

Our Movement in Action

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Creating Environments for Careful and Kind Care

The work of creating environments for careful and kind care requires affecting change at the policy, systems, culture, technology, and training levels.

Within our community, we are shaping and learning about policy and practice through from those who have pursued this work. Our community includes many people with experience designing, developing and implementing programs to support careful and kind care as patients receiving care, as professionals working within organizations, and as external consultants.



Early in his medical practice, Ralph had instituted the habit of always being available to his patients. He established evening office hours for those who could not leave their children or their jobs during the day. He regularly called patients at home to see how they were doing. Many of his patients had his home phone number; and they knew they could call him if needed. He visited nursing homes and made house calls right up to his retirement in 1996 at the age of 88.

From the biography of Dr Ralph Warburton, a family medicine physician who championed the patient-doctor relationship

Creating Environments for Careful and Kind Care

The role of policy

The radical transformation of healthcare from industrial to careful and kind care will require changing the rules that shape the healthcare system. These structures are in part responsible for healthcare's culture, for shaping the service innovation pipeline, and for advancing forms of healthcare devoid of care. These structures reflect the corruption in the mission of healthcare and contribute to further it. To fundamentally turn away from industrial healthcare, our movement must invest efforts to change the rules, to change healthcare policy.

Most of the existing healthcare policy exploration and discussion relates to health (which depends to a small degree on healthcare itself), access to healthcare (including issues of equity), and affordability. The latter is increasingly discussed using the lenses of value and equity. Comparatively, there is virtually no discussion about common care (as a social determinant of health and enabler of careful and kind care) and about enabling structures and processes to advance care itself (beyond some interest in patient experience).

For health care to contribute to improving the lives of people, it is not sufficient to study policies, programs, and their impact on outcomes and costs, between inputs and outputs. Because care takes place between inputs (policies, people, technology, and dollars) and outputs (access, health care utilization, practice variation, deviation, patient outcomes, and costs), it remains assumed and invisible to policymakers. Policymakers draw from analyses of health care financing, organization, and performance at the macro levels and not from analyses of patient-centered care innovations (e.g., shared decision making) short of the time and resources they take (input) and the variation in care (sometimes guideline discordant) and outcomes they produce (outputs).

The radical transformation of healthcare from industrial to careful and kind care will require changing the rules that shape the healthcare system.

Policy blindness about care results in a long list of unintended consequences of extant policies that threaten the sustainability of health care, including clinician burnout, the processing of categories of patients rather than of each one, the delegation of medical errands to overwhelmed caregivers and patients, the corruption and bloating of patient records, and the cruel dismantling of the patient-clinician relationship.

Our movement's policymaking work must bring policy awareness and focus on care. A focus on care must recognize that the social, economic, corporate, and political determinants of health that fuel the expansion of chronic psychological and physical health problems and contribute to care deficits. In addition to promoting common care, this recognition must translate into prioritized investments in primary care, supporting the clinicians and teams working to care for, about, and with people.

A policy agenda focused on care would capture contributions to quality using appropriate measures of process (e.g., timely, empathic, unhurried conversations, with attention to the problematic situation and co-creation of sensible care plans), structure (e.g., accessible and well-integrated care teams, continuity of care), and outcomes (e.g., patient enablement, quality of life, disease control, burden of treatment) of care.

The central tenet of this policy work is that it is possible and politically desirable to promote (a) careful and kind care for all, that (b) notices and responds to each person's evolving circumstances and values, within (c) strong personal, continuous, and trusting relationships, supported by (d) material, emotional, and data resources, by (e) highly collaborative interactions between clinicians, community services, and informal caregivers, within (e) equitable, sustainable, and always-learning health care systems.

The policy problems related to healthcare are universal. Healthcare systems with limited resources, regardless of mechanism (austerity, poverty, greed, or corruption) fail to invest or extract resources. This depletes care. Because care depletion is a global phenomenon, our policy efforts have a global reach. A global reach also helps us draw policy lessons across jurisdictions.

Our movement's policymaking work must bring policy awareness and focus on care.

This work initially takes two forms:

- Policy dialogues for careful and kind care: this initiative promotes close, interdisciplinary explorations of the problems of care.
- Joining with other advocacy groups as they discover the importance of a policy focus on care and seek solutions involving structural, legislative, and political effort to advance careful and kind care for all.

Policy dialogues must help policy makers and a broad array of health care stakeholders understand what methods help achieve a compassionate and competent response, and how extant policies promote or hinder the selection and use of these methods and their relative effectiveness.

Policy innovations and joint advocacy efforts can then contribute to change healthcare rules or their interpretation and application to promote the conditions that enable careful and kind care for all.

Creating Environments for Careful and Kind Care

The role of sensing

It is important to consider the effect of changes to the healthcare environment, but it can be limiting when the only meaningful measures are those that are easily captured and align with traditional business metrics. In healthcare, these are often measures of efficiency (e.g. issue addressed with a less expensive resource), throughput (e.g. saw more people), and time (e.g. accomplished the same in less time.)

To address that issue, we are encouraging organizations to think in terms of sensing rather than measuring. Sensing is more expansive than measurement; drawing on interviews, open ended questions, observations, and stories along with measures like satisfaction scores and assessments of burnout to create a holistic picture of what is happening. Sensing allows us to draw insights about the culture, operations, and relationship with the community alongside commonly collected data and helps us paint a picture for an organization on the pathologies of care and characteristics of careful and kind care.

Our Fellows have identified some of the characteristics that are indicative of the places where careful and kind care is likely to thrive. These can be used as a starting point to look at current culture, operations and staffing, and relationship with the community and the extent to which these conditions are present.

