

c/o Sense About Science
14A Clerkenwell Green
London EC1R 0DP
enquiries@senseaboutscience.org
+44 (0) 20 7490 9590

The Right Honourable David Cameron, MP, Prime Minister
10 Downing Street
London SW1A 2AA

By fax, email and Royal Mail

18th June 2014

Dear Prime Minister

Re: Late registration of the dead in England and Wales

We, the undersigned civil society organisations, are concerned that delays in the registration of deaths in England and Wales are having an unnecessary impact on important research that affects our work. We are writing to ask you to introduce urgent legislation to ensure that all deaths and especially premature deaths including suicides, sudden infant deaths, drug-related deaths and deaths in prison, are recorded on the national register soon after the event.

Currently, in England and Wales, deaths are added to the national register only when a cause of death is established. For about one in ten deaths, the cause of death needs to be established at an inquest. Inquest deaths include premature or unexpected deaths such as sudden infant deaths, accidental deaths, drug-related deaths, suicides, terrorism deaths and deaths that occur in prison or police custody. Inquests can take more than a year to come to a decision, some several years. Around 10,000 deaths a year in England and Wales are not registered for at least 6 months. In particular, one in five of all deaths at 5 – 44 years of age is not registered for at least 6 months (4,000 per year).

Until a death is added to the national register, statisticians and researchers are unaware that it has happened. Research relying on data about fact-of-death is delayed by waiting on the cause-of-death outcome of inquests; for example, researchers studying the effectiveness of treatments for opioid users between 1st April 2005 and 31st March 2009 had to wait for two and a half years until late 2011 before they could be almost sure that they had complete information about users who had died during the study. Interventions that could make a difference to people's lives are being held back. Studies into the safety and effectiveness of medicines cannot be completed until researchers are sure that complete information is available about who has died.

Delayed registration of deaths poses a risk to public health by potentially undermining the evidence base for public health research, policy development and monitoring of public health initiatives, all of which rely on knowing without undue delay who has died and when. Epidemics could be underestimated if unexpected deaths from a new disease are not registered immediately. With timely registration, it is easier to track an epidemic and to understand the lethality of the disease if researchers can at least know quickly the ages and locations of people who are dying.

Calendar trends are at risk of being missed or misinterpreted when analyses focus on registration-year rather than death-year; and commentators get muddled too. Researching whether there was a spate of suicides after the onset of the financial crisis, for example, requires analyses by death-year, not by the delay-staggered registration-year of suicides. The reduction in road traffic accident fatalities following legislation on the wearing of rear-seat belts was obscured in official statistics due to delays in registering these deaths but was immediately evident to police forces on the ground. The statistical system in England and Wales is embarrassed by its unacceptable failure to properly count the dead.

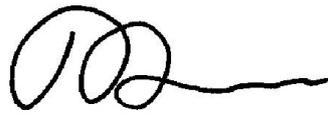
Scotland and 23 other European countries properly and promptly count the dead. In Scotland, once a post-mortem examination has taken place a holding diagnosis is issued as a cause of death which can be amended later. This enables the death to be registered typically within 5-7 days. The death certificate and registration of death enable National Records of Scotland to issue interim and then final year reports on causes of death after they are amended.

Legislation is needed, Prime Minister, in this Parliament to resolve the problem of late registration of deaths in England and Wales. Five years have elapsed since the H1N1 pandemic brought the registration-failure into sharp focus and the Royal Statistical Society first called for new legislation. Today, the case for legislation for all of us is overwhelming.

Yours sincerely



Sheila M Bird
Royal Statistical Society



Tracey Brown, Managing Director
Sense About Science



Marjorie Wallace, Chief Executive
SANE



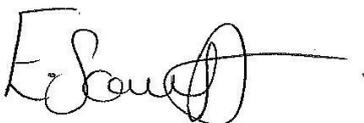
Steve Rolles, Senior Policy Analyst
Transform Drug Policy Foundation



Lynsay Allan, Executive Director
Scottish Cot Death Trust



Helen Shaw and Deborah Coles, Co-directors
INQUEST



Elizabeth Scowcroft, Research Manager
Samaritans



Frances Crook, Chief Executive
Howard League for Penal Reform