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Opportunities and Challenges of Learning Health Systems

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The University of Manchester

Soc-B Centre for Doctoral Training in Biosocial Research,
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About the presenter

Niels

Utrecht

University of Amsterdam

University of Manchester, UK

- Field: Health Informatics
- Background: Computer Science / AI
- Research interests:
  - prediction models
  - clinical decision support systems
  - electronic health records

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Christabel Pankhurst Institute for Health Technology Research and Innovation

External flagship for the University of Manchester's health technology portfolio

Integrates research from **all faculties** to accelerate the translation of health technologies, and create opportunities for business growth – including economic, social and behavioural aspects

Improve the connection between **technology development**, **innovation**, **health research**, and real-world **impact**

Focus areas:

- digital technologies
- artificial intelligence
- advanced materials

Dame Christabel Pankhurst

Planned new build on Dover Street

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This talk

1. What are learning health systems?
2. Why do we need them?
3. Discussion: What are the challenges?
4. Example: SMASH and the GM Care Record
5. Conclusions

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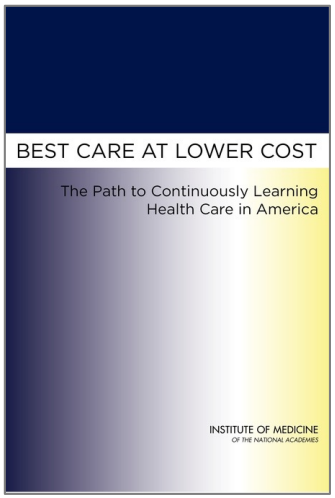
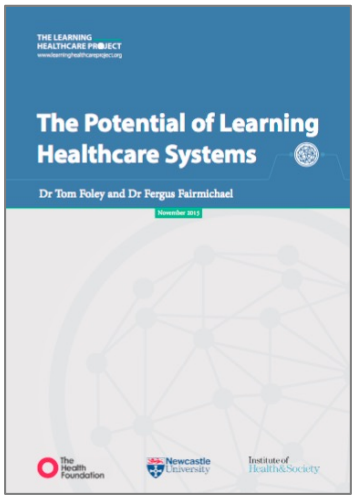
What is a Learning Health System?

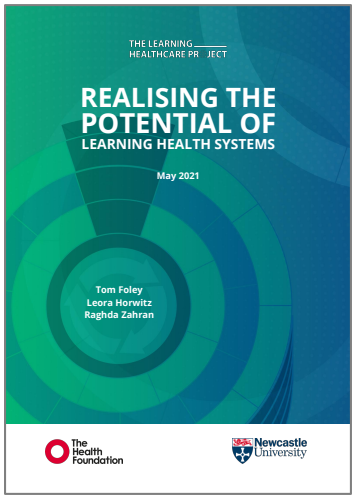
A system in which science, informatics, incentives, and culture are aligned for continuous improvement, innovation, and equity:

- best practices and discovery seamlessly embedded in the delivery process
- individuals and families are active participants in all elements
- new knowledge is generated as an integral by-product of healthcare delivery

[Institute of Medicine, 2006]







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Breaking down barriers

The landscape is changing …

Wearable sensors

Routine care data

- audits / registries
- administrative data
- electronic health records

Smartphones

- symptoms
- GPS

Omics data

- genome
- proteome

Home based sensors

- weighing scales
- blood pressure monitors
- glucose meters

Traditional research data

- trials
- case-control studies
- cohort studies

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Learning from every patient

Charles P. Friedman

Learning health systems harnesses the power of data and analytics to learn from every patient, and feed the knowledge of "what works best" back to clinicians, public health professionals, patients, and other stakeholders to create cycles of continuous improvement

Example: systems that learn

- Credit card companies routinely collect data on all credit card transactions

- They use data mining methods to create a "safety net" that issues early warnings when fraude is suspected

- The safety net
  - learns from every transaction
  - is continuously updated
  - varies by region/country
  - is fully integrated with services

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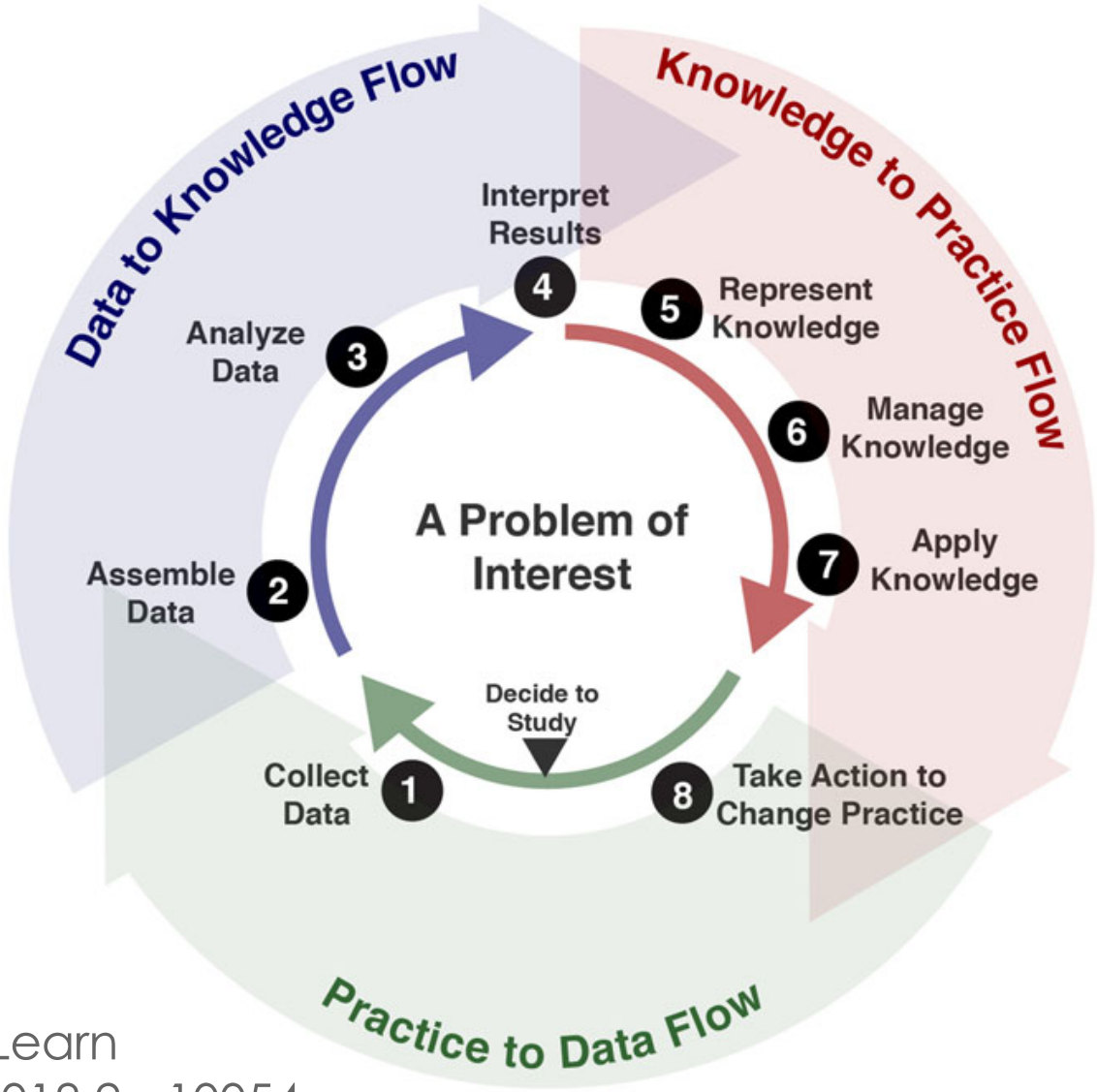
The learning health cycle



Flynn et al., Learn Health Sys. 2018;2:e10054.

