Working Together to ImproveCareNow

Co-Production Change Package
Version 3.0: Catalyzing Community Input
October 2015
Prepared by:

IMPROVECARENOW Co-Production Team:
Carrie Fritz (Project Manager)
Alex Jofriet (ImproveCareNow Patient Partner)
Lauren Moore (Project Coordinator)
Liz Monti (Project Specialist)
Sarah Myers (ImproveCareNow Executive Improvement Director)
Sarah Nocito (ImproveCareNow Strategic Communications Manager)
Lisa Opipari-Arrigan (Team Leader)
Jen Powell (Quality Improvement Consultant)
Tifini Ray (Project Specialist)
Rita Siedlaczek (ImproveCareNow Parent Partner)

Acknowledgements

We would like to acknowledge the following individuals who contributed ideas and expertise in the development of this change package:
Laura Eshee
Carrie Frost
Cindy Gessouroun
Shawna Ricks
Diane Russell
Michael Seid
Frederique Verly
TABLE OF CONTENTS

SECTION I. Background and Purpose: A Change Package to Guide your Co-Production Journey ..... 1

SECTION II. Setting the Stage: Creating Conditions for Co-Production ........................................... 5

SECTION III. Taking Action: Co-Production Key Drivers, Change Concepts, and Examples of Specific Changes to Test ............................................................... 11
SECTION I:

Background and Purpose: A Change Package to Guide your Co-Production Journey

ImproveCareNow (ICN) aims to transform the health, care and costs for all children and adolescents with Inflammatory Bowel Disease (IBD), including Crohn’s Disease and ulcerative colitis, by building a sustainable collaborative chronic care network, enabling patients, families, clinicians and researchers to work together in a learning health care system to accelerate innovation, discovery and the application of new knowledge.

Since 2007, ImproveCareNow has helped catalyze dramatic improvements in remission rates and care for children and adolescents with IBD. The network has developed into a model learning health system—one designed to support continuous improvement and innovation, seamless delivery of best practices, and generation and capture of new knowledge as a natural part of the care process.

ICN has made it a priority to develop the social, scientific, and technological infrastructure to transform how patients, parents, clinicians, and researchers engage in every aspect of the healthcare system. It is transitioning from a network where providers work “for” the patients to one in which everyone works “with” each other to co-produce health and improvements in healthcare.

What Is Co-Production?

Co-production is patients, families, clinicians, and researchers collaborating as equal and reciprocal contributors to produce information (e.g., clinical data, patient reported outcomes), knowledge (informal insights and formal research), and know-how (expertise) to improve healthcare and health outcomes. Co-production is about people coming together – providers of healthcare and users of healthcare – and working together in equal partnerships to define, plan, and deliver what is needed. It is a new way of thinking about and building the roles of professionals and patients. It challenges the assumption that patients are passive recipients of care and recognizes that both patients and providers have a central role to play in creating health and healthcare as they each

A learning health system enables “patients and providers to work together to choose care based on the evidence, drive discovery as a natural outgrowth of patient care, and ensure innovation, quality, safety, and value in healthcare; all in a more real-time fashion”

contribute different and essential knowledge. Everyone working together in this new way is central to achieving improvements in safety and quality, increases in patient and professional satisfaction, better health outcomes, and lower healthcare costs.

**What is a Change Package?**
A change package is a concise and practical document that includes ideas and inspiration for teams seeking to apply quality improvement methods to increasing the effectiveness and efficiency of their care processes and outcomes. Change packages focus on a specific condition, care process, or health system feature and generally include background material; a summary of evidence or best practices; and specific tools, strategies, and examples that can be applied to improvement work. This change package outlines strategies for ImproveCareNow centers to use as they begin or advance co-production efforts that include patients, families, clinicians and researchers.

**Who is This Change Package For?**
The ImproveCareNow community is comprised of clinicians, improvement specialists, parents, patients, and researchers working together to improve outcomes for children and adolescents with IBD. This change package is a tool for all of the contributors in this system to use together. Different parts of the manual may be more relevant to different types of contributors; we hope that this will encourage discussion that leads to shared learning.

