

HUMAN EXPERIENCE 2030: A Vision for the Future of Healthcare

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**T H E B E R Y L
I N S T I T U**

THE BERYL INSTITUTE

About The Beryl Institute

The Beryl Institute is the global community of practice committed to elevating the human experience in healthcare. We believe human experience is grounded in experiences of patients & families, those who work in healthcare and the communities they serve.

We define patient experience as the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care.

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LAYING THE PATH FORWARD

Eleanor Roosevelt is attributed as saying, “The future belongs to those who believe in the beauty of their dreams.” That may be no more apt then as we look at the topic of the Future of Human Experience and namely that future over the next decade.

The Future of Human Experience 2030 (HX2030) reflects the insights of a global community of patients, family members and care partners, healthcare professionals in all roles, who represent the shared voices of possibility for healthcare overall. It is also critical we recognize the very prescient nature of this group to understand, even before the full extent of the current health crisis hit, what was going to be necessary to lead us forward and its critical relevance to the moment in which we find ourselves today.

As we return to the words above, about believing in what our dreams call us to see, we also assert that the future itself is built on our very willingness to dream. In order for us to step forward, to look beyond the horizon in front of us, we have to have that capacity to think bigger than ourselves, to think beyond the boundaries of what we might even know is possible.

When we started this process, I don't think we'd have ever dreamed we would find ourselves where we are today in healthcare, where we are as a global community in terms of what we're trying to accomplish for healthcare overall, what we're facing in terms of a health crisis and what we are now tackling to break the hold of health disparities and the systemic racism in healthcare and beyond that this moment in history has unleashed in a bold call for understanding and action.

PROCESS AND METHODOLOGY

The Future of Human Experience 2030 Framework was built from the contributions of hundreds of individuals around the globe. The process was layered in a set of diverse focus groups framing the initial ideas, a global validation and feedback survey and structural guidance by a global steering team who helped polish the findings overall.

Phase 1 of the process began in December of 2019 and ran through mid-January of 2020 with a series of 15 community conversations. Community conversations were comprised of individuals from the global community at-large to engage in a conversation on what people saw the future of human experience in healthcare to be. Each conversation session was transcribed and the data from these sessions reviewed to generate key thematic concepts for review and validation by the community. The three guiding questions that framed the community conversations included:

- What do you think the future human experience in healthcare (in 2030) should look like? What will healthcare be doing, what practices and processes will be in place, how will patients, families and healthcare consumers be involved, etc.? Share your picture of the future and build on what you hear from others.
- What are the key milestones we need to establish and what are the actions we will need to take over the next ten years to realize that vision?
- What are the resources will we need to achieve this future vision, i.e., skills, technology or other resources, and do they exist, or will we need to create them? Do not be limited by what we think is available today.

2. Framing principles were created, as it was deemed there were some foundational elements to ensuring the success of any future facing roadmap.
3. Simplicity was needed in order to ensure clarity, for all who engage, and practicality, so the ideas were actionable and accessible, not theoretic and more difficult to realize.

The steering team's commitment was to honor the over 1000 voices that weighed in on the process and ensured a clear and forward-looking plan. It was grounded in the realities of the day, acknowledging the first step to any future is one you take in the moment today and recognizing it would need to be able to be acted on and built upon in the years ahead.

The overall process to frame the construct for the Future of Human Experience 2030 in many ways exemplified what you will see HX2030 is calling for us to do itself. That when we engage, listen to and act on the voices of the many, when we honor the diversity of experience and perspective that adds a critical and valuable seasoning and mix to any forward-thinking ideas, we build both a foundation and a vision for a viable and vibrant future. That future, the future of human experience, comes from you.

A CHANGE FOR THE FUTURE

The foundational idea for this whole endeavor is what is essential TO us as human beings is essential FOR us as human beings. That will not change and is of no greater importance than to the work of healthcare and the work of human beings caring for human beings.