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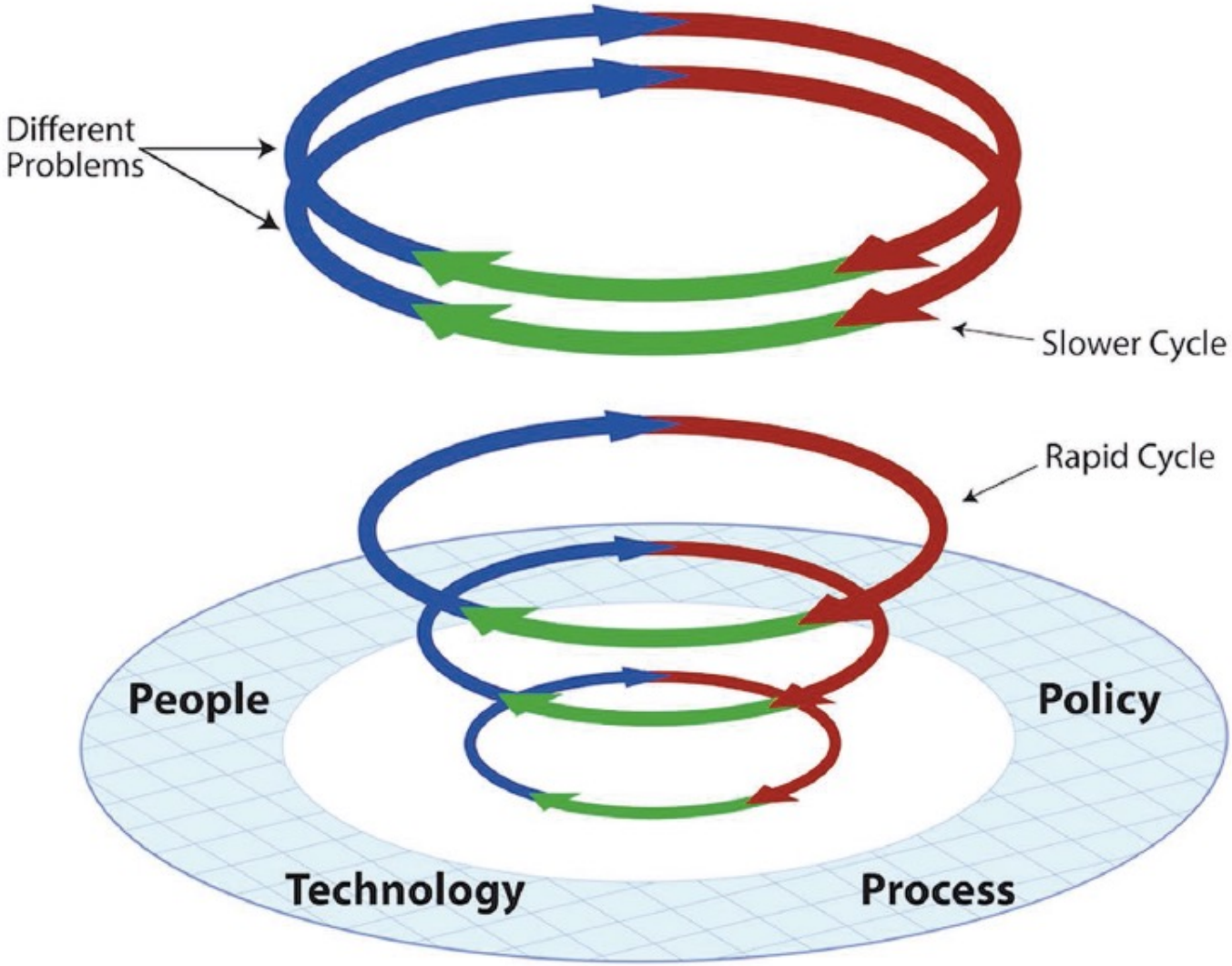
The LHS infrastructure



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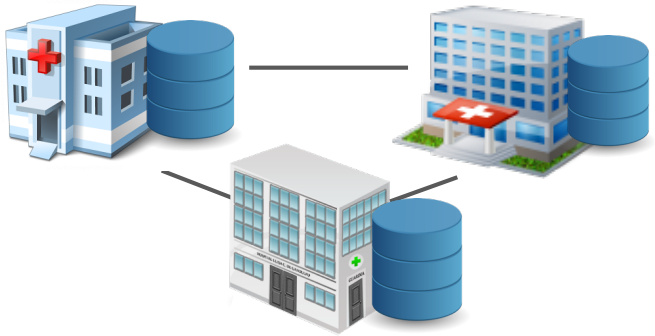
LHSs can exist at any level of scale

Single Organization

Network of organisations



Nation

Region

Planet

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What the LHS is *not*

- A technology
- An intervention
- "AI"
- Finished

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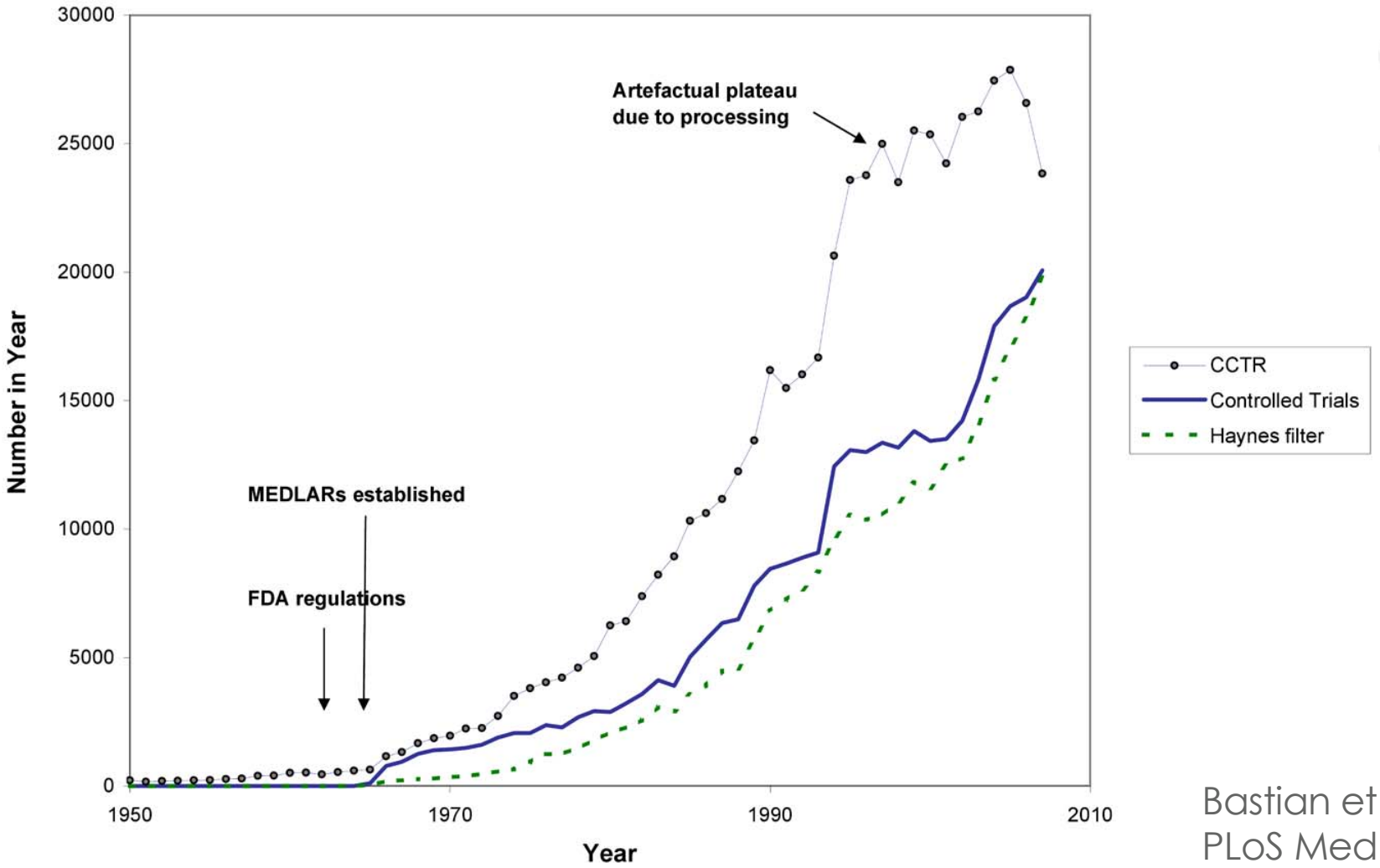
Characteristics of a fully functional Learning Health System

1. Secure availability of relevant data to learn from
2. Decision support, based on knowledge derived from these data
3. Learning and health improvement are routine and continuous processes
4. Infrastructure enables the routine execution of multiple learning cycles
5. Stakeholders within the system view these activities as part of their culture

Why do we need learning health systems?

