TRANSFoRm

GP's role and benefits in large scale Primary Care research

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Acknowledgements

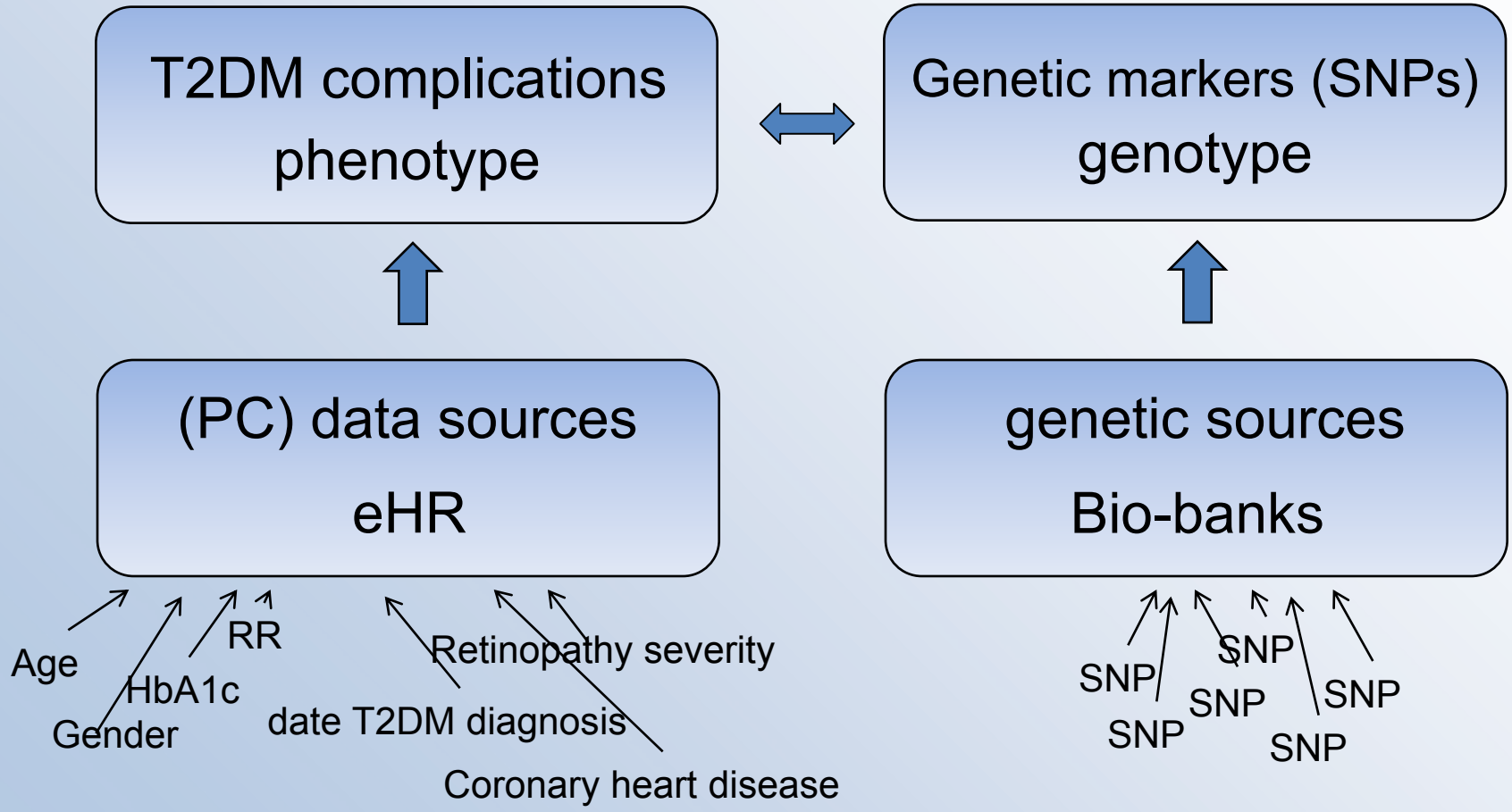
eHealth

European Commission
Information Society and Media

Imagine you could…

- … predict patients' vulnerability for developing coronary artery disease or diabetes retinopathy
- … predict patients' drug response to oral diabetics
- …

