
*Partnering with Patients as
Equals in Co-Designing
Primary Care:
Examples and Tools from the
LINCC Project*



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PARTNERING WITH PATIENTS AS EQUALS IN CO-DESIGNING PRIMARY CARE: EXAMPLES AND TOOLS FROM THE LINCC PROJECT

Summary

In 2014 and 2015, a team from the Kaiser Permanente Washington Health Research Institute (KPWHRI)¹ received funding from the Patient Centered Outcomes Research Institute (PCORI) to design and implement a new primary care clinic role—a lay staff person to connect patients with community resources. As part of the Learning to Integrate Neighborhoods and Clinical Care (LINCC) project, patients and staff from two of Kaiser Permanente Washington’s 25 clinics came together for a four-day design event and subsequent one-day “check and adjust” event a year later. We used the Lean model for process improvement to guide our design work. Twelve patients were recruited to participate along with 11 primary care team members.

The involvement of patients as equals of providers and staff led to a more patient-centered approach to creating the new “Community Resource Specialist” position at two pilot clinics—which since has been rolled out at all Kaiser Permanente Washington clinics. We created this guide in the hope that others in health care who wish to engage patients more deeply in care design and/or quality improvement can benefit from our experience. The guide includes a description of our process and examples and templates that can be adapted.

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For more information, please contact Clarissa Hsu, PhD, LINCC project principal investigator, clarissa.w.hsu@kp.org.

¹ In 2017, Kaiser Permanente, an integrated delivery system operating in seven other regions in the U.S., acquired Group Health, which became Kaiser Permanente Washington, and Group Health Research Institute (our organization when the PCORI project was implemented) became Kaiser Permanente Washington Health Research Institute.

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KPWHRI team: Clarissa Hsu, PhD; Erin Hertel, MA; Eric Johnson, MS; Carol Cahill, MLS; Paula Lozano, MD, MPH; Tyler R. Ross, MA; Kelly Ehrlich, MS; Katie Coleman, MSPH; June BlueSpruce, MPH; Allen Cheadle, PhD; Juno Matthys; Michelle Chapdelaine, MPH; Marlaine Gray, PhD; Janice Tufte, Michele Robbins, Ann Huston

Kaiser Permanente delivery system team:

Sponsor: Barbara Trehearne RN, PhD

Pace setters: Dan Delgado, MD; Pat Philbin, RN; Patty Wigington, RN

Staff Team members: Cindee DeWitt; Elaina Kook; Rebecca Parrish; Ling Lee, MD; Tanya Posa, MD; Amina Moalim, LPN; Dani Jorgenson, RN; Deanna Mroczkowski, MA; Sherry Hoffman, Kim Wicklund, MPH

Patient Co-designers: Naomi, Finkelstein, Laurel Stitzhal, Christa Rodriguez, Michael Neguse, Juan Jose Bocanegra, Bob Ridder, Brian Gaeta, Maria Brown, Laura Malarcher, Rhonda Watkins, Pat O’Hagan, Lillie Foster

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1. Introduction

Background

To make health care truly patient centered, health care organizations need to directly engage patients in care design and process improvement. Patient involvement, to date, has primarily focused on:

- Engaging patients in their own care through processes like shared decision making
- Gathering input from patients through surveys and focus groups
- 1-2 patients participating on committees or in larger design processes

Patients are seldom represented in quality improvement or care design efforts at the same level as providers and staff. According to the Center for Patient Partnerships, partnership and shared leadership is the highest possible level of patient engagement in quality improvement initiatives, where patients are involved in every aspect of decision making—from the early stages of defining problems to developing and selecting the most promising solutions.²

In 2014, a team from the Kaiser Permanente Washington Health Research Institute³ received funding from the Patient Centered Outcomes Research Institute (PCORI) to design and implement a new primary care clinic role—a lay staff person to connect patients with community resources. **The Learning to Integrate Neighborhoods and Clinical Care (LINCC) project was unique because it involved patients as equal partners with front line clinic staff in designing a new primary care service.**

Patients and staff from two of Kaiser Permanente Washington’s (KPWA) 25 clinics came together for a week-long design event and a subsequent “check and adjust” event a year later. These events were developed using the Lean model for process improvement. Twelve patients participated along with 11 primary care team members (primary care providers, nurses, an MA, front desk staff, and behavioral health providers) on the design team.