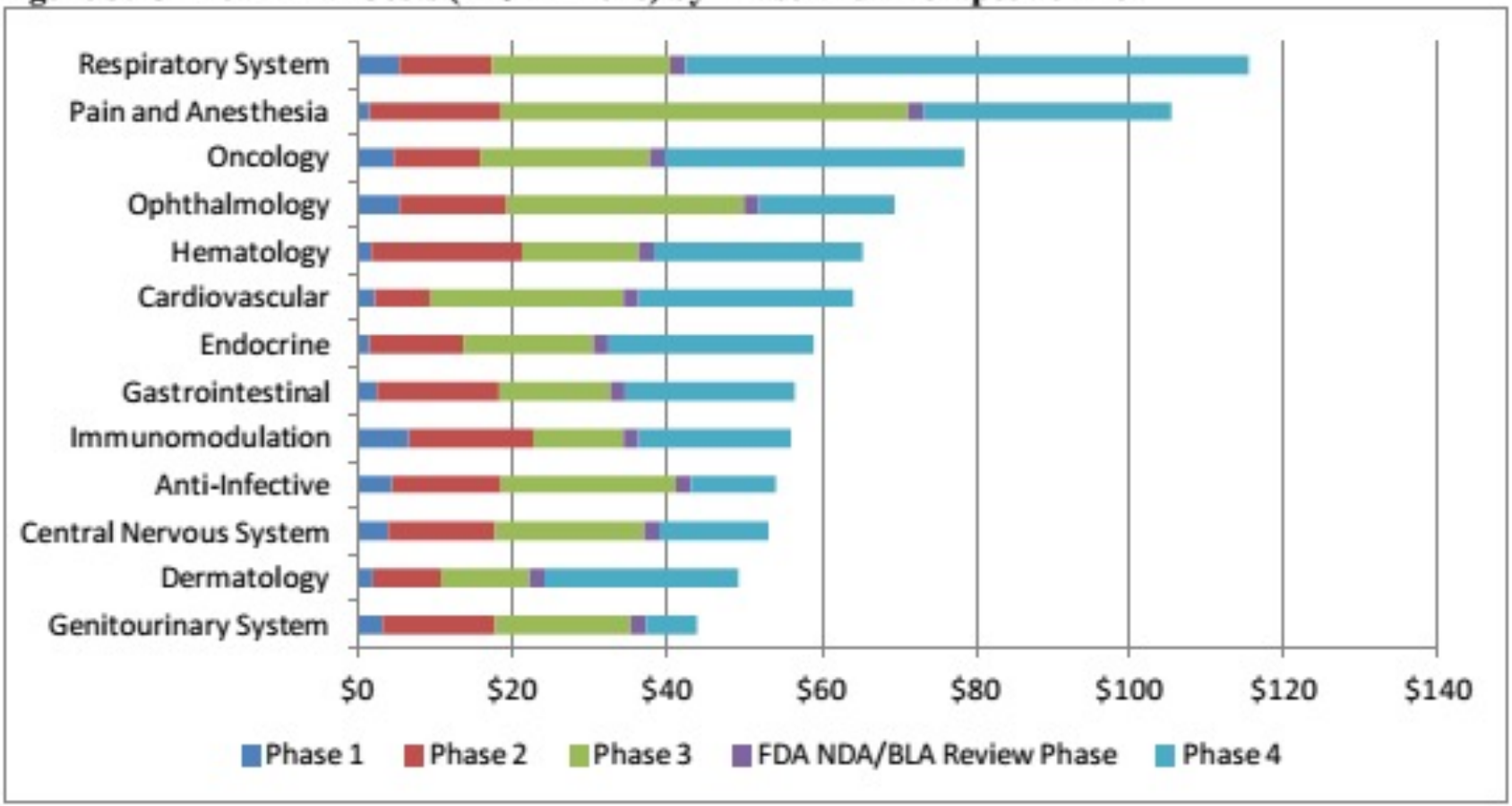
Number of trials grows exponentially



Bastian et al.
PLoS Med 7(9):
e1000326.

Clinical trial costs

Figure 3: Clinical Trial Costs (in $ Millions) by Phase and Therapeutic Area



Source: US Department of Health and Human Services, 2014

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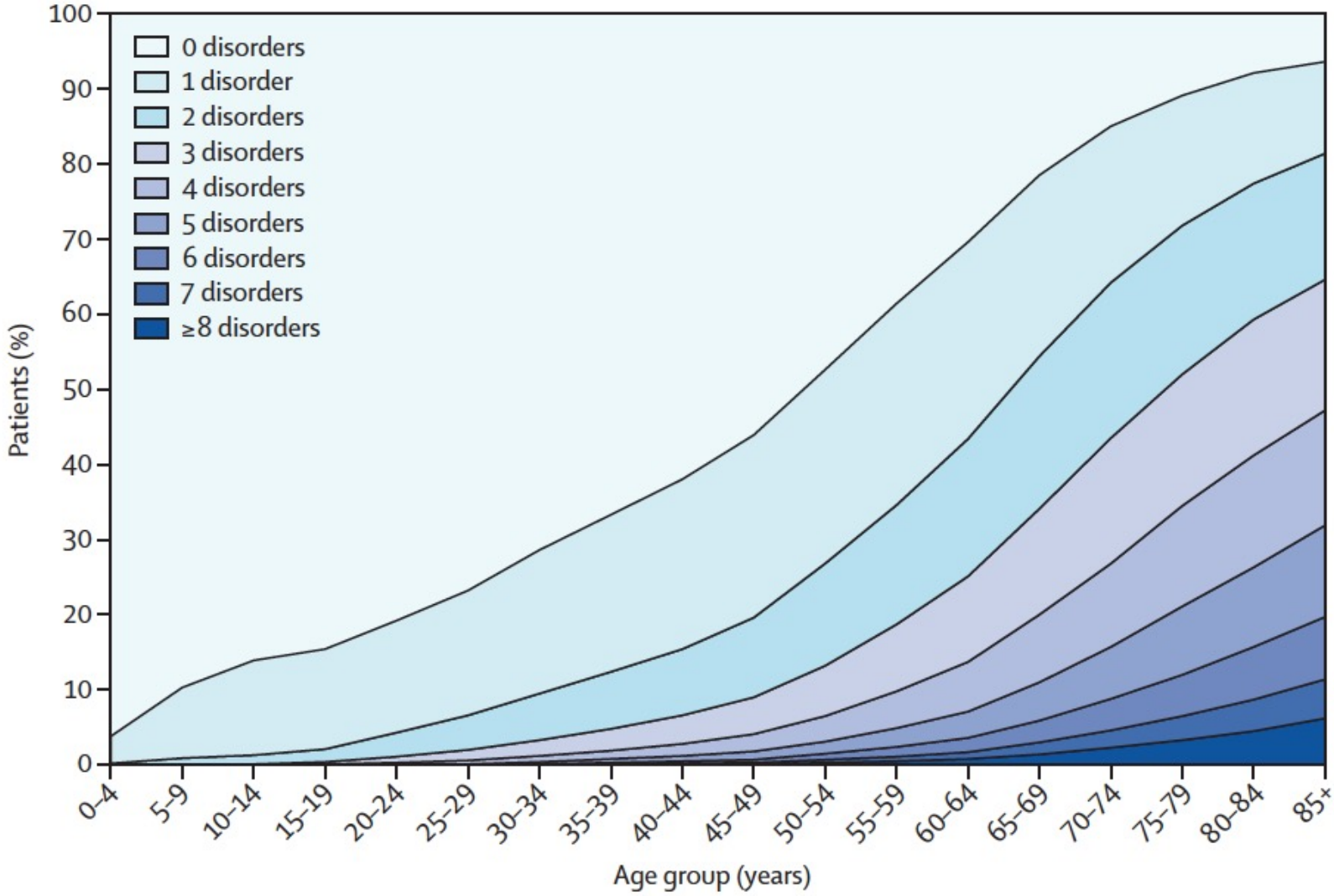
About 25% of the population have more than 1 long-term condition



