

## IMPROVE**CARE**NOW 2018 Engagement Campaign Plan

Chris Keck

IMPROVE**CARE**NOW Campaign Director

christian.keck@cchmc.org





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#### Overview

Testing and implementation of new medical procedures, clinical processes, and treatments isn't new. We have seen advancements in medical care that were unthinkable a generation ago. Over the past decade, Improve Care Now has been on the cutting edge of improving health outcomes and quality of life through collaborative research. We have seen unprecedented improvement in remission rates and hope to build on that success in the years to come. At the core of our success is the "All Teach, All Learn" philosophy that encourages input from everyone and is a driver for building a communication system that allows ideas to be shared from person to person and care center to care center. In short, we believe there is no monopoly on good ideas. The more people who engage in research, discovery, and implementation, the more we improve outcomes and quality of life.

The next frontier is to test and implement an organizing model that supports and encourages all patients and parents to take ownership of improving their quality of life. We believe that patients and parents taking active ownership of their care is as important to improving their quality of life as a doctor recording their height or weight. Over the past few years ICN staff, center staff, patients, and parents have begun to build that network. The national Patient Advisory Council and Parent Working Group have been at the forefront of developing new tools and participating in research. They regularly test new ideas and serve as advocates. They replicate themselves by effectively adding new members and transitioning leadership. 37 of the care centers in the ICN network have active patients or parents and, at the network level, we are able to regularly communicate with at least 717 patients or parents and potentially as many as 1,929. Their work is highlighted through tools like our national recognized blog, LOOP. Sharing the patient and parent experiences and ideas through LOOP facilitates relationship building within the network and is a driver of new people signing up. We are better able to communicate with and support those efforts through Nationbuilder, a database that serves as a hub for our engagement work. All of those efforts and even more that weren't mentioned position us well to expand the engagement effort.

We believe that there are more than 50,000 patients and parents in the ICN network that could can engage in teaching, learning, and sharing how they are improving their quality of life. That's tens of thousands of people who could benefit from ideas of others or who could share ideas that benefit others who aren't engaged. More than 60 centers do not currently have active patients or parents. That's hundreds of staff members who don't have the benefit of feedback from the people they seek to serve.

Our mission and the goal of this plan is to build a system that provides the opportunity for every patient or parent to activate; to support activate patients, parents, and center staff with training, coaching, and new tools; to provide the organizational structure for center level teams to grow and become self-replicating; and, most importantly, facilitates the sharing of the actions that thousands of patients and parents are using to improve their lives with other patients and parents.

When Improve Care Now started a decade ago, they knew that big change doesn't happen overnight, or in a week, or a month, or a year. They knew that you celebrate small victories along the way, as you grow, and as one year turns into ten you see transformative change. The same is true with our engagement campaign. Our goal is to see transformative change by the end of 2020. Our goal is that, by that time, there are more than 25,000 patient and parents engaged; 12,500 actively participating in Improve Care Now; 1,250 contributing to the creation, testing, or implementation of new tools or procedures; and 250 who are actively owning and leading. In this document you will see the roadmap for our next steps to transformational change through engagement. There are a few themes that define the next year and bind each section of this plan together- Developing the infrastructure to support rapid expansion in the years to come; Developing and testing interventions that will support growth in each of our four key measure areas(Awareness, Participation, Contribution, Ownership); and Strengthening relationships with care center staff, patients, and parents.

### **Care Center Team Structure**

The model of community organizing that presents the best opportunity for long term sustainability of ImproveCareNow's(ICN) engagement program at care centers is the team model of organizing. It is also referred to as the "snowflake" model because of how it looks (fig. 1). We will refer to it as the snowflake model because it is a more unique term, it reinforces that the model is customizable (every snowflake is unique), it helps for people to visualize their team, the communication flow, and the diagram is frequently used in coaching exercises.

Why is this model best for ICN? There are lots of reasons and I want to highlight some of the most important

- It builds on the existing culture of ICN- "All Teach, All Learn", "Share Seamlessly, Steal Shameless", the values of empowerment, inclusivity, community, transparency, honesty, and learning that are at the core of ICN's culture. The snowflake model is dependent on those values, reliant on communication structures that promote sharing, and allows ideas to develop from the ground up. It seeks to create the communication avenues and an environment for creativity that allow for new ideas to be developed and shared.
- Time is a valuable resource. The snowflake model allows us to create more. One of
  the most consistent pieces of feedback from care centers is that they are already
  stretched for time. Asking them to take on a large amount of new tasks to support
  the engagement program is likely unrealistic. It is also unlikely that ICN would be

Fig. 1: Team Model Volunteer Structure Diagram

- able to hire enough staff to support those activities at care centers. We can find more patients and parents who are invested in taking ownership of their care and sharing what works to improve their lives.

  It gives ownership to the people who are most directly impacted by IRD. Patients and parents IRD is a part of
- It gives ownership to the people who are most directly impacted by IBD- Patients and parents. IBD is a part of their day-to-day lives. The snowflake model puts them in positions of influence and invests in their training and development as organizers. They are the most important people in ICN's network. In this model we will be continually reinforcing their value.
- It allows for continuity of program. The model spreads out leadership, responsibility, and puts a premium on developing new leaders. It is less likely that activity stops or slows because any one person leaves and is more likely to have someone ready to take on that role.
- ICN is a network of individual organizations with their own set of strengths and challenges. The snowflake model is customizable. It doesn't matter how many or few parents or patients that are involved at a center or if their focus is on incorporating parents/patients into their QI work or a mentorship program- The communication structures, empowerment of parents/patients, and ability to develop leadership of the snowflake model still work.

We have an organizing model that is a good fit for ICN. How do we put that into action? That's what we will address below. This section of the engagement plan is organized into four subsections that will describe what roles patients/parents play in the snowflake model, our long term vision, where we stand now, what we want to accomplish this year, and potential challenges.

#### **Patient and Parent Roles in the Snowflake Model**

The core components of the snowflake model are

- Sustainable Management Ratios- These allow for adequate support for training and leadership development as well as oversight of tasks delegation.
- Empowering Patients and Parents as Leadership- The reach of the engagement program is only limited by how many patients and parents are willing to take ownership of their teams. A premium is placed on leadership development, delegation, and training so that if any one person is removed at any time the team continues to function.
- Specialization of Roles and Clear Responsibilities- Part of an organizer's job is to find a role for everyone to get
  involved who wants to be involved. Specialization of roles allows us to build on the strengths and preferences of
  individual parents and patients. Clearly sharing the responsibilities of those roles creates an objective set of
  standards can be used to guide coaching conversations, allow volunteers to be confident in how they help the
  team meet its goals, and allow coaches to identify training needs.

