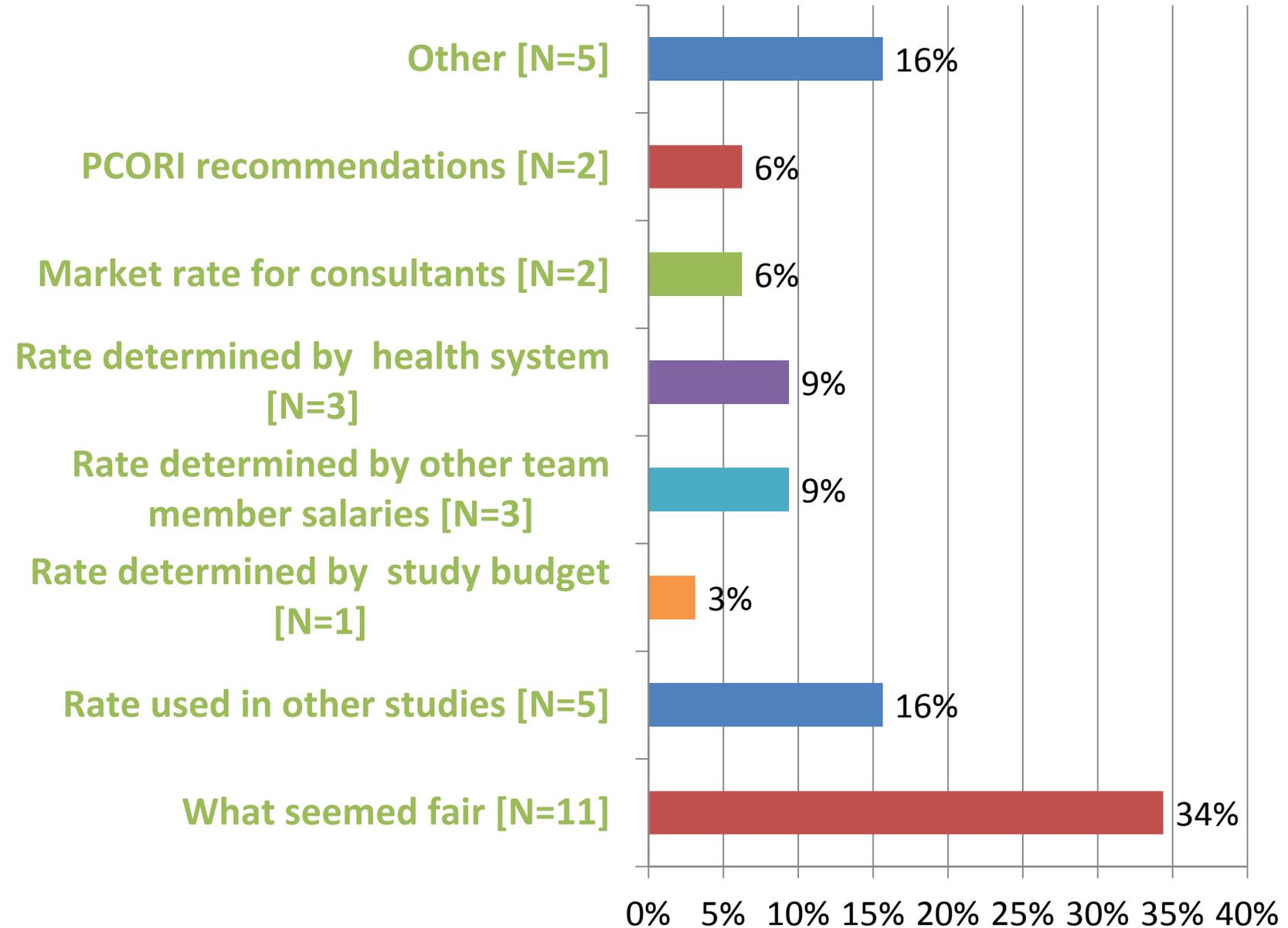


An Obvious Challenge:

How much should we compensate our patient partners?

Compensation Decision Making

N = 32



POLL Question #3

- How do YOU decide what to compensate patient partners?
- - rate determined by study budget
- - rate determined by other team member salaries
- - rate allowed by budget
- - rate used in other studies
- - other

STEP 2: Process

- Compiled results:
 - identified gaps in knowledge and practice; noted common methods
 - used free text comments on methods to highlight best practices.
- Drafted checklist of best practices
- Discussed checklist with PER SIG; received feedback on content and format – *wanted space for individualizing content*
- **Changed format from checklist to workbook: a “user manual”**

Patient Engagement Workbook – Table of Contents:

I. Why engage patient partners on THIS study?

TIP: Estimating the costs of engagement

II. Define role(s) of patient partner(s)

III. Engagement logistics

TIP: Compensation considerations

IV. Identification of patient partners

V. Recruitment

VI. IRB/Compliance

VII. Other organizational departments

VIII. Prepare to screen candidates

IX. Screening practices

X. Research team training

XI. Formalize relationship with patient partners

XII. Train patient partners

TIP: Retention of partners

XIII. Monitoring and evaluation

XIV. Closure: end of study

II. Define the role(s) of patient partner(s) on the team:

Roles	#	Stage(s) of Research	Define the roles and list the responsibilities
Advisory panel member			
Steering committee member			
Co-investigator			
Focus group member			
Consultant			

Research staff: who will have primary responsibility for communicating with patient partner(s)?

Outcome: Clear role statement(s) for patient partners

VII. Other Departments

Review the implications of your recruitment and engagement plans with:

Sponsored Projects office	
Human Resources	
IT	
Governance or Member Relations	

OUTCOME: Organizational approvals and cooperation in preparing for patient partners

X. Research Team Training

Train current research team members in preparation for working with patient team members

Review goals of engagement and role requirements for patient(s)

Clarify expectations for patient(s) engagement

Review any institutional restrictions (e.g., on information sharing)

Emphasize the rules of engagement; the patient(s)' expertise is her/his experience as a patient

OUTCOME: research team is prepared to work respectfully and effectively with patient partners.

