Coproducting Chronic Care:
A MULTI-STAKEHOLDER FOCUS GROUP STUDY

A technical report
Technical report was written by

Karen Homa, PhD
The Dartmouth Institute for Health Policy and Clinical Practice

Kathryn Sabadosa, MPH
The Dartmouth Institute for Health Policy and Clinical Practice

Katherine E. Titus, BS
The Dartmouth Institute for Health Policy and Clinical Practice

Aricca D. Van Citters, MS
The Dartmouth Institute for Health Policy and Clinical Practice

Tamara S. Morgan, MA
The Dartmouth Institute for Health Policy and Clinical Practice

Emily Morgan, BA
The Dartmouth Institute for Health Policy and Clinical Practice

Pam Mertz
Parent Advisory and Community Innovator

Terri Laguna, MD, MSCS
University of Minnesota Pediatrics

Adrienne Savant, MD
Ann & Robert H. Lurie Children’s Hospital of Chicago

Cynthia Brady, DNP
Children’s Respiratory and Critical Care Specialist

Maren Batalden, MD, MPH
Cambridge Health Alliance

Paul Batalden, MD
Emeritus Professor The Dartmouth Institute for Health Policy and Clinical Practice

Eugene C. Nelson, DSc, MPH
The Dartmouth Institute for Health Policy and Clinical Practice and Dartmouth-Hitchcock Medical Center
Technical report was sponsored by

The Dartmouth Institute for Health Policy and Clinical Practice

Robert Wood Johnson Foundation
# TABLE OF CONTENTS

**EXECUTIVE SUMMARY** .................................................................................................................. 1

**INTRODUCTION** ................................................................................................................................. 2
Theory of coproduction .......................................................................................................................... 2
Purpose of the study ............................................................................................................................... 3

**METHODS** ......................................................................................................................................... 4
Participating Health Centers .................................................................................................................. 4
Participants ............................................................................................................................................. 4
Study design ........................................................................................................................................... 4
Format and Content ............................................................................................................................... 6
Working Theory .................................................................................................................................... 7
Analysis.................................................................................................................................................. 8

**RESULTS** ........................................................................................................................................... 9
Mapping the comments .......................................................................................................................... 10
Thematic results of the effective and ineffective behaviors .................................................................... 11
Conceptual framework of effective coproduction behaviors .................................................................... 21

**DISCUSSION** ..................................................................................................................................... 22
Three principles of coproduction in healthcare ...................................................................................... 22
  - Role Flexibility .................................................................................................................................. 22
  - Inquisitiveness ................................................................................................................................... 23
  - Courage ........................................................................................................................................... 24
Study limitations ...................................................................................................................................... 25
Clinical implications ............................................................................................................................... 26

**CONCLUSION** .................................................................................................................................. 27

**APPENDICES**
Appendix 1: Information sheet to participate in focus group ................................................................. 28
Appendix 2: Transcription of Dr. Maren Batalden coproduction video.................................................. 33
Appendix 3: Montage video transcribed .................................................................................................. 38
Appendix 4: Focus group study supplemental information ........................................................................ 44
Appendix 5: Coproduction category results for definition and benefits ................................................. 53
Appendix 6: Excerpts from the two multi-stakeholder focus groups ....................................................... 58

**ACKNOWLEDGEMENTS** .................................................................................................................. 63

**REFERENCES** .................................................................................................................................... 64
EXECUTIVE SUMMARY

INTRODUCTION
This focus group study is one of several activities within a coproduction demonstration project, Enabling Uptake of a Registry-Supported Care and Learning System in the US, led by a team at The Dartmouth Institute for Health Policy and Clinical Practice at the Geisel School of Medicine. The goal is to develop a registry-enabled learning system that ‘feeds forward’ patient-reported and clinical data to a decision-support dashboard used at the point of care by both health professionals and patients to coproduce health and health services in chronic care. The primary purpose of the focus group study was to learn from health professionals, people with cystic fibrosis (CF) or inflammatory bowel disease (IBD), and parents of children with CF about their understanding of coproduction in order to identify key behaviors of healthcare coproduction.

METHODS
Five focus groups were convened from participants recruited from six health centers. The first three focus groups were for individual stakeholders: (1) health professionals; (2) adults with CF or IBD and parents of children with CF; and (3) teenagers with CF and their parents. The participants were asked to be aware of coproduction and share their experiences, reflections, and insights during a fourth multi-stakeholder focus group held two weeks later. This process was repeated over the subsequent two weeks, at the end of which a fifth and final multi-stakeholder focus group took place. Thematic analysis was used to identify behaviors of coproduction and develop a framework of coproduction for chronic care.

RESULTS
Thirty-nine people in total participated in the three individual stakeholder focus groups and seven people participated in both of the multi-stakeholder focus groups. Fourteen themes were identified from the data such as a shift in the stakeholder’s role during the healthcare interaction, communication, empowerment, and getting to know the person.

CONCLUSION
Several important coproduction behaviors were identified from the stories and reflections of people with chronic health conditions, parents of a child with CF, and health professionals. We consider three to be key principles for facilitating effective partnerships in healthcare – role flexibility, inquisitiveness, and courage. These may be important to emphasize in developing programs to improve the effectiveness of partnering during a healthcare interaction.
INTRODUCTION

THEORY OF COPRODUCTION

Coproduction has been recognized as a way to improve health outcomes and care.\(^1,2,3\) The concept of coproduction was developed by a group at the Workshop in Political Theory and Policy Analysis at Indiana University, Bloomington, Indiana in the 1970s.\(^4\) Coproduction is the recognition that consumers not only consume a service but might also participate in its production.\(^4,5,6\) Thus, coproduction is a process in which individuals can provide inputs although they are not members of the organization that actually produces the service.\(^5\) Individuals can directly contribute to the quality and outcome of a service by helping to coproduce it.\(^4,5,6\) The new economics foundation, a think-tank aiming to build a people-driven economy, provides the following understanding of coproduction:

“A relationship where professionals and citizens share power to plan and deliver support together, recognizing that both partners have vital contributions to make in order to improve quality of life for people and communities.”\(^2\)

Due to increasing costs and gaps in quality and safety, there is a need to find ways to make healthcare services more affordable; to improve the experience and quality of care; and to advance health outcomes, resulting in high-value care.\(^7\) Coproduction occurs during a healthcare interaction between a professional with medical expertise and a patient and/or family with expertise of the lived health experience. They exchange information, brainstorm options, solve concerns, or share decisions as they work together\(^5\) as they create and generate knowledge. Without patient and/or family input important information falls to the wayside and the service deteriorates.\(^4\) In summary, coproduction necessitates (1) the awareness that the patient and/or family is a producer; (2) that the patient and/or family contributes information and works with the producer; and (3) that service will deteriorate without the patient’s and/or family’s involvement.

It can be argued that the healthcare service industry is in the early stages of understanding the implications of coproduction\(^1,8,9,10,11,12,13\) Batalden and colleagues proposed a conceptual model for coproducing healthcare services that emphasizes three specific activities that occur during “good service coproduction”: “co-execution, co-planning, and civil discourse.”\(^12\) To execute these activities in a co-productive manner requires professionals and patients to have “specific subject matter knowledge, know-how, dispositions and behaviors” that enable respect, trust, effective communication, and understanding of another person’s values and preferences.\(^12\)
PURPOSE OF THE STUDY

This focus group study is one of several activities within a coproduction demonstration project, *Enabling Uptake of a Registry-Supported Care and Learning System in the US*, led by a team at The Dartmouth Institute for Health Policy and Clinical Practice (TDI) at the Geisel School of Medicine. The goal of the project is to develop a registry-enabled learning system that ‘feeds forward’ patient-reported and clinical data to a decision-support dashboard used at the point of care by both health professionals and patients to coproduce health and health services. The dashboard serves as a mechanism to prompt conversation between patients and health professionals to co-develop a treatment plan and to ease out of traditional roles to explore new roles that enable more effective coproduction. This project is based on a successful model developed in Sweden – the Swedish Rheumatology Quality Registry. TDI’s research team, along with health professionals, families, and people with cystic fibrosis (CF) or inflammatory bowel disease (IBD) from several academic medical centers co-designed the respective disease-specific dashboards.

The primary purpose of the focus group study was to learn from health professionals, people with CF or IBD, and parents of children with CF about their understanding of coproduction with the aim to identify behaviors that promote effective coproduction and to develop key principles of healthcare coproduction. These principles could be used in future educational programs to accelerate awareness of coproduction within the CF and IBD communities. A secondary purpose of the study was to expose participants to different viewpoints of effective coproduction, and to explore their ability to apply these skills within their own healthcare encounters.
METHODS

PARTICIPATING HEALTH CENTERS

Six health centers participated in this study. Five of the six were CF clinics: two pediatric and one adult clinic located in Minneapolis, Minnesota and a pediatric and an adult clinic in Chicago, Illinois. The sixth center was an IBD clinic located in Lebanon, New Hampshire. Each health center was asked to designate a site contact who would be responsible for coordinating study information between the TDI research team and their health center. Due to the dispersed geographic locations of the health centers and infection prevention and control protocols for people with CF, videoconferencing was utilized to conduct the focus group sessions.

PARTICIPANTS

The following lists the number of study participants asked to be recruited.

1) three health professionals from each of the five CF clinics, which included multiple disciplines (e.g., social workers, respiratory therapists, nurses, research coordinators, and physicians)
2) two health professionals from the IBD clinic;
3) three adults with CF from each of the two adult CF clinics;
4) three adults with IBD from the one IBD clinic
5) from each of the three CF pediatric clinics, two family members and one family with a teenager with CF and the teenager was also welcomed to join the focus group with his/her parents.

The site contact provided the TDI team with participants’ names, stakeholder type, and email addresses. Participants were emailed a calendar request with a videoconferencing URL and a phone number to attend the focus group.

STUDY DESIGN

The following lists the first three individual stakeholder focus groups and number of participants requested to be recruited. We expected less than half the number of participants.

1) Health professionals with 17 requested
2) Adults with CF or IBD and parents of a child with CF
   • 6 adults with CF requested
   • 3 adults with IBD requested
   • 6 parents with children with CF requested
3) Teenagers with CF (14 to 17 years of age) and their parents with 3 families requested

Dr. Karen Homa served as the focus group facilitator for the study. She was on site in Minnesota for the first three focus groups, which local participants could attend in person, while the participants from Illinois and New Hampshire attended by videoconferencing. The facilitated discussion encouraged participants to share their understanding of coproduction. Besides expressing one’s understanding of coproduction, the participants had the opportunity to learn from one another, as many had participated in the development of the coproduction dashboard.

To continue learning about coproduction, the focus group participants were asked to experiment with being aware of coproduction in their next five healthcare interactions or during interactions with a representative from a service industry (e.g., being a customer at a bank, restaurant, or clothing store). They were asked to share a journal of these experiences with the research team, and to share their coproduction experiences, reflections and insights during a fourth focus group that was held two weeks later. All participants in each of the individual stakeholder focus groups were invited to fourth multi-stakeholder focus group. The main facilitating question was: What have you learned experimenting with coproduction? This process was repeated two weeks later in the fifth and final multi-stakeholder focus group in which participants reflected on their coproduction experiences. During the last focus group participants were also asked to share their impressions of behaviors that promote coproduction and the benefits of effective coproduction. Figure 1 displays a diagram of the five focus groups, the timeline, and the main questions used to facilitate discussion.
All focus groups were 60 minutes in length and recorded. Recordings were transcribed by a professional transcription service. The Committee for the Protection of Human Subjects (CPHS #28656) at Dartmouth College approved this study. Study invitations and information sheets are included in Appendix 1.

**FORMAT AND CONTENT**

The agenda for each focus group was similar: (1) participants were provided a brief introduction; (2) a short video related to coproduction was shown; and (3) a facilitated discussion. Short videos (ranging in length from 3 to 12 minutes) were shown at the beginning of each group. These were used to help explain and portray the practice of coproduction, as some participants were not familiar with the term or related theory.

Dr. Homa produced the video shown in the first three individual stakeholder focus groups. It features Dr. Maren Batalden discussing her research and practice of coproduction. Dr. Batalden is a physician at the Cambridge Health Alliance where she leads a coproduction fellowship. In the video she explains that health outcomes are...
coproduced between the patient and the health professional within the context of a healthcare system. She shares how coproduction can be leveraged as a design principle to invite a better partnership between professionals and patients and how this design principle requires a change in paradigm. Appendix 2 contains a transcript of the video and it can be viewed via this link: https://vimeo.com/184052025.

The video shown in the fourth focus group (i.e., the first multi-stakeholder group) was another video produced by Dr. Homa, which was created from the digital recordings of the first three individual stakeholder focus groups. It is a montage of participant statements to hear again in their own words their understanding of coproduction. The last segment of the video features Dr. Batalden sharing insights of gaining a better understanding of a patient’s perspective as she has learned to be a more effective coproducer of health and healthcare services. The video concludes with an explanation of the session’s purpose, to share participants’ insights and experiences engaging in coproduction in the two weeks between sessions. Appendix 3 contains a transcript of the video (to prevent the identification of the focus group participants the video link cannot be shared).

Two videos were shown in the fifth and final focus group. The first video was The Swedish Rheumatology Quality Registry Approach to coproduction, which can be viewed at https://www.youtube.com/watch?v=Kmgzy1hqC ow. The Swedish national quality registry aims to improve health for people with chronic rheumatologic conditions. The second video was a skit performed during an ImproveCareNow Learning Session (Spring 2013). ImproveCareNow is a collaborative community of clinicians, researchers, parents, and patients dedicated to improving IBD care for children and young adults (http://www.improvecarenow.org). The skit included two scenarios: the first was a clinic visit with the provider talking to the parent and making no connection with the teenage patient; and the second was an effectively coproduced clinic visit. The video can be viewed at https://www.youtube.com/watch?v=ryDpYPwWdH8. After the introductions and viewing, the participants shared their understanding of coproduction along with behaviors that promote effective (or ineffective) coproduction, and the benefits of effective coproduction.