#### **General Roles**

A specific structure, that is consistent across organizations, supports those core components. These roles are always part of the snowflake model of organizing

#### <u>Organizer</u>

The Organizer is the center node in the snowflake (fig. 2). While they may have strengths in a specific area(s) they know enough about all the areas to effectively coach coordinators and see how the goals of any area fit in with the larger goals of the team. This allows them to prioritize their time and the team's time. They serve as the main advocate for the team's needs. This is the position that typically requires the highest investment of time.

#### Common Tasks

- Holding one on one meetings with Coordinators to review their goals, work through challenges, find areas
- Convening team meetings.
- Meeting with other teams or people who connect their team to the larger network.
- Tracking progress to the team's goals and sharing that information with team members.
- Celebrating team accomplishments.
- Identifying and training potential future coordinators or team leaders.
- Filling holes in team areas that lack coordinators or team members.

Fig. 2: "Organizer" role in the snowflake in blue

#### What to Look for in a Team Leader

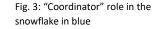
- Consensus builder.
- Ability to identify strengths and areas for improvement in team members.
- Communicative.
- Ability to see where their team and each team area fits into the global picture.
- Persuasive.
- Patience.
- They follow up and follow thru on commitments.
- To view success as a leader as being supportive of their team and identifying future leaders.
- Can articulate goals and ideas to people from a wide variety of backgrounds.

#### Coordinator

Coordinators lead individual subject areas (fig. 3). They work with the Organizer and other Coordinators to ensure that the goals and tasks of their area support the larger goals of the team. This role has responsibility for running specific events and owning specific projects. They need to have a passion for and ability to coach others in their subject area. These positions usually require less of a time investment than an Organizer and their time commitment can escalate with specific projects or events.

#### **Common Tasks**

- Planning and executing specific events and projects.
- Training Team Members in their subject area.
- Attending team meetings and communicating progress toward subject area goals to the Organizer and other Coordinators.



- Reviewing progress towards goals in their area.
- Sharing successes and challenges in their area with the Organizer and Coordinators of the same subject area from other teams.
- Scheduling Team Members for specific events.
- One on One meetings with new Team Members.

#### What to Look for in a Coordinator

- Task master.
- Follow up and follow through.
- A passion for their subject area and a hunger to learn more about how to be successful in that area.
- Ability to think on their feet.
- Creative problem solving.
- Ability to identify the interests of team members and what activities, either in their area or others, would best meet those interests.

#### **Team Member**

Team Members (fig. 4) regularly attend events and participate in projects. They are the largest group of volunteers and where most volunteers get started. They may only be able to attend events once a month, every couple weeks, or not be able to set a regular schedule. Some will pick one subject area to focus on, others will bounce from area to area depending on what events or projects in which they have the most interest.

#### **Common Tasks**

- Attending events.
- Participating in projects.
- Playing support roles at events.
- Recruiting new team members or scheduling for events.

Fig. 4: "Team Member" role in the snowflake in blue

#### What to Look for in a Team Member

- Reliable.
- Motivated to make a difference.
- Willing to push the boundaries of their comfort level.

#### **ICN Specific Roles**

Each organization that uses the snowflake model customizes those roles to meet the needs of the community. Below is a list of potential team roles based on the tasks that parents and patients already do at care centers and tasks that will support team and ladder of engagement growth. This is not an exhaustive list. As care centers implement this model they will identify additional needs. Roles to support those needs can be created and will fall under one of the categories listed under general roles. Under each role are listed tasks that they would own.

#### Three notes:

- 1. Tasks listed in general roles are not listed again, but those are still activities that they would complete.
- 2. Most care centers do not have the capacity to fill all these roles at this time. Some of the potential Coordinator roles are nested under a role that would be filled first. For example, training can fall within the scope of the Community Builder if there isn't capacity to have a specific Training Lead.

#### Community Organizer (Organizer)

- This is a role that every care center team needs to have.
- Support the team and help procure the resources and coordinate the logistics necessary for meetings, events, and team activities
- Curate opportunities that connect patients and families into new and ongoing clinical, research, or improvement projects. For example, if a research team is looking for a patient perspective or voice, the coordinator will present the opportunity to the team that then will help identify the patient or family partner best suited.
- Works with care center staff to write and execute PDSAs(Plan, Do, Study, Act) to test new engagement intervention at their care center.
- Manage the relationships with clinical and non-clinical allies to the engagement campaign.
- Sustain feedback loops for best practice sharing between the local team, ICN staff, and other care center teams
- Connects with care center team members (in coordination with the Provider Engagement Lead) to implement interventions into care center workflow and overcome challenges.
- Regularly reviews and shares progress towards ladder of engagement goals and other goals set by the team.

#### PWG/PAC Liaison (Coordinator/Team Member)

- Attends PWG or PAC monthly calls.
- Communicates information on new opportunities, ideas, and solutions to challenges with care center team.

#### Community Builder (Coordinator)

- Point person for growing the team. They work with other coordinators and the team leader to embed opportunities to join the team into every aspect of their work.
- Organize activities in and out of the center that spread the ICN message to the broader community such as house parties, education/awareness days, and fundraising events.
- Set and track growth and activity goals for the center.
- Reaches out to or trains and recruits team members to reach out to newly signed up parents and patients to let them know about services that are offered and opportunities to get involved.
- Holds one on one meetings with parents who are interested in volunteering to gauge areas of interest, let them know opportunities, and secure commitments for upcoming projects or events.

#### Training Lead (Coordinator)

- Identifies training needs of care center team members.
- Holds regular trainings.
- Works with other Coordinators, care center staff, and ICN staff to develop new training modules.
- Develops a team of trainers.

#### Data Lead (Coordinator)

- Serve as point person for NationBuilder or the database that the team uses to store contact info.
- Enters data or recruits a team of data entry team members who enter data for events, one on one meetings, and newly recruited parents and patients.
- Works with the training coordinator to develop trainings for NationBuilder or their database.

#### Story Teller (Coordinator)

- Lead the development and execution of a center specific promotional materials, newsletter, and/or blog that keeps people connected to issues proximate to their care and local context.
- Coach patients and parents on social media best practices, writing, and online storytelling.
- Encourage participation in network-wide online programming such as Facebook Q&As, Twitter Chats, and Instagram campaigns that connect and engage families across the network online.
- Participate in the development of family education materials or activities.

