"Listen to the patient! Look at the nose!" I heard these prophetic words many years ago when reporting on a workshop on allergic rhinitis as a young medical writer. These deceptively simple words were spoken by Dr Bill Frankland, one of the most distinguished clinicians of the 20th century.

Frankland put the patient experience first. He knew that hearing what the patient felt was critical to understanding what intervention might be needed. He was far too polite to say so out loud, but all the complex immunology and technical stuff on the agenda of the workshop were unimportant – when compared to the patient.

His interest in treating patients like grown-ups was way ahead of its time. Even today, when the patient is speaking, the doctor may not always be listening. They may be filtering what the patient is saying, potentially underplaying the discomfort or inconvenience they are experiencing.

This is not just a failing of the medical profession. Our healthcare commissioners talk about patient-centricity all the time, but this is too often a box ticking exercise and not real engagement. 'The system' almost always prevails over the patient, whatever the rhetoric.

Talking about a revolution?

The idea that pharma can lead the way in building a true understanding of a clinical condition from the patient perspective is very exciting. It will lead to a revolution in drug development, changing how clinical studies are conducted, the endpoints we measure, how we evaluate side effects, convenience and quality of life, and what support we provide.
People not patients
We do not want our lives to be defined by illness. We are people, not patients. We are sentient beings, not passive objects.

High expectations
We want a high sense of well-being – importantly, even in the face of chronic, severe illness. This highlights the importance of mental health as a cornerstone of physical health, and vice versa.

A real ‘health’ service
From both a patient and payer perspective, we need to move towards keeping well (public health interventions, adult as well as childhood education, etc.) and away from fixing us when we are sick. A true ‘health service’ rather than the ‘illness service’ that we operate today, at such overwhelming cost.

Holistic wellness
Breaking down the barriers between the providers of education, nutrition, exercise, transport, health and social care and creating a genuinely holistic approach will need a revolution in thinking, but it is the only way to put the person at the centre. The role of pharma here will be critical – as we move inexorably towards proving a wellness service rather than just a pill, that service must be tailored to the individual, so we’d better know exactly what he or she really needs.

Measuring health
We need our physicians to understand the impact of an illness on our lives; this raises interesting questions for pharma about how we might measure this impact. It clearly isn’t just about hard clinical outcomes (important though they are), but also about how our sleep, family life, work life and well-being are affected. Increasingly, regulatory authorities recognize the importance of patient reported outcome studies, but it will be for our industry to formulate and validate good, clear questionnaires and clinical algorithms that really do touch on the important factors for patients and measure them in a clinically meaningful way.

Rapid diagnosis
This assumes that the doctor will work out quickly what is wrong with us yet, sadly, and especially in rare diseases, this may not happen. For example, with Fabry disease, a leading UK expert said it can take 10 years and 10 specialists before a diagnosis is made in a child not previously identified as being in a genetically susceptible family. We need a greater understanding of the costs of such delays in diagnosis in terms of wasted medical resources, time spent, family disruption and loss of childhood. For the affected individuals these costs are almost incalculable.

Sharing the experience
These personal costs highlight the need for, and importance of, groups for patients to share their knowledge, offer each other support, speak in a strong voice and be powerful research partners. Even with more common diseases, there is a huge lag between proven best practice and what happens in the field. For example, it took years for ACE inhibitors to make it into everyday practice in the management of chronic heart failure and, even today, we struggle to manage the condition in the face of really clear outcome evidence, leaving patients incapacitated, hospitalized and unable to perform simple acts of daily life.

Education
More education is needed at every level, and pharma has a huge role to play in listening to and informing both physicians and those they treat. Let this education be both evidence-based and respectful.

While it’s not quite January 1st, now is a very good time for a resolution from us all – let us go out and talk to the people we treat and listen to what they really need! We might be surprised to hear what they tell us.