This repeated focus group design, the video content, and group facilitation created an opportunity for participants to examine their own assumptions about healthcare interactions by listening to other participants, personally experimenting with coproduction, and capturing written experiences to share in the context of a focus group.

**WORKING THEORY**

People accessing healthcare services have assumptions about how a healthcare visit should proceed relative to expertise, relationships, ownership, and agency. Thinking and acting with an evolving understanding of coproduction can disrupt these assumptions. In this study, participants were asked to listen to presentations about
coproduction and to express their opinions during focus group sessions. To deepen the learning process, participants were also asked to be intentionally aware (i.e., to be aware of one’s surroundings, one’s thoughts and motivations) of coproduction and to practice or experiment with it between sessions. This intentionality provided an additional opportunity for participants to learn about their assumptions and to reflect upon what they had experienced. By asking participants to practice, or to be mindful of coproduction during interactions, it was anticipated that they could begin to accelerate their practice of coproduction and subsequently experience better health outcomes.

ANALYSIS

The transcripts and the digital recordings of the five focus groups were systematically reviewed by Dr. Homa and Katherine Titus. The first step was a mapping exercise organizing the participants’ comments under the four facilitating questions: (1) defining coproduction; (2) behaviors promoting effective coproduction; (3) behaviors promoting ineffective coproduction; and (4) benefits of effective coproduction. An example of mapping a comment was, Dr. Homa asked: “What does coproduction mean to you?” A participant responded, “Really working with our parents and patients to achieve outcomes … on the individual level coproduction, [it occurs] between the clinician and the patient or parent in that clinic visit.” The comment was mapped to defining coproduction.

Thematic analysis was used to identify patterns to inform the key principles of coproduction for the comments mapped to effective and ineffective behaviors of coproduction. Comments mapped to definitions and outcomes of coproduction were uninformative relative to understanding behaviors of coproduction. The analysts had an understanding of coproduction and read articles that listed principles of coproduction, however the focus of the analysis was to learn how the participants understood coproduction and relative to their voice identify repeating patterns and develop a label for the pattern.

After Dr. Homa and Ms. Titus mapped the data and identify themes, they met repeatedly to reconcile coding and differences in interpretation until they reached a level of agreement on finalized set of labels. The themes and exemplar comments were reviewed with the research team. Ms. Titus entered the agreed upon coding of the comments using qualitative software (ATLAS.ti). Dr. Homa then created a conceptual framework of coproduction during a healthcare interaction. The three principles of coproduction emerged from consistent or prominent patterns among the coproduction themes.
RESULTS

A total of 39 people participated in the first three individual stakeholder focus groups and the following lists the number of participants for each focus group.

1) 29 health professionals
   - 28 CF professionals
   - 1 IBD professional
2) 7 adults with CF or IBD and parents of a child with CF
   - 3 adults with CF
   - 1 adult with IBD
   - 3 parents with children with CF
3) 1 teenager with CF and his parents

Seven people participated in the first multi-stakeholder focus group and 10 in the final focus group, which was also multi-stakeholder. Figure 2 displays the number of participants for the five focus groups.

<table>
<thead>
<tr>
<th>Three Individual Stakeholder Focus Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>29 Health Professionals</td>
</tr>
<tr>
<td>7 People with IBD or CF &amp; Parents</td>
</tr>
<tr>
<td>1 Teen with CF &amp; 2 Parents</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Two Multi-Stakeholder Focus Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st: 4 Health Professionals, 2 Parents with child or teenager with CF, 1 Person with CF or IBD</td>
</tr>
<tr>
<td>Final: 7 Health Professionals, 2 Parents with child or teenager with CF, 1 Person with CF or IBD</td>
</tr>
</tbody>
</table>

Figure 2. Number of participants
For the health professional individual focus group, the majority were from the three health centers in Minneapolis (in one of the health center’s conference room) and the other health centers attended using the video-conferencing line. Given the large number of participants, the focus group process was altered to facilitate the discussion with the six health center leaders while the others listened. Appendix 4 contains further information on the focus group process and the participant discussions.

**MAPPING THE COMMENTS**

The first three individual stakeholder focus groups were guided by the facilitating question: “What does coproduction mean to you?” There were 82 comments that were organized into the four groups: (1) defining coproduction; (2) behaviors of effective coproduction; (3) behaviors of ineffective coproduction; and (4) benefits of effective coproduction. Table 1 lists the distribution of the four groups by the individual stakeholder focus group. Fifty-six percent of health professionals’ comments were mapped to the group of defining coproduction. In contrast, 63% of the comments from the focus group of people with CF or IBD and parents and 50% of the comments from the teen and parent focus group were coded as behaviors of effective coproduction.

Table 1. 82 comments mapped into four groups by individual stakeholder focus group

<table>
<thead>
<tr>
<th></th>
<th>Defining coproduction</th>
<th>Behaviors of effective coproduction</th>
<th>Behaviors of ineffective coproduction</th>
<th>Benefits of effective coproduction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health professionals</td>
<td>9 (56%)</td>
<td>6 (38%)</td>
<td>0 (0%)</td>
<td>1 (6%)</td>
</tr>
<tr>
<td>People with CF or IBD and parents</td>
<td>3 (8%)</td>
<td>25 (63%)</td>
<td>11 (28%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Teen and parents</td>
<td>4 (15%)</td>
<td>13 (50%)</td>
<td>4 (15%)</td>
<td>5 (19%)</td>
</tr>
</tbody>
</table>

The facilitating question addressed in the first multi-stakeholder focus group was: “In the past two weeks of experimenting with coproduction, what have you learned?” There were a total of 15 comments of which 14 (93%) were about behaviors. During the fifth and final focus group, three questions were used to facilitate discussion: (1) “What is coproduction?” (2) “What behaviors promote effective coproduction?” and (3) “What are the main benefits of effective coproduction?” Most of the comments (52%) were mapped to behaviors of effective coproduction. Table 2 lists the distribution of the four groups by the two multi-stakeholder focus groups.
Table 2. 40 comments mapped into four groups by multi-stakeholder focus group

<table>
<thead>
<tr>
<th></th>
<th>Define coproduction</th>
<th>Behaviors of effective coproduction</th>
<th>Behaviors of ineffective coproduction</th>
<th>Benefits of effective coproduction</th>
</tr>
</thead>
<tbody>
<tr>
<td>First multi-stakeholder focus group</td>
<td>0 (0%)</td>
<td>8 (53%)</td>
<td>6 (40%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Last multi-stakeholder focus group</td>
<td>4 (16%)</td>
<td>13 (52%)</td>
<td>2 (8%)</td>
<td>6 (24%)</td>
</tr>
</tbody>
</table>

Appendix 5 contains exemplar comments mapped to defining coproduction and benefits of coproduction. These comments were not processed using thematic analysis, since they did not contain specific information about behaviors of coproduction. Appendix 6 contains excerpts from the multi-stakeholder focus groups.

**THEMATIC RESULTS OF EFFECTIVE AND INEFFECTIVE BEHAVIORS**

Across all five focus groups, there were 88 comments mapped to behaviors of effective and ineffective coproduction. Fourteen themes were identified and a comment could have more than one theme (not exclusively assigned to only one of the 14 themes). Table 3 lists the 14 themes and its definition along with the number comments containing the theme and percentage of these comments that were effective coproduction as opposed to ineffective. The majority of comments across all themes were about effective coproduction, which ranged from 67% to 93% so ineffective comments ranged from 7% to 33%. Most comments contained the themes of role shift, communication, empowerment, and/or getting to know the person. Table 4 lists exemplar comments for effective and ineffective coproduction by theme.
Table 3. Themes with definition and frequency distribution for behaviors of coproduction

<table>
<thead>
<tr>
<th>Behavioral Themes</th>
<th>Definition</th>
<th>Number of Comments</th>
<th>% Effective Coproduction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Role Shift</td>
<td>Behaving differently and being an equal partner</td>
<td>44</td>
<td>73%</td>
</tr>
<tr>
<td>Communication</td>
<td>Empathizing, encouraging, sympathizing, problem solving</td>
<td>33</td>
<td>76%</td>
</tr>
<tr>
<td>Empowerment</td>
<td>Being confident and self-determined</td>
<td>33</td>
<td>79%</td>
</tr>
<tr>
<td>Getting to know the person</td>
<td>Learning about the other as a person not a disease</td>
<td>32</td>
<td>75%</td>
</tr>
<tr>
<td>Asking questions</td>
<td>Understanding of the issues through inquiry</td>
<td>28</td>
<td>86%</td>
</tr>
<tr>
<td>Learning</td>
<td>Being inquisitive and interested person</td>
<td>15</td>
<td>87%</td>
</tr>
<tr>
<td>Risk aware</td>
<td>Being outside one’s comfort zone</td>
<td>14</td>
<td>93%</td>
</tr>
<tr>
<td>Joint decision making</td>
<td>Working together to develop care plan</td>
<td>14</td>
<td>79%</td>
</tr>
<tr>
<td>Recognize other’s expertise</td>
<td>Developing a shared understanding and relationship</td>
<td>13</td>
<td>85%</td>
</tr>
<tr>
<td>Goal setting</td>
<td>Making the aim of the visit explicit</td>
<td>12</td>
<td>67%</td>
</tr>
<tr>
<td>Shared knowledge</td>
<td>Accessing the same information</td>
<td>12</td>
<td>58%</td>
</tr>
<tr>
<td>Mutuality</td>
<td>Depending on each other, reciprocity</td>
<td>12</td>
<td>75%</td>
</tr>
<tr>
<td>Listening</td>
<td>Giving close attention to the other</td>
<td>6</td>
<td>67%</td>
</tr>
<tr>
<td>Pre-visit planning</td>
<td>Being explicit about the plan for the visit prior to the visit</td>
<td>5</td>
<td>80%</td>
</tr>
</tbody>
</table>
### Exemplar quotes by theme and behavior category

<table>
<thead>
<tr>
<th>Role shift</th>
<th>Effective coproduction</th>
</tr>
</thead>
</table>
|            | I think it comes from asking open questions that are very directive toward what the patient’s needs and wants are, and saying, “Here is something I’ve been thinking about, how can you approach this?” It's putting the seed of curiosity, and the thought of, “Hey, maybe this is something I should be thinking about.” As opposed to what occurs - they come to clinic, I tell them their numbers - running through the routine standard clinic visit.” ~HP
|            | I also think it's important to think about what we bring to each interaction. There's already this assumed interaction. It's like how are we approaching the interaction in a way that's going to say hey, I'm interested in learning more about this or I want to turn this into more of a relationship rather than how things have been in the past. ~PwCHC
|            | Even talking about her own life and what's important to her and why she can't get treatments done or what's changing in her life that she needs more help with something. ~Parent |

<table>
<thead>
<tr>
<th>Ineffective coproduction</th>
</tr>
</thead>
</table>
| Maybe it's because of growing up with CF clinics and having doctors where there is just this necessarily relationship and then being in a doctors office with a family member and maybe in the car ride over you hear all the different things that they want and all the different things that they're worried about. Then you sit with them in the office and it's turning into a five minute visit when it really should be a half hour conversation. Just noticing that people just become a little nuts, but the doctor is the expert and they kind of go along without stopping and thinking no, no, this is a conversation of equals. ~PwCHC
| Reflection on the encounter where I put the patient/family question at the end – was I busy? Rushed? Tired? At the end of a long day? Was the immediate illness a ‘distractor’ from my normal routine? Even though I have made a conscious effort to make the ‘flip’ in my own clinic, it is still not routine and there seems to be some special causes that prevent me from routinely prioritizing the patient/family. It can be harder and harder in today’s busy medical practice to sit and reflect on these things, and make conscious efforts to identify these special causes and work to change them, so that the improved coproduction of care is the normal all the time, not just when the perfect situation occurs. ~HP |

### Communication

<table>
<thead>
<tr>
<th>Effective coproduction</th>
</tr>
</thead>
</table>
| We might kind of go off on a tangent onto something very similar to what they originally brought to me, and I’d say, “Well this may be a better option for you.” It's coming to the table with a question that I think is the best way to have a co-produced visit. ~HP
| I think with the complexity of CF care with the amount of what we ask our CF patients to do certainly on the adult side and having experience on the pediatric side – on the adult side it is usual a discussion because you know we are routinely asking people to do more than they possibly can do so often it is a discussion of – it is a compromise discussion with patients. What are things they can accomplish right now what are the things we can
<table>
<thead>
<tr>
<th>Exemplar quotes by theme and behavior category</th>
</tr>
</thead>
<tbody>
<tr>
<td>think about later. So I think with CF care to a great extent necessitates coproduction. I think we can do it better and we can do it more intentionally. ~HP</td>
</tr>
<tr>
<td>I think just being mindful and not only making more of an effort to communicate in an understanding way that benefits whoever you’re interacting but also listening. ~PwCHC</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ineffective coproduction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some of the issues were, though– how do you coproduce when a family has a different idea of what they envision their care to be? We spent a lot of time trying to bridge gaps, explain as best we could, hear perspectives and explanations, and we weren’t closer to a joint plan. Coproduction is great if you’re willing to have people talk and compromise and understand each other’s perspectives. It was an extreme challenge for our team to be able to do this successfully. ~HP</td>
</tr>
<tr>
<td>Some of the issues were, though– how do you coproduce when a family has a different idea of what they envision their care to be? We spent a lot of time trying to bridge gaps, explain as best we could, hear perspectives and explanations, and we weren’t closer to a joint plan. Coproduction is great if you’re willing to have people talk and compromise and understand each other’s perspectives. It was an extreme challenge for our team to be able to do this successfully. ~HP</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Empowerment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effective coproduction</td>
</tr>
<tr>
<td>You know I’ve always found that in patient interactions, if I can affirm them or build them up on ... In some way, it gives them confidence to say what they're thinking or raise questions, become more curious. ~HP</td>
</tr>
<tr>
<td>I like to be more independent. For some other kids that are maybe younger than me, my parents when I was younger, they were a huge factor in helping me understand CF, and like, &quot;It's okay to tell the doctors that, oh, you don't like this or this&quot; and try to come up with a solution with them. ~PwCHC</td>
</tr>
<tr>
<td>Well when people over the years have asked for advice I always say find the best doctors you can and do what they tell you do and understand why you're doing it. That's my plan for success. I was lucky as a child my pediatricians taught me how to interact with doctors. It started with the fact that they respected me as a patient even as a child. They told my mother, “Well she's the one who's going to have to live with this so she's the one we're going to talk to in the exam room.” They taught me how to navigate that system which I needed. ~PwCHC</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ineffective coproduction</th>
</tr>
</thead>
<tbody>
<tr>
<td>There has to be a way of getting them excited about coproduction. I really think a lot of that is empowerment for patients, because most CF patients, as we all know, don't feel very empowered with this disease. They feel isolated and they feel helpless often. ~Parent</td>
</tr>
<tr>
<td>If the patient isn't interested it's going to be hard to engage them in even showing up to appointments or taking medications or vitamins or paying attention to symptoms. There's a problem that can break down right there. ~PwCHC</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Getting to know the person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effective coproduction</td>
</tr>
<tr>
<td>With the CF team it's a long-term relationship. I've been lucky to have and you want it to be the longest-term relationship possible. It's also, it's a condition where there's not one</td>
</tr>
</tbody>
</table>
### Exemplar quotes by theme and behavior category