While our health system had engaged patients as advisors in other design processes, this was the first design event with patients involved in equal numbers as clinical team members. At the end of the week, the design team created a Community Resource Specialist (CRS) role to be piloted at two clinics. The evaluation of the event included observation of each day’s proceedings, daily participant surveys, and follow-up patient and staff interviews (see section 7, Evaluation). We found that overall an egalitarian atmosphere promoted collaboration and most participants agreed that active patient participation ensured a more patient-centered design.

² HIPxChange, *Patient Engagement in Redesigning Care Toolkit*, <http://www.hipxchange.org/PatientEngagement>

³ In 2017, Kaiser Permanente, an integrated delivery system operating in seven other regions in the U.S., acquired Group Health Cooperative, which became Kaiser Permanente Washington, and Group Health Research Institute (our organization when the PCORI project was implemented) became Kaiser Permanente Washington Health Research Institute.

What's included in this guide?

We hope that anyone in health care who wishes to engage patients more deeply in designing processes and/or quality improvement can benefit from our experience. This guide includes: 1) a description of the steps we took to plan for, implement, and follow up on our design event, and 2) examples and templates that can be used and adapted should you wish to do something similar. Resources are organized as follows:

- Planning a design event
- Preparing patient advisors
- Design event
- Follow up/"check and adjust" event
- Evaluation
- Additional resources

Several sections list additional resources—these are compiled in the companion Template Package

While our workshop was a Lean design event, the principles and activities could be applied to any design or process improvement effort. You are free to use examples and templates without prior permission; however, we do ask that you acknowledge the source.

Suggested citation:

Kaiser Permanente Washington Health Research Institute (2017). Partnering with Patients as Equals in Co-Designing Primary Care: Examples and Tools from the LINCC Project.

2. Design event planning

Putting together the planning team

A first step is identifying the members of the planning team and clarifying roles and responsibilities. Lean improvement workshops at Kaiser Permanente Washington typically involve an organizational sponsor who holds leaders and those implementing changes accountable, a process owner (or pacesetter) who sets improvement targets, team members who design the improvement, and Lean consultants.

Our improvement workshop planning team included a physician champion, a clinic operations manager, and two Lean quality improvement consultants. Their responsibilities are outlined in the design event team charter and Lean roles summary. Because LINCC was a research project the team also included the LINCC project principal investigator and project managers. Many of these individuals also participated in the design event (see section 5).

Setting the design event goal

The planning team should decide on quality improvement goals at the very start. We used a team charter to document these goals along with design scope and deliverables and how success implementing the improvement would be measured. The charter also includes a clear statement about the boundaries including what is “in bounds” and what is “out of bounds.” For example, since both the project goals and other simultaneous health system initiatives focused on patients with the highest care needs was put in the “out of bounds” list. While not actively used during the event, we did include the charter in participants’ packets.

The goal for our event was to improve patient-centeredness of care, patient satisfaction, appropriate health care utilization, and health outcomes by creating a new clinic role to connect patients with community and health care resources. In the team charter we described the connection of this activity with overall delivery system goals and outlined deliverables and performance measures, including those related to provider referrals and patient and staff satisfaction.

Resources:

- 1. LINCC Team Charter*
- 2. Lean Design Event Roles & Expectations*

3. Recruiting patient advisors

For this project we wanted to recruit people who could represent the experiences of “typical” patients expected to be seen by a community resource specialist in the pilot clinics—racially/ethnically diverse, facing social and economic challenges, and likely to have at least one chronic health condition. To achieve this goal we designed what we believe is a unique approach to recruiting patient advisors.

