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Listening to Autistic Voices: Participatory Research in Prioritizing Mental Health

Participatory Research: Questions to Consider

- What is participatory research?
- What implications does authentic engagement of autistic people have for reliability and validity in autism research?
- What are some key factors indicating that successful participatory research is being accomplished?
- In what ways can participatory research be helpful in determining health priorities for autistic individuals?

Including (non-academic) community members on the research team
- Equal power sharing (e.g. CBPR, some PAR)
- Authentic inclusion (e.g. PCOR/Co-production)
- Consultation (e.g. Advisory board/Delphi panels)

https://youtu.be/1eofFWWHKM4

12:04-18:50

Christina Nicolaidis, MD, MPH
Funded by **Patient-Centered Outcomes Research Institute (PCORI)**, Eugene Washington PCORI Engagement Award (EAIN# 4208) to Accomplish the Project Goal…

… to meaningfully include and engage autistic stakeholders in identifying priorities and methods to support patient-centered outcomes research in collaboration with autistic people.

The views presented in this presentation are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors, or Methodology Committee.

Teal Benevides and Stephen Shore declare no financial conflicts of interest with entities who paid for the study described herein.
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Why? Fundamental Need to Ensure Autistic Individuals Are Involved in Research

- Autistic adults\(^*\) have multiple, chronic, and potentially preventable healthcare needs as compared to same-aged adults without ASD.

- Much of what is known about the health and healthcare needs of autistic adults has emerged from health services research without knowing the specific priorities of autistic people for addressing barriers to care (e.g. Croen et al., 2015; Zerbo et al., 2018; Schott et al., 2020).

- Approximately 2% of U.S. research funding in autism is spent in addressing adult outcomes (IACC, n.d.)

- *Noted increases in autistic involvement in research, particularly IACC and other funded studies, is promising.*

\(^*\) Identity-first language is purposefully used, as opposed to person-first language, in congruence with preferences expressed by adults on the spectrum.
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**How?** Participatory Action Research Design

- Established a **Project Team** comprised of autistic and non-autistic individuals

- Established a **paid Community Council** of autistic adults and other stakeholders to inform and guide patient-centered outcomes research
  - 18 Community Council members joined and contributed
  - Involved **other stakeholder individuals and organizations** in priority-settings
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Authentic Autistic Engagement in Research…

Why?  How?
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How? Enhancing Engagement

Engagement & Compensation Guide for researchers.

- Competence
- Communication
- Compensation
- Considerations


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How? Enhancing Engagement: Competence

WHAT IS GOOD FOR THE GOOSE IS GOOD FOR THE GANDER

1. Non-speaking individuals should be treated as if they understand all verbal language – **Presume competence**!

2. Modify your language.
   - Instead of “sensory dysfunction”, describe “sensory differences”. The differences may impact function, but aim to not describe the problem as being the individual.

3. Teach students, family members, postdocs, and others to communicate **WITH** the person on the spectrum, even if they are a child.
   - Do not talk about the child or adult as if they are not listening - they are, and listening to deficit-based language is detrimental to a person’s mental health.
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How? Enhancing Engagement: Competence

WHAT IS GOOD FOR THE GOOSE IS GOOD FOR THE GANDER

Does Paul Kotler have...

- communication?
- environmental awareness?
- agency?
- a voice?

https://youtu.be/uPreKqiglqQ
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How? Enhancing Engagement: Communication

**WHAT IS GOOD FOR THE GOOSE IS GOOD FOR THE GANDER**

*Example Email from the Engagement Guide*

**Purpose**
- To request feedback on Conference Summary (short, 3 page summary)

**Details:**
- We will incorporate feedback from the Community Council prior to sharing with the attendees of the year 1 meeting.

**Questions include:**
- Are the materials written in a way that is understandable? Clear? Respectful?
- Is there anything missing that you would want to know?

**Actions:**
- Read the Conference summary
- Use track changes to share edits or comments on the content of the summary
- Send feedback to sampleperson@email.com

**Deadline:** Wednesday October 4, 2017 at 5pm Eastern Time

*Template developed by Elesia Ashkenazy (AASPIRE Representative)*
**WHAT IS GOOD FOR THE GOOSE IS GOOD FOR THE GANDER**

- All individuals in research and practice should be compensated for their intellectual contributions.
- Authentic alliance and respect require compensation as team members, depending on role.
- For our project, Community Council members were paid $50/hour for their time in advisory roles.
- In recent CER grant applications, we have compensated at a rate of $100/hour for roles such as outcome assessor, intervention manual developer, and intervention implementer.
- Major barrier: payment can interfere with disability benefits. This requires future work to address how to best compensate.
How? Measuring Engagement: Considerations

