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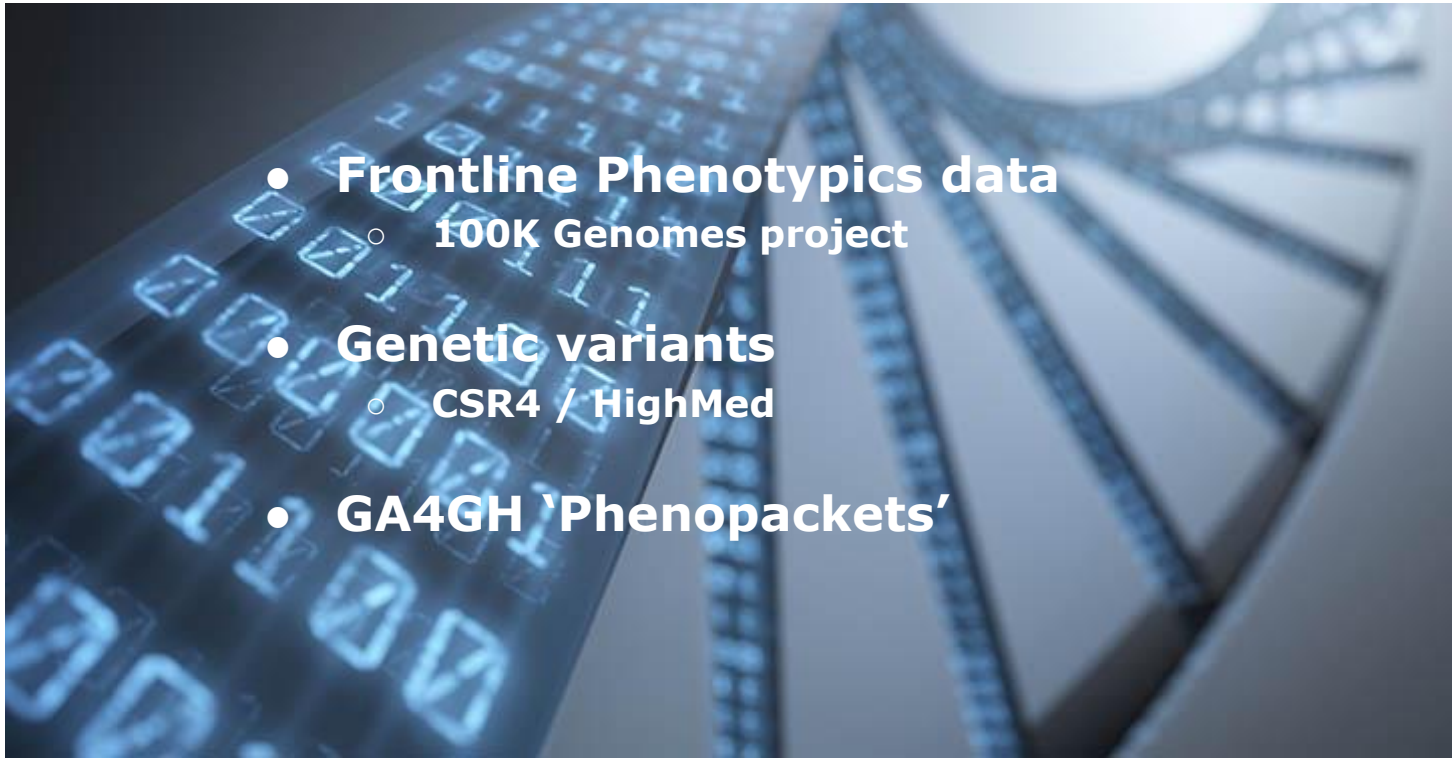
# Next Frontier: Archetypes for social care and genomics

Ian McNicoll and Silje Ljosland Bakke

# Archetype adventures in Genomics-land

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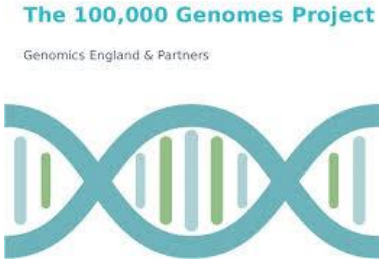
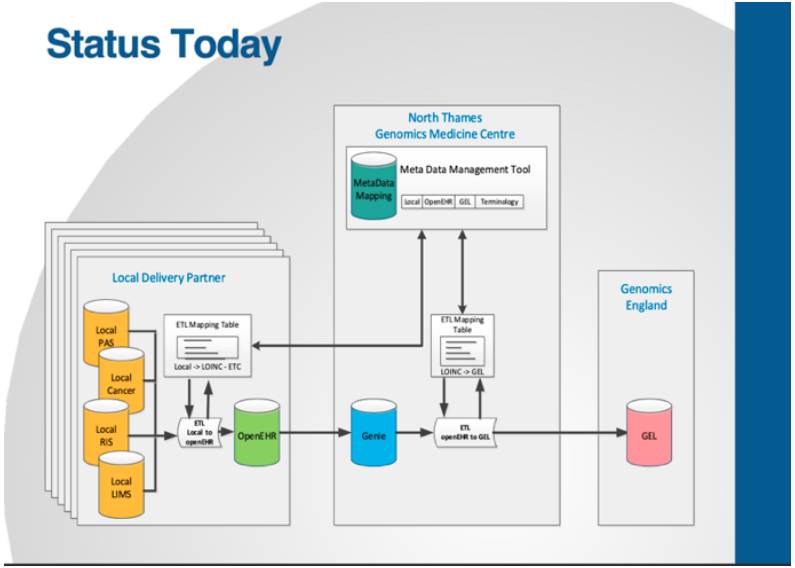
# Genomics England - 100K Genomes project

