

Privacy and the Electronic Patient Record

DPForum, London

Guido van 't Noordende
University of Amsterdam

guido@science.uva.nl

noordende@uva.nl

COMMIT/



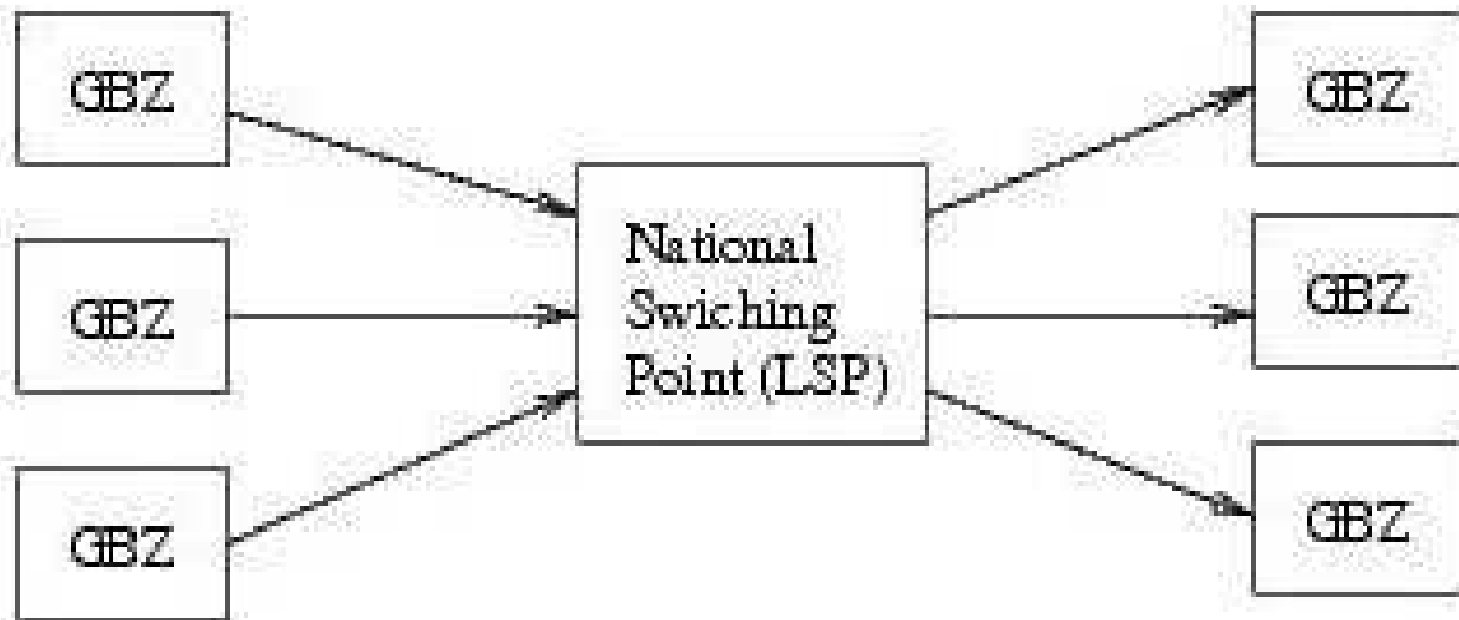
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A Kerfuffle – where to start?

- '80s?
- 2000?
- 2011: opt-out legislation for “pull-based” EPD rejected
- Call (motion) against any further government involvement with the EPD/LSP system
 - Bottom-up development of (regional) systems under existing treatment law (WGBO, DPD)
- 2012: privatized restart of a “different” LSP (National Switching Point)

