Catalyst Films about Health Experiences Guidebook

The CENTER FOR PATIENT PARTNERSHIPS

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Contents

Use of the Toolkit

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Introduction to Catalyst Films about Health Experiences

This guidebook introduces catalyst films about health experiences in the United States context, and offers actionable ways to use these films for improvement, co-design, research, and/or educational activities. It also describes how these films relate to other patient engagement and participatory visual methods and examines the strengths and limitations of other less intensive methodologies that capture patient experience. Finally, the Appendix offers handouts for implementation of a catalyst film viewing and reflection session.

> ## Catalyst Film Definition
>
> *"It's a call to action...it highlighted all the things that can be improved….and where it's done right... "* - **Patient Ambassador, Madison, WI**

Catalyst films about Health Experiences are designed to jumpstart an improvement, co-design or educational process focused on what matters to patients. Using catalyst films in health care quality improvement (QI), co-design, research, or educational processes is a way to ensure that transformations are grounded in the direct experiences of those whose health and well-being are most directly affected by care. They are made of clips that are carefully selected from interviews of patients discussing their diverse experiences with health and health care. The base material, the existing health experiences interview clips, are compiled through a rigorous qualitative research process that elicits diverse health experiences (HERN, 2019).

Catalyst films are an additional tool in the "patient engagement toolbox" that provide a robust, broad representation of patients' experiences. Films can offer perspectives that patients from your own setting may be reluctant to share. Coupling a catalyst film with methods to engage actual patients from a practice can provide a comprehensive understanding of patients' experiences of care. Resources on other patient engagement methods are provided in the Appendix.

Catalyst films (sometimes called "trigger films" in the United Kingdom (UK)) have historically been created as part of an Experience-Based Co-Design (EBCD) process which involves representing diverse patients' experiences to animate QI-oriented team processes. These teams include patients, QI experts, clinicians, and other stakeholders. More recently, UK researchers created catalyst films from existing health experiences interview clips compiled through a rigorous qualitative research process. These films have proven just as effective for co-design and allow for an accelerated EBCD process (AEBCD). Resources for EBCD are available in the Appendix.

> *Health Experiences* refers to how people experience health, illness, treatment, and the delivery of care. It is a form of knowledge that is as important as scientific, epidemiological, and clinical knowledge to inform healthcare. (Ziebland, 2013)

Uses for Catalyst Films

Catalyst films can be used in a variety of ways. Here are a few examples organized by type of activity:

- **Organizational Culture and Climate Change:** Show the film to reinforce values and beliefs to guide behavior, such as agreed upon practices, and procedures. (Robert, 2013; Nembhard, 2016). The film can also be used to reinforce a culture of patient and family-centered care and co-design (Caplan, 2014; Johnson, 2008)
- **System and Quality Improvement:** Show the film at a QI team meeting to provide a shared understanding of some of the ways experiences with a health condition are diverse and could be improved. Then initiate conversation about what the team wants to learn from patients and how they will do that (what methods they will use). Show the film to all staff and clinicians when a patient-centered process change is introduced (or as a refresh) to reinforce the value of the change to patients.
- **Research:** Use the film to identify potential areas for developing testable interventions which directly reflect patient priorities. (Raynor, 2020)
- **Patients' Experiences Education & Training:** Use the film to educate clinicians, social service providers and other stakeholders about patients' diverse experiences and groundwork in patient-identified needs. (Repper, 2007)
- **Co-Design Generally:** Use the film to include patient voices and perspectives in conversations.

> **Where to Find Catalyst Films**
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> **HealthExperiencesUSA:** This website offers a collection of Health Experiences Modules by the Health Experiences Research Network. Once they are produced, catalyst films created from these modules can be found here.
>
> **Healthtalk:** This website offers Catalyst Films (26 at publication) created in the United Kingdom using the process adapted by HERN in the United States. We include this resource since there are not yet many catalyst films created from US-based footage.

These films can be viewed in a group setting or by individuals. In the Appendix you will find materials to facilitate reflection and conversation.

Value of Catalyst Films

Catalyst film(s) create actionable nuggets from patients' perspectives. They can be effective and transformative because "narratives can engage care providers at a deep emotional level in reflecting on how services could be improved." (Locock, 2014b) A form of video ethnography, catalyst films are one of several "Participatory Visual Methods." (Balbale, 2016; Boaz, 2016; Neuwirth, 2010; Richards, 2011). Such methods aim to generate new awareness by highlighting dimensions of patients' experiences that are usually unseen. (Papoulias, 2018) In other words, a catalyst film expands the QI process by presenting experiential data often not captured through surveys and suggestion boxes alone.

Using catalyst films created from existing health experiences interview clips provides actionable insights without "confronting" viewers with specific examples from their own setting (Dimopoulos-Bick, 2018). This universal appeal can increase engagement and willingness to consider improvements (Locock 2014a).

Our own research adds to the existing literature on value. During 2019, we held focus groups with clinicians and clinic staff in Madison, WI and Albuquerque, NM. Perspectives voiced in these groups aligned with what has been reported in other studies, including that viewing the film: *'keep[s] the engine of motivation going'; 'pulls people into the project'; is 'a very powerful reminder of why we are doing what we do'; a 'very moving, a vivid reminder of patient experiences', and a 'resoundingly powerful look into individuals' lives and experiences with illness'.* (Bate 2007, Donetto, 2014) Overall, the staff involved in these film screenings remarked on the value of the patient films as giving them access to a new way of understanding the experiences of patients. They found the positive and negative feedback on practices "compelling," and indicated that the film led to "compassion and more understanding" for patients.

We also asked patient ambassadors - those patients who had been interviewed for the [HealthexperiencesUSA module on Young Adults with Depression](#) and helped us spread the word about the resource - what they thought of the idea of catalyst films. One Ambassador remarked, "I think it's a good way to remind... health professionals of the severity [and] novelty of this process [of seeking treatment] for some people." Another noted, "The key is authenticity...that [the film] is directly conveying what the participants have said, not trying to put it into any sort of narrative or message."

Clinicians, staff, and ambassadors all agreed that catalyst films underscore the diversity of patients' health experiences and care seeking. Quotes from our clinician/staff focus groups and interviews are shown in the thought bubbles.

Using existing catalyst films is also efficient. As described in detail below, using an existing catalyst film instead of creating one through the Experience-Based Co-Design process saves approximately 6 months of time and effort.

> "From a healthcare point of view, it's nice to hear people's opinions that you wouldn't hear in person. It's nice to be able to make improvements in care based on real experiences"

> "It's a reminder of the real reason why we are here."

> "Clarifies message from [the patient's] mouth to stop imagining what the problem is"

> "Helpful to hear real stories and multiple stories – not pretend it's all the same or 'one size fits all'

> *"To understand we have implicit bias and are not aware of what blinds us at times"*

> *"Watching as a QI team is a good use of time, getting provider-patient perspective"*

> *"I think this is a powerful way to convey the problem."*

> *"I was reminded about other modalities of caring for people...as I often focus on meds or therapy"*

Context

Improving health care quality is part and parcel of 21st Century health care delivery. From broad reform efforts to clinic-based "rapid cycle" small tests of change, improvement is constantly sought, and desired.

Health system culture change and improvement can take many forms: co-design and co-production, research, constant process improvement, and education. The language used to describe these improvement efforts continues to evolve; for this reason, we provide a glossary of terms in the Appendix.

