

MEDICALLY COMPLEX PATIENTS PROGRAM DESIGN GUIDELINES: GETTING INPUT FROM THE TARGET POPULATION

Recruiting Guidelines

- Recruit 5 people from the target population—people respond to a request for help improving care for people with ongoing health conditions. Consider interviewing a few caregivers for additional perspective.
- Allow time for 1-2 hour interview
- Offer a reward (e.g. \$50 gift certificate at Safeway). Reimbursement is key to getting their attention, making sure they show up or are at home at the appointed time.
- Get consent to take notes and share their story with others without identifying the source.

Interview Guidelines

- Interview in pairs: one person talks, the other takes notes and records the session.
- Start the interview getting to know the person. Take your time. Ask about their life history, job experience, and hobbies. Consider making a map with them of their significant relationships.
- Once you have established rapport and shown you can listen, you can ask about their health issues and experience with health care:
 - What do you struggle with the most?
 - What is the worst thing that happened to you in health care?
 - What has helped you do better with your health?
 - What did health care providers do that might have helped you?
 - What did health care providers do that was not helpful?
 - Tell me about any times you went to the emergency department or were admitted to the hospital.
- At the end of the interview, thank the person, review how what they shared will be used to improve care, and have them sign a receipt.

Reviewing Stories

- After all the interviews are done, the interviewers review the notes.
- Make sticky notes of the key points and group the sticky notes together by themes.
- Write up the themes, including quotes from people when relevant.
- Present to the broader team of evaluators to fine tune the message.
- A nice touch is to go back to the people who were interviewed to get their reactions on the product you designed or document you produced.
- Consider recruiting interviewees as patient advisors to your program.

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