Data and Knowledge Management SGG

Anthony Rowe, Janssen R&D
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IMI-1 Knowledge Management Projects

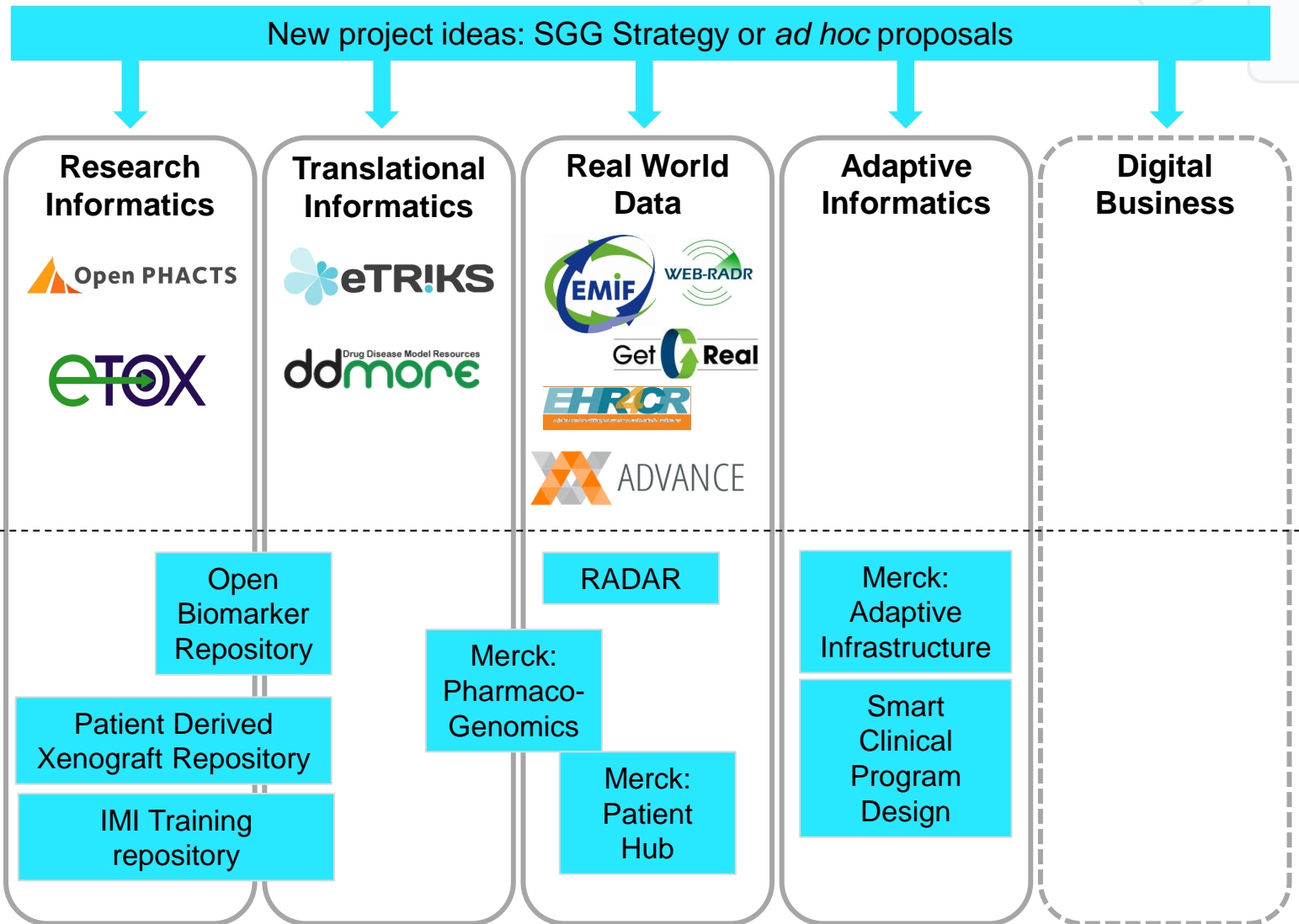| Research Informatics	Translational Informatics	Medical Informatics (RWD)
Open PHACTS	eTR!KS	EMIF WEB-RADR
eTOX	ddmore — Drug Disease Model Resources	EHR4CR
		Get Real
		ADVANCE

