CORBEL WP3.5

Integrating population cohorts to derive prognostic biomarkers

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Background

- Development of robust prognostic disease biomarkers:
- Access to prospective cohorts with reliable clinical, molecular and imaging data critical!

- *Harmonized*, *enriched* data sets greatly facilitate downstream studies by clinical scientists to develop robust prognostic and disease stage-specific biomarkers, for:

- epidemiological insights and disease subclassification
- early diagnosis,
- rational therapy development,
- improved prevention.

Use case: pancreas cancer

- Lethal, essentially untreatable
- Fifth commonest after breast, prostate, colon and lung cancer
- Fulminant and inexorable
- Lack of options → dramatic impact on patients, care providers, surroundings
- High unmet medical needs: early detection, improved treatment and prevention.
- Models a much broader area of similar diseases

PPC: prediction of pancreatic cancer

- A collaboration of four biobanks to pool data and samples.
  - PI in Leiden (GJB van Ommen LUMC, NL), partner BBMRI-ERIC, AT
  - Biobanks: Estonia, Norway, Finland, Netherlands
  - Started under BBMRI-LPC
  - Continued under CORBEL

  Aims:
  - 1-NMR Metabolomics by BrainShake (later Nightingale, Helsinki, FI). *For a strongly reduced tariff (40%) due to joint data generation with much bigger sample set for BBMRI-NL parties*
  - Later Olink proteomics by THL, FI and by SciLife, SE

Samples

Table 2: Summany of cases and controls per participant

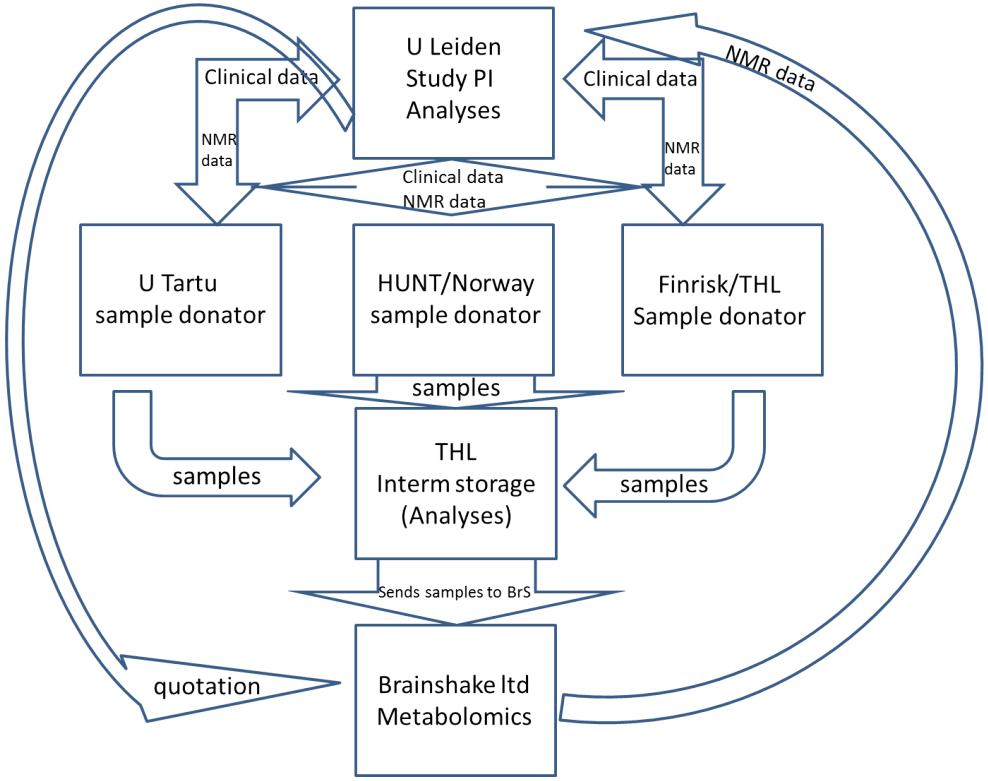
Source	Cases	Controls	Required Metabolomics
THL	64	128	64*
UTARTU	81	162	243
NTHU/HUNT	286 (235)	572(470)	858(705)
ErasmusMC	153(115)	103(230)#	256(345)
Total	584(491)	965(982)	1421(1343)