#### Provider Engagement Lead (Coordinator)

- Guide the design and planning of trainings to walk providers through center campaign program and enrollment best practices.
- Participate in the development of provider education materials or activities.
- Solicit feedback from providers on best way to maximize point-of-care to present campaign related asks and actions.
- Recruit providers to participate in action-oriented events with the local community such as teach-ins and recruitment events.

#### QI Lead (Coordinator)

- Attend care center Quality Improvement meetings
- Share potential quality improvement projects with the rest of the team.
- Work with the training coordinator to develop trainings on quality improvement fundamentals.
- Works with Coordinators from other areas to train them on Quality Improvement methods such as completing PDSAs and review their work.

#### **Identifying and Confirming Team Leaders and Coordinators**

Identifying, supporting, and testing volunteers to take on more responsibility is the most important thing we can do to ensure self-sustaining teams. A mistake that many volunteer organization make is assuming that the volunteer with the most time or the loudest voice in the room is the person who should be the one to take charge. In some cases they are, but that's not always the case. To ensure that we are finding the people who will support team growth, inclusion, and empowerment we need to use two methods.

- 1. Identifying the qualities for each role that lead to success. Many of them are outlined above ("What to Look For" under each general role) and I won't repeat them here. Organizers should identify those qualities, then focus on finding people who have the qualities that are hardest to teach. For example, for a Team Leader, you can teach someone how to identify strengths in other team members, but it is difficult to teach patience.
- 2. Testing and Confirming- Before someone takes on additional responsibilities it is important that they have demonstrated their ability to execute the tasks needed to be successful in that role and that they have made a specific commitment to take on that role.
  - a. Testing-Testing is the process by which a volunteer is asked to take on a new task, completes the tasks, and then gets feedback from the person who delegated the task to them. It needs to be engrained in every activity that we do. It is an opportunity for them to put their skills into action.
  - b. Confirming- Before someone takes on a role as an Organizer or Coordinator there is a specific conversation where the responsibilities of that role, including the time commitment, are laid out and the person being asked makes a specific commitment.

An example of how this all comes together, a team is growing and there is a need for a Training Coordinator.

(Identifying)The Organizer has identified a parent who has attended three events, asked good questions, and she knows he is a teacher because he shared it during their one on one. She thinks he is a good prospect for the position.

(Testing)There is a presentation coming up at a new patient orientation. The Organizer asks the prospective Training Coordinator to give the presentation. They meet beforehand to go over what is need and review materials. The potential Coordinator gives the presentation and they meet afterward. She gets his feedback and is ready to ask him to become the Training Coordinator.

(Confirming) The Organizer schedules time to talk with the potential Training Coordinator after their next event. She lets him know that there is a need for a Training Coordinator, reviews what the role requires, and asks if he is willing to take on that role. He says yes! After he commits they go over next steps and schedule their next time to talk.

#### **Long Term Goals and Where We Stand**

#### **Long Term Goals**

Our topline goal is to have self-sustaining care center teams that can keep growing regardless of staffing changes at the network or care center level. Additionally, we will document how we built the network of teams so that it can be replicated across the health care system.

That is an audacious goal and won't be easy, but it's the most important thing we can do to ensure long term success. I have identified seven key points that will help us to reach our topline goals.

- Universal knowledge of the snowflake model and centers are working toward the goal of building teams.
- At least 50 Care Center Leads identified and confirmed. At least 75 Coordinators identified and confirmed with
  at least one Coordinator at 40% of ICN care centers. All of parents/patients confirmed in those roles would be
  considered Owners on the Ladder of Engagement. Our Ownership goal by 2020 is 125. These roles would allow
  us to exceed that goal.
- Care Center teams have taken ownership of individualized goals, they are able to develop, and track their own goals for different aspects of their program.
- Those Care Center Organizers and Coordinators are tracked through regularly reports. We are able to, at any time, pull a list of all the team leads and coordinators and identify which care centers with which they are associated.
- Regular opportunities for care center staff and parent/patient volunteers for training and coaching on building teams in the snowflake model by ICN staff or highly trained volunteers.
- A communication system that allows Organizers and Coordinators to communicate with parents and patients in similar roles across the network.
- Identifying, testing, and confirming becomes engrained in every aspect of our engagement program.

#### Where We Stand

- The PAC and PWG are functioning snowflakes. They don't use all the concepts (like testing and confirming), but are great models.
- The centers who went through the WAVE trainings retained some of that training. Three challenges-1. Many staff members who went through the training are no longer with those centers 2. They have had challenges finding parents or patients to fill those roles 3. Care center staff identifies lack of time as a key challenge (not for the lack of trying or wanting). Those challenges helped to inform the 2018 goals- Offering lots of opportunities for training from the network level and focusing our coaching and support efforts on parents and patients.
- There are parents/patients who are acting as Organizers at their centers. My sense is that the number is somewhere between 5 and 15, though it could be more.
- We aren't able to communicate freely with the people who will fuel team growth. They are parents and patients who need to become aware. It's why one of the goals of the Engagement Innovation Community is to test interventions that make people aware.

#### **2018 Goals**

- 1. Create the tags in Nationbuilder to identify a parent or patient volunteer as a Organizer or Coordinator.
- 2. Offer training to the network that lays out the basics of the organizing model (similar to the training offered in 2015). These trainings would be offered at all major network gatherings (Community Conferences and Virtual Community Conferences) as well as in webinar, recorded video, and written form.
- 3. Create opportunities for coaching for parents, patients, and care center staff in a one on one or group setting. One on one coaching offered by the Campaign Director and Engagement Project Coordinator and group coaching during Engagement Office Hours (those have already been implemented).
- 4. Use the Engagement Innovation Community to put this model into practice.

#### **Potential Challenges**

There will be lots of challenges along the way. I want to use this space to bring up questions to which there aren't apparent answers. They are focus around the area of having the network level staff capacity to support a volunteer leadership network. Remember, sustainable management ratios are one of the core components of the snowflake model. If you grow too fast or can't support sustainable management ratios, then volunteer leaders don't get the coaching and support they need. They are more likely to have a negative experience and disengage.

- Team Leaders typically require one on one or small group coaching on a weekly or monthly basis. 50 or more Organizers is far too many for one person to support. At most, one person usually supports 1-7 Team Leaders. Is there any likelihood that we would be able to have enough staff to support a ratio close to that? My sense is no. If that's the case how do we offer the support needed?
- One of the 2018 goal is to identify all the parents/patients who are currently functioning as Organizers, train them on the snowflake model, and begin to offer them regular support. Do we have the staff capacity now? If not, what alternative do we have that allow us to reach a similar place?
- Will the network be receptive to the model? When it's implemented, it works, but people have to want to do it. Building snowflake teams is hard and fragile at first. We need the people implementing the model to trust the process. In some centers they are going to try for months and not be able to find a Team Leader. What do we need to do to ensure that everyone is willing to stick it out?