The Quadruple Aim

The quadruple aim highlights the essential role of improved patient experience in achieving optimal health care. (Bodenheimer, 2014) Patient experience positively correlates with other indicators of health care quality. (Papolius, 2018). Health reform efforts therefore increasingly mandate patient engagement/co-design as a critical component of practice transformation. (Pandhi, 2019)

There are many models for including patients and family in improvement efforts. Most offer a continuum of engagement strategies which correlate with various kinds of input from key stakeholders. These include: suggestion boxes, surveys, focus groups, advisory groups and including stakeholders as full participants on QI teams. (Davis, 2017) We share links to our favorite resources in the Appendix. The breadth and depth of patients' participation varies in these methods. In our own work, we have found great value from using methods that deepen participation. The investment of time, energy and resources is well rewarded by the project's ultimate quality and utility. (Davis, 2016)

> Catalyst films are an additional tool in the "patient engagement toolbox" that provide a robust, broad representation of health experiences.

Catalyst films are an additional tool in the "patient engagement toolbox" that provide a robust, broad representation of patients' experiences. Films can offer perspectives that patients from your own setting may be reluctant to share, as echoed by one of our focus group participants: "From a healthcare point of view, it's nice to hear people's opinions that you wouldn't hear in person."   Coupling a catalyst film with methods to engage actual patients from a practice can provide a comprehensive understanding of patients' experiences of care.

> "…the film was the catalyst to solving the problems... this was the thing that absolutely broke down the wall and made people really see clearly that it had to stop and that people's attitudes had to change… there is something very powerful about film… it engages everybody" - **Senior Nurse (Adams, 2015; Donetto, 2014)**

> "[My takeaway from the catalyst film is] understanding that process improvement without patient voice is inherently flawed" - **Clinician, Madison, WI**

How Catalyst Films are Generally Constructed

Catalyst films are constructed by analyzing the narratives from a national sample of people who have experience with a specific health issue. Researchers from universities represented in the Health Experiences Research Network (HERN) conduct video or audio interviews with people in states across the United States. Findings from these studies are available on healthexperiencesusa.org. The interviews cover a wide array of experiences; for example, signs and symptoms, receiving care, emotional reactions, impact on family members and other relationships, and the impact on work and day to day activities.

To create the catalyst film, members of the research team review the whole interview collection to identify content relevant for quality improvement -- for example, diverse experiences with health care services. The research team focuses specifically on "actionable" material -- that is specific details about "what, where, who, and how" that can be used to modify problematic practices and emphasize effective ones." (Grob, 2019)

The films include people selected purposively from different states across the country, who vary in other diverse ways (e.g., socio-demographics, stage of illness). Though each individual has some unique experiences, patterns also emerge when many stories are analyzed together. Films should include both positive and negative experiences, because we can learn a lot for improvement purposes from examples of both what went right and what went wrong. Even when people are largely positive about the rest of their care, one damaging moment can stand out. Including positive comments, such as where people remember some small act of kindness or a particularly good moment that made all the difference to them, can also be constructive and inspire clinical teams to continue cultivating practices appreciated by patients. (Grob, 2019; Healthtalk.org- Ethnic minority mental health)

Development of the First United States HERN Catalyst Film

To develop the Young Adults with Depression catalyst film, we showed part of a catalyst ("trigger") film on young adults with depression created by researchers at the Health Experiences Research Group at Oxford University, United Kingdom, and our own draft film to focus groups of primary care providers and staff in Madison, Wisconsin and Albuquerque, New Mexico. We received feedback on preferred content, length, potential use, audience, and context/framing. We also interviewed researchers who have made catalyst films or engaged in experience-based co-design efforts in the United Kingdom and the United States. (Locock, Bullock, Mendel), and engaged several participants who had participated in interviews for this module in selection of topics for and creation of this film.

Development of Guidebook

This guidebook is informed by a scoping review and the focus groups and interviews mentioned above. It is also informed by our collective experience with using, cataloging, and researching patient engagement methods (Davis, 2016; Pandhi, 2019) and with researching and disseminating patient experiences (Grob 2019; Schlesinger, 2015).

In constructing the film and guidebook, we have endeavored to follow best practices that can facilitate ease of implementation. As such, we created films with different foci and length, and offer scripts; discussion guides; and implementation ideas. This approach is designed to make the intervention ready to be tested on a small scale and then adapted to your context as needed.

Complementary Skills and Knowledge

Teams using a catalyst film may already have some skills in quality improvement (QI), co-design, co-production, research, or training. For purposes of this guidebook, we presume that teams are familiar with the value of including patients and families in these efforts. (Davis, 2016; see Appendix) Ideally, teams taking up this work already include patients as part of their improvement efforts.

In situations where teams are not experienced with engaging patients, the film can be used to "catalyze" such engagement. In other words, the film can be the first step in a journey of prioritizing patients' voices in activities.

The section on Other Ways to Include Patients in Activities in the Appendix provides details on other methods to ensure that patients' voices inform culture change and QI efforts. Links to resources for QI, co-design and patient engagement are also contained in the Appendix.

Why Use a Catalyst Film for Improvement or Educational Activities?

Catalyst films are an efficient, evidence-based way to include health experiences in healthcare improvement efforts (Locock, 2014a). They can provide a powerful jump-start to improvement efforts and have the added benefit of providing insights without any of the unintended consequences of including perspectives from one's current patient panel.

Provide a Visually Powerful Jump-Start

As a participatory visual method[1] Catalyst Films about health experiences generate new knowledge for health or social service systems by highlighting dimensions of patient experiences that are largely unseen. (Papoulias, 2018) Because catalyst films contain narrative - which "is a powerful way of accessing human experience" ... they enable viewers to see healthcare experiences through patients' eyes. (Locock, 2014a) The experience of showing catalyst films can be powerful. In the first pilot study of Experience-Based Co-Design in the United States, "the showing of the trigger [catalyst] film represented a sharp inflection point in engagement among participants." (Mendel, 2019)

A catalyst film can expand the conversation, informing change processes with essential stakeholders' perspectives. The film offers a "new 'lens,' or frame of mind. (Springham, 2015).

> *"Both the [catalyst] films and the ensuing discussions help to bring people's experience to light and then create the outcomes they want to see….The [catalyst]film is...a mechanism to spark things off;...it's those face-to-face encounters – watching the film together and then asking "What shall we do about it?" that's transformative. It breaks the ice and puts people into a different space, helping them see things through each other's eyes.'* - **Louise Locock, Director of Applied Research at the Health Experiences Research Group, University of Oxford (Point of Care Foundation)**

The viewing of patient experiences helps (re)connect all people - patients and providers - with similar experiences and stories, and offers an authentic, emotionally, and cognitively powerful starting point for discussions. (Donetto, 2014)

Anonymous Patients

> *"[It shows that] someone else has done it, we can do it too!"* - **Patient Ambassador**

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[1] In the Appendix, we provide a brief introduction to visual participatory methods, and place catalyst films in this context.

Another benefit of catalyst films created from national footage as opposed to local patient data is that a local QI team using them does not have to worry about privacy or potential HIPAA violations.[2] Pre-made films also avoid the potential awkwardness of patients sharing criticisms of one or two specific providers when the goal is to glean more universal lessons. It can be easier to neutrally address real concerns in one's work environment by using examples that are not too close to home. It may help staff "feel less threatened by negative comments and be able to externalize criticisms of care." (Locock, 2014b)

> The national nature of a catalyst film underscores that continuous improvement and learning is a goal of all of healthcare.

The national nature of a catalyst film underscores that continuous improvement and learning is a goal of all of healthcare. We all have room to improve; QI is about addressing root causes and systems that can improve the patient experience for all rather than pointing fingers or identifying one-off issues.

