HIV and death in the UK

• How is death in HIV+ persons managed?
  – Problems?
  – Medico-legal issues?
  – Can we do better?

• What can we learn from looking at HIV-associated deaths in the cART era?
  – Historical context of HIV clinical pathology
  – Real-time audit of deaths, remediable factors, improving patient care
HIV and death in the UK

- How is death in HIV+ persons managed?
  - Problems?
  - Medico-legal issues?
  - Can we do better?

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  - Historical context of HIV clinical pathology
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- My introduction
- HM coroner for Brighton & Hove

- Prof Rob Miller, UCLH
- Dr Chris Wood, N Mddx H

- General discussion for all
NAT concerns over deaths in HIV+ persons

• 1. lack of understanding about HIV amongst funeral directors re health risks
   – Preparation of bodies for disposal
   – Touching & viewing bodies after death

• 2. embalming
   – Timing of, or refusal
   – HSE guidance is averse; infection risk to embalmers?

• 3. pathologists refuse to undertake autopsy – infection risk
   – [SBL – competence/knowledge aspect]
Only 2 things can happen...

- Death certification
  or
- Reporting a death to a coroner
DEATH

Cause of death known/natural

Death certificate completed
Consented autopsy

Cause of death not known/unnatural

Refer to Coroner, who makes inquiries

Autopsy authorized
Coroner writes MCCD

No autopsy

Family take MCCD to Registrar of Births & Deaths

Cremation form

Body can be collected and buried or cremated or repatriated
Typical Medical Certificate of Cause of Death (MCCD)

1a. Acute cerebral oedema
1b. Toxoplasma encephalitis
1c. HIV disease
2. -

• 1a. multi-organ failure
• 1b. Multicentric Castleman disease
• 1c. HIV disease (treated)
• 2. HHV8 co-infection
Straight forward MCCD

- Patient seen <15 days of death by doctor
  - ‘Qualifying period’

- A natural cause of death

- Not a scenario that should/must be reported to the coroner

- National outcomes
  - 20% deaths have a coronial/medico-legal autopsy
  - 80% have a MCCD from a doctor

- HIV: ~530 deaths pa in England & Wales
Reliability of **clinical** cause of death on MCCD

• ~30% of medical certificates of cause of death are significantly wrong or incomplete [govt statistics........]

• Discrepancy rate unrelated to length of stay in hospital or time on GP’s list

• Potential loss of reliable clinical audit and public health data
How accurate is MCCD meant to be?

“to the best of your knowledge and belief”

DC Act, 1953; C&J Act 2009

*NOT beyond all reasonable doubt*
A question for the audience
A death is announced in 2015

- 61yr old male Iberian caucasian ex-IVDU
- Diagnosed HIV+ in 2000
- HCV+, HBV+, well controlled on ARVs
- Recently:
  - Polyneuropathy
  - Stroke with hemiplegia
  - Suspected CD8 encephalitis – *steroid Rx*
  - Steroid induced diabetes
- Increasingly frail and looked after at home by family
- Dies suddenly
- *Both GP and HIV unit consultant have seen him within the last 2 weeks of life*
Q – do you as doctors?

1. GP writes a death certificate
2. HIV consultant writes a death certificate
3. Refer the death immediately to HM Coroner
4. Do not know what to do

1. Ask the family what they would like to happen next
2. Arrange for his repatriation to Iberia in two days time
3. Request a hospital consented autopsy to investigate the presumed HIV brain disease
Q. My personal view

• No suspected malfeasance *re* the death
• Doctor writes a natural cause MCCD
  – 1a. frailty
  – 1b. chronic brain disease
  – 1c. HIV disease/AIDS
• Get a consented autopsy by a pathologist who is interested in HIV
  – Forensic & most coronial autopsy pathologists are not
Q. My personal view

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• *What actually happened:*
• Coroner took on the case without consulting HIV unit doctor
• Coronial autopsy
  – Coronary artery thrombosis
  – Brain under investigation
San Francisco – pro-active work

- Cardiovascular disease risk in HIV
- Pathogenesis?
- Need to correlate
  - Risk factors
  - Clinical
  - Pathology
- All (HIV+) deaths due to ‘sudden cardiac death’ are autopsied.
- How? Pre-death consent process
- Large grant funding

Priscilla Hsue – pers comm.
## Critical questions

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<td><strong>Critical questions</strong></td>
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<td>• Interaction of the medicine and the law regulating death</td>
<td>• HIV is both general medicine and ‘special’</td>
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<td>• Much confusion over obligations &amp; best practice</td>
<td>• It is expensive to manage</td>
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<td>• How best to optimise case review</td>
<td>• It affects younger patients</td>
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<td>• Stigma still influences processes after death</td>
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My Aims & Objectives for this Symposium

• Better understanding of the law around death
• Move toward more focused evaluation of cause of death
• Input into audit on a national scale