The Power of the Participant Perspective

Julie Brinker, MPA
Research Community Liaison
Clinical Translation Research Center
Objectives for this Presentation

• What is a research participant advisory group?
• What was the process for setting up a research participant advisory group at Children’s? And in the West End?
• What are the similarities/differences between the two Children’s advisory councils?
• What are some of the ways the Children’s advisory council has helped improve the research participant process?
• What are the goals of the two advisory councils for the future?
What is a Research Participant Advisory Group?

- Relatively new and innovative approach to informing what and how research is conducted

“...studies increasingly show that when health care administrators, providers, patients, and families work in partnership, the quality and safety of health care rise, costs decrease, and provider and patient satisfaction increase”

What is a Research Participant Advisory Group?

• Relatively new and innovative approach to informing what and how research is conducted
• Modeled after Patient and Family Advisory Councils

At Cincinnati Children’s….

*Research Participant Advisory Groups provide the forum for Research participants, family and/or community members to advise and engage with Cincinnati Children’s Hospital Medical Center (CCHMC) on research and its practices at the medical center and/or the Cincinnati community.*
Gathering Participant Input at Cincinnati Children’s

- **Research Participant Advisory Council (RPAC)**
  - Started February 2015
  - Located at Cincinnati Children’s
  - Focused on the overall participant experience at Cincinnati Children’s

- **West End Community Research Participant Advisory Board**
  - Started June 2016
  - Located at Seven Hills Neighborhood Houses in the West End
  - Focused on community health and research
The RPAC at Children’s

Becca Harper, DNP, RN

• Part of Doctoral thesis
• Saw need for input from research participants, just like receive input from patients at Children’s
The RPAC at Children’s: Inspiration for the RPAC

• Patient and Family Advisory Council
• IACRN Conference Presentation on Generation R: http://www.youtube.com/watch?v=KvamYWTDwQA&sns=em
The RPAC at Children’s:
The Process

- Steering Committee Development
- Research
- Meet & Greets
- CRP Community Support
- Recruitment Flyers

Children and Their Parents/Guardians Needed to Join Our Research Participant Advisory Council

Help Us Improve Our Research Study Process

What
We are looking for people to join our Research Participant Advisory Council to discuss and make suggestions that will help us improve the way we conduct research studies.

Who
Members with and without research participation experience are needed.
- Children at least 11 years old may be eligible to join the Research Participant Advisory Council.
- Parents/guardians may participate with or without their children.

Pay
Members may receive up to $240 for attending all 12 monthly meetings ($20 per meeting). Community service credit can also be given to students.

Contact
Becca Harper at rebecca.harper@echmc.org or 513-636-8750
The RPAC at Children’s: The Details

- RPAC consists of 30 research participants (pediatric and adult) and parents/guardians of research participants.
  - Ages range from 12-58 years.
- 10 Staff representatives who act as content experts and group facilitators for focus groups and discussions.
- Meet monthly
- Onsite at Children’s
- Food provided
- Transportation vouchers offered
The purpose of the Research Participant Advisory Council is to allow for research participants to advise and engage with Cincinnati Children’s Hospital Medical Center (CCHMC) on research and its practices at the medical center.
The RPAC at Children’s: Objectives

• Partner research participants and families with members of the research community to provide guidance on how to improve research across the academic health center, with a focus on participant experiences and building relationships of trust.

• Establish best practices and improvement initiatives to implement these changes.

• Provide a formal referral system for other patient and family advisory councils across the institution looking to engage in research.

• Humanize the face of research at the institution and in the surrounding communities.
The RPAC at Children’s: Improving Research

• T1 Clinic/Schubert Research clinic design feedback sessions

• Assent Project with College of Design, Architecture, Art, and Planning (DAAP) and Gamble Infectious Disease

• Review of current recruitment material with Research Marketing and Recruitment Core

• Genomics Focus group work with Human Genetics Division

• Review of the Clincard payment process

• Creating a training on research ethics and the research participant experience for potential and current research participants
### eMERGE REPORT - SUMMARY

DNA sequencing and copy number assessment of the coding regions and splice sites of 150 genes was performed (see methodology section below). Previously reported variants of likely or definitive clinical relevance as well as novel variants that are expected to be pathogenic are listed below. All results are summarized on page 1 with further details on subsequent pages.

#### A. MONOGENIC DISEASE RISK

<table>
<thead>
<tr>
<th>Disease (Inheritance)</th>
<th>Gene Transcript</th>
<th>Zygosity</th>
<th>Variant</th>
<th>Classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertrophic cardiomyopathy (Autosomal dominant)</td>
<td>MYBPC3 (NM_000256.3)</td>
<td>Heterozygous</td>
<td>c.2827C&gt;T p.Arg943X</td>
<td>Pathogenic</td>
</tr>
</tbody>
</table>

This individual has a pathogenic variant in MYBPC3 and is at risk to develop hypertrophic cardiomyopathy.

#### B. CARRIER STATUS

<table>
<thead>
<tr>
<th>Disease (Inheritance)</th>
<th>Gene Transcript</th>
<th>Zygosity</th>
<th>Variant</th>
<th>Classification</th>
<th>Carrier Phenotype*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congenital myasthenic syndrome (Autosomal recessive)</td>
<td>RAPSN (NM_005055.4)</td>
<td>Heterozygous</td>
<td>c.284C&gt;T p.Asn98Lys</td>
<td>Pathogenic</td>
<td>None reported</td>
</tr>
</tbody>
</table>
West End Community Research Advisory Board

Please Join Us for a Community Meet & Greet!

