Aisling Burnand – CEO, Association of Medical Research Charities (AMRC), UK

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Aisling Burnand, CEO of the Association of Medical Research Charities (AMRC), shares the organization's vision and the significant contributions of its member charities to the life sciences R&D ecosystem in the UK. She also outlines some of the main trends within the sector including digitalization and new models of fundraising, and the challenges and opportunities associated with Brexit.

Given that the Association of Medical Research Charities' (AMRC) 140 members fund 45 percent of all publicly-funded medical research in the UK, investing over GBP 1.6 billion in health research in 2016, it is clear that the charity sector plays an incredibly important role within the British life sciences R&D ecosystem. Could you please expand on the Association's vision for our international audience that may not be that familiar with AMRC's work?

The AMRC is a membership organization that has been around for 30 years. Our 140-strong membership reflects both the depth and breadth of the charity sector, spanning charities that depend on public fundraising – which in the UK is proportionately very large compared with other countries – to philanthropic foundations like Wellcome. They cover large organizations addressing major disease areas, like cardiovascular disease and cancer, to smaller, more niche ones that may be the only charity in that disease space.

Our vision is to be the voice of the health and medical research charity sector, supporting them in their delivery of high-quality research, and championing the public and patient benefits of such research. We achieve this in a number of ways: helping charities influence policy in the research landscape and playing an advocacy-type role; ensuring that a clear united voice comes from health and medical research charities; and creating a platform for our members to learn and share with each other through workshops and other knowledge-transfer activities.

Given the depth and breadth of your membership, how challenging is it for AMRC to represent their different interests?

Having previously headed the Bio-Industry Association (BIA), I do understand that it is difficult for an association to be everything to all of our members all of the time. It is critical to recognize and be sensitive to the fact that different charities will have different needs and interests – and to work with them in different ways. What is important is to be flexible enough to respond to their varying needs.

For instance, with smaller organizations, we often provide a policy function and provide back-office support to help with the strategic guidance or messaging that they might lack the time or resources to develop themselves. With larger organizations like Cancer Research UK or the British Heart Foundation, we would often be sharing information and knowledge in order to work with them on the big challenges they face, or to channel our resources appropriately. This is why, on my arrival three-and-a-half years ago, we conducted in-depth market to build a more comprehensive understanding of what the major issues for our members were. We also have various working and advisory groups to bring our members together so that they can provide input into our activities and share ideas.

From that research, are there some common challenges that your members face across the board?

Interestingly, over the past few years, the main challenges for our members are still – in spite of Brexit – research funding and the need to demonstrate impact.

Impact is an issue that many organizations, not just the charitable sector, have been reflecting on: how to show the impact of a donation of say, GBP 10, on the cause and beneficiary, in a way that is evidence-based? Historically, charities have tended to demonstrate impact through case studies, which still hold real value and resonance, but the trend is moving towards data-backed demonstrations. If a certain amount is being invested in this area, what are the tangible outputs and benefits that result?

Demonstrating impact is an area that we have focused on significantly over the past few years. We have produced a report titled ‘Making a Difference’ that pulls together the different areas in, and means through which, our members have an impact. For instance, charities funding academia, basic research or skills will have a different impact than those funding service delivery or clinical trials – and they will need different methods of measurement. We want to help our members understand the best measures for them, how to communicate them to their stakeholders – and more broadly, to help demonstrate the sector’s impact as a whole.

The fact that our member charities poured GBP 1.6 billion into medical research – more than the Medical Research Council (MRC) or the National Institute for Health Research (NIHR) – highlights the important contribution they make to the life sciences ecosystem. In addition to that, charity investment also has a significant impact in its role as a lever that de-risks that particular area of research and opens it up the area for further funding. Charities are good at identifying gaps in medical research. In many cases, they identify an unmet patient need, where no one else is operating in that space, and then enter that space early on. That funding then de-risks the early-stage research, allowing other actors to come in. Sometimes it works the other way around and charities might piggyback on public-sector or private funding.

We are now also seeing charities behaving more like investors, with Parkinson’s UK and Alzheimer’s Research UK as examples. Such organizations are either putting in money to have more ‘shots at the goal’, so to speak, by moving into the translational space while they might have historically worked more in the basic research space, or they are acting as ‘honest brokers’ and aligning investment from a variety of partners around an unmet patient need. The Dementia Discovery Fund is an example: initial development between the UK Government and Alzheimer’s Research UK (ARUK) brought six pharmaceutical partners on board. GBP 3.5 million from ARUK acted as leverage to draw in well over GBP 100 million. Recently, in November 2017, the Gates Foundation announced an addition of USD 50 million to reach a total of GBP 150 million! This is a very new development in the role of medical research charities, which has had a very positive impact.