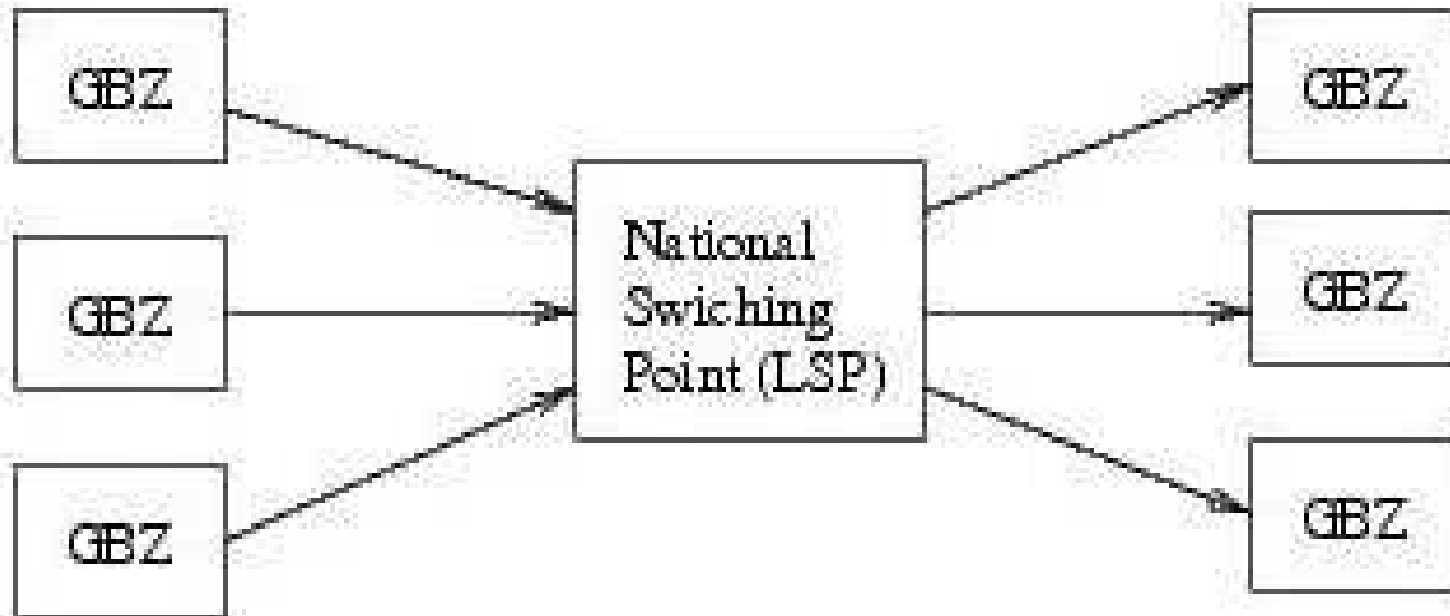
The National Switching Point

- Access from anywhere, 24/7
- Role-based access control using healthcare professional smartcards



