Written evidence from Dr George Julian

ABOUT ME: I am a freelance knowledge transfer consultant, legal commentator and citizen journalist (following years spent working as an academic, researcher and running a national network promoting the use of evidence to improve practice in health and social care).

I have a particular interest in open justice, and the interplay between it and what we know about the premature and preventable deaths of learning disabled and autistic people. I use crowdfunding to cover my costs to attend coronial inquests and live tweet what is happening in court. Since 2015 I have covered six inquests in their entirety (three of which were held in front of a jury) @LBinquest @HandleyInquest @TozerInquest @JusticeforCol @JoeInquest @SashaInquest). I have also attended numerous pre inquest review hearings.

In 2017/18 I visited Australia, Canada and New Zealand to research approaches to investigating the deaths of learning disabled people, and how bereaved families were involved in these processes. I draw on my findings in this submission. My report can be accessed on the Winston Churchill Memorial Trust website here.

During 2016 I worked as a Special Advisor to the Care Quality Commission, supporting them to engage with bereaved families as they reviewed how the NHS identified, investigated and learned from deaths in its care. As part of this work I reviewed evidence, including personal testimony and one-to-one conversations with family members with experience of NHS death investigations. Experiences relating to over 20 families were included in my final report, which includes exploration of their experience of inquests, and suggestions for improvement Family involvement in, and experience of, death investigations by the NHS.

SUBMISSION

1. *The extent of unevenness of Coroners services, including local failures, and the case for a National Coroners Service*

The inquests I have reported in their entirety were held in Oxford, Ipswich, York, Bedfordshire, Manchester and Winchester. Additionally, I have attended numerous pre inquest review hearings across England. It always feels like a lottery, in terms of accessing information, gaining access to court, and the ability to report hearings contemporaneously. It would appear that there are as many different approaches to, or varying levels of commitment and confidence in, open justice, as there are Coroners.

Coroners appear to have differing understandings and interpretations of the Chief Coroner's Guidance. There is also huge variation on what information is available online in relation to past, present and upcoming hearings. This variability can be an inconvenience for my role, but I have witnessed the unevenness, having detrimental impact on bereaved families.

Variation appears to exist in timescales taken to investigate deaths; in the scope applied to inquests (especially in relation to the applicability of Article 2); in the opportunity for families to 'introduce' their relative; and in physical resources and accommodation for the court.

In my experience there is considerable variation in understanding of learning disability and autism amongst Coroners. In the UK we know that learning disabled people die two to three decades prematurely, often due to poor experiences of/lack of access to appropriate healthcare.

The 2019 annual report from the Learning Disabilities Mortality Review Programme reported:

- 63% of learning disabled people die before their 65th birthday (only 15% of non-learning disabled people do)
- Of 1,946 deaths reviewed, only 32% were known to have been reported to a Coroner; 68% of deaths of this group were not reported
- Half of the deaths reported to a Coroner resulted in a post mortem, and less than a third of notifications led to an inquest being opened.

This suggest approximately 10%, or one in ten deaths of a learning disabled person will have an inquest. Which seems dangerously low, considering we know that this group die decades prematurely. We know that bias (conscious and otherwise) of health and care professionals has an impact on the care received by learning disabled people, and it is reasonable to suspect that bias (conscious and otherwise) is likely to extend to Coroners, which could account for the variability in success securing an inquest.

I welcome the suggestion of a National Coroners Service and believe that it would go a long way to addressing variability of experiences. It is unacceptable that where someone dies should have such an impact on the extent to which their death is investigated, and the experience of their family members.

2. *The Coroners Service's capacity to deal properly with multiple deaths in public disasters*

This is not something I have anything to contribute to personally, in relation to public disasters, although I commend the Special Procedure Inquest model proposed in the recent JUSTICE report When Things Go Wrong.

I would urge the committee to also consider other situations of multiple deaths, that may not have occurred on the same date, but in the same care setting. For example, a number of deaths over a period of time, all in one NHS service, but all currently treated as independent investigations.

3. Ways to strengthen the Coroners' role in the prevention of avoidable future deaths

I welcome the Committee's focus on this area. The current system does not appear to be well designed to actually prevent future deaths (PFD).

Limitations appear to include:

- lack of national oversight of PFD reports issued
- lack of thematic analysis (save that conducted by academics or other interested parties) of PFD reports issued
- lack of process to share PFD reports issued in one area with other areas, or similar settings
- lack of resources to share, promote, or secure learning as a result of PFD reports and responses to them
- lack of support for Coroners to know about pre-existing PFD reports, unless they themselves requested them (and remember that they did so)
- the limitations of the Coroner's role, so that they may require a response but have no remit to scrutinise the response submitted.

While there is a search function on the Ministry of Justice database of PFD reports issued, it is very limited.

My WCMT Report included discussion of the need for Coroners to have ready access to research evidence, to inform their practice and decisions, but also to ensure they are issuing appropriate PFD reports that address key issues:

> '…elsewhere in Australia, the Coroner's Court of Victoria have addressed head on with their model of a Coroners Prevention Unit. A model I am confident would be incredibly useful in England, in order to bring together learning from across coroners and ensure that Prevention of Future Death reports are distributed to relevant stakeholders, to actually bring about change and prevent future deaths.

