

Patient stakeholders play a critical, ever-changing role in a project lifespan.

Projects utilizing patient stakeholders should consider how to best engage them based on needs and be prepared to re-evaluate the relationship over time.

Evolving Patient Stakeholder Engagement in Invested in Diabetes

Ramona Koren¹, Sharon Trujillo¹, Tom Carrigan¹, David Downey¹, Barbara Clay¹, Dennis Gurfinkel², Anowara Begum², Jeanette Waxmonsky², Bethany Kwan²

1: Invested in Diabetes Patient Stakeholder; 2: University of Colorado Anschutz Medical Campus

INTRODUCTION

- Patient engagement in healthcare research may be beneficial to enhancing research studies in enhancing research feasibility, acceptability, rigor and relevance.
- The Invested in Diabetes project, a comparative effectiveness cluster-randomized pragmatic trial comparing two methods of implementing diabetes shared medical appointments, engaged patient partners from conception through implementation and continues to engage patients as findings begin to be disseminated
- **This objective of this presentation** is to describe the experience of the patient-researcher partnership and how engagement evolved throughout the course of the project.

METHODS

- Project notes and deliverables were reviewed to examine how patients were engaged over time
- An anonymous online survey was sent to all patient stakeholders and researchers. Survey development was led by patient stakeholders under supervision of research staff.
- Questions focused on patient and researcher perceptions of patient stakeholder roles and responsibilities on the project, engagement style, and change in roles and engagement over time. Questions were primarily open ended.
- Responses were reviewed by one stakeholder and researcher who summarized main themes across questions. The remaining authors reviewed summaries and provided feedback.

RESULTS & INITIAL THEMES

- Patient stakeholders were seen as instrumental to design of the study and keeping work focused on patient needs. They provided a perspective researchers were lacking.
- Patient stakeholders contributed at every step of the project. However, responsibilities and engagement changed with the different phases of the study. Sometimes this posed a problem for engagement.
- There was confusion around stakeholder role at times, reported by both stakeholders and researchers. This was sometimes due to patient stakeholder turnover or new phases of the project.
- Researchers who had not previously worked with stakeholders or trained in engagement were often surprised by how much more involved patient stakeholders were at every step of the project, and their perceptions of stakeholders evolved.
- There were some difficulties in working with patient stakeholders within the confines of sponsor and university regulations and real-world barriers
- Patient stakeholders were positive around their experience, liked the opportunity to have their voices heard and to help their communities. However some reported frustrations with working with researchers.

"Patient Stakeholders [played] a more active and collaborative role than I originally thought.." - Staff

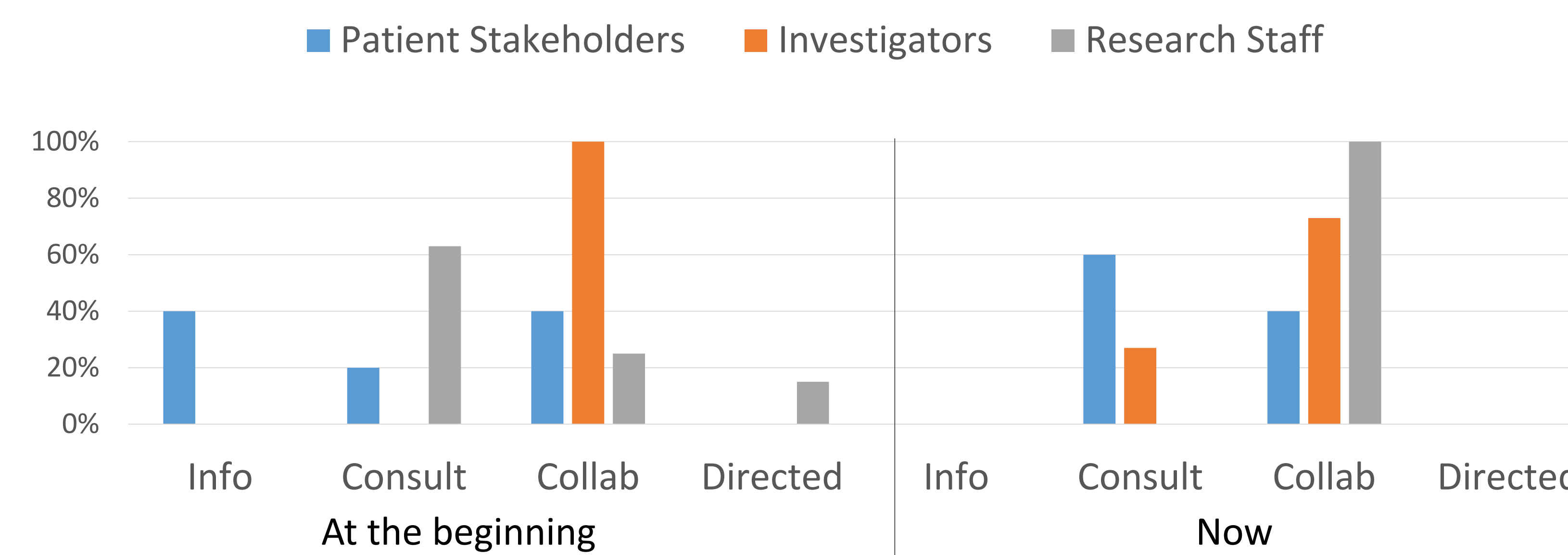
"It's important to bring my communities voices to the table no matter how hard or how under educated I think I am" - Stakeholder