These areas include:

Characteristics of the Culture - humility, trust, patience, transparency, ability, and willingness to speak up

Characteristics of the Operations and Staffing - space and time for unhurried conversations, attention to pace and tempo, support for cultivating reserves, space and time for reflection and learning

Characteristics of the Relationship with the Community - an understanding of how life experience and trauma impact health and the ability to participate in world, deep local knowledge of communities, connections to organizations and people within the community, seeing people where they are



CULTIVATE CARE

The following chart offers some questions and way of sensing as a starting point.

	Questions	Ways of Sensing
Leadership	<ul style="list-style-type: none"> • Is care a priority of our organization? • How does care show up in our actions? • Do we embrace critiques of our organization? 	Hold a town hall and solicit stories from patients and clinicians about hurry, blur, cruelty, and burden. What did you hear?
Hurry	<ul style="list-style-type: none"> • What is our approach to access? • What is our approach to continuity? • Why have we made these decisions? 	Open schedules for a handful of clinicians, ask patients how long they think a visit might take. Schedule accordingly. How did this effect visits and satisfaction?
Blur	<ul style="list-style-type: none"> • Do patients feel someone at the clinic knows them? • Are clinicians penalized if patients don't meet clinical targets? 	Bring in writers to capture the biographies of a handful of patients and share them with the clinic team. How do those biographies impact care plans?
Cruelty	<ul style="list-style-type: none"> • How do we respond when a patient is in crisis? • How do we respond when a clinician is in crisis? • How often do we say no to patients? 	Say yes to every patient for a week. Assign a group of clinicians to respond. What is the result?
Burden	<ul style="list-style-type: none"> • What work are we giving patients? • How do we integrate patient experience into the care plan? 	Do home visits for a handful of "non-compliant" patients. How do care plans change?

Creating Environments for Careful and Kind Care

Teal principles

Some of what we describe when we talk about the conditions for careful and kind care has similarities to features of 'teal' organizations.

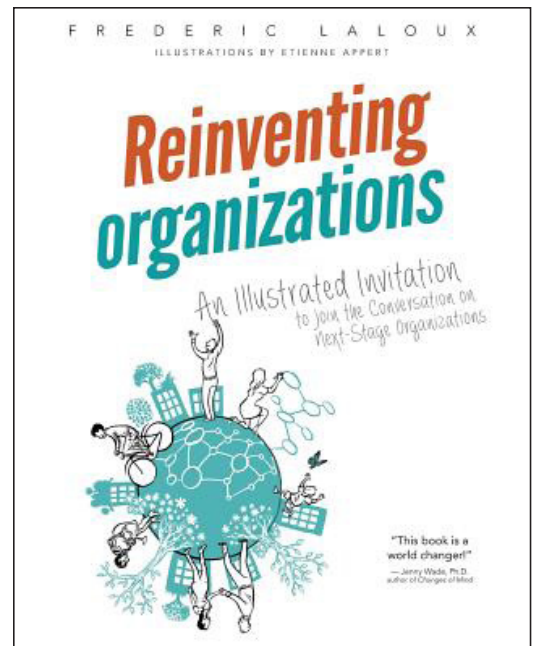
In his book *Reinventing Organizations*, Frederic Laloux talks about 3 core tenets that can fundamentally change management. We see opportunity in drawing from their recommendations, in particular regarding self-management and wholeness.

Self management

A key insight of Laloux is that "hierarchy cannot cope with complexity." This has enormous relevance to healthcare, where the work of developing a care plan for a patient is fundamentally complex and unique. But often the "things that must be done" are decided by people far away from the point of care and with little flexibility to respond to the needs of an individual patient. Rethinking organizational structure, decision making, and performance management, as well as supporting a collaborative team approach and incentivizing the team's ability to anticipate needs are ways to rethink the role of management in healthcare. Our work is starting to explore this.

Wholeness

To create a safe space for patients requires a safe space for clinicians and staff as well. The ability to bring your whole self helps to create a sense of belonging, comfort, validation, and legitimacy. This requires rethinking aspects of the staff experience around meetings, reflection, job titles, and recruitment. The benefit is that an organization will have a care team better able to respond not only to the clinical needs of patients, but to the emotional and practical elements of their situation as well.



Care for the people that care for the patients

Industrial healthcare is not only cruel to patients but also to clinicians. About 40% of clinicians exhibit symptoms of depersonalization and loss of empathy, the hallmark of moral injury and burnout. These clinicians often work in industrialized and unsafe environments in which they must exercise additional effort and judgment to notice and respond, to care for their patients. This exhausting effort often leads to many clinicians to abandon clinical practice or reduce the hours they dedicate to direct patient care, which compounds problems of access to care for patients, disruption of relationships, and workload to remaining clinicians. Moral injury and burnout are a consequence of industrialized healthcare. Our movement for care aligns with the ultimate intrinsic motivations of clinicians and, by fostering caring environments, enables the realization of their professional calling.

Fostering a caring environment must be the result of intentional strategic action about the physical design, organizational structure, leadership structure, employee autonomy and social and cultural determinants of a caring environment such as transparency, equity, inclusiveness and mission orientation.

The challenge for a healthcare organization wishing to foster careful and kind care is to provide careful attention to arranging physical and emotional resources in a manner consistent with this mission. Healthcare organizations should be focused on the care of patients. To do this well, organizations must focus also on its people and the environment in which they come together to be more than merely the sum of their individual parts.

As healthcare leaders focus their organizations on caring as their main goal, they must work to foster a caring environment for their staff to care for and about each other and for their patients. Designing and managing certain specific organizational attributes, for example, the relationship between staff wellbeing and patient care, changing work conditions to reduce burnout, and measuring staff performance, can increase the probability of fostering a caring environment that promotes staff wellbeing and optimal patient care.

