



Backbench Business Committee

Transcript of meeting Tuesday 19 April 2016

Representations made before the Backbench Business Committee on Tuesday 19 April 2016

Members present; Ian Mearns (Chair), Kevin Foster, Mr Philip Hollobone, Mr David Nuttall and Jess Phillips.

Geoffrey Clifton-Brown and Kevin Barron; Fiona Bruce and Stephen Timms; Stephen Timms, Greg Mulholland and Liz McInnes; Stephen Doughty; Nigel Mills made representations.

Questions 1-18

Geoffrey Clifton-Brown and Kevin Barron made representations.

Q1 Chair: Good afternoon and welcome to the Backbench Business Committee. We are just dot on time on the House of Lords clock, so we will begin proceedings. The first application is on the use of digital patient records in the NHS. We have the applications, so I would ask all applicants today to just give us a brief outline of why they want the debate. Thank you very much.

Geoffrey Clifton-Brown: Thank you very much for allowing me to put the case for this debate. I have brought along Kevin Barron and I have other supporters, as you have seen; 13 other Members have signed the application, including several from Opposition parties. Forgive me, but this is only the second time I have ever done this so I am a bit of a novice.

Fundamentally, this debate is about Government's plans to roll out full digital patient medical records and to give Members the opportunity to debate not only the enormous benefits that making patient records fully digital could bring to the NHS, but critically the obstacles that must be overcome in terms of privacy and protection of patient data. That really is the key to it all. It is absolutely right and vital that patient safety and individual privacy are at the heart of the discussions about how our data is used—it is our data, after all. That will be the key aspect of the debate. One of the reasons the Government have not proceeded with the plans so far is concerns over patient privacy. The debate would be an excellent opportunity for Members who feel those concerns to be heard and for the Government to better understand what they can do to provide the House, and indeed patients up and down the country, with the assurances they need.

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The Government have delayed progressing with digital patient records on numerous occasions, and they are currently well overdue on publishing key documents outlining their plans to launch a pilot of this scheme. This debate is a timely way of putting pressure on the Government to ensure that progress is made on this key issue, and to make them aware of all the points and concerns that they should be considering as they develop their plans.

Sharing patient records data across the NHS would create huge opportunities in the identification of rare diseases. I suppose you might ask where I am coming from on this. I think that if you have a bit of passion you should be leading these debates. I had a constituent who died of motor neurone disease, which is a horrible disease, and he told me that only one drug had been developed for that disease in the last 20 years. That led to the whole early access to medicines campaign, which is ultimately going to come about. This is the next part of that campaign: using anonymised data to identify trends of new drugs in treating rare diseases.

While I am keen to frame this debate as one of digital medical records, there are a number of hidden benefits to the NHS that follow from implementation of the policy. The Science and Technology Committee recently reported the value of big data to the health sector will equate to £14.4 billion by 2017. In fact, consultants have found that efficiency savings of between £16 billion and £66 billion a year could be generated in the NHS if data were properly used. This debate also represents an opportunity to showcase a “best of British” story when looking at the group of hospitals operating around Birmingham. Birmingham is really the centre of the work being done on using IT and patient data in exciting ways to improve patient outcomes and discover more effective treatment pathways.

With the current state of the national debate around the NHS, I think it is vital that we are not distracted from some of the central issues that are going on in the NHS at the moment, such as funding, junior doctor strikes and so on, but we concentrate on some of the core issues—the mundane but really important issues, if you like—about how we use data better, so that for the NHS we can deliver more for less.

Chair: Anything to add, Kevin?

Kevin Barron: Briefly, yes. I sit here because I chaired the Health Committee from 2005-10 and we did a report on electronic patient records. It was not without its difficulties in this place—a 60 million-person databank and all this that people were against. Things have moved on massively since then, but I’m afraid that this place has not moved on very much at all. I understand what Geoffrey says about the Science and Technology Committee looking at this.