- Launched 2012 – kick start UK genomics industry
- Enable breakthroughs in medical research, diagnosis and treatment
- Sequence 100,000 genomes of patients with cancer and rare diseases
- Established Genomics England Limited
- 13 Genomics Medicine Centres (GMCs) collect gene samples and accompanying clinical data from participating NHS trusts
- North Thames responsible for over 25,000 Genomes

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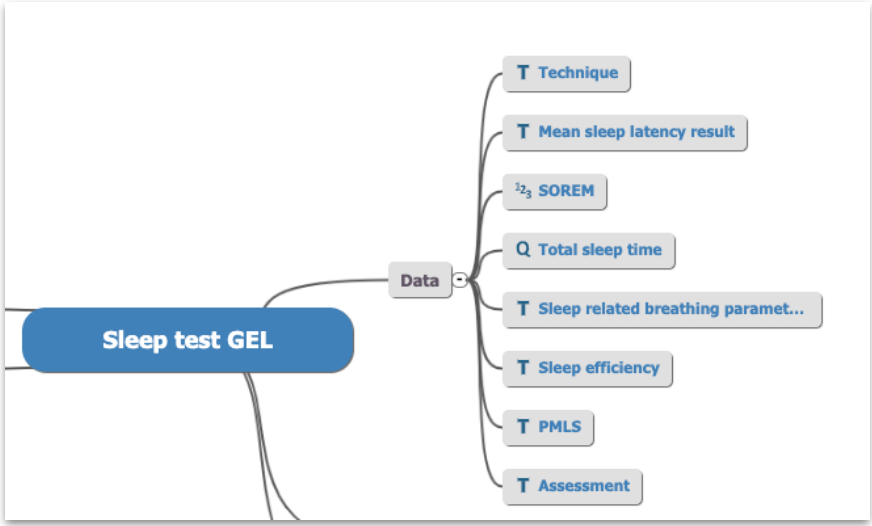
# Genomics England phenotypics

- 26 templates
  - 13 Rare disease ‘output’
  - 11 Cancer ‘output’
  - 2 ‘input’
- 99 archetypes
  - 44 international
  - 27 localised
  - 28 purely local




http://ckm.apperta.org/ckm/#showProject_1051.61.28

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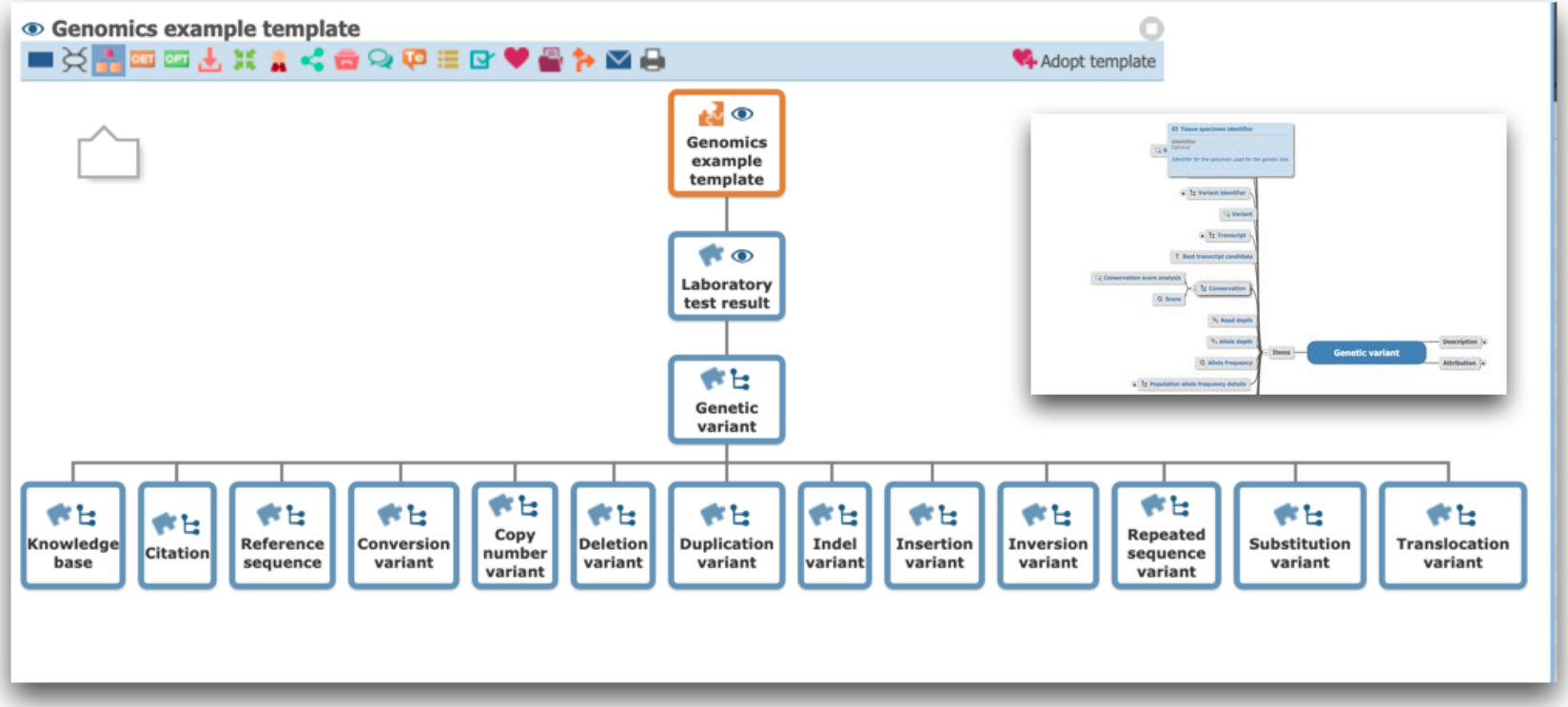
# CSR4/HighMed Genetic variants

