Interview: Liam O'Toole – CEO, Arthritis Research UK

"We recognize that there is an enormous amount to do in arthritis, but also recognize that we cannot do it on our own. As a result, we are very much keen to work with, not only the public sector and the university sector, but industry."

08.05.2018

Tags: UK, Arthritis Research UK, Charity, Arthritis, Research, Brexit

Liam O'Toole, CEO of Arthritis Research UK, discusses how arthritis impacts the British economy, raising public awareness of the condition, the potential ramifications of Brexit, and the importance of inter-stakeholder collaboration.

What is the social and economic impact of arthritis on the British economy?

At Arthritis Research UK we use the term 'arthritis' to describe 200 different musculoskeletal conditions, of which there are three broad groupings. The first are inflammatory conditions – such as rheumatoid arthritis that affect all organs in the body and are treated by drugs such as anti-TNF therapy normally in secondary care. There are over 400,000 adults aged 16 and over living with rheumatoid arthritis and 12,000 children with inflammatory arthritis in the UK. Then we have what we term conditions of pain, such as osteoarthritis and back pain. These are conditions usually associated with the aging population, where there is no primary drug treatment and these conditions are managed primarily in primary care. And then there is osteoporosis and high-risk fragility fractures. Taken together, these conditions are the major cause of disability in the UK and the third largest area of NHS program spend. One in five people consult a GP with musculoskeletal pain each year, so cumulatively treating the two most common forms of arthritis-osteoarthritis and rheumatoid arthritis will result in health care costs of GBP 118.6 billion over the next decade.

In terms of the economy, musculoskeletal conditions such as arthritis are the second most common cause of sickness and absence in the UK, with nearly 31 million working days lost to the UK economy. That's a little over 20 percent of total sickness absence. A quarter of people with arthritis

leave work or retire earlier than they would otherwise do. The cost of working days lots to the UK economy in 2017 for osteoarthritis and rheumatoid arthritis alone is almost GBP 2.6 billion.

The impact on people with arthritis, whatever the condition, is profound and means chronic pain, fatigue and isolation. We say that, arthritis doesn't kill you, but it takes away your life. It is severely limiting, and it is a growing condition.

As a child of the '60s, I remember my mother talking about "the C Word" and never mentioning the word 'cancer.' We have come a long way since then and will talk about diabetes, cancer, Alzheimer's, and beginning to talk about mental health, but we still don't talk about the pain of arthritis, it's hidden. Arthritis is something that you cannot see, it is misunderstood and is seen as something that is an inevitable part of aging. There are still healthcare professionals that talk to people about the condition as "a little bit of wear and tear."

What role has Arthritis Research UK played in progressing social awareness of the condition in the UK?

This is something we are just starting on. We are just beginning a long program of work over the next few years aimed at recognizing the impact of arthritis. The impact on the individual, their family, society and the economy is completely disjointed from the level of understanding and the priority it is given. We want to bridge that.

There are over 160,000 charities in the UK and the charity sector is very developed. However, only 50 of them merge each year, and we are one of those 50. We have just merged with Arthritis Care, which was a sister organization covering all musculoskeletal conditions. What they bring is quite a vibrant volunteer base providing people with advice, support and self-help. What we want to achieve as a merged charity is create more of a mass movement, empower people, get people talking about their condition and pain, advocate for change and support each other. Also ensure that more research is done on it.

What about the government and authorities? How would you describe their level of involvement?

I think there is a growing understanding of the enormous impact arthritis has on individuals, families and society. We've been working tirelessly with healthcare professionals, commissioners and healthcare professionals to raise the profile and understanding of the condition and there are reals signs that the pain of arthritis is starting to be taken seriously. For example, Public Health England, after years of working in partnership with Arthritis Research UK have just announced that

musculoskeletal disease is one of its new priority programmes.