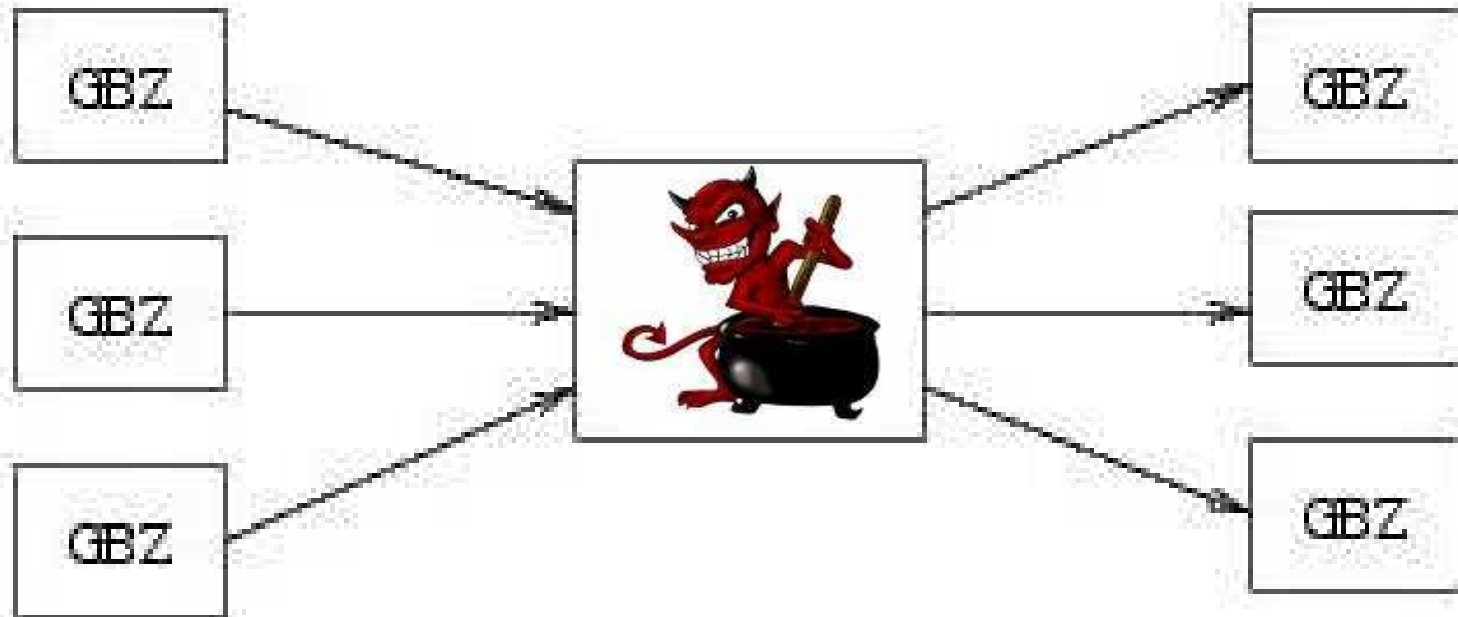
No Central Database

- (the UK taught us that)



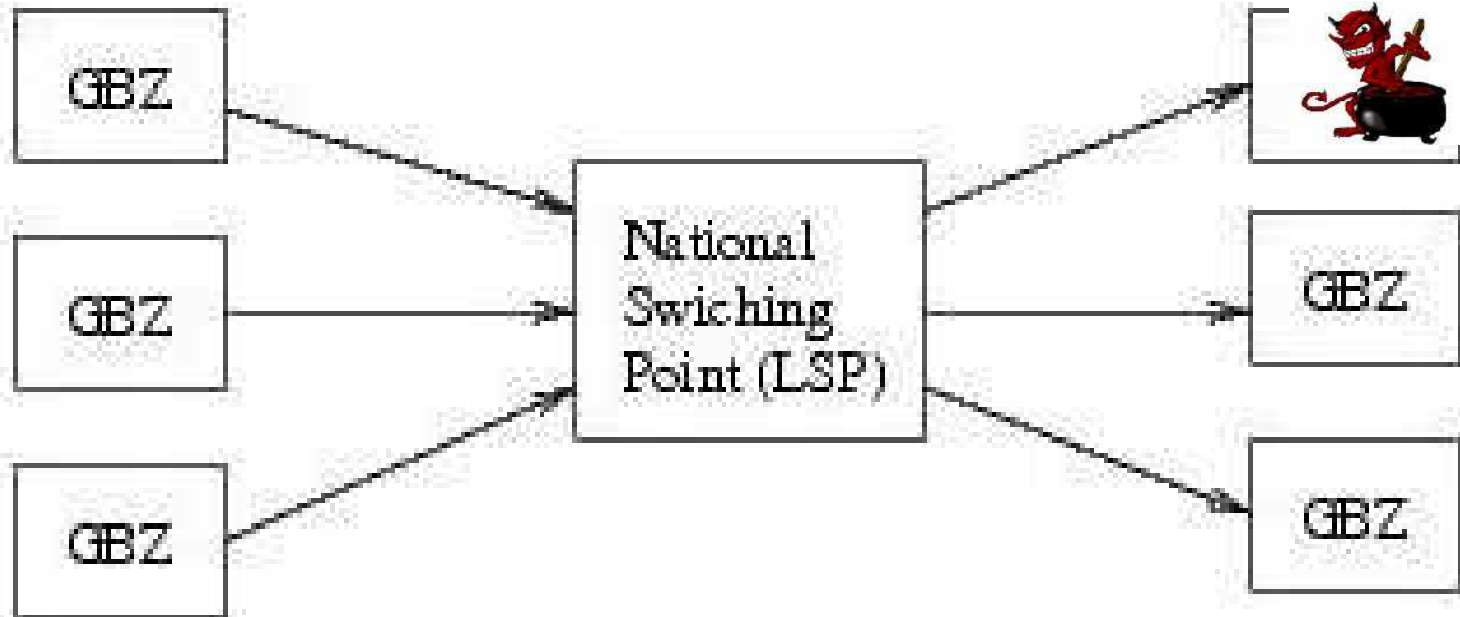
What risks were perceived? (1)