However, we recommend that use of catalyst films for QI be complemented with other methods for including local health experiences. As mentioned by one of our project's patient advisors, your own context may need to address relevant racial or ethnic representation, *mis-match with respect to urban vs. rural experiences, or showcase pragmatic differences regarding access to care*. Luckily, this is easy to do. We provide information and resources about complementary patient engagement/co-design methods in the Appendix. In addition, our film companion materials prompt reflection and discussion about local variation.

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[2] HIPAA and patient engagement share many goals. It is possible to videotape your own patients - with their permission - and use that footage for quality improvement without violating HIPAA. However, since HIPAA is often interpreted narrowly, it may be easier to use national footage. (IPFCC, 2010)

How to Use a Patient Experiences Catalyst Film

Viewing Options

In the United Kingdom, catalyst films are used to accelerate Experience-Based Co-Design (EBCD). EBCD is an extensive, multi-month process, which is briefly described below with accompanying resources in the Appendix. Here, we outline other viewing possibilities.

> Catalyst Films are uniquely designed to jump start conversations and facilitate additional engagement.

Catalyst films can be viewed anytime during an improvement, co-design, or educational process, but they are uniquely designed to jump start conversations and facilitate additional engagement. For this reason, we recommend using them early in a process.

Suggested Best Practices for Viewing

- View at the beginning of a process
- View in a group -- ideally with both patients and providers present
- Include ample time for reflection and discussion
- Follow-up with a plan to engage local patients

Since a catalyst film is designed to cause a reaction and facilitate conversation, it is best viewed in a group with ample time for discussion and identification of reactions and next steps. We recommend that you allot at least 30 minutes, and ideally 45-60 minutes, to have a thorough and action-oriented debrief. In the Appendix, we offer sample agendas for a film viewing meeting; an introduction to the film which can be read by the organizer; and a handout to guide an individual and/or group process of reflecting on the value of the film for improvement efforts.

We recommend that the film viewing catalyze additional engagement with your own patients. For example, you can watch the film with patients and talk together about their insights and reflections on the topic. Alternatively, clinicians and staff can watch the film and use it to determine what questions you have for your own patients, and plan to ask these through different engagement methods. (Resources on different engagement methods are listed in the Appendix).

Tools (in the Appendix)

- Sample Agendas for Film Viewing Meeting
- Film Introduction Script
- Participant Handouts

Catalyst films can also be used in patient focus groups, to spark conversation about patients' insights on a topic. (Materials provided in Appendix)

Limitations if Viewed Without Patients or Patient Input

The film can be used as the sole patient engagement activity to ground activities in patients' perspectives. However, if it is not supplemented with other input from patients, there will be significant limitations - including risk that a team without patients may interpret the narratives solely through a provider lens. Emerging best practice calls for data collectors to "first share their results back with the community to make sure that outsiders are accurately understanding, synthesizing, and representing their experiences." (Franklin, 2018) No matter how connected to patients' experiences we might personally feel, when we wear our professional hat, we must value patients themselves as the experts in their experience. If it is not possible to "share results back," then it is essential to proceed with the knowledge that actions taken based solely on the film may miss key data that is unique and fundamental to your situation.

> *"It is true that just seeing patient narratives on film can in itself have a powerful effect. But our observations suggest face-to-face encounters with patients have been even more transformative, inspiring and revelatory to staff in making them think differently about their values and practice. Having continued patient involvement helps ensure improvements really do address patient concerns and holds staff to account to see change through. Patients' physical presence constantly reminds everyone who change is for, and why it matters compared to other potentially overwhelming work pressures and demands."*
> **- Louise Locock and research team (2014b)**

Use in Accelerated Experience-Based Co-Design

> *"As well as being useful for all frontline staff, the [EBCD] approach is the natural next step in any improvement project work....[O]ur emphasis here is on building on and extending your work to better include the third and vital element of good service design – user experience."*
> **- NHS Institute for Innovation and Improvement**

Experience-Based Co-Design (EBCD) is a methodology in which patients and clinical staff work together, side by side, to co-design improvements and innovations to health care services. Accelerated EBCD (AEBCD) is a shortened process that uses existing catalyst films instead of making one during the process.

As of 2017, the EBCD method has been used in more than 60 projects in six countries; it has led to improvements in patients' experiences as well as transformations in health care workforce culture, values, and behaviors. EBCD efforts have been associated with reductions in formal complaints in a mental health ward; increases in the percent of patients with cancer who report always being treated with respect and dignity; and greater emergency department staff appreciation for how health care practices and environments affect patients, and how to work with patients to co-design and implement health care services. (Van Citters, 2017) In the United States it was recently first piloted with individuals returning to community from jail and service providers in Los Angeles County. (Mendel, 2019)

The EBCD approach has several distinguishing characteristics from other quality improvement efforts, including:

- Placing patients' experiences at the center of the enterprise from the very beginning;
- Engaging patients as full partners in improvement at a high level of engagement throughout the entire improvement project or initiative;[3] and
- Using catalyst films - videos of patients and staff describing their experiences with the health system - as a central component of the EBCD methodology. (IHI)

EBCD is a multistage, yearlong process which includes gathering experiences (from participants and staff), identifying priorities, and co-designing solutions (Mendel, 2019).
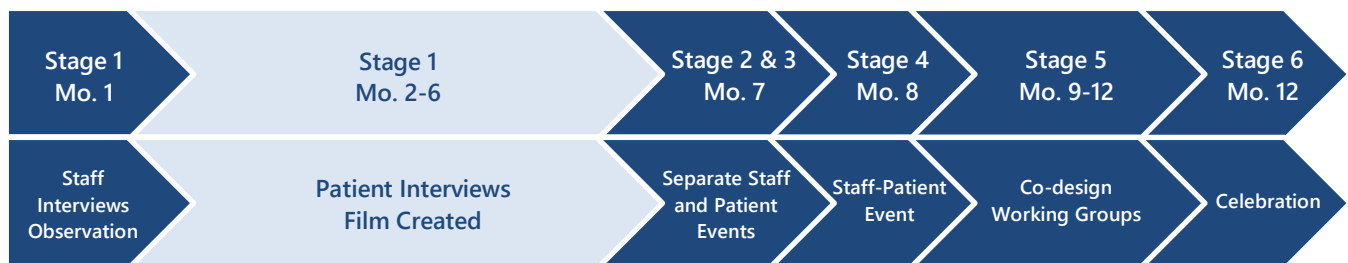
Stages of Experience-based Co-Design (Tollyfield, 2014; Point of Care Foundation)

As shown in the figure, EBCD is a six stage process. A significant part of the first stage of EBCD is interviewing patients and creating a catalyst film to use in quality improvement efforts. An accelerated EBCD process can be achieved by using an existing catalyst film, such as the ones available at HealthExperiencesUSA.org/catalystfilms. Doing so cuts the EBCD time in half, making it just 6 months, with a timeline that includes all the other same steps:
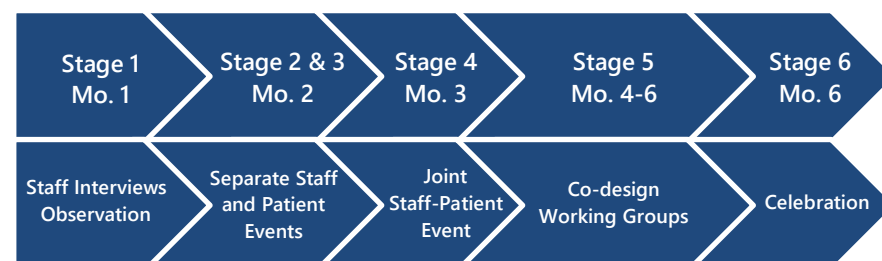
Stages of Accelerated Experience-based Co-Design (Tollyfield, 2014; Point of Care Foundation)

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[3] This is a higher level of engagement from the typical approach many health systems employ to solicit input from patients using surveys or focus groups.

