

PATIENT ADVISORY COUNCIL

Patient-centered care is increasingly important in the healthcare space, and because of this (*and more*) ImproveCareNow and the C3N Project teamed up to create a Patient Advisory Council (PAC). The PAC is a group of young, passionate and motivated patients with pediatric inflammatory bowel disease (IBD). Together, they provide expertise and thoughtful feedback, while participating in a variety of ways. PAC members draw on their own personal stories from having grown up with a chronic illness, to enlighten and educate the clinicians, researchers and other collaborators on how best to design and test innovations that will best serve the patient population. The ultimate goal: to help their generation, and the next.

Patient Scholars

To cultivate leadership and drive growth with the PAC, two members are selected by the PAC Chair and PAC project staff to serve for one academic year as Patient Scholars. In this position, Patient Scholars support the ultimate goal of the PAC and help the PAC Chair drive action and engagement throughout the group. Patient Scholars are also extended an invitation to join the ImproveCareNow Learning Session, which happens twice a year. In the Fall, Patient Scholars comes to learn more about what ImproveCareNow and the C3N Project are working towards; while in the Spring, the Scholars present their efforts from the past year and actively participate as leaders throughout the event.

Patient-to-Innovation Matching

For the 2012-13 term, the Patient Scholars work together with the PAC Chair to implement a plan that better connects patients with innovations. In this plan, patients were quizzed on their likes and skills, from which innovations were offered that best suited their responses. These matches allow for patients to add their voice as team members, volunteering their time alongside clinicians, researchers and other patients. Now, more than ever, patients are co-designers investing time and expertise to 7 innovations.

CONTACT

Project Staff

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PAC Co-Chairs

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Timeline

Fall 2012 - March 2013

- Design & promote patient matching
- Determine matches, and make announcements regarding placement
- Kickoff patient innovation matching

April 2013-Forward

- Evaluate & develop next steps for patient matching
- Present at Spring ImproveCareNow Learning Session
- Implement evaluation/monitoring methods; ramp up communication about progress
- Plan, recruit & select next Patient Scholars

Requirements to Participate

- Currently be a pediatric patient with IBD, or be recently transitioned to adult care
- Be between the ages of 13-25
- Have access to internet, in order to stay in touch with PAC via Secret Facebook Group or email communication
- Have interest in volunteering time to work with other patients, along with researchers and clinicians, on new innovations
- PAC accommodates a variety of levels of engagement; commitment is voluntary