Barnett et al. Lancet 2012; 380: 37–43

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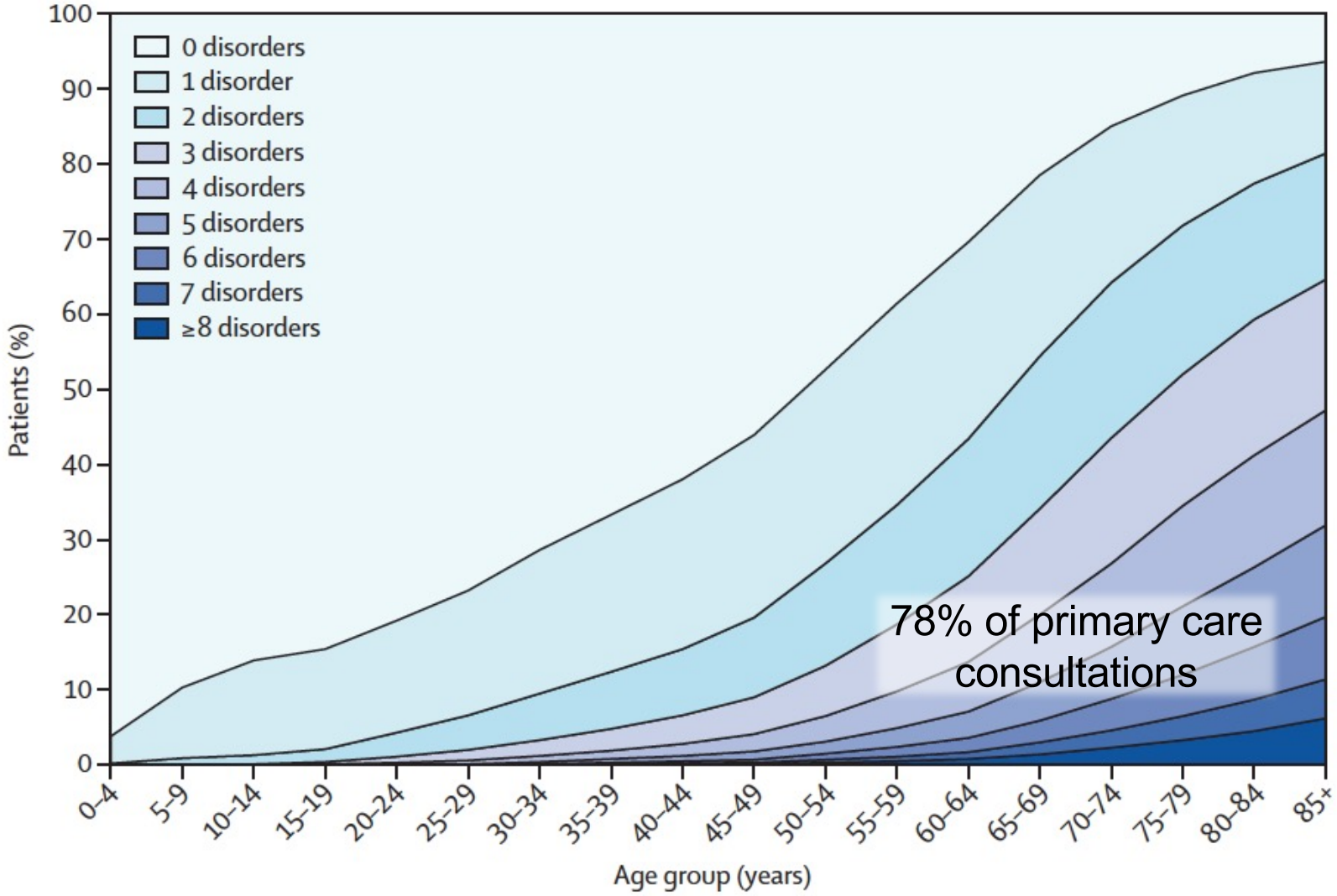

Barnett et al. Lancet 2012; 380: 37–43 Salisbury et al. BJGP 2011;61(582):e12-21.

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Most patients with multimorbidity are excluded from trials

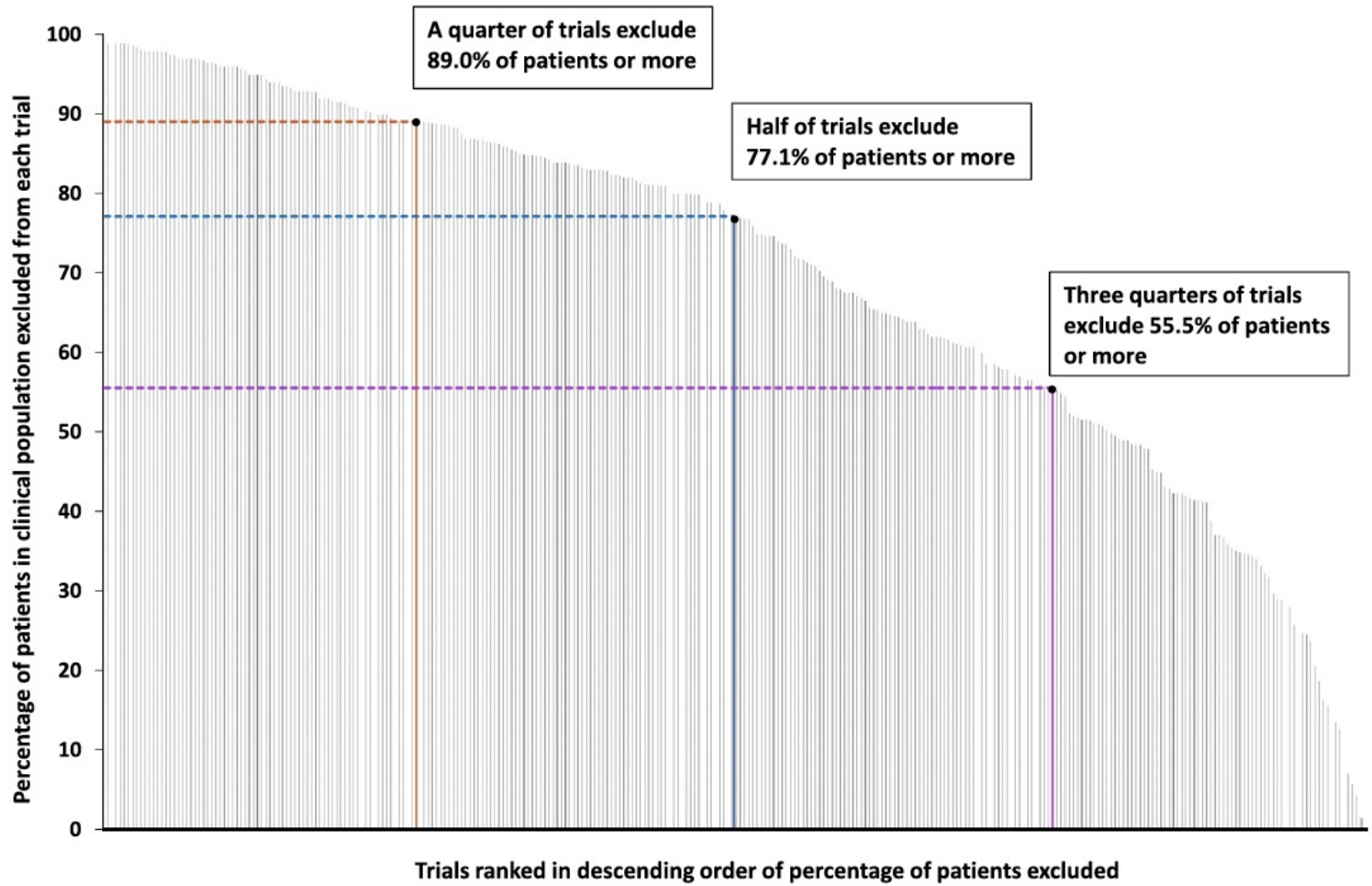

Fig. 2 Trials ranked in descending order of the percentage excluded in the clinical population studied

He et al. Trials 2020; 21:228

The NEW ENGLAND JOURNAL of MEDICINE

Perspective

JUNE 5, 2014

Learning from Big Health Care Data

Sebastian Schneeweiss, M.D., Sc.D.