Projects using EBCD often focus on 'small scale' changes, but these can be "of profound value" to patients. Co-design also leads to wider changes in staff attitudes and in organizational culture. Carving out the time and space to work together very often leads to a valuing of patients' perspectives. (Boaz, 2016) While EBCD requires a substantial time investment, the results are stronger and more durable than achieved through other engagement strategies. (Locock, 2014b)

The catalyst film's role in EBCD is to convey emotion and foster empathy about patient experiences with clinical services. This, in turn, facilitates reflective learning - individual and shared - and discussion about shared priorities for change. (Mulvale, 2019a; Locock, 2014a; Papoulias, 2018). Additional stages of the EBCD process use experience mapping, emotional

> The time that patients and providers spend together in co-design groups has been demonstrated to have a *"profound effect on staff in making them think differently about their practice and reconnect with their core professional values, resulting in renewed motivation."* - **(Locock, 2014b)**

mapping, and prototype development as elicitation techniques, to generate additional insights. Experience mapping has participants sharing their views of touchpoints (i.e. points of patient and health system interaction) to come to a collective understanding of their roles in service delivery and build consensus about priorities for action. (Mulvale, 2019a) Emotional mapping involves patients and staff describing in detail the emotions (positive and negative) experienced along the patient journey which helps to highlight emotional 'highs and lows' of the service or pathway. (Mendel, 2019; NIH Institute for Innovation and Improvement 2009). Prototype development - co-creating an initial model- helps a group of participants "move from abstract ideas to concrete tangible solutions." (Mulvale, 2019a)

In addition to saving time, the accelerated version, AEBCD, addresses other challenges found in EBCD, including staff feeling "confronted" by watching a catalyst film regarding patients' experiences with their own care system in a joint session with patients. (Dimopoulos-Bick, 2018) Research has shown "no discernible difference in experiences or outcomes between full and accelerated experience-based co-design." (Jones, 2020; Locock, 2014a)

If you plan to try EBCD or the accelerated version, in addition to learning the methodology, it is wise to consider if the patient population you wish to co-design with will need special considerations. Power differentials, health concerns, and economic and social circumstances have been identified as specific challenges to co-designing with people facing income inequality. In these cases, it is essential to have the work guided by principles and not predetermined steps. (See box, Mulvale, 2019b)

	Experience-Based Co-Design Principles To Consider When Co-Designing With Vulnerable Populations (Mulvale, 2019b)
	Share Power, through Shared Ownership, Shared Leadership, and Open Communication
	Foster Trust and Mutual Understanding
	Select an Accessible and Conducive Environment for Co-Design Activities
	Recognize the Emotional Toll That Illness Takes
	Understand the Person in their Context and Respect Cultural Differences

Is Your Team Ready for Experienced-Based Co-Design?

The Institute for Healthcare Improvement has created an Experience-Based Co-Design of Health Care Services — Implementation Guide which includes:

- Assessment questions to determine readiness
- Tips for Successful EBCD
- Lessons Learned
- Links to Additional Resources

🎥Can We Use Any Film? What is Unique About a Catalyst Film?

The benefit of using a Catalyst Film in quality improvement activities, Accelerated Experience-Based Co-Design, research, or education is multifold.

You can be assured that the content is accurate, that participants are willing contributors, and that it will evoke an emotional response to generate action. When you use a catalyst film from a trusted source, you know where the footage came from and that it was created with consent and respect for the patients who agreed to have their story used to improve healthcare.

Catalyst films are created to represent a diversity of voices. Since they are short, they can't represent of every possible viewpoint, but they do offer short clips of multiple patients dealing with a similar diagnosis, with the goal of presenting a balanced perspective. This can be hard to find other places.

Catalyst films on Healthexperiencesusa.org or Healthtalk.org are created through a process of rigorous qualitative research in which all medical information conveyed has been verified by a clinician to be medically accurate.

The internet contains lots of film footage. This "anecdotal" footage can be highly charged or one-sided - perhaps surprisingly, in the positive direction. (Schlesinger, 2015)

Conclusion

Catalyst films can be effective and transformative because *"narratives can engage care providers at a deep emotional level, in reflecting on how services could be improved."* (Locock, 2014b) We hope you will experiment with their use in your activities and provide us with feedback for our continuous improvement. We will release new films produced by the Health Experiences Research Network on our website at HealthExperiencesUSA.org/CatalystFilms and update this guidebook as new data emerges on film usage.

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Appendix

A. Sample Agendas for Catalyst Film Viewing

Below are three sample agendas which may help you plan when scheduling a meeting to view the film for improvement purposes. We recommend that you dedicate at least 30 minutes, and ideally 45-60 minutes, to have a thorough and action-oriented debrief. Sections of the films can be used in follow-up meetings to jump start further conversations. Within the sample agendas, places that require customization are indicated in [highlighted brackets].

1. Sample Facilitator's Agenda For Viewing by Quality Improvement Team With Patients

a. Welcome and Agenda - 3 minutes

Sample text: *Welcome. The purpose of this meeting is to jointly view a "Catalyst Film" about health experiences [with XYZ]. The film is [X] minutes long and contains the views of several different patients. We all have perspectives to offer regarding serving the needs of patients [with XYZ]. Collectively watching, reflecting on, and discussing the film will guide our quality improvement work in a way that is grounded in health experiences.*

b. Introductions - 0-5 minutes

If your group is new to working together, make sure to do introductions. *(Name tags are also a nice touch, especially because most staff/providers will have identification, so you want to make sure that participating patients feel welcomed)*

c. Watch Film - X minutes (depending on length of film selected)

Pass out the handout (Appendix C) and give the group a minute to review the questions. Read the Introduction to the Film (Appendix B). Ask if anyone has questions. Show the Film.

d. Individual Reflection - 5-8 minutes

Allow time for individual reflection to answer the questions on the first page of the handout. *(Providing individual time to reflect will garner richer feedback from a broader array of participants. Collect the handout in addition to capturing the group discussion.)*

e. Group Discussion - 10-40 minutes

Use the backside of the handout "Team Discussion" section as a guide. In many clinics there is not enough time carved out for quality improvement activities. If you only have 10-15 minutes to discuss the film, acknowledge that limitation and indicate that you can continue the conversation at a subsequent meeting. Facilitate the conversation so that patients and staff/providers get equal time. Ask for confirmation or disagreement after something provocative/controversial has been said.

2. Sample Facilitator's Agenda For Viewing by Quality Improvement Team Without Patients

a. *Welcome and Agenda - 3 minutes*

Sample text: *Welcome. The purpose of this meeting is to view a "Catalyst Film" about health experiences [with XYZ]. The film is [X] minutes long. The people who are describing their experiences are not from our clinic but may be similar to people we see. Watching and reflecting on the film can spark conversations and establish touchpoints to guide our quality improvement work in a way that is grounded in patients' experiences. But ideally, it will not be the only way that we engage patients to make sure we are focused on the right quality improvement projects and the best solutions. After we view the film, we can discuss other methods we want to use to engage our own patients for further insights.*

b. *Introductions - 0-5 minutes*

If your group is new to working together, make sure to do introductions.

c. *Watch Film - X minutes (depending on length of film selected)*

Pass out the handout (Appendix C) and give the group a minute to review the questions. Read the Introduction to the Film (Appendix B). Ask if anyone has questions. Show the Film.

d. *Individual Reflection - 5-8 minutes*

Allow time for individual reflection to answer the questions on the first page of the handout. *(Providing individual time to reflect will garner richer feedback from a broader array of participants. Collect the handout in addition to capturing the group discussion.)*

e. *Group Discussion - 10-40 minutes*

Make sure to include a discussion of other engagement/co-design methods you could use to gather additional, local, patient experiences data. (Additional Resources are available in Appendix F)

Use the backside of the handout "Team Discussion" section as a guide. In many clinics there is not enough time carved out for quality improvement activities. If you only have 10-15 minutes to discuss the film, acknowledge that limitation and indicate that you can continue the conversation at a subsequent meeting.