It’s important that arthritis is seen in the context of the rapidly ageing population. We are all wrestling with the aging population and are increasingly understanding the potential impacts. We are moving into a future where we are living longer, but we are collecting long-term conditions, 80 percent of people with osteoarthritis also have another long-term condition. We need to develop a service, a health and social care system, but also a charity system and an approach to research, that recognizes that growing reality.

Because the future is on of living longer, with multiple conditions, it’s important we as an organization and the system is geared up to care for people with arthritis, diabetes and alzheimer’s, for example. So as a charity we are leading a piece of work on Multimorbidity for the Richmond Group of charities; a partnership of long-term condition charities, including organizations such as Alzheimer’s Society or Diabetes UK. This is an issue of increasing interest to policy makers and an area where the charities know they will also need to evolve to meet changing demand.

[Featured_in]

How would you qualify the main priorities of Arthritis Research UK’s five-year strategic plan?

Let me first take a step back. As a research funder, we currently have 300 grants and GBP 120 million being spent on research. We are one of the top five charity research funders in the UK. We also do patient information and advocacy. What is unique about us is our links with the academic community (particularly clinical and translation), surgery & health professionals, and also, our link to people with arthritis – not only to support them but also with listening and engagement – that ‘patient voice’ that is so crucial to shaping what we do.

A few years ago, we led a survey encompassing thousands of people with arthritis and asked them “What really matters to you?”. The vast majority of answers were related to quality of life. First of all, people with arthritis want to manage their own condition but are not getting the support they need. They demand advice and empowerment. They also want an ongoing conversation about what they can do to manage their pain and manage their fatigue and isolation. As a result of that very strong voice, we merged with Arthritis Care and are putting in place is a support system that can provide personalized support through a number of different channels. For example, we are a world leader in the charity sector in the use of artificial intelligence. We have worked with IBM Watson to develop an online virtual assistant, enabling a person suffering from a musculoskeletal condition to have a live conversation about osteoarthritis, exercise and medication. We have been

working with over 500 volunteers – including health care professionals with osteoarthritis – teaching the chatbot to answer questions. The value is that it is 24/7. Many people get desperate in the middle of the night where they can't sleep from the constant chronic pain, so this represents an immense assistance. We are putting together a platform so that nobody is left suffering in silence.

The other focal point is related to pain. We have done a lot of audience segmentation and we believe that, of those 10 million people, probably between three and four million are really struggling with chronic long-term pain. We listened to that patient voice and one of the big focuses of our research now is about addressing pain. There has actually been very little pain research conducted in this country. We have developed, which we are about to launch, a Pain Research Road Map that we want to share across sectors and internationally. We want to encourage people to start doing more research on pain. It has been quite some time since any new painkillers came onto the market, in terms of new drug entities specifically designed to treat pain. You have to go back to the late 1990s, and we want to stimulate that agenda.

Why is arthritis not a priority for industry?

There might be something about the market. I would also put the question back to us and accept some responsibility for the low profile of the condition until recently, we were very much focused on primarily funding research into disease, mechanisms of disease and treatment. We were also focused on providing information. We are now a much more dynamic organization, with a greater insight into the lives of people with arthritis and a louder, clearer voice. We are now in a position to provide leadership, but we can't do it on our own we need to build effective partnerships.

Is it quite recent, this focus on pain?

Yes, it is new. I think one of the real strengths of us as a charity, and the charity sector as a whole, is that we are so close to the patient nowadays. They help us to set the agenda., and we then convene other experts to try and move us forward. Partnership is in the DNA of the organization. Our role is to fund research and help set the agenda – by talking to the patients, people with arthritis, and the academic community. The overall idea being to then convene and collaborate.

One of the partnership studies we did – that I think would be difficult to conduct in other places – is the MATURA study. It is co-funded by us and the Medical Research Council (MRC). We put in a £million, while the MRC put in four million. There are twelve academic research groups in the UK and ten pharmaceutical companies involved in it. It is about stratified medicine and the use of four drugs routinely used to treat rheumatoid arthritis (methotrexate, anti-TNF, rituximab and tocilizumab) and how we can get the right drug to the right person at the right time. Personalized

medicine, stratified medicine. The potential savings to the NHS are enormous, and I truly believe we are rather avant-garde in that sort of multi-sector collaboration – in comparison to other countries.

