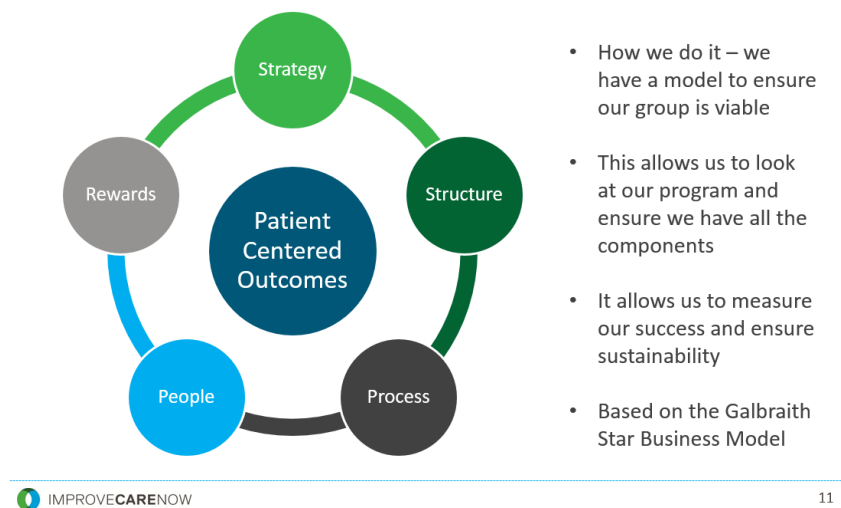# Patient Advisory Council Leadership Manual

Created by Michelle Spotts and the ImproveCareNow Patient Advisory Council

The purpose of this document is to lay out the leadership procedures of the PAC. This document is meant to aid the on-boarding process of new PAC leaders.

PAC Model

- How we do it – we have a model to ensure our group is viable
- This allows us to look at our program and ensure we have all the components
- It allows us to measure our success and ensure sustainability
- Based on the Galbraith Star Business Model

The PAC is built on 5 tenants, strategy, structure, processes, people, and rewards. These 5 tenants come from that of Galbraith's Star Model. If this model is a foreign concept and you are considering a leadership position, I would suggest familiarizing yourself with this model. In the manual, important pieces of each tenant will be highlighted to prepare new leaders fully to continue the work of previous leaders. The manual is also organized based on leadership position. A table of contents can be found on the next page.

Table of Contents

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PAC History for Leaders

- Name
  - We started on Facebook with 1 chair, (Name) in the fall of 2011.
  - Communication: Projects were announced via the Facebook group we had.
- (Names)
  - Our next chairs were (Names) who took over for (Name) in the Spring of 2013
  - Under (Names), the leadership under chairs were 2 patient scholars sort of like vice chairs.
  - The main communication strategy during this time was chat boards on the ICN exchange (didn't work all that well because of the limitations in the first exchange platform)
  - Started an organization strategy they coined "task forces" these task forces were basically 3 work groups, advocacy, communication, and recruitment
  - Community Conference attendance: co-chairs and scholars were the only ones funded for conference → 4 patients
- (Names) took over in the fall of 2015.
  - Expanded leadership from patient scholars to 2 task force co-chairs for the 3 task forces
  - Primary communication: expanded to calls monthly and a group messaging platform called Slack

Applying for the Co-Chair Position

Application Process

When a co-chair steps down the process will be as follows

- The co-chair turns in their 2 month notice. This means the co-chair is stepping down and chooses an end date that is two months out from the initial announcement.
- 1st Month - The process of choosing a replacement chair will take the first month
    - An application for the open position will go out.
    - The application will include essays about why the individual wants to be chair.
    - If needed the application process may include calls with the applicants to choose a new chair.
- 2nd Month
    - The newly chosen co-chair will be mentored by the old chair during the 2nd month
    - On-boarding will be composed of several calls
        - An on-boarding call to discuss the leadership manual
        - A call to catch the new chair up on any behind the scenes current issues that the chair may not have been aware of.

Responsibilities

- Co-chairs must be available for monthly 30 minute co-chair calls, 30 minute task force chair calls, and hourly monthly calls.
- One co-chair must be able to attend monthly hour long strategy council calls
- Co-chairs must be visible in group messages
- They must be available via email or text at any time of the day (except while sleeping, duh)

Skills to Have

- People skills
- Conflict resolution practice
- Professionalism
- Creativity and outside the box thinking

Co-Chair Term and Requirements
- Co-chairs typically serve a 3 to 4 year term.
- Looking for PAC members who are entering their first or 2nd year of university who have the maturity and ability to take on such a job
- Co-chairs must be in the PAC for 2 years prior to applying to be a co-chair and it is highly recommended they have experience as a chair of a task force or the innovation committee.
    - A call to get the new co-chair acclimated with their other co-chair

Things to know: New Co-Chairs

Strategy
Common Vision (important that this aligns with that of ICN)
- Be the voice for the 29,000 patients in the network
- Build tools and resources for centers and patients
- Share experiences
- Raise awareness of IBD and of ICN

Measuring that Success
- Strategic success is measured quarterly via survey monkey
- Those surveys are delivered in the first week of the months of January, April, July, and October.