3. Sample Facilitator's Agenda For Viewing With a Focus Group[1] of Patients

a. Welcome and Agenda - 3 minutes

Sample text: *Welcome. The purpose of this focus group is to gather your important perspectives on the care we are providing regarding [XYZ]. To start our time together we will view a "Catalyst Film" about health experiences [with XYZ]. The film is [X] minutes long and contains the views of several different people from a national sample, not from our clinic. Since [all, most, many, some] of you have experience with [insert illness/disease focus of film], you are uniquely positioned to help this clinic do a better job of caring for patients. Thank you for taking the time to share your expertise.*

Share details about refreshments, location of the restroom, and any other logistics.

b. Introductions - 0-5 minutes

Offer name tags and have everyone introduce themselves.

c. Watch Film - X minutes (depending on length of film selected)

Pass out the handout (Appendix C) and give the group a minute to review the questions. Read the Introduction to the Film (Appendix B). Ask if anyone has questions. Show the Film.

d. Individual Reflection - 5-8 minutes

Allow time for individual reflection to answer the first three questions on the handout. *(Providing individual time to reflect will garner richer feedback from a broader array of participants. Collect the handout in addition to capturing the group discussion.)*

e. Group Discussion - 30-35 minutes

Consider establishing guidelines for the conversation. Here is a sample modified from AHRQ:[2]

1. **What you say is private. We will share themes from this meeting, but not share who specifically said what. What was said in this room, stays in this room.** So please feel comfortable speaking openly and candidly with us.
2. If possible, talk in a **voice at least as loud as mine,** so everyone can hear.
3. Let's make sure **everyone has a chance to talk.**

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[1] An additional resource for patient focus groups is provided in Appendix F.

[2] AHRQ, Tool A.3-1 Patient Focus Group Guide. Available at:
https://www.ahrq.gov/research/findings/final-reports/crctoolkit/crctoolA31.html

4. There is **no one point of view,** so please allow all points of view to be heard.
5. Say what **you believe.** It doesn't matter whether anyone agrees with you.

Using the handout as a guide, have a conversation about patients' experiences in your clinic. Ask for confirmation or disagreement after something provocative/controversial has been said. Summarize what you have heard and capture themes on a white board.

a. Wrap-Up/Thank you

Thank patients for their contributions. Collect handouts for additional data. Offer stipend/gift card (it is essential to reimburse patients for their time and efforts). Share next steps.

4. Sample Facilitator's Agenda for Trainings to include Patient Perspectives

a. Welcome and Agenda - 3 minutes

Sample text: *Welcome. The purpose of this meeting is to jointly view a "Catalyst Film" about health experiences [with XYZ]. No matter where you work in your clinic, you deal with patients who have [XYZ]. In order to help our patients get excellent care, we cannot just assume we know what they need or want. We need to understand more about how they feel and what is important to them when they come to us for help. This film is meant to help you understand how patients feel--not just with your head, but also with your heart. Whether you work at the front desk, on the phones, as a provider, or as an RN or MA or manager, if you understand what it is really like for patients to seek care for [XYZ], you can make that experience a little easier, a little better for them. The film is [X] minutes long and contains the views of several different patients. We all have perspectives to offer regarding serving the needs of patients [with XYZ]. Collectively watching, reflecting on, and discussing the film will guide our training in a way that is authentically grounded in patient experiences. This training is meant to supplement other targeted training you are receiving [such as XYZ].*

b. Introductions - 0-5 minutes

If your group is new to working together, make sure to do introductions. *(Name tags are also a nice touch, especially because most staff/providers will have identification, so you want to make sure that any participating patients feel welcomed)*

c. Watch Film - X minutes (depending on length of film selected)

Pass out the handout (Appendix C) and give the group a minute to review the questions. Read the Introduction to the Film (Appendix B). Ask if anyone has questions. Show the Film.

d. Individual Reflection - 5-8 minutes

Allow time for individual reflection to answer the questions on the first page of the handout. *(Providing individual time to reflect will garner richer feedback from a broader array of participants. Collect the handout in addition to capturing the group discussion.)*

e. Group Discussion - 10-40 minutes

Use the backside of the handout "Team Discussion" section as a guide. *Can people recall a patient encounter that relates to [XYZ] that went well or could have gone better? Now that you've heard perspectives of real patients, what surprised you? What nugget of information are you going to take back with you to your work and how will you use that information?*

If you only have 10-15 minutes to discuss the film, acknowledge that limitation and indicate that you can continue the conversation at a subsequent meeting. Facilitate the conversation so that patients and staff/providers get equal time.

Ask for confirmation or disagreement after something provocative/controversial has been said.

B. Introductions to Film Viewing[3]

1. Introduction to Viewing by a Quality Improvement Team

If you plan to show this film to a Quality Improvement Team (with or without patients), we suggest the person facilitating the session use the following introduction to set the scene. An abridged version of the first two paragraphs appears in a voice over at the beginning of the film. Within the sample introductions, places that require customization are indicated in [highlighted brackets].

"The purpose of this short film is to spark conversations and establish touchpoints to guide our quality improvement work in a way that is grounded in health experiences. This film was put together from footage from a national sample of people experiencing [insert illness/disease focus of film]. The people who shared their stories did so for varied reasons. Their voices and personal experiences differed. But they shared a belief that speaking up and telling their stories would matter.

Obviously these are not people from our clinic. These clips were selected because they represent common patterns. Not everything you hear will be directly relevant to your situation, but each story can spark some ideas for continuous improvement. Listen for suggestions to enhance the experience for patients and families in your clinic.

[Add statistics about the illness generally, if valuable for your audience]

[Add framing about your system here:

- *Number of patients dealing with this condition*
- *Current relevant policies, processes, and workflows*
- *If there is something you want the team to reflect upon while they are listening, e.g. if you have a QI aim in mind, share that now]*

I have handouts for you to use to capture reactions to the film, and we will offer time for you to reflect after words and then time for us to discuss the film as a group."

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[3] Adapted from Healthtalkonline, HealthTrigger Films for Service Improvement, Ethnic minority mental health, DIPEx 2019. Available at: http://www.healthtalk.org/peoples-experiences/improving-health-care/trigger-films-service-improvement/ethnic-minority-mental-health#ixzz5trn5w6F0

2. Introduction to Viewing by Patient Focus Group

If you plan to show this film to a Patient Focus Group, we suggest the person facilitating the session use the following introduction to set the scene. An abridged version of the first two paragraphs appears in a voice over at the beginning of the film. Within the sample introductions, places that require customization are indicated in [highlighted brackets].

"We want to show you a short film about health experiences with [insert illness/disease focus of film]. We wanted to start our conversation with you by sharing this film so we all have examples to point to in sparking our future conversations. Since [all, most, many, some] of you have experience with [insert illness/disease focus of film], you are uniquely positioned to help this clinic do a better job of caring for patients. This film was put together from footage from a national sample of people experiencing [insert illness/disease focus of film]. The people who shared their stories did so for varied reasons. Their voices and personal experiences differed. But they shared a belief that speaking up and telling their stories would matter.

