

# Caldicott Principles & Information Sharing in End of Life Care

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15% group bookings discount\*\*

Wednesday 20th November 2024

Virtual Conference



## Chair and Speakers include:

**Christopher Fincken**  
*Former Chair*  
UK Caldicott  
Guardian Council

**Dr Gaby Tamura-Rose**  
*Consultant in Palliative Medicine*  
St Raphael's Hospice

**Andrew Harris**  
*Assistant Coroner*  
London Inner South

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***“At end of life, information sharing is especially crucial. We are particularly unwell and vulnerable and we need information to be shared amongst those caring for us without having to take that on and be the bearers of information between everyone involved in our care. We must ensure patients have the right information at the right time and that information is shared easily and seamlessly amongst the professionals and services involved in their care... effective information sharing truly can transform lives and transform care. We must ensure we safeguard patient data, but this shouldn't be seen as a barrier to seamless information sharing. We must ensure, at end of life, patients' wishes are a top priority and ensure advance care plans and other documents are shared amongst and utilised by all professionals and services involved in a patients' care, to ensure they have the support needed to have a good death.”***

*Lucy Watts MBE Ambassador & Young Avenger Together for Short Lives People in Partnership Steering Group Member Hospice UK*

***“The delivery of high-quality end-of-life care is an interprofessional endeavour, where the resources of various health and social care professionals must be combined for the benefit of the patient.<sup>8</sup> To achieve this, efficient interprofessional communication and information sharing across health and social care professionals involved in community end-of-life care is essential, but presents many challenges... Poor (or lack of) access to patient information can effect professionals' confidence in managing end-of-life patients, family members satisfaction with care and patient outcomes.”***

*Information sharing challenges in end-of-life care, BMJ Open Oct 5;10(10):e037483. doi: 10.1136/bmjopen-2020-037483.*

***“Access to the right information at the right time by the right person can make it much easier to provide high quality care to the patient including following their previously expressed wishes where appropriate. It can also make the experience more positive for their carers and people important to them.”***

*NICE*

Healthcare Conferences UK in association with Christopher Fincken, Independent Member UK Caldicott Guardian Council, (Former Chairman) are pleased to announce this eighth annual conference which will focus on Information Sharing and Caldicott Principles in End of Life care. Following the success of our previous Caldicott Guardian National Conferences, and feedback from our regular Caldicott Training Masterclasses, this conference will focus on developing your role in improving communication and information sharing and implementing the Caldicott Principles at the end of life. The conference will also update delegates on the PRSB Palliative and End of Life Care Information Standard.

***“The PRSB's Palliative and End of Life Care Information Standard helps ensure that people's end-of-life wishes are consistently recorded and shared and can be accessed by a health or care professional when needed...As a consultant in palliative medicine, I see how this is critical in emergency situations, where sharing information quickly in a consistent way can make all the difference to a patient, their loved ones and carers at this emotionally heightened time. Being able to respond to their wishes in a timely and effective way helps them feel respected, listened to and confident.”***

*Dr Kath Lambert, Consultant in Palliative Medicine at Harrogate and District NHS Foundation Trust 2023*

## **This conference will enable you to:**

- Reflect on the importance of information sharing at the end of life
- Network with fellow End of Life Care Professionals, Caldicott Guardians and IG Leads working to ensure adherence to Caldicott principles in end of life care services
- Understand and reflect on decision making around information sharing including the challenges
- Ensure effective adherence to the PRSB Palliative and End of Life Care Information Standard
- Update your knowledge on ethical decision making principles and frameworks and how you can implement these in decision making practice
- Understand when information can be shared with relatives, other professionals and services, and when it cannot
- Learn from established practice in the delivery of Caldicott Principles in End of Life care
- Understand the legal and ethical implications around information sharing and the Duty of Candour
- Explore how you can learn from deaths and share information with families, friends and staff to drive improvement
- Understand the new role of the Medical Examiner
- Ensure you understand the implications of information sharing after death including the complexities of the ethical as well as legal considerations in how we handle data relating to the deceased with relatives and bereavement services
- Hear from a Caldicott Guardian working in a hospice setting
- Learn from the Coroners perspective on information sharing and disclosure
- Understand the implications of GDPR to end of life care services, and how technology can improve information sharing
- Self assess and reflect on your own practice
- Supports CPD professional development and acts as revalidation evidence. This course provides 5 Hrs training for CPD subject to peer group approval for revalidation purposes