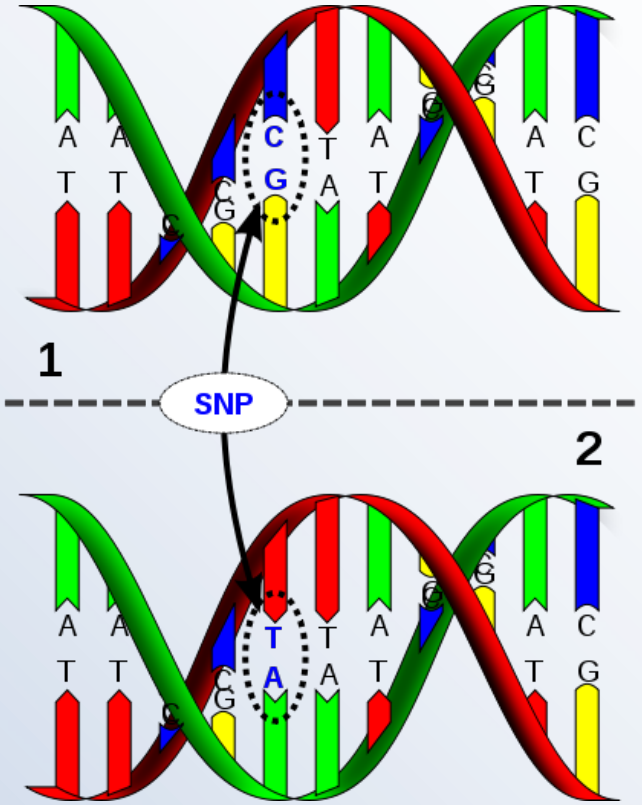
This could be possible if…



What is SNP?

- Single nucleotide polymorphism

  = DNA sequence variation occurring when a single nucleotide differs between members of a biological species



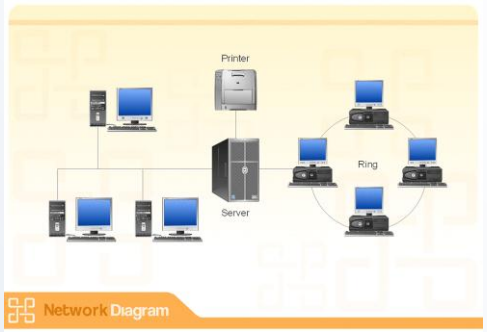
However…

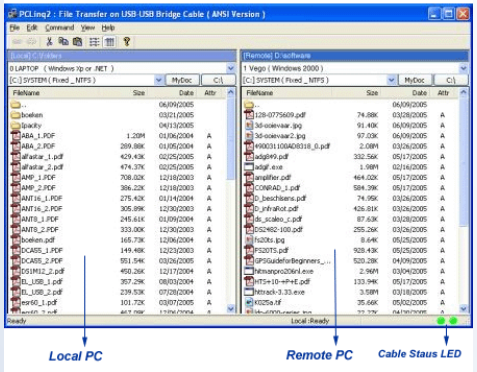
- Need for large scale research data
  - Genomic data sources:
    - 'Biobanks': Genome Wide Scans (GWAs)
    - Specific research databases (SNPs') i.e. Go-Darts (Scotland)

  - Phenotypic ('clinical') data sources
    - hospital
    - community
    - primary care
      - Electronic Health Records (eHR)
      - PC research databases (i.e. GPRD, Nivel, Intego,…)

However…

- Need for large scale research data
  - Interoperability
    - ‘understanding’ of different data sources
  - Link information at level of individuals
    - connecting of different data sources





- **With privacy and security regulations**

Applicability

- Type 2 Diabetes Mellitus as an example…
  - extracted clinical data from PC database (e-HR)
    - Coded diagnosis (definite / possible / probable)
      - *ICD, ICPC, snowmed CT,…*
    - Therapeutic data (drug therapy)
      - *Insulin / OAD + - metformin / none*
      - *CNK, ATC, DDD,…*
    - Laboratory data
      - *FBG, at random, HBA1c*
      - *???*
    - Complications
      - *CHD, neuropathy, retinopathy, …*
    - Other
      - *Age, gender, ethnicity,…*
    - Exclusion criteria

