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Death investigation systems and disease surveillance

To the Editor:

The Review Article ‘Death investigation systems and disease surveillance’ [1] makes an important point concerning institutional impediments to public health research, citing how the England & Wales coroners reacted negatively to the proposal that autopsy material be collected routinely for CJD research. Moreover, it suggests that this could have enabled a more precise estimate of the burden of latent prion infection in the community, with valuable information on the potential of a second, iatrogenic epidemic of variant CJD.

The Review states that the main reason the coroners did not participate in the study was that it would adversely affect their independence; and proceeds to criticize this view as unreasonable. However, the particular point the coroners were making was that relatives could then believe that the main reason an autopsy was being performed on a deceased person was to obtain spleen samples for the study – rather than for the standard medico-legal criteria.

There is a second important reason why the coroners did not participate, and I can state this since I was a member of the committee that proposed the autopsy study. Because of the requirements imposed by the Human Tissue Act 2004, for each coronial autopsy the coroner’s officer would have had to read through to relatives a prepared statement and request for the tissue material (spleen), indicating what the research was, and offering relatives an opt-in or opt-out. Furthermore, they would have to be able to justify how useful the research would be for public health, and end by stating that since the research programme would be anonymized and unlinked, no individual test results would be available to relatives. All this would have to occur in a multi-ethnic and

multi-lingual society. Not surprisingly, coroners decided that their already stretched resources could be applied to more appropriate and practical daily uses.

My personal opinion, given at the time, was that these particular sections of the Human Tissue Act 2004 were (and are) a major impediment to public health; if government wanted the autopsy study to progress, they should rescind those parts of the Act for the duration of the study, and just collect the material as a matter of course. Ministers did not agree.

Declaration of Interest

None.

Reference

1. McGowan CR, Viens AM. Death investigation systems and disease surveillance. *Epidemiology and Infection*. Published online: 15 December 2010. doi:10.1017/S09502688110002840.

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The authors reply

In response to Professor Lucas’ comment on our article ‘Death investigation systems and disease surveillance’ [1] we would like to raise the following points:

- disease surveillance is important for the protection of health;
- some surveys necessarily rely on post-mortem tissue, or on information collected at, or around, the time of death;

- many jurisdictions, by law, grant custodial powers over deceased persons to death investigators who may, or more likely may not, realize the importance of disease surveillance, and their critical role in its execution;
- vast numbers of deaths, depending on the jurisdiction, may come under the control of such investigators making them gatekeepers for large numbers (and largely representative samples) of human bodies;
- in many jurisdictions, the death investigator is situated outside of government control which effectively absolves them of any procedural obligation to participate in or facilitate disease surveillance, which may rely entirely on their cooperation;
- owing to this independence they are not required to provide a reason or rationale – spurious or otherwise – for refusing to participate;
- and, that this independence, though purportedly necessary for the protection of citizens from government, can put us all at risk when it allows for the obstruction of critical public health measures.

Although we hope that Professor Lucas would concur on many of the above points, it would seem that we disagree on the legitimacy of the rationale put forward by the Coroners' Society of England and Wales (CSEW) for not participating in the Health Protection Agency's (HPA) subclinical vCJD survey [2]. Professor Lucas has speculated on what is perhaps the primary reason for the CSEW's refusal to participate, this being the possibility that 'relatives could then believe that the main reason an autopsy was being performed [...] was to obtain spleen samples for the study – rather than for the standard medico-legal criteria'. We wish to point out that this claim is entirely unsupported by the public health literature. For example, a recent Scottish study demonstrated that, 'the vast majority of families are willing to support research use of post mortem tissues even in the context of sudden bereavement and despite previous adverse publicity' [3, p. 369] and that the next-of-kin, in most cases, believe that, 'all bereaved families should be offered, as their right, the opportunity of donating for research' [3, p. 372]. Not all of the next-of-kin referred to in the study consented to tissue donation; however, of the 4% who chose *not* to give consent, none stated the possibility of conspiracy or impropriety on the part of the death investigator as the reason for doing so [3].

Professor Lucas also suggests that the study methodology would have placed a considerable burden on the coroner's officer who, owing to the provisions of the Human Tissue Act 2004, would take responsibility for obtaining consent. It is well known that some coroners do lack sufficient resources to carry out their statutory duties effectively, let alone support a large and on-going surveillance survey. However, in response to this concern, the HPA had obligingly adapted the research methodology in order to minimize the involvement of both the coroners and their officers. The revised methodology required that coroners' officers merely forward the contact details of the next-of-kin to the NHS Blood & Transplant's tissue service – that this data transfer was lawful and in compliance with the Data Protection Act 1998 was noted by the Chief Medical Officer, as was the following assurance, 'The Department of Health is also prepared to pay for any additional administrative support needed to undertake the survey, in those coroner's jurisdictions that agree to participate' [4, 5].

In closing, although we agree with Professor Lucas that there are institutional impediments to public health research we seem to disagree on what those impediments are. Regardless, we argue that, given the regrettable immutability of the Human Tissue Act, the impediment to the protection of public health in this instance relates to the fact that government cannot direct coroners to participate in disease surveillance. Coronial independence, although purportedly necessary for the protection of citizens from government, can put us all at risk when it allows for the obstruction of critical public health measures. Coronial independence should not be thought of as an absolute principle. The consequences of making any public official entirely independent from government needs to be carefully considered as the health and safety of everyone is potentially at stake.

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