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# Pushing the boundaries of patient experience

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## Pushing the boundaries of patient experience

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### Abstract

This special issue is designed to push the boundaries of patient experience a little farther. Beyond just examples of applying the critical principles of patient and family centered care or even practices of patient engagement, we have been pushed to move further down the perspective of partnership, to the era of “doing with”<sup>1</sup> in which healthcare now finds itself. The idea of involvement as the descriptor selected to frame this issue, was due to its broad and representative nature. It reflects all the words on involving patients mentioned above, but gets further along to participation and ownership (or activation as many now tend to use) and even beyond partnership to the intimacy involvement connotes. Involvement here gets us to the personal and emotional levels that connects someone to what they are doing and reflects the whole person connected to that experience. That represents the opportunity reflected in this issue and in pieces that have comprised *Patient Experience Journal* to date. Through these contributions we have realized an opportunity to invite disparate voices and introduce new ideas, to gray the edges of what people deemed patient experience to be, and to push the boundaries of what patient experience truly is.

### Keywords

Patient involvement, patient experience, patient engagement, experience era, state of patient experience, innovation, experience based co-design, pediatrics

### Note

A formal announcement on the Call for Submission for July 2018 can be found as the closing article in this issue. The theme for that special issue will be patient & family experience in children’s hospitals and pediatric care. We invite you to consider a submission for that issue. The deadline to be considered is March 1, 2018.

### The Introduction of Special Issues

Welcome to the first special issue from Patient Experience Journal (PXJ). This issue was inspired by the great breadth and volume of contributions we are now seeing at PXJ.

With a substantive pipeline of thought-provoking submissions, we began to see a theme emerge and realized we had an opportunity – to offer a focused avenue to explore a specific area of the patient experience landscape with greater purpose and depth.

Typically, special issues arise from a call for papers, but in this case this inaugural special issue emerged from what the patient experience community itself is working to explore. And as a result, we are excited to present our first special issue on Patient Involvement. This recognition of the value in focusing on specified topics has led us to add a new issue to our annual publication calendar. We are happy to share we will now be offering a special issue every July. I will talk more about our call for next year’s issue below.

This opportunity is a significant milestone in our efforts to create a central place for the exploration of research, practice and narratives that bridge the scholar-practice gap

and expand the evidence base about the right things we can and must continue to do in healthcare. This may be no better exemplified than in the very engagement we now see in PXJ itself. With an average of over 10,000 individual article downloads a month in the first half of 2017 and readership representing over 190 countries and territories in that same period, we can say PXJ not only represents a publication, but also a rapidly expanding and fundamentally central conversation to what is important in healthcare overall.

Through the pages of this issue and those that came before it, we have realized an opportunity to invite disparate voices and introduce new ideas, to gray the edges of what people deemed patient experience to be, and to push the boundaries of what patient experience truly is. That is why we remain encouraged by your submissions and energized by the opportunities every issue ahead presents.

### A Focus on Patient Involvement

The special issue that follows is designed to do just what we hoped, push the boundaries of patient experience a little farther. Beyond just examples of applying the critical

principles of patient and family centered care or even practices of patient engagement, we have been pushed to move further down the perspective of partnership, to the era of “doing with”<sup>1</sup> in which healthcare now finds itself. The idea of involvement as the descriptor selected to frame this issue, was due to its broad and representative nature. It reflects all the words on involving patients just mentioned, but gets further along to participation and ownership (or activation as many now tend to use) and even beyond partnership to the intimacy involvement connotes. Involvement here gets us to the personal and emotional levels that connects someone to what they are doing and reflects the whole person connected to that experience. That represents the opportunity reflected in the pages of this issue and in pieces we hope to see more of in the future.

For this issue, we have been challenged by deBronkart<sup>2</sup> to think about this idea with a focus on shifting the paradigm we have traditionally used for patient in healthcare and working to increase the capacity of individuals, not just plugging them into a process as passive participants. This opportunity is represented in the personal narrative by Matz<sup>3</sup> as he reflects in what would have made a difference for him in his own healthcare journey and where he acknowledges the accountability both providers and patients themselves have in experience overall. We also see how involvement can begin to impact outcomes from Kemp et al.<sup>4</sup> and explore processes by which we can be more effective at application and results from both Morris<sup>5</sup> and Marshall<sup>6</sup> and their co-authors. We then have the chance to dig deeper into the processes of co-design itself from both Maher<sup>7</sup> and Fucile<sup>8</sup> and their co-authors, which is perhaps one of the greatest examples of moving beyond principles of centeredness or practices of engagement to truly involving people in the process as co-owners, as expert contributors and as team members who have a sense of control and even power in leading to better outcomes.

This subtle push at the boundaries of experience must remain central to our cause. Our call for you as reader or researcher, care deliverer or someone experiencing the efforts of a system, is to look for where we can continue to push ourselves even farther. A field of practice is only as strong as both the foundations on which it stands and its willingness to grow its branches. It is branches that soak up sun and capture water, it is branches that reach further and create greater possibility.

This metaphor and the opportunities it represents may be no better reflected than in our call for papers for our special issue for July 2018. You can see the full description in this issue,<sup>9</sup> as we call for papers on patient & family experience in children’s hospitals and pediatric care. We encourage you to think beyond the traditional to the evidence-grounded innovations, the practices that moved

you or a narrative that captures the essence of where differences were made. We look forward to your submission.

## Pushing Boundaries

As we look to the pages that follow, we also just saw the recent release of the State of Patient Experience 2017: A Return to Purpose<sup>10</sup> via The Beryl Institute. I offer this here as it revealed some very interesting things in the data. While I encourage you to read the full report, what evolved in that study was the very revelation we have found occurring on the pages of PXJ itself. The conversation on patient experience is expanding into an exploration of the integrated nature of healthcare. This is not integration from an operational excellence perspective, though it should and will drive how those efforts are implemented. Rather, this idea of integration is grounded in a comprehensive consumer perspective where all that takes place in healthcare across traditional delivery silos or points of focus now are converging to represent the one experience people have in healthcare. This calls for us to do nothing less than push boundaries.

At the same time, as the view of experience broadens and the issues that both impact and are influenced by it expand, we saw a return to purpose to the very humanity at the heart of healthcare. Namely, the data revealed that engagement of staff and employees was identified as the fastest growing focal point in experience efforts. This may not be surprising to most, to consider that taking care of those who offer care is the key to offering better care. Yet at the same time, as with many things in healthcare, sometimes the simple and obvious opportunities are the most overlooked in the need to simply manage the complexity of the system. This research provided not only a strong reminder of the importance of this perspective, but also a refreshing realization that people are recognizing the fundamentals can be a clear and intentional path to the great results healthcare aspires to.

While these ideas may be seen as simple, we know all too often they are complex in practice. More so, while common to the core of how organizations operate, there remains an opportunity to innovate and push the boundaries there too. That is our ultimate call. How can we reinforce the fundamentals at the heart of healthcare while innovating, reinventing and stretching perspective to expand this critical conversation overall?

We hope you will find this issue helps poke at and push those very boundaries that have restricted us and that you will consider how what you are working on can continue to stretch the edges even farther. When we not only speak to the value of an integrated effort, but also undoubtedly prove its worth, is when we will unleash even greater ideas and opportunities. That should be our collective cause and

one I believe will fill our days with excitement and enlightenment for the years to come. That is, if we are willing to step into this opportunity and act. We look forward to the steps we will all take in moving forward together.



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