**How Was This Change Package Developed?**
This change package is inspired by and grounded in tools, methods and approaches already being developed or tested by ImproveCareNow centers. The content was also informed by focus groups and interviews in which ImproveCareNow participants shared their experiences with co-production including what has worked, what gaps exist, and ideas for how to bolster centers’ capacity to co-produce. Finally, we conducted an extensive external environmental scan to determine what clinician/patient/parent experts, researchers, and thought leaders have found to be effective in co-producing across other health care quality initiatives\(^1\).

**What is in This Change Package?**
This change package is designed to be an implementation guide for care centers as they embark or continue on the journey of co-production. The package is comprised of three sections:

- **Section 1. Background and Purpose: A Change Package to Guide Co-Production**
  This section provides a general overview of co-production, quality improvement, and the purpose of this change package.
Section 2. Setting the Stage: Creating Conditions for Co-Production
This section provides the nuts and bolts for getting started and the ongoing structure and support needed to develop and sustain co-production initiatives at your care center.

Section 3. Taking Action: Co-Production Key Drivers, Change Concepts, and Examples of Specific Changes to Test
This section includes an overall theory of improvement illustrated in a co-production key driver diagram, a discussion of change concepts to guide your co-production work, and specific examples of changes to test.

A Grounding in Quality Improvement
The ImproveCareNow Network’s overall goal is to increase the number of pediatric IBD patients who are in remission. As participating centers work toward achieving this goal, they organize their work around a number of specific aims and activities related to improving care processes and outcomes. These include registering patients into the ICN registry, creating workflows to ensure high quality data, and incorporating pre-visit planning, population management, and self-management support into their day-to-day practice.

Key to achieving these goals is the Network’s quality improvement approach, which is centered on the Model for Improvement\(^1\). The Model for Improvement guides quality improvement teams through three key questions as they seek to test changes in care processes and outcomes: What are we trying to accomplish? How will we know that a change is an improvement? What changes can we make that will result in improvement?

---

As the ImproveCareNow Network launches new efforts to grow and expand the community, we want contributors at ICN care centers to have the knowledge and tools they need to engage in co-producing healthcare improvements. This is version 2.1 of the Co-Production Change Package. It is just the beginning of what we believe will be a living, evolving set of ideas and tools developed by and for the ImproveCareNow community. We will continue to capture key findings, identify new and tested approaches and tools, and seek continuous input from those involved in this work. We will update this change package as we learn over time what works (and what doesn’t work) to foster a dynamic and co-produced learning health system.
SECTION II:

Setting the Stage: Creating Conditions for Co-Production

STEP 1. The Care Team

Successfully launching a new way of working together requires preparation, not only around practical issues such as finding appropriate meeting times and determining the types of projects on which to collaborate, but also around being ready—and receptive—to working in new ways and with new kinds of contributors. As members of the care team consider involving parent and patient partners in their improvement work, “some will embrace the idea without reservation; others will need to be convinced of the significant value to be found in redesigning care in partnership with parents and patients.”

Likewise, parents and patients will vary greatly in their comfort and receptivity to co-designing and co-producing care delivery improvements. However, our early experiences with co-production in ICN suggest that when asked most people will be willing to be a part of making improvement happen.

Before parents or patients are recruited to work with the quality improvement (QI) team, the team should be sure they are ready for this new way of working. Creating conditions that enable all contributors (clinicians, staff, patients, parents, researchers) to be effective and remain engaged is an important first step. Evidence and anecdotal information indicate that if there is not enough structure to support co-production in place at the center, everyone will struggle to focus and effectively contribute to care center improvements.

Care Center Infrastructure to Support Co-Production
As centers begin to identify potential parent or patient contributors, it is important to have in place an infrastructure that will support this new way of working.

1. Identify a Champion
   First, it can be very helpful to identify a co-production champion—someone who will help you overcome barriers to this work, help identify new opportunities to leverage your new partnerships, and spread the word about your achievements. Like most of the improvements that are tested and implemented through the network, identifying a team champion for this work will increase your likelihood of success.

