

# Growing Our Movement

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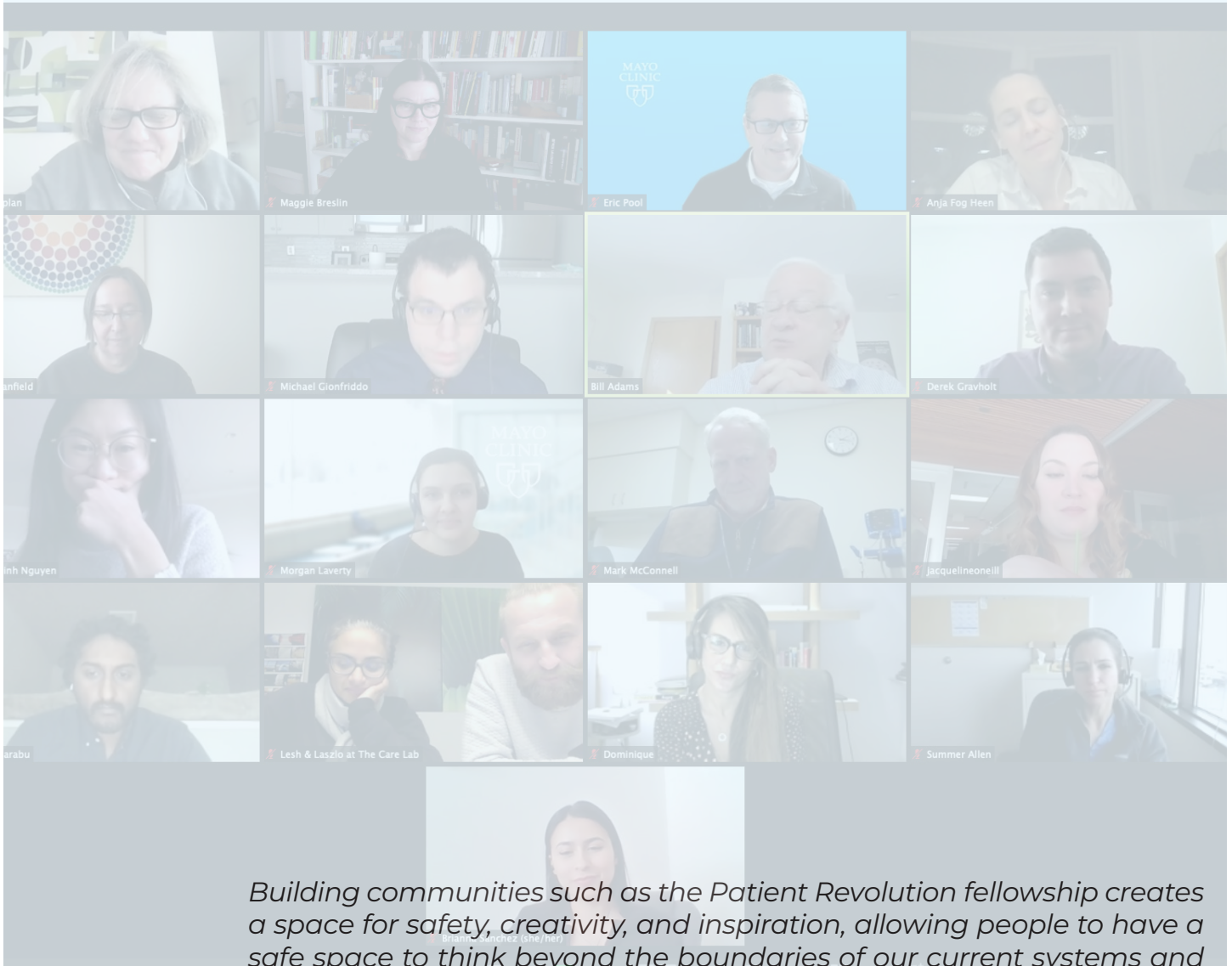
# Stewarding, Recruiting, Nurturing a Care Activist Community

## Preparing for advocacy and action

The activities of the care movement have something in common with careful and kind care itself; they are also rooted in noticing and responding.

Our learning and training programs are being developed to offer the skills, knowledge, relationships, and support necessary to help care activists notice and respond to the care related barriers and opportunities within their communities of influence. As we prepare the first of our own standalone courses to be available in fall 2022 and work with partners at healthcare professional programs (medical, nursing, health policy, and healthcare administration schools), we are committed to the following.

- Make patients and caregivers, as well as health professionals of every kind, common and equal participants in all education and training activities. Wherever possible, everyone must learn together.
- Create safe and supportive spaces for those with different backgrounds and perspectives to work together.
- Look to a wide range of disciplines in identifying skills and approaches, including those outside of healthcare. Storytelling, writing, speaking, observing, and making all occupy a prominent place in our collective action toolkit.
- Develop offerings to specifically address the challenges of working for radical change within a system that must continue to operate and attempt to serve the needs of patients.
- Design for resilience at the community level and cycles of engagement at the care activist level.



