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**European HIV and Law Seminar London, April 19-21**

Slide no. 1

Who is Douwe Korff?



*Not* a specialist in this field, I fear, but a general human rights & data protection lawyer

(you can try the search box on the londonmet website: [www.londonmet.ac.uk](http://www.londonmet.ac.uk) but it didnt work when i tried last time 😊 )

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first principle:

- my data (any data) are mine;
- my sensitive data are especially mine; and
- data on my HIV status are especially sensitive, in many ways

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two (connected) legal bases:

- European human rights law: right to private life (Art. 8 ECHR)  
(Eur Conv on Human Rights)
- European data protection law: “purpose-specification and –limitation”  
(EC Directive 95/46/EC) “informational self-determination” (right in principle to control over one’s own data)

connection: dp law is increasingly strongly backed by ECHR

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Slide no. 4

- ECHR & EC Directive implemented in all EU Member States (and beyond);
- similar principles elsewhere (if perhaps not as strongly set out);

in UK:

- ECHR implemented through the Human Rights Act (belatedly and imperfectly);
- EC Directive implemented through Data Protection Act 1998 (imperfectly)

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The basic principle that flows from both the ECHR and the EC data protection directive is that:

- **Any demanding of info on, or recording of a person's HIV status, and especially any disclosure of such data against the person's will, is an interference with that person's rights under these instruments.**
- This means that there must be a special, pressing reason to allow this, on a specific legal basis

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**TWO MAIN BUTs:**

- ECHR and DP Directive both contain exception clauses; and
- DP Directive is imperfectly implemented, and very weakly enforced, especially in the UK

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*Re* exception clauses (1):

exceptions to right to private life/to keep one's HIV status private must:

- be based on a **clear legal provision**, the effect of which must be **“foreseeable”**;
- serve a **“legitimate aim”** - such as public health;
- be **“necessary in a democratic society”** to achieve that aim - which means in particular that the exception must be **“proportionate”** to that aim, taking into account the importance to the individual of the right in question

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*Re* exception clauses (2):

- there must be appropriate **procedural safeguards** to ensure compliance with the standards set out in the previous slide.



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*Re* exception clauses (3):

- compliance is judged (ultimately, by the Eur Court HR) by European standards - BUT States are given a “**margin of appreciation**”. This makes it difficult to predict exactly what is and what is not allowed, and what kinds of procedural safeguards are required or sufficient.

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*Re* implementation of data protection directive (1):

- processing of personal data - and disclosure of personal data! - must be based on “**consent**” OR on a **clear legal provision** aimed at serving a “**higher**” **public interest** - BUT in principle such “public interest” conditions must comply with the ECHR standards: they must be strict and clear and foreseeable, and any inroads on privacy should be as minimal as possible.

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*Re* implementation of data protection directive (2):

- **special data subject rights:** to be **informed *in advance*** of what will happen to one's data; to be told so more specifically ***afterwards*** (including info on disclosures); to **object** "on legitimate grounds".

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*Re* implementation of data protection directive (3):

- **special supervisory bodies:** data protection authorities (in UK: Information Commissioner) (as well as courts) .

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**PROBLEMS (general):**

- lack of clarity of exception clauses
- clauses often too wide, esp. for supposed public interest purposes - proportionate?
- courts are expensive
- what is “consent”?? esp. in a contractual context - such as insurance, employment
- data protection law, esp in the UK, often contains excessively wide rules allowing for disclosures of data, e.g. for “health” purposes and/or research

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**PROBLEMS (UK-specific):**

- **the special clause re dissemination of sensitive data for (extremely-widely defined) “health” purposes, including medical “research” in the UK Data Protection Act violates the EC data protection directive and in my view also the ECHR;**
- enforcement of the DP Act by the UK Information Commissioner is very weak (in other countries - France, Germany - there is more awareness of the issues, and the dp authorities take stronger stands - but practice still also remains weak).

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**CONCLUSION (1):**

- there are good possibilities in principle for invoking European human rights and –data protection laws to protect individuals from improper demands that they reveal their HIV status, or from information on this status being improperly disclosed by authorities or private bodies to other authorities or private bodies.

**BUT:** this will need very considerable effort to be put into effect

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**CONCLUSION (2):**

- it would be good to get this on the agenda of the European data protection working group (established under the EC directive), and to work out principles with this group;
- a comparative-legal/multidisciplinary study of rules and practice in major European countries (including any that have given the issues special attention) would be a good start.