On health data architecture design

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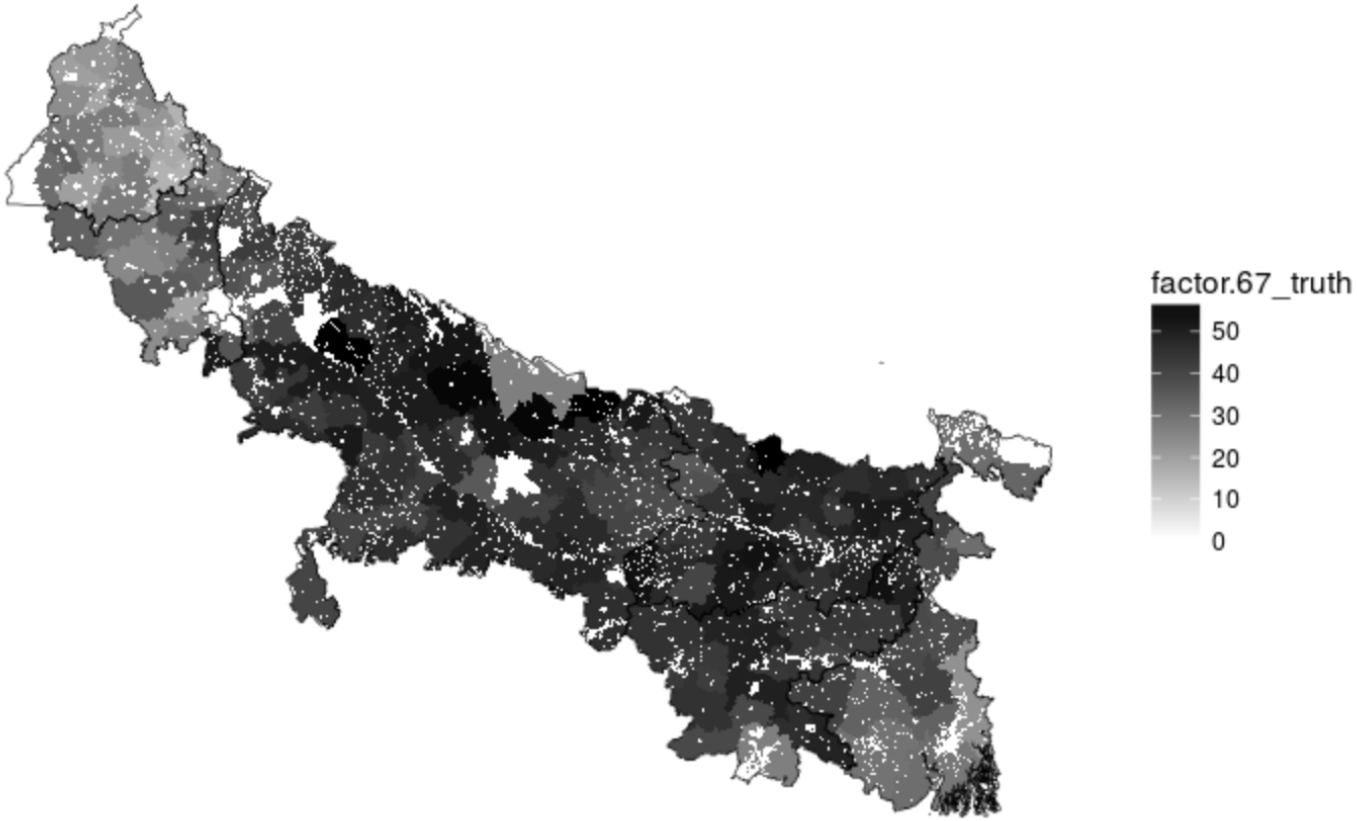
Why do we need it?

- Electronic Health Records.
- Public health monitoring.
- Socio-economic studies.
- Epidemiology.
- Research.

Caveat: Data cannot be a substitute for fundamentals - PHCs, doctors, . . .
Concerns: Privacy; potential imbalance between private and public.

Stunting in (North) India



Source: NFHS-4

Outline

- Objectives of a health data system design
- Operational considerations
- Design considerations: alternatives

Objectives: Health records (what should be recorded?)

- Birth record and certificate.
- Immunisation records.
- PHC records, all medical episodes, prescriptions and doctor's opinions.
- Tests, imaging, radiology and pathology reports.
- Hospital case records, discharge certificates.
- Llife-style indicators (dietary habits, smoking, drinking, activity patterns), chronic conditions.
- Optionally record history of self-medication (quackery included), home measurements of BP, sugar, etc., Garmin, FitBit and other wearables.
- **Genetic data**?
- Death record and certificate.