Selection criteria and identifying interested participants

Rather than the more common approach of soliciting suggestions from staff or a public affairs office we recruited patient advisors using the same processes we would use for research study participants. We defined a broad set of criteria and target recruitment goals; patients had to be 21 years or older and have had continuous Group Health coverage for at least a year. In addition, they needed to have made two in-person primary care clinic visits in the past year and be currently receiving care at one of the two pilot clinics. KPWHRI programmers identified potential participants from the pilot clinic patient population through administrative data.

Contacting potential patient advisors

The LINCC research team created recruitment materials with input from Group Health’s Lean consultants to ensure patient-friendly language and transparency. For example, we used the term “design workshop” instead of industry term “rapid process improvement workshop” and “check-back” instead of “plan-do-check-adjust (PDCA)” for the follow-up event.

We mailed 349 letters to the sample that was identified; patients who received the letters were invited to email or call a toll-free number if they were interested in participating. We also included a fact sheet with background information on the project. We wanted each pilot clinic represented in equal numbers, and made every attempt to ensure diversity in age, gender, and race/ethnicity, as well as having patients with chronic conditions, and patients with Medicaid coverage. To achieve this balance, after the initial response we did a second mailing of 149 letters targeting men and patients with Medicaid coverage.

Screening

One team member phoned the 23 patients who expressed interest in participating in the design event to conduct a screening interview. We created a screening interview script, and recorded notes from the calls in a Microsoft Excel tracking file. The screening process was primarily to ensure that all those invited could effectively participate in the design workshop. The screener asked questions to determine eligibility to participate, and noted which were clearly eligible and which required a follow-up conversation. A different team member made the follow-up calls and the final pool of participants was given to each clinic manager for review. We were looking for participants who were motivated by a desire to make a difference in quality of care rather than those who were mainly interested in the stipend.

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In the end, 12 patients from the two pilot clinics were identified and enrolled as patient advisors for the four-day design event. We kept a list of potential alternates in case any of them was unable to attend after accepting (and in fact, one participant did withdraw). Staff time needed to identify and recruit participants was estimated to be 44 hours total.

Incentive/compensation

We offered each patient advisor a stipend of \$2,000 for participation, approximately \$20 per hour. This stipend was allocated based participation in key events:

- \$200 upon completion of the training session
- \$1,200 upon completion of the four-day design workshop
- \$400 upon completion of the follow up activities (over the year after implementation)
- \$200 as a final payment when all activities were complete.

Confirmation packet and letter of understanding

Once the patient had agreed to participate a confirmation packet was mailed that included:

- Cover letter
- Letter of understanding
- Confidentiality agreement
- IRS W-9 form and instructions to receive the stipend

We created our own letter of understanding for patients to sign, based on examples from other organizations and Group Health standards for working with patients and non-Group Health employees. The letter included expectations for participating (including maintaining confidentiality), honorarium payment schedule, permission to use photographs and recordings, and costs the patient advisor would need to cover (e.g., child care). We also made it clear that participation was voluntary and the patient advisors could withdraw any time (with payment prorated). Patient advisors were asked to sign and mail back the letter in the business reply envelope we provided; we then sent them a copy of the signed letter for their own records.

Resources:

- 1. Patient Recruitment Letter*
- 2. Design Event Patient Advisor Phone Script and Screening Tool*
- 3. Patient Recruitment Tracker*
- 4. Letter of Understanding for Participation in Design Event*

4. Preparing patient advisors for design event

Orientation

While patient advisors did not need to be health care experts, they did need enough content knowledge and context to understand the conversations that would occur at the design event. To get them on a more level playing field with clinic staff, they each attended a four-hour late afternoon/early evening orientation session. We held two orientation sessions, one at each pilot clinic (i.e., the clinics where patients received their care). We made a special effort to assure the comfort of our patient advisors with logistics for both the orientation and the design event itself, including frequent contact and ample written information about the venues and schedules. Orientations were facilitated by six members of the research team, including two patients who actively participated as co-investigators.