- (the UK taught us that) but



What risks were perceived? (2)

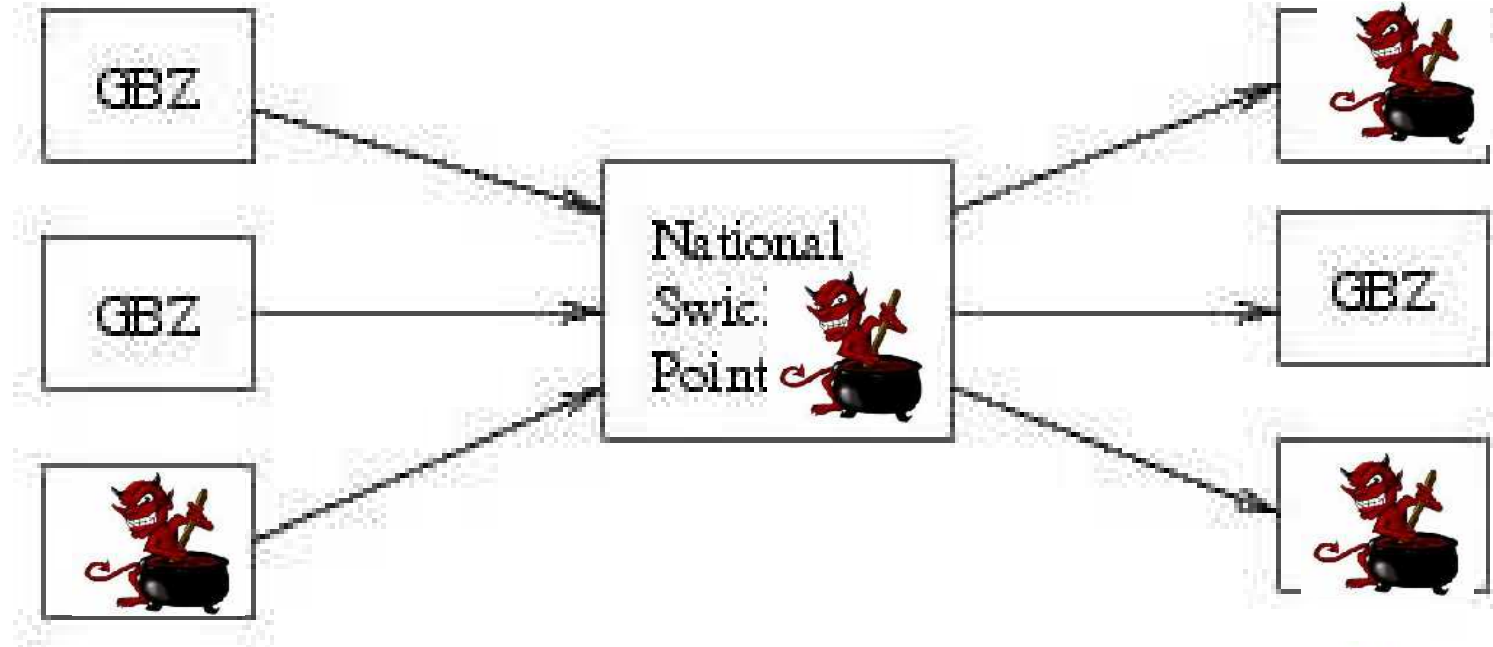
- (the UK taught us that) but more



Scale matters: easier entrance, higher yield for hackers

What risks are perceived? (3)