**Engagement Innovation Community** 

ImproveCareNow is built on a foundation of innovation, community, continuous learning, and empowerment. Over the past two years, this foundation has served as inspiration for our first steps towards developing a patient and parent engagement program that seeks to redefine the relationship between patients, their families, and their care. After months of reviewing our successes, challenges, and the ICN community, we are ready to launch our next innovation initiative.

When patients and families are engaged in their care, they are more likely to be active in self-management and in co-producing good outcomes. They have the power to come up with new ideas to improve their quality of life, share those ideas with the community, learn from others, and support their care center in their quality improvement efforts. As well, groups of active patients and their families supply additional capacity for care center staff to test new ideas, to research new treatments, and to get real time feedback from those who are most directly affected by their work. We believe, and anecdotal evidence suggest, that patient and family engagement is as important to quality of life as recording a patient's height and weight or making sure they receive the proper treatment. We will test this idea by enhancing engagement and measuring its effects.

Our goal, by the end of 2020, is to have more than 25,000 patients and family members aware of the resources available to them, 12,500 participate by using those resources to improve their lives, 1,250 contributing to developing those resources, and 250 owning the process of developing the community to support that work. These four tiers become the Ladder of Engagement. Self-sustaining patient and family engagement teams at care centers will be the engine that accomplishes those goals. In 2018, we take our next step. We need to test interventions designed to increase growth in all levels of engagement. These tests will prepare us for rapid expansion in 2019 and 2020. To conduct these tests, we need to convene a cohort of care centers that are willing to make engagement a key part of their work in 2018.

#### Benefits of Building a Community to Test Engagement

- <u>Test more quickly</u>- We are investing our time in executing test and refining tactics. It relieves the concern of finding the centers to be involved in the next tests.
- <u>Test in sequential order</u>- Depending on the specific centers' state of current engagement, we can start with an awareness test, then move to participation, contribution, and ownership. Each center will be developing the infrastructure needed to support the next step along the way.
- <u>Learn from a variety of centers</u> (ideally with a range of patient populations and clinic set-ups) how we can adapt engagement strategies to different settings
- <u>Create a learning community</u>- The centers will be going through a similar experience and will be able to share, learn, and improve from and with each other.
- Test the evaluation and reporting structures that we will need when we scale up.
- <u>Empower the centers</u> involved to become messengers to other centers when we are ready to roll out interventions to the whole community.
- Celebrate them as a group.

#### Benefits to Care Centers of Being a Member of the Engagement Community

- Part of a project that is on the forefront of healthcare engagement innovation.
- Active patient and family groups provide additional capacity for quality improvement and research.
- Professional development in project management and quality improvement for staff members.
- Potential for improved remission rates

#### **Characteristics of Engagement Community Members**

The following center specific characteristics are identified as being essential for successful testing:

- Centers have made a strategic decision that increasing engagement will lead to improved outcomes. Their reasoning
  may be that more engagement will improve self-management, unlock innovation, produce a source of organized,
  trained volunteers who increase center capacity, or something else. Whatever the reasons, this strategic decision is
  key.
- Centers are willing to incorporate engagement testing into their clinical workflow.
  - This means building a list of patients and family members who can be communicated with by patient/family member team leads; it is the most important step for making patients and family members "aware".
- Solid process and outcome results in their "bread and butter" QI work. This is indicative of a system ready to take on additional work and able to sustain their clinical improvements.
- Buy in from senior center leadership- Senior leadership at the center believes in the mission of engagement and that it is as important to improving quality of life as recording patient information in the registry. That they have made the strategic decision that increasing engagement will lead to improved outcomes and are willing to invest enough programmatic time to support parents and families communicating with each other.
- Willingness to learn and change- We are pushing the envelope and doing things that no one has done before in a clinical setting. We need a group that approaches each test and each action from the perspective of, "What can we learn?"

The following characteristics would be helpful, but are not required for successful testing:

- A history of being communicative- They have a history of regularly submitting their monthly reports and making their best effort to participate in network level calls and events.
- History of engagement- Not every center in this group needs to have active patients or parents, but it will help if they do.

#### **Engagement Champions**

Centers have at least one care center team member who can serve as an engagement champion and one patient or family member who can serve as the main point of contact for this program.

- Patient or Family Member- They will serve as the main point of contact between the national ICN engagement team and the care center. This means participating in monthly calls with other members of the cohort, trainings, coaching calls with ICN engagement staff, and spearheading the individual tests at the care center.
  - Time Commitment: 5-15 hours a month- This will fluctuate depending on the tests and ability to recruit
    other parents/patients to the team. This role could be filled by a small group of parents or patients (2 or 3) if
    there isn't one person who can make the time commitment.
  - Activities: Participate in monthly Innovation Community calls, trainings, coaching calls with ICN engagement staff. Work with the care center team member to implement tests into care center work flow. Spearhead design and implementation of engagement tests including recruiting other parents/patients to participate.
- Care Center Team Member- This person could be staff at a care center or an intern. It is someone who is able to
  coordinate tests with the patient or family member lead. Ideally, this person will have a working knowledge of the
  requirements for patients and families volunteer at their center, who can get approval for new actions to be
  implemented into care center workflow, and be able to work through challenges with the patient or family member
  lead.
  - o 4-6 hours a month- This will fluctuate depending on the tests. This role could be filled by a small group staff members or interns (2 or 3) if there isn't one person who can make the time commitment.
  - Activities: Support parent/patient lead(s) in incorporating interventions into the care center workflow,
     communicate progress of the tests to care center team members and leadership, and participate in regular

communication (primarily emails, conference call and check-in schedule would be decided by the group on our kickoff call)

#### **Timeline**

#### December 2017

- Plan finalized and sent to Executive Directors.
- Initial discussions with care centers.

#### January 2018

- Plan finalized.
- o Individual notifications to network leadership (patients, parents, and care center staff).
- Share info about the opportunity on Learning Lab Calls
- o Individual emails to parents, patients, and care center staff who have had 1:1s.
- Share info on PAC and PWG calls.
- o Info session calls with Parents/Patients and Care Center Staff. Two calls per group.
- o Patients and Parents reach out to care center leadership.
- o Emails from Executive Directors to the network as final reminders.
- o 1/26- application deadline #1, 1/31 "Extended" application deadline

#### February 2018

- Centers notified of their acceptance.
- Community Kickoff Call #1

#### March 2018

- Community Kickoff Call #2
- Draft of Community Charter Completed
- o Individual planning calls between care centers and Campaign Director.