Objectives: Health records and access

- **Federated** data collection and management of health records.
- **Individual centric** architecture. Individual is the data controller.
- Ensure that **no access** to health records is possible **without consent**.
- Exceptions? **Authorised accesses**? Mandatory/selective disclosures? Emergency overrides? Limited access to parent/sibling PHRs?
- **Selective**ly grant **read/write access** to health professionals, hospitals, test and imaging centres, insurance.
- All accesses to be **logged** in a **non-repudiable** and **immutable** manner.
- **No duplicated data** at hospitals, PHCs? Restrict post-treatment access?

Objectives: Analytics

- **Regular operational surveillance (anomalies and alerts)**
  - Epidemic and endemic conditions like dengue, malaria, TB, cholera, typhoid, ...
  - Malnutrition, vitamin or other micro-nutrient deficiencies in populations and regions.
- **Epidemiological studies**
  - Purpose specific analytics.
- **Research and non-profit studies**
  - May require aggregated digests and anonymised longitudinal data.
- **Commercial research**
  - Anonymised and aggregated data.
  - Data economics? Consent? Payments?

Objectives: Privacy and security

- **Access control**
  - Only **programmatic access** through secure APIs.
  - Only legitimate and authenticated access, enabled by **consent and authorisation**.
  - No unauthorised linking with other data and personal identifiers.
  - Non-repudiable and immutable logs of all accesses. Access control also for the logs.
- **Purpose limitation**
  - Ensure that **no access violates purpose** of **consent** or **authorisation**.
- **ex-ante** rather than **ex-post**.
- **Regulatory framework**.

Operational considerations: things to watch out for

- **UHID** derived from a **national digital identity**.
- **Digital literacy**? **Network access** in remote areas? **Authentication**, **authorisation** and consent methods?
- Local caching of data?
- **Inter-operability**. Data portability or where-is?
- APIs and use cases.
- **Standardisation** and **inter-operability** of software and Apps at PHCs, hospitals and clinics, imaging and test centres, pathologists, radiologists.
- **A comprehensive law** harmonious with digital identity, data protection and IT Acts. No money bill please!

Design considerations: Blockchains?

- **Permissioned Blockchains** to maintain non-repudiable logs of all data generation and data access.
- PHR data compartmentalised and **encrypted with** a hierarchy of **personal keys**. User in control of data.
- Each consensus participant maintains all data; either in **monolithic databases**, or in **decentralised**, distributed, fault tolerant, peer-to-peer file systems such as the IPFS.
- **Consent** and **authorisation** architecture based on **smart contracts**.
- **Consensus protocols:** Proof of Work? Proof of Stake? Proof of Authority? Practical Byzantine Fault Tolerance? Majority?

Design considerations: Blockchains?

- **Advantages:**
  - Transparency, correctness, non-repudiation, immutable.
  - Basic framework well tested and standard (except scalability, of course).
  - Can support federated generation of information.
  - Multiple central authorities (miners).
  - Distributed protocol (but not really decentralised in terms of storage and computations).
  - Can support APIs.
  - Smart contracts natural for consent and authorisations architecture.

Design considerations: Blockchains?

- **Disadvantages:**
  - State capacity?
  - PoW or BFT may require **excessive redundant computation**? Power plants?
  - Still require **strong regulatory framework** for **access control** (prevent bypass of access through smart contracts) and **purpose limitation**. Centralised DPA? Replicated at each consensus participant?
  - Support **access for analytics** through smart contracts? Private keys? Centralisation? Devil lies in details?

Design considerations: Monolithic?

- **Advantages:**
  - Easier, from a state-capacity point of view.
  - Can be made secured, fault tolerant.
  - Regulated access control and purpose limitation easier to implement?
  - Non-repudiable and immutable through fault tolerance and regulated access control?
- **Disadvantages:**
  - Transparency.
  - Convincing people.

Design considerations: Others

- Interface design for individuals, PHCs, ...
- Digital literacy? Interface design for consent.
- Methods for **access control** and **purpose limitation**.
- Limits of anonymization of medical data with guarantees against re-identification attacks?
- Key management. Reset? Hierarchy of master keys (Merkle tree based?) will imply centralisation.
- Connectivity? Caching design? Lazy commits?
- Above all, **whitepapers** and **public consultations**.