### EMIF: E-Managing the Future of Health Data

in association with









### Coupling Evidence with Real World:

A two-way street: rethink translation

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Optimizing Execution, Feasibility and Efficacy Budapest, 17th March 2016



### Big Data ≠ Big Discovery

#### **DATA**



Vast volume, velocity, variety...

TSUNAMI

#### **METHODS & OUTPUTS**



Supra-linear growth in papers & tools

BLIZZARD

#### **EXPERTISE**



Never enough data scientists

**DROUGHT** 

More data \* small-scale research = more small-scale research

Bigger sample but with more heterogeneity can REDUCE 'discovery power'

Ioannidis JPA. Why most published research findings are false. PLoS Medicine 2005 Aug;2 (8):e124.

Overhage JM, Ryan PB, Schuemie MJ, Stang PE. Desideratum for evidence based epidemiology. Drug Safety 2013 Oct;36 Suppl 1:S5-14.





### Real World Care Pathways are Mashups

Total evidence-base predicts < 30% healthcare outcomes
A fog of biomarkers is not a 'usefully complex' solution

His primary care clinician...

General view: diet, exercise, polypharmacy

His nephrologist...

BP focus

Valderas JM, Starfield B, Sibbald B, Salisbury C, Roland M. Defining comorbidity: implications for understanding health and health services. Ann. Fam. 2009;7:357–363.



Evidence needed is the union not sum of models

↑ Weight → ↑ BP Frank...



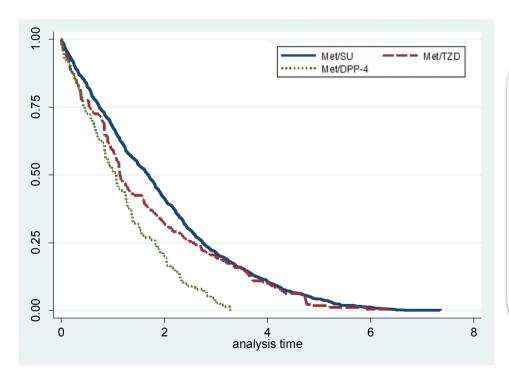
His diabetologist...

Glucose focus

Where is the evidence of how lifestyle factors affect say SGLT2 vs. DPP4 drug choices?



# Dual Therapy for Diabetes: Big Data?



Deep dive with CPRD data:

Time to microvascular event from diagnosis of diabetes using inverse probability weighted marginal structural model to estimate average causal effects of dual therapies

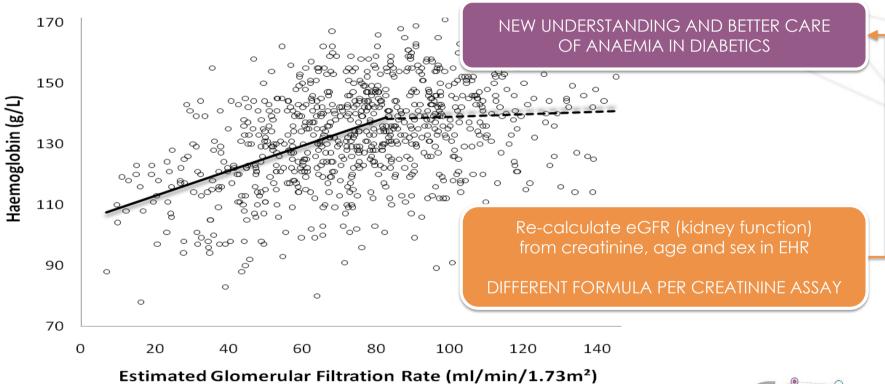
Heterogeneity of individual treatment response: need deeper contextual data for...

Stratified Med. (find & treat subgroups)
Personalised Med. (optimise individual response)

Data source: CPRD Analysis: A Wright, D Ashcroft, R Emsley



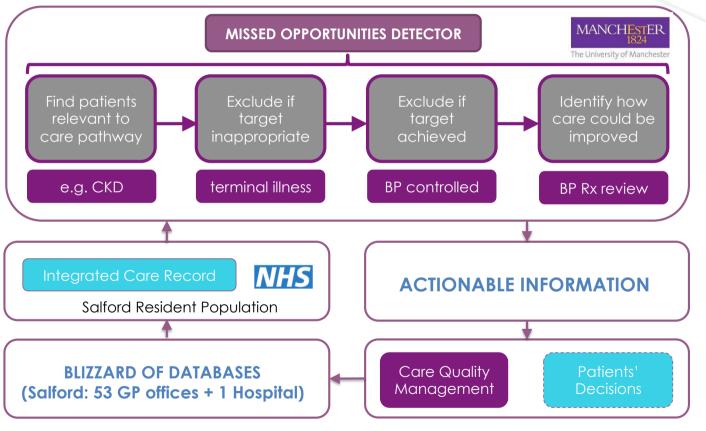
### Contextual Metadata



New JP et al. The high prevalence of unrecognized anaemia in patients with diabetes and chronic kidney disease: a population-based study. Diabet Med. 2008 May;25(5):564-9.



