Interview with Ross Carroll

Transcription

Of course, my name’s Ross Carroll. I’m the Public Affairs Director for the UK and Ireland for UCB pharma. Within that role, I’m responsible for government affairs, for trade association and industry engagement, and for patient-group interactions.

Yeah, in my role, I would regularly engage with patient groups. For UCB, more broadly as an organisation, compliant engagement with patients and patient groups is very important for us in our organisational strategy. The reason for that is that UCB is committed to developing and delivering the right medicines for the right patients at the right time. That’s within the context of our therapy areas of expertise. Of course, to be able to do that, we need to understand in greater depth and knowledge who the right patients are.

Ultimately, I think the only way to be able to do that is to get much closer to patients and patient groups in a compliant way, in order to be able to gain a greater understanding of disease biology and pathophysiology, but also to gain an understanding as to the patient experience of their condition and their disease. Also, to understand what an optimaltreatment outcome for patients may look like. By doing that, I think that enables us to better target our discovery research efforts and better stratify those efforts, but also to design things like clinical trials in a more patient focus and patient-centric way.

Ultimately, when our patients come to market, we’re better able to focus those medicines and some of the patient support programmes, programmes and initiatives that we would develop

in support of the medicines, to the patients that would gain the most benefit from those medicines. I think that hopefully results in turn, in the patients that gain the most benefit, getting the most value from our medicines, and of course as an organisation, and the NHS also getting optimal value as well.

WHAT IMPACT HAS THE INVOLVEMENT ON PATIENT EXPERTS HAD ON YOUR WORK?

One specific project and collaboration that we worked with a patient group on recently that delivered very good outcomes was an epilepsy service enhancement project in NHS Dumfries and Galloway. This was an exciting project because it was a collaboration across the public, private, and third sectors. It involved Epilepsy Scotland as a patient group, NHS Dumfries and Galloway, ourselves, UCB, and another pharmaceutical company, GSK.

I think the project was one of the first of its kind because of the cross sectorial nature of the collaboration. I think certainly from the UCB point of view, it's very important to recognise the contribution that Guy Armstrong and Elena Coward made in particular to the project from conception, through to coming through to fruition and the deliverance of some of the outcomes that were achieved from the project.

Specifically, the project started because in and around 2010/2011, the neurology services were extensively remodeled in NHS Dumfries and Galloway, but despite that, an area of opportunity for further improvement was the epilepsy service. I think the partners that were engaged in the collaboration specifically noted that up-skilling of primary care healthcare professionals was an area of opportunity, as well as generally raising the awareness of epilepsy across primary, secondary care and beyond. It was noted that a lack of resource but also clinician time led to patients not necessarily receiving as much information or optimal education around their condition,

which in turn led to perhaps a lack of support in self-management.

I think a number of protocols and care pathway elements could also have been improved, which was something that was recognised up front, as well as a broader patient experience of care, with regard to epilepsy services in NHS Dumfries and Galloway in general. Notably, one of the key elements that was contained within the sign guidelines,important in Scotland, as well as Health Improvement Scotland Standards, was the recommendation that provision of an epilepsy nurse specialist should be provided.

Having identified the problems collectively as organisations, we were then tasked with trying to work out how we could take that forward as a project. In the first instance, a joint working agreement was put in place. That basically outlined the aims, the aspirations, objectives, roles and responsibilities of each organisation within the collaboration. In addition, a business case and a public joint declaration was made as well.

I think because of the unique nature of the collaboration involving public, private and third sectors,but also because of some of the important and ambitious objectives behind the project, it was also launched in the Scottish Parliament by the Scottish Health Minister, which enabled the partners within the collaboration to raise awareness of epilepsy in the first instance. I think it also enabled us to publicly declare our commitment to work together to improve epilepsy services to patients in Dumfries and Galloway.