**focus.** There are so many things involved that our doctors have been forced to look maybe more holistically. Which I think is really where we're a perfect disease to look at coproduction because we've been doing it for while just to meet our needs, our patients needs. ~PwCHC

- When my daughter was first born I teased that I was seeing the CF team more than I was seeing anybody else because we went a week later then two weeks later and then a month later. Definitely that relationship is there and you get to know them. The pharmacist said to me the other day I consider you a friend. I thought that really triggered when they said that. I'm like I see them more then once week so it's definitely that relationship. ~Parent

### Ineffective coproduction

- I wanted to mention like when we think about the health outcomes where we could get focused on FEV1 or weight and not necessarily look big picture and think of how is the patient day to day? How are they managing their treatments? How do they feel about their care? How do they feel about their ability to get done what they need to do? ~PwCHC

- I know that there's - In past years, there was always a hard line that doctors and nurses had to stay on their side of the line and patients had to stay on our side of the line. ~Parent

- I'm not Samantha* when I'm in that room. I'm just a bad back. ~PwCHC *not participant's name

### Asking the questions

#### Effective coproduction

- All of the other factors in people's lives in terms of family, in terms of job, in terms of dreams and goals, and all of those things, and to get to the best outcome for each patient we have to have a better understanding of all of those facets. While that seems to be really overwhelming, it isn't when you're one-on-one in a clinic setting because asking the right questions can you lead you down that path much more quickly. ~Parent

- Have one question and you know what they are talking about – you walk in saying … I hear you want to talk about your vacation.. or whatever it is… your wedding coming up. They already know that you are on the same page. The tone of the conversation immediately shifts to a partnering tone. One question sets the tone for the provider as well as shapes the direction the visit. ~HP

- Actually as I've become an adult and taking control, going back and asking questions about why that test and why this drug lends, you get those answers, you have those longer conversations and maybe now that you're an adult you can understand those things better. I think it's improved my relationship, not only with my doctor but also with, I guess almost with myself, with my own healthcare. ~PwCHC

#### Ineffective coproduction

- Now I get what [CF team] were trying to do, but when I was younger, I always would think, "Why am I seeing more than one doctor?" I thought that one doctor would be enough. Now that I'm older I get the whole purpose of my whole team. ~PwCHC

- I wanted to mention like when we think about the health outcomes where we could get focused on FEV1 or weight and not necessarily look big picture and think of how is the patient day to day? How are they managing their treatments? How do they feel about their care? How do they feel about their ability to get done what they need to do?
### Exemplar quotes by theme and behavior category

<table>
<thead>
<tr>
<th>Learning</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Effective coproduction</strong></td>
</tr>
<tr>
<td>• I think if providers can understand - Less coaching, staying curious. Always being curious about the next thing and, &quot;Tell me more about that' and 'What's been going on in your life since we last saw you three months ago?&quot; And how has is been going? What have been some barriers to your optimum day or your best self-care day ever?&quot; You know those kinds of questions staying curious. ~Parent</td>
</tr>
<tr>
<td>• I guess to my thought on what I think a successful co-production is really related to when patients come wanting to learn and they really wanting to learn about themselves. I think that really is what I have found to lead to a really successful co-produced appointment and relationship. ~HP</td>
</tr>
<tr>
<td>• At the hospital they would take our son to do manual BD's on him while we were in a classroom with a whiteboard, literally learning everything there is to learn about CF in six days. It was hard. It was scary. Lots of tears, lots of anger. A team member was able to instill in us that, &quot;Dammit, this is your kid's disease, and your disease, and you're going to drive it, but you need to be equipped. We're going to do it fast. We're going to do it - You're going to learn a lot, but the one thing you're going to understand is there is hope here for his health, for the care he needs. Yes it looks big, it looks scary but you can do it and once you get into it - it won't be that bad.&quot; That was amazing for us. ~Parent</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ineffective coproduction</th>
</tr>
</thead>
<tbody>
<tr>
<td>• If the patient isn't interested it's going to be hard to engage them in even showing up to appointments or taking medications or vitamins or paying attention to symptoms. There's a problem that can break down right there. ~PwCHC</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Risk aware</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Effective coproduction</strong></td>
</tr>
<tr>
<td>• Some people are very open and others are more guarded. It's going to take a couple questions and some more probing questions for them to really open up. I think that's, it takes a bit more discerning on the part of the staff and the doctor. Because it's hard to open up to maybe all these people that you're just meeting for the first time or you've only met a couple times. You've never experienced having a doctor or staff actually interested in your life rather than just your health. ~PwCHC</td>
</tr>
<tr>
<td>• Listening – and asking questions and not being scared to have something clarified. That’s something that comes up during a visit, if you don’t understand things, providers can take things for granted, they’re used to the same type of flow that they have with all their patients. I have been more mindful, and everyone could benefit from that approach. ~PwCHC</td>
</tr>
<tr>
<td>• This is awkward for patients’ too not just clinicians, because we all want the same thing. It is this new dance, and to dance that well, we have to start out with the baby steps and we’re going to step on each other’s toes until pretty soon we’re Ginger Rogers and Fred Astaire and this a beautiful thing. I think that’s the stage that we’re at is we’re going in little boxes and trying to figure it out - who’s leading and who’s not. It’s just an exciting time I think for the delivery of care. Patients, parents, the clinicians, we get this opportunity to be on the cutting edge and the forging force to push this through and to walk it out and it is awkward. ~Parent</td>
</tr>
</tbody>
</table>
### Exemplar quotes by theme and behavior category

#### Ineffective coproduction

- As a provider, I had a patient show up and the reason for the visit was reviewing some results, but they hadn’t been processed yet, so I wasn’t sure what we were going to talk about. So, he brought the raw data for me to interpret while we were in the room. It was a little uneasy for me to have to look, process and discuss this data in a short period of time. It would have been easier if I knew he had that raw data ahead of time, so that I would be better prepared to help coproduce a plan. ~HP

#### Joint decision making

##### Effective coproduction

- On the adult side it is usually a discussion because you know we are routinely asking people to do more than they possibly can do – so often it is a discussion of - it is a compromise discussion with patients. What are things they can accomplish right now? What are the things we can think about later? So I think with CF care to a great extent necessitates coproduction. I think we can do it better and we can do it more intentionally. ~HP

#### Ineffective coproduction

- Sometimes what they ask of us is not reasonable. Or possible. I'm a pretty good patient but if he asks me to do something that I am not going to be able to do then we have that discussion. ~PwCHC

#### Ineffective coproduction

- Yeah I think it’s with the confidence. I think there’s sometimes where you just feel like I don't know what I'm talking about or I don't know what the options are. There's some sort of confusion in your own head. ~Parent

- If I go in as the clinician and say, you need to take this medicine and take it every day for 3 months. The patient is going to go home and say, “Yeah, well I’m not taking it because it makes me sick when I take it.” You’re going to get nowhere and the clinician is going to feel like there is poor adherence. ~PwCHC

#### Recognize other’s expertise

##### Effective coproduction

- I think when patients come to me with questions that they either found on social media or somebody brought it up, that's a really good starting point, but a lot of the belief system is changed based on the relationship with their physician, so they may come asking you about one thing and it will lead me to a whole new discussion about, “Well that's one concept, but here’s another concept that I know.” ~HP

- I think when you have relationship with the staff and your doctor and you’re able to talk about the other events going on in your life that aren’t specifically about your health but they affect your health, whether it's moods, how school is going, your family life, things like that. I think that gets really important. ~PwCHC

- Well, for me personally, I would be looking for a doctor that cares, that is willing to help along with the whole care team. Like the dietitian introducing new supplements that can help with your lungs, or help you with your food or even absorb more from your food, and the respiratory therapist suggesting Aerobika for travel. Stuff like that is a huge thing that I like about my care team. For anybody that's going to a new care team I would really stress that you look for those kind of things and build a very good relationship with your care team, because relationship is really key to your care team and to be productive with your health. ~PwCHC
**Exemplar quotes by theme and behavior category**

### Ineffective coproduction

**I've switched clinics a couple of times because the relationship just wasn't there. Me or my family, we just felt like our needs weren't being addressed. I've also seen situations, not necessarily in CF clinics but with family members who it seems like sometimes maybe don't even consider their needs.** ~PwCHC  
**It's not an easy road to create, because you've got that professional side, family side, you've got historical customs, for lack of a better term, between patients and the clinical side. Those are barriers that need to come down. It really needs to become hard partnership.** ~Parent

### Goal setting

**Effective coproduction**

- I had made a conscious effort to ‘flip’ my clinic encounters a year or so ago by not starting with my agenda and ending with the patient/families questions, but instead, starting with the patient/families questions/concerns and then moving on to my agenda. In doing this flip – I often found that the family had concerns that aligned with mine and our agendas were the same. Additionally, there were times that items that weren’t even on my radar were of concern to the patient/family- and I was happy that I had done this ‘flip’. ~HP  
- I think one of the things certainly that I learned is the idea that co-producing the goals of care. I usually walk in the room, I’ve always walked in the room with the assumption I knew what the goals of care were, but to the idea of being explicit about what’s the goal for that visit. ~HP

**Ineffective coproduction**

- I went in to see a 7 year old patient and his mom, midafternoon during a full day clinic -so near the end of a long day. As we were talking about his illness, I also opened up my clinical encounter on the EMR and started to add in my agenda items. Then, when I had addressed the illness concerns and my own agenda, I asked the family what questions/concerns they had for the day. Mom brought up several things that had not come up during our prior discussions and were not on my radar. I immediately realized I had not prioritized the concern of the patient/family. ~HP

