Message

From: CMO@gov.scot [CMO@gov.scot]
Sent: 14/05/2018 9:43:50 AM
To: Mark Woolhouse [mark.woolhouse@ed.ac.uk]; Name Redacted @gov.scot
Subject: RE: Seminar in Edinburgh

Dear Mark

Thank you for sharing your experience in relation to accessing health data for your research into the drivers of antimicrobial resistance (AMR) in Scotland. As Scotland's Chief Medical Officer, I chair the Controlling Antimicrobial Resistance in Scotland (CARS) group, which is made up of several key stakeholders including Health Protection Scotland (HPS).

AMR research is a vital component of Scotland's response to the threat posed by resistant infections and the CARS team in HPS is working with partners across a wide range of academic disciplines to promote and support research initiatives in this area as a key component of Scotland's contribution to the UK AMR strategy.

The demand for data for research is consistently high and during the period when this project was being processed there were over 370 other live projects. The process of accessing these data for research involves two separate stages, i) the Public Benefit and Privacy Panel (PBPP) application process which involves a panel granting permission for data access and, ii) the Electronic data research and innovation service (eDRIS) process which sends data to a safe haven for analysis once the PBPP has approved data access.

eDRIS functions to support research (primarily academic) and if data were required urgently (as for example in the case of a flu pandemic cited) then data would come from another source within Public Health Intelligence (PHI). There should not therefore be any risks to patient care in this regard.

I understand your experience of the overall process was complex. As you will know Dr Michael Lockhart is developing a public health microbiology strategy for Scotland including a number of measures with the aim of facilitating movement through the data access process for infection related projects. With that in mind HPS is currently exploring how they can facilitate improved infection data access and partnership working with eDRIS.

My officials have spoken to HPS who very much welcome the opportunity to work in collaboration with you and your team. I would therefore encourage you to contact Professor Jacqui Reilly, HPS (jacquelinereilly@nhs.net).

Kind regards

Catherine
Dr Catherine Calderwood MA Cantab FRCOG FRCP Edin

Chief Medical Officer for Scotland

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-----Original Message-----
From: WOOLHOUSE Mark [mailto:Mark.Woolhouse@ed.ac.uk]
Sent: 07 May 2018 11:30
To: Name Redacted
Cc: PS/CMO
Subject: RE: Seminar in Edinburgh

Dear NR

I am writing to follow up our discussion from last year regarding access to public health data in Scotland.

Our experience with PBPP is consistent with what you reported. However, gaining PBPP approval is just one additional step in a complex and protracted process.

I am pleased to report that we know have access through the Safe Haven to data allowing us to carry out a case-control study of risk of a patient in Scotland acquiring carbapenem-resistant organisms. As you

know, CPOs are a worrisome emerging health threat and these kinds of studies are urgently needed to identify which patients are most at risk.

The bad news is that this process was extremely difficult:
- It took well over a year. We initiated the process on 25/01/17 and finally received access to the data on 16/03/18.
- It took over 100 person hours. Much of this was spent by one of my PhD student, but myself and other academic staff were heavily involved, as were several colleagues from HPS. I have not estimated the time invested by PBPP and eDris.
- It was extremely complex. We were asked to complete and revise the paperwork on no fewer than 10 occasions (and we precisely followed the instructions given on every single one of these).
- It was expensive. eDris originally proposed a charge of £15000, although this was reduced when they subsequently decided that they did not have the resources to carry out the data processing required (which HPS subsequently did on our behalf).

You will readily appreciate that these points combine to produce a huge barrier to carrying out this kind of research in Scotland. Indeed, I will not be allocating projects involving Scottish data to any of my postgraduate students in the future, simply because of the difficulties of accessing it.

My personal view is that the system for accessing health data in Scotland is terminally dysfunctional. I am far from alone in this; similar views are being expressed by colleagues in meetings across the country. There is a compelling case that Scottish lives are being put at risk because research that needs to be done is not being done. This is a hugely disappointing state of affairs and one that urgently needs attention. I dread to think of the consequences if we ever find ourselves facing a health emergency such pandemic influenza.

I was hoping to have the opportunity to raise this issue with Dr Calderwood last month, as we were both speaking at the SULSA meeting on AMR. Unfortunately, on the day Dr Calderwood was unable to attend.

Kind regards,

Mark Woolhouse

Professor M.E.J. Woolhouse OBE FRSE FMedSci

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-----Original Message-----
From: NR gov.scot NR @gov.scot>
Sent: 04 April 2017 13:19
To: WOOLHOUSE Mark <Mark.Woolhouse@ed.ac.uk>
Subject: FW: Seminar in Edinburgh

Mark,

I contacted the PBPP on your behalf in order to get a response to your query. Their response is:

"There are some misunderstandings relating to the permissions process as the PBPP application approval and the data provisioning are entirely separate bodies. The PBPP have no role in the access to data beyond approval of the application form itself, it is the eDRIS team who undertake the role of data access and provisioning.

I can confirm that the average approval times for PBPP applications in 16/17 was 31 days - from time of submission to time of approval.

I have also passed your email to the eDRIS team for their attention."

The eDRIS team may contact you directly, however if they reply to me I shall pass on their response.

Best wishes

Name Redacted

-----Original Message-----
From: WOOLHOUSE Mark [mailto:Mark.Woolhouse@ed.ac.uk]
Sent: 31 March 2017 13:13
To: PS/CMO
Subject: re: Seminar in Edinburgh

Dear Dr Calderwood,

Thank you for a very enjoyable seminar at the Usher Institute earlier this week. We didn't meet properly then Irrelevant & Sensitive

I am writing to follow up on a very helpful encounter with one of your colleagues, NR NR kindly spoke at a meeting on AMR hosted by Edinburgh Infectious Diseases. The discussion turned to a cause of continual frustration for public health researchers in Scotland, the complex and prolonged process of accessing health care data. The new PBPP system, for all its good intentions, may make matters even worse. The collective experience was that data access can take of the order of 12 months, even for something as seemingly straightforward as a case-control study (as we are currently attempting to put in place for CREs in hospital patients).

Participants at our meeting reaffirmed that Scotland had tremendous potential for undertaking world class research using health care data, because we do have the right data - a view we embrace in the Usher Institute of course. Accessing these data is another matter though. One participant at our meeting put it very strongly: "this is costing lives". I fear that he might be right.

As you will know, this topic, along with other impediments to medical research, has been discussed in recent years in reports from both the Royal Society of London and the Academy of Medical Sciences. I was wondering whether it was something that was on your own agenda.

Kind regards,
Mark Woolhouse

Professor M.E.J. Woolhouse OBE FRSE FMedSci

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