   2 Source: Center for Medical Home Improvement (CMHI), A Guide for Parent and Practice “Partners” Working to Build Medical Homes for Children with Special Health Care Needs
2. Incorporate Into Your QI Work

Co-production should become “part of the woodwork” of the quality improvement work at your center. Building the groundwork for co-production into your existing improvement infrastructure, (such as by incorporating parent and patient partners into your existing QI team for example), will also help increase the likelihood of success.

3. Calibrate Care Team Attitudes and Expectations

Most clinicians and patients have not been trained to co-produce health or healthcare. Learning to collaborate in the co-production of healthcare services does not happen overnight – it takes time, dedication, practice and experience. It is important to recognize that co-production is much more than assessing patient opinions or letting patients ‘help’. Co-production requires a shift in how patients, parents and professionals view their roles in creating health and healthcare – it involves a new way of people relating to each other.

It’s normal for staff and clinicians to be both excited and anxious about involving parents and patients in their improvement work. Change is hard, no matter how obvious the potential benefits might be. Setting aside time to identify, acknowledge, and address team member concerns early in the process is critical to developing meaningful co-production at your center.

Key Characteristics of Teams Who are Successful with Co-Producing Healthcare

One way for teams to calibrate around each other’s views and expectations about co-production is to discuss their readiness as part of a standing team meeting. Reflecting on the following characteristics of teams that are ready for co-production may help get you started.

- Recognize people are assets and service users are valuable resources
- Develop people’s existing capabilities
- Promote mutual aid and reciprocity
- Break down barriers between professionals and patients
- Facilitate rather than deliver healthcare
- Listen well

The Staff Readiness Assessment is a brief questionnaire that you can use to help guide a team conversation (see Toolbox on page 10)

STEP 2. The Parent/Patient Partner

Think about Characteristics that are Important to Your Team

When beginning their co-production journey, many improvement teams focus on finding the ‘right’ parent or patient contributor(s). While it is certainly important to identify parents or patients who have the time, energy, and enthusiasm to collaborate and who are generally
compatible with the rest of the team, there is no single right set of characteristics. Teams that have been successful in identifying potential parents and patients partners have described the following as potentially important characteristics:

- Proactive and engaged in their own healthcare
- Clear about their values and aware that others may feel differently
- See beyond their own experiences
- Able to build consensus, collaborate on solutions, accept compromises
- Have resources – including time, relationships, knowledge and experience, and are willing to use them
- Have a learning orientation and are willing to take risks
- Listen well
- Ask questions
- Respect diversity and different opinions

**Identify Potential Partners**

When you are ready to formally build parent and patient partners into your work, begin by asking team members to identify 2-3 individuals who might be willing and able to work with your team (see above list of parent and patient attributes as guidance). If it’s difficult to come up with these names, try posting a flyer in clinic or sharing the opportunity via your clinic’s social media channels to see if those you may not have thought of approach you to share their interest.

**Reach Out with the Goal of Finding One or Two Partners**

Once you have identified potential partners, reach out in person or by phone to tell them about your needs and plans and to assess their interest. Here’s a basic way to describe co-production:

“Our care center is working to improve the way we provide IBD care by involving parents and patients in new ways of working with us. We believe that the best way to improve our care center is to work together with our families to improve the patient & family experience and create better care. I’d like to tell you about our efforts, find out about your interests, and see if you would be interested in playing a role. We want to make a new kind of healthcare where everyone – patients, parents, staff, clinicians – contributes to making care better.”
Co-Production: It’s Not about Attending Support Groups

Involving parents or patients in attending support groups is not the same thing as co-production. While support groups run through clinics can be a wonderful and very valuable service and experience for families – attending those groups is not co-production. Co-production is about parents and patients sharing their expertise with their care team to co-design and co-produce care improvements at the center. It’s about matching the parent’s/patient’s skills and interests to address gaps in the care process that you mutually agree could be improved.

- Develop a brief [survey or interview](#) for parents asking for their feedback about the clinic process—you are likely to learn who has ideas that they are eager to share!
- Ask a parent to review and give feedback on a clinical form, family-facing process, or teaching material.
- Support a family in their [fundraising efforts](#) related to IBD awareness.
- Ask a parent to work on a brief “elevator pitch” with you that you can use to help explain ImproveCareNow to new IBD patients and their families.