*Building communities such as the Patient Revolution fellowship creates a space for safety, creativity, and inspiration, allowing people to have a safe space to think beyond the boundaries of our current systems and discuss new ideas. This type of community creates a ricochet or domino effect that allows people to think outside the box and remain inspired.*

Fellow Michelle-Linh Nguyen

# Stewarding, Recruiting, Nurturing a Care Activist Community

## A Vision for The Patient Revolution School

The success of our movement for careful and kind care requires fundamental change of healthcare from industrial to careful and kind care for all. At the center of the effort are the relationships between patients and clinicians, and the environment in which they give and receive care.

Whenever possible, patients, caregivers, and clinicians learn together at the Patient Revolution School, developing deeper and mutual understanding, respect, and human connection.

The Patient Revolution School will offer patients, caregivers, family members, clinicians, health professionals, and clinical and administrative teams the inspiration, insights, tools, and language to speak more forcefully and effectively for the careful and kind care they want for themselves and their communities.

The Patient Revolution School will offer instruction and coaching to each person as they learn to recognize, capture, and tell stories of industrial healthcare and careful and kind care.

Patients, caregivers, and clinicians learn together at the Patient Revolution School, developing deeper and mutual understanding, respect, and human connection.

Additional instruction and experiential learning will immerse the learner in the language of care, ways to assess and measure the pathologies of care and careful and kind care in various settings, and methods for creating the systems, operations, and policies to support unhurried conversations, opportunities to see each patient in high definition, responsiveness, and minimally disruptive care.

As a school without walls, The Patient Revolution School will manifest in many different forms; as classes or complete courses within existing curricula for health professionals, as community education offerings, as part of Patient and Family Council on-boarding, as leadership training in healthcare, at trade and academic conferences, and anywhere else where people gather, in person or virtually, to learn or discuss about healthcare.

Furthermore, we intended to engage attendees of the school in learning collaboratives oriented toward implementing careful and kind care, as these experiments in practice are a rich source of experience, stories, and data and bring together multidisciplinary teams ready to learn.



## CULTIVATE CARE

### The Patient Revolution Elective

For the last two years, Dr. Paul Barr, a health services researcher at Dartmouth College, has taught a seminar class to students enrolled in the Master of Public Health program. As part of this course, the students read and discuss *Why We Revolt* among themselves and with invited faculty from our movement. Students are then invited to participate in our movement.



*A word cloud with the students responses to the prompt, share 3 words or phrases describing how you feel about The Patient Revolution moving forward.*



## CULTIVATE CARE



### Course Outline: Introduction to Careful and Kind Care

*A pilot version of Module 1 will be launched in Fall 2022.  
Information about sign-up will be available on our website.*

#### Audience

Patients, caregivers, family members, clinicians, administrators, care team members, Board members

#### Approach

Curriculum can be delivered to single stakeholder groups (aka patients), but will be more effective if health system personnel and patients/families learn together. Will deploy mixed methods for teaching including presentation, multi-media, storytelling workshop, and design thinking.



#### Outcomes

- Understanding the language of care, the pathologies of care, and the markers of careful and kind care
- Confidence in telling and owning your own story
- Confidence in speaking up for change
- Confidence in advocating for careful and kind care; speaking up in meetings and understanding of corporate language and practices
- Proficiency in basic change management and culture change strategies



## CULTIVATE CARE



### Modules

#### Module 1: The Power of Storytelling

2 hours. Could be stand-alone module

- Telling your own story to effectively advocate for meaningful change.
- How to make the story your own.
- How to feel safe sharing your story, and how to create safety for others

#### Module 3: How to make radical change happen

4 hours. Prerequisites: Module 1 and 2

- How to translate experiences into specific recommendations for change
- Theory of change
- Setting up a pilot project
- Applied design thinking
- Measurement
- Engagement and culture change

#### Additional options

- Facilitated book group with staff and patients together
- Patient Revolution 101 Video for widespread distribution and team engagement
- Individual and group coaching for storytelling

#### Module 2: Careful and Kind Care 101

2 hours. Could be stand-alone module, prerequisite is experience with storytelling

- Why the Patient Revolution
- What is industrialized healthcare
- What is careful and kind care
- Language considerations

#### Module 4: 90-day Reflection Session: Bringing it all together

Prerequisites: Module 1, 2, 3

Facilitated discussion group amongst all participants. What they learned. What is working. What are the struggles, barriers, etc.?



## CULTIVATE CARE

### Join the Fellowship

We will be accepting new fellows in January 2023. Sign up on our mailing list to be amongst the first to hear.