# Actionable Analytics for Health Systems



Actionable information attracts: trust & traction from patients, public and practitioners... and better data quality.

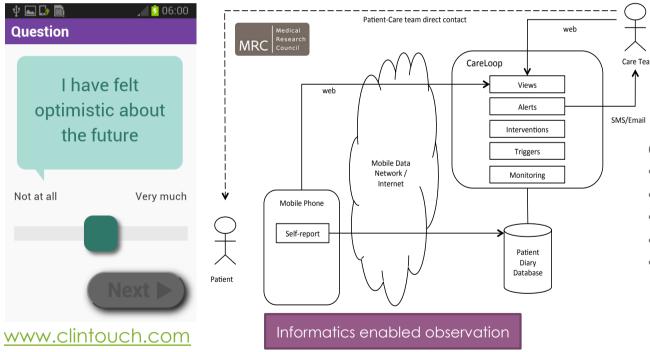
Brown B et al. Missed opportunities mapping: computable healthcare quality improvement. Stud Health Technol Inform. 2013;192;387-91.



## Combined Patient-Care System Actions

Aim: To Reduce Relapse in Schizophrenia via Smartphone

Drug + behaviour (information \* psychological endotype) = outcome



Informatics intervention

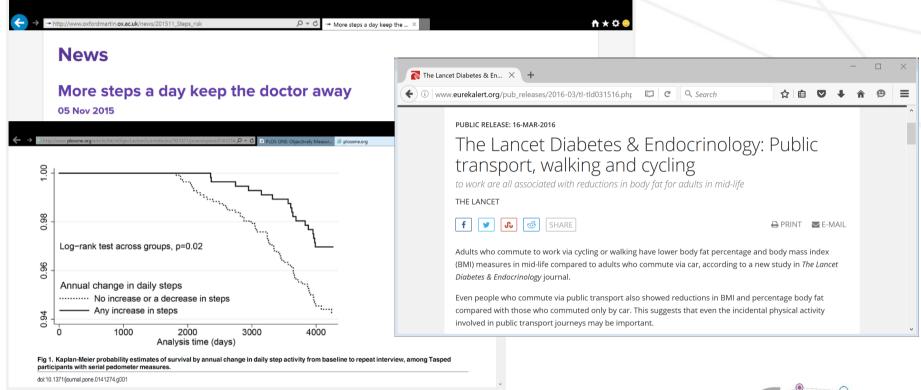
#### Generic:

- Self-measurement
- Symptom awareness
- Clinical workflow integration
- Self-efficacy / autonomy
- · Alert-fatigue avoidance



From J. Ainsworth & S. Lewis

# Co-produced Outcomes: Physical Activity



Dwyer T et al. Objectively Measured Daily Steps and Subsequent Long Term All-Cause Mortality: The Tasped Prospective Cohort Study. PLoS One. 2015;10(11):e0141274.



# Integrated Clinical-Wellbeing Modelling

Given:

Low-cost, easy wear and ubiquitous tech captures the digital by-products of the rhythms of life



Challenge:

Mrs Jones

76 year old lady with COPD and depression 2 previous falls

Accelerometry signals from: Respiratory U mental health U frailty

**Different** companies or research groups need **analytics** that **borrows strength** in an open innovation environment



## Causality and Frequent Observation

What came first, weighing or weight-loss?