### Shared knowledge

**Effective coproduction**

- I think it's really important to not only have co production in your personal care but to also educate others. That makes me wonder if co production can not only be between patient and provider but maybe between patient to patient and just educating others on how important it really is to be involved in your own healthcare and not just leave it all up to the doctor. Because while they are the experts, they're not the ones living your daily life. When talking about a patients biggest concern or their goal, not everyone's going to be the same. ~PwCHC  
- I would always encourage anyone in any healthcare situation to feel like they have that agency. Maybe they don't have a medical degree but they still have expertise over their own body and how they're feeling and that needs to be addressed at the doctor's office. Even so if, and if it's not to be courageous enough to go and seek it elsewhere. ~PwCHC  
- One thought I have is if it's the person themselves, the patient … you need to be as honest as you can because you're not going to get the best care from that doctor if you
<table>
<thead>
<tr>
<th>Exemplar quotes by theme and behavior category</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>don't share what's really going on in your world and what's happening. ~Parent</strong></td>
</tr>
<tr>
<td>• I think when patients come to me with questions that they either found on social media or somebody brought it up, that's a really good starting point, but a lot of the belief system is changed based on the relationship with their physician. So they may come asking you about one thing and it will lead me to a whole new discussion about, “Well that's one concept, but here's another concept that I know.” ~HP</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ineffective coproduction</th>
</tr>
</thead>
<tbody>
<tr>
<td>• My daughter had an unexpected eye-doctor appointment. When we went into the doctor’s visit, he immediately asked why we were there, and we were off to the races. Coming up with this plan and that test. It wasn’t until the very end, that I said that the piano teacher mentioned she had issues with seeing the music sheet while playing piano. I remember seeing the frustration in the doctor at “the throw away question” at the end of the appointment – the question that’s asked off-hand at the very end that makes you have to start the whole conversation over again. ~Parent</td>
</tr>
<tr>
<td>• I think a lot of times patients just go to the doctor and they do expect okay, I’m going to tell him or her what I think and what I want and then he or she is going to give me something or I’m going to go to another doctor. They think that that's how it works. ~PwCHC</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mutuality</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Effective coproduction</strong></td>
</tr>
<tr>
<td>• Our son is very athletic and into lacrosse. Last summer he was traveling and didn’t want to take his device. He was in charge of all of his medications and treatments. The RT came in with the Arobica, “Would this work for you?” Son initiated the conversation; “This is going to be difficult for me, what can I do?” And they came up with that solution. He had several so he didn’t even have to clean them when he was traveling. Also, there’s this CF Life grant application that our social worker sent to us to help us pay for this. Coproducing with us and his lacrosse career. ~Parent</td>
</tr>
<tr>
<td>• My provider immediately just ... Her tone in the way she was I guess giving the information immediately made me feel comfortable and made me feel like I was in a safe space. She asked me questions and she didn't use the words co-production or quality or anything, but I just could tell that she cared about getting my input, and ... but also cared about getting to her input. I think she knew the importance of hearing and giving both sides. ~PwCHC</td>
</tr>
<tr>
<td>• There is a young baby that I take care of with CF who was admitted with bronchiolitis, got through hospitalization and was back shortly afterwards with another episode and other cold. They live several hours away and this is a small baby with a lot of care needs. We had a long conversation, where is the best place for care, hospital or home? They felt confident about taking the baby home and doing everything at home. That was a real moment for me for a real shared decision making. It wasn’t a situation where there was black and white. Sometimes it’s gray. Sometimes my decision or bias may be influenced by the amount of miles this family has to travel and their access to other care and my perception of their hardships. Their bias is to be home and be in touch and they did great, and the baby is probably much better cared for than we could over the weekend. Relationship building, it does work both ways, I have to let go of my biases about the best place for care is and what I see is barriers, vs. their perception and knowing they’re the best people to take care for that child. ~HP</td>
</tr>
<tr>
<td>Exemplar quotes by theme and behavior category</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td><strong>Ineffective coproduction</strong></td>
</tr>
<tr>
<td>• It's not an easy road to create, because again you've got that professional side, family side, you've got historical customs, for lack of a better term, between patients and the clinical side. Those are barriers that need to come down. It really needs to become hard partnership. ~Parent</td>
</tr>
<tr>
<td>• If I go in as the clinician and say, you need to take this medicine and work on it and just take it every day for 3 months. The patient is going to go home and say, “Yeah, well I’m not taking it because it makes me sick when I take it.” You’re going to get nowhere and the clinician is going to feel like there is poor adherence or whatever word you want to use for adherence. ~HP</td>
</tr>
<tr>
<td><strong>Listening</strong></td>
</tr>
<tr>
<td><strong>Effective coproduction</strong></td>
</tr>
<tr>
<td>• I know that a lot of times we're saying that we want the patient to have more of a voice but a lot of times I think really listening and asking questions when you don't really understand what your provider is asking of you or what they're saying, it's just as important sometimes as putting in your own input. ~PwCHC</td>
</tr>
<tr>
<td>• Sometimes patients have said these amazing things they don't even realize it is such a big deal – they are just kind of bringing it up. For instance, this past week the number one concern from 25.5 year old patient – age is very relevant – “Ooh I don’t have insurance when I turn 26.” But someone who has been on Medicaid for a number of years and has no plan and no idea how to get insurance – that was actually the most critical thing that we talked about at that visit. ~HP</td>
</tr>
<tr>
<td><strong>Ineffective coproduction</strong></td>
</tr>
<tr>
<td>• I almost have the feeling sometimes like I’m not being heard. I think those are when the co production isn't happening, if that makes sense. ~Parent</td>
</tr>
<tr>
<td><strong>Pre-visit planning</strong></td>
</tr>
<tr>
<td><strong>Effective coproduction</strong></td>
</tr>
<tr>
<td>• A simple question that patients are asked before they come into the office - what is the most important thing is that they want to discuss at that office visit today with their provider? We call out to them in that question and they fill out this on electronic survey or paper/pencil depending on the site. We call out that we are just not asking about their symptoms but we really want to know what the biggest thing that is weighing on their minds related to their illness. We get these unbelievable responses that absolutely changes the office visit. Being about symptom based control to about the chronic nature and the impact their disease on them. It's a really different angle then sitting there saying how are feeling today how are your symptoms let’s tweak your medication. It’s been a huge obvious win in the way we have interacted with our patients. ~HP</td>
</tr>
<tr>
<td><strong>Ineffective coproduction</strong></td>
</tr>
<tr>
<td>• As a provider, I had a patient show up and the reason for the visit was reviewing some results, but they hadn’t been processed yet, so I wasn’t sure what we were going to talk about. So, he brought the raw data for me to interpret while we were in the room. It was a little uneasy for me to have to look, process and discuss this data in a short period of time. It would have been easier if I knew he had that raw data ahead of time, so that I would be better prepared to help coproduce a plan. ~HP</td>
</tr>
</tbody>
</table>
CONCEPTUAL FRAMEWORK OF EFFECTIVE COPRODUCTION BEHAVIORS

A conceptual framework was developed representing a way to co-create effective partnerships during a healthcare interaction. Figure 3 displays the framework, which is embedded within high-level process flow diagram of a healthcare encounter. During a healthcare encounter is a healthcare interaction and in its simplest form, involves a health professional and a patient (and family). They interact to address the patient’s health. During an encounter, they may engage in effective behaviors, such as listening, asking questions, and being curious and they may also practice relationship skills, such as mutuality, sharing information, and recognizing the other’s expertise. An intentional awareness of these behaviors while working together can aid in better partnering and if needed make adjustments to their strategies to improve partnering. If their work together is coproduced well, then they know more about one another, feel heard and understood. The process ends with arriving at a healthcare plan, which may lead to a better outcome.

Figure 3. Conceptual framework of coproduction during a healthcare interaction
DISCUSSION

People with chronic health conditions have a lifetime of interactions with health professionals and relationships are developed, which provide an opportunity to explore ways to improve care. One of the many strategies used to improve outcomes has been to improve patient engagement or patient-focused interventions (health literacy campaigns, shared decision making, self-management, etc.). These interventions target the behaviors of the patient to become a more active participant in healthcare.

Coproduction theory offers an opportunity to see how multiple stakeholders contribute to better outcomes. This study examined stakeholders’ stories and reflections of a healthcare interaction through the coproduction lens. As Dr. Batalden stated in the first focus group, “My job as a health professional is recognizing that my task is to try to understand, as deeply as I can, this person and their priorities and to figure out how I can be helpful to them because that’s ultimately what is going to be the outcome of our shared work.” Clearly, a good partnership must involve more than an activated and engaged patient.

THREE PRINCIPALS OF COPRODUCTION IN HEALTHCARE

The shared work during a healthcare encounter can be considered a complex adaptive system containing interactions that are often complex and dynamic. These complex adaptive systems follow simple rules guided by a common goal or outcome. For example, the three simples rules for flocking behavior of birds are: alignment, cohesion, and separation. The findings from this research indicate there may be three simple rules at work during effective coproduction. If people can communicate honestly, learn about each other’s views, and shift enough out of their traditional roles, then the partnership can move towards the common goal of improved outcomes. The three key principles of role flexibility, inquisitiveness (or genuine curiosity about the other person) and taking risks, thus courage are described next.

1. Role flexibility

Coproduction can challenge both professional and patient/family identity and change the balance of power in this relationship. Health professionals have expressed that it is not traditional to keep the patient’s priorities in the forefront during a clinic visit. Patients and family expressed the learned behavior of being a submissive and passive patient or want to be a partner in care but find it is difficult to do. If health professionals experiment with shifting their role from a command and control mode to an expert coaching and helping mode, and patients experiment with shifting from I’ll do what you say mode to an active evaluator of and contributor to the co-created treatment mode, then both may become capable partners in decision making and treatment planning. Then, instead of a clinic visit being driven by a health professional’s agenda and his/her assumptions about the patient’s capacities or totally driven by only understanding the
concerns of the patient and family, a coproduced visit will also take into account a patient’s disease urgency, evidence-based practice guidelines or standards of care, logistics of transportation, and how that impacts treatment compliance, etc. Thus, role flexibility in the face of situations that deviate from traditional norms was a repeating theme in the qualitative analysis, and can be considered a key principle of effective coproduction.

2. Inquisitiveness

In addition to thinking about and experimenting with one’s role during healthcare interactions, there are ways for healthcare systems to support interactions characterized by effective partnership. In the IBD registry-enabled care and learning system, a patient is asked to answer an open-ended question, the answer to which is displayed on the dashboard and available during the clinic visit. The question reads: Currently, what is your number ONE concern or goal related to your IBD? This could be related to a specific symptom (e.g., diarrhea), worry for the future (e.g., need for surgery, cost of care) or how IBD might impact an upcoming life event (e.g., wedding, travel). Or you can report that you have no current concerns or goals. Health professionals can gain a deeper understanding of “where the patient is coming from just now” and can elicit information that would otherwise be unknown, which can lead the way to enriched communication and developing a better plan of care that matches the patients interests.

People with a chronic health condition and parents also noted in the focus groups that asking the right questions can “make a big difference” and moves the conversation beyond the boundaries of how one is feeling or issues going on with health or illness. Therefore, another key principle is inquisitiveness, which is linked to the roles we embrace during a clinical interaction and can lead to building confidence, understanding, and getting the right plan of care.

Richard Davies deBronkart (also known as ‘e-Patient Dave”) advocates in his handbook Let Patients Help!24 that patients engage fully in their care, which frequently entails asking questions such as:

- “I’m the kind of person who likes to understand as much as I can about my health. Can I ask some questions?”
- “I found this site. What do you think?”
- “How can I talk to other patients?”

The handbook also includes ten things health professionals can say to encourage patients as partners in their care, such as:

- “Here are the things I’d like to address today; what are your concerns?”
- “Did I address all of your concerns? Is there anything else?”
• “Learn as much as you can about your condition. Here are some ways to get started.”

Asking questions is linked tightly to role flexibility because questions can help dislodge the traditional patterns of care and remind us of our part in forming an effective partnership to attain the best outcomes.

3. Courage

The last principle is often a precursor to asking questions and relearning the roles we carry into a clinical encounter. Asking open-ended questions and being genuinely curious about an individual or a health condition takes a certain amount of courage because it leaves us open to feeling vulnerable. Dr. Brown’s book, On the Power of Vulnerability, provides relevant insights about vulnerability in which this feeling can actually bring purpose and meaning to our lives. Although vulnerability can be considered a weakness in our culture, her research shows it as an accurate measure of courage.

Health professionals might be uncomfortable asking questions that create unpredictable circumstances or feel put on-the-spot to provide information that is not prepared prior to the visit or known at the time of the asking. For patients, there can be a host of uncomfortable experiences, such as feeling isolated, frightened, guilty, confused, anxious, or depressed. Additionally, living with a chronic health condition can bring a daily onslaught of uncertainties, challenges, and at times a constant stream of bad news. Vulnerability can be experienced in a variety of ways such as trusting a health professional with your health or understanding when a health professional may not have a readily available fix for a health issue.

Being courageous may be the most challenging principle we face in effectively partnering with others. Dr. Tom Delbanco, a founder of the OpenNotes movement, illustrates this principle. He discovered the OpenNotes idea through an encounter he had with one of his patients 35 years ago. While writing his assessment of the patient he realized that the patient was reading what he wrote. Dr. Delbanco decided to ask whether he should include ‘alcohol abuse’ on the problem list. The patient thought about his question for a bit and stated that it could be included. This respectful inquiry turned out to be a risk worth taking. Note this story involved the three key principles – role flexibility, inquisitiveness, and courage.

A situation of a risk worth taking can be precarious for most people not to mention people involved with high-stakes outcomes of health. However, a theory espoused by William Gudykunst suggests that the management of anxiety and uncertainty are essential to effective communication, which communication was a repeated comment from the focus group participants. From Dr. Gudykunst’s anxiety/uncertainty management theory, uncertainties are thoughts we have about the past and future
while anxiety is a feeling of being uneasy, tense, and worried. When strangers or people with different backgrounds or cultures (e.g. healthcare interactions between people with different expertise) communicate, both anxiety and uncertainty can “prod us to communicate effectively.”

If a person becomes bored or disinterested during communication, then it is easy to become careless about the message, which leads to invalid assumptions and ineffective communication. Therefore, to become an effective coproducer in healthcare it may be helpful to know or expect and be prepared to experience some level of anxiety and uncertainty. These feelings can keep people engaged enough to partner well to produce a care plan. Dr. Gudykunst suggests that anxiety and uncertainty can be managed by being mindful.

Relative to healthcare interactions, examples of mindfulness are using open-ended questions and establishing the agenda for the visit with mutual understanding.

**STUDY LIMITATIONS**

While the study design had several advantages such as obtaining detailed information from a variety of people within a short time commitment and participants interacting to learn and encourage thinking about coproduction; there are limitations. These include the possibility of participants’ only expressing socially acceptable opinions and certain participant’s opinions dominating the research process. To mitigate this limitation, an individual stakeholder focus group was held first prior to bringing all stakeholders together.

The small sample size and the homogeneity of its participants relative to chronic care with two types of diseases, which adults with CF were unable to participate in the multi-stakeholder focus groups and only one person with IBD participated in the study limits the extent to which findings and conclusions can be broadly applied. More stakeholders from these two chronic conditions and conducting similar interviews in other healthcare settings should be considered.

The coding of coproduction behaviors themes was dependent on the skills of two researchers who challenged each other’s interpretations to ensure that the process of identifying themes was grounded in the voice of the participants. Therefore, analysis was to understand the meaning of coproduction in chronic care from the stakeholders’ perspective, although researchers were aware of the coproduction literature. The themes identified were not meant to describe all possible behaviors of coproduction. In addition, the analysis did not examine the exchanges between participants in which specific topics of discussion may have been over-represented or under-represented especially in the multi-stakeholder focus group sessions. The focus group design was to create a conversation about partnering among the health professionals, people with CF or IBD, and families, which most likely occurs infrequently in daily life. A strength of the research was the participants (health center leaders, parents with a child with CF, and people with CF or IBD) were given a report of the findings to contribute to the paper revisions, clarify, and confirm information.
**CLINICAL IMPLICATIONS**

During a clinical encounter, the focus group study findings suggest people can ask themselves these three questions during a healthcare interaction that may help with being mindful and produce better partnering, which can lead to better health outcomes:

1. Did I allow my role to be flexible enough to be a more effective co-producer?
2. Did I ask enough questions to understand the other person better?
3. Did I have the courage to be uncomfortable – to move slightly outside my comfort zone?

The findings may help to develop programs to accelerate the awareness of coproduction during a healthcare interaction and additional research is needed to either confirm or modify the three principles of coproduction.
CONCLUSION

Several important coproduction behaviors were identified from the stories and reflections of people with CF or IBD, parents of a child with CF, and health professionals. We consider three to be key principles for facilitating effective partnerships in healthcare – role flexibility, inquisitiveness, and courage. These may be important to emphasize in developing programs to improve the effectiveness of partnering during a healthcare interaction.
APPENDIX 1

INFORMATION SHEET TO PARTICIPATE IN THE FOCUS GROUP
Study Title: Accelerating Principles for Coproduction of Health and Healthcare Services

Principal investigators: Eugene Nelson, Professor of Community and Family Medicine, The Dartmouth Institute, Geisel School of Medicine, Dartmouth College, Hanover, NH, USA.