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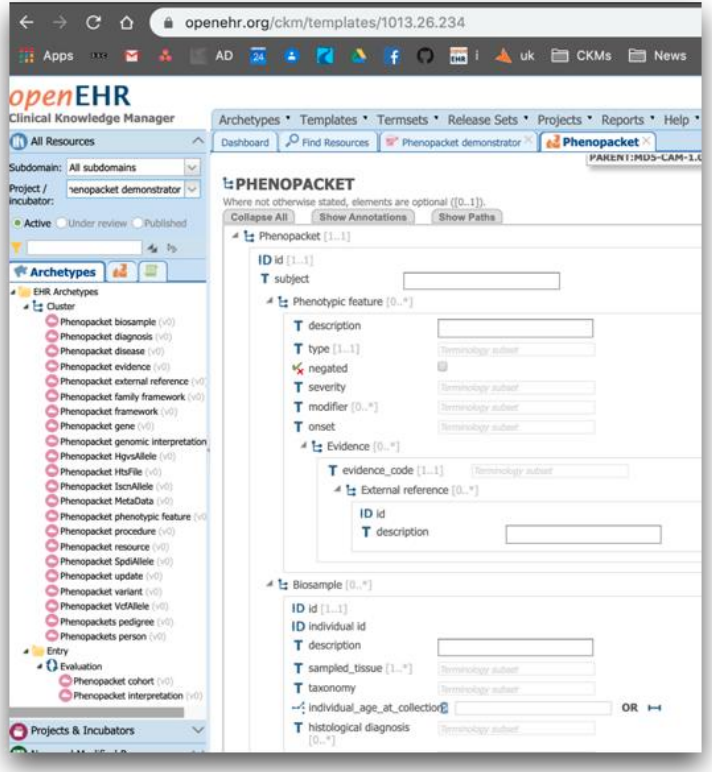
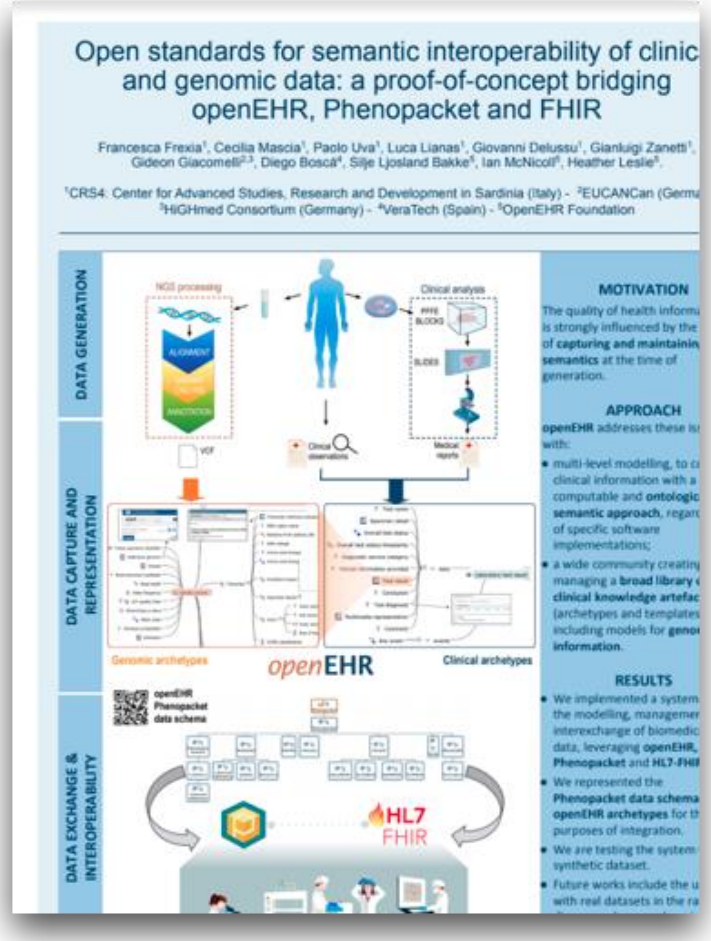
# GA4GH and Phenopackets

