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# Caldicott Principles & Information Sharing in End of Life Care

Tuesday 4th October 2022

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

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# Caldicott Principles & Information Sharing in End of Life Care

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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.8 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 2021 Oct 5;10(10):e037483. doi: 10.1136/bmjopen-2020-037483.*

Healthcare Conferences UK in association with Christopher Fincken, Independent Member UK Caldicott Guardian Council, (Former Chairman) are pleased to announce this fifth annual Virtual 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 at the end of life whilst ensuring patient confidentiality.

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

- Reflect on a person with experience of living with a terminal condition on the importance of information sharing
- 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 of Covid-19
- 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
- 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

**100% of delegates at our previous conference on this subject would recommend it to a colleague**

## 10.00 Chair's Welcome and Introduction

### **Christopher Fincken**

*Former Chair UK Caldicott Guardian Council*

- principles & rules of information sharing at the end of life

## 10.15 Improving information sharing at the end of life

### **Tony Bonser**

*Member of NHS Patient Experience Workstream;  
Volunteer Hospice UK;  
Member NHS EoLC Programme Management Board;  
and Vice-chair, Trustees St Catherine's Hospice Preston*

- end of life care: a personal journey
- removing the barriers to information sharing at the end of life
- working together across organisations
- implications of Covid-19
- working with, sharing information with and people who are dying and their families and carers

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

### **Dr Sam Edward**

*Medical Director and Consultant in Palliative Medicine  
North London Hospice*

- what issues do I see as a Caldicott Guardian? Examples in practice
- case studies and information sharing around Covid-19
- caldicott decision making: improving practice and supporting frontline staff

## 11.25 Comfort Break & Virtual Networking

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

### **Professor Andrew Harris**

*Senior 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

## 12.25 Small Group Breakout Sessions

## 12.45 Lunch Break and Virtual Networking

## 13.25 GDPR: Implications for End of Life Care

### **Barry Moulton**

*Information Governance Consultant; Chair Eastern Region  
Information Forum; Former Chair, Regional Strategic Information  
Governance Network (East of England); DPO for GP Practices and  
IG Consultant, Data Privacy Trainer*

- 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

## 14.00 Improving Information Sharing at the end of life

### **Dr Gaby Tamura-Rose**

*Consultant in Palliative Medicine  
St Raphael's Hospice*

- improving our access to, and sharing of, our patients' information
- difficult and challenging issues
- consent, data sharing agreements and information to improve care

## 14.30 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*

- information sharing and legal issues at the end of life
- the Duty of Candour and End of Life Care
- making sustainable disclosure decisions and sharing information responsibly and legitimately
- the right of individuals to delete data
- key legal developments

## 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 include Small Group Breakout Sessions

## Bring your Caldicott issues and challenges - led by Chair and speakers

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

# Caldicott Principles and Information Sharing at the End of Life

## Tuesday 4th October 2022, Virtual Conference

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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

Tuesday 4th October 2022

#### 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 Carolyn Goodbody on 01932 429933, or email [carolyn@hc-uk.org.uk](mailto:carolyn@hc-uk.org.uk)

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