You are being asked to take part in a research study. Taking part in research is voluntary.

You are being asked to participate due to your expertise. Some people may be experts in healthcare others may be experts in long-term health condition and care while others may be experts in coproduction (or a combination of these). We want to have a robust diversity of opinions to honor a variety of knowledge domains in healthcare, care, and coproduction.

Healthcare coproduction refers to people such as a patient and clinician interacting to produce a service. A coproduced delivery of a service is based upon the patient and the clinician sharing information effectively and together making decisions for next steps, which meets the complex and unique needs of the patient. Coproduction challenges the idea of a clinician dominating the communication process with a passive patient and the service involving the clinician determining both the diagnosis and treatment. Coproduction involves creating the expectation of both the patient and clinician having equal and active roles in producing the delivery of the service with each sharing their unique perspective, skills, and knowledge.

**What is the purpose of this study?**
Our aim is to accelerate the practice of coproduction among patients/families and clinical teams for better health and better healthcare services in the context of chronic health conditions.

**Will you benefit from taking part in this study?**
You will not personally benefit from being in this research study. Your contributions will help us discover and/or refine principles and habits that you think are important in the coproduction of health and healthcare services.

**What does this study involve?**
Your participation in this study is voluntary. Below is a table listing the focus group sessions and the date of the survey. We have also included an outline by session to help you understand the study process.

**Round 1 Sessions 1a-1c:**
Aim: To build consensus around defining coproduction—assumptions, knowledge, behaviors and practices and to set-up a test of coproducing care.
Three separate 90-minute sessions will be convened stratified by stakeholder group: a provider group, a patient/family group, and a group of adolescents (14-17 years of age)/parents. The coproduction expert will participate in each group session. Each session will be recorded for those who cannot attend. Dr. Homa will be on-site with the provider group and an on-line link shared in the event the providers cannot join in-person.

We will show the group a short video of an expert talking about coproduction. Reflecting on the content of the video, we will then ask the group to discuss their understanding of coproduction—their assumptions, behaviors and practice. We will close the focus group by suggesting Plan-Do-Study-Act (PDSAs) that people can test on ways to improve their ability to coproduce health and healthcare services in their own life/practice/clinic.

**Round 2 Session 2:**
Aim: To build consensus on important principles and habits necessary to coproduce health and healthcare services and to continue to test coproducing care.

A 90-minute session will be convened with mixed stakeholder representation: providers, patients/families, and the coproduction expert. The session will be recorded for those who cannot attend. Dr. Homa will be on-site with group members who wish to join in-person and an on-line link will also be shared for participants to join.

We will review a summary of findings from Session 1. We will ask participants to report on what has been learned as they test out ways to accelerate coproduction and to build new habits into their everyday lives and into everyday work. We will present a few cases of clinicians and patients telling their coproduction stories using videos. We will then invite the group to discuss the underlying assumptions and principles. We will reflect back a summary of the conversation. We will revise our assumptions and principles and collect their comments and set up the next round of PDSAs to build more effective coproduction ways of behaving into their life and work.

**Round 3 Session 3:**
Aim: To finalize a set of principles and habits for coproducing health and healthcare services.

A 90-minute session will be convened with mixed stakeholder representation: providers, patients/families, and the coproduction expert. The session will be recorded for those who cannot attend. Dr. Homa will be on-site with group members who wish to join in-person and an on-line link will also be shared for participants to join.

We will present a case of a clinician and patient telling their coproduction story using a video. We will then invite the group to discuss the underlying assumptions and principles. We will reflect back a summary of the conversation. We will review this feedback and issue a survey that includes a final set coproduction principles and behaviors and ask participants to rank order and comment on the principles and habits.
<table>
<thead>
<tr>
<th>Focus Group step*</th>
<th>Date</th>
<th>Time commitment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respond to the invitation letter of your agreement to participate in the focus group process</td>
<td>By September 7, 2016</td>
<td>15 minutes</td>
</tr>
<tr>
<td>Focus Group Session 1a: Providers Only</td>
<td>September 14, Noon, Central</td>
<td>90 minutes</td>
</tr>
<tr>
<td>Focus Group Session 1b: Patients/Families Only</td>
<td>September 14, 7 PM, Central</td>
<td>90 minutes</td>
</tr>
<tr>
<td>Focus Group Session 1c: Teens/Parents Only</td>
<td>September 15, 7 PM, Central</td>
<td>90 minutes</td>
</tr>
<tr>
<td>Focus Group Session 2: Providers, Patients/Families—including Teens</td>
<td>September 28, Noon Central</td>
<td>90 minutes</td>
</tr>
<tr>
<td>Focus Group Session 3: Providers, Patients/Families—including Teens</td>
<td>October 12, Noon Central</td>
<td>90 minutes</td>
</tr>
<tr>
<td>Survey – <em>to be determined if needed</em></td>
<td>By November 9, 2016</td>
<td>20 minutes</td>
</tr>
</tbody>
</table>

If you take part in this study, what activities will be done only for research purposes?
If you take part in this study, the following activities will be done only for research purposes:

- Attending the focus groups to learn results and share any opinions. Other people in the focus group may recognize you and/or voice. A recording will be available for others who cannot attend.
- Quotations from the focus group, report, and survey will be used in presentations, reports and publications arising from the study and any of your quotes will remain anonymous.

What are the risks involved with being enrolled in this study?
A possible (albeit very low) risk is that confidentiality could be breached. We will be adhering to our procedures to minimize the likelihood of such a breach occurring and to reassure you of full anonymity and confidentiality.

Other important items you should know:

- **Leaving the study:** You may choose to stop taking part in this study at any time. If you decide to stop taking part or not taking part in specific parts, it will have no effect on your academic standing, job status, or participation or contribution to this study. If you do not want to receive invites to the next steps in this process, please email homakaren@gmail.com or ignore any email invites that you receive.
• **Number of people in this study:** We expect around 12 participants though it may be more or fewer depending on how many people respond to the request to take part.

• **Funding:** This work is being sponsored by a grant from the Robert Wood Johnson Foundation to the Dartmouth Institute for Health Policy and Clinical Practice.

**How will your privacy be protected?**
The information collected as data for this study includes a digital recordings of the focus groups and the data from the reports and survey. Although the researchers will know names of participants, your name is not requested when you complete the report or the survey so information will be anonymous. Any information that may identify you will be removed. We are careful to protect the identities of the people in this study and the information collected will be maintained anonymously. The information will also be kept secure and confidential -- electronic transcripts will be kept on a password encrypted computer and no paper version of the transcripts will be maintained. Names and other identifying information will not be used in any presentation or paper written about this project.

**What about the costs of this study?**
There is no cost to you as a participant in this study.

**Will you be paid to take part in this study?**
No

**Whom should you call with questions about this study?**
If you have questions about this study or concerns about a research related injury, you can call or email the research director for this study: Eugene Nelson, Eugene.C.Nelson@dartmouth.edu

If you have questions, concerns, complaints, or suggestions about human research at Dartmouth, you may call the Office of the Committee for the Protection of Human Subjects at Dartmouth College (603) 646-6482 during normal business hours.

**CONSENT**

We appreciate you considering taking part of the focus group, sharing your PDSAs, and completing the questionnaire to help determine the simple rules of coproduction in health and healthcare services. Attending the on-line focus group, sharing your PDSAs and completion of the questionnaire is your consent of participating in the study.

Please respond to the invitation email by stating whether you will participate or not. Thank you for your consideration.
APPENDIX 2

TRANSCRIPTION OF THE DR. MAREN BATALDEN COPRODUCTION VIDEO
What is co-production? In many ways the term has its roots in this basic distinction between goods and services. Good as a tangible thing, a car, furniture, a book and services are intangible like education and healthcare. For our purposes, the most important thing here about the distinction between goods and services, although there are many distinctions between goods and services, the most important distinction is that in services the outcomes are always inevitably co-produced to some extent and have outcomes that a person enjoys are a function in part of what their doctors and nurses and healthcare system does. It's also a function of the choices and behaviors that the person seeking well-being makes. It matters a lot where your healthcare service is being provided. If you are anesthetized in an operating room you obviously have very little agency. As soon as you come to, your agency is restored and you begin to have more say in what happens to you and how your health outcomes unfold.

Obviously if you're at a primary care setting or in rehab setting or in your living room your agency for the health outcomes is significantly greater. It's also the case that people are very different from one another in terms of their desire to be co-productive partners in their healthcare and their capacity to be effective co-productive partners in their healthcare.

It remains the case that no matter what the setting is or who the players are, to a certain extent healthcare service outcomes are always co-produced. Still the case that it is not the dominant culture within our contemporary healthcare service system. This is a picture of a billboard that my father had snapped in Minnesota a couple years ago in which the healthcare system here is promising we can handle everything except naming your baby. Anybody who's had a baby or anybody who's ever known somebody who had a baby knows that's an absolute bold-faced lie.

I think that this construction of co-production is really inviting us into a paradigm shift in healthcare service delivery. We're moving from this paradigm in which health related value is something that is made by health professionals and then given or pushed to patients to a new paradigm in which we recognize that health related value is principally made by patients in collaboration with their families and in the context of their communities and health professionals have a role to play, but it's actually a role in which our patients are pulling a little bit of assistance from health professionals.

In this picture, you have a dad and a little boy and a boo-boo and a Band-Aid. You have a relationship and you have an activity. I would argue that in every healthcare encounter we have a relationship and an activity. It's not the case that healthcare activities are simply Band-Aids and that the true healing is in that relationship. We have very, very powerful activities in contemporary healthcare: Organ transplantation and chemotherapy. The net effect of our dominant culture in healthcare, which I think inadvertently, uses a product paradigm for the work of a healthcare service, is that we have disproportionately focused our energy on the activities of healthcare. The activities
are easier to measure. The activities are easier to standardize and so in many ways we have focused our efforts in recent decades on the activities of healthcare work.

In so doing, we have perhaps neglected the importance of these relationships that are at the core of our ability to co-produce effectively. It's a relationship that allows us to determine which activities are worth doing. It's a relationship that allows us to determine whether these activities are accomplished in groups. The outcomes are always co-produced. If you think about this at the level of the individual clinical encounter... If I am going as a patient to see my primary care doctor, what happens in that encounter is a function of what I bring to it and what my primary care doctor brings to it. Either I tell her what is really on my mind or I don't. She asks me the right questions or she doesn't. She listens or she doesn't. She makes the recommendation and I go to see a specialist or I start taking the medication. I either think that's a good idea or not. I do what she says; I don't do what she says. This individual clinical encounter, the outcome of that is going to be coproduced.

That happens in the context of a healthcare system. Maybe it was hard to get an appointment with her. Maybe it was easy. Maybe she's available on email. Maybe she's not. The team that she's working with is either a high functioning team or not. The front desk people who work in the clinic that I see my primary care doctor in either help me feel invited to be an active agent in my own care or they don't. Co-production is happening at both the level of the individual clinical encounter and the system all of the time - Whether we intend to be good co-productive partners or not.

Part of the premise here is that it's possible to use co-production as a design principle. It's possible to be intentional in an individual clinical encounter about inviting a better co-productive partnership. It's possible in designing a system to be more effective in designing a system that invites true co-productive partnerships between health professionals and patients.

This slide comes from Canada in which they experimented with this construct of partnership at the level of a population for public health. I think that the diagram points out to us that co-production is not an either or proposition. It's not either we are partnering or we are not partnering. It puts the degree of partnership on a spectrum here. Moving from the left to the right, where on the far left hand side you have a big blue ball, let's call that big blue ball the health professional who is communicating effective to the little blue balls. Let's call those little blue balls patients.

As you move among that diagram you can see that it's not just about how the health professional talks but it's also about how the health professional listens. Then the next, again moving towards the right, it's not just about talking or listening but it's about the quality of the conversation that's between that health professional and the patient. Then because we're thinking here about healthcare service at the level of population, you can see that as we dig more deeply into co-production we invite this network or this
relationship between family members within a population. Then ultimately true partnership requires that the size of that big blue ball representing the health professional shrinks a bit so that the power is more evenly distributed and that the relationships can be more truly reciprocal. Than just partnerships can be, the true partnership requires a change in the paradigm.

The idea of co production - What we're doing is moving this line of interaction from one side of this diagram to the other as we experiment with deeper and deeper ways of partnering. As an individual clinician, I have been experimenting with this movement, with the movement of this line of interaction in my own practice as I think about how to make decisions with patients who may or may not need to be admitted to the hospital. How I make decisions about when it's time to discharge a patient from the hospital. What's the best way of managing pain in the hospital? Whether we're thinking about our role as patients, family members or whether we're thinking about our role as health professionals. Have an opportunity to experiment with this moving, this line of interaction intentionally in the way that we talk, in the way that we listen, in the way that we have true conversations - In the way that we share our power - In the way that we invite engagement within a network.

At the center of this construct of co-production is a relationship between patients and health professionals and the nature of that relationship. That relationship takes place within the healthcare system that both enables and constrains true partnership between patients and health professionals. This relationship in the context of the healthcare system produces some kind of healthcare service outcome. The healthcare service outcome or the medical care outcome is related in some way to a health outcome that matters to patients and/or family members. In cystic fibrosis it may be that what we follow is the FEV1 or the amount of air that is expired within the first minute on a pulmonary function test. The health outcome that really matters is not the FEV1. The health outcome that matters is the degree in which person with cystic fibrosis can live fully in school, at work and friends and family.

