Strategies to overcome challenges for creating a PBRN

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Challenges

Like all research, success with PBRNs requires a great deal of attention to *process*. This presentation deals with process issues related to building the “machinery” of a PBRN.

- **Infrastructure and funding**
  - Personnel—usually the greatest expense
  - Electronic data collection technology

- **Participation factors**
  - Interest
  - Time and paperwork
  - Follow-up
    - By participating office
    - By patients
Infrastructure and funding challenges and strategies
Personnel challenges

- PBRNs are large, complex organizations with complex data management and analysis needs
  - Remote data collection from clinicians and patients presents quality assurance needs which require a skilled coordinator or data manager to address. Data integrity is a key issue.
  - Communication with and training of participants must be timely, frequent and effective, requiring a coordinator with excellent interpersonal and organizational skills.
  - “Kids, don’t try this at home!” — a biostatistician with experience with large, complex datasets, including survey data, is essential.
  - A program director with a track record of publications and relevant research experience will provide cohesion and direction to the team.
Personnel strategies

• Develop collaborations! Personnel may be at different institutions or in private practice.
  ▪ Faculty may not need funding; publications and grant proposals are requirements for promotion so this may serve in lieu of salary.

• Coordinator is essential—but training is not; the right person can be trained on the job.
  ▪ Detail orientation
  ▪ Excellent interpersonal skills
  ▪ Persistence
Data collection technology challenges

• Essential to collect the information necessary to answer your research question
  ▪ However, developing your own forms presents reliability/validity challenges
• Paper forms are becoming a thing of the past.
  ▪ Many DCs and patients are new to electronic data collection.
• DCs use a variety of EHR software, which makes it challenging and/or expensive to coordinate
Data collection technology strategies

• Rather than create your own forms, use standard outcome measures as much as possible, such as PROMIS: [http://www.nihpromis.org/about/abouthome](http://www.nihpromis.org/about/abouthome)

• Commercial systems such as SurveyMonkey are acceptable ways to gather patient follow-up data.

• PROMIS will also collect and manage data online for individual projects.
Participation challenges
Interest

• Buy-in from practitioners is key.
• Buy-in from their office staff is also key, but is often overlooked.
• Willingness of patients to complete forms is usually directly related to the enthusiasm of the clinicians and office staff.
Interest—strategies to overcome challenges

- ASK practitioners which topics they think are most important
  - Provide a brief description of a few different possible projects, not just a list of single-word topics

- ASK office staff for their input on the best way to administer forms, etc.

- Provide incentives before, during and after the project.
  - Press releases
  - Gift cards
  - Certificates/plaques for participation
  - CE credit if possible
Time and paperwork challenges

• Lack of time is one of the key barriers to participation.
• Practitioners have more paperwork than ever, and less time to do it.
• The PBRN must not be seen as adding to this burden excessively.
• Patients also have little time to spend on completing forms.
Time and paperwork strategies

• Assure participants that the project will not be time consuming
  ▪ If possible, calculate the actual time required and back your statement up with data. (Obtained by careful pilot testing)

• Collect *only* the data you will actually use—busy practices do not have time for lengthy “fishing expedition” questionnaires.

• Conduct pilot projects with a few practices and identify procedures and protocols that are inefficient—and fix them!
  ▪ Interview clinical and office staff who pilot the forms and protocols to find out what works and what doesn’t
  ▪ Take as long as necessary to develop efficient protocols!
Follow-up—one of the biggest challenges

• Cross sectional studies are MUCH easier than follow-up studies.
  ▪ Short, single follow-ups done in-office are next in terms of ease.
  ▪ Longitudinal studies over many months are extremely difficult.
  ▪ Follow-up done by direct patient contact decreases bias but requires more complicated protocols and is much more expensive.

• However, PBRNs have the potential for valuable contributions in terms of Phase III and IV trials and comparative effectiveness studies.
Follow-up strategies

• START with a cross-sectional study, publish it, give all participants a copy of the article and generous praise, before moving on to follow-up studies! (Secure buy-in and build enthusiasm.)

• Find out the most effective incentives (by asking) for both doctors and staff, and use them.
  ▪ Drawings for substantial prizes for offices with high follow-up rates (at least 75%, for example)
  ▪ Gift cards for staff who achieve high follow-up rates
  ▪ Gift cards for patients who complete follow up (approved by IRB of course).
  ▪ Our experience was that gift cards don’t motivate patients to comply, but motivated office staff and doctors do increase patient compliance.