IMI 2 Data and Knowledge Management SGG Enabling Platforms – Early Thoughts

New project ideas: SGG Strategy or *ad hoc* proposals

	Research Informatics	Translational Informatics	Real World Data	Adaptive Informatics	Digital Business
IMI	Open PHACTS, eTOX	eTR!KS, ddmore (Drug Disease Model Resources)	EMIF, WEB-RADR, Get Real, EHR4CR, ADVANCE		
IMI-2	Open Biomarker Repository; Patient Derived Xenograft Repository; IMI Training repository	Merck: Pharmaco-Genomics	RADAR; Merck: Patient Hub	Merck: Adaptive Infrastructure; Smart Clinical Program Design	

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So some opportunities…

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

* What trends are going influence out 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
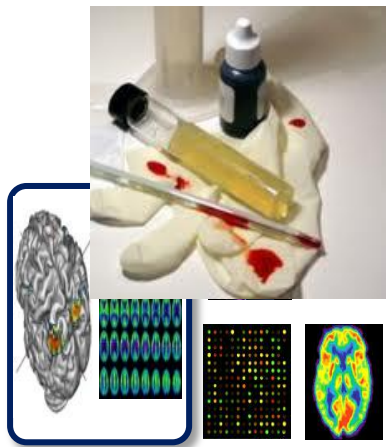
* **Changes in disease state** for each of these diseases can occur on timescales **much shorter than the interval between physician visits**

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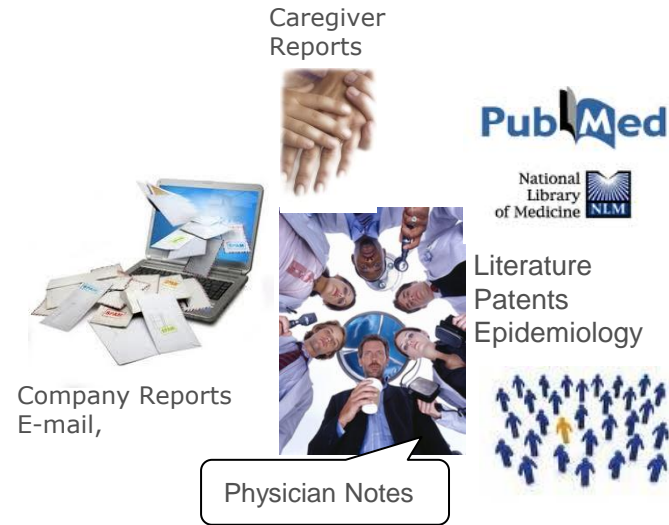
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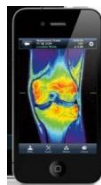
Escalating Data Challenge:
From Discrete Information Events To......

Discrete Centralized

Diagnosis/ Prognosis

Drug Monitoring PK

Theranos

Discrete Decentralized

Caregiver Reports

Company Reports E-mail,

Physician Notes

Literature Patents Epidemiology

Non-Discrete Decentralized

➢'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
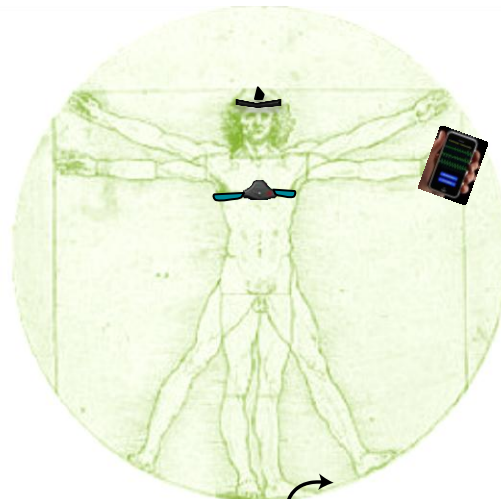
➢Semi-Continuous
➢Semi-Structured data
➢Multiple sources

.....Continuous Streams of Information
'Quantification of Man'

Mobile Computing Devices

Remote Monitoring Sensors

Social Media

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

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

Brain Fitness Centers

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Example: Technology Correlates to Clinical Parameters

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

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– Vision

Research and Validation Studies

Platform Activities

Analytics Development	
Public Datasets	
Open Innovation Network	
Data Management	
Data Capture Standards	
Sensor Communication Standards	

Neuroscience

Biosignatures of Depression Relapse

CVM

E.g. Biosignatures for predicting MI/Stroke

Inflammation

E.g. Biosignature of exacerbation in COPD/Asthma

Multi Indication

High Risk populations (e.g. aging)

Biosensor Innovation

WP Stakeholder Engagement & Policy Advancement

WP Data Protection, Confidentiality, IP

WP Project Management & Governance

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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 developement

* 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