The orientation included staff presentations on the LINCC project and primary health care delivery, a clinic tour, and an opportunity to share personal experiences of using community resources.

PATIENT ADVISOR ORIENTATION AGENDA	
3:00-3:10	Introductions and agenda review
3:10-3:30	“Where were you in ...?” icebreaker <i>Pass around a basket of nickels. Have everyone take one and then go around the table asking each person describe something they were doing during the year on the nickel</i>
3:30-4:00	Part I: Introduction to LINCC, and health care delivery <ul style="list-style-type: none"> • LINCC project introduction • Primary Care Team: What is a primary care team and “A Day in the Life of a Primary Care Clinic”
4:00-4:15	HIPAA orientation
4:15-5:00	Clinic tour and introductions to care team members
5:00-5:30	Dinner and discussion Personal experience from LINCC project patient co-investigators
5:30-5:50	Part II: Health care delivery and community linkages <ul style="list-style-type: none"> • Health system overview • Evolution of the medical home
5:50-6:30	Sharing session: Guided discussion of personal experience using community resources/challenges & barriers [to see how project relates to their own lives]
6:30-6:50	Next steps/Design event prep <ul style="list-style-type: none"> • Logistics • Questions
6:50-7:00	Wrap up and survey

Patient advisors appeared less interested in didactic material like health system history and general information on health care delivery—we could have provided some of that information as advance reading or viewing of videos. They were most engaged when they could interact with each other and share their own experiences with their clinics. They also appreciated hearing the perspectives of the research project patient co-investigators who talked with them during dinner.

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Lessons learned:

- In a long group session with patients, it is important to have a facilitator to keep the discussion on track—some patients may “overshare” about their own health conditions.
- The orientation session provided an opportunity for patient advisors to provide important input for the design event. For example, they stressed making sure everyone knows what common abbreviations and jargon mean, such as “EMR” or “clinic flow.”

Resources:

- 1. Patient Training Prior to Design Event: Agenda*
- 2. Design Event: Patient Orientation Sample Presentation*
- 3. Design Event Orientation Evaluation Questionnaire*

5. Design event

Preparation

Overview: We held a four-day design event. The first day was setting the stage, and days 2 and 3 focused on developing event deliverables, which included defining the scope of the role and job description for the new clinic position, creating documentation tools, and developing referral processes for the new service. Day 4 involved finishing the deliverable and reporting on what the group had accomplished to health system leaders during a concluding celebration.

Below is an outline of our event agenda.

DESIGN EVENT AGENDA	
Day 1: Setting the stage	Day 2–4: Developing and testing
<ul style="list-style-type: none"> Leadership kick-off, introductions, setting norms Orientation: care design goals, patient co-designer role Icebreaker to encourage teamwork Overview: care design process and principles Examine current state of care delivery: Full-group role-play, discussion Look to future state: Review potential best practices Full-group role-play to generate design ideas Final discussion, report 	<ul style="list-style-type: none"> Icebreaker to encourage teamwork <p>Alternate activities:</p> <ul style="list-style-type: none"> Full-group role-play to test design changes Small-group work on deliverables, full-group discussion of suggested model revisions <p>Final discussion, report</p> <p><i>Day 4: Invite leadership to final report and review of proposed design</i></p>

Key design event roles: We found that defining roles was an important task for ensuring the design event ran smoothly. The Lean design event includes a number of standard roles: a pacesetter who is the “owner” of the event and eventual implementer of what is designed, the design team (traditionally health system staff), facilitators, a management guidance team (MGT), resource representatives who may be called on to share expertise at the event, an “air traffic controller” to keep things moving, and a “pair of hands” to help with daily logistics. All roles are described in the “Lean Design Event Roles & Expectations” tool from Section 2.

It is important that facilitators have a deep understanding of the goals of the design event and ensure that participants treat each other with respect. They need to stay on top of group dynamics and encourage participation with prompts. Our design event was co-facilitated by experienced Group Health Lean consultants and pilot clinic and research team leaders.

