

Written evidence submitted by Marie Curie for Data Protection and Digital Information (No.2) Bill (DPDIB34)

Submitted to the House of Commons Public Bill Committee

1. Introduction

- The submission of written evidence is from Marie Curie, a leading provider of palliative and end of life care in the UK which provides care and support to over 40,000 people with a terminal illness and their families, including bereavement support.
- Marie Curie was a member of the steering group for the UK Commission on Bereavement, which was an independent Commission established in 2021 to explore how, as a society, we support people through bereavement and how that support can be improved
- Marie Curie is also the largest independent funder of palliative and end of life care research

2. Executive Summary

- In its report [Bereavement is Everyone's Business](#) published in October 2022, the UK Commission on Bereavement (UKCB) set out a vision for change according to eight principles or '1 statements'. This included the vision that 'The Things I have to do after a Death are Simple and Straightforward.'
- Marie Curie, along with other members of the UKCB, believes the Data Protection and Digital Information (No.2) Bill can go further in how it addresses current burdens faced by bereaved people when notifying organisations after a death. The Bill should also address the UKCB's recommendations on death administration, by carrying out a review into the feasibility of extending the remit of the Tell Us Once service.
- Policy Recommendations in this area for the UK Government include:

1. The Government must legislate so that people can choose whether to register a death in person or online
2. The Home Office, Department for Work and Pensions and other relevant departments must conduct a review of the flow of information from death registration to relevant public bodies and industry, including the feasibility of extending the remit of Tell Us Once

- Bereaved people face many practical and administrative responsibilities and tasks after a death, which are often both complex and time sensitive. These include death registration, notifying a wide range of organisations (from banks and energy suppliers to the council and social media sites) as well as legal and coronial processes.
- Tell Us Once is a cross-government service, which enables a recently bereaved person to report a death to most government organisations in one instance. This and other initiatives to simplify administrative processes have helped to reduce some of the burden felt by bereaved people.
- However, many challenges prevail, causing stress and distress to people already grappling with the emotional turmoil of recent bereavement. The complexity and volume of administrative tasks stem from a lack of streamlining and coordination across death administration processes. While the Tell Us Once service goes some way to addressing the volume of Government paperwork, more needs to be done to ease the burden on grieving people.

Examples of Lived Experience

- *“When you are newly bereaved, you are expected to organise a huge array of practical things- at a time when you feel exhausted, confused and at a loss. It adds to the pressure and anxiety you feel. What can be done legally and practically to ease this burden for grieving people?”* - Woman in her 50s whose aunt, mother-in-law and father-in-law all died (England)
- *“18 months later, I still haven't sorted out financial affairs - life insurance, TPS pension ... there are forms to fill in that I just can't get my head around. It's like a foreign language to me. And I'm trying to navigate it on my own. Very stressed about it.”* - Woman in her 50s whose husband died of COVID-19 –19 (England)
- *“There is no support with an unexpected death. There's no guidance, nothing was clear cut and there was no step by step guide of what to do. Even searching online was very murky and minimal, and there are aspects that even 18 months on we struggle with and still haven't found answers for. The bereavement was bad enough but not knowing what to do and where to go for support just added to our distress. The worst, most vulnerable time of your life and there is no help or guidance unless you can afford to pay for it.”* – Tiffany Jones, 40, from Winchester, whose dad died during the pandemic (England)

3. Key findings from the UKCB report: Death administration

- The UK Commission on Bereavement made three major recommendations to government to improve the experience of bereaved people and reduce the burden of death administration. These are:
 1. Governments across the UK must legislate so that people can choose whether to register a death in person or online.
 2. Governments across the UK must conduct a review of the flow of information from death registration to relevant public bodies and industry, including the feasibility of extending the remit of Tell Us Once.
 3. Government departments and regulators must ensure bereaved customers are treated fairly and sensitively by working with relevant industry groups to develop minimum standards for death administration processes.
- The first of these recommendations will be addressed by the Data Protection and Digital Information (No. 2) Bill. Clause 96 of the Bill would reform the way births and deaths are registered in England and Wales, enabling the move from a paper-based system to an electronic register. **This provision will make a real difference to bereaved people.**

4. A Review of Tell Us Once

- When someone dies, the Tell Us Once service informs the various parts of the national and local government which need to know. That means the local council stops charging council tax, the DVLA cancels the driving license, the Passport Office cancels the passport, the Department of Work and Pensions stops paying the pension etc.
- It is a relatively simple service which significantly reduces the administrative burden for those recently bereaved, as well as for government itself.