This idea, that at healthcare's core we are fundamentally human beings caring for human beings, is a key starting place for this conversation. It is why this work focuses on the future of human experience. It calls on us to understand the breadth of people engaged in the healthcare equation from patients and family members/care partners to healthcare practitioners and professionals to the very communities healthcare serves. These components are inextricably linked and are only best served when seen for their connected versus disparate nature.

This idea, of thinking of healthcare from this holistic and multi-perspective lens, calls for a shift in some of the very fundamentals on how healthcare itself operates. Framing the future of human experience in healthcare will ultimately require transformational change. This exploration revealed and this framework for the future calls on us to consider three essential changes.

A change in perspective from siloed and specialized to integrated and systemic.

Healthcare for all its complexities and dynamics has worked diligently to establish processes and protocols to manage its intricacies and breadth of scope. This perfect combination of distance between points of work has driven the establishment of specializations, critical for clinical expertise and ensuring positive outcomes from that expertise, but damaging to a living system that relies heavily on collaboration, shared information and evidence, and communication

to ensure overall success. Healthcare has built itself as a collection of silos, not just clinically, but more so operat/La (y its in.1 1 (enlf)21.2 ()TJ9.1)13 (ed and s)1io

clinics, and other organizations—although part of the delivery system—often act as independent entities. We often call this arrangement a “health care system,” even though it was not created as a system and has never performed as a system. Moving from the current conglomeration of independent entities toward a “system” will require that every participating unit recognize its dependence and influence on all other units.

Eight years later, in the 2013 discussion paper, *Bringing a Systems Approach to Health*,² also from The National Academies of Medicine, this call for action was sustained in providing a working definition for a systems approach to health:

A systems approach to health is one that applies scientific insights to understand the elements that influence health outcomes; models the relationships between those elements; and alters design, processes, or policies based on the resultant knowledge in order to produce better health at lower cost.

This reality holds true today, even with the best attempts at policy and programmatic changes. If we are to truly address the issues that will support the best in human experience, we need systemic solutions where the pieces of the systems work with, through and for one another, not in competition with or against. This requires collaborative conversations from all perspectives engaged in healthcare and from all operational lenses that drive it forward. This remains a daunting task, but a fundamental one to achieve a fully realized future for human experience.

As we focus on the future of human experience, we must make a dramatic shift to lead with the relational, for the primary means of delivering on care, be it clinical or emotional, is between two people. Even now with the use of technology, we cannot, and more so must ensure, that the humanity at healthcare's core is not diminished, but rather elevated. This is what those who seek care expect and those who chose this path for their life's work chose to do every day.

A change in focus from aspirational to active.

In looking at the two needs for change above, in moving to a systemic and relational effort in healthcare, it is clear these are not new calls to action. As seen in the papers from 2005 or 2013, to the long-standing calls for patients' rights or the powerful commitment to employee engagement that blossomed in that same period, the need to connect and care for people has always been called for. It has always been aspirational.

The opportunity now, but even more so the need, is to move beyond aspirations to the actions that it will take to move this idea forward. The future of human experience is not about things that will be nice to do or suggestions for others to ponder in the years to come. In healthcare, more so than in most other industries, the art of great reflection on the known issues, with a lower level of coordinated action in addressing them, remains a challenging characteristic.

This is not to suggest that people or organizations have not raised or are not currently trying to address these ideas. But a call to an idea by a small group of voices can only move it forward so far. The challenge remains

FOUNDATIONAL NEEDS

In the review of the initial 15 core action statements, based on overall feedback and the analysis of the steering team, three concepts emerged as broader and more foundational needs in moving towards the future of human experience. These ideas frame a conversation of action on what groundwork must be laid to ensure a solid and strong path to the future. These three essential actions touch on larger efforts that will begin to drive the very changes called for above.

They establish that to ground the efforts to lead the future of human experience, there must be a continuous focus on and sustained commitment to:

Advocate, actively and directly, for global and local governmental policies and incentives that ensure expanded access to care, a focus on issues of sustainability, and a commitment to caring and human experience.

