Data and Knowledge Management SGG

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Data and Knowledge Management SGG
IMI-1 Knowledge Management Projects

Research Informatics
- Open PHACTS
- eTOX

Translational Informatics
- eTRIKS
- Drug Disease Model Resources
- ddmore

Medical Informatics (RWD)
- EMIF
- WEB-RADR
- EHR4CR
- GetReal
- ADVANCE
New project ideas: SGG Strategy or *ad hoc* proposals

- **Research Informatics**
  - Open PHACTS
  - Open Biomarker Repository
  - Patient Derived Xenograft Repository
  - IMI Training repository

- **Translational Informatics**
  - eTRIKS
  - Merck: Pharmaco-Genomics
  - Merck: Patient Hub

- **Real World Data**
  - ddmore
  - WEB-RADR
  - RADAR

- **Adaptive Informatics**
  - EHR CR
  - Merck: Adaptive Infrastructure
  - Smart Clinical Program Design

- **Digital Business**

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*Data and Knowledge Management - IMI2 Workshop of 26 November 2014*
So some opportunities…

✶ What does Data & Knowledge Management look like in 2020?

✶ What trends are going influence our platforms:
  ✶ Externalisation
  ✶ Patient centricity
  ✶ Adaptive pathways
  ✶ New data types
  ✶ Systems/Network biology
  ✶ Stratified medicine

✶ How do we take advantage of these to develop the platforms of the future
EXAMPLE PROJECT - RADAR
Challenges in Managing Chronic Disease Today

- Physician visits are **time-limited evaluations** based on **subjective observations** of both the patient and the physician or psychiatrist.

- **Changes in disease state** for each of these diseases can occur on timescales **much shorter than the interval between physician visits**.

- Through technological advances over the last decade it is now possible to **objectively, remotely, and continuously** measure aspects of patient physiology, behavior and symptoms.
Escalating Data Challenge: From Discrete Information Events To......

- ‘Point-of-Facility’
- Discrete, Structured, Information Events
- Controlled Populations (clinical trials, longitudinal disease studies)

- ‘Point-of-Need’
- Real-Time Multiplexed Read-Outs (Diagnostic, Prognostic, Drug Monitoring)
- Distributed Populations in Physician Settings

- Semi-Continuous
- Semi-Structured data
- Multiple sources
Continuous Streams of Information
‘Quantification of Man’

New Data Types, New Tools for:
Information Extraction
Knowledge Representation

Integration
Mining

On-Patient
- Actigraphy
- Speech
- Eye movement
- EKG, HR, HRV
- EEG
- Sleep
- Galvanic skin response
- O2 Sat
- Skin temperature

Off-Patient
- Fixed cameras
- Bed embedded sensors
- Computer usage
- Phone usage
- Refrigerator usage
- Motion sensors

Social Media

Mobile Computing Devices

Brain Fitness Centers

Remote Monitoring Sensors

Mobile Computing Devices
### Example: Technology Correlates to Clinical Parameters

<table>
<thead>
<tr>
<th>EWSQ 10 Patient Version</th>
<th>Potential Technology Correlates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has your sleep worsened since the last evaluation?</td>
<td>Sleep EEG (iVigil)</td>
</tr>
<tr>
<td></td>
<td>Actigraphy (Hidalgo)</td>
</tr>
<tr>
<td>Has your appetite decreased since the last evaluation?</td>
<td></td>
</tr>
<tr>
<td>Has your concentration, e.g., ability to read or watch TV, worsened since the last evaluation?</td>
<td>Eye tracking</td>
</tr>
<tr>
<td></td>
<td>Computer tracking (Monarca)</td>
</tr>
<tr>
<td>Have you experienced fear, suspiciousness, or other uneasy feelings while being around people since the last evaluation?</td>
<td>Skin Conductance (Hidalgo)</td>
</tr>
<tr>
<td></td>
<td>Heart rate / variability (Hidalgo)</td>
</tr>
<tr>
<td></td>
<td>Cell phone location (Monarca)</td>
</tr>
<tr>
<td>Have you experienced increased restlessness, agitation, or irritability since the last evaluation?</td>
<td>Actigraphy (Hidalgo)</td>
</tr>
<tr>
<td></td>
<td>Galvanic Skin Response (Hidalgo)</td>
</tr>
<tr>
<td></td>
<td>Speech Analysis (Hidalgo/IBM)</td>
</tr>
<tr>
<td>Have you noticed that something unusual or strange is happening around you since the last evaluation?</td>
<td></td>
</tr>
<tr>
<td>Have you experienced loss of energy or interest since the last evaluation?</td>
<td>Actigraphy (Hidalgo)</td>
</tr>
<tr>
<td></td>
<td>Computer Tracking (Monarca)</td>
</tr>
<tr>
<td>Has your capability to cope with everyday problems worsened since the last evaluation?</td>
<td>Speech Analytics (Hidalgo/IBM)</td>
</tr>
<tr>
<td>Have you experienced hearing other people’s voices even when nobody was around since the last evaluation?</td>
<td></td>
</tr>
<tr>
<td>Have you noticed any other of your individual early warnings signs since the last evaluation?</td>
<td></td>
</tr>
</tbody>
</table>
Remote Assessment of Diseases And Relapse (RADAR) - AIMS

- Develop and validate the science of using biosignatures to characterise disease and predict changes in disease state through observational studies
- Understand the regulatory and patient pathways for using remote assessment in healthcare
- Encourage innovation and development of novel biosensors and the associated knowledge management technology
- Develop standards for Information Exchange that enable seamless integration of sensor, data capture, data management, & analysis technologies
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RADAR Topic 1 CNS - Launched

- **Aim:** Characterisation and Prediction of Changes in Disease State in CNS disorders via non invasive remote sensing at three levels
  - Changes in disease state
  - Changes in disease state due to drug
  - Predict change in disease state

- **Focus on Multiple Sclerosis, Epilepsy and Depression**
- **Apply a common set of measures {Sleep, Activity, Social Connectivity} to all diseases**
Topics in development

- Diabetes – Development to tools and mechanisms for patient self management

- Pulmonary – Development of tools and mechanism to help predict severe exacerbation events

- Others
  - RADAR Platform
  - Rheumatoid Arthritis
  - Cardiovascular events
RADAR – Opportunities organisations outside Pharmaceuticals Industry

- For example:
  - **Software**
    - Research and application in real world setting to capture, manage, analyse and detect events in patient centric data
  - **Telecommunications**
    - Developing messaging services to enable critical events to be transmitted with QOS
  - **Sensor**
    - Ability to test sensors in real patient studies
  - **Device**
    - Developing further roadmaps for healthcare applications