

Chapter 4

Listening to the Voice of the Patient to Facilitate Earlier Access to Promising Medicines: Interview with Sjaak Vink

Pierre A. Morgon

The discussion with Sjaak Vink provides a fascinating account of what can be accomplished when the industry gears itself properly to work more closely with the patients or the nongovernmental organization (NGO) representing them. The insights are particularly relevant not only to the management of clinical development but also to the global corporate governance as they address the need to evolve management practices, towards a long-term strategic orientation, openness to real-world data, and responsiveness to societal pressure. The industry will need to flex its procedures, to open up to broader collaborative approaches, and to foster a company-wide orientation towards innovation.

Pierre A. Morgon: **What's your opinion about the role and place of sustainable development in the health-care industry? How does it contribute to its evolution and what it means in your scope of accountability?**

Sjaak Vink: Echoing the concepts illustrated by Jim Collins, in turbulent times more than in stable times, a greater attention should be paid to timeless fundamentals so that companies are built to last. These fundamentals include the recognition by companies that they have great responsibilities, including the preservation of freedom of entrepreneurship and freedom of mind, and the contribution to a sustainable society. New concepts such as transparency, sharing of knowledge, and open innovation are increasingly taking root in the corporate world, even in the largest companies. But beyond the understanding, companies have to act upon it....More spe-

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cifically looking at the pharmaceutical industry, the main obstacle to overcome is the tremendous amount of distrust that this industry has generated in the lay public. This is both surprising and discomfoting, as when one works closely with industry staff involved in the development of innovative medicine, one meets intelligent and committed people who put their minds and their hearts in the search for new cures. The mind-set changes when you look at the upper echelons of the management, as the top layer is concerned by short-term shareholder value. I'd posit that the senior management of these companies would be better off if it was setting free the intellectual spirit of their staff. In other words, the health-care industry needs shareholders that take a different view at value creation and in order to get there, it needs brave leadership that makes them understand the value of thinking differently, of taking a longer-term perspective and of creating a unique selling proposition resting on value for society. Critics of such longer-term orientation often argue about cash and profitability. Arguably, money is the fuel and as such, it remains important, but the most important is the momentum, the "why" that has to be answered with deeds and not just with words. I understand that it can be difficult to obtain approval internally for long-term focused initiatives, as the costs are borne immediately while the return is often hard to assess and is expected to materialize in a longer timeframe. But beyond the classical "business case," there are other forces at play that will increasingly drive decisions, and in this respect one shouldn't underestimate patient power, amplified by social media. There have been several recent examples of this rise of patient power. Think for instance about the melanoma patients who, supported by their treating physician, challenged the fact that they have been denied enrollment in clinical trials on melanoma. They took their cause to Twitter and Facebook and they attracted so much attention that one of them was invited to the David Letterman Show; the discussion shamed the company involved in the trial and the magnitude of the awareness triggered moved America. Another force that increasingly drives the decision and pushes shorter timelines is the nowadays treating physician. Being enabled to be up-to-date on latest innovation 24/7, this caring physician demands for the best possible treatments as soon as possible. In the US, health-care professionals were questioned on the timelines for new medicines. Over 75% of oncologists thought it takes too long before they are allowed to work with latest develop-

ments. Furthermore, they argued Real-World Data collected by them while treating their patients might appear to give valuable insights for pharma companies, payers, and regulators on treatment patterns, patient characteristics, quality of life of patients, quality of life of patients, et cetera. And on outcome and duration of treatment required. As Patients-LikeMe data already proves us. New grounds to explore for the better of all. In the future, we will witness more of such pressure to ensure earlier access to medicine if the complex and time-consuming approval procedures for new medicines don't change. The pressure will also be exerted through other conduits. In addition to the patients' voices being heard on the social media, you can think about the pressure applied on company employees in their lives as citizens, in their family circle, but also when with their friends or in any other social interaction context. Recently, I visited the Innovation for Health Congress in Barcelona where I spoke with Nigel, a scientist from one of the big pharma companies. He told me that the younger employees within his company see potential for innovation. I think this generation could force a change of the system. I'm convinced this "Generation Next" will reach out for a tipping point. Within the companies they work, within the industry. Young researchers, scientists, and physicians creating a new moral awareness within which it goes without saying that patients come first. As it was meant to be in the earlier days by the founders of the Merck's and Johnson & Johnson's of this world. The industry needs to flex its procedural attitude. The staff within the companies is increasingly challenging their senior management. We at myTomorrows are striving to engage them and to join forces so that we reach a tipping point.

PM: **Could you describe sustainable development initiatives you've been working on with pharma companies? What were the hurdles to overcome and practices to apply? How eventually does it bring value? What do you think would be important to implement them successfully?**

S Vink: The first observation is that all companies are not alike in this respect; a short and simplistic answer would be that small and innovative companies are easy to work with, while large ones are not since they are driven by accountants, bankers, and lawyers. But the reality is more complex than that, and a culture of innovation plays a pivotal role: Companies that have such a culture tend to behave and interact in an entrepreneurial way, irrespective of their size. Overall, myTomor-

rows has good relationships with the small companies. But at times, you see small, innovative companies which add board members coming from the “big pharma” world and you witness some change as these big pharma former executives introduce a lot of the old, stiff reasoning. And as a consequence, such small companies are not easy to partner with. Luckily, most of the time this is not the case. Also, there are some large companies that are genuinely trying to work with us and we are managing to run projects together (for instance, we are working with a company on a project for a treatment for cancer). These companies become more and more interested to work fluidly with a patient-centric organization like ours. In all instances, myTomorrows is willing to retain its independence and to ensure that patients and doctors get the transparent, reliable, and trustworthy insight that they need. Partner companies will not be allowed to jeopardize our speed of execution. The question that we’re indirectly asking to our partners is “are you ready to move fast?”, and the corollary—yet unspoken—question is “can you move fast?”

PM: **What would you recommend the industry should change towards ensuring sustainability?**

S Vink: Within the industry habitat, there are other stakeholders and a number of them are also displaying clear conservative traits, such as some “key opinion leaders” and sometimes the medical associations. I challenge them to be part of the growing movement that doesn’t accept the status quo and aims to make innovative medicines more accessible for patients with unmet needs. For instance, in the field of oncology, the ASCO (Note: American Association of Clinical Oncology) has recognized that things have to change in terms of the way the patient voice is factored into drug development and access. This is really encouraging. It’s important that the association dares to lose control and organizes the evolution in such a way that the voice of society is leading. If this is what they have in mind, the association will realize their aim to serve society. “Are we daring enough to be humble,” ASCO President Clifford Hudis asked an audience of oncologists, “and serve our patients?” I would recommend to the industry to tone down its obsession for control. Unquestionably, safety is important, but let us not allow it to go too far. At the moment, the authorization of innovative treatments takes 15 years. Seriously ill patients don’t have this time. My goal is to contribute to a growing number of patients

that get access to promising medicines. When one looks at companies such as Google, Facebook, eBay, etc., they create an environment in which it is free to go and to make use of it. From the user's vantage point, it is a noncontrolling environment which it's upto the user to act. In the medical world, a decision to act should be taken by the physician and his patient. Without delving in the motives of these companies, one has to recognize that this is very positively perceived by the lay public, while the willingness to retain control and the paternalistic tone of the pharma industry is not going down well with society. Industry bosses should act less as managers and more as enabling leaders, freeing up the willingness to innovate and to go the extra mile in their teams with passion.