

More surveillance, more abuse -  
Critical reflections on digitalized  
medical files:

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# Prologue:

«To understand everything, you have to know everything» (Erich Fritz Emil Mielke, Head of the East German Ministry for State Security (Ministerium für Staatsicherheit)).

# Some preliminary observations about new technology (NT):

- NT can *create* new values
- NT can *strengthen* old values
- NT can *threaten* – or be perceived as threatening - old values
- NT can *change* old values
- One never knows in advance in what ways – and to what extent - NT will influence our values

# Digitalized medical files – envisaged assets:

- More participation ('mer delaktighet')
- Democratization
- Easier access
- Increased efficiency
- Increased data safety
- Better patient care
- Increased surveillance
- More research (the resource argument/health industry argument).

# Digitalized medical files – envisaged drawbacks:

- Infringement on patient confidentiality
- Depletion of the principle of informed consent
- Information overload
- More abuse
- More hacking
- More surveillance
- Blurring of the border between patient care and health research

# The normative bedrock of health-related research: Two formulations:

- “The interests and welfare of the individual should have priority over the sole interest of science or society” (*Universal Declaration on Bioethics and Human Rights*, 2005, Article 3,1).
- “While the primary purpose of medical research is to generate new knowledge, this goal can never take precedence over the rights and interests of individual research subjects” (*Declaration of Helsinki*, 2012, General Principles, 8).

# Two opposing claims for discussion:

- Digitalized medical files will increase citizens' possibilities of self-determination
- Digitalized medical files will move society in a direction that becomes more and more ill-liberal.