We start thinking seriously not only about healthcare service outcomes, but about health outcomes. We remember the importance of the wider community and society in which the healthcare system is nested. Where might we leverage improvement? One place is to think about patients and how we invite better understanding, better self care, more agency from patients. Another place we might intervene is in the domain of health professionals. How might we prepare health professionals to be better listeners, better partners, more prepared not to create value for patients but to think about how they add value to the patients’ work of creating value for themselves? We would be working intentionally to design a healthcare system that enabled patients and professionals to have the best possible co-productive partnership.
We might think more intentionally about the relationship between the healthcare service outcomes that are easy for us to measure and the health outcomes that really matter to patients that are sometimes harder for us to measure.

Finally we might think about these porous boundaries, the dashed line between the healthcare system and the wider community and society so that we think about new kinds of partnerships that will make it possible for patients and health professionals to work in new ways to produce, to co-produce better healthcare outcome.
APPENDIX 3

MONTAGE VIDEO TRANSCRIPTED
Female: What is your understanding of coproduction?

Female: That I understand a little bit better as far as the concept of working more collaboratively with patients and families.

Female: This is really, specifically, working on the individual clinic encounter.

Female: Really having an improved understanding of where the patient is coming from.

Male: Simple question that patients are asked before they come in the office that asks them what the most important thing is that they want to discuss at that office visit today with their provider, and we call out for them in that question. We're not just asking about their symptoms. We want to know what really the biggest thing is that's weighing on their minds related to their illness. We get these unbelievable responses that absolutely changes the office visit from being about symptom-based control to about the chronic nature and the impact of their disease on them. This is a new way of interacting with their providers.

Female: Have to be flexible and make the coproduction process very individualized.

Female: The coproduction being dependent on the interest and capacity of those involved. The interest is really very high, and over that time, I've been very lucky to have worked with medical professional who have helped me build capacity.

Female: How important it really is to be involved in your own healthcare. They're not the ones living your daily life and when talking about a patient's biggest concern or their goal, not everyone's going to be the same.

Male: It's hard to open up to all these people that you're just meeting for the first time, or you've only met a couple times. You've never experienced having a doctor or staff actually interested in your life rather than just your health.

Female: I'm trying to get my daughter to coproduce more as she's entering the teen stage. The doctor kind of knows how she's going to act and react, so she's able to ask the right questions and know her reaction so that she'll respond better to her than she even will to me. Talking about her own life and what's important to her and why she can't get treatments done, or
what's changing in her life that she needs more help with something.

Male: This is coproduction. It almost feels like what we're doing now. It's coproduction by default because of the necessity of the disease process.

Female: I would always encourage anyone in any healthcare situation to feel like they have that agency and that, maybe they don't have a medical degree, but they still have expertise over their own body and how they're healing.

Female: I think coproducing is not only having your own voice, but listening to the other voice for both patient and provider.

Female: When true coproduction is happening, that you feel heard, you don't walk away from the interaction feeling frustrated. You have some feel of confidence, I think.

Female: Coproduction, understanding the patients and the families. They have a lot to offer, and we can learn from one another, not just be recipients of the product of the healthcare service that's being offered or given, but being open and sitting down with patients as care providers and asking them, "What truly works?"

Female: Coproduction is not an either/or proposition. It's not either, "We are partnering" or "We are not partnering", but it puts the degree of partnership on a spectrum.

Female: I love the diagram of just being told what to do and then moving to that next paradigm of being a good listener, and then communicating back and forth, and then, ultimately, the partnering piece, so that everyone is engaged. There's a level playing field. There's equality. There's ownership of everybody's part in that level five. That's, ultimately, where want to be in every relationship we have.

Male: In past years, there was always a hard line that doctors and nurses had to stay in their side of the line, and patients had to stay on our side of the line. I'm very excited about this idea and this program of being able to cross those lines. Kind of like crossing the streams from Ghostbusters, if you will. It's scary. It's dangerous, but it's exciting and necessary and needed from the standpoint of both the medical professionals and the patients.

Female: In every healthcare encounter, we have a relationship and an activity. In many ways, we have focused our efforts in recent decades on the activities of healthcare work. In so doing, we have perhaps neglected the
importance of these relationships that are at the core of our ability to coproduce effectively.

Female: There aren't a lot of miracles in our disease. There are examples of cures. They can't just go in there and do a surgery and be done. They can't give you a medication that's going to fix everything.

Male: I think when you have a relationship with the staff and your doctor and you're able to talk about the other events going on in your life that aren't specifically about your health, but they affect your health, whether it's mood, how school was going, your family life, things like that. It's taken time, but I have a really good relationship with everybody and they're aware of things going on in my life. That makes such a big difference.

Female: Factors in peoples' lives in terms of family, job, dreams, goals, and all of those things ... To get to the best outcome for each patient, we have to have a better understanding of all of those facets. While that seems to be really overwhelming, it isn't when you're one-on-one in a clinic setting, because asking the right questions can lead you down that path.

Female: Why that test and why that drug? You get those answers, you have those longer conversations, like improve my relationship not only with my doctor but also with, I guess, almost with myself, with my own healthcare.

Female: In the end, it's a long-term relationship, so I think all those things have contributed to putting us in a situation where we see the need and we really value those relationships.

Female: We're on that cusp of this revelation and realization that this is how relationships really works and we can do this in healthcare, as well.

Female: You have one question, you already know what they're talking about, to walk in saying, "All right, I hear you want to talk about your vacation today", or whatever it is. "You're weddings coming up." They already know that you're on the same page, and the tone of the conversation immediately shifts to a partnering tone.

Female: What is the ultimate goal of this encounter? Otherwise we fill it up with our own assumptions about what the most important stuff is.

Male: Patients have said these amazing things that they don't realize is such a big deal, they're just kind of bringing it up.

Female: My doctor sat down with me and before even going over anything health-
related, she just asked personal things and wanted to get to know my social life, got me interested and she told me about different ways to get involved and helped me connect with other patients.

Female: My pediatricians taught me how to interact with doctors, starting with the fact that they respected me as a patient, even as a child. They taught me how to navigate that system.

Female: You need to be as honest as you can, because you're not going to get the best care from that doctor if you don't share what's really going on in your world and what's happening.

Female: "I come back next time and I haven't followed your advice, what would you tell me now?", you know, to sort of force the doctor to engage in some kind of scenario play to keep their side thinking.

Female: Really listening and asking questions when you don't really understand what your provider is asking of you or what they're saying is just as important, sometimes, as putting in your own input.

Male: For a patient to be able to make cohesive and competent decisions in the direction of their care, they need to understand the complexities and the speed-bumps that lie ahead for the clinical side of the equation, as well.

Female: "How does it feel when we give you this list of things that you need to do and all the shoulds? How do you manage that at home? What else is going on in your daily life?" so that we can understand how you're going to implement this - being curious about the next thing, and, "Tell me more about that.", and, "Tell me more about what's been going on in your life since we last saw you three months ago."

Male: My parents, when I was younger, they were a huge factor in helping me understand and it's okay to tell the doctors that you don't like this or this and try to come up with a solution with them.

Male: We found that you really need to let the patients know, especially the older population of patients don't expect that they're going to be asked to be engaged in that plan and in that issue of coproduction. We find that sometimes they're taken aback by it - that they don't get that you're actually asking for their input and their opinion and kind of waiting there.

Male: Interact more and test the waters on the depth of their maturity and their knowledge and keep testing those waters and seeing if you can go deeper, because the deeper they go, the greater the depth of the relationship that
will happen between the clinical side, and the patient, and the patient families. From a clinical side, we almost should be pulling them along, bringing them even quicker, if possible, because the relationship will definitely become greater, because when you do that, you're showing the patient and family the depth of your caring for the individual rather than the disease.

Female: I have been experimenting with the movement of this line of interaction in my own practice as I think about how to make decisions with patients who may or may not need to be admitted to the hospital. How I make decisions about when it's time to discharge a patient from the hospital, what's the best way of managing pain in the hospital. The true partnership requires a change in the power dynamics.

I am remembering a patient that I discharged from the hospital a few months ago who was an elderly gentleman undergoing chemotherapy for cancer. He had, because of that, a compromised immune system. He was admitted to the hospital with an infection that started in his urine. He lived pretty close to the hospital, and he lived with a very supportive wife, and he didn't sleep well in the hospital, and he knew, because of his cancer, that his days were, in some ways, numbered. It was really important to him to spend as little time as possible in the hospital. He felt fine and he felt like he was well enough to go home. In conversation, we were able to come up with a plan in which I felt comfortable letting him leave the hospital. We were, both of us, experiment with where is the right place for this line of interaction between the two of us as we're coproducing the outcomes that matter most to the both of us.

I used to privilege my own decision-making about whether they were ready to be discharged and I've now started to privilege theirs.
APPENDIX 4

FOCUS GROUP STUDY SUPPLEMENTAL INFORMATION
INDIVIDUAL STAKEHOLDER FOCUS GROUPS

The individual stakeholder focus group with the healthcare care professionals was held at a healthcare organization’s conference room in Minneapolis, MN. Prior to the focus group, the TDI research team member emailed a reminder and agenda to 12 participants recruited from the six health centers. However, 29 participants attended the focus group with most attended in person at the conference room site location, which were healthcare professionals from three CF health centers in the Minneapolis area. The other participants attended virtually using the video conferencing platform. Dr. Batalden also joined using the videoconference method along with four observers (two research directors from The Dartmouth Institute and two people from the Cystic Fibrosis Foundation).

Focus groups are usually conducted with a relatively small number of people, (e.g., between four and 15 participants), and thereby enabling all participants to share their thoughts on the topic in the time allotted. The unexpectedly large number of people who attended called for a change in the focus group process. The focus group was converted into a grand rounds format (a teaching experience in medical education in which a guest speaker shares research or knowledge about a medical topic with the audience consisting of health professionals and students). After the video, the leaders from the six clinics shared their thoughts on coproduction with Dr. Batalden who in turn made comments and answered participants’ questions with the rest of the healthcare professionals listening.

Dr. Batalden expressed concerns about being present during the focus group and did not want to be perceived as selling coproduction and possibly constraining honest dialog. This could have been the case, however with the format changing into a grand rounds it was helpful to have Dr. Batalden available to answer questions. For example, one participant stated that coproduction “seems very similar to patient/family-centered care” and others shared possible limitations of patients being able to coproduce effectively. Dr. Batalden offered some clarity:

> Patient family centered care feels sort of like an aspiration. The idea is to provide patient centered care or not patient centered. For me the ah-ha with coproduction is the outcomes are coproduced whether we are producing well or poorly. The idea is we could produce better outcomes if we leaned into our partnership more intentionally. So certainly it is the case that sometimes the people we are coproducing with have all sorts of other priorities besides their health or they are limited in their capacity to understand what the health professional is telling them to do or there just distracted in their capacity to be effective agents in their own health for any number of different reasons. But that doesn’t mean the outcomes are not being coproduced – they are still being coproduced. For me it’s the idea that I learned to think differently in the last year or so about my job as a health professional recognizing that my task is to try understand as deeply as I can this person and their priorities and figure out how I can be helpful to them because that’s ultimately what is going to be the outcome of our shared work. For me it’s a subtle kind of shift. It has had pretty significant ripple effects for me in my own sense of professional identity.
and the way I engage both individual patients in a clinical encounter and also the way I engage my work as an improvement leader.

The next individual stakeholder focus group was for adults with CF or IBD and family members and there were seven participants with four observers. The last individual stakeholder focus group was for teenagers and their parents, which there were one teenager and his parents. The three people were from one family unit so the focus group was similar to a one-on-one interview than a focus group format. All participants participated using the video conferencing line. Dr. Batalden was unable to attend these focus groups.

After the three individual stakeholder focus groups, participants were reminded of the next multi-stakeholder focus group in two weeks and to test ways to improve one’s ability to coproduce health and healthcare services prior to the next focus group. A suggestion was to be aware of the next five healthcare encounters or service industry interactions and to be intentionally aware of coproduction. We asked participants to journal their story and share with the research team and share their story in the next focus group. Two participants shared five stories.

**MULTI-STAKEHOLDER FOCUS GROUPS**

The TDI research team assumed not all participants who attended their individual stakeholder focus group would be able to attend both the multi-stakeholder focus group. An email reminder was sent to 39 people. The agenda for the first multi-stakeholder focus group was to watch the focus group montage video and then share their coproduction experiences. The number of focus group participants was four health professionals, two parents with a child or teenager with CF, and one adult with IBD. Four health professionals shared five stories, two parents shared three stories, one adult with IBD shared her story, and the principle investigator shared one story. The participants were again asked to practice or be intentionally aware of coproduction in five healthcare or service industry interactions over the next two weeks. Five stories or reflections on coproduction were shared with the TDI research team from five participants, observers, and the facilitator (one was from Dr. Homa emailed to all participants as a reminder to send the research team their stories). The agenda for the last multi-stakeholder focus group was to watch two videos and to explore three questions: 1) what is coproduction, 2) what behaviors promote effective coproduction (partnering, democracy, and agency), and 3) what are the main benefits of effective coproduction? The number of focus group participants was seven health professionals, two parents with a child or teenager with CF, and one adult with IBD.

**COPRODUCTION STORIES SHARED WITH THE TDI RESEARCH TEAM**

Not all participants shared coproduction stories. The majority of the time spent in the first multi-stakeholder focus group was sharing a coproduction story. A common
thread in the narratives was the experience of joy of partnering with someone. In addition, the task of writing the story also helped the author. One of the participants stated, “I have to say writing this out helped – I am going to try to write some more in the next two weeks as this allowed me to ‘reflect’.” Another participant stated, “Really fun exercise.”

The following are the stories shared by focus group participants:

**Medical visit with Family Medicine**

Thought I would add to your coproduction examples. I had a routine visit this morning with family medicine – due for diabetes, cholesterol, colonoscopy (the joy of turning 50!) screening, a tetanus vaccine, and a flu shot. This was first appointment with a new provider as my prior provider has retired. I was sent numerous reminders via mail, phone and in my EMR and a 2-page pre-visit survey prior to the visit. I completed the PVP survey via my patient portal to the EMR. I have attached the PVP survey (MyD-H.pdf) as it contains the PROMIS measures and questions regarding confidence and my ability to access healthcare. I was very excited to see the survey as you can imagine.