Adapted from writing of fellow Mark Linzer

Our movement for care aligns with the ultimate intrinsic motivations of clinicians and, by fostering caring environments, enables the realization of their professional calling.

Applying Careful and Kind Care Principles to Designing Care Services

Design Principles

There are several principles that we think would demonstrate careful and kind care in practice.

Care

Noticing and responding well requires some **continuity of care** and **unhurried conversations**. They also require healthcare that makes it easy to access and use resources across the range of patient capacities. A focus on noticing should not be confused with a commitment to surveillance and monitoring. These technologies (for behavioral monitoring, for instance) should be part of the co-created plan of care and not be introduced by default.

Deliberately noticing and co-creating responses for each patient should make care less susceptible to the contextual challenges introduced by longstanding disadvantage and racism. Making healthcare easy should further reduce disparities based on other socioeconomic injustices such as illiteracy, social and geographic isolation, and material poverty.

Noticing and responding may also require a range of care partners, within and outside the clinic, who can be brought into the care plan (not just handed off or referred to) to enhance its effectiveness. To this end, clinicians should be aware, work well, and contribute to sustain any pro-care and pro-health community and family assets and support common care.

Team

Healthcare professionals should embody a commitment to care, to notice and respond. Each one is trusted to notice and respond well to a person's needs. To support this work, we need to foster relationships without hierarchies, relying on mutual commitments and accountabilities based on self-management and ownership. Services need to be designed to optimize presence and minimize distractions and noise, enabling conversations that reset compassion and sensing, adjust perceptions, and expand repertoires of response through collaboration, co-mentorship, and mutual learning.

Every patient has a story that goes beyond the symptoms that lead them to seek healthcare. Ensuring that the 'biography' of the patient is present in the healthcare encounter enables a more compassionate and competent response, including how, when, and where to address a patient's care needs. Consider what might be different if the clinician always saw a brief biography or life story of the patient when they reviewed the care record.

The notion of noticing and responding should extend to the way the staff relate to each other. Staff must care for each other. This is facilitated by the expectation that every healthcare professional can bring their whole self to work – their technical expertise and intellect but also their creativity, intuition, and emotions – while behaving in ways that extend comfort and caring to others.

The back office should be limited to minimal and legally mandated tasks and responding to external entities, but less so to the management of personnel. This should be entrusted to the team itself where possible.

In its language and actions, staff need to ensure that patients, their interactions, their data, and their stories serve to fulfill the “care and learn” missions of healthcare. Safeguards to avoid loss of privacy and other threats to patient safety should be designed and evaluated (as with other “care and learn” functions) with transparency, timeliness, and rigor with all stakeholders. The response to a breach of care, privacy, or safety should include timely, complete, and truthful disclosure, restricted only by any competing priorities stemming from the primary mission. The legal, economic, or reputational protection of the organization should not take priority over advancing the problematic situation of patients first and of staff second. To enable careful and kind care, not only should teams care for and about each other, but should care with each other in an environment that all – in the most inclusive sense possible – agree is safe physically, emotionally, and intellectually. This environment facilitates learning and improvement, the thriving of staff who bring their whole self to work and taking ownership of noticing and responding as everyone takes part in the care of patients.

PRINCIPLES

CARE

- Co-create care for, about, and with any and every patient and their patient-defined families
- Notice the biology, biography, and social aspects of a person’s situation to respond with careful and kind care

TEAM

- Let care guide the use of language and the selection of communicative tools with patients and each other. Communication must be generous, true, and clear
- Teammates must care for each other and trust each other to determine how best to look after patients. Each staff member should bring their whole selves to this work
- Staff learn by drawing insights from the care experience and by evaluating the impact of care on aims that patients value
- Teams create an environment that is physically, emotionally, and psychologically safe

ORGANIZATION

- Continuously learn to ensure sustainability, elegance, and innovation
- Partner with the community to co-create care practices inside and outside the clinic
- Embrace the idea that not all care needs to be professional and promote, support, and sustain common care

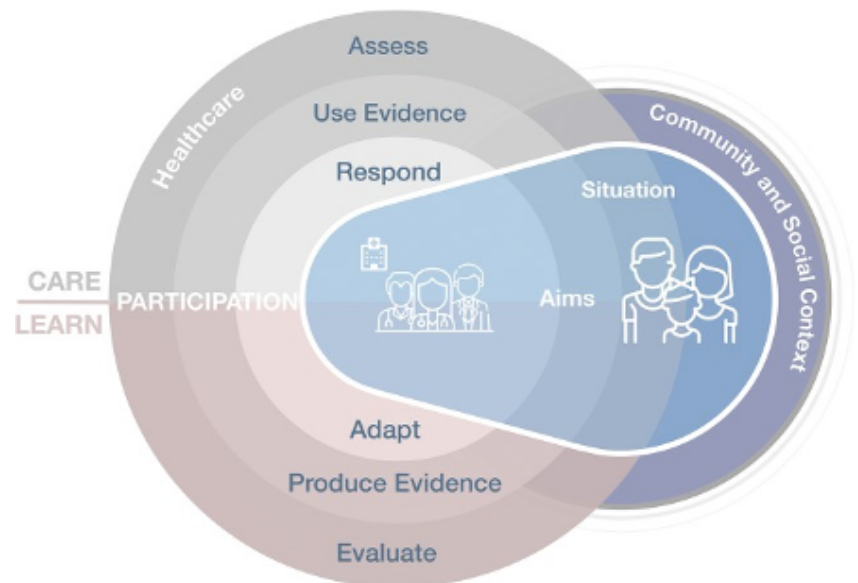
Applying Careful and Kind Care Principles to Designing Care Services

Organization

Organizations should implement both ‘care’ and ‘learn’ functions. The latter requires developing information, data, and story gathering capabilities that can determine how well the organization and the staff are noticing and responding. Without this ongoing learning, the organization cannot claim that it is acting with competence, cannot be a good steward of limited resources, and cannot orient its energy to innovate to better respond to the evolving needs of patients. Thus, sustainability, elegance, and innovation are key capabilities that support careful and kind care.