The routine operation of modern health care systems produces an abundance of electronically stored data on an ongoing basis. It's widely acknowledged that there is great potential for utilizing these data, within the system that generates them, to inform treatment choices in ways that improve patient care and health outcomes.[1] Imagine entering your office in the morning and finding an e-mail message reading, "Thanks to your new vaccination screening program, as of yesterday your practice had given 120 more vaccinations than similar practices had." Or "As compared with the period before your network's implementation of the new policy of referring patients with atrial fibrillation to the anticoagulation center, seven strokes have been averted, but two additional upper GI bleeds have occurred." Or even "Judging from her track record and the characteristics noted in her medical record, there is an 80% likelihood that Patient C, whom you are about to see, will not fill her prescription for an antihypertensive." In theory, such ongoing structured learning based on routinely collected data could seamlessly augment the knowledge physicians have gleaned from their experience, which involves the same patients and more detailed observations but is less formal in its evaluation processes and more likely to be subject to unintended bias.[2]

Two key "learning" applications of big health care data that hold the promise of improving patient care are the generation of new knowledge about the effectiveness of treatments and the prediction of outcomes. Both these functions exceed the bounds of most computer applications currently used in health care, which tend to offer physicians such tools as context-sensitive warning messages, reminders, suggestions for economical prescribing, and results of mandated quality-improvement activities.

Physicians currently struggle to apply new medical knowledge to their own patients, since most evidence regarding the effectiveness of medical innovations has been generated by studies involving patients who differ from their own and who were treated in highly controlled research environments. But many data that are routinely collected in a health care system can be used to evaluate medical products and interventions and directly influence patient care in the very systems that generated the data.

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Benefits of Electronic Health Records

- Representative of real-world populations
- Very large cohorts sizes (e.g. CPRD Aurum: 17m)
- Longitudinal data
- Very long follow-up times (UK primary care >20 years)
- Available against low cost

Discussion: What are the challenges in creating learning health systems?

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How long will it take to create learning health systems?

- 1 year
- 5 years
- 10 years
- It will never happen
- It should never happen

sli.do

#402911

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What are the challenges in creating learning health systems?

- The LHS infrastructure is capable of engendering virtuous cycles of health improvement
- The LHS is trusted and valued by all stakeholders
- The LHS is economically sustainable and governable
- The LHS is adaptable, self-improving, stable, certifiable, and responsive

Friedman et al. J Am Med Inform Assoc 2014;0:1–6.

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Electronic Health Records: Limitations

- **The data were not collected for research**
  - incomplete data
  - variable follow-up times
  - selection biases (e.g. lack of attendance)
  - variable data quality (e.g. depth of coding)
- **Retrospective cohort / case-control design**
  - no protocol for either clinical management or data collection
- **Confounding**
  - routine care
  - hard to make causal inferences

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Electronic Health Records: Challenges

- **Fragmented data**
  - data often collected in "silos" with poor inter-operability
- **Data protection**
  - we need to protect people's privacy to ensure their trust in the LHS
  - data protection rules are becoming increasingly complex
- **Phenotyping**
  - we need to reconstruct clinically meaningful concepts from transactional data

Example: SMASH and the GM Care Record

5 DEC

Innovative IT system that prevents prescription errors wins prestigious national prize

Richard Williams, a Senior Software Engineer at The University of Manchester, based in the NIHR Greater Manchester Patient Safety Translational Centre (Greater Manchester PSTRC) and Centre for Health Informatics, has been awarded the respected John Perry Prize by BCS: The Chartered Institute for IT.

Announced at a glitzy ceremony in early October, the prize recognises Richard's outstanding contribution to Primary Care Computing. Having been awarded annually since 1985 it is one of the IT industry's most respected accolades, acknowledging innovation and excellence in computer science.

The Prize along with £500 cash was awarded in recognition of Richard's work developing and disseminating the Smart Medication Safety Dashboard (SMASH). This potentially life-saving piece of software, which was developed with support from the Greater Manchester PSTRC and Health eResearch Centre (HeRC), was created to improve patient safety by reducing the number of prescription errors. Such errors occur in 5% of prescriptions according to a recent study of English general practices with one in 550 considered to be life-threatening.

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PINCER/SMASH methodology

1. Identify evidence-based medication safety indicators for primary care
2. Select most relevant indicators based on observed incidence
3. Represent selected indicators in computable form (SQL queries)
4. Embed computable indicators in feedback tool

Spencer et al., Br J Gen Practice 2014; 64(621):e181–90
Akbarov et al., Drug Safety 2015;38(7):671–82.
Williams J Innov Health Inform. 2018;25(3):183–193.

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Example indicators

Prescription of an oral NSAID without co-prescription of an ulcer-healing drug in a patient aged ≥65 years.

Prescription of aspirin in combination with another antiplatelet drug without co-prescription of an ulcer-healing drug.

Prescription of a non-selective beta-blocker to a patient with asthma.

Prescription of an oral NSAID to a patient with heart failure.

Prescription of an oral NSAID to a patient with chronic renal failure (eGFR <45)

Prescription of Amiodarone without a thyroid function test

Williams J Innov Health Inform. 2018;25(3):183–193.

Patient Safety Dashboard Users Richard Williams

Single Practice / Glendale Medical Centre

Glendale Medical Centre

Report date: 15 Nov (Latest)

Comparison date: 16 Oct (30 days ago)

Sort by: Affected patients

Practice summary | Table | Charts

Export

Indicator	Affected patients	% of eligible patients affected	CCG Avg (%)	New cases	Trend	Show on top
Age≥65 no GastProt and NSAID	19	2.04	0.32	3	1	☐
Mtx and no monitoring	12	11.01	2.67	2	-3	☐
GiB/PUD no GastProt and Antiplatelet	8	6.61	2.49	1	-1	☐
Asthma and BB Click to view patients...	8	3.67	1.51	2	0	☐
Aspirin and Antiplatelet	7	3.47	1.11	7	7	☐
CKD and triple whammy	5	2.86	1.30	5	5	☐
Warf/NOAC and NSAID	4	19.05	9.05	1	0	☐
HF and NSAID	3	2.94	2.11	2	-2	☐
LABA and no ICS	2	0.85	1.07	0	2	☐

Patient Safety Dashboard Users Administrator

Single Practice / Glendale Medical Practice / Affected patients for Asthma and BETA BLOCKER

Asthma and BETA BLOCKER

Report type: Affected patients

Report date: 1 May 2015

Comparison date: 30 April 2015

Patients Trend Information

NHS number	Indicators breached	Since
96510	WARF no GP and ASP Asthma and BETA BLOCKER	20 February 2015 16 January 2015
110726	Asthma and BETA BLOCKER	1 May 2011
153980	Asthma and BETA BLOCKER	1 May 2013
51507	Asthma and BETA BLOCKER	20 November 2014
132469	Asthma and BETA BLOCKER	30 July 2013
43458	Asthma and BETA BLOCKER	9 July 2013

Patients with a history of asthma who have been prescribed a β blocker

What is the risk to patients?

