

IMPROVE**CARE**NOW

# Methods of Research Co-Production in ImproveCareNow

*How to involve parents and patients in your study*



IMPROVE**CARE**NOW



# Research co-production: *What are we trying to accomplish?*

To develop a vibrant, collaborative and inclusive community of parents/patients, clinicians and researchers with the capabilities and infrastructure to support effective research partnerships.

Doing research **with** parents/patients,  
not **for** or **about** them.

# RESEARCH CO-PRODUCTION MEANS

that all patients and parents are  
collaborators in all research activities  
and integral to the research process.

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LISA PITCH


- ImproveCareNow Research  
Review Committee
- Parent Working Group  
Research Subcommittee



# Opportunities for Research Co-Production

In addition to being research participants, parents/patients can also be research team members involved in:

- Idea Generation
- Proposal Development & Securing Funding
- Study Design
- Recruitment
- Study Conduct & Management
- Data Analysis & Interpretation
- Dissemination



No matter how complicated the research, or how brilliant the researcher  
**patients and the public always offer  
unique, invaluable insights**

Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well.

-Professor Dame Sally Davies, Chief Medical Officer, NHS

# Research Co-Production in Action

*Examples from the field*



# Idea Generation

**Parents/patients provide feedback on what their priorities are for research.**

➤ **Research Prioritization Study (2015)**

Lead PI: Katherine Bevans (Children's Hospital of Philadelphia)

In 2015, Katherine Bevans led an effort to poll the ICN community to gauge research priorities among the various groups in the ICN community. The topics were then grouped and ranked by priority.



"Parents have affected research by providing critical input about what is important to patients and parents, influencing policy decisions, and developing co-production teams, which ultimately has contributed to increasing the health and success of children with IBD."

-Lisa Pitch



- Parent Working Group Research Subcommittee
- ImproveCareNow Research Review Committee
- *COMBINE* Study Co-Investigator
- *Healthy Mind Healthy You* Study Co-Investigator



A portrait of a young woman with long brown hair, smiling slightly, wearing a dark blue sweater over a light green top. The background is a blurred indoor setting with a window. The image is overlaid with a semi-transparent green filter.

“

I am an equal and active team member at our monthly meetings, where we discuss our active projects and research.

*-Sami Kennedy  
ICN Transition  
Task Force*

# Proposal Development

## Community collaboration around choosing a study name.

### ➤ COMBINE Study ([www.combine-trial.org](http://www.combine-trial.org))

Lead PI: Michael Kappelman (University of North Carolina, Chapel Hill)

### ➤ PRODUCE Study

Lead PIs: Heather Kaplan and Lisa Oipari (Cincinnati Children's Hospital Medical Center)

In order to pick a name for the PRODUCE study, the project team put out a call for name proposals. 11 name suggestions were submitted, and over 100 community members voted to choose the name.

# Proposal Development/Securing Funding

**Parents and patients provide feedback on application.**

## ➤ PRODUCE Study

Lead PIs: Heather Kaplan and Lisa Opipari (Cincinnati Children's Hospital Medical Center)

## ➤ Healthier Together (2014)

PI: Lisa Opipari (Cincinnati Children's Hospital Medical Center)

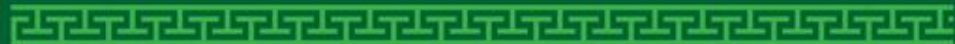
To supplement the proposal submitted for the Patient Powered Research Network grant, a Healthier Together campaign was conducted to demonstrate how the community supports collaborative care. The target was to gather 1,000 messages of support from the community, via posts to the Healthier Together website or Instagram (#HealthierTogether).



Parents and patients  
provide constant  
awareness of the  
motivation for  
the work.

*-Heather Kaplan*

Co-PI, *PRODUCE* Study



# Study Design

**Participants provide input into the design of the technology application to be used for study participants**

➤ **PRODUCE Study**

Lead PIs: Heather Kaplan and Lisa Opipari (Cincinnati Children's Hospital Medical Center)

Parents and patients reviewed the application used to track patients' medication and diet.