#### April 2018

- Test Cycle #1 begins (One testing cycle include a PDSA, test, and debrief).
- Community charter finalized.
- Community planning session at Community Conference.

#### May 2018

- Remaining care center tests begin.
- Testing cycle number 2 begins for fast moving centers.

#### • June- August 2018

- Testing cycles continue.
- Virtual Community Conference "watch parties".
- o ICN Training webinars (bootcamp) begin.

#### • September 2018

- Autumn Community Conference planning session.
- Testing cycles continue.

#### October 2018

- Testing cycles continue.
- Planning for final report completed.
- o Goals set for 2019 Innovation Community membership.

### November 2018

Final report writing begins.

#### December 2018

- Final report completed.
- o Final meeting of the 2018 Innovation Community.

#### **Community Communication**

#### Weekly

• Engagement Office Hours- ICN Network engagement staff available to answer questions or work through challenges.

#### Monthly

- Monthly Summary- Sent from ICN engagement staff
  - o Relevant community updates from tests.
  - o Best practices, challenges, and solutions.
  - Measure report.

#### As Needed

- Calls to roll out and wrap up tests
- Summaries of tests and recommendations for the community at large
- Meeting time at the Spring 2018 and Fall 2018 Community Conferences
- Reports to ICN network staff on cohort progress.
- Progress reports at the community conferences(in person and virtual)

#### **Interest Survey**

#### Information Collected on the Survey

Nine questions that identify why they want to be involved, what value they see in engagement, their current engagement infrastructure, and their teams openness to being involved in the program.

#### General

- Why do you want to be involved in this innovation community?
- What potential does a parent or patient being involved in a learning network have to impact their quality of life?

#### **Current Infrastructure**

- Do you currently have parents or patients involved at your care center and what activities do they participate in?
- Share an example of an engagement related intervention that you tested and implemented?
- How do you currently inform parents and patients know about the resources available from ImproveCareNow?
- Do you currently have any parents or patients on your QI team or who regularly attend QI meetings and what role do they play?
- Have you identified a staff member who will serve as the main point of contact and a parent or patient who will be the lead for the program?

#### Care Center Team Openness to the Program

- Please rank on a scale of 1-5 how you prioritize innovation and change and why.
- Who on your team was involved in completing this application?

#### **Review and Acceptance**

Applications will be reviewed on a rolling basis.

#### **First Look Review**

- All applications reviewed by Campaign Director and Engagement Project Coordinator
- Applications are available for review for other members of ICN Leadership and members of the Engagement Workgroup Leads Call
- List of candidates narrowed
- Finalists will be reviewed on late January Engagement Workgroup Leads calls.
  - o The group will decide on which centers to move on to a call with the Campaign Director

#### Acceptance

- Centers that are accepted will be notified via email by the Campaign Director.
- That email will provide details on the first call for the community and next steps.

# IMPROVECARENOW Training (Bootcamps)

The goal of the engagement effort is to increase patient and parent well-being by providing them with to the information, materials, and support that allow them to take ownership of their care and find their place in this community of improvers. If the only benefit of engagement was increased well-being for themselves, then it would be worth the effort. It's not the only benefit. Having a team of motivated parent and patient volunteers offers many more opportunities. They can play a key role in supporting care centers to increase capacity for improvement by organizing education nights, helping to guide new parents and patients through the system, becoming advocates and fundraisers, and growing clinic's self-management support efforts.

Parents, patients, and center staff need support to be able to develop the teams that will be able to increase capacity at care centers and take ownership of their care. Below you will find how we will development the trainings and who will play a role in development, how topics and modules are structured, topics and module titles, and information about initial rollout.

#### **Development Teams**

Each training module will have a team that is responsible for creating the content. The first year (2018) these teams will be led by ICN Engagement Staff. In future years, these teams will be led by patients and parents. One of our 2018 goals is to prepare parents and patients to take over and led development teams in 2019.

#### **Development Teams**

- Team Leads- These are ICN staff, center staff, or parent/patient volunteers who are going to oversee the process of developing a whole module, start to finish. This is the most time intensive involvement in the development of the bootcamps. They will recruit the team to help develop the module, hold planning meetings with the campaign director, and are responsible for ensuring that the team meets deadlines.
- Content Developers- They develop agendas, materials, or powerpoints that will be used for the trainings.
- Reviewers- They review the materials as they are developed and provide feedback for adjustments. Ideally, these are people who are not the Team Lead or Content Developers for that module.
- Presenters- They specialize in presenting the module. In many cases these will be people who serve in other roles on the development team.

#### **Module Structure**

They are structured for maximum flexibility. Centers, patient, or parent groups could choose module a la carte or as a series. They could choose to do them as a series of webinars or as a half day to full day training.

- National webinar series- Weekly webinars of one module per week
- Center or group webinars- Parents/patients groups (at the center or national level) or center staff could request one module or a series of modules over webinar.
- In person half or full days- Coming to sites or having many sites come to a location to get all the modules in one topic on one day.

We will use the "20,60,20" training model as a guide for development- 20 percent of each module introduces new information, 60 percent is participants working with that information, and 20 percent is planning for how to incorporate those things into their program. The percentages are approximate and what's most important is that each module includes- New information, interacting with that information, and planning.

#### **2018 Module Development and Rollout**

Below is a chart of module topics and descriptions. We have divided the modules into two waves.

- Wave 1 will be ready for public presentation starting at the Spring 2018 Community Conference.
  - 2 modules will be presented at the Spring Community Conference and 2 will be completed by June 2018.
  - Wave 1 module will begin to be presented via webinar with the Spring 2018 Virtual Community Conference (June 2018). Bi weekly webinars will continue through 2018.
  - Care centers will have the opportunity to request to be trained to present modules to their team, have webinars presented by national staff, or plan a full day of training with ICN network staff in person(subject to travel availability).
- Wave 2 will be ready for public presentation starting at the Autumn 2018 Community Conference.
  - o All Wave 2 modules will be ready for presentation at the Autumn 2018 Community Conference.
  - o They will be incorporated into the Bi weekly webinars.
  - Care centers will have the same opportunity to request trainings as with Wave 1.

