Michael Painter GRO-C on 20/07/2001 12:50:46

Sent by: Michael Painter GRO-C

To: Nicky Connor/PH6/DOH/GB

cc:

Subject: local reporting of CJD - identifying retrospective cases

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Hi Nicky,
This proposal does cause me a few worries.

The purpose of this exercise is to assess and manage appropriately the public health risk from surgery on people with CJD.

Taking the "assess" bit first. I thought that Bob Will's Unit had these data, at least since 1990. In terms of assessing the risk to public health how much more detail is needed? Even knowing the number, and type, of surgical procedure we are still not able to use these data to predict the number of secondary cases because the EOR risk assessment model was never intended to be used for such predictions. We can't just put the number and type of surgical interventions in, crank the handle and wait for the result.

If the purpose is to add cases to the national database of "contactables" and whatever the other category was, then there there probably is value in collecting the data on people subsequently exposed to the same set of instruments used on the person with CJD. However, the ease of doing this will coloured by other factors such as identifying instruments (see below) and what to tell people who have been identified; it's one thing to be told that you may be at-risk because of recent surgery, I think it's quite another if the surgery was 20 years ago.

Also, I do wonder how necessary is it to obtain detailed data on patients with sporadic CJD who have undergone surgery anyway. Nothing has changed with regards sporadic CJD so the public health impact will be as it always was, probably very small, maybe almost non-existent. If the aim is to gauge
the impact on public health with regards sporadic CJD and surgery then it might be better to set up a case control study and see if the results obtained by Colin Masters can be replicated.

Now, what about managing the public health risk?

Taking sporadic CJD first. Even bearing in mind Colin's work in Australia, is there anything that we could reasonably do now to manage the public health risk for surgery that may have taken place up to 20 years ago? I suspect not.

With regards vCJD we are still working out what it is we want to do when a surgical incident arises. The further back in time you go the less likely it
is that there would have been an instrument tracking system in place. I'm concerned that if we start identifying incidents going back 20 years we are going to find ourselves being asked what to do with, possibly, thousands of

instruments some of which will be very expensive. The danger then is that we will be setting the CJDIP's policy on instruments in an ad hoc way, which
could well create problems in the future.

Without instrument tracking the number of subsequent patients capable of being precisely identified must be small. That would leave two options. First, don't try to identify them so there will be no data to put on the database. Second, include a large number of people so as to be sure of getting the correct ones (ie a high sensitivity) and accept that a lot of them will have no risk (ie low specificity). This would totally screw up any epidemiological study. In either event the conclusion seems to be that,
without instrument tracking, there is little hope that anything positive would come out of all the work.

I'm also worried that where we can identify people at-risk we would run into
problems when telling a, possibly largish, group of people that they may have been exposed to an infection risk through surgery. It's one thing to deal with one incident at a time, quite another to open multiple fronts all at once!

I'll leave you with three questions:
1) have the reasons for carrying out this work been clearly defined?
2) has an assessment been made of the likelihood that the outcome will meet the needs?
3) is this the most appropriate time to be doing this?

Mike

Why — 1° – reduce PH risk
L instr
people
2° understand – db (other methods cc etc)

– Cases last year? what to do
if should Ix, then how far back to go?
~~agreed~~ + Sometime Ix all zero
Agree not much point + lots of effort
but agree – who db? could just do Syrs
Poss of ID people for contact low
Poss of id instr – low