

Strategies to overcome challenges for creating a PBRN



Cheryl Hawk, DC, PhD
**Associate Vice President of Research and
Health Policy, Logan University**

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>
- 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.