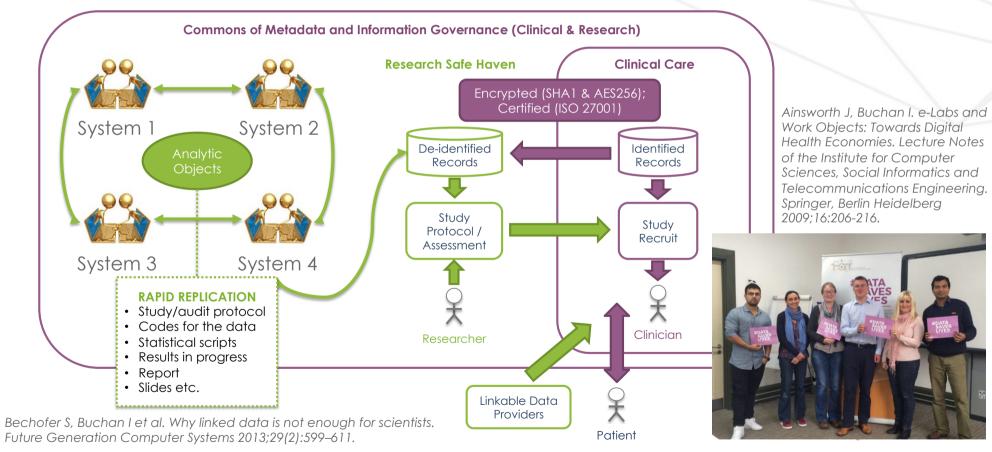


- An additional monthly weighing is associated with an extra 1kg weight lost over the course of a year
- Recent weight loss encourages subsequent measurement: a person who has recently lost 1kg is twice as likely to reweigh on a given day compared with someone who has remained the same weight

Sperrin M et al. Who Self-Weighs and What Do They Gain From It? A Retrospective Comparison Between Smart Scale Users and the General Population in England. J Med Internet Res. 2016;18(1):e17.



### Scalable, Always-on Analytics



## Real World Trials: Need Reusable Apparatus

**Clinical Trial:** 

Open label; mass participation; NWEH NorthWest EHealth

clinical & social contexts

Salford Royal NHS
NHS Foundation Trust

**Care Quality Management:** 

Depression vs. readmission

**Commissioning:** 

Risk stratification; scenario planning; needs assessment

Aim: Different users of data borrowing insights from each other: linking perspectives in Google / Amazon like ways

Research:

CareLoop...

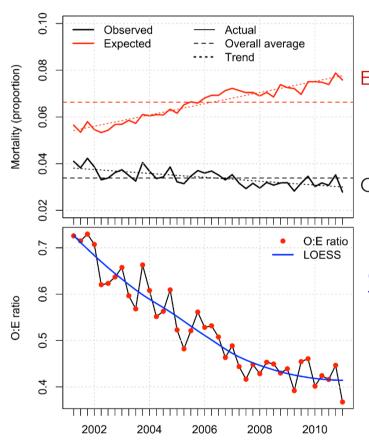
Missed Opportunities Detector; Medicines safety dashboard;

**Salford City Council Public Health:** 

Neighbourhood profiles



### Outcome Prediction: Calibration Drift



EuroScore prediction

Observed death rate

Calibration drift: Typical of many published models Academia rewards publishing papers on the same topic every 10y or so

Law sees algorithms as medical devices (EU Directive 2007/47)

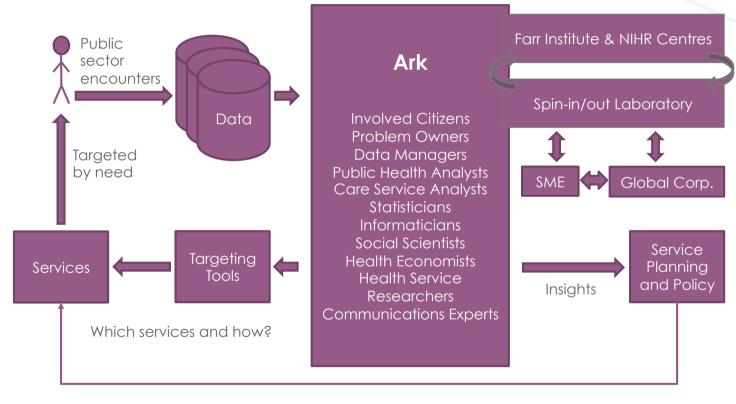
Industry has no trusted 3<sup>rd</sup> party lab for validating algorithms/models

Hickey GL et al. Dynamic trends in cardiac surgery: why the logistic EuroSCORE is no longer suitable for contemporary cardiac surgery and implications for future risk models. Eur J Cardiothorac Surg. 2013 Jun; 43(6):1146-52.



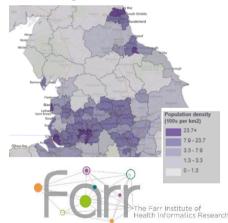
#### twitter.com/hashtag/datasaveslives

## Civic Health Data Analytics



#datasaveslives

**Connected Health Cities**Pilots 2016-9
North England



Ainsworth J, Buchan I. Combining Health Data Uses to Ignite Health System Learning. Methods Inf Med. 2015 Nov 27;54(6):479-87.

### Parting thoughts

Somewhere over the big data rainbow, my health **avatar might say no** to your care pathway.

Prepare for patients to **own clinical equipoise**, but who governs routine randomisation?

Start modelling real world care from the **middle out**, biology-to-patient AND patient-to-population/place/system.