## Our Community of Care Activists

The Patient Revolution fellowship started in 2019 as a community of people who were moved by our mission and interested in helping us reimagine what careful and kind care would look like if we were to develop it anew from the ground up.

The fellowship is a hub for a community of care activists, those who are interested in expanding the existing capacity of people to care for, about, and with each other inside and outside of healthcare's walls. Building on our collective experience, the work of the Patient Revolution Fellowship is firmly rooted in co-creation, participatory design, research, and iteration.

The fellowship has grown organically, largely by word of mouth. The diversity of experiences, backgrounds, and points of view is what makes this group so unique and so powerful. Our fellows contribute to create, develop, and improve our programs and projects. They lead workgroups and suggest new avenues of exploration. They are ambassadors, speakers, facilitators, and partnership brokers. Patient Revolution Fellows are dedicated care activists. They contributed heavily to the content of this document.

The Fellowship program itself is an experiment in self-organization, shared power, self-management, natural and dynamic hierarchies, emergence, and collective intelligence. This means that fellows often must decide as a group which goals to address and how to organize and work to address them. Fellows meet monthly, contribute to and receive a newsletter every two weeks, and participate in collaborative platforms.

As of 2022, The Patient Revolution Fellows join us from over 10 countries and include patients, caregivers, clinicians of all specialties, healthcare professionals, researchers, lawyers, professors, and students.





# Learn to Elicit and Tell Stories

Stories are key to the movement for care. It is in stories that we are able to see and feel the power of care and the tragedy of its absence. You will see stories throughout this document that attempt to give you a glimpse of care through the eyes of patients, clinicians, and caregivers.

Over the last few years, we've been working to build out a story library. As our fellowship grows, we draw on the talents of some of our fellows to expand our outreach for stories. Over the next few pages, we offer some tools and tips to support story gathering.



*Stills from an animated story about cruelty*



## CULTIVATE CARE

### Eliciting Stories with Barrier Cards

We developed these cards as a way to help patients and clinicians talk about what can make conversations hard. The cards are a great way to foster discussion drawing from personal experiences.

The cards can be used to capture stories one-on-one or as a catalyst for group discussions at a workshop or conference.

I don't want my comment or question to make me appear unintelligent or concerned about the wrong things.

I don't want to be a burden to my doctor.

I worry I'll be judged if my choices are different from what most other people would do.

I assume that decisions need to be made right away.

I don't want my doctor to think of me as a difficult patient.

I worry I'll be judged for considering cost in making decisions about my health.

I assume that the doctor's recommendation is the only option or the best option.

I assume that if an aspect of my life is important, the doctor will ask me about it.

*Patient Barrier Cards*

I don't want my patients to think of me as cold or uncaring.

I worry that my patients don't fully understand the medical terms and concepts I translate for them.

I worry that my personal biases prevent me from helping my patients make the best decision for them.

I struggle to bring up sensitive topics like rape, abuse, discrimination, or how to prepare for death.

I worry that my inability to identify with a patient may limit my capacity to care for them.

I worry that I will become overwhelmed by my patients' needs.

I'm uncomfortable saying that I don't know or I don't have the best answer.

I worry that my workload is depleting my own emotional capacity.

*Clinician Barrier Cards*



## CULTIVATE CARE

### Tips for Interviewing to Elicit Stories

Interviewing consists of four parts: preparation, holding space with active listening and insightful questioning, transcription and editing, and storyteller review.

#### Prepare

Know a bit about the storyteller's topic and reflect on what you may be bringing to the conversation. For example, a story about caring for an ill parent will be held differently by an interviewer who doesn't have that experience versus an interviewer whose parent recently passed away. In the latter scenario, it may be harder to hold emotionally safe space and not muddy feelings.

#### Holding Space

Let the story free flow, even ramble at times. The fewer interruptions the better. Interrupt the storyteller only at natural pauses and when there is a sense that more could be known. Be alert to non-verbal cues. State what you heard and also what you wonder about. This can help the interviewee go deeper.

#### Transcribe and Edit

Transcribe the interview through whichever format you choose. Turn the interview into a story by pulling out parts and putting them in an order that supports the intended context and flow. You might need to form a few sentences or words to help with transitions, but 95% of the story should be the storyteller's words. Ask yourself what are you most drawn to and what parts feel the most powerful. Form the story around those. This is mostly intuitive and felt rather than taught. It is not uncommon for me to pull bits from a 7-10 page document to end up with a one page story.

Once the story is there, try not to edit it too much. The more editing, the more sterile and less authentic the story becomes. Remember, especially when discussing personal and emotional content - humans aren't always grammatically correct.

#### Storyteller Review

The last step is to ask the storyteller to review their story before it is used. This is about gratitude and respect. The storyteller has the right to change their mind, which understandably can happen (albeit rarely), even with the standard offer of anonymity. Depending on the situation, I may have them sign a release and confidentiality forms. Most importantly, enjoy connecting with a person who trusts you enough to be vulnerable with you as he/she/they share their story.