The sustainability of the healthcare requires managing demand for care. At the macro level, medicalization of suffering and de-skilling of common care contribute to that demand. Organizations must therefore participate in the process of skilling people up in their ability to care for, about, and with each other and be a beacon of solidarity in their community.

The sustainability of the community as a place to flourish is a responsibility of every citizen, and that extends to healthcare organizations as a party to the community. To this end, as these ‘anchor organizations’, should offer entry level jobs and training for young people, work opportunities to a diverse workforce, and operating with the smallest possible ecological footprint. This not only extends the noticing and responding to the social and material worlds in which they operate, but also contributes to the health of community members, reduces demands on the clinic, and therefore sustains careful and kind care for all.



Care and Learn model

A 360° assessment of careful and kind care

Industrial healthcare, like other industries, measures and improves the quality of service and processes. This work improves the reliability, safety, and efficiency of these processes. Across all industries, however, those same methods fail to adapt well to the processes that rely on human interaction, often finding that improve the reliability and efficiency of these process they must remove the ‘human’ element. They offer an external motivator, a test to ace.

Focusing on “acing the test” and getting high scores on measures ‘provide the illusion of good, better or improved care, while favoring measurable care that is predominantly standard, technical, mechanical and context-blind’. Focusing on “acing the test” instead of improving the underlying care dehumanizes care and degrades health care professionals. Healthcare devoid of care is what we are trying to fundamentally change. Care, like love, is a human capability and we are working for a healthcare capable of careful and kind care for all.

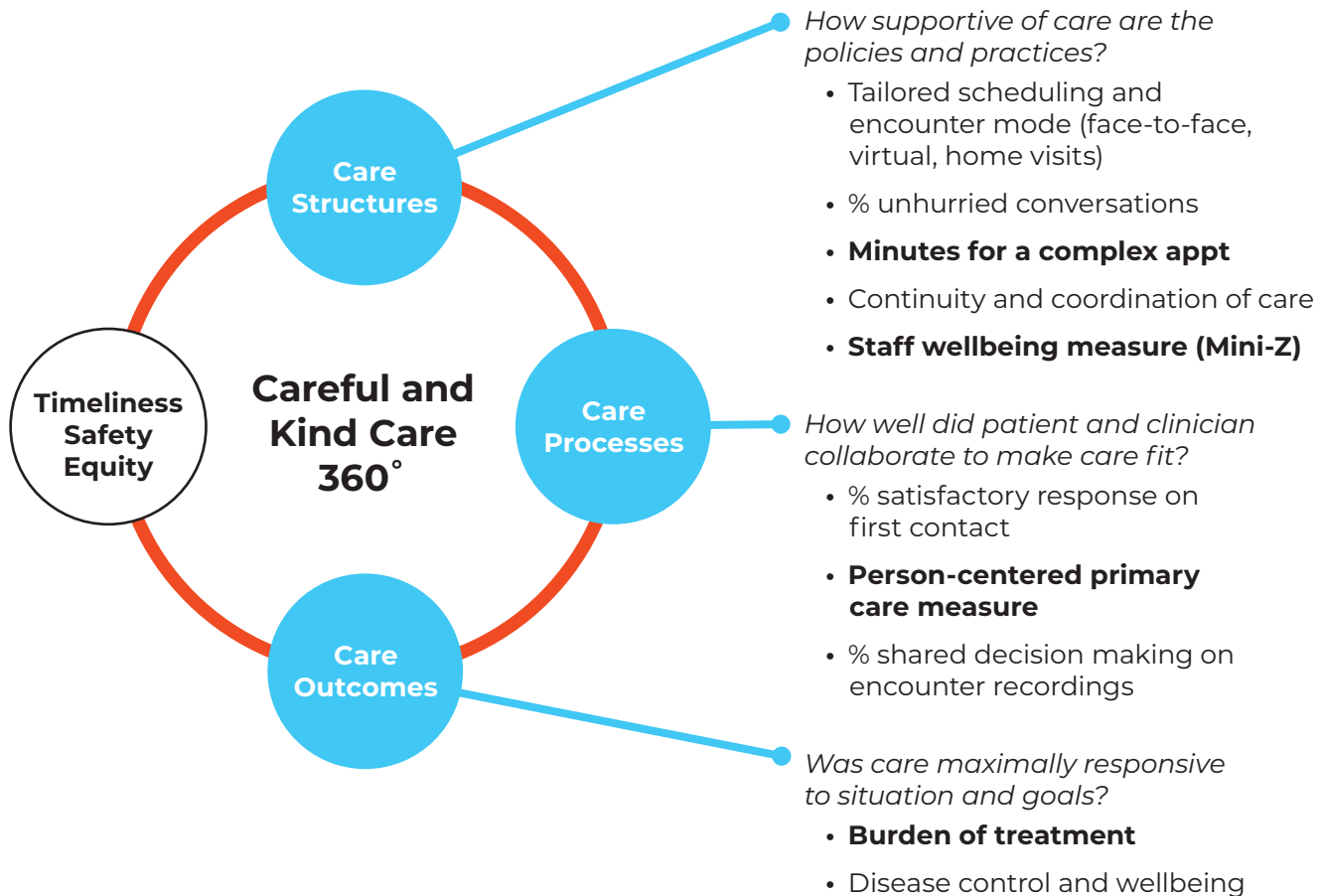
However, we still need to know if we are making progress. Pending further exploration, this determination should deploy multidimensional assessments that closely track with underlying improvements – as noticed by those giving and receiving care – and are linked to intrinsically rewarding care experiences and better patient outcomes.