You may not agree with everything you hear. Your individual experience, and the experiences here may be different. These clips were selected because they represent common patterns. While not everything you hear will be directly relevant to our goals today, each story can spark some ideas for making care better.

[Primer: Share your goals. If you have a specific area of concern, or issue you want patients to think about add it here. For example: "We are struggling with helping patients complete diabetes self-care and we want your help to do a better job"]

I have handouts for you to use to capture reactions to the film, and we will offer time for you to reflect after words and then time for us to discuss the film as a group.

3. Introduction to Viewing for Trainings

If you plan to show this film to a clinic team (with or without patients), we suggest the person facilitating the session use the following introduction to set the scene. An abridged version of the first two paragraphs appears in a voice over at the beginning of the film. Within the sample introductions, places that require customization are indicated in [highlighted brackets].

"The purpose of this short film is to spark conversations and establish touchpoints to guide our workflows with patients in a way that is grounded in health experiences. This film was put together from footage from a national sample of people experiencing [insert illness/disease focus of film]. The people who shared their stories did so for varied reasons. Their voices and personal experiences differed. But they shared a belief that speaking up and telling their stories would matter.

Obviously these are not people from our clinic. These clips were selected because they represent common patterns. Not everything you hear will be directly relevant to your situation, but each story can spark some ideas for continuous improvement. Listen for suggestions to enhance the experience for patients and families in your clinic.

[Add statistics about the illness generally, if valuable for your audience]

[Add framing about your system here:

- *Number of patients dealing with this condition*
- *Current relevant policies, processes, and workflows*
- *If there is something you want the team to reflect upon while they are listening, e.g. if you have a QI aim in mind, share that now]*

I have handouts for you to use to capture reactions to the film, and we will offer time for you to reflect after words and then time for us to discuss the film as a group."

C. Handouts: Reflecting on the Film

1. QI Team Reflection on the Catalyst Film

While you watch the Catalyst Film, consider the following questions. Ideally you will have time to discuss your reflections with other views and make an action plan inspired by the film.

INDIVIDUAL REFLECTION

What resonates with me in the film?   What do I strongly agree or disagree with?

What, if anything, did I learn from the participants? How has my "way of knowing" shifted? How might we reframe our improvement work considering their perspective?

What might be missing from the stories that are important for us to consider? In what ways might our local environment or patient population be different?

What is MY Call to Action? What am I motivated to do?

TEAM DISCUSSION

What did we learn collectively about, and from, the health experiences represented in the film?

Discuss with the team each Call to Action. How has the film inspired us to adapt our plans or actions?

What structure or process will our team put in place to make sure our activities honor patients? How else shall we engage patients?

What are our next steps?

2. Focus Group Reflection on the Catalyst Film

While you watch the Catalyst Film, consider the following questions. We will give time for you to write reflections after the viewing and then talk as a group about your thoughts.

INDIVIDUAL REFLECTION FOLLOWED BY DISCUSSION

What do I strongly agree or disagree with in the film?

What might be missing from the stories? How has my (or my family's) situation been different? What questions does it raise for me?

What do I want my providers and clinic to know? About the experience of living with this illness? About the care they offer?

ADDITIONAL QUESTIONS FOR GROUP DISCUSSION

What, if anything, should we keep doing that we are doing? In other words, what is an experience that went really well for you that we should do over and over again?

What is an experience that we should stop immediately?

What else should we know?

Some questions informed by: Papoulias, C. (2018). Showing the unsayable: Participatory visual approaches and the constitution of 'Patient Experience' in healthcare quality improvement. Health Care Analysis, 26(2), 171-188; J. Bullock, D. Borrowman, F. Dest, S. Flores, Kaiser Permanente, personal communication, September 16, 2019

3. Training Group Reflection on the Catalyst Film

While you watch the Catalyst Film, consider the following questions. Ideally you will have time to discuss your reflections with other views and make an action plan inspired by the film.

INDIVIDUAL REFLECTION

What resonates with me in the film?   What do I strongly agree or disagree with?

What, if anything, did I learn from the participants? How might we adapt our workflow in light of their perspective?

What might be missing from the stories that are important for us to consider? In what ways might our local environment or patient population be different?

TEAM DISCUSSION

What did we learn collectively about, and from, the health experiences represented in the film? Can people recall a patient encounter that relates to [XYZ] that went well or could have gone better?

Now that you've heard perspectives of real patients, what surprised you?

What nugget of information are you going to take back with you to your work and how will you use that information?

D. Other Ways to Include Patients in Activities

Patient Engagement/Co-Design Strategies

Many models exist to include patients, family members, staff, and clinicians in quality improvement efforts, and most offer a continuum of engagement strategies to seek a variety of input from key stakeholders.
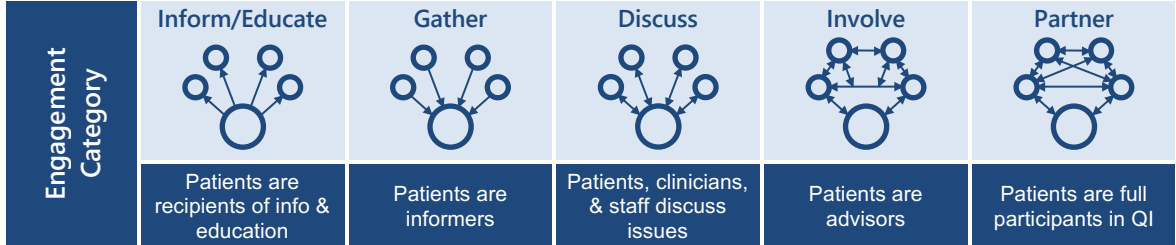
Continuum of Engagement from no participation to full participation (Davis, 2017)

These include suggestion boxes, surveys, focus groups, advisory panels, and including people as full participants on Quality Improvement teams. (Davis, 2017) We share links to selective resources in Appendix F below.

The intensity of patients' participation varies in these methods. In our own work, we have found great value from enhanced participation from advisory roles and co-design activities. (Davis, 2016) Others agree. Lessons learned from quality improvement in the Veterans Administration included that participatory methods "*can help to systematically explore the complexities of today's health care system and illuminate the factors that drive the success or failure of health care interventions.*" (Balbale, 2016) Further, they can "*extract key insights into local contextual factors*" and "*yield actionable data.*" (Balbale, 2016) A related concern is that passive methods-such as surveys - can contribute to a "tick-box or compliance" mentality that stops at information gathering, failing to lead to action or learning. (Locock, 2014b)

Each method has strengths and weaknesses. For this reason, we recommend "mixing and matching" methods to suit your specific goals. (Davis, 2017) For example, the strengths of widely distributed surveys is that they are representative, and they are "good at identifying issues with *functional* aspects of an experience." (Tsianakas, 2012). Their potential downside is that they can be used to confirm "pre-determined" issues if patients are not engaged in creating the survey, and while they may uncover issues, they usually do not provide sufficient detail to facilitate an intervention. (Tsianakas, 2012; Schlesinger, 2015) It is recommended that the patient experience data produced from surveys be explored through interactions that activate the data so it is useful for QI. (Donetto, 2019)

In contrast, Experience-Based Co-Design (EBCD) is good at focusing on the "*relational or emotional*" aspects of experiences, but it requires specific skills and can be timely and costly, significant barriers for many clinic environments. (Tsianakas, 2012). Accelerated EBCD, described in the guidebook, is a good alternative - balancing the pros and cons of several methods. (Locock, 2014b).

