Certification of Death (Scotland) Bill

Diabetes UK Scotland

Diabetes UK Scotland is one of Scotland’s largest patient organisations. Our mission is to improve the lives of people with diabetes and to work towards a future without diabetes through care, research and campaigning. With a membership of over 11,000, including over 600 health care professionals, Diabetes UK Scotland is an active and representative voice of people living with diabetes in Scotland. We welcome the opportunity to submit evidence to the Health & Sport Committee on the Certification of Death (Scotland) Bill.

What is diabetes?

Diabetes is a common life-long health condition. There are 228,000 people diagnosed with diabetes in Scotland and an estimated 60,000 people who have the condition but don’t know it.

Diabetes is a condition where the amount of glucose in your blood is too high because the body cannot use it properly. This is because your pancreas does not produce any insulin, or not enough, to help glucose enter your body’s cells – or the insulin that is produced does not work properly (known as insulin resistance). If you have diabetes, your body cannot make proper use of this glucose so it builds up in the blood and isn’t able to be used as fuel.

Diabetes is a serious condition that, if not treated properly, can lead to some very serious complications, such as heart disease, stroke, kidney disease, blindness and amputation.

Summary of main points

- statistics based on death certificate data seriously underestimate mortality from diabetes
- recording diabetes on the cause of death certificate is low in Scotland compared, for example, to Sweden and New Zealand
- excess global mortality attributable to diabetes is three times higher than suggested by international statistical reports mostly based on death certificates

General principles of the Bill

Our comments are focused solely on the principles of the Bill and, in this context, we welcome the Bill as an opportunity to reflect the impact of diabetes on mortality in Scotland and to help drive diabetes-related health policy and provision.

Diabetes was the underlying cause of 730 deaths in Scotland in 2008 and contributed to a total of 4,052 deaths¹. However, statistics based on death
Certificate data seriously underestimate mortality from diabetes, because the ultimate cause of death is usually from complications that are not uniquely related to diabetes.

The impact of diabetes on mortality is well known. Despite this it is difficult to achieve an accurate picture of the number of deaths that can be attributed to diabetes, owing to poor death certification recording. We, therefore, welcome the Certification of Death (Scotland) Bill as an opportunity to address this issue through its aim to improve quality and accuracy of ‘medical certificates of cause of death’ forms in order to: improve public health information; and help ensure that public health resources can be directed where needed.

We know life expectancy can be reduced by more than 20 years in people with Type 1 diabetes and up to 10 in people with Type 2 diabetes. We also know the long term complications of the condition have a major impact on mortality:

- Kidney disease accounts for 21 per cent of deaths in people with Type 1 diabetes and 11 per cent in people with Type 2 diabetes
- Within five years of an amputation as a result of diabetes up to 70 per cent of people will die
- Cardiovascular disease accounts for 44 per cent of fatalities in people with Type 1 diabetes and 52 per cent in people with Type 2.
- Patients with diabetes have an increased risk of all-cause and a higher risk of cardiovascular mortality in every age/sex group, evident after only 2 years of diagnosis, compared with patients without diabetes (Type 2 DM, Tayside).

Despite this, poor death certification recording means that it is difficult to achieve an accurate picture of the number of deaths that can be attributed to diabetes. The Yorkshire and Humberside Public Health Observatory states: “clinical coding practice means that only a minority of deaths among people with diabetes from causes that can be associated with the disease have diabetes identified as the primary cause of death.”

The UK prospective diabetes study found that diabetes was reported on 42% of all death certificates and on 46% of those with underlying cardiovascular disease causes (considered still low). This recording was associated with social class, age, underlying cause and it may be lower in certain ethnic groups. The study called for a need to raise awareness in clinical practice of the importance of diabetes as a risk factor for cardiovascular death.

In 2008, researchers examined the death certificates of 1,872 people with type 2 diabetes in Tayside. This study showed that less than half (42.8%) of the patients with type 2 diabetes had any mention of diabetes on their certificate, even among people with cardiovascular disease as the underlying cause of death. The authors suggest that diabetes is under-recorded.
The rate of recording diabetes on the cause of death certificate is low in comparison to Sweden\textsuperscript{v} (57%), and New Zealand\textsuperscript{vi} (55.1%).

Other research has highlighted endocrinologists may be more likely to report diabetes mellitus as underlying cause of death than cardiologists and nephrologists\textsuperscript{vii}.

Complex methods have been developed for estimating cause-specific mortality for some conditions - AIDS, tuberculosis - but not for diabetes. The World Health Organisation Global Burden of Disease Project modelled worldwide data from 2000\textsuperscript{viii}. This estimated that the excess global mortality attributable to diabetes is three times higher than suggested by international statistical reports mostly based on death certificates. This moves diabetes from the eighth to the fifth place in cause of death ranking. The number of excess deaths attributable to diabetes is similar in magnitude to numbers reported for HIV/AIDS in the year 2000.

The British Heart Foundation (2009)\textsuperscript{ix} estimates that five times as many deaths are indirectly attributable to diabetes as directly attributable; about 35,000 deaths a year in the UK attributable to diabetes – about one in twenty of all deaths.

**Conclusion**

Diabetes is a growing public health issue in Scotland. The number of people with type 2 diabetes has doubled over the past 10 years and is expected to grow to near 400,000 by 2030. Capturing accurate data on diabetes-related mortality improve public health information and help ensure that public health resources can be directed where needed.

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