Coroners Prevention Unit

The CPU may contribute at any stage of the coronial process.

Death initially reported	• support coroners to decide on the direction of the investigation • identify and ensure essential data and records are gathered
Recommendation development	• review the nature/extent of causes and risk factors • review current evidence on countermeasures • identifying relevant stakeholders • consideration of relevant legislation, standards and codes of practice • review similar previous cases and recommendations
Recommendation finalising	• identify prevention opportunities relevant to an individual case • engaging with relevant stakeholders at coroner's direction to ensure proposed recommendations are reasonable, viable and likely to be effective
Receiving response to recommendations	• collecting information on responses to, and implementation of, coronial recommendations and publishing on court website (up to first 3 months)

The CPU also undertakes individual and collaborative research projects to generate a better understanding of preventable deaths in Victoria and identify intervention opportunities'. (Julian, 2020, 52-53).

I would recommend that the Committee look to the Coroners Prevention Unit (CPU) in Victoria, Australia. This multi-disciplinary specialist team provides evidence-based advice to Coroners to assist them with prevention-focused aspects of their investigations, to support public safety and administration of justice. The CPU have developed databases for coding the deaths that pass through their court annually, and they have examples of how their work analysing these deaths have led to changes and improvements in policy, practice and law that have been shown to reduce preventable deaths.

4. How the Coroners Service has dealt with COVID 19

A number of inquests and pre-inquest review hearings I was scheduled to attend have been postponed due to covid. It seems that the coronial

service has not been able to respond as proactively to holding telephone, online or hybrid hearings as other courts.

5. Progress with training and guidance for Coroners

I would welcome training and guidance for Coroners in two particular broad areas:

1) **Learning disability and autism and what is known about the preventable and premature causes of death for this group**. I would recommend that this training is delivered by, or in conjunction with, self-advocates with a learning disability and/or autism.

   Our Coronial system relies on doctors, care providers, police and Coroners recognising a death as unnatural or premature. Throughout my work learning disabled and autistic people, bereaved families and academic research have all reported that many of these same people are biased and apathetic, expecting learning disabled people to live short lives.

   I am not suggesting every single death of a learning disabled or autistic person will require a full coronial inquest, however, too often the deaths of this group are not identified as premature or unnatural and therefore evade any scrutiny at all. It is essential that being learning disabled or autistic is not considered as an explanation for a premature death.

2) **The impact on bereaved families of repeated death investigation processes requiring their participation, often with no support or access to funding for legal counsel**. I would recommend that this training is delivered by, or in conjunction with, bereaved families who have experienced multiple investigation processes including an inquest.

   Investigations are most meaningful for families when they are timely, robust and genuine in their intent to bring about change. Yet far too often it appears that families are left fighting to secure scrutiny into the deaths of their relative, often leading to additional harm and trauma.

   In my experience inquests are far from inquisitorial, and often incredibly adversarial. I have witnessed counsel for NHS Trusts, and large national charitable care providers, subject bereaved families to long periods of adversarial questions, with little or no intervention from Coroners. I have also witnessed expert Coroners

demonstrating real compassion and leadership, although that has been the exception not the norm.

6. Improvements in services for the bereaved

I think there are others best place to provide submissions on this point, namely bereaved families who have experience of the system. That said I will observe the disadvantages of the current variability in the system, the lack of standardised information and advice and the unequal footing that bereaved families find themselves on without Legal Aid.

I think it would be useful for the Committee to consider the role that Family Liaison Officers could play to support bereaved families.

It would also be useful if bereaved families were considered of equal importance to other interested persons. On many occasions I have sat in court and heard Coroners offer concern for the availability of a hospital consultant due to give evidence, or the challenges to a care provider who has to run their service while staff attend court. I do not recall ever hearing a Coroner share the same level of concern for bereaved families, in relation to their experiences of delay or their availability to accommodate changes. It feels like families are expected to fit in with professionals, as opposed to be considered of equal importance.

I have also witnessed families learning for the first time of previous deaths in identical situations, that an NHS Trust failed to disclose to the Coroner in advance. I am not sure the true impact of such admissions, and the lack of candour and timely disclosure, is understood.

I also imagine that it would also be helpful for families to know that they will be guaranteed the opportunity to display a photograph of their loved one in court throughout the inquest. Again, the variability between Coroners in how they address this issue, is marked, and it is hard to understand what the challenge to this action is, if the court is being human centred.

7. Fairness in the Coroners system

The current situation of lack of oversight of the coronial process is problematic. I would recommend that the Committee look to the model of the Death Investigation Oversight Council of Ontario, Canada. Established in 2010, as a result of the Goudge Inquiry (a judicial review into the Province's forensic pathology system following a large number of wrongful convictions of family members due to failings in forensic pathology services). DIOC provides oversight of Ontario's Coroners and Forensic Pathologists and administers a public complaints process. While limited in its remit, the model may be of interest to the Committee.

Finally, I do not consider that we can accept our current Coroners system is fair, while it remains a lottery whether your death will be investigated or not. It is my firm belief that learning disabled people should not be dying decades earlier than others without a learning disability. There is no fairness, or justice, unless the premature deaths of disabled people are considered as unnatural, and therefore warrant the same scrutiny as that afforded to those without a disability.

2 September 2020