

From: McClumpha, Ann
To: gcl328@clinmed.gla.ac.uk
Cc:
Date: 21/05/08 08:35 am
Subject: Caldicott Matter - EuroDSD Programme
Attachments:

Good Morning Dr Ahmed –

Once again, apologies for the delay in getting back to you about this.

Richard Copland, Director of Health Information & Technology, in his role as Caldicott Guardian is happy to grant Caldicott approval on the following proviso. This should be an opt-in process and parents should give consent for data to go on the register and to be shared across other countries.

Richard has taken the advice of the NHS Greater Glasgow & Clyde Director of Public Health and the Acute Division Medical Director in this matter.

Ann

Ann McClumpha

PA to Director of HI&T

NHS Greater Glasgow & Clyde

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From: Faisal Ahmed [gcl328@clinmed.gla.ac.uk]
Sent: 20 February 2008 16:19
To: Richard.copland@ggc.scot.nhs.uk
Cc: Richard Sinnott
Subject: Caldicott matter - EuroDSD programme

Dear Mr Copland

I wonder whether I can seek your advice on this matter.

I am the lead clinician for the Scottish Genital Anomaly Network which is a national MCN. As part of this network we have maintained an electronic stand alone register which is managed by the SGAN coordinator. It collects a core dataset on an opt-out basis. Once the clinician informs the office of a case, the case is registered, an information sheet goes to the case/parents and they are asked to contact us if they do not want any information on the register or they do not want us to contact them about any future surveys/studies. In Scotland, I am told that the National Information Systems Group will help us to develop this into a proper GCS toolkit. The timeline for this is a bit uncertain.

Whilst I have been working on this, I also linked up with a group of people around the EU and the rest of the UK. We were successful in obtaining some money from the European Society of Paediatric Endocrinology to create a web-based version of this register. Richard Sinnott at the National E-Science centre helped us with this aspect. Based on the potential that this kind of collaboration would bring to research and clinical management of these rare conditions, the EU has granted Richard and I further funding to do this properly across a few centres as part of a larger programme grant as an EU framework project grant.

I have been just speaking to Andrea Torrie at West Ethics and explained to her what we plan to do. I have discussed this with her before and she reiterated, as before, that this is not an ethics issue but I do need to clear it with the Caldicott guardian as far as data protection goes.

The way it will work is that in Scotland (and the UK, esp Cambridge, London. Birmingham) clinicians will enter cases into the register on the opt-out consent basis practised here. Other partner centres in the EU will also do this but based on their local protocols for collection of such data. Partner sites within EU (UK and beyond) who are members of the consortium would be able to search the register for cases that are suitable for their research projects. If they find any cases, they will contact the clinicians who will obtain informed consent for an ethics approved study. The register will, therefore, function as a data resource. If this works, then we would like to extend this model across the UK.

I can send you a further details about what kind of information we will collect in the core dataset. I have read around the subject of data protection and data sharing across the EU in some detail and feel that we are on safe grounds and am also reassured by the grant that the EU have awarded us for this purpose.

My specific queries are as follows:-

1. Is the opt-out consent sheet sufficient for cases in Scotland?
2. Will this apply to cases in the rest of the UK?
3. Are there any limitations on exchanging data across EU countries?
4. Is there anything else I need to address?

Thanks and look forward to hearing from you.

Faisal

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