The starting point for determining progress toward careful and kind care for all should include asking “is this the most careful and kind care response we can muster?”. Answers will come from:

Carefully selected quantifiable measures relevant to care receivers and care givers (relevancy that is likely to differ over time and across patients); and Stories from the point of care to make judgments about the care received and given.

While a selection of quantifiable measures may help with tracking and benchmarking and can supplement narrative assessments, stories are more likely to provide specific, contextual, motivating, and actionable insights for improvement. The use of stories requires a commitment to sensing, listening to understand, and noticing to respond.

The starting point for determining progress toward careful and kind care for all should include asking “is this the most careful and kind care response we can muster?”



The figure shows a prototype of a 360° assessment of careful and kind care for all at a health system level.

In addition to capturing relevant stories, it proposes assessing measures of care structure, processes, and outcomes.

How well the care plan responds to the situation can be determined primarily by the care receiver and their account of how well they are doing. Lab tests, physiologic measures, and imaging studies and the quantification or rating of experiences and symptoms can contribute to assess disease control and wellbeing. These assessments tend to be associated with a veneer of objectivity, facilitate some activities of the learning healthcare system (using aggregate data), and their consumption is efficient, but they must stand in secondary support of the patient's narrative account of wellbeing, which remains primary.

System-level assessments about the healthcare system's timeliness of access, safety and reliability, and equity, complement these care-level measures.



CULTIVATE CARE

A Story about Measurement

‘Measurement’ of careful and kind care might sound like an oxymoron.

If we are to turn towards careful and kind care, the methods by which we operate must also be careful and kind. I am very drawn to sensing as a way of understanding our care and recognize many merits in the approaches. However, as long as measurement is required by payors and regulators, this will draw the focus of organizations. In trying to navigate these tensions, we have begun to develop a set of questions for staff and patients about careful and kind care.

I have witnessed firsthand the power of simple questions such as ‘was today a good day at work?’. These ‘red day / green day’ measures give a rapid ‘temperature’ check on staff morale and highlight where further investigation might be needed. Similarly, simple, regularly asked questions on careful and kind care could be used to identify bright and dark spots and look for trends. One thing to note in developing these questions with patients and staff is that a brief explanation of our language will need to accompany them.

Ask staff and patients “did we offer careful and kind care today?”

Possible ‘measures’ of careful and kind care:

Staff measures -

Did we give careful and kind care* today?

On a scale of 1 to 5 (1 strongly disagree to 5 strongly agree, with a 6th not sure option), please rate the following

1. Today I felt our care of patients was careful (our care was effective, safe and personalized) [careful staff measure]
2. Today I felt our care of patients was kind (our care was respectful, the patient was treated as a real person, like a member of our family) [kind staff measure]
3. Today I felt like staff cared for each other [mutual care staff measure]

For each answer, please give a reason for your score (optional text box)

For each answer what would make this a higher score (optional text box)

Patient measures -

Was my care / the care of my relative careful and kind* today?

On a scale of 1 to 5 (1 strongly disagree to 5 strongly agree, with a 6th not sure option) please rate the following

1. I felt my care was careful - my care was competent, compassionate, and personal [careful patient measure]
2. I felt like staff cared for me with kindness - my care was respectful, I was treated as a real person, like I was a family member [kind patient measure]
3. I felt like staff cared for each other [mutual care patient measure]

For each answer, please give a reason for your score (s) (optional text box)

Measures such as these could provide additional insights for supporting, enabling, and enacting careful and kind care alongside measures of care experience e.g., unhurried conversations and burden of treatment; and more traditional measures of patient and clinician satisfaction, patient and clinician wellbeing, resource use, e.g., appropriateness of place of care (online or in person).

As well as 'global' measures of careful and kind care, we have also been exploring specific measures around pathologies of care including hurry. Hurry is made up of a number of elements such as scheduling, interruptions and distractions.

Potential direct indicators of hurry

- Experience of pace and duration of the visit
- Satisfaction with number and severity of interruptions and use of the electronic medical record
- Experience of the scheduling process
- Actual duration of the visit vs. scheduled duration of the visit
- Satisfaction with how well the plan of care responds to the situation and makes emotional and practical sense

Potential indirect indicators of hurry

- Continuity of care
- Timely access

The outputs of the questions could provide a quantitative summary of hurry through measuring the proportion of encounters classified as unhurried and categorizing frequency e.g. less than 50% of encounters are unhurried. Equity should form an important part of measurement. These indicators should be measured overall and in subgroups by extent of clinical, social, and economic complexity.

The quantitative measures should not be seen as stand alone and should be complimented by stories of hurry and unhurried care, and the tempo of care could be ascertained to determine the extent to which it enabled and did not prevent noticing in high definition and responding with sensible solutions.'

Shared by fellow Dominique Allwood

Partnering for Careful and Kind Care

The Patient Revolution represents experts in human-centered design, culture change, leadership development, storytelling, staff wellbeing and engagement, and patient engagement. Our team of internal and external collaborators is eager to partner with healthcare organizations who are committed to a new future that is grounded in careful and kind care. We see these tenets as guiding our partnerships.

Build Trust

Much like careful and kind care, change at the practice level benefits from trust and ongoing relationships. Project and consulting engagements are often short. We are interested in ways to work with practices to develop trust over time and to help them understand that our interest in this work is focused on advancing careful and kind care.