My understanding now is there were two issues at that time: one was this big databank; the other was what type of records you should have on patients. The summary care record was one that it was recommended that you should have: it would have the details about you and your current condition as opposed to all your past. Some 96% of people now have summary care records in the national health service. I have heard no debate about it in this place at all—in fact, there has been no debate since we debated the outcome of the Select Committee report back in 2007, I think it was.

Chair: Thank you very much indeed. Any questions?

Q2 Mr Nuttall: I realise you have a substantive motion, but given that time in the Chamber is at a premium, would you be interested in taking time in Westminster Hall? You would need to slightly tweak the motion—it would have to be “considered the issue of patient records”—but if it meant being able to debate the subject at all, would you prefer to do that, if it came to it? We are approaching the end of the term, as you will both be well aware.

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Geoffrey Clifton-Brown: I absolutely understand what you are saying, Mr Nuttall. Of course we would much prefer to have it in the main Chamber so that it gets as wide an audience as possible, but if it is a question of debating it or not at all, of course we would then want to have a debate in Westminster Hall.

Mr Nuttall: Okay. That is very useful.

Q3 Chair: Thank you very much. We understand that the House will rise before the Queen's Speech sometime during the week beginning 9 May—we do not know definitely yet, but that is the best guess. There is not an awful lot of time that we have allocated between now and then. We have an early break in May and then Whitsun to come. With those constraints and the time that we already have allocated up to 28 April, we have very little time to allocate.

Kevin Barron: I understand that, Chairman. I reiterate that we have had no debate on this issue—a major issue that could really progress the national health service and patients in it. We have had no debate on the Floor of the House since we last debated the Select Committee report.

Q4 Jess Phillips: Is there a time limit per se? If it was a matter of waiting for the Chamber until long into the future—

Geoffrey Clifton-Brown: In a sense there is, because the Government's response for the trial is well overdue. There seems to be a problem—otherwise it wouldn't be overdue—and we want to put pressure on the Government to actually begin this trial. That is why it is quite time—

Q5 Jess Phillips: I am delighted to hear Birmingham is, as I thought, the centre of the world.

Geoffrey Clifton-Brown: I put it in especially for you.

Q6 Kevin Foster: Listening to this and reading the motion, is this likely to be a contested debate, or is it actually likely to be more people exploring the opportunities of a digital NHS?

Geoffrey Clifton-Brown: I think it will be contested, and I don't mind that in the slightest. That is why I think we need the debate. Several Members of Parliament I have approached say that they are worried about patient safety. I welcome that debate, because I think we need to have it. The Government need to hear the debate and then we need to react to it.

Kevin Barron: It was certainly contested when the Select Committee had the debate on the Floor of the House many years ago, but it is about time we heard it, given that people out there are signing up to summary care records and we have not yet discussed it.

Q7 Kevin Foster: I take that point on if we were to make it, let's say, "Summary care records and sharing them are a great idea," but that's not actually—

Kevin Barron: No, but it's part of the debate. It is quite wide—a catch-all. There are many other things happening as well. There is the issue about research and development and using it for trailing anonymously to find out about where diseases are, what type of people are prone to what

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disease and what lifestyle diseases they are likely to pick up. There is a whole host of things happening there; you couldn't put them in a motion, to be honest. The potential is there.

Q8 Chair: Notwithstanding what we have already said about the potential time constraints, is 90 minutes enough?

Geoffrey Clifton-Brown: It may or may not be, Chair. Judging from the interest that we have had from the Members of Parliament who have signed up, I suspect there is probably an interest in this—I was thinking about this this morning—for longer than 90 minutes, but that must be a matter for you.

Chair: Absolutely. Thank you very much indeed. We will make our consideration in due course.

Fiona Bruce and Stephen Timms made representations.

Q9 Chair: Good afternoon and welcome. This is an application on the contribution of faith organisations to the voluntary sector in local communities.

Fiona Bruce: Yes. Thank you very much, Mr Mearns. I make this application as the vice-chair of the all-party parliamentary group for faith and society, of which Stephen Timms is the chair. We have both served for some years now in that capacity. Faith groups play a huge and vital role in building and developing stronger communities. They have a grassroots connection in every community in our country and serve all, but especially the most vulnerable and those in need, from cradle to grave. I am making this application and am completely flexible. Ideally, it would be a three-hour debate. It could be in Westminster Hall—it does not have to be in the Chamber—so if you would amend the application on that basis, I would be grateful.