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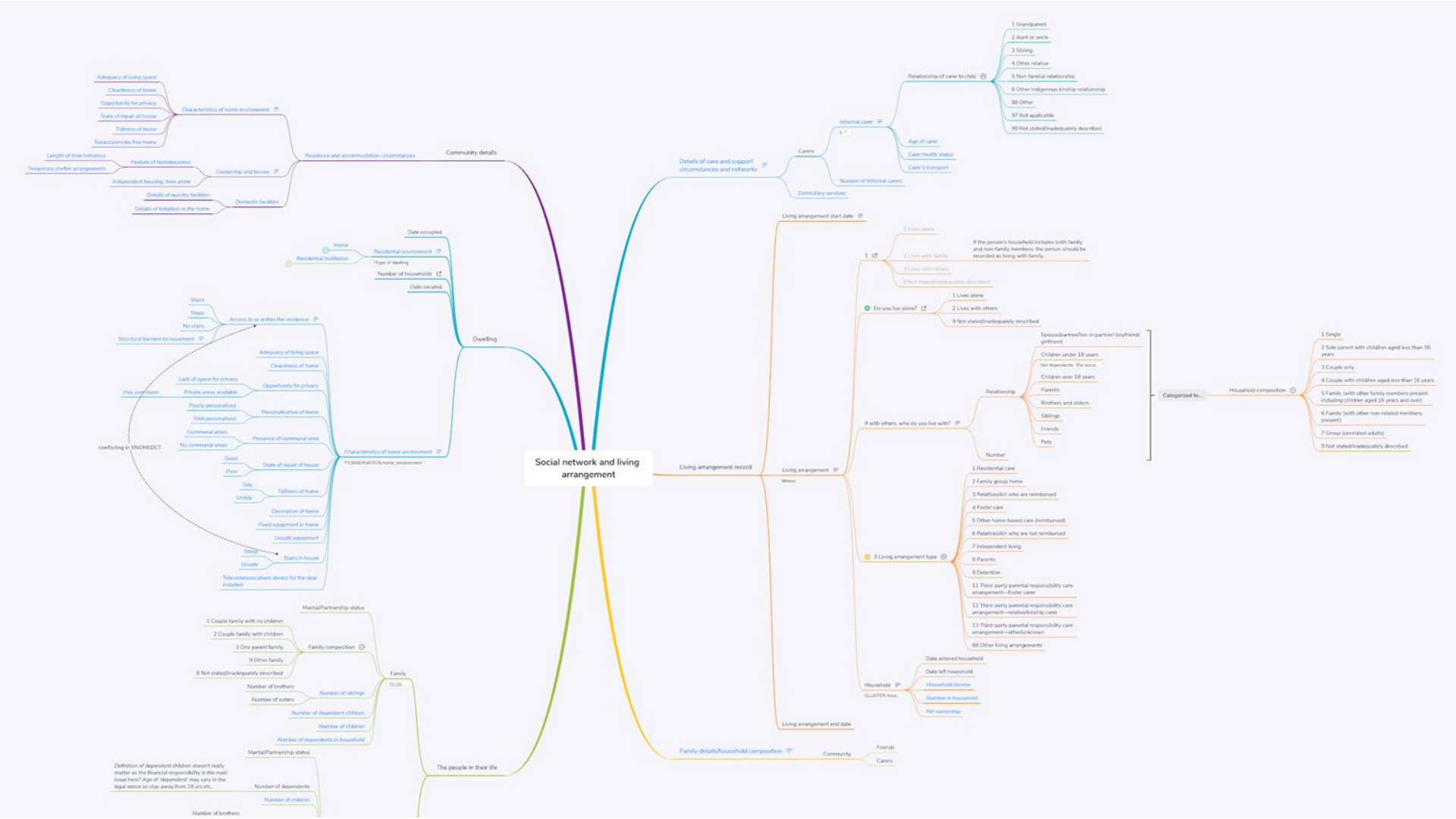
SOCIAL INFORMATION


