

Backbench Business Committee

Representations: Backbench Debates Tuesday 15 November 2016

Ordered by the House of Commons to be published on 15 November 2016.

Watch the meeting

Members present: Ian Mearns (Chair); Bob Blackman; Gavin Newlands; Mr David Nuttall; Dr Daniel Poulter; William Wragg.

Questions 1-9

Witnesses

[I](#): Calum Kerr and Matt Warman.

[II](#): Ian Austin and Kerry McCarthy.

Written evidence from witnesses:

– [Add names of witnesses and hyperlink to submissions]

Matt Warman and **Calum Kerr** made representations.

Q1 **Chair:** Good afternoon and welcome to the Backbench Business Committee. We have two applications before us this afternoon. The first is from Matt Warman and is regarding the broadband universal service obligation.

Matt Warman: I have got Calum Kerr with me, who is a co-signatory. As you know, 90% of us are bombarded by complaints about the state of broadband, and the other 10% represent constituencies in which the broadband is so bad that our constituents can't send those emails.

I am conscious that I could come every week and ask for a debate on broadband, and I think you would agree that there would be parliamentary interest in having a collective whinge about it. With this proposal, I am trying to say that Ofcom is currently considering the Government's universal service obligation, and it would be very helpful for Ofcom and the Government to hear from Parliament while that process is going on, partly because a lot of people welcome the commitment, but also because there is a genuine debate about what the USO should look like. I think I used this phrase in the submission, but there is as yet no definition of what "universal" should mean, what "service" should mean and what "obligation" should mean, so there is quite a lot of debate to be had.

My perspective is that it is broadly something that we should welcome, but we should push it further. It might be useful to hear a bit about the other side of the debate from Calum, and some of the broader concerns you might hear in the debate if you were to grant it.

Chair: There are lots of broad things in there, aren't there?

Calum Kerr: Although we initially welcomed the USO, the direction of travel on it is worrying. You may have something that, rather than closing the digital divide, cements it in. The mechanism that they are using could be highly restrictive. Rather than being what I would rather we called a universal service opportunity, which empowers the regions of England and Wales and the devolved Administrations in Wales, Scotland and Northern Ireland to go further, as the Scottish Government aims to do, this scheme might not help at all.

The desire to ensure that it is a USO—in other words, a framework by which the Government can avoid spending any money—seems perverse. Why would you not support the last few percent, given that you have funded those that preceded it? That means that the mechanism might drive an outcome that nobody wants. It won't actually fix the issue, and we will be back here annually saying, "If only we'd done it a different way." I think we need to flush that argument out into the open. There are specific suggestions that I have been trying to drive, such as voucher schemes, which also found favour from some of the independent operators.

Chair: Thank you very much indeed. Any questions?



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Q2 Bob Blackman: What do you actually want to happen as a result of this debate? The reason I ask is that at the moment it is a general debate without a specific motion that would give a view from the House. It may lead to a lot of discussion, but not a clear view from the House.

Matt Warman: We could invent a divisible motion. It would have to be quite motherhood and apple pie, in the sense that it would say, "The House would like to see a sustained, sensible USO that rises over time", or whatever. What I would like to do at this stage in the process, while Ofcom is working out what it should look like at the end, is to allow them and the Department to hear from Parliament what the issues we face locally actually are, so that when we try to regulate a sensible version, it takes into consideration a whole load of issues. In a sense, what I am hoping to do is promote a genuine debate, rather than come out with an answer that says, "This is what Parliament wants," because actually I think Parliament wants effective regulation that emerges through a sensible process and takes all the different issues into consideration.

Q3 Bob Blackman: I think I know the answer to this question, but what is the timeframe in which this debate needs to be held for what you want to effect?

Matt Warman: Effectively, the bulk of this stuff needs to happen before Christmas. To do it after Christmas would be denying them an opportunity to think deeper thoughts over a necessary time period.

Chair: We welcome Dr Daniel Poulter to the Committee as a new member.

Q4 Dr Poulter: There is a history in broadband debates of people bringing their own constituency issues forward in a fairly prominent way. How much do you see this debate as being aimed at allowing people to vent frustration at broadband, or perhaps celebrate success in certain areas? How much do you see this as being focused on the future of the USO?

Matt Warman: I do not want to pretend that I can constrain colleagues from mentioning villages in their patch that may not have as good a broadband service as they would like, but as I said at the beginning, the point of coming here now is to say that this is the right time to talk about a genuinely national issue, rather than simply provide people with the opportunities that you mention. At the same time, we need to make sure that a USO genuinely captures and deals with those individual examples, rather than being universal in name but having a lot of holes that villages might fall through. There is value in the individual anecdote as well as in the broader debate.

Calum Kerr: I picked up the digital portfolio, as well as the DEFRA portfolio, in the SNP after going to Matt's first broadband debate, which I left after half an hour because it so quickly descended into a farcical debate. It was speeches for press releases: BT bad—tick; broadband rubbish—tick; name a business, name a village. Bingo, you have a press release. I quite like the idea of having something that is a bit more focused. Granted, as Matt says, we know fine well that colleagues will use it as an opportunity, but we want an outcome to be a proper debate on

the topic of a USO and its capability. I defer to the greater knowledge in this place about how to do that, but I agree that inevitably certain colleagues will use it as a chance just to talk in general terms. What we have here is something that will be highly significant. We need to have a more informed, intelligent debate than just the usual, "We need faster broadband than our BT rubbish," which is obviously not helpful.