I have been thinking about this application for some considerable time and will explain why in a moment. The trigger for my coming to you this week was a reference during questions to the Leader of the House last Thursday when the Leader of the House essentially said, "Will someone please make an application to the Backbench Business Committee to enable members across the House to talk about the very positive contribution that many voluntary organisations make in their communities, because so many Members have sought parliamentary time to be able to do this in regards to different groups?" That propelled me to come to you.

The reason I have been thinking about this for some time—just to set it in a political context, and then I will hand over to Mr Timms—is that in late 2015 the Government put out a consultation saying that it was considering requiring faith organisations that taught young people for over about six hours a week to register with the Government. That consultation is now the subject of consideration by the Government; however, it had been brought to my attention, particularly by the Evangelical Alliance, which represents over 2 million people across the country, that many individuals were very concerned about it and there was a risk that it could cause many to stop volunteering with their local faith group because of this sense that they were going to be watched—for example, Ofsted inspections of youth groups in churches could be undertaken. I wanted the Government to be aware of the contribution that faith organisations make to our voluntary life and to our local communities, and to perhaps think again about whether this was the best approach. That is really the background to this application.

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Stephen Timms: I very much support the application. I think it is high time for wider recognition of the fact that faith groups are playing a larger and larger role in communities up and down the country. The most obvious and spectacular example, I think, is food banks. The Trussell Trust published its annual data last week. It reckons that it gave out more than a million three-day emergency food supplies to probably half a million separate households over the course of last year. I think there are about 420-something food banks in the Trussell Trust network, and every single one of them is based on a church.

[We] are seeing churches, mosques, temples and synagogues taking on more and more in their communities. **[The all-party parliamentary group for faith and society exists to draw attention to this. I think it is time there was better recognition, in Parliament and on the part of the Government, of just how much of a contribution is now being made. That contribution is certainly growing very rapidly and has grown rapidly over the last few years, and I think it is time for it to be better recognised, better understood and, I hope, celebrated as well.]**

Kevin Foster: First, I presume by the amendment of it that the application is on a motion that “this House has considered the contribution of faith organisations to the voluntary sector in local communities.” That is the motion, because there is not one on the paper. The second part of the issue is the number of people. A three-hour debate is going to involve some quite long speeches from five people; usually we would look for about 15. Have you had expressions of interest from that number of colleagues on a reasonably cross-party basis to take part in this debate?

Fiona Bruce: You will see that we have representatives from four parties who want to take part. I have to acknowledge that in view of the kind response of the Committee to my application last week for a debate, which is now taking place tomorrow, I have been somewhat engaged in garnering support for that debate. I am absolutely confident that if I went out of this room and spent half an hour contacting any number of MPs, I could come back with 20 names within that period of time.

Chair: I must admit, Kevin, having been at questions to the Leader of the House when he made his strange appeal—I mean, the Leader of the House can devote time for parliamentary debates, but he was suggesting that a Member from the Back Benches bring forward an application about the voluntary sector—it did seem to gather some momentum among the Members who were present there.

[Anyone] else? In that case, **[I]** thank you very much for your application. We will be making some decisions in due course.

[We] now have an application from Stephen Timms and others on the impact of universal credit on children.

Stephen Timms, Greg Mulholland and Liz McInnes made representations.

[I] **Stephen Timms:** Thank you, Chairman. **[When universal credit was announced almost six years ago, it was widely recognised across the House that it did potentially offer some significant advantages compared with the current benefits system. The Government published an impact assessment at the time, in 2011, when the Welfare Reform Bill was going through Parliament, which estimated that universal credit would lift 350,000 children out of poverty on its introduction. A couple of years after that, in January 2013, there was a written answer that revised that figure to “more than 150,000”, which is a significant reduction compared with what we first thought. Earlier this month, big cuts were made to universal credit, because the counterpart to the proposed cuts in tax credits,**

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which the Chancellor didn't in the end go ahead with, has gone ahead in the case of universal credit, but we have not yet had any information about the impact of those cuts on people as a whole or on children specifically. **The** Institute for Fiscal Studies forecast last month a big increase in child poverty between now and 2020. They predicted that for families with three or more children, the absolute poverty rate would go up from about 20% last year to over 30% in 2020. I think it is high time that Parliament took a look at the impact of universal credit specifically on children.