T2DM Diagnosis

- Fasting* plasma glucose ≥ 7 mmol/l (126 mg/dl)

  * no caloric intake for > 8 hours
- OGTT (2h plasma glucose > 11,1 mmol/l) (200 mg/dl)
- Random plasma glucose > 11,1 mmol/l with classic symptoms of hyperglycaemia
- HBA1c > 6,5 % (48 mmol/mol)

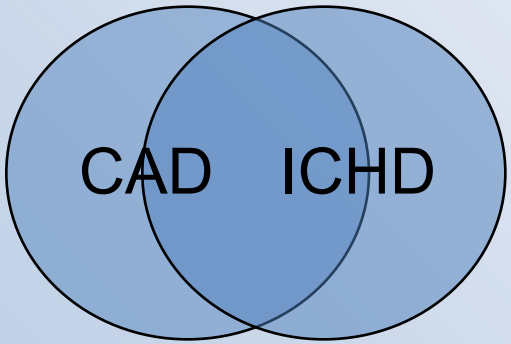
ICPC codes: T2D = T90 (T90.2?)
SNOMED-CT: T2D = 44054006
ICD-10: NIDDM (obsolete)=E11 doesn't cover all type 2 diabetics, namely the T2D patients treated by insulin.

Coding example: type 2 diabetes

theoretical	Definition	A subclass of DIABETES MELLITUS that is not INSULIN-responsive or dependent (NIDDM). It is characterized initially by INSULIN RESISTANCE and HYPERINSULINEMIA; and eventually by GLUCOSE INTOLERANCE; HYPERGLYCEMIA; and overt diabetes. Type II diabetes mellitus is no longer considered a disease exclusively found in adults. Patients seldom develop KETOSIS but often exhibit OBESITY. (2005)
	Common diagnostic criteria	•fasting plasma glucose ≥ 7.0mmol/l (126mg/dl) •2–h plasma glucose ≥ 11.1mmol/l2424 (200mg/dl)
	New or complementary diagnostic criteria	HbA1c ≥ 6.5%
operational	Coded diagnosis + degree of certainty	ICPC2, ICD10, SNOMED CT, READcodes
	Laboratory data	(Fasting) blood glucose, HbA1c
	Therapeutic data Other data	AD Age>34

Complications

- Coronary heart disease
  - Synonyms +++
  - clinical ≠ imaging ≠ technical
    - CAD (coronary artery disease) = anatomical lesion
    - ICHD (ischemic coronary heart disease) = clinical definition



SNOMED CT: Coronary arteriosclerosis (disorder) =53741008
ICD-10: Atherosclerotic heart disease = I25.1
ICPC-2: Coronary atherosclerosis = K76


Double-click, Control, Shift
— it's totally intuitive!
Chris Madden
www.chrismadden.co.uk

Availability

- Questionnaire about databases of e-HR
  - aims
  - methods of data collection
  - relation with GPs e-HR
  - description of data set characteristics

Availability

- *What kind of data are available in your country?*
  - Prescriptions?
  - Morbidity / mortality records?
  - Numbers / kinds of patients seen?
  - Physicians' procedure records for payments
  - …
- *What are the aims of these databases?*
  - Research?
  - Administration?
  - Public health issues?
  - ...

Availability

- *How are the data collected?*
  - e-HR?
  - remote data entry?
  - Paper forms?
  - Central web based?
  - …
- *Relation with GP's e-HR?*
- *Are all data from e-HR centralized in one center?*
- *Is other information linked to this e-HR data?*
- *Are the data reachable for research purposes?*