Social network and living arrangement
Community details
Residence and accommodation circumstances
Characteristics of home environment
Adequacy of living space
Cleanliness of home
Opportunity for privacy
State of repair of house
Tidiness of home
Tobacco/smoke free home
Ownership and tenure
Feature of homelessness
Length of time homeless
Temporary shelter arrangements
Independent housing, lives alone
Domestic facilities
Details of laundry facilities
Details of telephon in the home
Dwelling
Date occupied
Residential environment
Home
Residential Institution
*Type of dwelling
Number of households
Date vacated
Characteristics of home environment
**OBSERVATION home_environment
Access to or within the residence
Stairs
Steps
No stairs
Structural barriers to movement
Has one room
conflicting in SNOMEDCT
Adequacy of living space
Cleanliness of home
Opportunity for privacy
Lack of space for privacy
Private areas available
Personalisation of home
Poorly personalised
Well personalised
Presence of communal area
Communal areas
No communal areas
State of repair of house
Good
Poor
Tidiness of home
Tidy
Untidy
Decoration of home
Fixed equipment in home
Unsafe equipment
Stairs in house
Steps
Unsafe
Telecommunications device for the deaf installed
The people in their life
Family
CLUB
Marital/Partnership status
Family composition
1 Couple family with no children
2 Couple family with children
3 One parent family
9 Other family
8 Not stated/inadequately described
Number of siblings
Number of brothers
Number of sisters
Number of dependent children
Number of children
Number of dependents in household
Marital/Partnership status
Definition of dependent children doesn't really matter as the financial responsibility is the main issue here? Age of 'dependent' may vary in the legal sense so stay away from 18 yrs etc.
Number of dependents
Number of children
Number of brothers
Details of care and support circumstances and networks
Carers
Informal carer
0..*
Relationship of carer to child
1 Grandparent
2 Aunt or uncle
3 Sibling
4 Other relative
5 Non-familial relationship
6 Other Indigenous kinship relationship
88 Other
97 Not applicable
99 Not stated/inadequately described
Age of carer
Carer health status
Carer's transport
Number of informal carers
Domiciliary services
Living arrangement record
Living arrangement start date
Living arrangement
Meteor
1
1 Lives alone
2 Lives with family
3 Lives with others
9 Not stated/inadequately described
If the person's household includes both family and non-family members, the person should be recorded as living with family.
Do you live alone?
1 Lives alone
2 Lives with others
9 Not stated/inadequately described
If with others, who do you live with?
Relationship
Spouse/partner/live-in partner/ boyfriend/ girlfriend
Children under 18 years
Not dependents. The socia...
Children over 18 years
Parents
Brothers and sisters
Siblings
Friends
Pets
Number
Categorised to...
Household composition
1 Single
2 Sole parent with children aged less than 16 years
3 Couple only
4 Couple with children aged less than 16 years
5 Family (with other family members present including children aged 16 years and over)
6 Family (with other non-related members present)
7 Group (unrelated adults)
9 Not stated/inadequately described
3 Living arrangement type
1 Residential care
2 Family group home
3 Relatives/kin who are reimbursed
4 Foster care
5 Other home-based care (reimbursed)
6 Relatives/kin who are not reimbursed
7 Independent living
8 Parents
9 Detention
11 Third-party parental responsibility care arrangement—foster carer
12 Third-party parental responsibility care arrangement—relative/kinship carer
13 Third-party parental responsibility care arrangement—other/unknown
88 Other living arrangements
Household
CLUSTER:Hous...
Date entered household
Date left household
Household income
Number in household
Pet ownership
Living arrangement end date
Family details/household composition
Community
Friends
Carers

- [x] Social summary
- [x] Housing summary
- [x] Housing record
- [x] Occupation summary
- [x] Occupation record
- [x] Communication capability
- [x] Interpreter request
- [x] Translation requirement
- [x] Language

- [x] Religious affiliation
- [x] Gender
- [ ] Education summary
- [ ] Education record
- [ ] Income
- [ ] Social network
- [ ] Dwelling
- [ ] Living arrangements
- [ ] Nutrition

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# CHALLENGES GOING FORWARD

# From frontline to analytics


Frontline data formats ⇏ analytics/research/registry formats

- open vs. closed questions
  - questionnaires
  - “Diagnosis”: Diabetes
  - “Diabetes” : “yes”;”no”
- AORTIS
  - Feblowitz: Summarization of clinical information: a conceptual model
- Need for quality curation

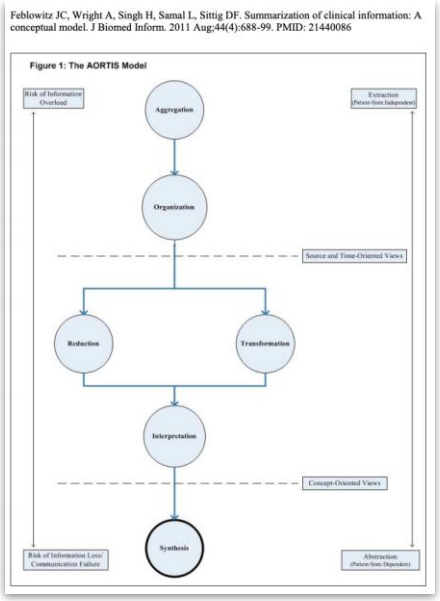
Feblowitz JC, Wright A, Singh H, Samal L, Sittig DF. Summarization of clinical information: A conceptual model. J Biomed Inform. 2011 Aug;44(4):688-99. PMID: 21440086