Create recognition of the ways in which industrial healthcare is negatively impacting an organization's patients, staff, and community

While agreement with the diagnosis behind industrial healthcare may be generally accepted, we know it is important for healthcare organizations to become more aware of how it may be specifically impacting their practice before being willing to consider substantive changes. Helping organizations assess how their policies, systems, culture, technology, and training may be contributing to their challenges is a primary focus of our work.

Offer practical, doable steps towards radical change

Having built trust and exposed the problems of industrial healthcare, it is incumbent on us to offer our support and vision as the organization takes steps towards change. Our deep experience in human-centered design and research offer an approach for this work which brings patients, clinicians, staff, and leadership along.



CULTIVATE CARE

How We Revolt Co-Creating the Conditions for Care

A partnership between Stoked and The Patient Revolution

Working with the design group Stoked, we've put together an initial set of offerings to help partners launch their transformation efforts. If you're interested in seeing the full proposal, reach out to Executive Director, Sheila Moroney.

Deep Dive

Understanding the Condition for Care - An introductory, hands on learning experience that reveals the conditions that are impacting care and how changing those conditions can move you closer to careful and kind care. The primary focus of this workshop is education and cultural awareness and to explore the foundational components of transformation.

This experience is appropriate for:

- Clinicians
- Patients and Caregivers
- System leaders

Project: Sensing Conditions and Opportunities

Develop a deep understanding of the ecosystem headwinds and tailwinds your organization faces in delivering more careful and kind care. The primary focus is innovation opportunity framing and culture change.

Project: Creating the Conditions for Careful and Kind Care

Identify and test a portfolio of solutions to learn what has the biggest impact and then scale to deliver more careful and kind care (this is typically done after a Sensing and Opportunity Framing Sprint). The primary focus is innovation concept development and culture change.





Comfortable Outsiders - An Interview with The Care Lab

In this interview with Lekshmy Paramaswaran and László Herczeg of The Care Lab in Barcelona (and Patient Revolution fellows) they talk about their work and the ways that they advocate for careful and kind care with their partners.

What are the ways that industrial healthcare presents itself in your work?

László: Time as a commodity is really lacking. With our partners we try to do the maximum with a minimal amount of resource in the shortest amount of time. This puts lots of pressure on everyone involved. So time I think is probably the most visible kind of sign of industrial healthcare.

Lekshmy: We also see a loss of what we call sparkle, amongst professionals, losing their mojo, burning out, exhaustion. People don't have room to recover, to reflect or express. We were talking with the head of the pain unit, about how many doctors are leaving the profession changing to go open bars and restaurants or like, just do something completely different so they can have more balance in their life.

László: For the patients especially in long term care, we see this expectation that these places will be safe, but soulless. I think this reflects our expectations as caregivers that care is designed and delivered in a very technical and mechanic way.

Lekshmy: There is also just the enormous sense of rushing in all the work. In our partnerships as well as the care setting. The feeling that you need to talk faster and do things quickly because everything is urgent. It doesn't leave as much space for the relational.

How have you seen careful and kind care in your partnerships?

Lekshmy: Well in contrast to the rushing issue, we've had the opportunity to work with some real wonderful healthcare leaders and they often set the tone in different ways. We worked with a CEO in Singapore. When we went to visit for the first time, she showed us around the facility. And I remember she made everyone in that meeting a coffee. She went off and came back with all the drinks, taking like 20 minutes of a few hours meeting. Her whole manner and demeanor was not this rushing CEO, it was like we were in her home and she had time for us. Then she goes on to talk about her ethos in how she tries to give the team space to problem solve and come up with their own creative solutions without jumping in too fast. They had a patient who was really distressed in the dementia ward, and for two weeks, he couldn't stop screaming. And of course, it was disturbing and upsetting for the residents on that floor. And it would have been easy for her to just try to stop it, shut it down and solve it fast. But she gave the team two weeks to figure it out with the patient, with the family and it was not comfortable. But that was her approach. And in the end, she has a team that feels confident and capable. They have the freedom to problem solve in a way that is true to their values.

Can you share about work that was focused on creating more caring environments?

László: We created a tool for a hospice project called Munch and Grow, for the care team to be able to care for themselves and each other, so they can better care for the patients. So we designed this ritual for them - quite a basic tool and a framework. They can talk about careful



and careless practices in their work, there is a safe space, where they can really discuss this very clearly without pointing fingers to anyone and hopefully turn careless practices into careful practices.

In this particular organization, the medical director decided to make space in the agenda of the organization for this activity. So one half day each month, the team is focused on this activity. They don't have to also care for patients during this time, I would say these are the types of wedges we are trying to put inside the industrial healthcare system in a structured way.

Lekshmy: And this illustrates another challenge and an opportunity. There's this aversion to risk. And the example that László just gave of the medical director and the one that I gave of the CEO, they were bold, brave. They're willing to do something that is not the norm in the sector. They're exposed and vulnerable. We've met leaders that can't take that kind of risk, because they feel too exposed and too scared in case they fail. So in some projects, that kind of structural shift has been either impossible to achieve or really hard fought, in some ways really boiling down to how courageous people might be. And I know it's something that we've talked about amongst the fellows.

Do you see a benefit in your role as designers and consultants?

László: We call ourselves comfortable outsiders; which means that we understand their world, we understand their issues. It's familiar for us, we know the complexity, but we clearly are not from their discipline, and not with their responsibilities. So we can bring another perspective, and it's very useful.

How do you talk about the value you bring to an organization or partner?

Lekshmy: We recently had an organization we did some work with reach back out to us for some help with coaching; essentially making sure the interventions we designed with them get implemented the way they were intended.