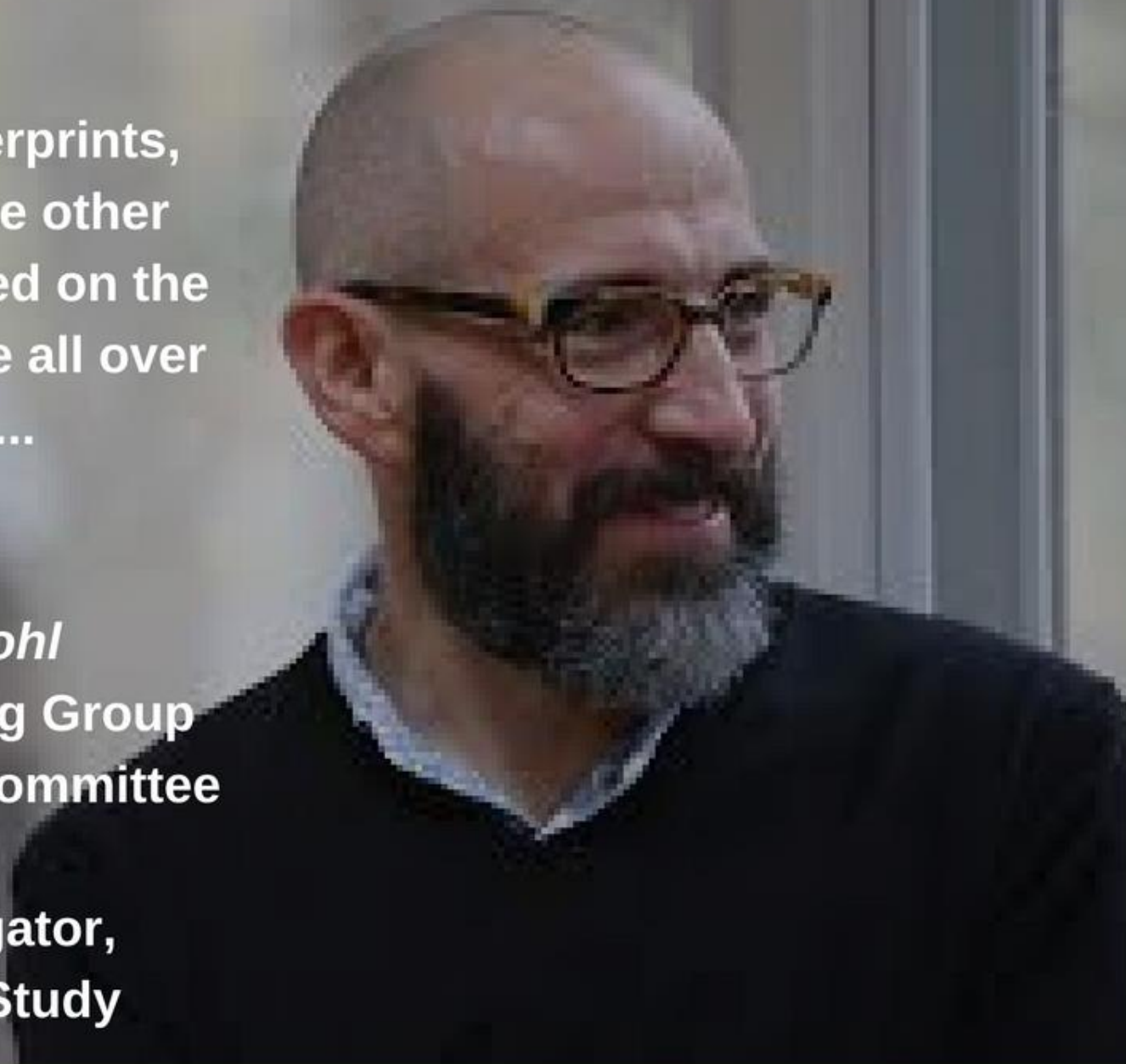




**I feel my fingerprints,  
and that of the other  
parents involved on the  
study team, are all over  
the trial...**

***David Wohl***

**Parent Working Group  
Research Subcommittee  
&  
Co-investigator,  
COMBINE Study**





# Study Design

**Parents/patients provide feedback on materials that will be used throughout the study (consent forms, surveys, etc.)**

- **Patient Reported Outcomes (PRO) Study**

Lead PI: Lisa Opipari (Cincinnati Children's Hospital Medical Center)