WHAT IS GOOD FOR THE GOOSE IS GOOD FOR THE GANDER

- **Trust**
  - Able to bring up differing ideas and concerns
  - Measurement: Concerns are raised and meaningfully heard

- **Respect**
  - Contributions are valued
  - Measurement: Equality of voices in meetings and decision points
  - Measurement: Contributions are included and recognized in process and products

- **Support**
  - Multiple options for remaining engaged make it easier to participate
  - Measurement: Number of people who prefer or use different options
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How? Enhancing Engagement: Considerations

WHAT IS GOOD FOR THE GOOSE IS GOOD FOR THE GANDER

- **Include** autistics in the development, implementation & dissemination of research
- **Ensure** participation through appropriate accommodation
- **Presume competence and focus on abilities** in all interactions
- **Value** autistics as an integral part of the team (avoid tokenism)
- **Present** research results in several modalities to accommodate different communication styles
- **Compensate** autistics for time and experience brought to the table
- **Consult** autistics regarding priorities for research and systems change
Priority Setting for Health Research... Methods
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Priority Setting Methods

- Year 1 Large group stakeholder meeting
  - July 2017 ($n=51$)
- Online survey of autistic adults
  - Aug 2018 ($n=236$)
- Face-to-face focus groups of autistic adults
  - Aug-Nov 2018 ($n=26$)
- Year 2 Large group stakeholder meeting
  - November 2018 ($n=64$)
Priority Setting for Health Research... Results
Results of priorities revolved around the following areas…

1. Mental health interventions and outcomes

1. Access to healthcare and needed accommodations to get care

1. Gender inequalities in diagnosis, treatment, and sexual well-being
Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project

Table 5. Top mental health priority topics and questions.

1. What is the impact of trauma on mental health outcomes in autistic individuals, and what approaches can be used to effectively address trauma among autistic adults (e.g., trauma-informed care)? What are the best indicators or measures of PTSD, trauma, and adverse childhood experiences in autistic individuals?
2. What is the impact of social isolation, stigma, discrimination and other forms of marginalization on mental health and well-being in autistic individuals? Conversely, what is the impact of radical inclusion, such as being part of a social movement, on mental health and well-being?
3. When, for who, and under what conditions do self-managed interventions and preferred activities used to address well-being and mental health result in improved quality of life and reduced mental health symptoms? What is the effect of employing community-available approaches and techniques such as exercise/physical activity, yoga, mindfulness and meditation, tai-chi, animal-assisted therapy, art and music-based approaches to well-being?
4. What are the potential long- and short-term negative side effects or adverse outcomes of currently recommended therapies and interventions (including behavioral and pharmacological), as measured in autistic individuals across the life span?
5. How can we develop better measurement tools for autistic quality of life, depression, anxiety, social well-being, and sleep as experienced by autistic adults?

PTSD: posttraumatic stress disorder.
### Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project

**Table 4.** Online survey participants who endorsed “This Outcome Matters to Me” and weighted rank (n = 136).

<table>
<thead>
<tr>
<th>Outcome</th>
<th>“Yes—matters to me,” # (%)</th>
<th>Relative weighted rank&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of life</td>
<td>130 (95.6)</td>
<td>1</td>
</tr>
<tr>
<td>Anxiety</td>
<td>122 (89.7)</td>
<td>2</td>
</tr>
<tr>
<td>Depression</td>
<td>111 (81.6)</td>
<td>3</td>
</tr>
<tr>
<td>Social well-being</td>
<td>107 (78.7)</td>
<td>4</td>
</tr>
<tr>
<td>Sleep</td>
<td>107 (78.7)</td>
<td>5</td>
</tr>
<tr>
<td>Interpersonal relationships</td>
<td>103 (75.7)</td>
<td>6</td>
</tr>
<tr>
<td>Suicidal ideation</td>
<td>92 (67.6)</td>
<td>7</td>
</tr>
<tr>
<td>Level of participation in activities of daily living</td>
<td>94 (69.1)</td>
<td>8</td>
</tr>
<tr>
<td>Level of participation in work</td>
<td>92 (67.6)</td>
<td>9</td>
</tr>
<tr>
<td>Suicidal attempts</td>
<td>87 (64.0)</td>
<td>10</td>
</tr>
<tr>
<td>Level of participation in your community</td>
<td>79 (58.1)</td>
<td>11</td>
</tr>
<tr>
<td>Intimacy and/or sex</td>
<td>76 (55.9)</td>
<td>12</td>
</tr>
<tr>
<td>Level of participation in leisure activities</td>
<td>77 (56.6)</td>
<td>13</td>
</tr>
<tr>
<td>Brain activity/EEG</td>
<td>47 (34.5)</td>
<td>14</td>
</tr>
<tr>
<td>Heart rate</td>
<td>44 (32.4)</td>
<td>15</td>
</tr>
</tbody>
</table>

<sup>a</sup>Weighting for ranks were calculated as the sum of the number of participant responses ranking that item as “1,” “2,” . . . “15” multiplied by the weight. A rank of “1” was given a weight of 15, and a rank of “15” was given a weight of “1.”
What about physical health?