To achieve the kind of long and lasting change this vision calls for, it is clear that that policies that dictate and the incentives that focus action must garner critical attention. These conversations at a global, national and local level will need to align on core priorities to ensure fundamental issues are considered, such as equitable access to care, incentives aligned with actions that support an elevation of the human experience and more. There are great efforts underway here and more opportunities revealed, more so as the issues of systemic racism and health disparities have been elevated in the current health crisis. The social awareness and action on the very issues of race and discrimination societally will call for broader and

Expand partnership and collaboration, between and within healthcare systems in the sharing of essential ideas and proven practice and by openly and actively seeking to learn from industries outside healthcare to more effectively address consumers' needs and drive better outcomes.

The need for partnership and collaboration in healthcare was framed earlier in exploring the need to think systemically and act relationally as we work toward the future of human experience. This calls for healthcare organizations to first and foremost break down the barriers historically built between them from a sense of competition and, dare I say, brand pride. One incredible emergence from the current health crisis has been a new sense of local collaboration among organizations from shared public statements on public health, to coordinated campaigns to reinforce the safety to return to care, to alignment on such critical issues such as visitation policy to ensure consistency in action and a common and shared public health message about the critical nature of this pandemic. This sense of collaboration was elevated during this crisis in how work was done as well, from the sharing of actual staff to meet the volume of care providers needed in hot spots like New York or Milan, to the reassignment of people within organizations to address immediate needs, seeing internal silos broken and more functional and agile interdisciplinary and interprofessional teams stood up to tackle immediate needs.

The call here reaches beyond breaking down the interior walls of healthcare to the willingness of healthcare organizations to learn together from

FUNDAMENTAL ACTIONS FOR THE FUTURE OF HUMAN EXPERIENCE

In building a vision for the future of human experience as a community, it remains important to note this is not, nor is it intended to be, a fixed model. This is not as simple as a checklist for the future, but rather it represents a dynamic framework. What this moment in history has shown us and taught us is that now more than ever what is needed is an unprecedented level of agility for healthcare. It requires the ability to respond, to rapidly reconfigure, to see things in front of us in ways we never have before and to act with that knowledge and insight, blended with passion and commitment, to address the needs of this time and set the foundation for the future.

The future of human experience and the actions it calls for are steps to take on a dynamic and enlivening journey that we will take step by step over the next decade together. With that, it is recognized that circumstances change, environments shift, and innovations emerge that may make one path obsolete or not as effective as

new ones that appear. It is critical that the conversation on these actions not be lost in seeing these as the only things to do, for as a plane must make constant calculations and adjustments on its flight path due to conditions, air traffic, weather and more, so too will this effort. Its strength emerges by not providing itself as a final static model, but in serving as guideposts for what

presented in an order of importance, but rather grouped around three core areas essential to the future of human experience overall – patients and their care partners, the healthcare workforce and the communities served by healthcare. They are all included with a balanced level of importance, while it is evident and will be discussed further where some may take and require more effort.

The six actions as presented are also clustered in these core areas in groupings of two. The first two touch on the opportunities with patients and care-partners, the next two for the healthcare workforce and the final two for the communities in which healthcare exists and that it serves. They are framed by this initial statement: *In working to elevate the human experience in healthcare over the next decade, patients and consumers of care, healthcare organizations and the communities they serve will work together to ensure that healthcare efforts:*

Reframe consumerism to patient and consumer partnership.

Transform power dynamics by a global commitment to (1) partnership, where patients, families and consumers are actively engaged in co-design and (2) transparency, where both performance metrics and cost of care are accessible and understandable.