If I was to describe Arthritis Research UK and our unique role I would say it is linked with the academic community and close contact with the patient. It has a role as a convener and collaborator, while showing leadership on issues such as pain research, multi-morbidity and artificial intelligence. We recognize that there is an enormous amount to do in arthritis, but also recognize that we cannot do it on our own. As a result, we are very much keen to work with, not only the public sector and the university sector, but industry.

How does Arthritis Research partner and collaborate with industry?

We have a number of Centers of Excellence that link together those researchers working in rheumatoid arthritis and osteoarthritis, and consequently, we contribute to that infrastructure. We are starting to have the conversations around pain for example; but are also stacking the odds in favor of a cure. We know we cannot come up with a cure on our own, but we can stack the odds by convening and working in partnerships.

I think what is unique about the UK research landscape is that, it is a complex eco-system that has public, industry and charity funding, as well as the NHS base. What has happened over the last couple of decades is that those different sectors have come around the table together, and believe industry appreciate having those different leaders come together and work together on the strategic development of the research and regulatory landscape. It is a complex eco-system and we are not working alone – the MATURA project shows that quite clearly. We couldn't have done that without collaborating with industry, the vibrant university sector with those researcher groups, and input from the clinical translation community.

We feel very positive about the government's *Life Sciences Industrial Strategy* because the successive governments in the UK have passed the baton on, continuing the conversation across the multiple sectors involved in research. The Life Sciences Strategy is the next manifestation of that conversation. Having heard the mood music for the last 15 or so years, this seems like, not only a continuation but an augmentation, and a further commitment. There is a dynamic tension in the system. If it isn't a real commitment, then, the charity and academic sectors will hold the government and industry to account.

How do you think Brexit might impact the research landscape in the UK?

One of the things I would say is that having this complimentary landscape with such a vibrant charity sector, a good industry investment, and the public sector commitment through the research councils, plus the NIHR – well, it is not going to go away! While we are heading into a period of uncertainty, I think the charity sector, and the fact we are all around the table will give us the sort of robustness to carry on.

We do know that science is increasingly collaborative, without borders, so we and our colleagues will be working very hard to do what we need to do to continue those collaborations, facilitate them, because that is what people with arthritis need from us.

[related_story]

What are your key strategic priorities today?

As we look forward, we will be interacting with people with arthritis on the ground, giving them support and enabling self-help. We will be increasing the arthritis voice around key decision-making tables, and we will remain ambitious about setting and accelerating the research agenda. Our strategy is to work in partnership, convene wherever we can, be clear about what we do ourselves, what we do in partnerships, and where we try and influence others to achieve it. That’s the recipe for success; being clear where we fit in.

You have an extensive experience in the charity field. What keeps you going every day?

I have been in this role for eight years now, and over that time, the charity has become unrecognizable from where it was in 2009. We were quite a traditional charity, that had delivered some great results. Our research led to the development of anti-TNF therapy which has given back the lives to people with rheumatoid arthritis. Before that, we used to have rheumatology wards which were really about pain management when people had a flair up. As a result, it has been life-changing for people with inflammatory arthritis.

However we needed to be more than that and what we have been doing is getting much closer to our beneficiaries, becoming much more strategic in terms of what we do ourselves and what we do in partnership, and also making sure we are set for the challenges of the 21st century which are very different and not talked about: multi-morbidity, the digital solutions etc.

What keeps me going is that we have only just started, what keeps me awake at night is a real sense of urgency because I know there are growing numbers of people really struggling with chronic, long-term pain, fatigue, isolation and depression. I think we have a role to play in terms of creating a louder voice for those people, but also convening and working in partnership with

others. I continue to be motivated because I know this is a condition whose time is rapidly coming, as Alzheimer’s was.

See more interviews