Figure 1: The AORTIS Model



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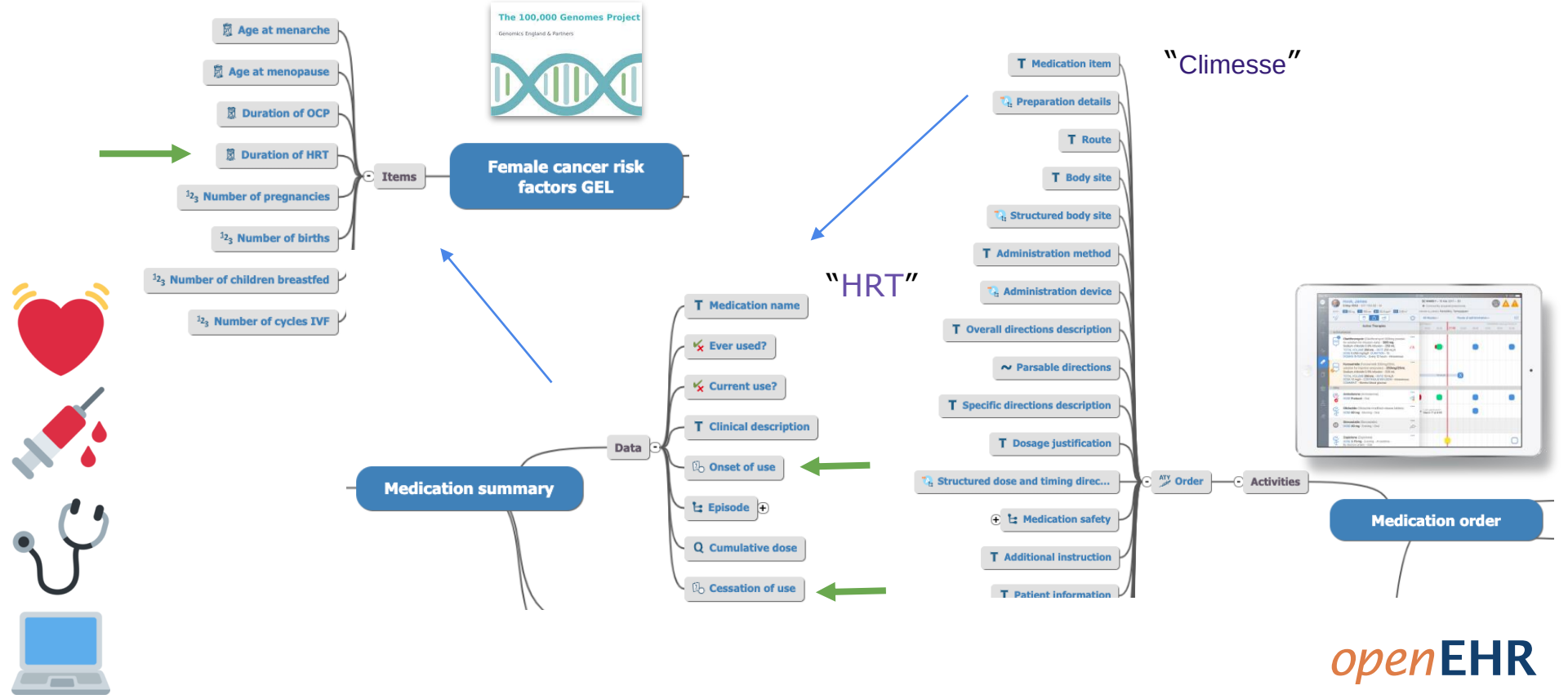
# 100K Genomics: “Duration of HRT”

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# LHCRE and Data lakes?



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ALGERIA
AFRICA
SUDAN
CHAD
NIGERIA
MALI
TANZANIA
ANGOLA
NAMIBIA
SOUTH AFRICA
BRAZIL