Learn about the *NEWLY Forming* West End Community Research Advisory Board (CRAB) Supported by Cincinnati Children’s Hospital Medical Center

Adults & Teens (12+ years) are invited to learn more about how you can...

- **ENGAGE researchers** to ensure they support the West End’s health goals in addition to collecting their study data
- **Provide your OPINIONS** on how to make research easier and more understandable to you, your family and families like yours!
- **Share your VOICES** - Guide what research happens in the West End.

**Thursday, April 21st** or **Tuesday, May 3rd**

5:30-7pm

Location: Seven Hills Neighborhood Houses, 901 Findlay St.

*Light refreshments will be served. Child-care provided with an RSVP.*

For further questions or to RSVP, please contact Julie Wijesooriya at julie.wijesooriya@cchmc.org or by phone at 513-517-1076.

*Photo of an existing Participant Board that meets at Cincinnati Children’s; several West Enders are members!*
The purpose of the West End Community Research Advisory Board is to allow for research participants and community members to advise and engage with Cincinnati Children’s Hospital Medical Center (CCHMC) and its researchers on research and its practices in the West End Community.
West End Community Research Advisory Board

- RPAC consist of 17 West End community members
  - ages range from 17-73 years.
- 2 Staff representatives who act as content experts and group facilitators for focus groups and discussions. One from Children’s and one from Seven Hills.
- Meet monthly
- Food provided
- At Seven Hills
- Board Roles: President, Vice President, Secretary, Liaison
West End Community Research Advisory Board: Objectives

• Humanize research in the West End community.
• Engage researchers to ensure they support the West End’s health goals in addition to collecting study data.
• Provide opinions on how to make research easier and more understandable for West End community members.
• Guide what research happens in the West End.
West End Community Research Advisory Board: Objectives

In Their Own Words....

Why are we here?

• Advocate for the West End
• Advise and help people with health goals
• To help our people/culture better understand the importance of research and find out about how research is done and to learn more about research.
• Get to know each other
• Learn about the community
• Share our voices with researchers
West End Community Research Advisory Board: In Their Own Words...

In Their Own Words....

What are we trying to accomplish?

• Helping people with opportunities for their health and to inform the people
• The importance of finding cures through research and to help others. Also to inform others in the community and other areas how being a part of research can enhance research in a major way.
• Safe environment & studies
• Participants understand research studies
West End Community Research Advisory Board: In Their Own Words...

In Their Own Words....

Who are we trying to help?

• Every member of the community, young and old
• Trying to help the research community reach out to others by being there for them to engage with those who seem to be hard to contact and relate to concerning research.
• Make research better for the community
• Help researchers understand how to invite those in lower-resourced neighborhoods
West End Community Research Advisory Board: Projects

• Participating in Research and Reviewing the Recruitment Process
• Survey of the West End Community on Research and Health Needs
• Research Participant Ethics Training
West End Community Research Advisory Board: Community Survey

60 surveys conducted by 9 community researchers
57% female
60% are age 50 or older
West End Community Research Advisory Board: Community Survey

68% Live in the WE
33% Work in the WE
25% Are members of a WE Organization

Connection to the West End

- Lived/Grew up in WE
- Work in WE
- Members WE Org
- Live in WE
- Live & Work WE
- Live & Work WE & Members WE Org
- Live in WE & Members WE Org
- Mother lives in WE
West End Community Research Advisory Board: Community Survey

Research Participation

- 70% Have NOT Participated
- 30% Have Participated

- HAVE NOT participated in Research
- HAVE participated in Research

42
18
West End Community Research Advisory Board: Community Survey

38% No risks
21% Someone asked

Why have participated?

- No risks involved: 13
- Someone asked: 7
- Benefits my/others child: 5
- Because it was fun: 4
- Child has terminal illness: 2
- Thought drug would cure my child: 1

UC Women’s Health Program
West End Community Research Advisory Board: Community Survey

Why have NOT participated?

30% Never been asked
20% No transportation
14% No study relevant to me
West End Community Research Advisory Board: Community Survey

Willingness to participate in Research

- 76% Willing
- 20% Not Willing
- 3% Maybe

45 Total Participants

43 Yes
2 No
2 Maybe
80% Willing
17% Not Willing
3% Maybe/Depends
West End Community Research Advisory Board: Community Survey

- From taking these surveys, who will benefit from it? How will this help the community?

- How does your research help the West End?

- How will it change the West End?

- Not willing to participate unless all data and purpose of study belonged solely to residents.

- Are there recorded findings accessible to the "lay" public? Where can this information be found about the different studies?

- What would the study be? Will it benefit us all?
More research studies are needed.

Most people don't have any knowledge about what research is doing or what's going on and do without our knowledge. They give us $20 and make multimillions.

Will they be relevant to us? How will we know about them?

Do they pay? Who can we go to about the different studies?

Need to know more information

How do we qualify to participate in research studies?
Research Participant Groups: Next Steps

• Getting the word out:
  • Development CCTST Webpage
  • Speaking to various groups
  • Identifying other places to share the information
• Opportunities for collaboration between groups
• Helping with the development of a UC RPAC
• Development of an RPAC database
The Power of the Participant Perspective

Questions?

Julie Brinker, MPA
Research Community Liaison
Clinical Translation Research Center