- (the UK taught us that) more but



Cyberaanval op Nederland
Citadel-malwareonderzoek
"Pobelka" botnet

Scale matters: easier entrance, higher yield



The new LSP

- Now “regionalized”, opt-in, bottom-up?
- The antics don't change: pressure, slow but steady.
 - Government hand clearly noticeable
 - Covenant between healthcare and patient organizations, ICT producers
 - Healthcare inspection (dept of ministry) pressed for very fast – 1-year deadline - introduction of a information exchange solution
 - Contractual pressure (e.g., night/weekend-shift organizations)

Context

- No alternative presented, older systems “phased out”
- Healthcare insurers: contractual clauses pressing for exchange of informatio
- 2013: court procedure VPHuisartsen (10% of GPs). Currently in appeal:
 - Opt-in procedure
 - Interesting: may an external system manage access to records that are a specific healthcare professional's responsibility and should (according to VPHuisartsen) be under professional control?

Opt-in procedure LSP

- Different folders/differing content
- Different questions (by GP/pharmacists)
- Gps/pharmacists “opting in” for each other
- Website “ikgeeftoestemming.nl” (I give permission) to register consent online
- A DP(A) mess...
 - First mistaken consent registrations: 8/149 patients - ~5% (note: decentral registration)

Legislative approaches after 2011:

33509: “patient rights in HCIE”

- 2013: broad permission (“toestemming”)
 - Right to exclude (categories) of healthcare professionals
- 2014: patient can choose for a generic opt-in OR a “specified” opt-in
 - interesting: choice of the patient!
- 2015: “specified” consent
 - accepted by House of representatives '14, now in senate

Back-door

Artikel 15c

1. De zorgaanbieder geeft de cliënt informatie over zijn rechten bij elektronische gegevensuitwisseling, de wijze waarop hij zijn rechten kan uitoefenen en over de werking van het elektronisch uitwisselingssysteem dat voor de gegevensuitwisseling wordt gebruikt. Indien nieuwe categorieën van zorgaanbieders aansluiten bij het elektronisch uitwisselingssysteem, of de werking van het elektronisch uitwisselingssysteem anderszins substantieel wordt gewijzigd, informeert de zorgaanbieder de cliënt over deze wijziging alsmede over de mogelijkheid om de gegeven toestemming, bedoeld in artikel 15a, aan te passen of in te trekken.

2. De zorgaanbieder houdt een registratie bij van de op grond van artikel 15a, tweede lid, door cliënten verleende toestemming waarbij wordt aangetekend vanaf welk tijdstip de toestemming van kracht is geworden. Een zorgaanbieder kan deze registratie beschikbaar stellen via het elektronisch uitwisselingssysteem.

33509's back-door

- Article on 'specified' consent, followed by clause two articles down:
 - HC professional must register the (specified) consent
 - And can **share** this registration through the healthcare information exchange system
- Note first article: “observe” (vaststellen) that consent is given formula

Fundamental change

- Consent registration is *NOT* within bounds of current legislation as requested by senate in 2011 – it changes the view on doctor-patient secrecy fundamentally
- Disclose information on a consent not following the concept of medical secrecy with the physician guarding his or her own professional records,
- but disclosure instrumented based on a consent given once to another doctor
- With potentially broad consequences: one “**weakest link**” overly broad – and possibly ill-informed or mistaken - consent can cause disclosure of (m)any (past) medical record(s) at once, unwittingly

Now what?

- 33509, currently in senate, vote after summer
- What happens with VPHuisartsen appeal case
 - Impact if 33509 accepted?
 - Possibly EVRM?

Alternatives?

Amsterdam GP initiative for healthcare information exchange that follows WGBO

GP/HC professionals responsible, shares only in course of treatment (push-like), or for stand-in replacement

No external processing of personal data

Exception handled as exceptions, with specific consent (e.g., emergency data/access)

Thanks

- Guido van 't Noordende
- guido@science.uva.nl / noordende@uva.nl
- Www.science.uva.nl/~noordend/epd/