1. What outcomes matter to you? What does ‘being healthy’ mean to you?

2. What health professionals should be involved in future research?

3. If you could wave a magic wand, what would you want to change about healthcare? What is a breaking news headline about autism research you would want to read?
Open Ended Responses Revealed Additional Outcomes that Matter

- Pain, chronic pain, fatigue
  - Migraine and headache pain
- Gut/bowel health
- Dyspraxia, mobility, joint and muscle connectivity, flexibility as aging occurs
- Stress hormones and cortisol
- Immune and autoimmune responses or conditions
- Cancer as an indicator of health
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Priority Setting: What does “being healthy mean?”

- Being healthy means absence of chronic illness, access to resources that help me stay healthy, and being physically and mentally well without pain.
- Being healthy means being able to do everyday things with little to no assistance. It means being comfortable in your abilities and being in tune with your body.
- Not being sick or in pain.
- Getting enough sleep, eating that energizes you, drinking fluids, self-esteem, low stress levels.
- Ability and well-being.
- Ability to regulate and manage body/mind systems, not being overly extreme or compulsive.
Priority Setting: What health professionals should be involved in future research?

- Primary care providers
- Counselor/psychologist
- Dental professionals
Priority Setting: Access to Care Priority Topics

- For autistic adults attempting to access healthcare, what is the effect of systems navigators or technology portals on outcomes such as improved access and use of preventive and specialty services?
- Would providing autistic adults the option of non-emergency medical transportation (non-para network, rideshare service) at little to no cost increase their engagement with in-person healthcare services such as preventive and sick visits?
- What is the effect of implementing a healthcare tool to support communication between autistic patients and providers on their experience of care, engagement, and care outcomes?
- What is the impact of sensory-friendly, optimal healing environments on the initiation, obtaining, and sustaining of ongoing medical and dental care in the autism community?
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Priority Setting: Access to Care – Improving communication between health providers and autistics

Respondent Quotes: What would you change?

- Communication between patient and provider
  - “Making it definitely easier to tell your doctor what's going on primarily because it's so anxiety-ridden when you go to the doctor, right?”
  - “I'll get focused on one thing that's been told to me, and they've moved on, and now whoa, we're three steps down the way. I would like a written summary at some point, word for word”

- Provider understanding of autism, presumption of competence
  - “I would wave a magic wand to stop doctors from treating me as a subhuman or a little child as soon as they learn I'm on the spectrum”
  - “I would love ... if doctors and clinicians understood aspects of autism.”
Respondent Quotes: What would you change?

- The environment of care
  - “Changing the way waiting rooms work…. because waiting in a waiting room with loud noises, smells, like people wearing perfumes, lights ... It's so taxing”

- Access barriers
  - “I have to do everything myself because everyone has their own things to do and my parents work a lot and live 2 hours away. I do not get good care and I cannot tell if it is because I am bad at communicating and I forget a lot or if they just do not care. I say things and they don't listen and sometimes it feels like I am a child with no say in the care I get. I stopped going to the doctor because I did not get the care I needed and it was too expensive.”
Priority Setting: Gender and Sexual Health

- How can we improve autism diagnosis in females and non-binary individuals on the spectrum?

- How do hormonal changes across the lifespan affect the skills, abilities, and sensory systems of autistic individuals?

- How can we improve gender and sexual health resources for better relationships and reducing rates of sexual abuse and trauma among autistics?
How do hormonal changes across the lifespan affect the skills, abilities, and sensory systems of autistic individuals?

Research Questions Posed by Respondents

- “Does menopause in women or midlife in men accelerate sensory sensitivity and executive functioning difficulties?”
- How can we improve the pregnancy experience and motherhood despite overwhelming sensory and physical changes?
- Does “long term use of selective serotonin reuptake inhibitors increase risk of fractures in post-menopausal autistic women?”
How do we improve autism diagnosis in females and non-binary individuals?

