PRO-active RE-active

Stakeholder Feedback on an Innovative Engagement Model in a Head and Neck Cancer Pragmatic Trial

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Module 03 SAB meeting led by Dr. Cameron Macdonald in Madison, WI, USA

Module 03 SAB meeting led by Dr. Margaret Fitch in Toronto, ON, Canada

INTRODUCTION

A growing body of evidence supports stakeholder engagement as an important component of successful research.

Various levels of engagement and roles for stakeholders have been described. However, little consensus exists about how to best accomplish successful engagement with specific cancer populations.

Few reports have described perspectives about stakeholder engagement experiences from the engaged stakeholders themselves.

Head and neck cancer patients and survivors have unique characteristics which could influence how they engage in stakeholder activities and the roles that enact in a research program.

This project gathered perspectives from head and neck cancer patients, survivors and family caregivers, regarding their experiences participating in an innovative approach to stakeholder engagement for this specific population in a pragmatic research trial.

METHODS AND MATERIALS

As the Engagement Team for an international, multi-site pragmatic trial aimed at comparing the effectiveness of swallowing interventions during radiotherapy for Head and Neck Cancer (PRO-ACTIVE), we adopted core principles of stakeholder engagement based on literature and guidelines from our funder (Patient-Centered Outcomes Research Institute).

We crafted strategies to facilitate meaningful contributions, generate a range of trial ideas, and mobilize collaborative consensus from diverse perspectives.

Feedback about the engagement processes was gathered from all stakeholders through:
-Evaluation surveys following each meeting
-Summative evaluation survey at two years
-In-depth interviews at two years

Quantitative and qualitative analyses were conducted as relevant.

RESULTS

Members recruited for panels (Canada an USA)	Patient/caregiver	N=16
	Allied health professionals	N=16
	Medical/surgical oncologists	N=13
	Decision/policy makers	N=16
Number of meetings held over 2 years	Across Canada & USA	n=26
Topics addressed by stakeholders	Ethical considerations	
	Recruitment processes	
	Study outcomes (primary and secondary)	
	Trigger point for referral	
	Patient education materials	
	Ideas for ancillary studies	

Table 1. Panel members and inputs.

Category			Canada	United States	Totals
Head and neck patients			7/8	5/8	12/16
Family caregivers					
Allied health clinicians	Nurse, Social worker Radiation technologist Speech language pathologist, Dietician		6/9	6/10	12/16
Doctors	General practitioner		4/6	4/7	8/13
	Oncologist	Medical			
		Radiation			
		Surgeon			
Payer/policy decision-makers			3/9	3/7	6/16
Totals for survey responses			20/32	18/32	38/64

Table 2. Respondents to summative evaluation survey.

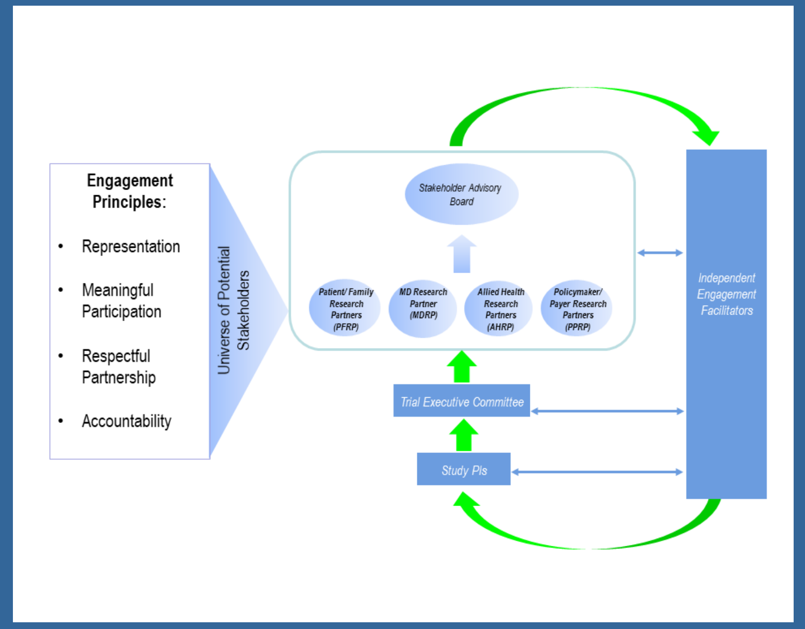

Figure 1. Model of engagement based on principles.