I think the involvement of Epilepsy Scotland was absolutely critical in the collaboration. I think that was noted by all of the partners, and publicly so by the medical director of NHS Dumfries and Galloway. I think their involvement ensured that the patient voice was heard loud and clear in every element of service improvement in regards to some of the work

that took place over the three year period that this project occurred within. Specifically, when the joint working agreement was put in place, it enabled Epilepsy Scotland's own epilepsy nurse specialist to be seconded to NHS Dumfries and Galloway for three days a week for three years.

That role was very, very important. It therefore provided competence, capability and capacity to enable NHS Dumfries and Galloway to make improvements against some of the key standards contained within the sign guidelines. What that looked like in practice at the and of the project was an up-skilling of primary care and secondary care clinicians, a great awareness around epilepsy in general, greater multi-disciplinaryteam working, more training of staff within the locality with regard to medical interventions andknown medical interventions when patients suffer with seizures, improvement in protocols in care pathways, and standardisation of those. For example, standardised prescribing pathways, standardised content for annual epilepsy reviews, and so forth.

I think testament to the success of the project and the outcomes that were achieved at the end of it was the NHS Dumfries and Galloway continued to co-fund the part-time epilepsy nurse specialist position, but also decided to invest and put in place a full-time position as well, showing that the project did deliver tangible outcomes, but also in a very cost-effective way for the health service in Dumfries and Galloway.

WHAT WERE THE CHALLENGES IN THIS PROJECT?

Because this type of collaboration was unique at that point, different organisations from different sectors working together, but at that stage in an untried and untested manner, there were some initial skepticism that I think the medical director of NHS Dumfries and Galloway has publicly stated himself. There was probably a reasonable nervousness as to how the collaboration wouldwork in practice. I think linked to

that, governance and contractual arrangements, and who would be responsible for what and when and to what extent all needed to be clearly defined up front. I think because of that nervousness I alluded to, buy-in of senior medical staff and board level management individuals within Dumfries and Galloway was important early on. That was something that needed to be worked at.

WHAT WOULD YOU DO DIFFERENTLY NEXT TIME?

I think the project worked very well. It's delivered some very good outcomes, and to thatextent, because the work that was undertaken up front to ensure that the governancearrangements, the roles and responsibilities, the objectives and so forth, were clearly set, led tolimited regret as the project gathered pace and ultimately concluded. However, I always think it'svery useful to measure as much as you possibly can do in terms of these types of undertakings. The more data you track, the more information you have, and the more information you have, the more knowledge you can ultimately derive at the end of a particular project such as this.

I think perhaps more metrics, more indicators that assess the impact of the project on those that were delivering care, including carers, potentially could have been incorporated into the project. I think because a lot of work was done up front to put the governance arrangements in place, there weren't too many regrets or areas of concern around the fact that we could have done things differently with regard to this particular project, which is of course pleasing.

WHY IS THE INVOLVEMENT OF PATIENTS IMPORTANT FOR RESEARCH AND DEVELOPMENT?

Well, I think from UCB's point of view, we are convinced that partnership is very important for pharmaceutical companies now, moving forward. Whether that's partnership directly with

the NHS,partnerships directly with patients and patient groups where we can do so in a compliant manner, orindeed partnerships in a broader coalition or collaboration such as the project described. I think the benefits are very clear. This particular project I described, delivered again most if not all of theobjectives that were set out at the start of the project. I think involving patient groups is critical to that because they have such a deep level of knowledge and understanding around the patient experience of care. Therefore, that can feed its way into some of the service improvements that aproject such as this was trying to tackle. Therefore, if you weren't to have the patient voice and the patient group voice engaged in this type of project, I think you would necessarily be missing somethings as a consequence.

From UCB's point of view, we think it's very important to engage with patient groups. They have such a level of knowledge in detail around the patient experience that can then be applied to create mutual value for organisations such as ourself, but patient groups and the NHS more broadly. To that end, UCB is very much committed to putting in place more capacity and capability to enable us to undertake more of these type of projects and initiatives, and to do so in a more proactive manner, so that we can engage more consistently with patient groups as close partners and in a respectful and mutually value adding way.