

**In the end, and the beginning, it is about me...**

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“What does this mean *for me*?” This is and remains the Number One question about the current focus on patients by industry, regulators, and other health care stakeholders. Indeed, with all that is written and said about Patient Centricity, Patient Engagement and the like in glossy mission statements and public communication, this fundamental question remains a struggle for many organizations and consequently, individuals in them. “It’s all about the patient” is so easily said, but when it comes down to implementation of true patient engagement, it’s often something that “somebody else” should do, or should have done. This article is an effort to address our individual need for understanding and support. So, if you have this question, read on!

The first thing to realize is that the “What does this all mean for me?” question is an entirely normal phase in the adoption of any new belief or approach. So, the question is both normal (as in, “Relax, this is both frequent and expected”) and it is also a phase (as in, “Do not despair, this too will pass!”). In the nineties, colleagues working in health care (e.g., regulators, providers, and the pharmaceutical industry) asked this question about evidence-based medicine and health economics; in the 2000s, we wondered about the internet and full compliance; more recently, it’s been asked about social media and big data, and there are several other examples. It took a while each time, but many of us today can no longer imagine (or even explain) that there was a time when we did without the tools and innovations that are now so deeply ingrained into the culture of both organizations and individuals. However, not only asking patients for their opinion, but having that opinion impact the way medicines development is being planned and implemented is probably one of the most fundamental changes over the past decade – and in ten years, we will wonder how R&D have ever led to meaningful outcomes without incorporating patient preferences from the start.

And thus, your question, my question, her or his question, about “What does it (patient centricity, patient focus) all mean FOR ME” needs to be asked, explored and addressed, especially since outcomes as the result of any health intervention often seem far away from the individual’s contribution to a lengthy research process.

Second point, and let us be clear: A marathon is made of many single steps of many runners. Organizations do not engage with patients; people within organizations do. And that means that I, you, all of us, need to move on an individual level. I cannot sit back and wait for my organization (or my boss) to engage, and neither can you. Because WE ultimately ARE the organization. We are the ones to change when we talk about culture change. As a patient engagement community, across industry departments, clinical institutions, patient advocacy organizations or regulators, we need no one’s approval or instruction to engage with patients for better outcomes. Remember the simple wisdom of Gandhi that led to such deep societal change: “If we could change ourselves, the tendencies in the world would also change.” So let’s start running ourselves, rather than waiting for someone to organize the next big marathon.

What is the change that people living with medical challenges – and this includes patients and their families – want to see? Imagine if thousands of individuals working in health care made a personal commitment to listen to patients, to co-create health care solutions and strategies with patient

organizations, and to communicate with patients and their experienced advocates in a transparent, timely, and respectful way. Imagine how these thousands of individuals, the building blocks of each organization, would change their organization’s patient engagement culture and customs in practical ways. Imagine blurring the self-made boundaries and silos in health care and offering a common focus and joint effort and experience with patients. That is the change patients want to see. That is the change that so many of us working in health care want to see. It is why we joined this battle in the first place.

Patient engagement is not a new invention. It’s been a reality – for example in HIV research, in many rare diseases and certain cancers – for more than a decade. Let’s not waste our energy asking about the “Why”; goals, benefits and good practice examples are already well-documented. Once everyone understands that our personal part is not just “someone” but me (The “Who”), we can apply existing patient engagement tools to help us with the “What” and “When.” Such tools have only one purpose: to enable and accelerate the cultural change and practical implementation toward meaningful and effective patient engagement that truly seeks and values patient input in addressing health challenges and finding solutions.

This is where the Pledge to Patients comes in. This tool combines the power of the individual’s desire for more meaningful patient engagement with the three guiding principles of listening, co-creating, and communicating. It forms a unifying platform and a community of individuals with a common vision regardless of organizational differences and diversity. The Pledge to Patients has been developed by Patient Focused Medicines Development ([PFMD](#)), an independent global stakeholder coalition co-created with patients. PFMD aims to synergize fragmented but complementary efforts to establish meaningful patient engagement over the medicine development pathway and lifecycle.

The Pledge to Patients allows individuals within stakeholder groups to translate their vision and commitment into action by answering three key questions:

1. How can I (in my individual role, which I know best) listen to patients?
2. How can I co-create with patients?
3. How can I communicate with patients?

Let’s give some examples of what a pledge could look like. Imagine an individual within the pharmaceutical/life sciences industry stakeholder group: What kind of concrete, actionable pledges could this person make? Table 1 shows some real-life pledge examples. These are not intended to be exhaustive but demonstrate the principles of the individual pledge; to make potentially small but achievable changes that have a wider impact for the good of patient engagement.

**Table 1: Real-Life Pledge Examples**

Listen	Co-create	Communicate
I will build a “patient voice” phase into each project plan	I will include people living with Parkinson’s in our scientific grant view	In weekly planning, I will schedule meetings with patients ahead of all other meetings
I will find a patient and spend time with them in the next six months to learn how I can take their needs into consideration more when I arrange meetings that involve patients	I will work with at least one patient or patient organization representative from outline to completion for every publication planned	As a patient affairs manager, I will always respond to any patient request within ten working days
I will talk to my family member with ovarian cancer in the next	I will invite patients to join the planning committees in the	I will find someone who can act as a patient mentor and advise if

month to understand more about her experience as a patient expert and what she has appreciated/not appreciated about her various engagements with industry	formative stages of my meetings and projects	what we think is a good idea actually addresses need
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Anyone at any level in any organization can make a difference in their everyday role. Anyone? Yes, anyone! In the same way that a NASA janitor famously said his role was to “help get a man on the moon,” each one of us has a role to play, a contribution to make. If you can’t answer any of these three questions, why are you drawing your salary? Do not wait for someone else to come to that conclusion, or to answer these questions for you: No one knows better than you the importance and value of your role!

This grassroots approach and call to individual action also serves to connect the people who already engage with those who do not (yet) know how to engage with patients and patient organizations. Everybody can make a difference. This differs from the more common top-down approach where discussion and decisions on what patient engagement should be are made by those arguably the furthest removed from regular patient engagement, before being “passed down” for implementation. Starting with the people who are already aware and engaging with patients will lead to approaches that are better patient-focused, forming a foundation through which the whole organization can be influenced, even if sometimes in very small acts, not necessarily from the usual suspects, and in positions very disconnected from patients.

In practice, you can look for other people in a role like yours and get inspired by how they translate our common vision into action, not following easy procedural excuses why this or that can’t be done. Indeed, pledges to Patients are shared on the open-access online PFMD platform, thus providing practical examples across peer settings and inspiring individuals in their own organization (and others) to join the Pledge community. Your Pledge to Patients can be a personal and motivating reminder of your original purpose, a source of inspiration on how to do it in your role, and a way of reconnecting with enthusiasm for improving the lives of patients.

The Pledge to Patients is not just symbolic – it is an individual making personal, specific, and measurable commitments to, and sharing, three guiding principles. Anyone who has ever made a verbal or written pledge knows how powerful this can be and how it can drive ideas into concrete action. The Pledge to Patients is also a cultural barometer, an indicator of how the needle is moving towards more meaningful patient engagement driven by individuals with a shared vision. Or to take the symbol of a marathon: start running and training to reach the goal.

**Join the Pledge to Patients:** <https://involvement-mapping.patientfocusedmedicine.org/pledge>

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