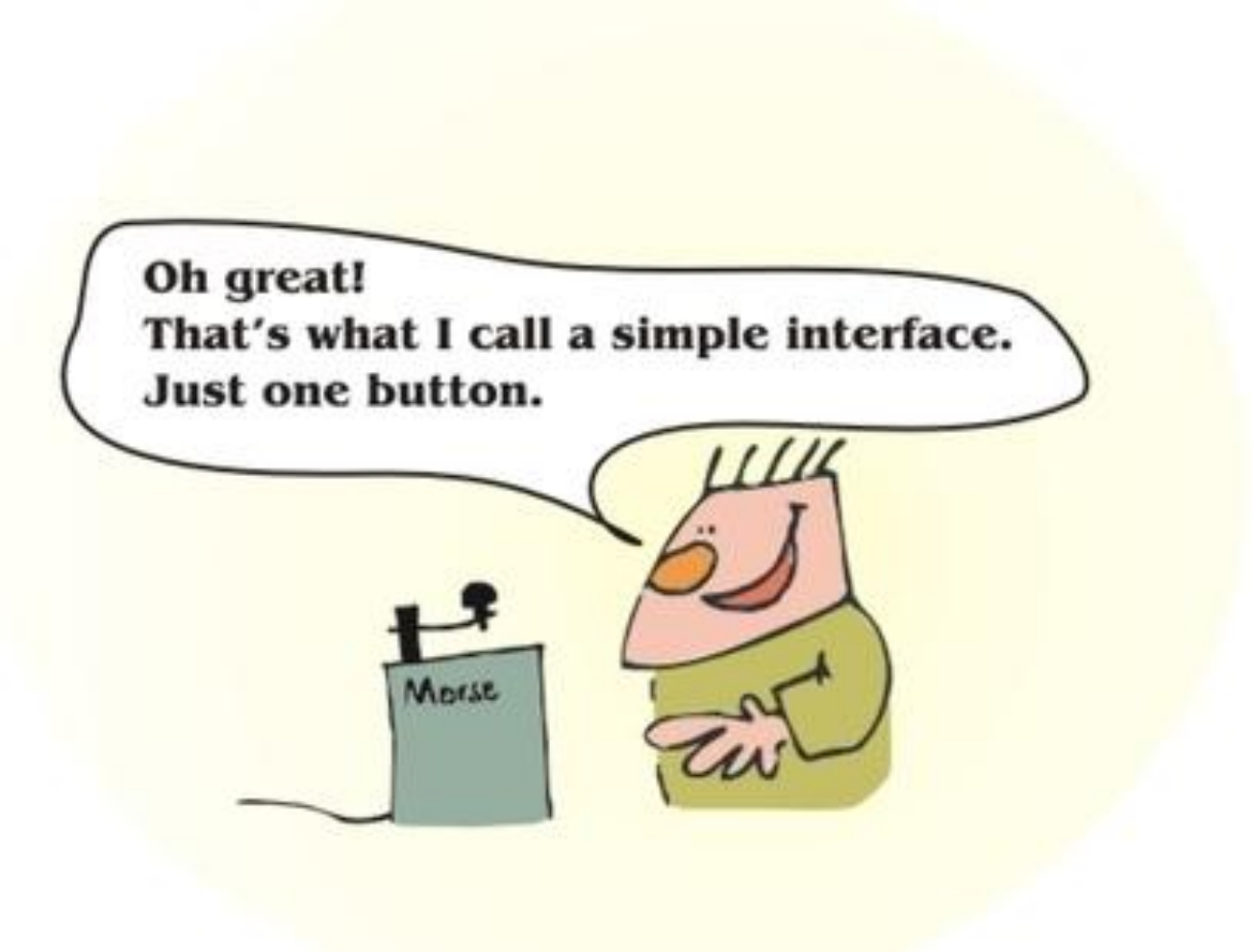
Availability

- *Results*
  - *Information from 29 countries*
  - *67 national/regional health care databases*
  - *49 databases have clear linkage with GP's e-HR*
  - *55 databases centralized in 1 centre*
  - *Diagnostic coding systems:*
    - ICPC = 20
    - ICD 9 / ICD 10 = 31
    - Read codes = 5

