Introduction to Data4lifesciences

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Challenges & opportunities for UMCs

- Innovation gap between research and care
- Fragmentation of initiatives
- Call for more transparency and open data/science
- Stricter (interpretation of) regulations
- Scientific need for more data sharing: personalised medicine
- Opportunities in Europe requiring joint effort

Too much to handle for one UMC → clear need for collaboration
Data4lifesciences program lines

• **Support for data stewardship**
  – WP1: guidelines for data stewardship: HANDS manual
  – WP9: (building a) network of data experts to support researchers
  – WP6: software, tools and procedures to properly implement the HANDS data stewardship guidelines

• **Connecting research (digital research environment)**
  – WP4: environment to share and analyse (multi-center) research data

• **Supporting technical services**
  – WP2: harmonisation of IT architecture for research data (if needed)
  – WP5: provide care data for research (in particular EHR data)
  – WP7: sharing parts of (expensive) high-performance computing facilities

• **Make data and samples collections findable & accessible**
  – WP3: cataloguing existing collections and clinical cohorts on a national level making them findable and accessible
The program’s “true north”

“All clinical data of all patients should be made available by every UMC of the Netherlands for every valid research question now and forevermore in a scalable, distributed environment with full protection of privacy of patients”
reuse of clinical care data in research -
A learning health care system

[..] the problem is not really technical [...]. Rather, the problems are ethical, political, and administrative.

Lancet Oncol 2011;12:933
A culture of data sharing

Tools themselves are not *all* that important

What is important: FAIR data!

(however, tools help to enforce FAIR data policies)

- Findable
- Accessible
- Interoperable
- Reusable
Support for FAIR data stewardship

- HANDS manual
- UMC network of expertise
- Software, tools and procedures for proper execution of data stewardship: TTP, ELN, GRP toolbox
Catalogue: reuse of data and samples

- Existing collections findable and accessible via a catalogue
- Broadening and enrichment national catalogue with local datasets
- Local biobanks connected to national & EU network
Data4lifesciences: Next steps

- Scale up from pilots to shared solutions
- Implement and embed Data4lifesciences results in local UMC research IT programs
- Attain sustainability in a broad coalition of knowledge institutes, research infrastructures and funders → Health-RI