Embracing Co-Design: Engaging Patients and Families Related to the Cures Act

What was the opportunity, issue or challenge you were trying to address and in what setting?
The 21st Century Cures Act Final Rule (Cures Act) ensures greater patient access by offering enhanced transparency and utilization of digital tools and platforms. Updated regulations were recently launched in April 2021. This national policy requires healthcare providers “to give patients access to all of the health information in their electronic medical records ‘without delay’ and without charge.” Intended to empower and inform individuals, the Cures Act impacts patients across all care settings and diagnoses.

Northwell has been on a cultural transformation over the past seven years. One of the steadfast pillars has been seeking, listening to and incorporating the ‘voice’ of patients and family caregivers. Given the expansive and impactful reach and scope of the Cures Act, Northwell’s interdisciplinary steering committee executing against the regulatory mandate sought to engage patients in key decision areas.

What process did you use to develop a solution?
Northwell remains committed to growing and sustaining a robust Patient & Family Partnership Council (PFPC) model. Supporting our journey to patient and family centeredness, these forums elicit the perceptions, ideas and sentiments of those served. Sitting side-by-side with healthcare leaders, providers and team members, participating patients and family caregivers provide meaningful insights.

As of September 2022, Northwell has 16 hospital-based PFPCs and 4 service-line based PFPCs which focus on local issues, programs, and deliverables. The Northwell Office of Patient & Customer Experience (OPCE) team also leads a Northwell Health System PFPC which weighs-in on more organizational-based strategy, priorities and focus areas. Since the Cures Act has far-reaching impacts, the interdisciplinary team spearheading this work collaborated with the OPCE to host a dedicated virtual Patient Focus Group.

What outcomes were you looking to achieve?
The purpose of Cures Act Patient Focus Group was to obtain direct feedback from Northwell Health patients related to:

- Navigating Northwell’s current patient portal platform (called FollowMyHealth)
- Reviewing content of a draft Patient Portal Guide
- Considerations for diverse patient populations

What specific steps did you take to address the problem?
Implementing the Cures Act Patient Focus Group required synergistic teamwork, preparation, and cross-team organization. The Chief Experience Officer, Sven Gierlinger, recommended gathering patient feedback early-on in the process as a patient experience best practice. An interdisciplinary steering committee team of professionals representing Health Information Management (HIM), Revenue Cycle and Enterprise Change Management then reached out and worked with the OPCE regarding format and participants.

After discussing purpose and benefits, a virtual Patient Focus Group was unanimously decided as the optimal approach. This type of forum was selected over electronic surveys and one-on-one interviews because it offered an opportunity for content deep dives, peer-to-peer group discussion and rich conversation. OPCE invited members of the system PFPC to voluntarily participate via email. Eight patients participated for a one-hour Focus Group via Zoom in mid-July 2022. One week prior to the Focus Group, the OPCE team sent a reminder

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email with the drafted Patient Portal Guide document as recommended pre-reading.

The facilitators (leaders from HIM and Enterprise Change Management) organized the Focus Group into three major segments and used various facilitation techniques and approaches:

1. Navigation of the current patient portal – This entailed assessing for user experience, accessibility, and ease of navigation for commonly-sought-after features or tasks.

2. Content of a draft Patient Portal Guide – This included reviewing a comprehensive FAQ-type document to ensure it was informative and to assess for flow, clarity, readability, and health literacy. Participants were provided the draft document one week prior to the session as recommended pre-work so Focus Group time could be optimally spent discussing suggestions and/or initial reactions.

3. Open Discussion – This dialogue was regarding special considerations, for example pediatrics, health care proxies, and limited English proficient patients. Northwell Health serves the most culturally diverse communities, so this segment was fruitful in conversation.

What resources, if any, did you engage - internally or externally - to address the problem?

The subject matter experts representing HIM and Enterprise Change Management team facilitated the virtual session. Their roles varied from group facilitator, timekeeper, and scribe. They created and utilized a script to introduce the group, outline the meeting ground rules and provide a brief overview. Leveraging Zoom, participants were also oriented in technology considerations such as cameras, microphones, chat features, and reactions. The facilitators used the app “PollEverywhere” for an ice breaker activity.

What measures did you establish to determine success of this effort?