Module Topic	Description		
2018 WAVE 1			
Story of self, story of us, story of the	How to develop and use stories to talk about engagement at your		
moment- Talking about ICN	center.		
Building Your Team #1	Basics of the snowflake model and how to identify team roles.		
Best Practices for Volunteer Recruitment	How to identify patients and parents to be involved in your team.		
Relationship Building to Support Team	Why relationship building is important to team growth and how to		
Growth	incorporate it into your team.		
2018 Wave 2			
Parents, Patients, and Quality Improvement	How to use the basic tools of quality improvement to help your team		
	grow and work with Q.I with your care center.		
Building Your Team #2	Stages of team growth, how to identify where your team is, and next		
	steps.		
Best Practices for Working with Care Center	Best practices for how parents and patients can facilitate relationships		
Staff	with care center staff to promote team growth		
Tools for Communicating with Your Care	Sharing tools that can create regular communication with volunteer		
Center Team	teams with a low investment of time.		

#### 2019 Module Development and ImproveCareNow Training Corp

At the Autumn 2018 Community Conference we will convene a meeting of patients, parents, and care center staff with two purposes.

- Brainstorm ideas for the eight 2019 training module topics.
- Begin to develop the ICN Training Corp- This is a group of parents and patients who specialize in training, serve as module team leads, and presenters of material at their care centers and nationally.
- This meeting may be supplemented by national webinars to include parents and patients who cannot attend the community conference.

Following those meetings and by December 2018 we will finalize the modules with 2019, the production schedule (Wave 1 and Wave 2), and the module team leads for Wave 1.

## **Relationship Building**

Relationship building is fundamental to community organizing and we need to embed relationship building into our engagement program for it to be successful. When people have strong personal relationships it means that they are more able to be responsive to the needs of volunteers, feel more accountable to each other, and take ownership of their teams.

By the end of 2020 patient, parents, and care center staff need to hold regularly relationship building events and one on one meetings with other members of their team. In 2018 our goals are to incorporate those relationship building tactics into the relationship between our network level engagement staff and care centers teams, to create the infrastructure that will support our ability to train parents/patients, and to track outcomes.

#### Where We Want to Be by the End of 2020

- ICN Engagement Supporters hold regular (weekly or monthly) one on ones (1:1s) with care center team leads.
- ICN Engagement Staff holds regular (weekly or monthly) one on ones (1:1s) with PAC and PWG Leadership.
- ICN Engagement Staff holds periodic one on ones (1:1s) with key care center staff members.
- Care Center Engagement Team Leads or appropriate Team Coordinators are holding one on ones (1:1s) with potential team members and each other.
- All of these meetings are recorded in Nationbuilder.

#### What We Need to Accomplish by the End of 2018

- Campaign Director holds 1:1s
  - Total goal for 2018- 86 (average of 2 per week starting with the first full week of March)
- Relationship Building training completed, piloted, and included in the first phase of bootcamp rollout.
- We are able to tag 1:1s in Nationbuilder.
- 1:1s sample agendas created.
- Campaign Director holds regular 1:1s with patient/parent Engagement Champions who are part of the Engagement Innovation Community. This is a way of testing the 2020 goal of regular 1:1s with care center team leads.

#### **Potential Steps for 2019**

- Begin regular (weekly or monthly) 1:1s with PAC and PWG Leadership.
- Test: Care Center Engagement Team Leads or Coordinators hold 1:1s with potential new team members.

2018			
Campaign Director 1:1s			
Deliverable	Action		
A prioritized list of center	Reach out to QICs, Michelle, PAC, and PWG Leadership to ask for recommendations		
staff, patients, and parents.			
Hold 1:1s	Meet with people that have been scheduled		
1:1s tagged in Nationbuilder	Update profiles in Nationbuilder to indication that a 1:1 has been held with that		
	person. Weekly.		
Quarterly Readout of 1:1s	Write a summary of who was met with and insights.		
Tag Created for 1:1s	Request tag from Mary Havens, create tag, add to list of participant tags		
1:1s held from 8/1/17-	Apply tags to profiles		
2/28/18 are tagged			
Intro 1:1 Agenda	Create intro 1:1 agenda and upload to the Exchange		
Support/Coaching 1:1 Agenda	Create support/coaching 1:1 agenda and upload to the Exchange		
Escalation 1:1 Agenda	Create escalation 1:1 agenda and upload to the Exchange		

## Testing, Evaluating, and Implementing Tools

Creating self-sustaining care center teams will require using the development and implementation of new tools as an opportunity for parent/patient skill development. It provides an opportunity for volunteer growth and increased ownership which prepares volunteers to take on more responsibility in their team (as Coordinators or Organizers). Including SMART (Specific, Measurable, Achievable, Relevant, Time Limited) goals in the tool development and rollout process provide an opportunity to objectively gauge the success of new engagement tools.

By the end of 2020 our goal will be to incorporate those methods into care center engagement teams. In 2018 we start that process by incorporate those methods into our engagement work at the network level.

#### Where We Want to Be by the End of 2020

- Testing, evaluating, and implementing tools serve as an engine for volunteer growth- At each step of the process and at each level of the engagement organization, "What skills could be developed by the tasks associated with this tool?", "How can our team benefit from developing those skills?", and "Who can benefit from developing those skills?" are used as criteria when deciding who works on the project.
- Engagement focused SMART (Specific, Measurable, Achievable, Relevant, Time Limited) goals like Ladder of engagement growth are used to evaluate the effectiveness of tools.
- Implementation of new engagement tools is shared through the care center team structure.

#### What We Need to Accomplish by the End of 2018

- Develop interdepartmental communication norms for tools that originate at the network level so that the engagement team has awareness of 1. Any point in the tools production process patient or parent volunteers become involved 2. When it is likely a tool will need promoted network wide.
  - This is so the engagement team can 1. Tag patient and parent volunteers in Nationbuilder so that we can see their process through the Ladder of Engagement 2. Serve as a resource for recruiting patient and parent volunteers for projects (if needed) 3. Develop a promotion plan that raises awareness to the widest network of patients, parents, and care center staff as possible.
- Set and engagement focused SMART goals to evaluate effectiveness for tools that have the potential to increase patient/parent participation.
  - There are two possibilities for what this could mean 1. The engagement team is included in goal setting
    for the tool 2. The team of people working to develop the tool are trained on how to set engagement
    focused goals like Ladder of Engagement growth and share those goals with the engagement team.
- Build a list of parents/patients at centers who we can reach out to individually 1. When parent/patient volunteers are needed to develop and test tools 2. To promote tools when they are ready to be implemented.
  - Create tags in Nationbuilder that allow us to track the involvement of patients and parents in those projects.
- Use the Engagement Stakeholders group, Engagement Innovation Community, PAC/PWG, and individual
  communication with patients, parents, and clinicians to get feedback on ideas for new tools and to get ideas for
  new tools.

#### **Potential Steps for 2019**

- Develop communication norms with care centers and/or train them to tag patient/parent volunteers in Nationbuilder who participate in the development, testing or implementation process for tools that originate at the care center level.
- Care centers incorporate engagement focused SMART goals into their goal setting process for evaluation of tools that have the potential to increase participation by patients or parents in care center teams.