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It also was important to define roles, particularly when including patients, to underscore the value that each participant brought to the process and empower their full participation. For example, the role of patients was to be an expert in their patient experience but they did not have to be an expert in clinical processes. Staff members brought expertise in their particular role in the clinic team.

Logistics

Room set up and seating arrangements:

- Schedule a room that is large enough for participants to get up and stretch and get snacks without disturbing others
- Set up the room so that it is conducive to collaboration. We used a U-shaped table arrangement so everyone could see each other and there was space in the middle for role play activities. We also had separate rooms for small group work.
- Ensure the room accommodates people who have wheelchairs or other special needs

Pre-event communication:

- Patient participants may need more information and communication for the event than staff participants, including providing directions, staff contact numbers, help arranging transportation.
- After the orientation sessions we sent confirmation packets to patients as well as reminder emails.

Food:

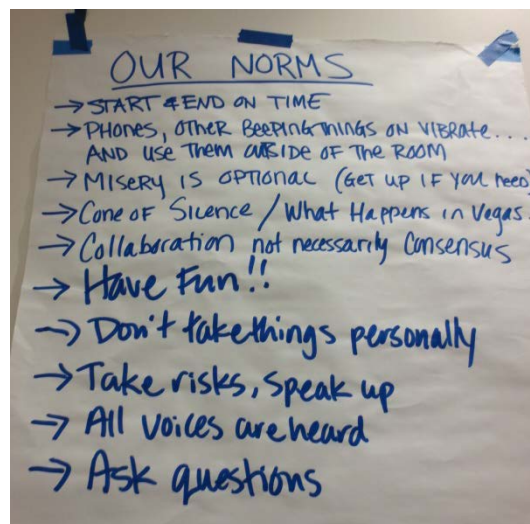
We provided breakfast, lunch, snacks, and coffee and tea on all four days. Having to bring food from home or purchase meals would have been logistically difficult and would have added a financial burden to patient advisors. We found that meal times together provided important opportunities for networking, and that afternoon snacks helped keep participants' energy levels up.

Transportation:

Patients may not have easy access to transportation so this should be kept in mind when selecting the location for the event. Because our design event venue was not close to either of the pilot clinics (it was 30 miles from one pilot clinic) and was not easily accessible by public transit we arranged for a town car to pick up patient advisors at their clinic in the morning and drive them back in the evening. Clinical staff were also given the option of using the town car but most chose to get to the event on their own.

Establishing meeting norms/ground rules:

After introductions on day 1, facilitators outlined the event's "spirit of improvement," which encouraged challenging the status quo, honoring each person's expertise, and reminding participants to "be hard on the process but gentle on each



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other.” Participants also agreed on event norms, including taking risks and ensuring all voices are heard.

Ice breakers/relationship building:

Each day began with an icebreaker to foster team engagement. These were critical to ensuring that all participants developed positive working relationships. The icebreaker times were also a good opportunity for patients to have a chance to facilitate activities and included:

- The “[marshmallow challenge](#)”
- Individuals wrote down a childhood dream of what they would be when they grew up; these were collected, and drawn out of a bag, and the group guessed the dream’s “owner”
- Small groups worked together to develop a map/visual representation of their community and shared these with the group



Didactic content/information sharing:

Day 1 had the most didactic content, including an overview of the research project plus the current state and potential future of health care delivery.

Role play/trystorming:

Role play was a major technique to both understand current practice and test out alternative/new practices. “Trystorming” involves brainstorming a change and then trying it out using role play. Role play activities were highly engaging to all and generated many useful insights.

Small group work:

Participants broke out into small groups to work on individual aspects of designing the new clinic role, including job description, clinic work flow, electronic health record (EHR) documentation, and methods for keeping track of community resources. Overall, we found that patients were very engaged and able to participate in this detailed design work. The one area they had challenges participating was in the group that was working on the technical details of developing tools for the new role to document patient encounters (including in the electronic health record).

End of day recaps and morning debriefs:

Time was built in at the end and beginning of each day to reflect on what had been accomplished and set goals for the day to come.