I arrived at my appointment on time, checked-in, paid my co-pay and was handed another survey to complete (see attached). Two pages of questions but since I am under 65 I only needed to answer 2 questions. As I had already spent 5-10 minutes answering a 2 page PVP survey electronically via my EMR I decided to avoid duplication or waste in the system left the second questionnaire empty. I feel like I had already done my part to initiate the co-creation of my health.

The MA called me back to the exam room, check my vital, height, weight, and ask me why I had come today. I pulled out my phone and said the list of alerts in my phone, prompted me to schedule a preventive visit. Knowing that he looked the questionnaire and said you didn’t complete it. I said, I had completed the 2-pages with the same questions and showed it to him on my phone. He said okay ask me about any pain and how I like to learn (listening, visual, reading, etc.) and in what language. He turned the monitor so I could see the questions. I was thinking they could have included the questions in the PVP.

Next up was the MD. She introduced her herself, sat down an opened her laptop. Aside from asking questions while pouring over the EMR and glancing up to catch my responses, she explained she was trying to carry forward my medical history, there were pieces of my EMR missing, dates, during the transfer from paper to the electronic version, and apologized for being so involved the EMR and not engaged with me. Just when I thought this was not a co-productive experience, she asked the golden closing question “Is there any we should know about you and your health and how like to partner in you care, I’d like to note it for myself and my team?” When she made eye contact, I was smiling ear to ear, I said “I am so glad you asked”. It completely turned around our conversation. I felt like I had her attention and she had mine, we could begin a relationship.
While we didn’t use any of the survey data, there was nothing that stood out as an issue, and the physician did not know how the data is used beyond screening. I really didn’t care, because she asked about partnering with me and we do share the important data via the EMR. And for the record, it was a 30-minute visit and I am going to screen with a FIT test.

**Working with a Social Worker**  
We are in the midst of a co-production process right now with our Care Team, specifically our social worker.

I got word that after 31 years with the company I represent, they are terminating health insurance, as it is becoming too costly to provide, with another 40% rate hike again this year. This has been a devastating piece of news for our family, as we must now go out into the health insurance market to try to duplicate the coverage we have enjoyed for so long. My fears are that [my son] will not get the care he needs, and it will be a paperwork nightmare for us to get new insurance.

I contacted our social worker via email and she immediately went to work on rescheduling [my son’s] annual studies appointment in November to inside October, so we could be covered...she is working with his doctor to get any refills done before our insurance changes, so we have a buffer of meds. We all anticipate this to be a rough transition, but [social worker] is going above and beyond and providing me emotional support and comfort as we navigate this new journey that the ACA has created.

With appointments rescheduled, I can now focus on researching a new healthcare plan for our family. This has helped a lot, to know we have our clinic care team aware of our situation and working with us, as well as Compass resources pending. I have yet to hear from them, but know it is a busy “pillar” of the Foundation.

**Dental Appointment**  
My son [name] had an appointment with a dentist so I tagged along to observe. [Name] is 19 years old and had an accident last year in which a tooth was cracked, so for the last year he has been getting various procedures to receive a tooth implant. This visit was a simple - to get an impression of the gum area for the implant to be made.

[Name]’s last visit to the dentist, which was about 3 weeks ago didn’t go well. The procedure was to get a screw placed into his bone to hold the future implant in place. This procedure needed Novocain and a few months’ prior [Name] got light headed with a procedure that needed Novocain. So this second time receiving Novocain [Name] got shaky and passed out. The dentist shared that type of reaction to Novocain happens rarely, but receiving another shot of Novocain is not something [Name] wants to experience again.

So for this recent appointment, which was a simple get-an-impression visit ended up
being complicated because [Name]’s gums to the dentist’s surprise are ultra healthy and grew over the screw, which was very unusual as the screw head was well above the gum line. This meant the dentist needed to pull back the healthy gum, which meant that his gum needed a local anesthetic.

The dentist was explaining all of this to us as he was looking at [Name]’s opened mouth. He looked at [Name] and in a micro second began partnering. It was like watching a couple that finishes each other’s sentences. The dentist said, so I can do a Novocain shot and… [Name] mumbles and shakes his head no. The dentist then says I can do a topical but when I cut your gum to pull it away from the screw it may get … [Name] mumbles it’s okay.

After the appointment was done and we walked to the car I asked [Name] - so how do you think that went. He said, “It went smooth.”

There is more about this visit I could share, but to briefly summarize – the dentist was all about sharing, caring, and partnering, not just with us, but with his staff. As he shared with us his grandfather who was also a dentist told him that if you treat people like family or how you would like to be treated then the money will follow.

A visit on Friday
Went it to see a 17 year old with CF who has been admitted to the hospital frequently with pulmonary exacerbations, who I have been following for a few years. As part of my routine process, I reviewed his chart the day prior and made notes as to ‘my agenda’ which included needing to discuss his second positive NTM culture (he already had NTM and had to go through years of treatment and this is a second one), going over his routine care needs (i.e. obtaining culture, annual nutrition evaluation, baseline Dexa since almost 18…)

When I first went in room, I just asked how things were going – what was going on in his life. We chatted a bit about his long term girlfriend having gone to college while he is a senior in high school and his upcoming homecoming which she was ‘making him’ attend. After a bit of banter back and forth, I asked him - What so you want to do with your PFTs [pulmonary function test]? They were down a significant amount and he was already on oral and inhaled antibiotics. His first response, was “I don’t know”, to which I replied “o – come on…” At this point, he opened up completely and talked to me for about 5 minutes straight about how things were affecting his life. He said he was coughing really bad and knew he needed to get the mucus out, but couldn’t expectorate during class due to embarrassment and so he was suppressing it. He was coughing more in the morning and was really wiped out by 4th period. He has had a hard time playing hockey (a passion for him) because he has been so tired. He said the best days he had are when he would spend many sessions throughout the day on his VEST and cough as much as he wanted – this was the way to get the mucus out. I knew he was already doing his Cayston during school hours and wondered if he could do
airway clearance at school? He said he had two study halls that he could go to nurse’s station and do airway clearance – thus giving him frequent sessions throughout the school day. He really came up with the solution (getting the mucus out with frequent airway clearance and expectorating) and only needed a simple alternative view to see he could do this during school. Of note, his mother was in the room the whole time and although she was engaged and paying attention, she was not ‘telling him what to do’ – in fact she was asking him questions to help facilitate him discovering/coming up with the solution on his own. Much of this is also related to transition of care in that he is becoming more of the driver of care over his mother.

So it was decided that these extra sessions would be added to his 504 plan (which was being reviewed next week). As his lung function was down and he was already on therapy, I then asked him when he wanted to come in for his next IV tune up – he immediately shared that he did not want to be in on his birthday, Halloween or during a hockey tournament and so we looked at the calendar to determine what potential days would work best for him and his life. Although we did not finalize plans (as he was coming back for another PFT in a couple weeks), his desires to be home for those days will be taken into account.

So then, I got to my agenda. (okay so addressing the decline in PFTs was my agenda as well). One of the things he was ‘due’ for was an annual nutritional evaluation. He asked if it was possible to do this during his next admission when he has loads of time, versus spending more time in clinic. This seemed like an appropriate request, so I communicated this with the RD, who agreed and went in and said she would see him during next inpatient stay – he said - “wow, look what happens when you ask”.

Overall, I think this was a well co-produced visit – the patient was able to come up with a plan to improve his health, share his desires for his quality of life (avoiding hospitalization on birthday, Halloween and during hockey tournament) and determine when he would have his annual nutrition visit. I am personally concerned that although this was a great encounter, I almost forgot the rest of my ‘agenda’ like telling him I needed to get a CT scan (in fact, I forgot to mention that he needed a baseline DEXA). Again, the patient had an acute care needs that prioritized the visit, and thus some of the chronic ongoing care needs were reduced in priority. Perhaps, when this happens, I need to address the chronic care needs in another way - a sooner follow up, a message to the family, etc., so it is not forgotten. How are the acute needs partnered with the chronic care needs in a coproduced patient/clinician encounter?

**Endocrinology visit**

I have a family history of hyper & hypothyroidism (both sides of my family), was experiencing fatigue and hair loss and was referred to an Endocrinologist. The Endo asked to run a battery of tests. Being a “good student”, I asked her to explain what the tests tested for and how it would change her recommended treatment plan. One of the tests she recommended would result in a “good to know”. When I pressed,
she said it would not change anything but it would “just be good for all of us to know.” I subsequently declined the test. This surprised her and she said I’d have to sign a waiver if I really did not want to move forward with the test. The mood immediately changed from an experience about my health to one that felt litigious.

I signed the waiver and did not return to that Endo office.

The experience left me feeling cynical. Rationally, I know my feelings should be directed at the “system” for making the Endo feel she needed to protect herself, but her delivery (which felt dismissive & insensitive) caused me to direct my resentment/distrust towards her as a clinician.

So I wonder if there’s a need to help clinicians carry out their legal obligations (which may include medication reconciliation and other rote checklists) in a way that can preserve the humanity in healthcare.

A participant shared four stories
Eye doctor - Had an unexpected eye doctor appointment for my daughter. Was interesting as she shared why she was there (couldn't see board at school), but we shared at the very end that another issue we had was the piano teacher mentioning she was squinting. That threw off the doctor's suggestions, and felt like we had to start all over again with the exam. Confirmed the importance of asking the right questions at the beginning and sharing all relevant information.

Yoga class - only two participants - I was new but the other one was a regular. Teacher focused the majority of the questions and direction of the class to the regular participant. Thought about the parallels to the parent/child relationship in the doctor's office and felt the focus/direction should be on her, the patient, but what is the role of the parent, especially as the child transitions to handling more responsibilities on her own? Felt unimportant/not as valued - what is parent role in coproduction - huge as child is baby and evolves as child grows up.

Buying new gym shoes - having problems with my legs, realized I needed to get a good fitting for gym shoes. From the second I walked in the door, the sales person was all about coproduction - "what brings you in? How can I help?" He asked lots of clarifying questions - how did you use old shoes, where is the pain, what will you use the new shoes for? As I was trying on 4 pairs - it was almost like he was forcing coproduction (but not in a bad way - maybe insisting is a better word) - would have me walk to see legs and form, but said multiple times that he could not determine fit and feel, and I had to provide that information to him. Was very interesting in terms of "I need this from you" and here are my suggestions - very parallel to coproduction - here is the expertise of the doctor but the patient needs to share how those recommendations fit into their life.
Cancelled event for my Girl Scout troop - felt very frustrated as the event producer was giving options for a make-up, alternative event vs. straight cancellation. I was feeling that the conversation could go better - thought, how can we both achieve our goals - you want to be fair in this last minute cancellation vs. we want the event as we envisioned. Shifted thinking to here are my goals - give my girls the spirit of the weekend - can we still do archery, as an example, vs. here is your refund. Felt conversation would have gone better if we had asked better questions initially and understood options better, worked together for a solution

**A physical therapy appointment**

Funny story. I went to physical therapy right after our focus group. I was telling the receptionist I still needed another surgery but had to recover from first surgery before I could get it – the physical therapist said, “yup, that’s my job, to get you better” and I said (without thinking) -“no, that’s my job, you are just giving me the tools to do it” – perhaps that is my first reflection (from the patient side)
APPENDIX 5

COPRODUCTION CATEGORY RESULTS FOR DEFINITION AND BENEFITS
The main purpose of the study was to examine the behaviors of coproduction to define key principles. This appendix gives exemplar quotes of the two other categories of coproduction: (1) Definition of coproduction and (2) benefits of coproduction.

**DEFINITION OF COPRODUCTION**

**A new concept:** For some participants’ coproduction was a new concept, which can take a while to understand.

> I remember when we were first informed about this project and the concept of coproduction I had absolutely no idea of what the word meant. I heard [a prior] talk about this and saw various videos and still had no idea what this meant so it has really taken some time seeing various examples before it has become something that I understand better… (Health professional)

> I haven’t heard the word coproduction prior to this project. (Health professional)

**Similar to other concepts:** Learning is about making connections with already familiar concepts.

> [Coproduction is] working more collaborative with patients and families. (Health professional)

> It seems very similar to patient/family-centered care that we all kind of practicing. (Health professional)

> This concept of shared decision making, engagement and patient-centeredness. (Health professional)

> [Coproduction] seems very similar to patient/family-centered care that we all kind of practicing. (Provider)

> It's revelatory in terms of applying relationships skills that we have in other relationships in our live into the healthcare model. (Parent)

> I love how she said intentionally moving this line. I love the diagram of just being told what to do. Then moving to that next paradigm of being a good listener and then communicating back and forth. Then ultimately the partnering pieces so that everyone is engage in an equal, level, I guess? There's a level playing field. There's equality, there's ownership on everybody's part in that level five. That's ultimately where we want to be in every relationship we have. (Parent)

**A natural extension of chronic care:** Some participants related to coproduction as it is already occurring due to the nature of chronic care.