Participatory Visual Methods

Video, photos, and audio are increasingly being used to improve care internationally and in the United States. Collectively, these qualitative methods produce data that stands on its own. These data are also used to enhance other qualitative and quantitative data. The specific goals of different participatory visual methodologies are distinct as are the benefits and challenges. Some methods are used to prime stakeholders, such as patients, to provide richer information. This priming occurs through a variety of mechanisms: by building rapport between researchers/those engaged in QI and the stakeholder; by facilitating deeper communication; or by encouraging reflection. Visual methods can be used to express abstract ideas, subconscious knowledge or emotions, or know-how. (Pain, 2012) Others are used to illuminate "what is" to facilitate improvement. As part of an initiative to improve care transitions for elders with heart failure, video ethnography - videoing of everyday health care practices - contributed to greatly reduced thirty-day hospital readmission rates. (Neuwirth, 2012)

"When embedded within an established quality improvement framework, video ethnography can be an effective tool for innovating new solutions, improving existing processes, and spreading knowledge about how best to meet patient needs." (Neuwirth, 2012)

Another benefit of visual methods is to connect with vulnerable persons to make sure you are including unheard voices. (Pain, 2012) "Visual methods do not require participants to... have high levels of literacy" or skill to explain this verbally. Use of cameras (reflective photography) allows access to participants' lives to which one would not be privy, such as unsafe environments or those where outsiders are not welcome. (Pain, 2012) In public health, reflective photography has been used with participants for whom the spoken word may not be the most effective way to communicate (e.g., young children, people living with dementia, the side effect of a stroke, or intellectual disabilities) or to express emotions or know-how knowledge. (Papoulias, 2018; Balbale, 2016). Offering a variety of visual methods to collect and convey data can build trust. (Mulvale, 2019b)

Participatory visual methods are also used to improve *individual* care - as opposed to the care of multiple patients - such as in the use of video intervention/prevention assessment (VIA). (Rich, 2000) Lastly, visual methods that are non-participatory are also used to facilitate change. For example, procedure videos, recordings of medical procedures, are used for quality improvement, safety, and continuous professional development. (Makary, 2013)

E. Abbreviations and Glossary

Abbreviations

AEBCD	Accelerated Experience-Based Co-Design
EBCD	Experience-Based Co-Design
QI	Quality Improvement
VRE	Video-Reflexive Ethnography
VIA	Video Intervention/Prevention Assessment

Glossary

Accelerated Experience-Based Co-Design (AEBCD), is an approach that enables staff and patients (or other service users) to co-design services and/or care pathways, together in partnership through a systematic, participatory process of reflection and collaboration. It involves using an existing catalyst film about patient experiences, instead of making one during the co-design process, and viewing it separately and together to inform the co-design process. In this way it modifies Experience-Based Co-Design (read this definition on the following page) by using existing catalyst films made from archival nationally representative film footage, which have been found to catalyze a similar response in co-design participants. It requires half the resources of the full EBCD approach and shortens the process by several months. (Point of Care Foundation; Bate 2007)

Catalyst Films are short films made of existing interviews of patients discussing their health experiences and experiences receiving health care. They are designed to jump start a health care quality improvement (QI) or Accelerated Experience-Based Co-Design (AEBCD) process by infusing it with patient experiences from the very beginning, so that transformations are grounded in values of the people at the center of health care. (They are sometimes called "trigger films" in the United Kingdom).

Co-Design is an approach to participatory design (traditionally of a new product) that seeks to actively involve all stakeholders in a process to help ensure the results meet their needs and is useable (Prestantia Health). *Patient-Centered Co-Design* is defined as the act of collaborating with patients, families, and caregivers as equal partners in designing healthcare activities that affect quality of care and experience. (NQF, 2020) *Co-Design for Research* is defined as meaningful end-user engagement in research design and includes instances of engagement that occur across all stages of the research process and range in intensity from relatively passive to highly active and involved. (Slattery, 2020)

DIPEx Methodology is systematic qualitative research designed to represent the broadest possible range of health experiences, respect the expertise that comes from lived experience, deeply engage participants and advisors, and identify relevant patterns and themes. This is achieved by we find a diverse sample for each population we are studying; beginning each interview by asking participants to tell us their own stories, in their own words; giving participants access to full transcripts and full ownership over how their interviews are used; assemble an advisory group which includes participants, clinicians, advocates, and representatives of community organizations; and having multiple researchers analyze and categorize transcripts from each of the interviews (http://healthexperiencesusa.org/our-methods/)

Health Experiences refers to how people experience health, illness, treatment, and the delivery of care. It is a form of knowledge that is as important as scientific, epidemiological, and clinical knowledge to inform healthcare. (Ziebland, 2013)

Experience-based co-design (EBCD) of Health Care Services is an approach that enables staff and patients (or other service users) to co-design services and/or care pathways, together in partnership through a systematic, participatory process of reflection and collaboration. It involves making catalyst films about patient and staff experiences during the co-design process and viewing them separately and together to inform the co-design process. (Point of Care Foundation; Bate 2007)

Participatory Visual Methods aim to generate new knowledge for health systems by highlighting dimensions of patient experiences that are largely unseen.

Patient Engagement for Quality Improvement is an active, continuous process of ensuring that lessons drawn from our patients' experiences, wisdom and insight are integrated into the design of our care systems. (Davis, 2017)

Patient Experience is the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care. (Beryl Institute; Wolf, 2014) Patient experience is one of the three main pillars of quality of care, alongside safety and effectiveness. It positively correlates with these other indicators of quality, suggesting, and in some cases mandating, that "attention to patient experience...is seen as central to continuous improvement." (Point of Care Foundation, Papoulias, 2018)

Patient Stories/Narratives are carefully elicited patient accounts - in written, audio, or video form - that richly describe details of patients' experiences that are essential for assessing the "feel" of these interactions and their emotional overtones. Narratives can cover clinicians' bedside manner, caring attitudes, professionalism, and treatment style, in much more depth and nuance than conventional surveys. (Schlesinger, 2015)

Photo-Elicitation (including Reflective Photography) is a technique aimed to enhance interview data that initially did not have a participatory element. Patients are shown photos related to the improvement topic to prime and focus responses. Participatory forms include "autodriving" and

"reflexive photography" where patients take their own photos to drive the conversation in unstructured or semi structured interviews. In public health it has been used with participants from populations for whom the spoken word may not be the most effective way to communicate (e.g., young children, people living with dementia, the side effect of a stroke, or intellectual disabilities) or to express emotions or know-how knowledge. (Papoulias, 2018; Balbale, 2016; Pain 2012)

Quality Improvement (QI) is the systematic and continuous actions that lead to measurable improvement in health care services and the health status of targeted patient groups. (US DHHS)

Video Ethnography is the videoing of everyday health care practices and/or participant accounts of health care.