- **However, respondents to the UK Commission on Bereavement’s consultation felt that Tell Us Once could do more to reduce the administrative burden on bereaved people.** Currently, bereaved people are required to separately notify other private companies such as banks and building societies; energy, electricity and water providers; telephone and internet providers, TV license and social media sites, etc.
- The UK Commission on Bereavement found that the administrative burden caused by these demands remained a significant challenge for bereaved people.

Respondents to the UKCB’s consultation reported several key challenges with death administration:

- 61% of adult respondents with administrative responsibilities reported difficulties with at least one practical or administrative task
- 39% of respondents had difficulty sorting out financial affairs
- 21% of adults had difficulties registering a death
- 10% had difficulties with other practical responsibilities (for example, coroners, utility accounts, vacating/selling houses)

Respondents reported difficulties at all stages of death administration including:

- Not knowing what to do
 - Not being aware of the wishes of the person who died
 - Feeling overwhelmed by both the volume and complexity of tasks
 - Feeling under time pressure to complete tasks
 - Facing inefficiencies and delays from organisations
- The complexity and volume of administrative tasks stems from a lack of streamlining and coordination across death administration processes.
 - While the Tell Us Once service goes some way to addressing the volume of government paperwork, more needs to be done to ease the burden on grieving people, particularly when it comes to notifying private organisations, utilities companies and others.

A review of the Tell Us Once service, and of the flow of information from death registration to relevant public bodies and private organisations, should be carried out to address these issues.

5. Extension of Tell us Once

- Respondents to the Commission’s consultation, however, felt the Tell Us Once service could go further in addressing the ongoing challenges and distress grieving people continue to face
- We believe the Data Protection and Digital Information Bill, alongside enabling online death registration, offers an opportunity to capitalise on the pioneering success of Tell Us Once in promoting coordination and streamlining between organisations, and to explore the extension of this into industry.

“If there was truly 'one service' that dealt with all the different companies.” – Woman in her 40s whose mother died of aortic dissection (England)

- A review of the Tell Us Once service, and of the flow of information from death registration to relevant public bodies and private organisations, should be carried out to address this.

6. Background to UKCB

Bereavement is a universal experience, yet we know that the circumstances of each death, and the support received by those left behind, makes everyone's experience different. Working in partnership with several UK charities, including Marie Curie, Cruse Bereavement Support and the National Bereavement Alliance, the UKCB was established in June 2021 to explore these issues and make recommendations to better support bereaved people.

- Chaired by Dame Sarah Mullally, Bishop of London, the 15 Commissioners cover a breadth of expertise and experience in bereavement across many different sectors, all four nations of the UK, and the three largest religions in the UK
- The Commission's work was supported by a steering group of charities: Marie Curie, Cruse Bereavement Support, the National Bereavement Alliance, the Childhood Bereavement Network, and Independent Age, with research input from academics at the Universities of Bristol, Cardiff and Warwick
- The Commission conducted one of the largest ever consultations on bereavement support in the UK, taking written evidence from over 1000 bereaved adults, 100 bereaved children and young people and 130 organisations working with bereaved people. In addition, over 31,000 school and college students engaged with the Commission through the organisation Votes for Schools
- The Commission held eight oral evidence sessions and six stakeholder roundtables
- Its work was shaped at all stages by the Lived Experience Advisory Forum, a group of 14 individuals with recent lived experience of bereavement

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