"They provide perspective that no one on the research team has and ensure that patients are represented in a project that they are meant to benefit from" - Staff

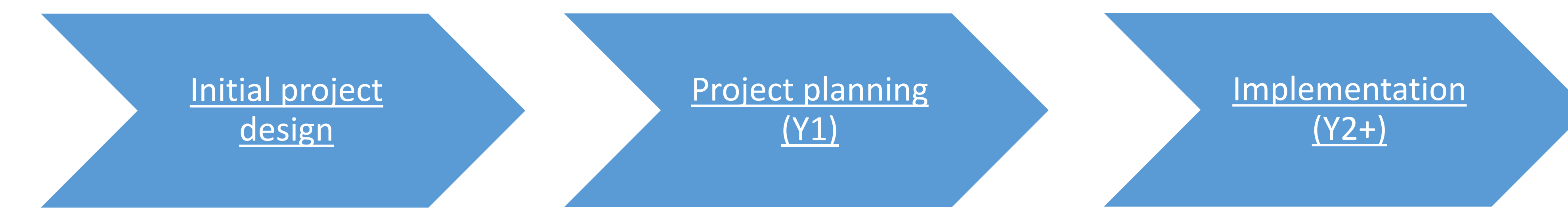
"[At first I was] Confused, mainly because I did not understand the research process due to it being "foreign" to me" - Stakeholder

"Patient stakeholders often expressed a lack of clarity about their roles as we went along, and I guess I'm a bit unclear, too." - Investigator

What role did you expect [yourself/stakeholders] to have at the beginning of, or when you started, this project? What role do you think [you/stakeholders] play currently?



Info = Informational: Stakeholders kept informed of project decisions
 Consult = Consultation: Stakeholder feedback considered to inform decisions
 Collab=Collaborative: Stakeholders worked with researchers to inform decisions
 Directed=Stakeholder direction: Decisions were led by stakeholders



- Create and refine protocol
- Come up with what elements to test
- Decide setting and population

- Finalize protocol adaptations
- Finalize curriculum changes
- Create practice and peer mentor material
- Study outcomes

- Practice support for patient issues
- Assist qual team in guide and analysis
- Peer mentor training and support
- Dissemination

How did the role change?	Patient stakeholders (n=5)	Investigators (n=11)	Research staff (n=8)
100% increase considerably		9%	14%
increase considerably		18%	57%
increase somewhat		55%	29%
no change		18%	
decrease somewhat			

RESPONDENT CHARACTERISTICS	Patient Stakeholders (n=5)	Researchers – Investigators (n=11)	Researchers – Staff (n=8)
Previous experience (with patient stakeholders or on research projects)	1 (20%)	11 (100%)	3 (38%)
Time on project			
Joined at the grant funding	2 (40%)	9 (82%)	3 (38%)
Joined during planning year (Y1)	1 (20%)	1 (9%)	1 (13%)
Joined during start of implementation (Y2)	2 (40%)	1 (9%)	2 (25%)
Joined in middle of implementation (Y3+)	0	0	2 (25%)