Living well with rheumatoid arthritis: Engaging patients highlights the unmet need

Graeme Johnston

Board Member, Patient Focused Medicines Development (PFMD)

Lumanity Expert Patient Council

We sat down with Graeme Johnston to talk about the challenges facing the rheumatoid arthritis (RA) community. We learn about his experiences as someone living with RA and how this inspired him to become a patient advocate and advisor to pharma. We also learn about the establishment of PFMD and the role he's played to provide a standard for patient engagement in new drug submissions and the development process.

Hear my Voice™

Q&A

Please introduce yourself and give us a brief history of your involvement with patient advocacy.

I am Graeme Johnston and I am living with rheumatoid arthritis (RA) which is a chronic, autoimmune disease that causes joint inflammation and pain, among other things. As I approached 50, I was in good health, and, therefore, health actually meant very little to me. I underwent a medical examination at the end of June 2006, which showed I was in perfect health; all my inflammatory markers were normal. Then just two months later, I was crippled by agonizing joint pain all over my body leading to a diagnosis of rheumatoid arthritis. With a successful career in banking and mergers and acquisitions, I wasn't at all prepared for the life changing diagnosis of RA. This propelled me from a relatively blasé attitude towards medicine and health to it becoming a principal focus in my life.

I attended a National Rheumatoid Arthritis Society (NRAS) self-management course which was totally enlightening and allowed me to see how I could experience life not just in spite of RA, but almost because of it, to bring positive benefits. That was my cue to take control of my situation and a gateway into activism. As the course was coming to an end, a member of NRAS invited me to become treasurer, and over time I got increasingly involved and became Chair of the Trustees at the best – the only – patient-led RA charity in the country.

This led to more advocacy positions over the following five years. A well-known manufacturer of a biologic widely used in RA invited me to attend a scientific advisory board to discuss their entire immunology pipeline. At one point in the meeting, we started discussing self-administering drugs, and typically I had a lot to say. I was surprised, and I think they were surprised too, that I was providing answers which weren't what they expected. I realised then how important it is to put the patient perspective forward, and I have been doing this whenever and wherever I can since!

Overtime I realised that I wasn't just representing RA patients, so armed with the knowledge and depth of insight I'd gained, I saw the potential to play a positive role to better represent the involvement of patients at all stages in the development of new medicines. This led to me being a founder, and now board member, of Patient Focused Medicines Development (PFMD), a global pharmaceutical industry and patient initiative to improve and standardize the involvement of patients in all stages of new drug development and use.

Why is your advocacy in this area particularly important to you? What is PFMD aiming to achieve?

It was becoming clear that regulatory bodies like the FDA in the US and the EMA in Europe were moving from a position of welcoming patient engagement in new drug submissions to starting to expect it. As patient advocates, the feeling was that this could be an opportunity to set the tone and to lead the way. And an opportunity which, if missed, would lead to the regulators imposing what they believe is best. Many companies claimed to be including patients but it was in a disparate, unconnected way. We felt there needed to be a 'corpus', a body of agreed knowledge, a book of good practice rules which would demonstrate how to involve patients, how to contract with patients and how to reward patients. As an example, one of the things which frustrated many patients was being asked to do a small piece of work for a pharmaceutical company, and being handed a 14-page incomprehensible contract. This compelled us to set up a group to look at the gap in patient engagement within medicines development, and PFMD was born.

One of the biggest things I think we've achieved so far is gaining the support of most major pharmaceutical companies. We have helped them reflect on their policies and to use the principles that we have been advocating for patient engagement. We are really pushing for better communication, particularly in areas like clinical trial development. We want people to know exactly what they're getting into and know exactly what the outcome of the clinical trial is expected to be. So often clinical trials do not give proper feedback to the participants. In many cases, a clinical trial is seen as a beacon of hope for patients with challenging diseases, and to not be told if the beacon worked, or whether the process, the procedure, the molecule was of value – is very disappointing.

What are the biggest challenges facing you and other RA patients?

Once, I was in a meeting with very senior top management of a pharmaceutical company in which they told me, "Well, the thing about RA is there is really no unmet need anymore. We have biologics for people who have severe disease, and then people like you who are in remission, can manage fine with disease modifying drugs." To which my response was, well, I'll be polite, "Nonsense!". I've gone from being one of the fittest men of my age group to one of the least fit men of my age group. I have no stamina. I'm a good golfer and I still play golf

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pretty regularly, but I have to drive around in a buggy because if I try and walk around the golf course, which isn't really all that far, by at the time I get to halfway round, it's not worth keeping score because I'm so tired. My co-ordination is going and I stop hitting decent shots." There is a huge amount of unmet need for people who are apparently in remission. I'm almost permanently tired. I don't have many flares, but, when I do, they are excruciating. I've got good painkillers, yet they come with side effects. I occasionally go on courses of steroids. I take a range of drugs, and because I take those drugs, I take other drugs to counteract some of the side effects of those drugs. And that's a pretty clear sign of unmet need to me. I am told I am not ill enough or incapacitated enough for an £8000–£10,000 a year biologic or biosimilar; that would not be a good use of public money. But I would love a small molecule taken by mouth that could help alleviate some of the symptoms that are making my life particularly difficult.