Structure
PAC structure is the most fluid part of the PAC and one that must be focused heavily on in an effort to support the growth of the PAC.
- The PAC is currently structured into 3 task forces with task force co-chairs in charge of these task forces
- 2 co-chairs serve over those task forces and oversee all the behind the scenes decisions that are made
- The PAC also has an innovation committee that serves as an oversight committee for PAC projects in an effort to screen, better organize, and approve PAC ideas on their way to becoming completed PAC projects.
- Task Forces allow each member to maximize their strengths and work toward a common PAC goal

Key: As the PAC grows, leadership positions will have to increase in the same linear fashion as PAC membership growth in order to sustain involvement of incoming members.

Processes

The PAC has standardized an operating system as well as core processes like our on-boarding process and design process. Images of those two process can be seen below. PDF versions of these processes can be requested from the ICN PAC Liaison, Michelle Spotts.

Operating System Processes
- Standardized monthly calls
  - General PAC call once a month (reevaluate call time annually)
  - PAC leadership call once a month hour before general call (reevaluate time annually)
- Each meeting is recorded and meeting minutes are kept by a PAC scribe or if they are not on the call another individual serves as a backup.

On-boarding process in a nutshell
- Patient signs up on the website and they get a series of next steps delivered to them before they are considered a part of the PAC
- If this "prospect" completes all the steps then they are entered into the PAC.

Design Process
- An oversight committee, the "Innovation Committee" oversees and approves all PAC projects before they are produced.
- During the design process the Innovation Committee also makes sure the project leaders and project pass through all necessary project checkpoints

People

PAC is built on valuing the contributions of its members. One main point we always make in PAC is that we value all IBD patients experiences no matter the level of complexity. It is not our place to say whether or not a patient's experience is not good enough. We have created a vibrant community filled with inspiring young people. But coming into this community there's a lot to learn.

- We value supporting our members and that's why we assign buddies to each of our new members.
- See the on-boarding process for more information about this process we call the buddy toolkit.

Rewards

We value our members so highlighting them and their accomplishments and rewarding them for what they are doing is just common sense.

We reward our members for a job well done in a couple of ways:

- Twice a year, we have funding for a few patients to attend conference. These patients are the ones who are working the hardest and may also be serving in a leadership position. Conference is a rewarding experience and we use it to reward members for doing a good job.
- Each month we highlight our highly active members on a PAC call so that we can learn more about our virtual community. This is a great example of one from two patients Kelsey and Missy who did their highlight together because through PAC they've become fast friends

Member Highlight

Important Dates to Know

- First week of August - Planning for the PAC year
  - Co-chair call (hour and a half long) map out each month and note important dates for the year
  - Task force leads suggestion call (hour long)
    - Co-chairs gather task force lead feedback and suggestions then take it and incorporate it into their previously drafted year plan
  - Task force leads planning call (30 minutes, if needed)
    - Co-chairs report on what the year will look like after taking the leads feedback and incorporating it into a final yearly plan

- Beginning of September - Fall Conference
    - Bi-annual conference held in Chicago
- October - PAC retreat
    - Annual retreat for all PAC members held in the fall
- Mid to end of April - Spring Conference
    - Bi-annual conference held in Dallas

Applying for the Task Force Co-Chair Position

Application Process
If a position opens, an interested applicant must fill out the task force application survey.
- This survey asks why the applicant is interested in the position as well as what conflicts the person may have while serving their term.

Term
- The term for a task force co-chair is a minimum of 1 year.
- Task force co-chair positions are reevaluated every year in August.

Responsibilities
- Co-chairs must be available for monthly 30 minute task force chair calls, and hourly monthly calls.
- They must send weekly or at least biweekly updates to their task force members
- Co-chairs must be visible in group messages
- They must be available via email or text at any time of the day (except while sleeping duh)

Things to know: New Recruitment Chair

Skills to Have

-

Responsibilities

Within Task Force

-

Overall PAC

-

Collaboration

-

Conference

Things to know: New Advocacy Chair

Skills to Have

- Strong leadership skills are beneficial
- Strong public speaking skills are beneficial
- Strong role model for what it means to be an IBD advocate

Responsibilities

Within Task Force

- Follow up with members who may be inactive
- Set timelines for projects
- Delegate work within task force

Overall PAC

- Attend all task force lead calls
- Attend monthly PAC calls
  - Feel confident to present updates
  - Be organized before calls

Collaboration

- Be willing to get feedback on all ideas
- Collaborate with entire PAC to get full collaboration on projects
- Communicate and collaborate with co-chairs and innovation committee regarding project status
- Communicate comfortably with ICN staff members
- Maintain relationships with ICN centers to get support for advocacy effort

Conference

- Be willing to present breakout sessions at PAC conference or plan them
- Be able to develop proposals for possible breakout sessions

- Innovation is incredibly important to develop advocacy tools for pediatric IBD patients

Advocacy Model

Strategy

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Structure

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Processes

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People

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Rewards

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Things to know: New Communication Chair

Skills to Have

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Responsibilities

Within Task Force

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Overall PAC

-

Collaboration

-

Conference