XIII. Monitoring and Evaluation

Schedule a regular opportunity for patient partner(s) to provide feedback on their experiences.

Should be a “safe” space for truthful feedback

Establish clear ground rules for facilitated group discussions

Online or written evaluation

Provide feedback to patient partner(s) on her/his participation

Respond to patient partner concerns or issues

End the patient partner’s participation if necessary

At the final evaluation, ask patient(s)’ preferences for being contacted again in the future for information updates or possible participation in other studies

OUTCOME: *Patient partner(s) feels heard and respected as valued study team member(s)*

STEP 3: Dissemination

- Via presentation at HMORN conference
- Posted on the HMORN website:
 - www.hmoresearchnetwork.org/en/Tools%20&%20Materials/Plan_Field/
- Distributed via email to all PER SIG members: shared with their organizations' research teams
- Shared with Director of Patient Engagement at PCORI

In process: a PER SIG patient engagement consulting service for research teams.

POLL Question #4 (last one!):

- Would you - or do you know of a research team that would - use engagement consulting services?
- - Yes
- - No
- - I don't know

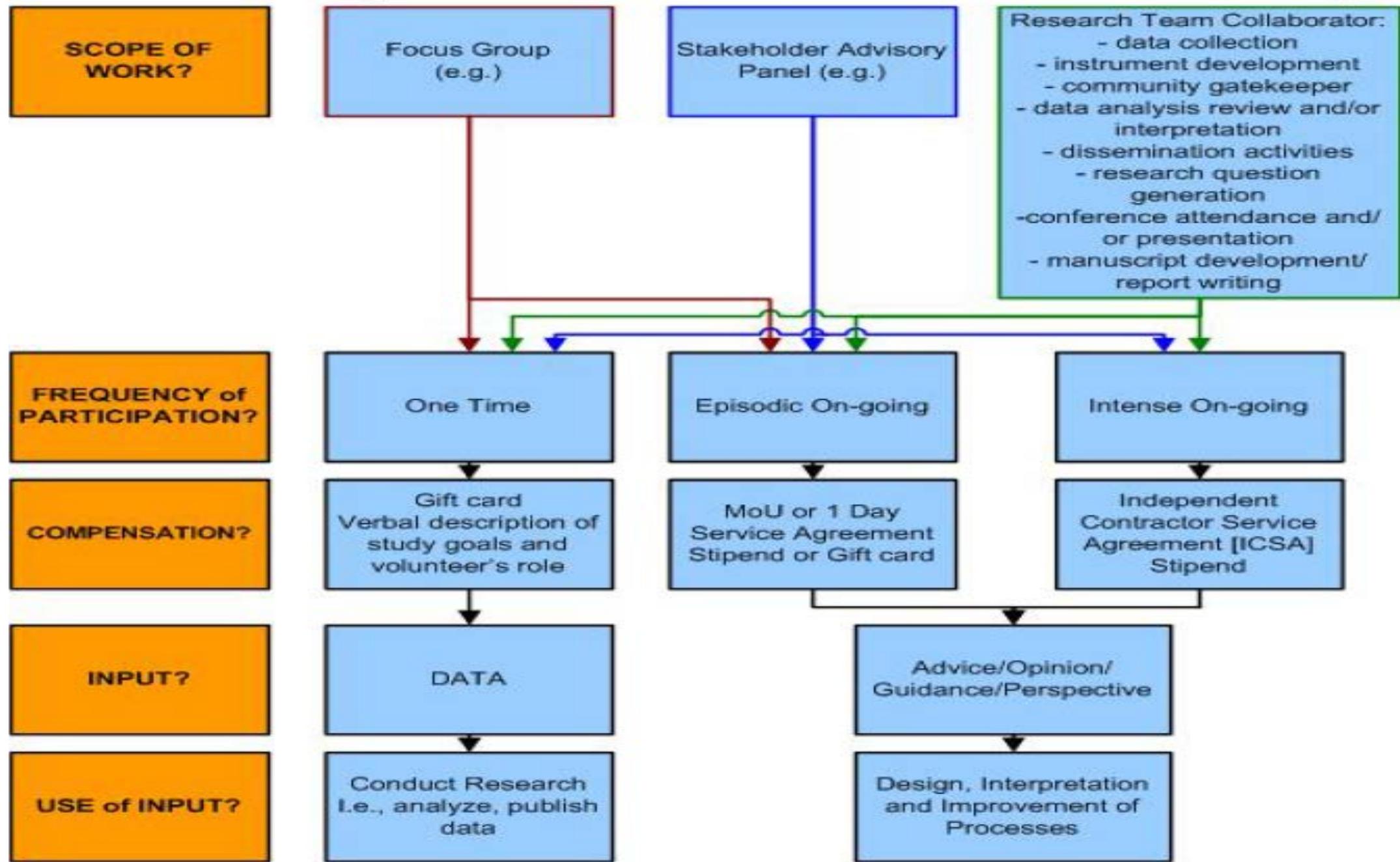
STEP 4: Ideal Use of Workbook

As a basis for customization to individual research teams or research shops

Examples:

- include organization-specific templates for contracting or hiring
- add decision flows for determining appropriate compliance trainings depending on intensity or duration of engagement
- incorporate organizational standards for compensation

Continuum of Engagement



Questions/Comments?

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- http://www.hmoresearchnetwork.org/en/Tools%20&%20Materials/Plan_Field/HMORNPatientEngagementWorkbook.pdf