It is now increasingly accepted that healthcare is a consumer industry and with that acknowledgement also comes the recognition that healthcare remains unique in that it cares for people often at the most

vulnerable time of their lives. This does not make the concept of consumerism bad, and it must no longer be seen that way. Rather, it can be seen that healthcare now recognizes with increasing importance that it must

In all cases, information for the sake of information or blanket transparency only works if what is shared is also supported in a way that it is accessible and understandable to all wishing to access this information. In working to ensure not just foundational health literacy but also a clear understanding of metrics, we balance the power in healthcare and level the means by which the best decisions can be made and outcomes achieved. This is where true accountability in healthcare will flourish.

Provide a precision experience through the use of real-time data and decision analytics, including the application of AI and other technologies.

Enable and extend healthcare technology as an enabler and extender of human connection by ensuring simplicity, efficiency and expanded access to care, information and knowledge.

The realities of healthcare technology extending the reach and capabilities of healthcare has long been a commitment and goal. It remains a rapidly evolving component of care, and its application was catalyzed by the current health crisis that saw in-person care delivery rapidly transformed to the full range of telehealth. But technology also emerged and will continue to be needed for much more as it relates to the future of human experience. As the COVID crisis exploded the need to connect people through new means, healthcare saw the implementation of virtual connections that were slow to be implemented just weeks before. This realization that healthcare can move with speed to innovation makes the idea of precision experience all the more possible.

As participants in the feedback sessions offered, there were some connotations that the concept of "personalized" care rang of privilege in some cultures.

continued distancing of those who work to provide care being pulled further and further away from the actual work of caring. In many cases, people feel separated from the purpose that called them to the healthcare

about the delivery of medical care, but around the overall experience each individual is provided.

In the same light, it is evident that technology can no longer be seen as an impediment to human connection, but rather it can and should serve as an enabler of experience. Technology should extend connection as it has in the current crisis. It also will require a commitment to simplicity, connectivity and accessibility. Caution must be taken to ensure that an increase in the use of technology does not create new inequities in healthcare, so technology and its role in the human experience will require a broad and systemic view as it evolves. Technology for the sake of technology is not the answer, but using the very resources being developed by innovations globally to align access to information, rapid decision-making, closer connection and greater understanding in healthcare overall can fundamentally shift the experience of all on both sides of the care equation.

Address process burdens and workload issues for healthcare workers to increase opportunities for human connection, reinforce purpose and reduce burnout.

Hire people in healthcare in new ways, selecting not just for greatest skill or clinical ability, but also for lived experience and fundamental behaviors essential to a positive experience.

The reality of burnout in healthcare has been broadly researched⁶ for years leading up to the COVID crisis only to see its final layers peeled back in this moment of history. Process burdens have been widely documented, some driven by the very technology issues we addressed above. Many from the volume of work or more so the

the need for intentional interdisciplinary connections, both in education and practice, that would be vital to success. The future of human experience will call for new models of education both through formal academic training and through continuing education for healthcare professionals across disciplines. This includes ideas such as establishing fully integrated programs versus specialized learning tracks, i.e., spending all your learning time in medical or nursing school or in an administration program, and engaging patients, family members and care-partners as faculty in ensuring learning from lived experience as much as through theories and science.

This idea for interdisciplinary education is not new. Almost 20 years ago, Hall & Weaver⁶ suggested there were two issues emerging in healthcare as clinicians faced the complexities of the moment: one being the need for specialized health professionals and two being the need for these professionals to collaborate. In fact, this issue was also raised more than 15 years before in 1985 by Shepard⁷ who also called for this effort. This is not to suggest efforts have not been taken, but in now 35 years we have again been provided the perfect example of the aspirational in the face of comprehensive action.

To complement this for practitioners and professionals, a commitment to education on health must be brought into communities. From the beginning in primary education, to expanding health literacy in support of generating better informed patients and care-partners and a commitment to health and well-being. This linkage between how professionals, patients and the community

learn and contribute will serve as a vital bridge in the efforts to lead to a future for human experience.