Video-Reflexive Ethnography (VRE) is an established, collaborative methodology focused on understanding the complexity of health care and improving the delivery of health care directly from the healthcare experience. VRE methodology comprises "*video ethnography*," the videoing of everyday health care practices and/or participant accounts of health care; and "*video reflexivity*," involving the reviewing of video footage with participants to make sense of visual data that they have gathered or feature in themselves. The principal focus of VRE is an emphasis on the expertise of providers and patients, and the new knowledge and problem-solving that is generated through a collaborative viewing, analysis, and interpretation of videos of care. (Iedema, 2019; Collier, 2016)

Video Intervention/Prevention Assessment (VIA) is a self-examination process in which patients are trained to use video camcorders and record visual narratives of their illness experience, including documenting their daily lives, interviewing family and friends, and recording "video diaries" about their beliefs and understandings of their illness. (Rich, 2000)

F. Additional Resources

Patient Engagement in Quality Improvement		
Resource & Hyperlink	**Author**	**Summary**
Patient Engagement in Redesigning Care Toolkit, Version 2.0.	Davis S, Gaines ME, Pandhi N., Center for Patient Partnerships, UW Health, Primary Care Academics Transforming Healthcare, UW Health Innovation Program; 2017.	Contains a toolkit for staff and a Welcome booklet for patients. The toolkit includes worksheets, tools, and resources to guide engagement work.
Patient Engagement: Heard and Valued	Snow, B. et al, Fraiser Health, 2013	A handbook for meaningful engagement of patients that have not traditionally been heard in healthcare planning. It includes guidance to identify subpopulations facing barriers, incentivize participation, and effectively communicating value.
Using Patient Experience for Improvement	Point of Care Foundation	A guide supporting clinical, patient experience and quality teams to draw on patient experience data to improve quality in healthcare. Offers resources to support data gathering, including focus groups, surveys, and patient narratives.
A Roadmap for Patient + Family Engagement in Health Care: Practice and Research	American Institutes for Research; Gordon and Betty Moore Foundation	The roadmap includes eight strategies and specific actions to partner with patients and their families to improve how care is delivered, including partnering with them in organizational design, governance, and policy making for healthcare to improve health and health care.

Resource & Hyperlink	Author	Summary
Strengthening healthcare through patient and family engagement in quality Improvement and research: A user's guide for patient and family advisors and their learning healthcare systems	Joffe S, Gleason K, Grob R, McGraw S, McLean P, Solomon M., The University of Pennsylvania Perelman School of Medicine, Philadelphia, PA; 2019.	Developed by a team of researchers and patient and family advocates, the guide is primarily intended for patients and family members, acting on their own or within Patient and Family Advisory Councils (PFAC) or other committees, who seek to partner with their healthcare systems to improve care through quality improvement and research. The guide can also be used by learning healthcare system personnel who seek to partner with patients and families to improve care.
Focus Groups: An Essential (Not Extraneous!) Tool of Patient-Centered Care	Planetree, 2017	A concise guide to focus groups, which "remain a vital component of any health care establishment's efforts to achieve a greater understanding of the experiences, attitudes and behaviors of their patients, employees and community-at-large." It offers rationale, resources, and tips.
GoShadow	Devanney, A. & DiGioia, T	Offers products, services, and free tools to facilitate shadowing the experience of patients and families to improve outcomes and experiences.

Experience-Based Co-Design

Resource & Hyperlink	Author	Summary
Experience-Based Co-Design – A Toolkit for Australia	Dawda, P. and Knight, A., Prestantia Health, Australia	A thorough toolkit with templates to use to facilitate co-design activities. It also contains 7 case studies of co-design in action.

Experience-Based Co-Design Toolkit	Point of Care Foundation, United Kingdom	Comprehensive, web-based step-by-step toolkit to guide an experience-based co-design process. Includes 4 cases studies, including one on accelerated experience-based co-design.
Experience-Based Co-Design of Health Care Services — Implementation Guide (Requires free registration to log in)	Pelton L, Knihtila M. Boston, Massachusetts: Institute for Healthcare Improvement; 2018.	Provides details on implementing the experience-based co-design (EBCD) innovation based on the experience of US health care systems participating in the International Innovations Network Learning and Action Community, led by The Commonwealth Fund and IHI. It's a companion to a case study available with the same link.
The Experience-based Design (EBD) Approach	NHS Institute for Innovation and Improvement, 2017.	Provides an introduction to the EBD approach (experience-based design) and companion tools and templates. Includes details of how to engage in Emotional mapping (a technique that can be used by patients and staff to describe in detail the emotions (positive and negative) experienced along the patient journey which helps to highlight emotional 'highs and lows' of the service or pathway.)
Co-Design of Services for Health and Reentry (CO-SHARE)	Mendel, P., Davis, L. et al, Rand Corporation, USA; 2019.	An Experience-Based Co-Design (EBCD) Pilot Study with Individuals Returning to Community from Jail and Service Providers in Los Angeles County. CO-SHARE is the first pilot study of EBCD in the United States. Results of the project focused on the feasibility of applying EBCD in a community-wide service system in the United States.
Experience-based co-design—Adapting the method for a researcher-initiated study in a multi-site setting.	Raynor, D. K., Ismail, H., Blenkinsopp, A., Fylan, B., Armitage, G., & Silcock, J., 2020.	Article describing the adaptation of research initiated EBCD for a multi-site study.

Quality Improvement

Resource & Hyperlink	Author	Summary
Improving Healthcare Services: Coproduction, Codesign, and Operations	Williams S.J., Caley L. (2020), Palgrave Pivot, Cham.	Epub with chapters on Quality Improvement, Co-production, Co-design, and accompanying case studies.
IHI's Science of Improvement: **How to Improve** **Forming the Team** **Setting Aims** **Establishing Measures** **Selecting Changes** **Testing Changes** **Implementing Changes** **Spreading Changes**	Associates in Process Improvement	The web-based Model for Improvement developed is a simple yet powerful tool for accelerating improvement. The model is meant to complement and accelerate improvement. It has been used successfully by hundreds of healthcare organizations nationally and internationally to improve a diversity of health care processes and outcomes.
Quality Improvement	U. S. Department of Health and Human ServicesHealth Resources and Services Administration, 2011	The purpose of the module is to provide a foundation and an introduction to quality improvement (QI) concepts and key topics for developing or improving a QI program within an organization. It offers a readiness assessment, and 14 additional governmental and non-gov't resources.
Organizing for Quality: The Improvement Journeys of Leading Hospitals in Europe and the United States.	Bate P, Mendel P, Robert G. Radcliffe Publishing; 2008.	This book contains international case studies of quality improvement efforts in hospitals and identifies themes across all sites. Of particular interest for QI teams, authors offer a "practitioner's codebook for the quality journey" offering a needs assessment organized by the six universal areas of challenges health systems face: structural, political, cultural, emotional, and physical and technological.

Resource & Hyperlink	Author	Summary
The CAHPS Ambulatory Care Improvement Guide: Practical Strategies for Improving Patient Experience.	Agency for Healthcare Research and Quality, Rockville, MD.	A comprehensive resource to guide performance improvement in the domains of patient experience measured by CAHPS surveys of ambulatory care. Designed to help organizations: Cultivate an environment that encourages and sustains improvements in patient-centered care; Analyze the results of patient feedback to identify strengths and weaknesses; and develop strategies for improving performance.

Other Participatory Visual Methods

Resource & Hyperlink	Author	Summary
Getting Started in Video Ethnography- A Catalyst for Guiding and Motivating Quality Improvement	Neuwirth, E., Price, P. M., & Bellows, J. Care Management Institute at Kaiser Permanente; 2010.	This toolkit offers a step-by-step guide to using video ethnography to guide and motivate quality improvement. It contains instructions, examples, and annotated resource lists for combining ethnographic techniques of interview and observation with video recording to understand patients' experiences more fully in health care, and online tools and templates.
Realities Toolkit #17: Using Participatory Visual Methods	Richards, N. University of Sheffield, 2011. Part of a collection of Toolkits of the Morgan Centre for Research into Everyday Lives	This toolkit aims to share experiences of using a variety of participatory visual methods, including photography. It covers practical ways of enhancing and sustaining participation.