



European
AIDS Treatment
Group

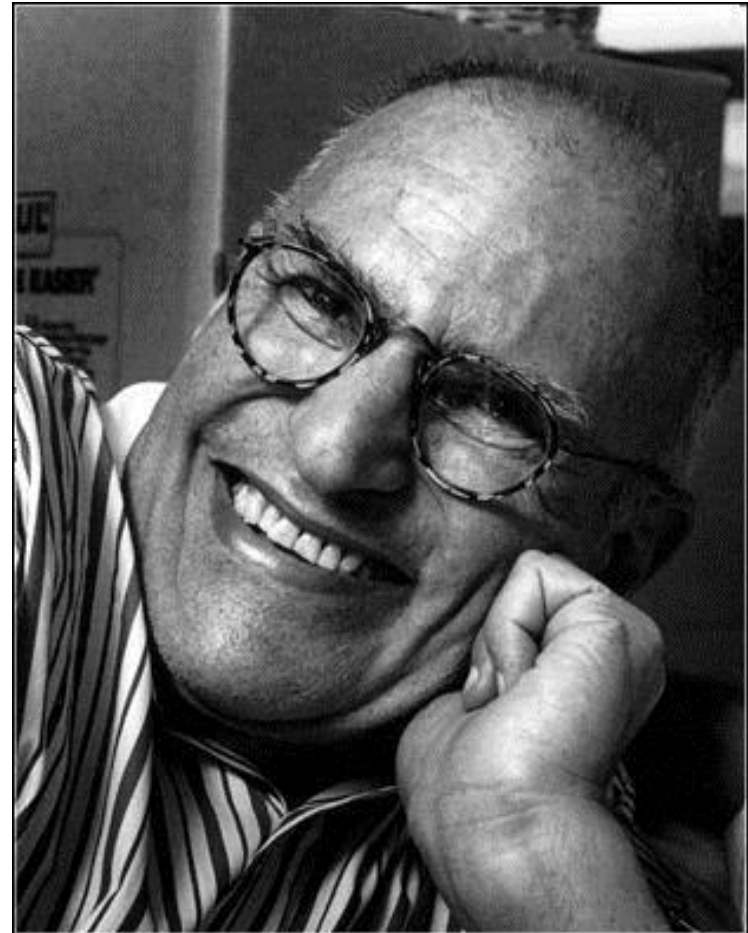
Future of electronic health information: patient's expectations

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HIV history

**“Our continued
existence depends
on just how angry
you can get”**

*1,112 and Counting,
Larry Kramer, March 1983*



History

EATG founded in 1992

Purpose & mission

- To achieve effective treatment & access to experimental therapies for as many PLWHA as possible & as soon as possible
- To enable people with HIV to have maximum control over the treatment and research agenda
- Treatment and research information dissemination throughout Europe via Dr Fax

Status quo

- Health research & product information paper driven & stuck with Gutenberg
- Industries & health services who stress their image as drivers of innovation look surprisingly out of place
- Hyper-regulation of the sector one of the reasons – every move out of the old path makes everybody else nervous
- Need to learn how to come out of the cave

Pre-requisite: trust

- Communication, consultation, integration of society and relevant stakeholders is key

Other requirements

- ✧ Use of existing information & databases;
- ✧ Enhance existing information tools using new technologies to reach more people – example: package leaflet;
- ✧ “Patients Like Us” issue – good intentions on a bumpy road;
- ✧ Address data privacy issues – need to redefine privacy in a digital environment;
- ✧ Who are trustful sources of information?

Example: ongoing issues re e-health record

- ✧ Health data protection;
- ✧ Grant patients access & control to record;
- ✧ Informed consent for storage & health data sharing;
- ✧ Adopt identification & authentication system for patients & HCP
- ✧ Reinforce legal framework on data protection (e.g. privacy by default, multi-layered liability, etc)
- ✧ Promote interoperability
- ✧ Secure system against breaches & crashes;
- ✧ Society wants tools to seek redress & compensation for breaches of privacy;
- ✧ Enforce dissuasive penalties against abuses;
- ✧ Ensure transparency of EHR systems (content & functioning);
- ✧ Educate consumers & train health care professionals.

Solutions?

✧ Potentially a good topic for IMI to address