Availability

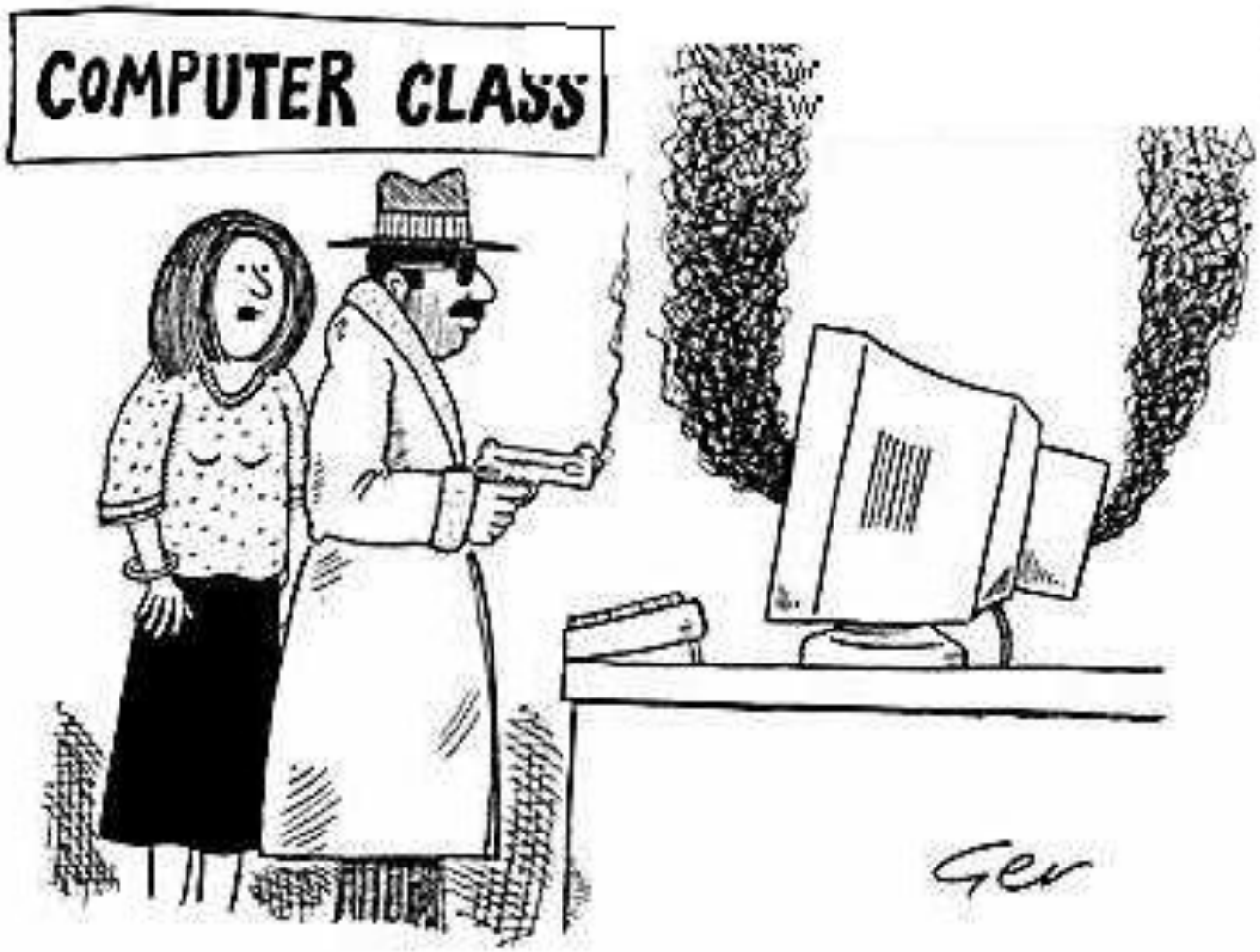
- *Conclusions*
  - In all European countries, EHR' databases and/or PC clinical data repositories are available
  - … but of variable quality
  - Good overview of PC's capacity for linkage to TRANSFoRm and similar European projects

Applicability + Availability



Conclusions

- Linking at patient level data from Primary Care data resources and data sources containing genetic information
- Fulfilling all privacy, legal and security regulations
- Interoperability by coded e-HR
- As a basis for the development and validation of a system to integrate Primary Care e-HR and research databases



'Now, can you remember the way I showed you how to terminate the session, Luigi?'