Then you have new investment models like integrated fundraising. Charities are starting to say things like, we will invest this amount of money but we would like to recoup a level of this investment, which will then go straight into funding more research. At the far end of the spectrum, you have models that work in a similar way to venture capital approaches, with venture philanthropy becoming a trend too. We like to call it ‘passion capital’, because it is about people being passionate about wanting to make a difference and think differently about fundraising. Examples include Parkinson’s UK’s Virtual Biotech, the Brain Tumour Charity’s Brain Tumor Fund, and the Dementia Discovery Fund mentioned earlier.

There is a growing need for innovation in this financial climate, and charities are stepping up, particularly as the pharma industry has moved away from some disease areas when they have not been able to make a profitable business case. By working in this way, charities can perhaps set a new paradigm to entice these larger players back into the area.

With digitalization being a new trend, and there being talk of Charities 2.0, how can AMRC help charities bridge the digital gap?

What has been very interesting is the power of digital to transform and impact the charities space. This is still something relatively new and untested that we are all trying to grapple with, but we are seeing some promising new initiatives. Arthritis Research UK is also trialing a chatbox-type piece of technology to deliver tailored information at home. We have coined the term Charities 2.0 for innovative digital organizations operating in this space, many of whom came to our Delving into Digital conference in February. The conference showcased examples of digital projects including apps and artificial intelligence being developed by AMRC member charities and facilitated links with digital technology companies and public-sector representatives.

We have also produced a report titled “On the Front Foot” that explores areas for further improvement and change in the medical charity sector. We highlighted great examples of charities doing things differently and more effectively, as well as the challenges that come with the need to transform organizational culture and capabilities in the digital age. One very important factor is the need for charities to prioritize collaboration. Some have been a bit reluctant to work with industry and others, but this mindset is gradually changing. This, of course, raises issues such as what is the best way for charities to work with industry, concerns about transparency, and so on, that then have to be addressed. Another conversation has revolved around value. One of the key focuses of “On the Front Foot” was arbitrating research projects. Charities are now asking themselves where their money can best be invested to have the most impact.

What are some of the other trends you would like to highlight in the medical research charity sector?

There is an increasing focus on patient-centricity. Many charities have traditionally focused on dedicating their funds to academia and basic science; this will continue because there is still a fair amount of knowledge creation that needs to happen. Increasingly, however, some of them are now going to academia and asking to fund research in specific areas that they have identified themselves, through engagement with their beneficiaries. This has been a little destabilizing for the academic community, but they need to understand that funding from medical research charities should not be taken for granted. No doubt charities will choose to continue to fund basic research, but more and more they also want to see research that is patient-centric and driven by patient needs – sometimes with patients shaping or influencing protocols. This is an area we explored in our second Patient's First conference in March, organized in conjunction with the Association of the British Pharmaceutical Industry (ABPI). Strengthening the patient voice can be challenging for the pharma industry because they have regulations that restrict their engagement with patients. Appropriate transparency and governance structures do need to be in place but, in the pre-competitive area, engaging with patients about their conditions should lead to better research and better products, so we need to find a solution. During our conference, we had a fantastic example from AstraZeneca so we know it can be done by big players.

Multiple morbidities is an area of research that doesn't seem to be well-addressed by anyone at the moment. What is the role that charities can play to drive this agenda? If issues like pain and fatigue are common across disease areas, it makes sense for a few charities to come together to fund research collectively.

Coming to the topic of Brexit, what are the challenges and opportunities you see pertaining to the medical research charity sector?

This is obviously an issue that has sucked a lot of oxygen from the sector, as it has in the political world and wider business community. We have been very clear that whatever happens in the post-Brexit world, there should be no negative impact on patients, whether in the UK or in the rest of Europe. What people do need to understand is the incredible complexity of these issues we currently face. It is not simple at all. If someone's medication cannot enter a country because of logistical issues, this is very problematic. Patients currently take part in pan-European clinical trials, which is critical especially for rare disease patients and those with a less common condition. Medical research funding is often pan-European as well. The past 40 years of harmonization in the medical research area have been hugely beneficial for all patients in Europe. As a country, we still want to remain internationally attractive as a location for research and collaboration. What the European Medicines Agency (EMA) achieved with the Orphan Drug designation was highly transformative for the rare diseases research space. With the trend towards personalized medicine and the stratification of disease types, we certainly expect to see patient cohorts shrinking further. We need to have the systems in place to continue to conduct quality research at both a European and international level, since science is inherently a global endeavour.

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