*Shared by fellow Melissa R'kingsley*





## CULTIVATE CARE

### Tips for Sharing Stories

Sharing your own experiences in health care is a way to encourage careful and kind care. Here are some basic tips about sharing stories:

#### **Know your audience**

Take the time to understand the challenges of the audiences you are speaking to

#### **Pick three key messages**

Using the language in this document, pick three key messages that you want to share with your audience

#### **Encourage one bold take-away action**

Leave the audience to consider one bold practical action that will bring them closer to careful and kind care

#### **Be kind to yourself**

Sharing health care stories can make the storyteller feel vulnerable. Ensuring you have a safe space to share your story is key as is recognizing the emotions that can come up from telling stories.



*Photo by Stephen Wreakes*

*Shared by fellow Sue Robins*

# Disseminate Our Message

## A Partner Approach to Speakers and Facilitators

As part of our movement, The Patient Revolution will train care activists in public speaking and facilitation. Directly engaging with diverse audiences is an effective way of disseminating our message of careful and kind care for all.

A particularly effective approach is to partner speakers and facilitators. This partnering offers several advantages: speakers can offer different perspectives, stories, and language, these diversity of views “from the podium” encourages dialogue and conversation, and the speakers can give each other feedback to continuously improve.

## Speaker Partners

As part of our commitment to creating space for all voices in healthcare, we encourage inviting speakers as partners. The combination of experiences encourages a different conversation. We've highlighted a few examples of speaker pairs below.



### Patient + Physician

Victor Montori MD and Sue Robins present about the ways the failures of industrial healthcare and the promise of careful and kind care through their unique experiences.

### Designers + Pharmacist

Lekshmy Paramaswaran and László Herczeg present with Michael Gianfriddo about the ways that design can help in creating the conditions for careful and kind care.

### Patient + Medical School Student

Greg Merritt and Andrew Yang present about how learning to care for patients is taught in medical school and what role patients can play in moving it more towards careful and kind care.





## CULTIVATE CARE

### Responding to those who are engaged skeptics

One of the biggest challenges we face as a movement for change in healthcare is not that people don't believe change is needed. It is that change at the scale and level we are talking about seems impossible. This is a reasonable response to the state of healthcare today. As priorities have shifted towards business interests, the people who must engage with the system - patients, caregivers, clinicians, and staff - have been repeatedly asked to lower their expectations and get comfortable with less. It is a lot for anyone to hold.

These are a few ideas that may be useful for connecting with these people. And they might not be ready to join us yet. That's okay. We lead with generosity.

#### Invite them into our community

We spend a lot of time talking about the barriers and challenges around radical change in healthcare. We welcome those who want to engage in those dialogues. While our vision for the future may be utopian, our expectations for how we get there are not.

#### Share your own reasons for joining the movement for care

If you have joined us, you have probably also dealt with your frustrations and disillusionment around change in healthcare. Your own strategies for finding space for hope may be most meaningful.

#### Introduce them to the idea of micro-revolutions

Micro-revolutions, coined by one of our fellows, Mark McConnell, who would likely consider himself an engaged skeptic, are small acts of rebellion that feed your spirit. This is Mark's list of micro-revolutions that he is working on.

##### What micro-revolution can I start today?

I have decided that the following are under my control...these are the areas where I can choose to act.

1. I can dream.
2. I can support organizations that seek a mission aligned with mine: careful and kind care.
3. But mostly, it comes down to the 3 x 5 index card I have taped to my computer screen that says: "Smile. Be Kind to Everyone. SEEK to understand"

*From fellow Mark McConnell*

# Disseminate Our Message

## Reading and Watching Clubs

Gathering people together to discuss books like *Why We Revolt*, journal articles, or watching movies or documentaries is a good way to kickstart a discussion about industrial healthcare and careful and kind care.



## Reading (and Watching) Club Tips

- Try to invite a diverse group of people with different experiences. Do you know people who live with chronic conditions? People who work as doctors or nurses? Encourage them to join and share if they are comfortable. If you need more voices around the table, reach out to us, we love to join if we can.
- Be thoughtful when choosing readings. Aim for diversity of experiences in these choices as well.
- Use conversational prompts to get the conversation going
- If you are facilitating the discussion assign a scribe to capture and share participant stories into our Story Library
- Make sure to create space for joy in the discussion. Encourage sharing about positive experiences.

This is an excerpt from  
How We Revolt v 1.0 | Published June 2022

**The conversation continues.**

For the most up to date summary of our work and thinking, as well as links to relevant resources, visit our website at [patientrevolution.org/hwrdoc](https://patientrevolution.org/hwrdoc) or scan this QR code.



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