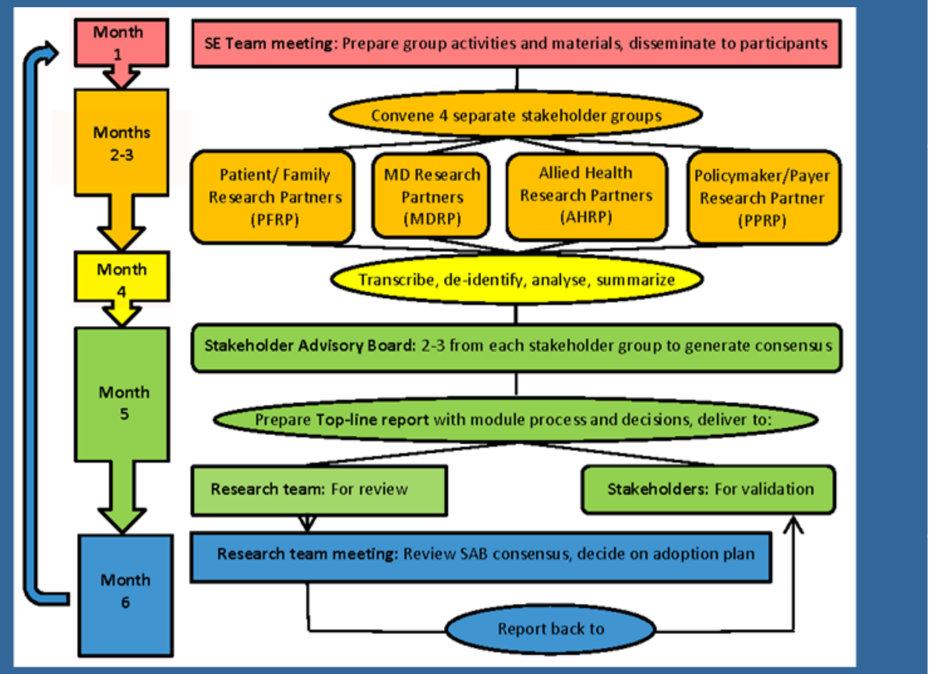

Figure 2. Workflow for Stakeholder Engagement Modules

Figure 2. Workflow based on model.

Perceived benefits of the stakeholder model design	Illustrative survey responses
Perceived value of stakeholder input	"This study is VERY focused on patient experience and thus the input of patients/families is important and makes sense. All members of the team could see and understand that." "Having the stakeholder input is invaluable and is being used appropriately and will ultimately make the design of this study even better…I believe these groups will improve the study outcomes."
Development of consensus on group norms; Clear description of roles and timelines for stakeholders	"I was able to participate in a meaningful and important head and neck research subject." "I felt I could contribute a perspective based on my experience." "This provides me with a basic idea of what to expect for discussion"
Facilitation of groups by professional facilitators	"The conversations were well facilitated and I always felt that I was heard." "I felt our opinions were being considered and respected."
Design of specific 'asks' of stakeholders regarding trial topics/decisions where uncertainty was evident	"This allowed actionable input on areas of the trial design where genuine uncertainty existed in the trial and focused discussion in the stakeholder groups." "I feel that sometimes there are moments in the course of our discussions that shed previously unseen light on areas that the investigators had not recognized or understood as clearly prior to our discussion. It seems that we are fulfilling the goal of helping guide a more relevant, meaningful design."
Having homogenous panels followed by a heterogenous panel to achieve consensus on stakeholder input	"I really love the model of the homogeneous group and then the heterogeneous SAB. I think that is respectful of the opinion of each groups…but at the end of the day we've got to bring it down to what's best for the collective group." "The committee made a serious effort to listen to stakeholders."

Table 3. Illustrative feedback about experiences from Stakeholders

DISCUSSION

Lessons emerging from experiences:

- Being clear about the roles and expectations for all stakeholders was important
- Value was seen in having the full range of stakeholders: patients, family caregivers, allied health professionals, medical/surgical oncologists, policy/decision-makers
- Regular on-going communication about the trial progress contributed to stakeholder engagement
- Creation of processes and zones of comfort, taking power dynamics into account, was key to having all stakeholders feeling able to contribute
- Stakeholders receiving feedback about how their input was used by the Trial Executive (how it was incorporated into the trial procedures) was seen as important and contributed to a sense of their input being meaningful

CONCLUSIONS

Stakeholder input can improve patient-centeredness and effectiveness of trial implementation.

Stakeholder engagement requires concerted design planning and implementation of processes to ensure meaningful and respectful involvement by all stakeholders concerned with specific populations.

Key principles to operationalize for successful stakeholder engagement for pragmatic head and neck trials include representation, meaningful participation, respectful partnerships and accountability.

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