In susceptible patients β blockers can precipitate acute attacks of bronchospasm or worsen daily symptoms resulting in mortality or low grade morbidity respectively. The BNF advises that "β blockers should be avoided in patients with a history of asthma or bronchospasm; if there is no alternative, a cardioselective β blockers can be used with extreme caution under specialist supervision. Atenolol, bisoprolol, metoprolol, nebivolol, and (to a lesser extent) acebutolol, have less effect on the β_2 (bronchial) receptors and are, therefore, relatively cardioselective, but they are not cardiospecific. They have a lesser effect on airways resistance but are not free of this side effect". The Committee on Safety of Medicines[1] issued the following advice: "...β blockers, even those with apparent cardioselectivity, should not be used in patients with asthma or a history of obstructive airways disease, unless no alternative treatment is available. In such cases the risk of inducing bronchospasm should be appreciated and appropriate precautions taken."

What evidence is there that this pattern of prescribing is harmful?

β blockers vary in their affinity for β_1- and β_2-adrenoceptors, and are divided into two groups, cardioselective (affinity for β_1), and non-cardioselective (affinity for β_2). The majority show little selectivity for one receptor over the other, except for bisoprolol (14-fold greater affinity for β_1-adrenoceptors) and timolol, sotalol and propranolol (26-fold, 12-fold, and 8-fold greater affinity for β_2-adrenoceptors, respectively).

Table 1: Cardioselective and non-cardioselective betablockers

Cardioselective beta-blockers (relative selectivity for β_1-adrenoceptors)[2]	**Non Cardioselective beta-blockers (relative selectivity for β_2-adrenoceptors)[2]**
Acebutolol (2.4)	Labetalol (2.5)

Patient Safety Dashboard Users Administrator

Single Practice / Glendale Medical Practice

Glendale Medical Practice

Report date: 1 May 2015

Comparison date: 30 April 2015

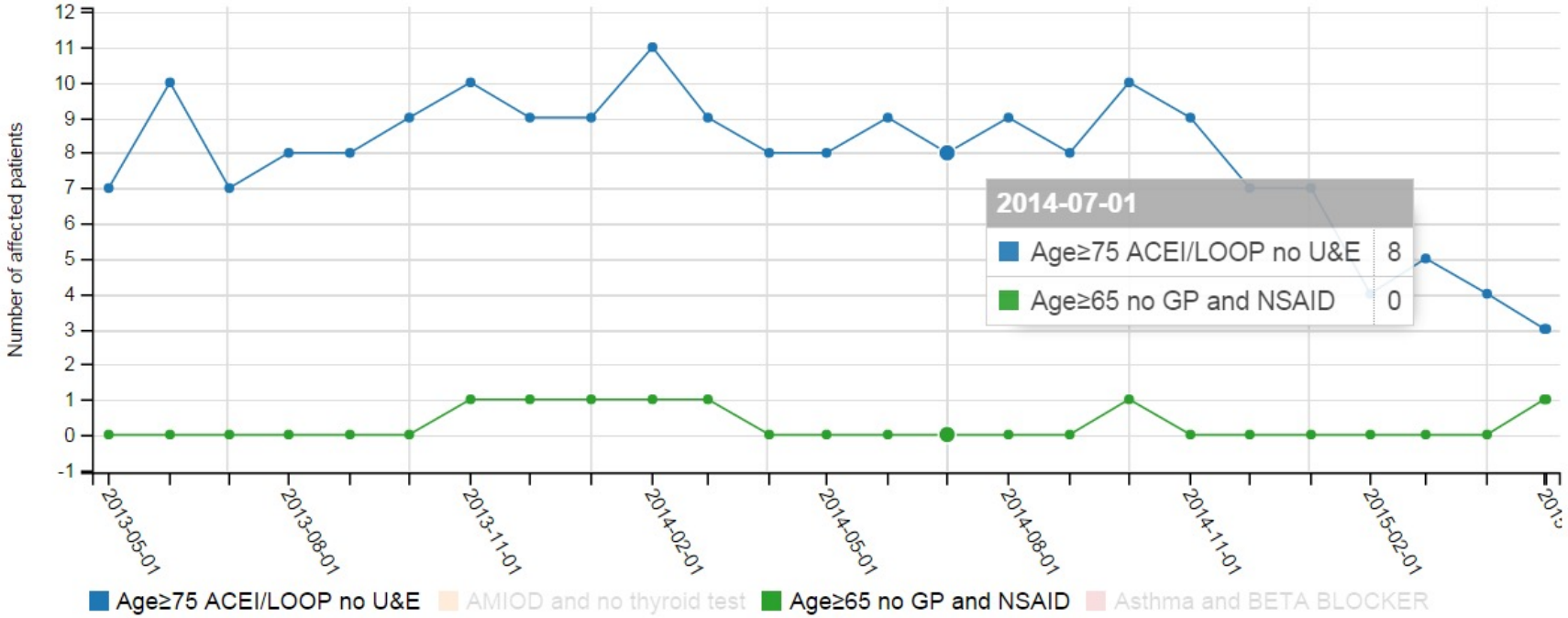
Sort by: Affected patients

Practice summary | Table | Charts

Number of affected patients over time

Start date: 1 May 2013

End date: 1 May 2015



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SMASH – Salford roll-out

- SMASH was rolled out in 43 (out of 44) general practices in Salford (Greater Manchester, UK)
- Practices had a combined list size of 236k patients
- Roll-out started in February 2016 and was completed in August 2017
- Newly trained pharmacists were allocated to practices over time
- We used a “train the trainer” apprach

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What users said

"I think the main benefit is that it's just how quick and easy it is to access these patients. Running searches on the GP clinical system is a nightmare." (pharmacist)

"We want our pharmacist to look at the new initiations. She then sends a message to the prescribing doctor that that's a high risk prescribing area and then leave it to the doctor to decide whether to action it or not." (GP manager)

"Having this tool depersonalises feedback. [...]. It's not ... you know, you've done this and I don't think it's safe ... it's the system that has picked this up." (pharmacist)

Jeffries et al. PLoS One. 2018 Oct;13(10):e0205419.