> When I think about how we provide CF care I think without knowing the word I think we there is an inclination towards coproduction. (Health professional)

> It is a compromise discussion with patients. What are things they can accomplish right
now what are the things we can think about later. So I think with CF care to a great extent necessitates coproduction. (Health professional)
I think that many of us, most of us probably have been co-producing plans of care for a while. I think in CF it is usually the only way you come to plan this together. (Health professional)
If it’s coming down to this is coproduction it almost feels like what we’re doing now is coproduction by default because of the necessity of the disease process. (Parent)

**Preconditions:** Some participants related to coproduction by stating some elements need to be in place to be able to coproduce well with another person.
It's a little complex in pediatrics… Maybe asking a child - What do you think we should do? - that is not an appropriate approach with a child that doesn’t have cognition to understand the choices. (Health professional)
I think part of coproduction is really educating families and patients as much as possible to the nuances of their conditions so they can be more active participates and decision makers. (Health professional)
Something we learned we have to educate [patients] not about their disease, but this is a new way of interaction with their providers - asking for their input, their opinion. (Health professional)
Patients need to understand the nurses and doctors side of this care equation as much as they need to know more about the patient’s side. Really, that has to be two-way street. It's not only about the patient. From the standpoint of the patient’s needs, yes that is first and foremost, but for a patient to be able make cohesive and competent decisions in the direction of their care, they need to understand the complexities and the speed bumps that lie ahead for the clinical side of the equation as well. (Parent)
If the patient isn't interested it's going to be hard to engage them in even showing up to appointments or taking medications or vitamins or paying attention to symptoms. There's a problem that can break down right there. As a medical provider you don’t have any control over that so the question is do you need to build interest and capacity in the patients for this kind of system to be successful? (Person with chronic health condition)

**BENEFITS OF EFFECTIVE COPRODUCTION**

**Better and easier than traditional medical interaction:** Some participants noticed effective coproduction leads to learning about the impact of the disease on a person’s life and it’s ‘a huge obvious win.’ Some participants noticed effective coproduction leads to better outcomes, such as follow through with the care plan,
We really want to know what the biggest thing that is weighing on their minds related to their illness. We get these unbelievable responses that absolutely changes the office
visit. Being about symptom based control to about the chronic nature and the impact their disease on them. It's a really different angle then sitting there saying how are feeling today how are your symptoms let's tweak your medication… It's been a huge obvious win in the way we have interacted with our patients. (Health professional)

The essence of coproduction what we have seen is really having an improved understanding of where the patient is coming from. (Health professional)

This is what we all need in all disease modalities is more coproduction, more involvement, and buy-in from the patient and family because that's where compliance and adherence happens, because if someone comes up with an idea or something that works for them then they're going to do it. If you tell them to do something - Not so much. (Parent)

Coproduction understands the patients and the families. We have a lot to offer and we can learn from one another, not just be recipients of the product of the healthcare service that's being offered or given. (Parent)

It is time for change because it can be done better. It can absolutely be done better, and easier! It won't be harder, it will be easier. That's what I think is the barrier to this. I feels like it's going to be much more difficult, much more laborious, more time-consuming, when I think it's going to be just the opposite. (Parent)

There's less responsibility and ownership on the provider to make sure that there's compliance, and their metrics are not based on adherence and compliance. It's outcome, and quality of life metrics and measurements that the patients can feed back to the provider and to the team. (Parent)

There'll be more trust. (Parent)

I feel like you have some feel of competence I think. When true coproduction is happening. You feel heard and you feel, you don't walk away from the interaction feeling frustrated. I think that's where I live in that world, of those feelings. (Person with chronic health condition)

I remembered how it is important to ask the whole breadth of information in the beginning, as it saves time and helps with that coproduction. (Parent)

I know that's not the best word, but adherent to the plan because they co-produced it. It's going to make all of us happy. The patient and the clinician. (Health professional)

We were able to come up with a really good plan. That really meant a lot to me. I guess that's one thing that stood out from my visit last week. (Person with chronic health condition)

**Better health:** Some participants noticed effective coproduction leads to better health.

*Relationship is really key to your care team and to be productive with your health.*

(Person with chronic health condition)

I think having this joint decision making and knowing that both you and your provider agree on what is the best I guess road for you to take. I think that if that were the case, I would be ... I would take more of an initiative in my own care and start seeing the effects of this co-production and working together really has a positive impact, both immediately and in the long term. (Person with chronic health condition)

That helps me as mom go understand it isn't just a time constraint, which I get being
efficient with time, it’s a new thing for us all. We all want that same goal that’s way out there at the end. It’s better outcomes, more tomorrows, better todays. (Parent)
APPENDIX 6

EXCERPTS FROM THE TWO MULTI-STAKEHOLDER FOCUS GROUPS
FIRST MULTI-STAKEHOLDER FOCUS GROUP

Three coproduction stories from the first multi-stakeholder focus group in which two were from health professionals and the third was from a parent with a follow-up from the principle investigator.

• (My) story is about coproduction that was uneasy and complex – it’s about shared-decision making. There is a young baby that I take care of with CF who was admitted a few days before with bronchiolitis and went home fine, but was back shortly afterwards with another episode and another cold. The family lives several hours away and this is a small baby with a lot of care needs. We had a long conversation, where is the best place for care, hospital or home? They felt confident about taking the baby home and doing everything at home. That was a real moment for me for real shared decision-making. It wasn’t a situation where there was black and white. Sometimes it’s gray. Sometimes my decision or bias may be influenced by the amount of miles this family has to travel and their access to other care and my perception of their hardships. Their bias is to be home and be in touch and they did great, and the baby is probably much better cared for than we could do over the weekend. Relationship building - it does work both ways. I have to let go of my biases about the best place for care and what I see as barriers, versus their perception and knowing they’re the best people to take care of their child.

• I went in to see a 7-year-old patient, mid-afternoon during a full-day clinic so (it was) near the end of a long day. The patient had been sick, so we immediately started talking about his illness, how it was for him, what they had done, etc. They had actually been out of the country and although we had sent him with antibiotics for a possible pulmonary exacerbation, he got sick and was not getting better despite what we had sent him with, so we worked with them to get medications in another country. As we were talking about his illness, I also opened up my clinical encounter in the EMR and started to add in my agenda items. Then, when I had addressed the illness concerns and my own agenda, I asked the family what questions/concerns they had for the day. Mom brought up several things that had not come up during our prior discussions and were not on my radar. I immediately realized I had not prioritized the concern of the patient/family.

• This isn’t medical but it is analogous to coproduction in care. I needed a new pair of gym shoes because I was having a lot pain in my leg and I realized I needed to go to one of those stores that really do a good fitting to make sure you have the right shoes. The minute I walked in the door the sales person was all about coproduction – why are you here – how can I help? He asked a ton of clarifying questions. How did you use the old shoes? Where is the pain now? What will you use the new shoes for? He asked all these really good questions. In the process I felt like he was forcing me to coproduce. Force is a strong word – I don’t mean it in a negative way. Insisting might be a better word. He kept saying I can look at your form and you are going to
walk for me and you are going to do all this. But I need you to tell me about the fit and feel because I can’t possibly know that side of it. I realized when he was asking these questions – it was really his expertise combined with my personal experience or my life or what was happening – was combining to a good answer for these shoes.

- In response to this a focus group observer shared a story to link the shoe story with a healthcare situation. The story was about an orthopedic surgeon’s thoughts on conversations with patients during a follow-up post-operative visit. [The orthopedic surgeon] was saying – I have my clinical view of the patient outcomes after surgery. I look at films and I really don’t know how that surgery procedure has done until I hear from the voice of the patient. What are their outcomes? Like she was saying, the fit and feel. How does what I’ve done for you in terms of surgery – fit and feel in your life? And that is what really matters at this point.

LAST MULTI-STAKHOLDER FOCUS GROUP

Excepts from the focus group.

- Health professional: I was just going through my morning here and not even a patient with cystic fibrosis, an asthmatic trying to get a teenager to coproduce then tell them to put their phone down, and engage somewhat in the visit, and it wasn't all that successful. The parent was also trying to get the teenager engaged, who really didn't want to be here. I guess the takeaway is just (that) coproduction is a spectrum and a process that evolves over time, and there's times you're not going to get much coproduction, and other times you're going to get a lot.

- A story an observer heard from a colleague: The clinician thanked the mother and the son, 13 year old son, for sending in their report in advance of the visit. They had their dashboard before the visit [the report provided some essential information for the dashboard that would be used in the clinic visit]. The mother said, “Oh, what are you talking about. We didn’t send that report yet.” The 13-year old son said, “Oh I sent it in on Sunday night because they asked us to do that last visit.”

- In response to that story a parent typed in the chat box: Love that story and every mom hopes in coproduction.

- Health professional: I think one of the things certainly that I learned is the idea of coproducing the goals of care. I usually walk in the room… I’ve always walked in the room with the assumption I knew what the goals of care were, but to the idea of being
explicit about what’s the goal for that visit. What’s the goal in a long term, I think is really helpful, and as we figure out how to do it on a consistent basis. I think it does help for more effective visits.

- **Facilitator asks, what is getting in the way of doing it on a consistent basis?** I think it’s difficult to figure out how to word it, how to ... it’s not what the patients are used to. It’s not what we’re used to, and so how to start the conversation without sounding contrived or ... you don’t want to come out of left field with a patient. They don’t want to ... you don’t want them thinking what is he getting at, does he have some agenda. It’s a weird question, not that it’s a weird question, but it’s not a question we typically ask and so it can come across in a strange way if the patients aren’t attuned to this new approach.

- **A parent responded to the provider’s comment:** It’s a new thing for us all. We all want that same goal - that’s way out there at the end. It’s better outcomes, more tomorrows, better todays. How do we do that? How do we waltz this out? It’s [like] we’re learning a whole new dance step, and it’s awkward. Toes are going to get stepped on. We’re going to laugh. We’re going to cry, and it’s going to be good. It’s a beautiful thing.

- **An observer had a suggestion as to how this can be introduced to patients and families:** I’m going to share a little bit of a coproduction experience I had with my primary care provider, and one of the questions she asked me: How do I like to partner in my health care? I thought, “Wow.” She said, “I want to make a note in your chart, so that I have it, and [so] that the rest of our team has it, you know it’s a group practice about how you like to receive information, and how you like to partner in your care.” I just thought, “Wow, that’s cool that they’re opening up that opportunity for me to say I would prefer not to be as active, or I like to hear more from my doctor, or hey, I Google everything myself and I’m going to bring it to you, and we’re going to talk about it.” I just thought do we step and say to people with CF who we know and see quite often, “I’ve never really asked you this, how do you like to partner in your healthcare? Do you think it’s working well?” It was a really simple question, and it just ... It was a great conversation we had.

- **Person with a chronic health condition:** I went to my doctor and my appointment was just a check-up appointment, but from the start we were talking about something a little bit uncomfortable, and I was being mindful of coproduction, so I was simply paying attention to how she was acting to things. My provider immediately just ... Her tone in the way she was, I guess, giving the information immediately made me feel comfortable and made me feel like I was in a safe space. She asked me questions and she didn’t use the words coproduction or quality or anything,
but I just could tell that she cared about getting my input, and ... but also cared about getting to her input. I think she knew the importance of hearing and giving on both sides. We were able to come up with a really good plan. That really meant a lot to me. I think having this joint decision making and knowing that both you and your provider agree on what is the best I guess the road for you to take.

- **Health professional:** I think when patients come to me with questions that they either found on social media or somebody brought it up, that's a really good starting point, but a lot of the belief system is changed based on the relationship with their physician, so they may come asking you about one thing and it will lead me to a whole new discussion about, “Well that's one concept, but here's another concept that I know.” We might kind of go off on a tangent onto something very similar to what they originally brought to me, and I’d say, “Well this may be a better option for you.” It’s coming to the table with a question that I think is the best way to have a coproduced visit.

  - **In response a health professional stated:** I think that curiosity is key. I really agree. There’s all these ways to maybe foster curiosity. People are coming from different places. Some are very motivated, and naturally curious. Others are more passive. Maybe that has something to do with ... And I’m just speculating here, maybe it has something to do with the patient’s own self-confidence. You know I’ve always found that in patient interactions, if I can affirm them or build them up on ... In some way, it gives them confidence to say what they’re thinking or raise questions, become more curious.

  - **A parent wrote in the chat box:** Yes staying curious is key.

In summary, this last focus group reiterated stories and ideas about behaviors of effective and ineffective coproduction from the previous focus groups. Healthcare professionals can help empower patients – ignite their curiosity by using open-ended questions, by genuinely caring, and being interested in the individual as a person not just a patient. Engaging in a partnering role may surprise some people seeking care and others in charge of the care service. However, people may find they enjoy the role of helping to find a solution with another person, which can also be linked with sustaining the care plan.
ACKNOWLEDGEMENTS

We appreciate the time of the focus group participants – their enthusiasm and words of wisdoms were enormously valuable. We are grateful to the 6 medical centers: Ann & Robert H. Lurie Children’s Hospital of Chicago, Northwestern Medicine, Children’s Hospitals and Clinics of Minnesota, University of Minnesota, Dartmouth Hitchcock Medical Center. The Robert Wood Foundation provided funding for this research (grant number 72313).
REFERENCES

3 von Thiele Schwarz U. Co-care: Producing better health outcome through interactions between patients, care providers and information and communication technology, Health Services Management Research, 2016, 29:10-15
4 The concept of coproduction and its implications for public service, LL Kiser and SL Percy, unpublished white paper. Internet URL: https://dlc.dlib.indiana.edu/dlc/bitstream/handle/10535/1466/lkiser01.pdf?sequence=1&isAllowed=y
5 Bettencourt LA, Ostrom AL, Brown SW, Roundtree RI. Client co-production in knowledge-intensive business services, California Management Review, 2002, 44(4)
6 Ostrom E. Crossing the great divide; coproduction, synergy, and development, World Development, 199624(6):1073-1087
8 von Thiele Schwarz U. Cocare: producing better health outcome through interactions between patients, care providers and information and communication technology, Health Service Management, 2016, 29(1-2): 10-15
11 Cooke J, Langley J, Wolstenholme, Hampshaw S, “Seeing” the difference: The importance of visibility and action as a mark of “authenticity” in co-production, Int J Health Policy Manag, 2017, 6(6), 345-348
13 Johnson LC, Melmed GY, Nelson EC, Holthoff MM, Weaver SA, Morgan TS, Siegel CA. Fostering collaboration through creation of an IBD learning health system, Am J Gastroenterol, 2017; 112(3):406-408
17 The Swedish Rheumatology Quality Register (SQR) URL: http://srq.nu/en/
22 Lipsitz LA, Understanding health care as a complex system: The foundation for unintended consequences, , *JAMA*, 2012; 308(3):243-244
26 OpenNotes http://www.opennotes.org/rwjf-year-in-research/