# How many children under 18 years of age live in the same dwelling unit as the patient?

## Number of own children

0-6 years 2 7-12 years 0 13-17 years 0

## Number of others' children

0-6 years 0 7-12 years 1 13-17 years 0




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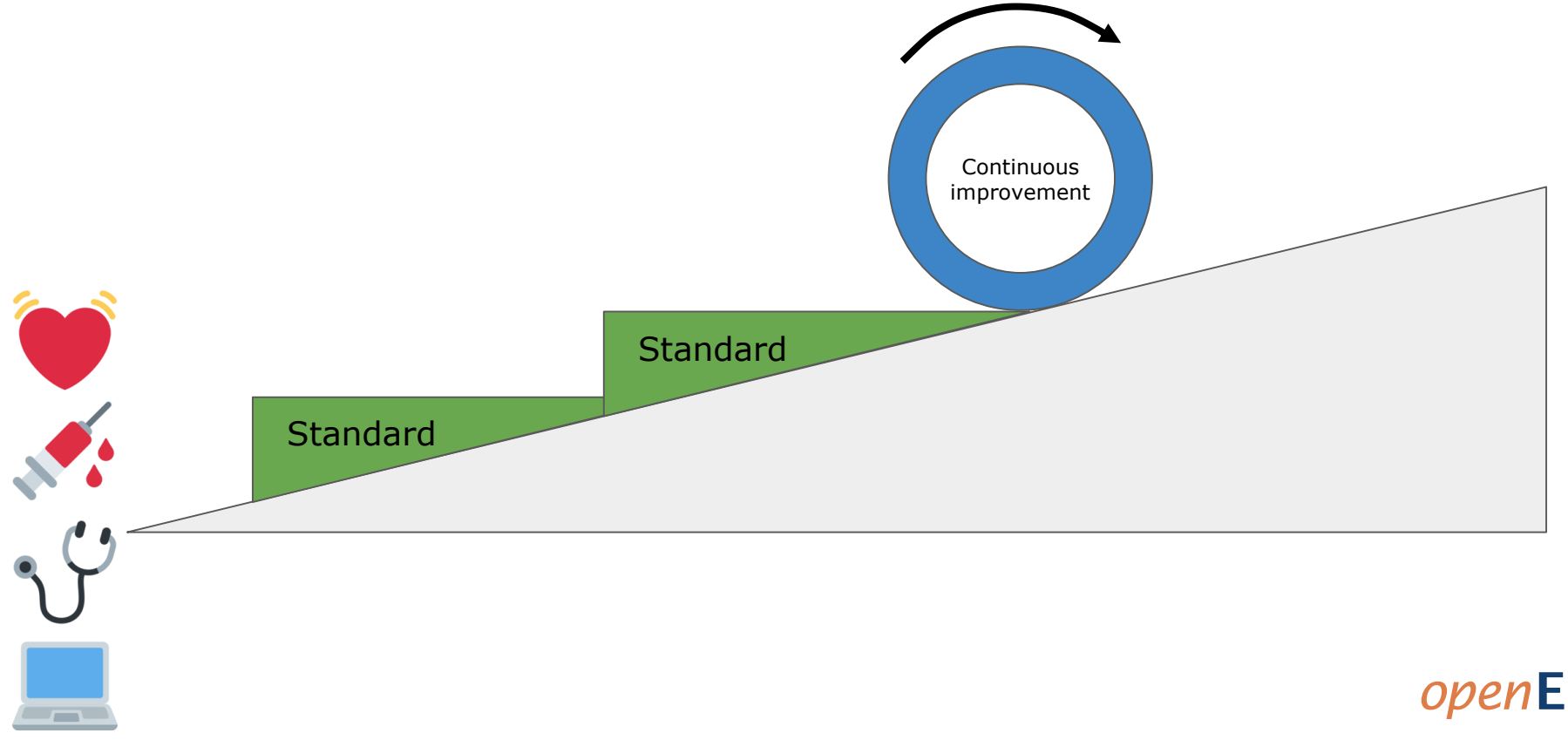


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# Principles for modelling the clinical world

- Low participation threshold
- Changeability
- Governance
- Vendor independence
- Sharing and free licences
- Use case independence




# Pragmatic standardisation

- Gradually and step by step instead of all in one go
- Constant maintenance instead of 5 year revision cycles
- Careful selection of what to standardise and what not to
- Some standardisation is infinitely better than no standardisation