Reflecting on past Patient Focus Groups, the Northwell team recognized that any and all patient feedback is considered a success. Any time we can engage patients in the spirit of co-design, it is a win for our communities. The team was particularly interested in:

- patient participation (attending the session and engagement throughout)
- quality and depth of the feedback

Agenda items were strategically crafted using open-ended questions, group discussion prompts and utilization of the chat feature to ensure all participants felt safe, included and valued members.

What was the ultimate outcome of your effort?

The Cures Act Patient Focus Group was a successfully held in July 2022. All eight participants who initially RSVP’d joined and actively participated. As a result of their feedback and experiences, multiple edits were made to the Patient Portal Guide, including but not limited to:

- Increasing the visibility and focus on patient portal benefits.
- Reorganizing and prioritizing FAQ topics to best meet the initial needs of patients
- seeking this type of information and/or resources.
- Including more content and FAQs to better assist understanding and utilization of
  - the guide and patient portal.
- Updates to language (words/sentiments) throughout the portal and support documents.
- This helped achieve a warmer tone of partnership, cooperation, and patient-centeredness.

What lessons did you learn to share with others as they consider addressing a similar issue?

Northwell Health has been on a human-centered transformation journey for the past seven years. Actively engaging patients into co-design is a choice that requires visionary leadership, an organizational culture that values patient feedback and consistent engagement with communities. Having undergone this important work, we are proud to share the following lessons learned:

- Don’t recreate the wheel! Tap into your existing Patient & Family Partnership Council structure when deep diving into a focused topic or initiative.
- Consistently lead with a spirit of gratitude and appreciation, as many patients are eager and interested in providing their feedback. This is important to do in all written communications, initially upon starting the Focus Group and upon closing the session.
- Strategically choose the time for the Virtual Focus Groups. This can be extremely effective because it allows participants to join from across a wide footprint. We chose noon-time because many participants could join during their work lunch-break.
- To avoid virtual ‘quiet room’ scenarios, do live polls for message testing or have backup plans to pulse reactions to certain topics that do not require people speaking audibly to increase engagement.
- Be prepared. Come to the Focus Group organized around:
  - Roles (co-facilitators, scribe, timekeeper, etc.)
  - Agenda (start with the most important topics)
  - Opportunity for open discussion and facilitation
  - Script (decide who will be saying what)
  - Gameplan on how to engage real-time conversation and chat participation
  - Logistics of technology troubleshooting, if needed
About Northwell Health

Northwell Health is a dynamic organization of 23 hospitals, and more than 800 physician practice locations spanning geographically across New York City boroughs, Long Island and within Westchester County. With 80,000+ employees, Northwell is the largest healthcare system and private employer in New York State, caring for more than 4 million individuals each year. Named a Fortune 100 Great Place to Work, Northwell’s mission is grounded in improving the health and quality of the life for the people and communities served by providing world-class service and patient-centered care. The system Office of Patient & Customer Experience (OPCE), led by the Chief Experience Officer, strategically focuses on culture, care delivery, hospitality, and accountability in an effort to continually raise health.

Northwell Health Author Bios

Nicole Giannmarinaro, RN, MSN, CPXP is the Director of Patient & Customer Experience Education for Northwell Health. In her role, she focuses on creating patient and family centered programs and education aimed to elevate the human experience in healthcare.

Shawn Ingram, RHIA is the Director of Health Information Management (HIM) at Northwell Health. He is responsible for developing HIM resources to centralize medical records processes for the ambulatory physician offices.

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Mallory K. Tuomey, MS, is a senior manager within Northwell Health’s Office of Patient and Customer Experience. She brings her background knowledge and experience in Human Resources, Diversity and Inclusion, and Communications to spearhead large system events, programs, and various initiatives that support the overall experience strategy and effectively optimize human centered care.

About The Beryl Institute

The Beryl Institute is a global community of healthcare professionals and experience champions committed to transforming the human experience in healthcare. As a pioneer and leader of the experience movement and patient experience profession for more than a decade, the Institute offers unparalleled access to unbiased research and proven practices, networking and professional development opportunities and a safe, neutral space to exchange ideas and learn from others.

We define the patient experience as the sum of all interactions, shaped by an organization’s culture, that influence patient perceptions across the continuum of care. We believe human experience is grounded in the experiences of patients & families, members of the healthcare workforce and the communities they serve.

Resources