* Of the 120 THL controls Brainshake metabolomics data are already available

Controls can serve for more cases

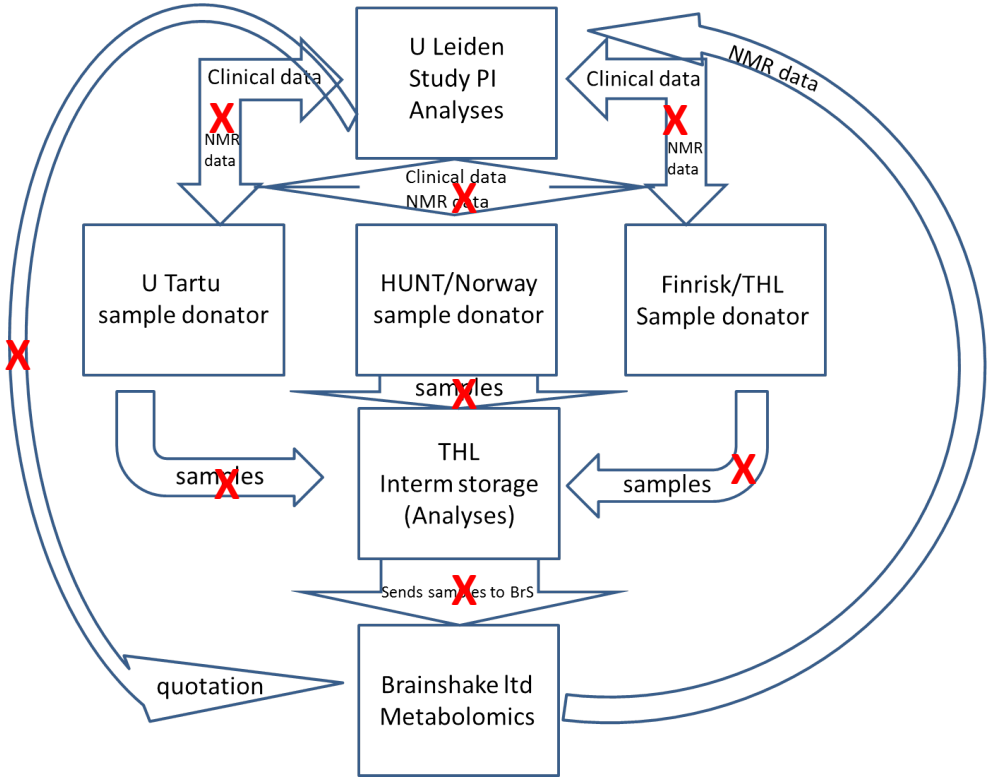
The final sample count was in fact higher than initiallly anticipated (arond 350 scases and 700 controls). This is mostly due to initial counts being somewhat outdated

The study schema



The study schema

Written and signed agreements needed: X



At least 8 different agreements with different signees needed for this simple endeavor

Roadblocks for access

- ✓ Nobody's priority in busy biobanks
- ✓ Locating the local contact/collaborator
- ✓ Access denied
- ✓ Sample n low (after weeks/ months of time to fin
- ✓ Official documents
  - ✓ Rewriting to fit local rules.. **AND PREFERENCES**
  - ✓ Missing information – bouncing back and forth th
  - ✓ Justification of variables (why they are needed)
- ✓ Committee/Board meeting schedules (only meet in cert many:
  - ✓ Ethics
  - ✓ Scientific
  - ✓ Registers
  - ✓ Other
- ✓ Data release waves (sometimes researchers have to wait for new data to be released to get the optimal nb of cases)
- ✓ Variables
  - ✓ Don't match up between different bbs -> expertise needed to solve this
- ✓ No project (FUNDS) commitment by local legal departments

1 ½ years of PPC : 01-01-15 / 01-09-16

From	Nr OF MAILS	From	Till
THL Finland (1)	349	12-01-15	02-08-16
UTARTU Estonia (2)	174	02-02-15	14-03-16 ♪
HUNT Norway (3)	138	06-03-15	01-09-16
ErasmusMC (4)	~ 40		
1-2-3	86	11-08-15	
1-3	361	02-03-15	
2-3	88	08-03-15	
TOTAL	**1236 (!!)**		


Shit happens:
Zum Glück gibt's Mobil-Toiletten von Pipifine.
www.pipifine.at
DROLLANDIA

NO, SHIT *DOESN'T* HAPPEN ..

IT TAKES A LOT OF WORK TO MAKE SHIT HAPPEN!

Crossborder biobanking

- Time is OF THE ESSENCE!
- Don't let the perfect be
  (*or rather: stay..*) the enemy of the good!
- **Who explains to (consented!) Biobank participants why it takes two years to move paper around?**
- **For a few weeks data generation?**
- **And ~12 months of JOINT analysis?**
- **For having ½ , 2 or 4 years more to, someday, do something about pancreas cancer?**