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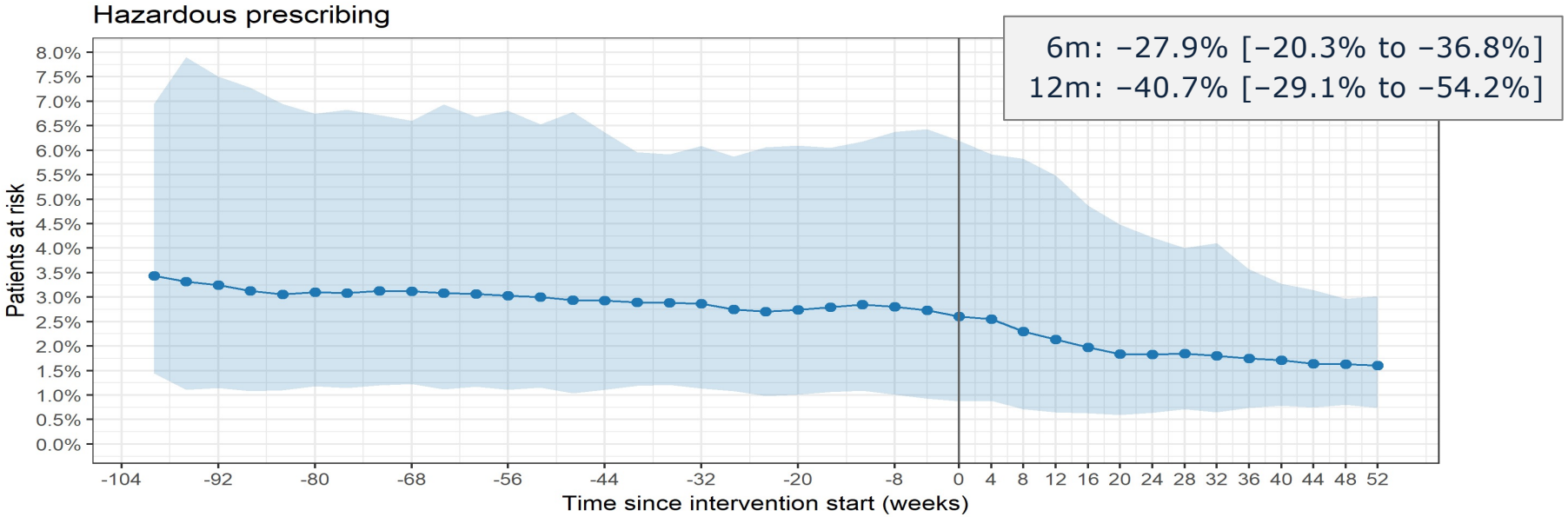
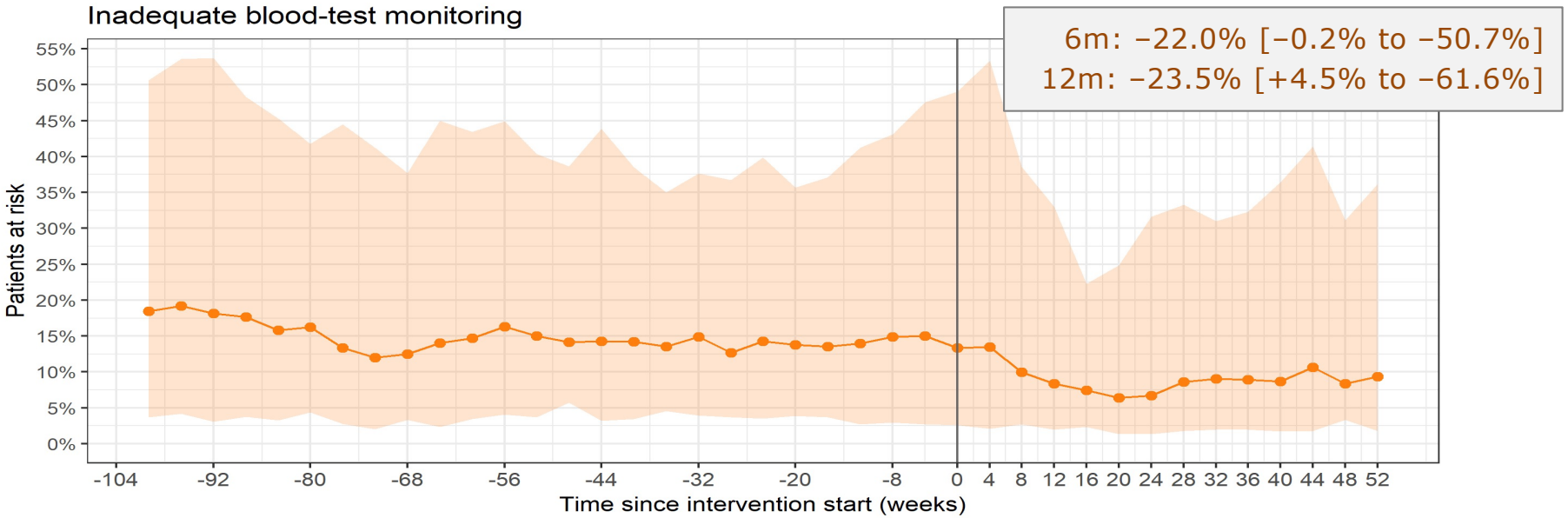
SMASH – Quantitative evaluation

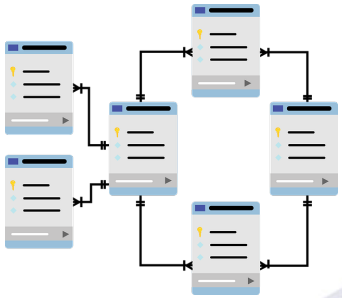
- **Design**: Interrupted time series analysis (43 practices)
- We measured outcomes during **24 months before** and **12 months after** start of the intervention
- **Outcome measures**: Prevalence of exposure to
  - any potentially hazardous prescribing (composite of 10 indicators)
  - any inadequate blood-test monitoring (composite of 2 indicators)

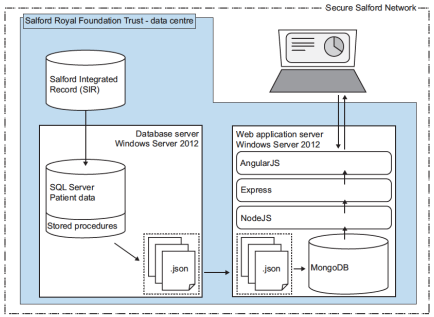
Peek et al. PLoS Med. 2020 Oct;17(10):e1003286.

ITSA – Aggregated results

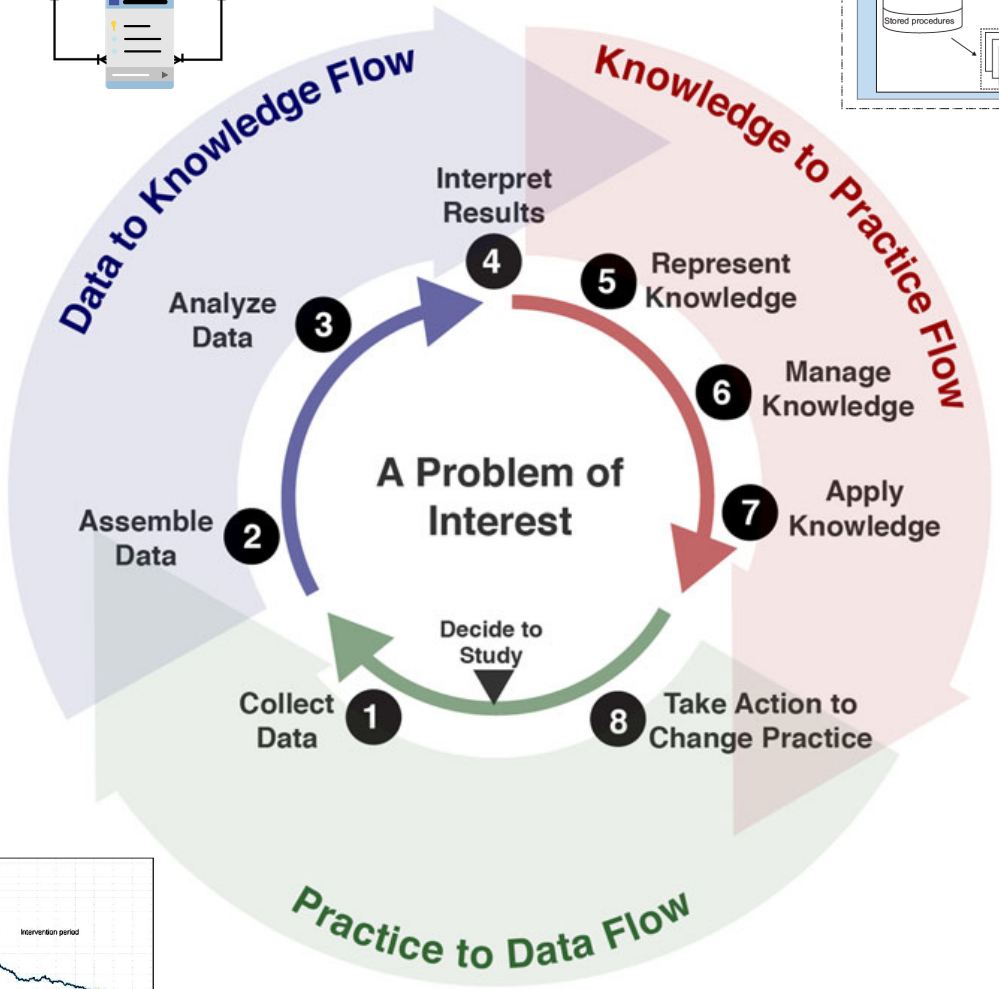


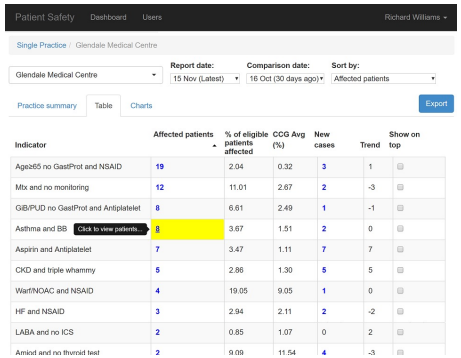


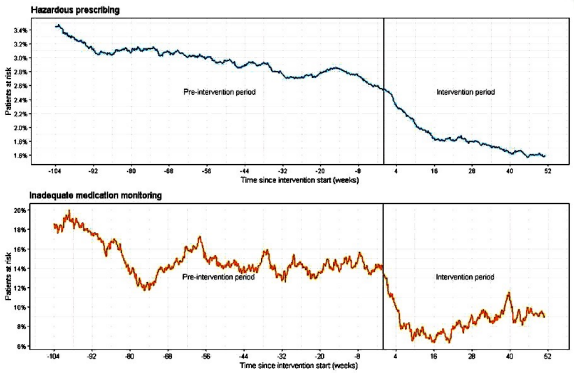




Salford Integrated Record







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Greater Manchester Health and Social Care Partnership

Graphnet Integrating Care

Health Innovation Manchester

What is the GM Care Record?

