ENSAT-CANCER
Digital registry for adrenal tumors

Anthony Stell
Melbourne eResearch Group
eResearch Australasia 2011

Adrenal Cancer

- ACC - Adreno-Cortical Carcinomas
- Pheo - Pheochromocytoma and Paraganglioma

Summary

<table>
<thead>
<tr>
<th></th>
<th>ACC</th>
<th>Pheo</th>
<th>NAPACA</th>
<th>APA</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Records</td>
<td>1017</td>
<td>232</td>
<td>157</td>
<td>785</td>
<td>2101</td>
</tr>
<tr>
<td>Patients Alive</td>
<td>606</td>
<td>86</td>
<td>4</td>
<td>1</td>
<td>697</td>
</tr>
<tr>
<td>Biosamples</td>
<td>315</td>
<td>259</td>
<td>479</td>
<td>315</td>
<td>1553</td>
</tr>
<tr>
<td>Clinical Annotations</td>
<td>9493</td>
<td>1073</td>
<td>285</td>
<td>373</td>
<td>11203</td>
</tr>
<tr>
<td>Annotations Per Patient (Mean)</td>
<td>0.33</td>
<td>4.53</td>
<td>1.82</td>
<td>0.47</td>
<td>5.11</td>
</tr>
<tr>
<td>Biosamples Per Patient (Mean)</td>
<td>0.51</td>
<td>0.98</td>
<td>3.05</td>
<td>0.40</td>
<td>0.70</td>
</tr>
<tr>
<td>Active Centers</td>
<td>17</td>
<td>10</td>
<td>5</td>
<td>5</td>
<td>22</td>
</tr>
</tbody>
</table>

THE EVOLUTION STARTS HERE
Rare Diseases

- Pheo: 2-8 patients per 1,000,000 of the population

- Same chromosomal/genetic basis for other rare diseases:
  - Disorders of Sexual Development
  - Alstrom Syndrome
  - Wolframs, Bardet Biedl

- International Symposium on Pheochromocytoma (ISP)
  - ~1000 attendees

ENSAT

- ENSAT
  - European Network for the Study of Adrenal Tumors

- Network started life circa. 2004
- Data distribution until 2009: CDs in the post
ENSAT-CANCER

- FP7-funded project
- 5 years duration, started January 2011
- ~ €38 million

Goals:
- Digital linkage and harmonisation
- Information exchange systems
- Virtual research environment (VRE)

https://registry.ensat.org
The Registry #2

Virtual Research Environment

- PMT
  - Prospective Monoamine-producing Tumor Study
- ADIUVO
  - Adjuvant Mitotane Therapy
- FIRSTMAPPP
  - Malignant Progressive Pheo/Para Study
- EURINE-ACT
  - Urine steroidobolomics in ACC/NAPACA tumors
- FAMIAN
  - Tumor Imaging

THE EVOLUTION STARTS HERE
Ethics, Data Types and Value

- Ethics
  - Template document for each country (all approved)

- Data types
  - Biomaterial
  - Clinical annotations
  - Imaging

Infrastructure

- Connected through IDs
  - Center: GYWU, FRPA1, GBBI, ITTU, etc

Other relevant information:

18/11/2011
Infrastructure #2

- Google Analytics/Statcounter
- Data size
  - ~ 2000 records
  - Currently 10’s of Mb transfer but imaging support will impact this
- Security
  - SSL server and client certificates issued.
  - Byte-code and SQL-injection protection
  - Session protection
  - Hashed passwords and separate account database

Backups

- Nightly: mysqldump → scp → gzip
- Monthly: TrueCrypt for off-site backups
Ongoing and future work…

• Develop the security policy
  – More fine-grained authorisation control

• Develop monitoring platform
  – Who, what, when, where, why…

• Add in more data from new contributing centers
  – Padua, Berlin, Turin, Florence, Budapest

Conclusions

• Real cancer registry being used heavily and available for further contributions and studies…

• Ethics procedures for many countries achieved

• Accountability enforced by rigorous EU FP7 reviews

• Follow-on and support by the European Science Foundation (ESF)