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“Live” evaluation/fine tuning

A number of mechanisms were built into the design events to provide rapid formative feedback and allow for fine tuning specific aspects of the design event. They included:

- **Facilitators’ meetings at end of the day; what worked; assignments for next day:** Facilitators and evaluator-observers gathered at the end of each day to discuss what went well and what needed adjustment and to assign roles for the next day.
- **Daily surveys:** A one-page written survey was handed out to all participants and collected at the end of each day (see section 7, Evaluation). The survey was aimed at assessing how participants felt about team functioning, their own participation, any changes they would suggest, and satisfaction with the design event outcome.
- **Other evaluation activities:** Because of the research component of this project there were several other data collection activities that were aimed at documenting and assessing how the event rolled out and participants’ experiences. Please see the section on evaluation for more information on assessing the design event.

Event products

The design event achieved its goals and developed the intended deliverables, including defining the scope and job description of the new CRS position, referral processes, and documentation tools for the new clinic service. (Some of these were used as designed during the event, while others were revised as the implementation unfolded.)



Specific tools created during the event included:

- A CRS job description and posting
- Communications about the new service (flyer, newsletter article, etc.)
- Drafts of EHR documentation templates for the CRS position
- A CRS training timetable and key topics
- A community resource tracking spreadsheet

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Celebrate!

The final day of the design event involved wrapping up loose ends and preparing to report results to the MGT in the afternoon. Participants also created a design event newsletter they could distribute to the MGT and other guests. The report out was essentially a celebration, and all participants were recognized for their contributions.



Lessons learned

- Ensure your rooms are large enough for participants to stretch and move around and can accommodate participants with special needs
- Establish “do and don’t” guidelines for role play such as those in the box at right.

ROLE PLAY GUIDELINES

Do:

- Base role plays on your own or your family members’ experiences
- Behave with the level of courtesy you would expect from your ideal health care professional

Don’t:

- Over share personal health information
- Act silly or inappropriate, even if it is more fun that way.

Resources:

1. Design event newsletter

6. Follow up

Keeping in touch

We reached out several times to the patient advisors, including:

- An email shortly after the design event thanking them for participating, reminding them that we would contact them again in about a year, letting them know they would be contacted to participate in an interview and verifying when they could expect to receive payment for participating
- An email with the event newsletter they had created at the design event attached
- A personalized holiday card at the end of the year
- An email update about progress with the research project that implemented the CRS pilot

Improvement event

Fifteen months later, design event participants came together again for a three-day “check and adjust” improvement event. This provided an opportunity for patient advisors to see how the role they helped create was working and provide input on how it could be improved. All 12 patient advisors were invited to participate; eight of them were able to attend.

The three-day event included one day of facilitated review and discussion of how the role was currently working and how it could be improved. Participants prioritized issues to focus on and developed new processes and tools aimed at addressing those issues. Days 2 & 3 were focused on in-clinic testing of the improvements to the CRS role at both pilot clinics. Patient advisor attendance at the in-clinic testing (split into morning and afternoon sessions) was optional; four chose to attend at one clinic and two at the other. The improvement event wrapped up with an optional “report-out” meeting that people could join by phone or in person at each clinic.

The key challenge identified at the improvement event was that the CRS had lower than anticipated patient volumes. Patient advisors stressed the importance of referrals being initiated by a personal “warm handoff” to the CRS from clinic staff and helped revise workflows to support warm handoffs. They also helped develop a “cheat sheet” to remind providers and clinical staff about the types of patients they should consider for a CRS referral.