Deliverable	Action
Schedule a regular meeting between the	Schedule the meeting
engagement campaign and communications	
departments	
Develop of process for how the people can	Write steps for how that information is communicated and what
communicate 1. When patients or parents	happens once it is.
become involved 2. When it is likely that a	
tool will need to be promoted network wide.	
Develop a list of the places where	Reach out to the people on the first list and the operations team to
information about tool development is	find out where they track their progress.
currently stored and evaluate if any of them	
could work as a coordinate engagement tools	
database(tools in the idea phase,	
development phase, testing phase, and	
implementation phase)	
Choose a tracking method for new	Look at the info collected in the above step, see if any of them meet
engagement related tools	the needs of the engagement team, if not, develop a new method.
	Finalize the method.
Create a list of actions that need to be	Review the list of Nationbuilder tags, identify which ones can be
tracked for parents/patients in this process,	used for this process. Create and get approved new tags using the
create Nationbuilder tags.	Nationbuilder tag creation process.
Develop a one page guide to engagement	Write the steps for setting engagement related goals to include-
goal setting	What measures are used to track engagement and how to
Davidan have sails will be treated for each	determine what a goal should be for that project.
Develop how goals will be tracked for each	Include this as part of the database created to track projects that
project	are engagement related.
Implement engagement goal setting as part	When the other new processes are implemented include goal
of the tools development process  Develop a list of actions that patient, parents,	setting.  Make the list
or clinicians can take to promote tools at the	Make the list
local level.	
Identify parents, patients, or clinicians who	Ask questions in One on One meetings, PAC, PWG meetings, and
we can reach out to when we need to	based on past information who we can reach out to promote tools
promote tools	based on past information who we can reach out to promote tools
Begin to reach out to promote new tools	Emails and calls
Get feedback and ideas, then transfer that	In 1:1 meetings with parents, patients, and clinicians, on the
feedback to the tools tracking database	Engagement Stakeholders calls, and when possible, on PAC/PWG
Total day to the tools trucking addays	calls ask for feedback
	cano don to recapació

# Patient Advisory Council and Parent Working Group Integration

The PAC and PWG are integral parts of ICN engagement. Over the past few years they have developed organizations that allow for patients and their families to participate in creation of new tools, sharing of information, and making the ICN community stronger. They serve as a blueprint for developing the engagement campaign. Our goals for this section of the engagement plan are to lay out the guidelines for how the engagement campaign will work with the PAC and PWG in a way that: respects their cultures and autonomy; creates a clear path for two way communication; describes opportunities for them to offer feedback and support; addresses questions that need to be answered by the end of 2018.

#### **General Relationship**

- The Engagement Coordinator will remain the primary point of contact with the PAC and PWG with additional support from the Campaign Director and other ICN team members.
- The Engagement Campaign exists to support the development of care center engagement teams. This is also true of the PAC and PWG. The engagement campaign will be developed in a way that respects, supports, and includes members of the PAC and PWG. We won't develop programs that support the development of care center engagement teams at the expense of ICN support for the PAC or PWG.
- Data and Analytics- One of the goals of the data and analytics section of this plan is to create a report that allows us to view key ladder of engagement and organizing measures on the care center level. Care center level reports will be aggregated to the network level. For the purpose of those reports the PAC and PWG will be treated the same as a care center engagement team. They will be a line on the report that is aggregated to the network total.

#### Communication

- Engagement updates on their monthly calls- As their agendas allow we provide updates on our progress to ladder of engagement benchmarks, review of new tools or interventions that have been developed over the previous month, and what we have coming up over the next couple months.
  - These updates should include a list of ways that PAC and PWG members can get involved with ongoing or upcoming engagement projects and time for their questions or feedback.
  - This includes sending PAC and PWG leadership metric reports as they develop as part of our data and analytics program.
- Rollout of major engagement initiatives- PAC and PWG leadership will be informed of major engagement
  initiatives before they get rolled out to the general community. This could be a quick email the day before
  something is rolled out or a quick call. Doing this
  - o Provides an opportunity for them to ask final questions.
  - o Is a way for us to show respect for the place they hold in ICN.
  - Makes sure they have the information they need to answer questions if PAC or PWG members come to them.
- One on One Meetings- We have been holding one on one meetings with PAC and PWG members. These will
  continue. There are three types of one on one meetings we will hold with PAC and PWG members
  - Introductory- If we haven't met with that member one on one previously. We have an opportunity to learn why they are involved, what they like to do, how they are involved at their care center, share about the engagement program, and answer any questions they have.
  - Sustaining- These could be one on one or in a small group (under 3 people) and will mostly be with members of PAC or PWG leadership (Chairs, Co-Chairs, or Committee Chairs). A time to review progress on projects, discuss strategy, and work through challenges.
  - Coaching- Time for one on one coaching that develops skills to support ongoing projects or help support becoming more self-sustaining.

#### **Feedback and Support**

- Engagement Stakeholders Advisory Group- This group is being convened to receive updates, offer feedback, advice, and work through challenges as our engagement campaign grows. As long as the group exists the PAC and PWG will be offered representation.
- Feedback on Major Engagement Initiatives- PAC and PWG members will be offered the opportunity to review and offer feedback on major engagement initiatives. A good example of this is the development of the engagement bootcamps. PAC and PWG members are involved in each stage of development and review.
- Training
  - O By Request- PAC and PWG Leadership will have the opportunity to request training related to engagement. Those requests should go through the Engagement Coordinator or Engagement Campaign Director. If the requested trainings already exist, then they will be delivered to the PAC or PWG in a reasonable period of time after the request. If the training needs to be developed ICN engagement staff will work with PAC or PWG leadership to determine if the capacity exists to develop that training during the period in which it will be beneficial.
  - Engagement Bootcamps- The PAC and PWG can request one off or a series of Engagement Bootcamps.
     PAC and PWG members will be informed when the bootcamps are presented at the network level and have the opportunity to attend.
  - Recommended Trainings- The Engagement Coordinator and Campaign Director will regularly discuss and share recommendations for trainings to be presented to the PAC and PWG. After discussion with the Engagement Coordinator and Campaign Director the PAC and PWG members will have final decision making power on if they will accept those recommendations.
  - Future Training Development and Training Needs- In October or Early November 2018 the Engagement Coordinator and Campaign Manager will meet with PAC and PWG Leadership to discuss needed training development for 2019 and recommendations for trainings specifically designed to support PAC and PWG development.