There has always been a lot of interest across the House in child poverty. The Government recently agreed to continue publishing child poverty data required by the Child Poverty Act 2010. They estimate that about half of all children in the UK will be in households entitled to universal credit once it is fully in place, so this topic is one with very wide impact.

So far, I have had support indicated for the application, as you will have seen, from Frank Field, the Chair of the Select Committee on Work and Pensions, plus 16 Labour Members, seven SNP Members, one Lib Dem—Greg is here—and two Conservative Members. The application has also had expressions of support from the Children's Society, Child Poverty Action Group and Gingerbread. I very much hope the debate will give the Government an opportunity to update the information we have on the impact assessment of universal credit, given the recent changes, and also to explore policy issues around universal credit and children, of which there are quite a number, and where there are quite important questions to be **raised**.

Greg Mulholland: I shall be brief. Thank you again, Chair, for your consideration of this. The point is that there has been lots of discussion and a lot of hot air, but there hasn't been any discussion at all about how this will affect children and families with children.

The only thing I would draw the Committee's attention to is the Government's own assessments have changed quite dramatically. The original impact assessment said that universal credit would lift 350,000 children out of poverty. By 2013, in a parliamentary question, it said that that was down to "more than 150,000"—less than half the previous estimate—and there was no assessment then of the negative impact on other groups of children, which I think is what particularly needs to be explored. Although the principle of universal credit is one that everyone would generally sign up to—seeking to simplify the benefits system—when you look below the surface there are so many complexities with the different rules that apply and affect children and families with children. I think it is time to have a chance to highlight that.

Liz McInnes: I am happy to support Stephen in this application. The presentation he has just given, together with Greg's comments, highlight that there is a real lack of clarity about how universal credit is affecting children. It is important to have this debate and try to bring some clarity **to** the situation for **everybody**.

Q10 Mr Hollobone: I appreciate and respect your application. As a Committee, we try to be impartial between the different parties in the House. I think perhaps the weakest part of your application is that you have only two Conservative Members, neither of whom is among the lead Members. I would say exactly the same were it a group of Conservative MPs with no Labour MPs supporting them. It seems to me there would be more Conservative MPs out there who would support your application, some of whom might also wish to be lead Members, which I think would strengthen your **case**.

Stephen Timms: You make a perfectly fair comment. I agree with you that there will be wide interest across the House in this subject, certainly among more Conservative Members than the ones we have been able to identify so far. I had not quite picked up the point before today about the

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importance of the lead Member. That is perhaps something that I can reflect on and try to ensure that that is in the application.

Q11 Chair: You did indicate that you had more names in your possession than we have, Stephen. If you could let us have those as soon as possible that would be useful.

Stephen Timms: Would it be helpful, after the meeting, if I spoke to those two Members and see if they were willing to be lead Members?

Chair: Absolutely.

Q12 Mr Nuttall: Is it worth reminding everyone, particularly with this present application, that Members listed do not necessarily have to be in support of the proposed motion? They might oppose the proposed motion, but that does not matter to us. It does not matter which side of the debate they wish to be on, merely that they wish to participate in the debate. I am trying to be helpful.

Stephen Timms: That is helpful.

Greg Mulholland: Briefly, one important point to make is that this has the full support of the Children's Society, which is known to be a very non-party political organisation, not coming from any part of the political spectrum, and has a lot of support from MPs of all sides. That is important to note as well

Q13 Chair: You will have heard the discussion we have had with previous applicants. It is a general debate. If we could not find time between now and prorogation for the Queen's Speech in the main Chamber, would you accept time in Westminster Hall?