## 10.00 Chair's Welcome and Introduction

**Christopher Fincken** *Former Chair UK Caldicott Guardian Council*

## 10.15 Improving information sharing at the end of life

**Rachel Woodcock** *Implementation Lead*  
**with Emma Davies** *Assessor & Clinical Safety Officer*  
PRSB

- the importance of information sharing at the end of life
- the PRSB standard for sharing palliative and end of life information
- removing the barriers to information sharing at the end of life
- working together across organisations
- working with, sharing information with and people who are dying and their families and carers

## 10.45 Caldicott Principles and information sharing at the end of life

**Dr George Fernie**  
*Senior Medical reviewer and Caldicott Guardian*  
Healthcare improvement Scotland

- caldicott principles & rules of information sharing at the end of life
- improving our access to, and sharing of, our patients' information
- difficult and challenging issues
- consent, data sharing agreements and information to improve care
- key issues for Caldicott Guardians

## 11.15 Questions & Answers followed by Comfort Break & Virtual Networking

## 11.45 EXTENDED SESSION: Information Sharing, the Duty of Candour and Legal Issues at the end of life

**Andrew Latham**  
*Senior Solicitor, Clinical Law*  
Capsticks Solicitors LLP

- key principles
- how to approach disclosure as a team
- capacity
- tools for decision making
- CHC pathways

## 12.45 Lunch Break and Virtual Networking

## 13.25 GDPR: Implications for End of Life Care

**Tania Palmariellodiviney**  
*Founder & Director*  
Data Privacy Simplified

- GDPR: ensuring compliance
- guidance and practicalities
- key considerations information sharing in end of life care
- what is likely to have the greatest impact on your organisation
- raising awareness in your organization
- practical advice for managing a breach
- GDPR and smaller organisations

This session includes interactive breakout group discussion

## 14.00 Improving information sharing whilst ensuring patient confidentiality at the end of life My experience as a Caldicott Guardian in end of life care

**Dr Gabrielle Tamura-Rose**  
*Consultant in Palliative Medicine*  
St Raphael's Hospice

- what issues do I see as a Caldicott Guardian? Examples in practice
- case studies and information sharing
- caldicott decision making: improving practice and supporting frontline staff
- case discussion

## 14.30 EXTENDED SESSION: Learning from Deaths: The Coroner and Medical Examiner's Role

**Andrew Harris**  
*Assistant Coroner*  
London Inner South

- medical Examiner Role and Certification
- notification of deaths to Coroner
- investigatory roles of Coroner
- information sharing with the Coroner: information that may be required, requested or shared during the end to end process
- rights of interested persons: listening to the concerns and meeting the expectations of the bereaved for greater transparency and accountability
- learning from deaths: Preventing Future Death Reports

## 15.10 Small Group Breakout Sessions

## 15.30 Comfort Break and Virtual Networking

## 15.50 EXTENDED SESSION: Information Sharing after Death

**Christopher Fincken**  
*Former Chair*  
UK Caldicott Guardian Council

This extended session, using real case study examples, will demonstrate the complexities of the ethical as well as legal considerations in how we handle data relating to the deceased with relatives and bereavement services.

This session will incorporate small breakout groups

## Bring your Caldicott issues and challenges

This session will allow delegates to question the panel on issues they are facing in practice

## 16.50 Question and Answers, followed by Close

*There will be time after each speaker session for Questions and Answers*

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Please also ensure you complete your full postal address details for our records.

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#### Virtual

This conference is on Zoom with interactive breakout sessions and a dedicated, secure landing page with resources available for three months after the event date.

#### Date

Wednesday 20th November 2024

#### Conference Fee

- £295 + VAT (£354) for NHS, Social care, private healthcare organisations and universities.
- £250 + VAT (£300) for voluntary sector / charities.
- £495 + VAT (£594) for commercial organisations.

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#### Exhibition

If you are interested in exhibiting at this event, please contact Sarah-Jane O'Reilly on 01932 429933, or email [sarahjane@hc-uk.org.uk](mailto:sarahjane@hc-uk.org.uk)

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