In general, working together to identify gaps in services or ideas for improvement that fit with the parent’s/patient’s interest and expertise is a great way to start. This approach makes it easier to find a role for them enhancing a current improvement effort that is already underway and get

Start Small with a Specific, Time-Bound Goal

Think about starting your co-production work with 1 or 2 parents as part of a time-limited, discrete project. This allows you to assess interest and fit without establishing a long-term commitment that may not work. Some parents may feel uncertain about how or what they can contribute. Small projects provide the opportunity to give clear direction and help parents understand the value and purpose of co-production. Other parents may have big ideas of things they would like to develop in the clinic such as a mentoring program or support for hospitalized families. These are big projects that may be a more challenging place to start.

Think of a few smaller projects that you can suggest to get started and begin to incorporate the parent’s/patient’s ideas. Here are some examples:

- Invite a parent to attend one QI meeting as a visitor.
- Host a lunch and learn on a topic of interest to your patients and their families. Ask one family to help plan the agenda and share their experience.
- Connect a parent with another family that is in need of one-time mentoring around a specific issue.

Involving parents or patients in attending support groups is not the same thing as co-production. While support groups run through clinics can be a wonderful and very valuable service and experience for families – attending those groups is not co-production. Co-production is about parents and patients sharing their expertise with their care team to co-design and co-produce care improvements at the center. It’s about matching the parent’s/patient’s skills and interests to address gaps in the care process that you mutually agree could be improved.

- Develop a brief [survey or interview](#) for parents asking for their feedback about the clinic process—you are likely to learn who has ideas that they are eager to share!
- Ask a parent to review and give feedback on a clinical form, family-facing process, or teaching material.
- Support a family in their [fundraising efforts](#) related to IBD awareness.
- Ask a parent to work on a brief “elevator pitch” with you that you can use to help explain ImproveCareNow to new IBD patients and their families.

In general, working together to identify gaps in services or ideas for improvement that fit with the parent’s/patient’s interest and expertise is a great way to start. This approach makes it easier to find a role for them enhancing a current improvement effort that is already underway and get
started. The bottom line is that starting small works. If the project goes well, it can be a launching board into a longer term relationship or commitment.

**Should We Interview Parents?**

Some teams may want to ‘interview’ a potential contributor to find out about their experiences, story, expertise, and interests – other teams may not find this step necessary or appropriate. Whether or not you ‘interview’ a potential contributor, take the time early on to ask about his/her story and share your own. Relationship building is an important part of successful co-production.

Explain what is involved (hospital or clinic onboarding requirements and training, possible roles/types of activities, meeting expectations, time commitment) and assess the parent’s/patient’s interest in moving forward together. Remember that sometimes the best way to assess interest is to just get started and test a joint project together. Some ICN teams have successfully used surveys when trying to reach a larger number of families.
Co-production Toolbox

- Preparing for Recruitment Supplement
- Staff Readiness Assessment
- Parent Partner Role Description
- Adding a Co-Production Section to Your ImproveCareNow Charter
SECTION III:

Taking Action: Co-Production Key Drivers, Change Concepts, and Examples of Specific Changes to Test

A Key Driver Diagram for Co-Production in ImproveCareNow Centers

Before tackling a new improvement challenge, it’s essential to understand the big picture of how specific changes or interventions can help you achieve improvements in care processes and outcomes. One way to do this is to use a key driver diagram. A key driver diagram is a picture of the theory behind an improvement effort—a roadmap of sorts. It illustrates the linkages between an overall aim (in this case, increased evidence of and satisfaction with co-production at your care center), key drivers (the conditions that need to be in place for you to achieve your aim), and the interventions that can help you get there (changes like those included in this change package).

A sample key driver diagram for co-production in the ImproveCareNow community is included on the next page. While your center will likely identify additional drivers and interventions that will lead to improvement in your unique environment, this is intended to help you get started thinking about choosing changes to test that are most likely to lead to improvement.
Framing Your Work Together: Change Concepts

Care centers that have developed meaningful partnerships with parents and patients report a lot of satisfaction with this new approach to working together to improve care. The discussions, ideas, and concrete tools that result, better address the needs of families. And everyone—including members of the clinical team—is exposed to new knowledge, perspectives, and expertise in the process. Change is not always easy, and centers with experience building these partnerships acknowledge that getting started with co-production can be the hardest part. Knowing what to do first—and where to target your valuable time and energy—can be daunting.

