

## Patient Experience

1. Recruitment: how to get people to participate
2. Consent: clear, informed decisions
3. Interventions: where and how to be involved in research
4. Patient-reported outcomes (PROs): data reported by patients
5. Monitoring and feedback: getting information back to people in study

## Recruitment

- At primary care clinic: ask the patient, “would it be ok if we use your info?”
- Find what motivates that particular person: info could encourage them or scare them away. Example: helping others like yourself, “Collective Impact”
- Who delivers the message, how is the message delivered
- Someone on the team, other than the provider
- Before or after seeing the MD, some like after. Possibly not right at time of diagnosis’
- Trust, ease, and asking questions

## Recruitment (for research)

Find out about through:

- Computer (websites)
- Mail
- Sign letter/waiver in clinic to join biobank/registry
- Social media/friends
- Text messaging
- Emails and (e-)newsletters

Where are the doctors? Physicians **can** and **should** be important source (in many cases)

## Consent

- Timing: quick and clear vs enough time to discuss with support team (patients and families)
- Presentation: not scientific
- Technologies: tablet or iPad available for patients
  - Patients ability to use technology
  - Literacy levels
  - Apps to obtain information re: patient experience—some have found helpful, but does not apply to all patient situations (e.g.: homeless, socio-economic status, literacy level)
  - These seem to be improving
- Condense/shorter
- Images and pictures
- Language too technical
- Opportunity to review and ask questions
- Don’t rush the consent process
- Know the names of persons you are enrolling

- Health literacy: staff consenting should check in with patients to make sure they understand

### Monitoring and Feedback

- How do we make it understandable to everyone?
- Website or link posted
- Common terminology
- Common ground throughout process
- “Health Literacy Board”
- How could population be educated about research before they are “ill” or “need it”
- Patients assumption researchers are already using clinical data in the records
- Greater Plains having information available at more of their sites
- Having conversations within the community
  - Community partnerships: understand how people in their communities use research or know about it

### Communication of Results

- **Require** that studies have a plan to communicate results
- Most/all want to know results
- Personalized letter of thanks
- Let participants know when they expect to get results
- Communicate what will happen with their data and study results
- **What are PCORI’s plans to communicate results?**

### What helps decision making to participate in research?

- Expense
- Sense that there is no other option
- Transportation (and \$\$)
- Accessibility
- Prognosis of diagnosis
- Travel required
- Side effects
- Cultural relevance of recruitment materials
- Helping others/altruism
- Potential for inter-generational benefit (e.g.: grandparents to grandchildren)

### Design Considerations

- Can local/geographically closer docs administer study meds or other procedures?  
E.g.: blood draws, etc.
- Accommodate participants and their families in being able to easily participate.