Resources:

1. *Follow-up event confirmation letter*

7. Evaluation

Methods

We used a mixed-methods approach to assess the impact of patient co-designer engagement on the design event process and outcomes. Our data sources included:

- **Interviews with participants and delivery system leaders:** The research team interviewed each staff and patient advisor participant after the design event and the eight participating patient advisors after the improvement event. Interviews captured perceptions of the patient advisor role, degree of engagement and collaboration, and patient advisor impact on the process and final design. The research team also interviewed five health system leaders for their perspectives on the value of including patient advisors in care design. The interviews were conducted over the telephone or in person, and were audio-recorded and transcribed.
- **Event observation:** Two members of the LINCC project research team observed the design and improvement events using a form that prompted them to document detailed information on content, group collaboration, facilitation, and level of patient advisor engagement and input.
- **Participant surveys:** In order to gather formative feedback to fine-tune the design event, we asked each participant to complete a daily survey that included an opportunity to suggest changes.

Results

Themes that emerged from analysis of the interview and observational data covered the impact of patient advisor engagement in the design of the new role, key elements of collaboration, expertise brought by patients, and impact of the design event on participants.

Overall, patient advisors were viewed as valuable by other participants and facilitators. Most participants were very satisfied with the final outcome of the design event, which included defining the scope and job description, referral processes, CRS workflow specification, and clinical documentation tools for the new CRS role. The patient advisors elevated awareness of how the new service would affect patients in their lives outside the clinic.

Although participants found it difficult to identify specific impacts during the design event, many commented that having patient co-designers engaged made the designed service more patient-centered because patients could describe what they needed in a given care situation and how processes could be revised to accommodate patient perspectives. All participants reported an egalitarian atmosphere; despite a clear difference in technical expertise between patient advisors and clinical providers and staff, they did not experience a power differential.

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The impact of patient advisors was more explicit in the improvement event when participants learned what was and was not working with the new CRS role. The patient advisors insisted on exploring why the “warm handoff” element from the design event had not been implemented, and helped revise the CRS workflow and tools to better support warm handoffs.

All 12 patient advisors felt their thoughts and opinions were respected during the design and improvement events. Several described being pleased to be in a room with health care professionals who valued what they had to say. Participants thought that interactive elements of the design event were key ways to engage patients, particularly through role-playing and small group discussions. They also stressed the importance of having strong facilitators to make sure all voices were heard.

Resources:

1. Design event daily survey

8. Additional resources

Patient engagement in health care quality improvement

Patient Engagement in Redesigning Care Toolkit, Version 2.0

University of Wisconsin Health Innovation Program, 2017

<https://www.hipxchange.org/PatientEngagement>

A Roadmap for Patient + Family Engagement in Healthcare

Gordon and Betty Moore Foundation and American Institutes for Research, 2015

<http://patientfamilyengagement.org/>

Partnering to Improve Quality and Safety: A Framework for Working with Patient and Family Advisors

Health Research & Educational Trust, 2015

<http://www.hpoe.org/resources/ahahret-guides/1828>

Patient and Family Engagement Resource Compendium

Health Research & Educational Trust, 2015

<http://www.hpoe.org/Reports-HPOE/2015/pfe-compendium.pdf>

Conducting a Lean design event

The Rapid Process Improvement Workshop [video]

Saskatchewan Health Quality Council, 2013

https://www.youtube.com/watch?v=Dxx1LIWf9aA&list=PLsmd5sbzhSch5TpQ_ZnPIWAKLtYuEINEU&index=20

Lean methods and training at Virginia Mason Institute

<https://www.virginiamasoninstitute.org/>

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Patient participation in Lean

Patient & Family Involvement in Lean Improvement Events [video]

Saskatchewan Health Quality Council, 2013

https://www.youtube.com/watch?v=uBCP0CgewHY&list=PLsmd5sbzhSch5TpQ_ZnPIWAKLtYuEINEU

Incorporating the Patient Voice into Rapid Process Improvement Workshops (RPIWs) [slides]

Saskatoon Health Region, 2009

<https://www.slideshare.net/SaskQualitySummit/incorporating-the-patient-voice-into-rapid-process-improvement-workshops-lisa-clatney>

Design event icebreakers

Icebreaker Ideas

<https://icebreakerideas.com/icebreaker-questions-biggest-list-ever/>

50 Icebreaker Questions for Work

<http://www.signupgenius.com/business/icebreaker-questions.cfm>