Our engagement with them originally had some highs and lows but I think they saw that we were equally committed to the work and committed to helping the patients and their families and that built trust. When we were co-creating with their teams, they started to see what their own teams could produce working along with us. And they started to value those results. Those ideas, and also our commitment to the process to get there. In the end, what we produced together, they felt it was so precious, that they did not want to risk saying goodbye to us and trying to implement it alone.

László: One thing one detail to mention is that after the initial challenges of trust between us and the management, we came up with this idea to have frontline workers take on this role of being a parent to an idea. We delegated responsibility to these care team members, who until then had never really been empowered to do anything like this. And actually the opposite, often the management would shoot down any ideas they would have. We decided that we were going to get the trust of the management through their own team. And it worked out. I think if you might be able to measure one thing quite clearly it would be how much the team feels they are involved, and how much they have ownership to their work. They didn't track this but they could have.

Making Care Fit

The Patient Revolution promotes careful and kind care. Careful care requires that clinicians go beyond applying guidelines for patients like this to formulate plans of care for this patient.

Doing so requires understanding the patient's problematic human situation, in particular the aspects of it that require action and figuring out what action the situation demands. This work must be done in collaboration, with patients and clinicians uncovering, discovering, or co-creating a response that makes sense. The method to make care fit and achieve these goals is called shared decision making.

In contrast to customary calls for increased patient involvement and participation, we have observed that in industrial healthcare, it is clinicians who neither engage nor become involved in the problematic situation of their patient. Accelerated practices, tight schedules that favor access, quality of care parameters, insecurity, inexperience, and burnout promote the “processing” of patients and the offer of recommended, generic care that piles over the existing patient's regimen often overwhelming their capacity to implement it. Apparent efficiency without effectiveness, healthcare without care.

To do shared decision making requires participation from both patients and clinicians. The Patient Revolution offers tools that have been shown in clinical trials to effectively and efficiently support shared decision making, many developed by our research sister unit, the KER Unit at Mayo Clinic. Contrary to widely held beliefs, this work showed that promoting shared decision making improves patient and clinician satisfaction, possibly reduces inequities (by supporting those who need more support when approaching healthcare), does not take longer than usual care. Shared decision making has not been shown to consistently improve outcomes or reduce costs.

The method to make care fit and achieve these goals is called shared decision making.

Careful and kind care can be made to happen within industrial healthcare. When it does, it feels like a happy accident, often the result of individual (patient or a clinician) initiative. Our experience implementing shared decision making in practice demonstrate how difficult it is to sustain or scale-up successful normalizations of careful and kind care when the policies and practices of the system remain hostile to care. Examples of this hostility include brief clinical appointments, incentives to standardize care plans, and emphasis on documentation of patient-centered care (which turns these practices into a “box-checking” exercise). So why try to implement interventions such as our shared decision making and conversation tools?

Akin to the notion that the language we use can shape our thinking and doing, we propose that the experiences that arise from doing can shape our thinking and doing. The implementation of shared decision making and other care-full interventions can (a) demonstrate the inadequacy of industrial arrangements to support care, (b) create a burning platform for whole-system change, and (c) signal a commitment to care in the face of a hostile environment. Indeed, observing shared decision making in practice may signal the emergence of conditions favorable to care.

Designing interventions to support conversations

Our work with shared decision making and conversation tools has also given us deep experience using a human-centered design approach to create tools and programs that support careful and kind care through building partnerships with patients.

Observation, interviews, and prototyping are central to the human-centered design approach. This approach helps identify the complexities in making care fit and supports and assists clinician and patient as they find their way towards the conversation they need to have.

On the following pages, we highlight some of the tools and materials we've developed over the last 18 years to support patients and clinicians along with example conversations that we'd observed during the development process. These tools have worked as demonstrations and provocations toward careful and kind care.





CULTIVATE CARE

Tell Us About Your Life Tool

This tool was developed in partnership with a primary care practice. It asks four questions about the patient's life.

- What is one non-medical thing about your life you think your doctor should know?
- What is one thing your doctor is asking you to do for your health that feels like a burden or feels harder than it should?
- What is one thing your doctor is asking you to do for your health that is helping you feel better?
- Where do you find the most joy in your life?

During one visit, a patient asked his wife to write his answers as she asked the questions. To the question “where do you find the most joy in your life?” the patient answered, “sex.” His wife laughed, rolled her eyes, and wrote it down. When we shared the document with the patient's doctor before the visit, he noted, even as he chuckled a bit, that this was actually really helpful. “Many medications have side effects that can effect sexual function,” he said. “Knowing that an active sex life is important to the patient helps me bring that information into any discussion we might have.”

TELL US ABOUT YOUR LIFE.

Please take a moment and try to answer the following 4 questions before your visit with the doctor. It may help you to think about your family and friends, your work, your neighborhood, your finances, your faith, your emotions, your sleep, your eating habits or what you do for fun while you answer these questions.

Tell us one NON-MEDICAL thing about your life that you think the doctor should know. (Where did you grow up? What do you do when you aren't at the clinic? What makes you famous?)

What is one thing your doctor is asking you to do for your health that is helping you feel better?

What is one thing your doctor is asking you to do for your health that feels like a burden or feels harder than it should?

Where do you find the most joy in your life?



Diabetes Issue Cards and Depression Issue Cards

These tools are designed to help patients participate more fully in decisions about medications for diabetes and depression. They use issues that are likely to be recognizable and meaningful to the patient as an entry point to the conversation.

Issues include...