Headlines Posed by Respondents

- “Researchers confirm that higher diagnosis of boys was due to bias in diagnostic criteria”
- “Autism in women just as common as men, diagnostic criteria adjusted accordingly”
Priority Setting: Summary

Physical Health Priority Outcomes:
- Sensory processing
- Quality of life
- Sleep
- Pain

Physical Health Priority Topics:
- Mental health - as linked to physical health
- Access to healthcare
- Gender and sexual health
Priority Setting: Limitations to Priority Setting Activities

1. Convenience sample of self-selected adults
2. Self-reported diagnosis is not confirmable for survey respondents
3. Limited to those who have access to the internet and the ability to read and participate in an online setting (survey) or attend a focus group
4. Online survey composed more of females (65%) than males, which is not similar to current diagnostic distributions, BUT is similar to other adult studies

Future Priority Setting Activities Need to Occur With:
- Individuals who do not have the ability to consent to participate on their own in research
- Racially and ethnically diverse respondents
- Non-binary autistic adults
Priority Setting: Next Steps

PCORI Funded Comparative Effectiveness Research Study
Jan 2022-Dec 2027
$9.1 million dollars

Study Goal
- Compare two different approaches to suicide prevention tailored for autistic youth.

Study Questions:
- Which approach results in better outcomes for autistic youth?
- Which approach leads to better satisfaction for autistic youth and their providers?
- What factors impact the effectiveness of these interventions?

PI: Dr. Brenna Maddox, PhD (UNC Chapel Hill and Dr. Shari Jager-Hyman, PhD (University of Pennsylvania)
Engagement Core Leads: Benevides + Shore
AASET Members: On multiple study roles
Next Steps…

Decision-Making Process
Priority Setting: Next Steps – Evolution in Decision Making Process

Step 1: Discuss options as a team

Step 2: Assess permission to proceed

Step 3: Finalize decision or return to Step 1
**Priority Setting: Decision Making – Step 1**

**Step 1: Discuss options as a team**

<table>
<thead>
<tr>
<th>Goal:</th>
<th>Method:</th>
</tr>
</thead>
<tbody>
<tr>
<td>● To obtain input and clarify all possible options</td>
<td></td>
</tr>
<tr>
<td>● To determine options to eliminate</td>
<td></td>
</tr>
<tr>
<td>● Communication via email or virtual meeting</td>
<td></td>
</tr>
</tbody>
</table>

**Example**

- **Age:** Discuss various options via email or during a virtual meeting
  - 11
  - 12
  - 13
  - 14
### Priority Setting: Decision Making – Step 2

**Step 2:** Assess permission to proceed

<table>
<thead>
<tr>
<th>Goal:</th>
<th>Method:</th>
</tr>
</thead>
<tbody>
<tr>
<td>● To ascertain members’ preferences for option</td>
<td>● Voting via Google Forms</td>
</tr>
</tbody>
</table>

**Example**

- Vote on whether to lower age to 13
- Vote on whether to lower age to 14
1. I do not have an opinion
2. I prefer for this option to move forward
3. I don’t prefer for this, but would be okay if it moves forward
4. I don’t prefer this, and am uncomfortable moving forward with this choice

Examples

- Lowering the eligibility age to 13
  4. I don’t prefer this, and am uncomfortable with this choice moving forward
- Vote on whether to lower age to 14
  2. I prefer this option to move forward
Priority Setting: Decision Making – Step 3

1. I do not have an opinion
2. I prefer for this option to move forward
3. I don’t prefer for this, but would be okay if it moves forward
4. I don’t prefer this, and am uncomfortable moving forward with this choice

- No acceptable alternative option(s)
- Proceed with another option based on majority vote
- Discuss Individually
- Option maximizing “2” votes will be selected

Permission to Proceed

Alternative option(s) acceptable to everyone
Step 3: Finalize decision or return to Step 1

Goal:
- To select final decision or determine that is necessary to discuss other options.

Method:
- Review of Google Form by Teal & Stephen; sharing of results with Brenna & Shari
- Individual conversations, if needed
Priority Setting: Next Steps – Evolution in Decision Making Process

Step 1: Discuss options as a team

Step 2: Assess permission to proceed

Step 3: Finalize decision or return to Step 1
Case Study & Discussion
You are leading a research team in which there are a variety of stakeholders working to develop a shared framework for outcomes. The team has been working for several months on the framework. One member of the team feels that the framework that was discussed is not acceptable.

In teams of 2-3, discuss the following and prepare to share…

1. What are the potential sources of disagreement?
2. What are ways that you can resolve this challenge within your research team?
3. Additionally, consider methods that you could use to ensure that all stakeholder voices feel heard that you could put into place for the next project.
Discussion & Application for Research Methods

- **Share** ways that you can promote authentic engagement in your work, or ways that you have found to be successful.

- **Identify** how you can use the research priorities to tailor your own research and/or practice with autistic individuals.

- **Name** 1 thing you will do to take this information and use it in the future.


Thanks for your participation!


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