Expand beyond treating illness to addressing

who deserve the same rights, opportunities, freedoms and respect regardless of race, ethnicity, socio-economic status, gender, gender identity or beliefs.”⁸

imbalance of death found in minority and especially black communities. This was not driven by the disease alone, but by the lack of a health system around people that focused on the very things this action calls for – a systemic solution to health.

A sick care system by its nature cannot provide equitable care, for it is focused on those who can access it, trust it, can pay for it and more. This skews numbers and misrepresents the true impact healthcare has and could have. It is not enough to say things such as social determinants exist. In fact, with the conversations of recent weeks, the term social determinants has been called out for what it does not address; that those distinctions, the inequities healthcare perpetuates are grounded in very real, tangible and long-standing systemic racism and discrimination that has even in the best efforts of those in healthcare to “care for all,” ensured people were simply missed, overlooked, left out of what it had to offer.

The reality of human experience has always been recognized to exist, as this statement of action was formed before the elevated conversations and global protests on racism and disparities. The question is, why has it been so difficult to address? This action represents a fundamental idea to the future of human experience. A future for human experience cannot ultimately be achieved if it does not intentionally seek to break these systemic binds and to say unequivocally that a future for human experience only exists if as shared in the statement An Unwavering Commitment to Human Experience, “We cannot stand by in declaring an unwavering commitment to human experience if we cannot ensure that all humans are seen in that light, as people

PATIENTS & CARE PARTNERS

Reframe consumerism to patient and consumer partnership.

—
Provide a precision experience through the use of real-time data and decision analytics.

WORKFORCE

Address process burdens and workload issues for healthcare workers.

—
Transform professional models for a new healthcare workforce.



HX

COMMUNITIES

Expand beyond treating illness to addressing the health and well-being of communities.

—
Meet people where they are, where they need it and follow them where they go.

THE FUTURE OF HUMAN EXPERIENCE: ALIGNING FOR ACTION

As we look at these six items and the framing around them, it would not be said by most, "Wow! I've never thought about that before." But that is one of the most incredibly magical parts of all the participants and the experience community has built together overall. This idea for the future of human experience represents all the pieces and parts of fundamental conversations, commitments, innovations and hope that have driven healthcare forward through the years past and have laid a foundation for the years ahead.

The dynamic framework that has emerged brought us back to the very framing of human experience by The Beryl Institute which offers, "We believe human experience is grounded in experiences of patients & families, those who work in healthcare and the communities they serve." The framework, through the voices of more than 1000 contributors, quite unintentionally, brought this back to a focus on those three essential components. With that, the dynamic framework helps align the actions needed to co-create what the future can look like; its gives all a place to stand, to make a contribution, to push change in a way that matters, rooted in the essential changes and foundational needs shared above. The power of a dynamic framework is its realization that it's only as strong as its ability to bend. The agility of what has been created together is the ability to continue moving this conversation, not as a definitive declaration of what the future will look like, but rather a commitment to work together to change the nature of healthcare.

and valid challenges to society globally on social justice and equity. These are not roadblocks to progress, but rather are catalysts to ensure a commitment to the future of human experience that change the nature of healthcare, and will have ripple effects well beyond healthcare itself.

That calls for a clear declaration for action as well, a commitment to what will be done as this effort unfolds. This declaration offers “We will”:

- Ensure the voices of all engaged in healthcare are heard, respected and acted on for what matters to them.
- Advocate for and act to sustain practices, processes, and policies that have supported experience excellence.
- Address the systemic issues that undermine our capacity to support the health and well-being of all global citizens.
- Co-create a future in which new possibilities sprout from the deep roots of human experience.

This effort is not ultimately an invitation to adopt a new model. Rather, it is a call to action around what the community collectively is committed to do about it. Helen Keller once said, “Alone we can do so little, but together we can do so much.” That is the foundation on which this framework was built, and it is in the ability to stand together that will drive this effort forward.

So what does that mean in terms of where this goes

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APPENDIX

HX2030 GLOBAL STEERING TEAM

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