Stephen Timms: I would be interested to know what the others think about that. My view is that, given that half the children in the country are going to be affected by this, it really should be in the main Chamber. I take the point that time is now running short. If it is not possible to fit us in before prorogation, perhaps I should come back after the Queen's Speech and have another go at that stage.

Chair: Okay. Thanks for that clarification. We will consider the application immediately following the public session. Thank you.

Stephen Doughty made representations.

Q14 Chair: Welcome, Stephen. This is an application on stimulating research and development for neglected areas of disease and non-communicable diseases.

Stephen Doughty: That is correct. Although I may be alone here today, I am not alone in terms of support for this application. It is supported by four of the main APPGs dealing with this issue: on TB, on malaria, on HIV and AIDS—for which I am one of the vice-chairs—and on global health. It is also supported by a cross-party group of MPs, including SNP, SDLP, Labour, Green and

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Conservative Members, and I know it will be of great interest to others across the House, because it does not fall across partisan lines.

I want to make one slight correction. The motion should read, “neglected areas of disease and other communicable and non-communicable diseases”. Communicable, infectious diseases such as HIV and others are obviously crucial, but others such as diabetes can be neglected sometimes, particularly in developing countries, and I want to make sure the motion covers all of those.

There are a number of reasons why it would be extremely timely to hold the debate as soon as possible. One is that the World Health Assembly is due to meet between 18 and 26 May and the Consultative Expert Working Group on Research and Development will meet to discuss its findings between 2 and 4 May. These are crucial international forums at which a number of these issues are going to be discussed, and I know that members of all those APPGs and others with an interest have a great desire to get them aired on the Floor of the House before then, so that we can send a message and a strong signal and understand the UK Government position on them before those crucial international meetings.

These issues cross domestic and international agendas. The debate will draw interest from Members interested in health issues generally, from a practitioner, health, clinical and scientific point of view, but also from those interested in international development, human rights and other related issues, markets and the financial arrangements around the pharmaceutical industry. I also want to flag up that the Government have recently announced significant funding for the Ross Fund, a £1 billion fund to look at anti-microbial resistance, at epidemics—including possible future epidemics, such as Ebola—at neglected tropical diseases and at where the research and development is going globally.

The debate has a specific interest for the UK, given the size of our life sciences and biomedical, medical and pharmaceutical sectors. It is very topical at the moment: the World Health Assembly is due to convene in May, as I said, and it is going to be discussing a global treaty on research and development and ensuring that funding is available for it. We want to be able to raise our concerns in relation to those meetings.

I have just a couple other points to flag up. Over the last couple of decades, the World Health Organisation has been discussing approaches to deal with the problems ensuing from our current biomedical research and development model: primarily, the lack of investment in research and development for diseases that affect the developing world or that are sometimes seen as unprofitable; and the high price of drugs, which affects both the north and the global south. I am sure members of the Committee will be aware of some of the very high-profile cases related to those issues that have been in the press in recent months.

There are two key issues that we think will be of interest, and we hope to generate debate on both sides—or potentially on multiple sides—of the argument. The first is de-linking, which is removing the cost of research and development from the equations that eventually decide the price of drugs. I am sure both sides of the argument will be made in the debate. To give an example, Gilead’s latest drug for hepatitis C, which is called Sovaldi, was very expensive. There was a lot of debate around that. As usual, the arguments were put forward that pharmaceutical companies put a lot of money into research and development. Actually, in that case both NHS England and many practitioners were very unhappy with the end cost price of the drug, because the cost of research and development was not borne by Gilead itself; it was purchased from another research company. The original research had actually been done in my own city, Cardiff. There are some really important issues there that we want to get to the heart of, about where costs and prices for pharmaceuticals come from, whether they reflect research and development or need, and all the other considerations we have to look at.

The second issue is where Governments, including this Government, should fit in setting priorities for research and development and where the state should get involved. The committee I mentioned earlier, the CEWG, is looking at how to develop a financing model at an international level. It has made a number of suggestions, including looking at treaties and so on, and whether to set aside some percentage of global development funding from Governments that give global development assistance for research and development.