Photo: Haukeland University Hospital https://www.flickr.com/people/haukeland/

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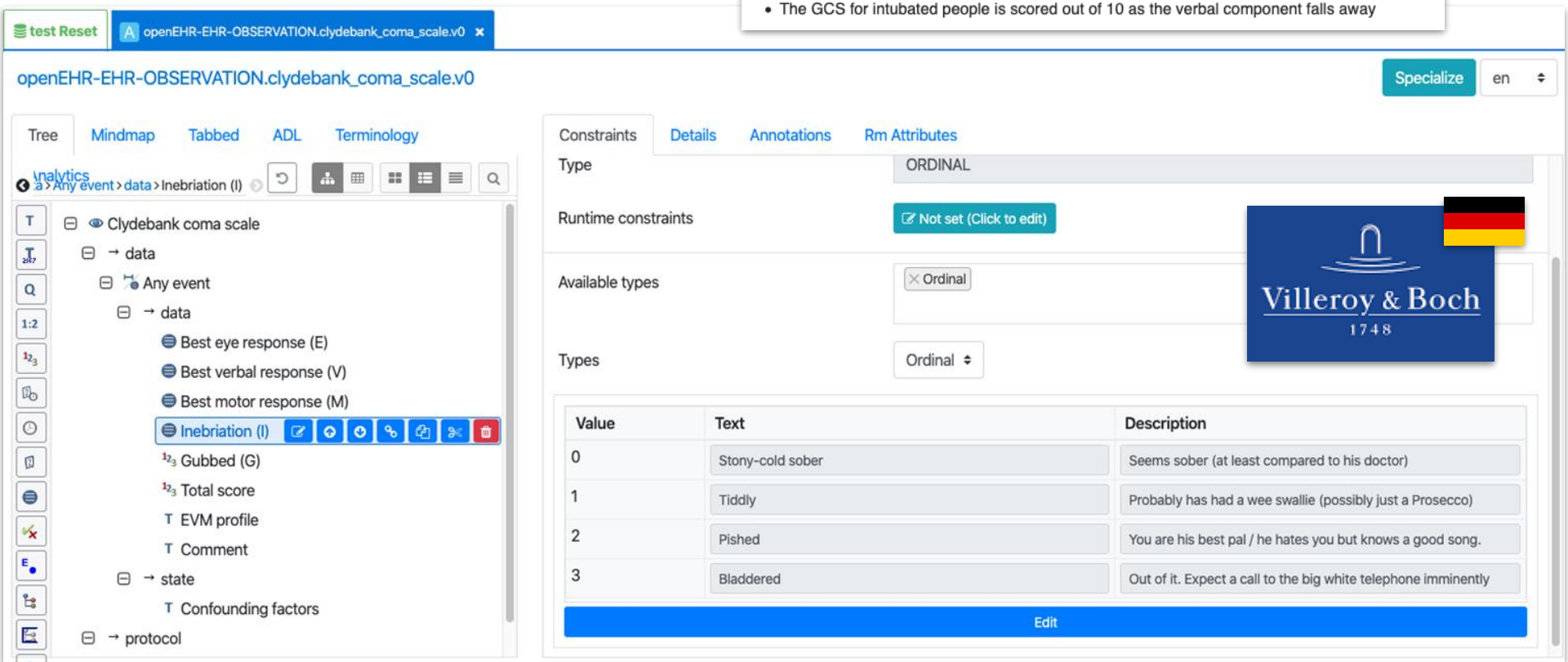
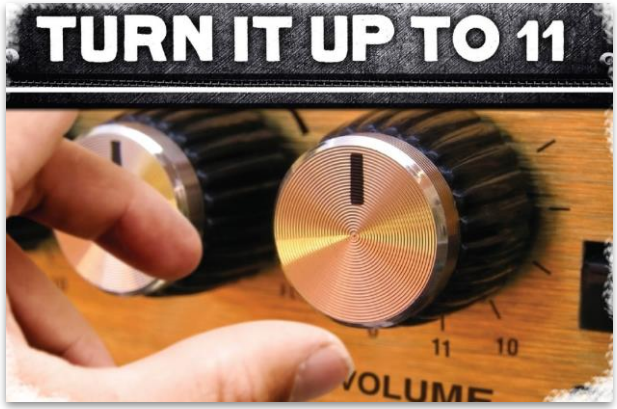
# Oh Glasgow...

## Revisions [ edit ]

- Glasgow Coma Scale: While the 15-point scale is the predominant one in use, this is in fact a m
  original scale was a 14-point scale, omitting the category of "abnormal flexion". Some centres s
  done) have adopted the modified one.
- The Rappaport Coma/Near Coma Scale made other changes.
- Meredith W., Rutledge R, Fakhry SM, EMery S, Kromhout-Schiro S have proposed calculating t
- The most widespread revision has been the Simplified Motor and Verbal Scales which shorten t
- The GCS for intubated people is scored out of 10 as the verbal component falls away



# The Borg CR10 Scale: ‘Spinal tap’ edition




| Borg CR10 Scale (1982)[12] | | Borg CR10 Scale® (2010)[20] | | |
|---|---|---|---|---|
| 0 | Nothing at all | 0 | Nothing at all | |
| 0.5 | Extremely weak (just noticeable) | 0.3 | | |
| 1 | Very weak | 0.5 | Extremely weak | Just noticeable |
| 2 | Weak (light) | 0.7 | | |
| 3 | Moderate | 1 | Very weak | |
| 4 | Somewhat strong | 1.5 | | |
| 5 | Strong (heavy) | 2 | Weak | Light |
| 6 | | 2.5 | | |
| 7 | Very strong | 3 | Moderate | |
| 8 | | 4 | | |
| 9 | | 5 | Strong | Heavy |
| 10 | Extremely strong (almost max) | 6 | | |
| • | Maximal | 7 | Very strong | |
| | | 8 | | |
| | | 9 | | |
| | | 10 | Extremely strong | “Maximal” |
| | | 11 | | |
| | | ∫ | | |
| | | • | Absolute maximum | Highest possible |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