To help you think about making your ideas for co-production a reality, we list a number of change concepts. Change concepts are ‘big ideas’ for the kinds of actions that are likely to yield improvement. You will notice that the change concepts listed here are closely related to the key drivers of co-production highlighted on the previous page. These change concepts will help focus your team on what matters most for co-production, but it’s up to you to determine the specific ideas to test that will have the most impact for your team.

(See page 16 for concrete ideas to get started!)
Change Concepts for Co-Production

Create and Promote Meaningful And Varied Opportunities Together

Just as people are drawn to different careers, volunteer opportunities, and lifestyle choices, so too are they motivated by a variety of ways to share their time and talents with their care centers. Think about the various ways in which patients and parents can contribute. For example, while some people thrive on participating in event planning as part of a group and other visible roles, others may prefer a task that can be done quietly at home such as summarizing articles for other parents or working on a checklist for families new to the clinic. Push your team to think outside the box and move beyond the traditional roles that parents and patients take on. Encourage each other to think about parents and patients as valuable resources with a wide range of possible skills and experiences to bring to your care team. Asking parents and patients to participate in brainstorming ideas will lead to a much richer beginning list of opportunities.

Once you have developed an initial list, make it visible. Identify ways to promote the needs and opportunities available. Contributing to care center activities is not currently part of most patient’s and parent’s view or expectations of the health system. In order for patients and parents to co-produce, they have to understand this is even possible at your center and become aware of what opportunities exist.

Identify Partner Skills and Experiences and Align with Opportunities for Co-production

If you don’t learn about the skills, circumstances, and life experience that potential contributors bring—getting to know them as people—it is challenging to include them in meaningful ways. A key QI principle is deference to expertise—making sure that the person who is best able to do a job is the one doing it. That frees up others to do the same and also makes sure the task gets done as well as possible. Whereas some things are a good fit for parent and patient contributors, some are more clearly in the purview of the clinical team. Sometimes there is not an identified task that matches the skills that someone has to share—it’s ok to let the skills drive the work too.

Reduce Barriers To Co-Production

Even when the clinical team is committed to enhancing their partnership with parents and patients, organizational bureaucracy and routines can get in the way. Hospital and clinic policies and procedures set up to protect privacy can make it challenging to get parents and patients involved as partners. Meetings may take place during traditional work hours—times that parents and patients are attending to their own jobs, families, and other responsibilities. Working in new ways, requires thinking in new ways about how we work.
| **Create Norms and Routines Around The Value Of Co-Production** | Co-production is not prevalent in many of the systems in which clinicians have worked and received training. Co-production is not prevalent in many of the systems in which patients and parents have received healthcare. Most of us have not seen good examples of co-production in action—traditionally, improvement work is the purview of the clinical team. Committing to make co-production explicit and visible in the system will help set expectations that this is the new norm—the way that the center will get work done moving forward. |
| **Describe And Develop Needed Knowledge, Roles, And Skills** | Effective co-production requires education and preparation for all contributors. In order to “even the playing field,” patients and parents need skills (i.e., quality improvement, understanding data), confidence, and authority to partner with their care team. Care teams also need core competencies to enable effective collaboration with parents and patients. Everyone needs skills in group communication, collaboration and group learning. |
| **Focus on Relationships, Trust, And Mutual Respect** | Patients, parents, clinicians, staff and researchers working together to improve care is new territory for most of us. While at the core we all want to improve the care for children with IBD, our priorities, language, and skill differences can create challenges for collaboration. Like any partnership, taking the time to know one another as people and actively seek out better appreciation of each other’s unique backgrounds, priorities, and talents is an important way to build understanding—and to enhance what one gains from the work being undertaken together. Everyone focusing on relationship and team building, as well as showing appreciation for the contributions of all contributors is important for developing successful co-production relationships. Breaking down barriers between professionals (service providers) and patients/parents (service users) and viewing everyone as bringing unique expertise to produce the best health and health care is key for establishing trust and respect. |
| **Reflect, Learn, And Adapt Together** | As with a care center’s other improvement activities, co-production efforts will go through much iteration. Key to continuous improvement as the involved partners work together over time is taking the time for honest, transparent reflection; ongoing assessment of lessons learned to date—both via successes and “failures;” and application of these lessons learned. |
Ideas & Examples of Changes to Test