There are some crucial issues that we would like to air, and we think that the debate would generate a significant amount of interest. Ideally, we would like a three-hour debate, but we are very happy for that to be either in the Chamber or in Westminster Hall, depending on availability. Although I am sure we could debate this matter again in future, it would be particularly timely now, before these two crucial meetings, to discuss where it is going to be on the agenda. I hope the Committee will give consideration to that in its deliberations. I hope that is helpful.

Q15 Chair: Thank you very much, Stephen. Have any other Members indicated that they would support you? The list we have is particularly light on Conservative Members.

Stephen Doughty: Yes, there are Members from my own APPG. I am pretty positive that we would have interest from Ben Howlett from Bath, and from others, so I could happily get you an additional list of those who would be interested. I know that Mike Freer, who chairs the all-party group on HIV and AIDS, takes a great interest in these issues as well. In fact, I am meeting, with him, some of those pharmaceutical companies in the next few weeks, so I think we will get quite a lot of interest from across the House. I will happily get you additional names if that helps.

Chair: That would be really useful. Thank you very much for your application. It is much appreciated.

Nigel Mills made representations.

Q16 Chair: Nigel, your application is about the anti-corruption summit.

Nigel Mills: Yes, that's right. The Prime Minister has arranged a special anti-corruption summit in London on 12 May, which is the reason for wanting a debate in Parliament before that. It is clearly very topical. I don't think I need to tell you, after the last couple of weeks' news, how much interest there is in this, both in the country and in Parliament. We have, at the latest count, 27 MPs supporting this debate, including Conservative, Lib Dem, Labour, SNP, Green and SDLP Members, so we have real cross-party interest in this.

The reason for wanting a debate, ideally for three hours in the Chamber, is that this will be a high-profile summit, and it is one that the UK Government is taking the lead on. It is not a regular summit that happens every now and again; it is a one-off chance to tackle a huge issue facing the country and our economy and that, in some ways, taints the very city we are in now. I think it is very important that Parliament gets the chance to have a say in what the Government's priority should be for that summit, to try to explore what the Government are trying to achieve from the summit, and indeed who will be on the final list of attendees. We could actually have a chance to discuss what measures can be agreed, what can be negotiated and what the timescale for those can be, so that we can actually see some real action on this.

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I think it is right, when we have a major summit that our country is taking the lead on, that Parliament has a chance to input into what the subject of that will be and what the Government will actually be trying to achieve. The Organisation for Economic Co-operation and Development is holding a discussion event in Paris today on exactly the same theme, so I think it would be right for there to be something here, in the Parliament of the country in which it is taking place.

I am sure I don't need to set out for you how important tackling corruption is, with around \$1 trillion of illicit flows going around the global economy at any one time. It adds 10% to business costs globally. It has a real impact on developing nations and their ability to have viable economies and budgets. It taints nearly every part of life: business, sports, property markets and the ownership of companies. Clearly we have a big interest, given our overseas territories and Crown dependencies. It makes it particularly important for us to be taking a lead on this.

I hope you can all see that it's an important debate. It will not be an attempt to rerun what happened last week. It is not necessarily about tax evasion; it is about corruption, bribery, money laundering, terrorist financing and taking money out of developing countries. It is not something that we have been debating recently, but I think there is great interest, and it is clearly very timely, with the summit coming up around the time we **prorogue**.

Q17 Mr Hollobone: What inducements will you give us to award you such a debate?

Nigel Mills: I suspect if I tried to answer that we would both end up in **prison**.

Q18 Kevin Foster: Is there a preferred time, given that the conference is on 12 **May**?

Nigel Mills: Yes. I think it makes sense to have it before, so that we can hold the Government to account before they go and negotiate, or don't negotiate, as we would like to see them do. Ideally we would like three hours in the main Chamber, given the profile of the event, but if that is not available we will take whatever you can give us.

Chair: Thank you very much indeed. That concludes the formal business. I thank everybody for attending. We will now go into closed session.

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