A professor friend of mine from the University of Oxford, described how someone diagnosed with severe RA and doing well on a biologic will have a better radiographic score within ten years than the person 'doing well' and in remission and therefore not offered a biologic. In other words, the drugs that I get aren't enough to stop the gradual but inevitable and inexorable deterioration in my joints. And that's a pretty crap outlook for someone who is 'doing well'.

Sixty percent of the people in Britain who have RA are not on a biologic but could benefit from one. At £10,000 each, that would be 2.5 billion pounds. We can't expect every disease and every condition to be met at whatever the cost. My hope is for a smaller, less expensive, oral biologic at some point that doesn't involve the huge cost of an injection or infusion.

How well does the pharmaceutical industry understand the challenges? And how are they helping you address them?

What makes the path bumpy are sclerotic processes within pharmaceutical companies. I had a very difficult conversation with one drug company because their global risk department were unwilling to pay the rate that they had agreed for me in the past. According to them, "We can't pay that much to a patient. We don't pay some nurses and doctors as much as that on an hourly rate. We would like to carry on working with you, but would you do it for half the price we agreed?" One of the best companies I worked for had the inspired idea of bringing someone from legal compliance into conversations with patients, to demonstrate the value they bring in tapping into their understanding of the disease. They get great value from it because they can find out what their drugs and competitors' drugs do and what the absence of drugs does in day-to-day life. When the head of legal compliance and risk joined this call, she had a fabulous time and ended up being one of the principal

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people who was asking those questions, as she was learning things about the patient experience that she didn't know and that she found revealing and relevant. I'm afraid in too many companies there is a lack of understanding.

The pharma industry is one of the few industries that doesn't regularly consult its end customers to understand the effectiveness and the usability of the products it makes. In the car industry, you would consult on how the dashboard is laid out and ask about all the things customers want in a car. Yet in pharma, companies say, we have to sell this drug to doctors and patients should take what their doctors give to them and be satisfied.

What more could be done for patients in your view?

In my mind there are three key targets. The first is to go upstream, back up to the lab and translational medicine to get far greater patient involvement and understanding of where the unmet need lies. I've talked to around 100 people that work in immunology about living with RA. Having an articulate patient who can talk reasonably lucidly about what living with the disease is like and some of the issues was both inspiring and incredibly useful to them. They may not have gone directly back to the lab and done something different, but it fired up their enthusiasm and filled their work with better context.

The second is going downstream. This is putting more emphasis on, and gaining a greater understanding of, the patient experience of the drug in use. My favorite example is I take methotrexate and I take 15 mg of the tablets once a week, but you can only get them in 2.5 mg and 10 mg tablets. For reasons I don't understand, I have to take six 2.5mg tablets because, goodness me, I can't be trusted not to take two 10mgs and one 2.5 by mistake instead of one 10 and two 2.5s. They are made about the size of a red lentil and put in a blister pack. Because of my disease, some mornings my fingers feel and look like a bunch of sausages, and to fiddle to get six tiny lentils out of a blister pack is incredible. It's a trivial example, but it's the sort of thing that, with a bit of patient feedback, could be improved.

The third area is innovation in medical devices. Increasingly companies are moving to better technology and wearable devices and this is a key area for patient engagement. There seems to be very little thought being given at the product and devices end of the market to patient engagement. I share the example of a type 1 diabetic patient. They get equipment from their drug company continuously, and a case for the insulin pump. Unfortunately, the case strap obscures the read out from the monitor. Further, some of the continuous monitoring software only has a shelf life of 14 days. And the monitors quite often fall off, which costs another £40.

All this illustrates that very little thought is being given to the patient in terms of product and devices and the end user – who is ultimately the patient living with the disease day in and day out. Wearables are fantastically exciting but an absolute Wild West of people doing what they think is best, with very limited patient interactions. When talking about patient focused medicine development, we are trying very hard to get some standards agreed both for devices and for digital technology.

If you could change one thing to benefit your communities and reflect their needs, what would it be?

I'm afraid I'm asking for two wishes. So, my wish as a patient advocate is that there would be an agreement by the EMA and the FDA over the next five years to impose the rule book as derived by the industry within the process of PFMD, urging pharma to take the necessary steps forward in patient engagement. I recognise the real and multiple challenges of getting a new drug to market, but we have to be able to think about it in human terms. Rather than just welcoming patient engagement in new drug and new technology development, the industry should expect it.

My answer from a personal perspective would be for pharma to develop a small molecule, take-home, RA targeted drug for the 'living well' patients as this is a huge unmet need.

Graeme Johnston is a founder and board member of PFMD, a global pharmaceutical industry and patient initiative to improve and standardize the involvement of patients in all stages of new drug development and use.

Graeme was formerly a member of the Scientific Advisory Board of Immunology at UCB Pharma from 2012-2018 and Chair of Trustees of the National Rheumatoid Arthritis Society from 2009-2016.

Graeme has advised several drug companies on their patient engagement activities and on living with a lifelong condition as well as other related topics. His clients have included UCB, GSK, Gilead Life Sciences, Lumanity, Bayer, and Novartis.