Medical standards, free or proprietary.

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Do you remember?

- The Internet
- WWW(HTML, HTTP)
- HTML5
- Wikipedia

- Compuserve
- Gopher
- FLASH
- Encyclopaedia Britanica(paper)

The Internet Standard and FLOSS

- Synergy effects
  - Open standard/specification
    - IETF RFC, Draft
    - W3C
  - Reference FLOSS implementations
    - TCP/IP stacks, Apache HTTPD, sendmail, BIND
- Non-free standards could not survive

Health care information standards

- More than 150 standards

- "Guild standard"
  - "Guilds" are consisted with paid members(mainly big companies)
  - "Guilds" lobby to Government that they obligate the "standard".
  - Resources are only available for guild

- Momentum from proprietary to free/open
  - HL7 policy changed from proprietary to CC0 in 2013
  - The openEHR project has developed specification with FLOSS and published as ISO 13606

- But still remains "non-free standards"
  - Mainly <u>terminology</u> domain

Clinical/Medical terminology

- Fundamental basis of medicine

  - Anatomy, Biology, Biochemistry, Pharmacology, Procedure, Pathology...

- ICD series

  - International Classification of Disease.

    - Basis of world wide statistics of health and epidemiology
    - Used for categorized evidence of insurance payment

- SNOMED-CT

  - The hugest clinical terminology system with more than 300,000 terms by ontology theoretical background.

ICD10 License

- WHO is license holder
- License for commercial use
  - <u>Non-exclusive, non-transferable, and time-limited</u>
  - Authorizes the use of codes in a product that will be distributed to customers in <u>specific countries</u>.
  - Not permitted to <u>modify, translate or amend</u> the codes or description of the codes in any way.
- License for internal use with its own organization.
  - Need registry
  - Not transmittable
- License for non-commercial use
  - Need registry
  - Only for research

SNOMED-CT license

- The hugest terminology with ontological hierarchy

- IHTSDO(International Health Terminology Standards Development Organization) is the license owner.

  - North America and Europe

- No charge for member countries

- Affiliate license for non-member countries

  - Country membership fee by GDP escalation

  - Fee for hospital, academic, personal, commercial use

What the problems are

- Software distribution
  - Conflicts of FLOSS license
  - Regulation/limitation for countries
- Cost sharing
  - Development for terminology
    - Update, maintain, governance for 300,000 terms(SNOMED-CT)
    - Domain specialists, academic society
    - Massive efforts

Discussion

- Terminology users should share the costs
  - The costs were funded by our taxes(WHO)
  - It is controversy how to re-fund IHTSDO costs with non-member countries.
- Qualified members should be engaged in to terminology
  - Wikipedia shows the evidence that it is not inferior to established encyclopedia.

What can we do?

- Action to change license of existing terminology

  – They knows what the problem is, and they are moving to.

- Wikipedia way to clinical terminology

  – OpenGalen, MyNA

  – Wikipedia extraction for clinical terminology