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Engaging Emergency Department Patients in the Creation of a Shared Decision-Making Tool Regarding CT Scanning in Kidney Stones: Challenges to Traditional Stakeholder Engagement

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Background

Each year, approximately 2 million patients are seen in US EDs for suspected renal colic and the majority receive CT scans. The objective of our study was to develop a stakeholder-informed conversation aid to help clinicians use Shared Decision-Making regarding the use of CT for patients with suspected renal colic.

Traditional Decision Aid Development involves iterative stakeholder engagement. However, ED patients represent a challenging population for many reasons:

• No shared identity (no identity as “ED patients”)  
• No clear way to recruit/retain  
• No longitudinal relationships

We sought to use multiple methods to engage stakeholders in the development of this decision aid. Traditional benefits of Focus Groups and Interviews are below.

Methods

A. Direct from ED recruitment for Focus Groups

• Research assistants approached patients age 18-50 and asked if they would be willing to return for focus groups. If yes, they collected contact information.
  • Texts/emails/phone calls used to gather participants  
  • Participants offered $20 to return to ED for focus groups  
  • Participants invited to bring friend who would also be reimbursed $20  
  • Focus groups set for 4 or 5 pm after 9am focus groups failed to attract participants  
  • Pizza provided at focus groups

B. In-ED interviews

• PI directly approached appropriate patients  
• Interviews occurred at the same time, recorded

Results

Our Experience with Focus Groups

108 patients agreed to share contact information (phone numbers, email addresses) to be invited to future focus groups.

• Research assistants sent invitations via text, email, and some phone calls at least three time prior to each focus group, asking for participants  
  • Most didn’t respond, ~25 responded that they would attend  
  • 17 showed up (between 5 scheduled focus groups)  
  • Several were under the influence of substances and had difficulty participating in focus groups. Several focused on their own ED care and used focus groups to vent about perceived injustices relating to their ED experiences

Total = 17 participants in 4 focus groups  
~ 4 hours of transcription  
Effort: >120 hours, over 3-4 months for research staff

Our experience with Interviews

Eight ED patients approached for decision-aid review and commentary, during the course of their ED care (as of March 15)  

• In-ED patients generally happy to participate and be of help, surprised to be reimbursed for their time.  
• Nearly always consented to involvement.  
• Despite medications, able to focus on issues.

Total = 8 participants in interviews (not including family members)  
~ 4 hours of transcription  
Effort: ~ 8-16 hours, for PI (requires flexibility)

Conclusions

1. Engaging ED patients IN the ED is much easier than recruiting them for a later event.

2. Asking patients to return to the ED may not be worth your time.

3. Consider training research staff to do semi-structured interviews with patients in the ED.

4. The traditional benefits of focus groups are not likely worth the costs, for this population.

Figure 1. Overview of Decision aid development and testing.