Easy access to patient information is **critical to support decision-making for health and care workers** – especially in situations such as the COVID-19 pandemic. That's where the GM Care Record comes in.

The GM Care Record supports data sharing for **direct care and treatment for the city region's 2.8m citizens.** Two years tech development has been condensed into two months.

The amount of data that the GM Care Record holds is increasing. Data is constantly being added so a combined record can be developed for all our citizens.

The GM Care Record is an extension of shared care records live in each area of Greater Manchester (e.g. Manchester Care Record, Bolton Care Record). However, it collates patient information into one place, making it easily accessible for health and care workers to inform direct care from across geographies and organisations.

The GM Care Record means that:

- patients **won't have to keep repeating their medical history** to each professional in different organisations
- care plans will be **followed consistently**
- clinicians will be better equipped to identify patterns and **plan care more effectively** to meet the patients' needs.

The GM Care Record will contain data from:

444 GP practices across **10 CCGs in GM**

10 councils

9 acute trusts (hospitals)

7 community services

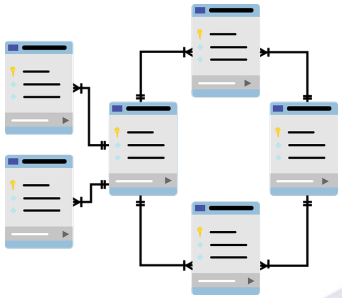
3 mental health trusts

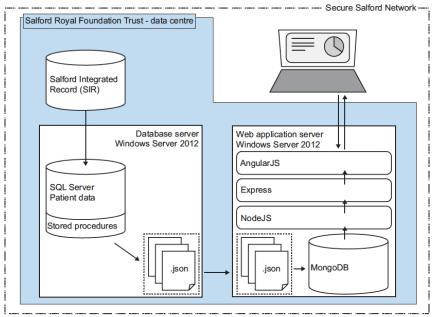
1 specialist (The Christie)

N.W. Ambulance Service, Out of Hours & 111 will also be included.

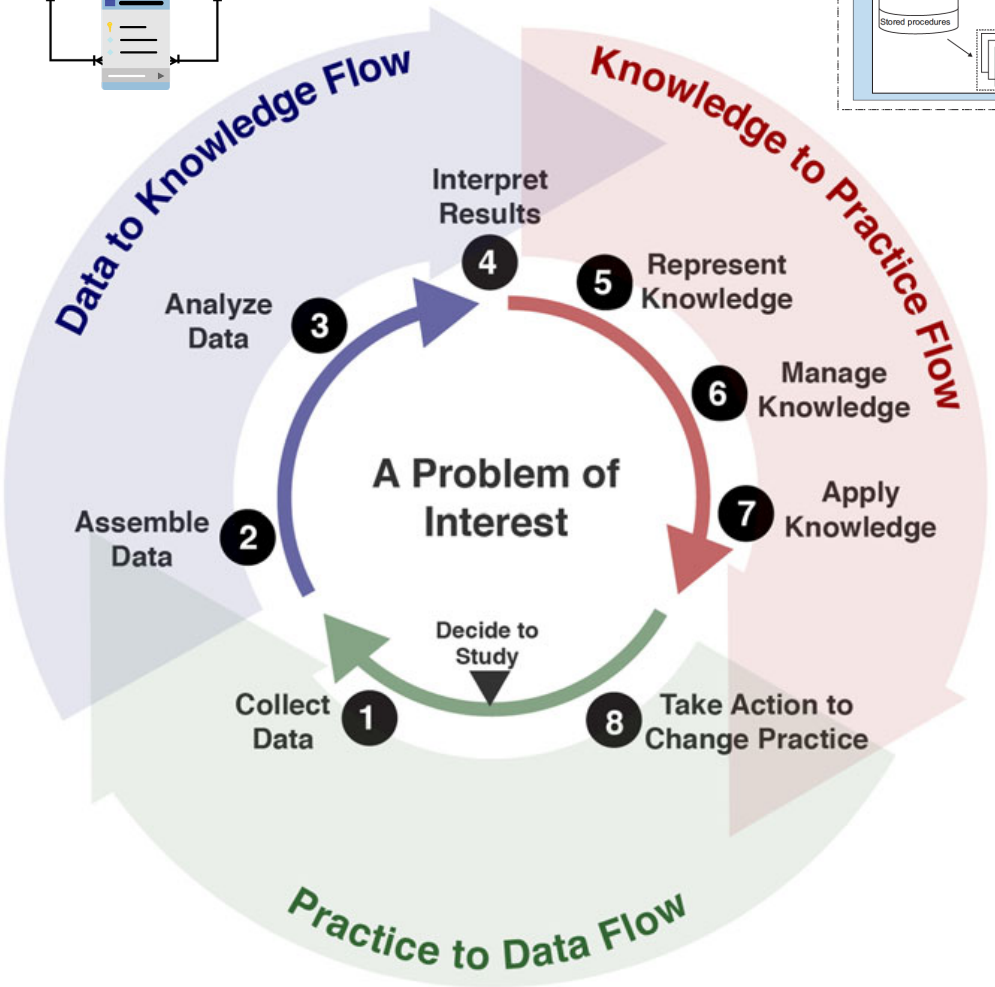
The GM Care Record supports clinical decision making by providing access to important information on:

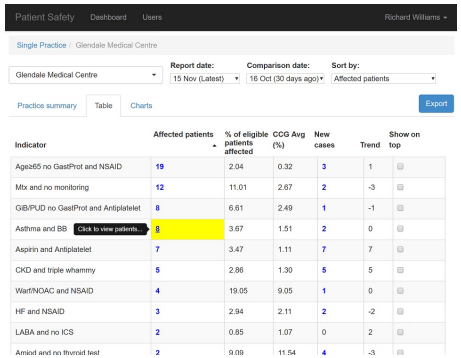
medications | **allergies** | **test results** | **care plans** | **social care support**





Greater Manchester Care Record





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Conclusions

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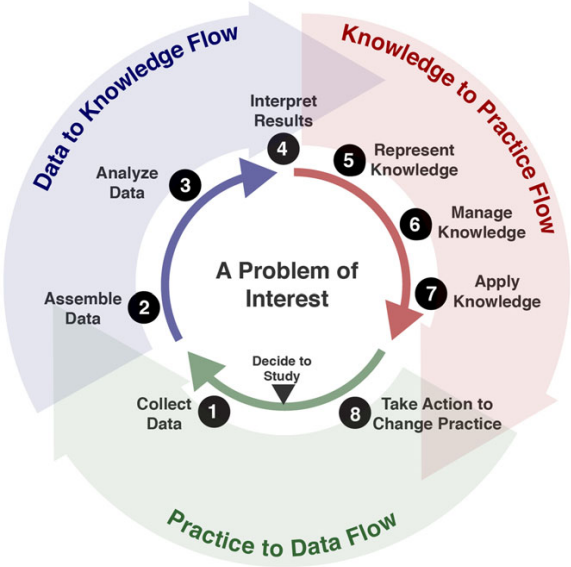
Conclusions



- The learning health system is a paradigm blends data science, improvement science, and technology
- It aims to capitalise on opportunities provided by the data revolution – as has happened in other industries
- LHSs require an infrastructure consisting of people, technology, processes and policies
- SMASH is a learning health system for improving medication safety in primary care
- The deployment of the GM Care Record has significantly improved the capability to develop a LHS in GM

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Thank you

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