- Cost
- Sleep
- Weight Change
- Daily Routine
- Daily Monitoring
- Sexual Issues
- Stopping Approach
- Low Blood Sugar



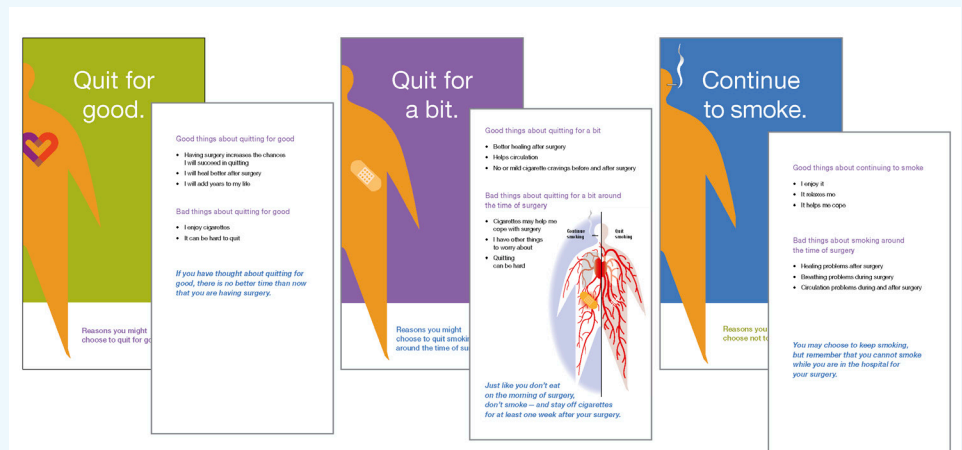
In one visit in which the diabetes issue cards were used, the patient and clinician were talking about the patient’s desire and efforts to lose weight. One motivating event for the patient was her son’s upcoming wedding. She shared with her doctor the diet and exercise plan that she was committed to trying but, she said, “if those things aren’t working in a few months, I might reach back out to try one of these other medications.”


CULTIVATE CARE

Quit for a Bit

This tool was designed to introduce the option of “quitting for a bit” to pre-operative patients who also smoked. While there has been a lot of learning in the past decades about the value of motivational interviewing and incremental effort in smoking cessation programs, clinicians and healthcare providers are generally reluctant to offer any advice other than the advice to quit for good and patients are generally tired of hearing the same lectures from doctors.

The challenge and opportunity for this tool was that there is good evidence that even quitting smoking for a little while around the surgery, in the weeks immediately before and after, has significant impact on wound healing and overall recovery. We also wanted to acknowledge that continuing to smoke is a decision that makes some sense. For many people who smoke, smoking is a way of managing stress and provides comfort.



Encouraging these conversations was incredibly difficult. Both patients and clinicians were reluctant to engage, but when they did, patients appreciated the sense of choices and options. What made this tool challenging to implement was its integration with the other programs and systems related to smoking cessation. Even if patients and clinicians made the decision in the pre-operative visit for the patient to quit for a bit or continue to smoke, the patient was going to receive visits in the hospital encouraging them to quit for good. There was no way for the patient and clinician to tell the system what decision had been made and have the system respond with acknowledgment and understanding. This left the patients feeling frustrated. Having been offered an option and making a decision, they then weren't heard.



CULTIVATE CARE

QBSafe Cards

These cards were another tool designed to help patients living with diabetes and their clinicians have conversations about the condition beyond a focus on lab values and A1C measures. QBSafe is an acronym derived from quality of life, burden, safety, and avoidance of future events and the goal was to create more space for these topics in the conversation.

These 14 cards were developed with input from patients and clinicians. Diabetes nurse educators gave us the idea to add the two positive cards, numbers 13 and 14.

I struggle with remembering, taking, or managing my medications. 1	I struggle with monitoring my blood sugar. 2	There are things I would like to do but can't or won't because of my diabetes. 3	My diabetes limits my ability to work, do hobbies, or spend time with family and friends. 4	I am frustrated by the amount of time I spend managing my diabetes. 5
I am having problems with low blood sugar. 6	I would benefit from more help managing my diabetes. 7	I find it hard to follow your suggestions about diet and exercise. 8	Diabetes is impacting my sex life. 9	I worry about my ability to pay for my healthcare. 10
I have another issue related to my diabetes that I'd like to talk about. 11	I have something I'd like to share with you but I know you probably won't be able to do much about it. 12	Diabetes has had some positive impacts on my life. 13	I have felt moments of pride while managing my diabetes. 14	

- Diabetes has had some positive impacts on my life.
- I have felt moments of pride while managing my diabetes.

The positive cards were some of the most commonly picked. This opportunity for patients to share what they felt good about was usually met with enthusiasm and support on the part of the clinician, contributing to trust and relationship building


CULTIVATE CARE

Plan Your Conversation Cards

The Plan Your Conversation cards were developed as a way to help patients “practice” a conversation they’d like to have with the clinician. The cards can be used for any condition or issue and help the patient think through what they’d like to share.

The cards offer the start to 5 statements.

- I want to talk about...
- It is important to me because...
- It might help you to know...
- I want this conversation to lead to...
- I’m nervous this conversation will lead to...

One patient used the cards to talk to his doctor about his fear of losing his vision. You can see a video of him on our website talking about how the act of saying what he was worried about out loud to himself was really meaningful.





Hello, lovely human! Just wanted to let you know that [child] had her first appointment at a trans care clinic today. And we used the [Plan Your] Conversation Cards. [child] was skeptical, but then started pulling them out at various points during the appointment.

The doc - who was wonderful - asked [child] to bring the cards again next time.

I loved a lot of things about this visit, despite being scared to death beforehand. But I especially loved carrying what felt like a bit of you with us, to help shape the space into something we needed.

Shared by community member over text

This is an excerpt from
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The conversation continues.

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