**From Change Concept to Concrete Ideas for Co-Production at Your Care Center**
There are a number of ways in which clinicians, parents, and patients can co-produce at the care center. This section includes ideas for changes to test to help you get started. These ideas are organized around the change concepts outlined above. We also include “gems” where applicable—quotes or key ideas gleaned from interviews and focus groups with ImproveCareNow centers.

**For specific tools, documents, and other examples of ways to test these ideas, please visit the Engagement Boards on the ICN Exchange**

**Click on the headers below to be taken directly to each topic’s board!**

These are just initial ideas to get started on the co-production journey; as partners get to know one another’s talents, expertise, and priorities and as they assess the impact of their initial work together, new ideas for working together will emerge.

**Create and Promote Meaningful And Varied Opportunities Together**

Catalog the work your team is doing now and what you would like to have underway six months from now. Identify the current gaps in skills or time to get that work done and ask family members with those skills to take on the task.

Work together to assess issues in need of improvement in your IBD clinic and develop a plan for working on them together.

**Gems from ImproveCareNow participants:**

“When asked what was needed by me (the parent), they said they didn’t know.” Make it a dialogue and brainstorm together.
**Identify Partner Skills and Experiences and Align with Opportunities for Co-Production**

Ask family partners to develop a list of ideas for materials or tools that they would have liked to receive during their care journey and allow them to take the lead in developing them.

- Involve families in fundraising efforts using their skills and creativity.
- Involve families in designing learning opportunities for your center—and beyond.
- Leverage family partners’ skills and expertise to learn and develop resources for your center.
- Have family partners take the lead in developing and running family support groups and mentoring programs.

**Reduce Barriers To Working Together**

Establish policies, charters, ground rules, and/or job descriptions for volunteer participation, including recognition and/or compensation for parents.

Document and compile the process and tools needed to navigate organizational hurdles.

*Gems from ImproveCareNow participants:*

“Some parents don’t understand the difference between seeing the care team during meetings and seeing the care team during appointments. Rules and expectations need to be established.”
Develop Needed Knowledge, Roles, And Skills

Share ImproveCareNow materials and presentations related to enhancing partnership and then have joint reflection and discussions on implications for partnership at your care center.

Share quality improvement training resources and opportunities with parent partners and help them determine which skills are most applicable to their work with your center.

Gems from ImproveCareNow participants:
Some centers have Family Advisory Groups or other resources to help provide training and orientation to parent and patient partners. Check and see if this kind of help is available.

Create Norms and Routines Around The Value Of Working Together

Create a charter or mission statement for work with family partners.

Formalize the role of families in your system through the development of working groups (know as advisory councils, committees, or working groups) with concrete.

Publicize your partnership to make others in your center—and beyond—aware of your shared work and vision.

Gems from ImproveCareNow participants:
Regular participation in QI meetings is preferred, otherwise ideas (and sometimes the entire group) will lose momentum. Meeting via conference call or Skype can facilitate the inclusion of long-distance parents.
Focus on Relationships, Trust, And Mutual Respect

Develop fun and easy ways to share information about each of the partners in your work—fact sheets, “trading cards,” or other tools.

Include parent and patient partners in team-building activities and in celebrating successes.

Create a standing QI meeting agenda item related to soliciting family partner feedback or ideas.

Gems from ImproveCareNow participants:

Physicians who are open to co-production can be important champions and role models for those who are less receptive.

A relaxed atmosphere, including meeting outside of the clinic, can make it more comfortable to move forward and find common ground—a shared meal goes a long way toward community.

Reflect, Learn, and Adapt Together

Apply quality improvement approaches and tools to your work together.