Q5 Chair: I hope that we can also mention urban not-spots.

Calum Kerr: Absolutely. It is not exclusively rural.

Matt Warman: On that point, the list of people who have signed the application is by no means comprehensive, but I was very keen to try to demonstrate to the Committee that there is an urban and a rural interest in this.

Chair: One of the perverse things in my area is that virtually everyone's household is covered—I have a very urban constituency—but I have a very large industrial and commercial estate that has significant not-spots. Hundreds of people's jobs depend on this, so the way in which it has been rolled out seems rather perverse. Thank you very much indeed.

Ian Austin and Kerry McCarthy made representations.

Q6 Chair: The application is on the implications of the accelerated access review for cystic fibrosis and other conditions.

Ian Austin: Thank you, Mr Mearns. Your Committee gave us a debate on a similar topic in December 2015. I think we had nine or 10 MPs taking part, but more than 1 million people followed the debate on social media, so there was a big impact outside here. There is strong cross-party support for another debate on this subject, as many of the questions that were posed last time went unanswered because of what we were told then was the imminent accelerated review on access to innovative drugs, which was due before the summer. People affected by this have not been able to ask meaningful questions of the Government while the review has been delayed and because of changes in government. The accelerated access review has been published, but it has not been debated and the Government are yet to indicate when they plan to respond.

We think that raises many questions that require parliamentary scrutiny, and MPs should be given the chance to influence the Government's response. There are lots of encouraging recommendations in the accelerated access review for many promising cystic fibrosis treatments that are under development, but we are concerned that such a strong focus on the future will come at the cost of Orkambi, which is available now.

New data published this week show that Orkambi slows declining lung function, which is the main cause of death among people with cystic



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fibrosis by 42%. Those data were unavailable to NICE and clearly demonstrate the point that drugs such as Orkambi need the chance to prove their worth in the long term. The drug was licensed a year ago. It meets many of the criteria referred to in the review for transformative designation. The manufacturer is keen to come to a commercial arrangement, but negotiations have stalled because none of the flexibility recommended in the review is currently available. More importantly, 2,700 people with cystic fibrosis in England who desperately need access to Orkambi do not have time to wait for NICE and NHS England to consult on their processes.

At the moment, users of the drug only continue to receive treatment thanks to a compassionate use programme that is run by the drug's manufacturer, but they want to know whether they will be able to access the drug on the NHS well into the future. Many other people with cystic fibrosis want to access the drug because of the immense improvements to quality of life that it brings.

We need the Government to seek guidance from NICE and NHS England on what immediate action can be taken to reach agreement with the manufacturer that will enable the drug to reach those who desperately need it. The accelerated access review has significant implications for many people: those with cystic fibrosis, anyone else hoping to benefit from new and innovative treatments, the NHS and the life sciences industry in general. That is why we would like another debate on this at some point before Christmas, if possible.

Kerry McCarthy: If I may say very briefly and on a personal note, I have a niece with cystic fibrosis—she is 12 on Sunday—which partly explains my interest. Also, in Bristol we have a very good children's cystic fibrosis unit at the Bristol Royal Infirmary, as well as an adult service. It is a condition where, quite often, there is a sudden deterioration in the late teens and early 20s, which is when medics start having to look into lung transplants for patients. Although life expectancy has increased massively, there are still a lot of people who, sadly, die in their early 20s.

Time is of the essence. We are talking about the people who could start to benefit from these drugs now. The quicker you get them on to these drugs, the better their chances. There is a similar drug, Kalydeco, which is only suitable for about 5% of cystic fibrosis patients as it depends what particular form of the illness they have. That drug has shown amazing results, and is in use. Orkambi would extend those benefits to many more children or young people with the illness. My plea is that we put pressure on the Government to act as quickly as possible.

Q7 **Chair:** In essence, you want a general debate to gain a response from Ministers.

Ian Austin: Yes.

Kerry McCarthy: Yes.

Q8 **Bob Blackman:** You talked about a review. Is there any time sensitivity



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for this topic? Clearly you want the matter debated as soon as possible, but is there an approaching deadline?

Kerry McCarthy: The review should have come out before the summer and has not. It is a question of how long you keep waiting. There is no deadline now because the deadline has passed.

Ian Austin: The time sensitivity is that people out there need this drug. We want to push Ministers to speed that up. There is strong interest in the topic. I am not an expert. Unlike Kerry, nobody in my family has cystic fibrosis—I have no direct experience of it—but a constituent of mine who was on the trial for Orkambi came to see me. She told me that when she could not look after her kids properly because of the amount of treatment she was having, she faced a choice between losing her job and being plunged into financial hardship, and carrying on working with huge challenges for her health. When she got on to the trial, it transformed her life. It has made a huge difference to her and to lots of other people in the country. At the moment, she is only able to continue with the drug because the manufacturer has put this special arrangement in place.

Q9 **Bob Blackman:** I was merely looking at it from the point of view of our scheduling debates. If a particular anniversary or deadline was coming up, we would try to fit around that.

Ian Austin: We would like to do it as quickly as we can.

Bob Blackman: I understand that.

Chair: Thank you very much for your application. That concludes the formal business of the Committee.