#### **Potential Future Engagement Coordination**

In 2018 the focus of the engagement campaign is to test a number of interventions with a small group of centers to prepare for expansion in 2019 and 2020. During the third and fourth quarter of 2018, while the 2019 engagement plan is being developed, we need to answer at least these questions about the PAC and PWG role in care center team development

- How can the PAC and PWG support information sharing between care center teams as we scale up?
- Do we have the capacity to implement a care center buddy systems through the PAC and PWG where members who have more experience with engagement at the care center level can serve as coaches or advisors for members who want to expand their engagement program?
- Should each care center team have a representative to the PAC and PWG? If so, does this change the function of the PAC or PWG in any fundamental way?

### **Data Processes and Evaluation**

This document is not intended to have all the answers and that's because we don't have them yet. By the end of 2018 we want to have answers and have the systems built that will prepare us for expansion in 2019. Those goals for 2018 fall into three categories 1. Predictability- Being able to use data to determine which people and centers are ready to escalate their involvement in the engagement campaign and what actions are triggers for increased involvement 2. Evaluation- Using data to evaluate our program week to week and month to month and to help us answer the big question- Does engagement work to help improve the quality of life of patients and parents and why? 3. Nationbuilder-Developing Nationbuilder as a hub for parents and patients to use to organize and communicate with their teams at care centers. Outlined below is our timeline for development, what we want to accomplish in each of those categories, and why.

#### **Predictability**

We will produce two products in 2018 that we can use to determine which centers and community members are most ready to escalate their involvement in engagement.

- Community member- This model will allow us to target patients and parents for escalation through the ladder of
  engagement. There are a few different ways that models like this are used to support development of care
  center teams.
  - o Finding Volunteers to Participate in Care Center Activities- One of the challenges that is frequently discussed is how to get more people involved. Finding patients and parents to step up and take on new activities is how we are going to grow exponentially and it's how we are going to create self-sustaining care center teams. This model makes that process more efficient. It makes sure that when we reach out we are reaching out to the right people. It helps parent/patient volunteers by making it possible for them to only have to call 10 people to find a volunteer instead of 50 or having 10 people show up to an education day instead of 3 because the communication is going to the right people.
    - A practical example of the difference this can make- Karen is working with her care center staff to hold an IBD night. She is the only parent that is organizing at her center and wants to use this as an opportunity to get new folks involved. NOW- She works with her care center to post flyers and have office staff hand flyers to parents and they send a letter snail mail. 3 people show up. USING THIS MODEL- Karen logs onto Nationbuilder and pulls a list of everyone who is considered aware at her center, who are likely to volunteer. She scheduled an email to be sent to them and then calls the people who opened the email, but didn't sign up. 12 people commit. She makes confirmation calls to them the night before and 9 of the 12 show up. 4 of them agree to come to their next volunteer event.
    - Escalating Involvement Through the Ladder of Engagement- Parents, patients, care center staff, and network staff are able to see people who are considered good prospects for moving from aware to participant to contributor to owner and people at risk to drop down the ladder of engagement. That will allow us to target interventions with those folks to move them up more quickly or prevent them from falling back.
- Finding care Center that are more likely to be ready to increase engagement- 2019 needs to be a year of rapid expansion to new care centers. Having a model that ranks their readiness to take on more engagement work will allow us to target asks for tests and resources to support team growth at those centers.

#### **Data for Improvement**

We think of data evaluation in two ways- 1. How does it help us to see what's interventions are working, identify care centers that are producing at high level so we can replicate their work, and communicate our progress to the community? 2. How can data help us to prove that engagement improves the quality of life of patients and parents and demonstrate that to members of our community to motivate them to action? Our goal for data evaluation in 2018 is to

develop the tools that lets us answers those questions. Think of it like this the first way helps us to move our program forward, day to day and week to week. The second way helps us to answer the big question.

#### Answering the Big Question

We believe that engagement is as important to quality of life and to the development of our community as recording height and weight at each appointment or getting patients added to the registry. We don't have the data to support that claim yet. We don't have the direct line, like we do for other parts of ICNs work, which says investing in engagement will lead to an increased remission rates. Our goal for 2018 is to begin to have answers to those questions.

#### **Ongoing Program Evaluation**

Below are the characteristics of the regular program evaluation that we will develop

- Tracks progress towards ladder of engagement benchmarks and other key organizing measures- We are able to create a snapshot that allows anyone in the network to quickly review our progress to goals.
- Data Visualization- Identification and implementation of tools that allow us to tell the story of our engagement campaign through data that is represented in visuals like charts, graphs, heat maps, and infographics.
- Produced at regular intervals- We are able to produce and share the data at least monthly and ideally weekly.
- Care Center Level Detail- Care centers will be able to see a snapshot of their center and we will be able to use
  that data to identify centers that are producing more than expected and areas where we can provide more
  support. That data will aggregate with data from our national groups (PAC, PWG, sign ups that come at the
  network level) to produce network level data.
- Care Center Level Analysis- Using care center level data to produce quarterly or yearly care center reports that allow patient/parent team members and care center staff to see strengths and room for growth.
- \*\*\*Bonus\*\*\*Data can be accessed through a dashboard- The process of compiling and sending out reports is
  an investment of staff time. Eventually, we would like to be in a place to produce a self-populating dashboard
  that can be accessed at any time to see the most up to date stats.

#### Nationbuilder

The end vision for Nationbuilder is for care center and network level teams to be able to use Nationbuilder as a hub for their organizing and communicating with their teams. They will be able to log in, easily see what parents and patients are assigned to their team, their level on the ladder of engagement, create lists of parents and patients to email or call, track the progress of those emails (who opened emails, who clicks on links), post local events online, see parents and patients past activity, and see new parents and patients who have recently signed up. This is important because the most common challenge mentioned by parents in one on ones is the ability to freely communicate with other patients and parents at the local level. We believe we have the functionality to do all those things in Nationbuilder. Our goal in 2018 is to confirm that and test those systems. Below you will find the tasks, activities, or questions we need to finalize, test, and answer in 2018 to be ready for rapid expansion in 2019 and 2020.

- Tagging A system for developing and reliably applying tags that describe engagement behaviors we are interested in (the engagement ontology).
- Process for Volunteer to enter center level data- Is it through Nationbuilder or an alternative form?
- What permissions are required to allow/limit access to Nationbuilder to the care center level?
- Training for parents and patients to be able to pull lists, sending emails, and track their team's activity through Nationbuilder.
- How will we incorporate Nationbuilder data into our evaluation process?
- What capacity do we have to fulfill support requests? Is that enough to support all the care centers using Nationbuilder? If not, what are alternatives?