- **COMBINE Study ([www.combinetrial.org](http://www.combinetrial.org))**

Lead PI: Michael Kappelman (University of North Carolina, Chapel Hill)

- **PRODUCE Study**

Lead PIs: Heather Kaplan and Lisa Opipari (Cincinnati Children's Hospital Medical Center)

□ — □

“I believe that the parent perspective in developing a recruitment plan, education material and training for those performing the research has been valuable. As a parent, being able to ask questions has allowed the researchers to consider a different perspective that I believe will be helpful for the process as a whole.”



## Gisele Woodward

*Parent Working Group  
Research Subcommittee Member  
&  
Produce Study Team Member*

# Recruitment

**Parents and patients provide input and feedback to the participant recruitment strategies.**

➤ **PRODUCE Study**

Lead PIs: Heather Kaplan & Lisa Opipari (Cincinnati Children's Hospital Medical Center)

Parents assisted in the development of educational materials that will be given to parents during the study. Parent representative Gisele Woodward also developed the first draft of the recruitment brochure and flyer for the study.

➤ **Children's Hospital of Philadelphia Sleep Health and IBD Study**

Lead PI: Christopher Forrest (Children's Hospital of Philadelphia)

Study team connected with the ImproveCareNow Parent Working Group Research Subcommittee to discuss strategy and messaging for the study recruitment efforts



Parent and patient involvement has allowed the ICN Transition Task Force to better target our work to areas of need in our community...



For example, before we started any work on the Transfer Toolkit, I was able to help organize a survey of 40 patients and parents to be sure we understood what young adults look for on the brink of adult care.

-Sami Kennedy  
Patient, Member of  
ImproveCareNow  
Transition Task Force

# Study Conduct and Management

**Parents and patients actively participate in the implementation of the study plan.**

➤ **COMBINE Study** ([www.combinetrial.org](http://www.combinetrial.org))

Lead PI: Michael Kappelman (University of North Carolina, Chapel Hill)

➤ **PRODUCE Study**

Lead PIs: Heather Kaplan and Lisa Opipari (Cincinnati Children's Hospital Medical Center)

Parents on the research team are involved in training participating sites in the Specific Carbohydrate Diet.



“Parents have contributed specific ideas in the development of all of the resources, from SCD [Specific Carbohydrate Diet] trusted resources to favorite SCD snacks and brands. We have also contributed ideas for the materials used in the recruitment of study participants. We know what information we would want to hear when presented with this study, and what resources we would need to have to be successful when following the SCD.”

-Sheri Pilley

Parent Working Group (PWG)  
Research Subcommittee





# Data Analysis & Interpretation

Still to come...

Lead the way in this area of research co-production for ImproveCareNow and tell us about your experience by completing a [\*My Research Co-Production Story Card\*](#)!



The involvement of the parents and patients has brought in a viewpoint - that of the most important stakeholder - to the study team.

It has strengthened the study design and protocol, has helped refine different iterations of interventions, and has also helped researchers and clinicians to think in a different way.

-Shehzad Saeed, Clinician  
COMBINE & PRODUCE Studies

# Dissemination

Still to come...

Lead the way in this area of research co-production for ImproveCareNow and tell us about your experience by completing a [\*My Research Co-Production Story Card\*](#)!

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# PARENTS AND PATIENTS HAVE UNIQUE EXPERTISE

in understanding  
the pragmatics of  
research  
participation and  
the impact of the  
intervention.

*-Heather Kaplan  
Co PI: PRODUCE Study*

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Learn more about the ImproveCareNow  
[Parent Working Group \(PWG\)](#) and the [Patient Advisory Council \(PAC\)](#)

Looking to connect with parents and involve them in your study?  
[Connect with the PWG Research Committee](#)

Want to share your story of Research Co-Production?  
Tell us about your experience [here](#)



Interested in more research happening in ICN?  
Check out current research [here](#)