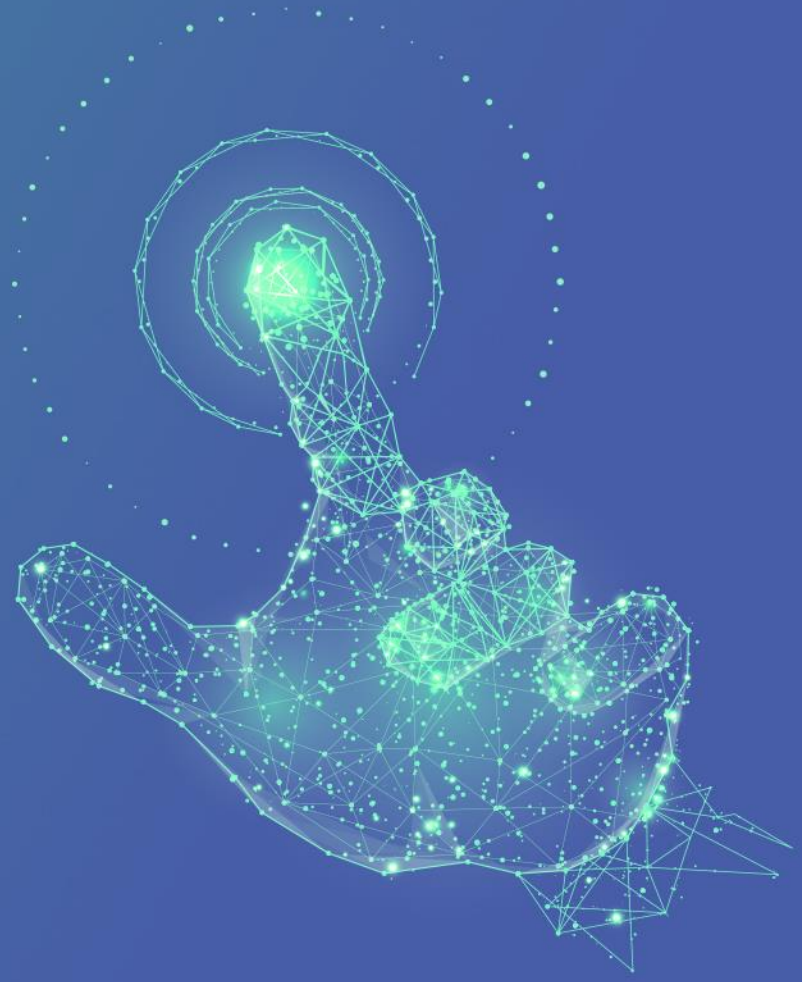
HDRUK
Health Data Research UK

Better Care Insight Sharing Day

22nd April 2021

HDRUK
Health Data Research UK

Introduction and welcome



Overview of today:

09:00-13:00, Insight sharing event:

- Showcasing exemplars of the Better Care approach in action

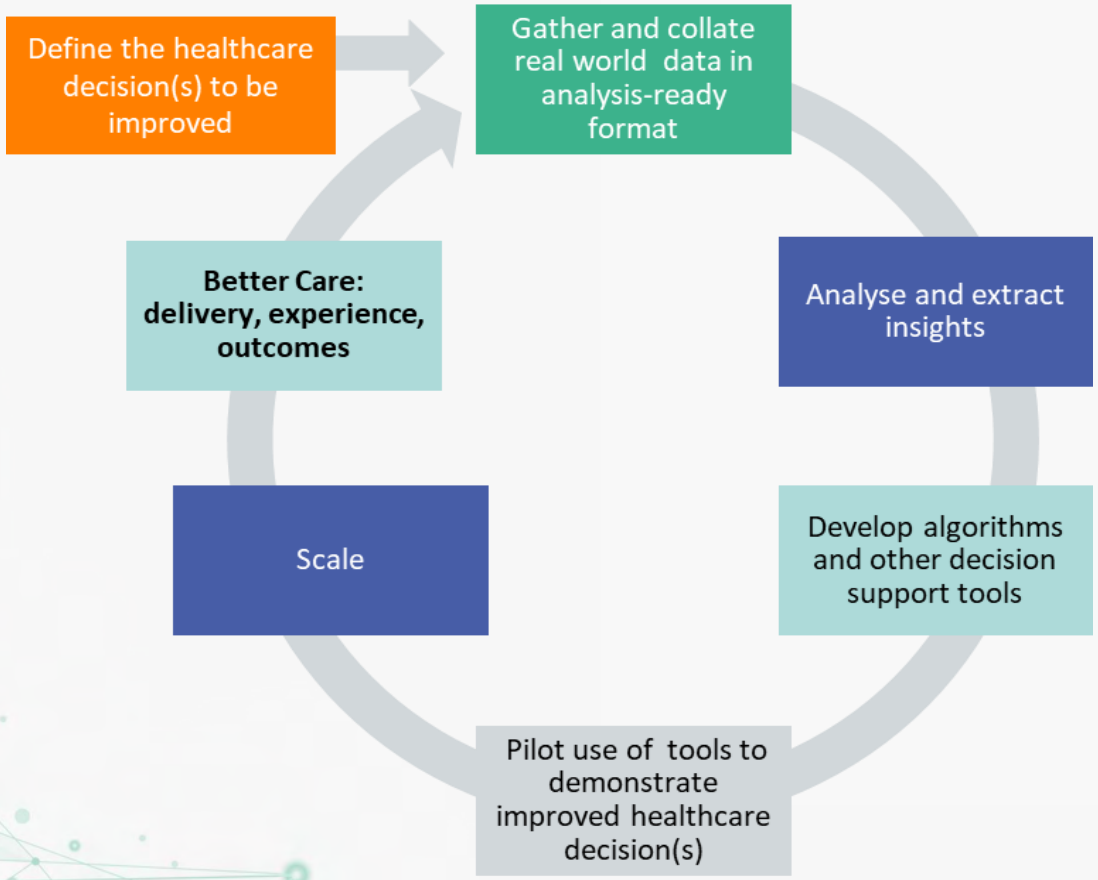
14:00-16:00, Better Care QQR ‘Blue Skies’ thinking:

- An opportunity to discuss the current impact and future vision / priorities for the Better Care programme

Better Care Approach:

HDRUK
Health Data Research UK

Our vision is that by 2030, patients will benefit from healthcare decisions informed by large scale data and advanced analytics to identify what will work best for them



Aim:
Improve people's lives by equipping clinicians and patients in the UK with the best possible data-based information to make decisions about their care.

Delivering through:

Sharing and learning:
- Sharing across the network
- Providing evidence of learning
- Adopting across the network

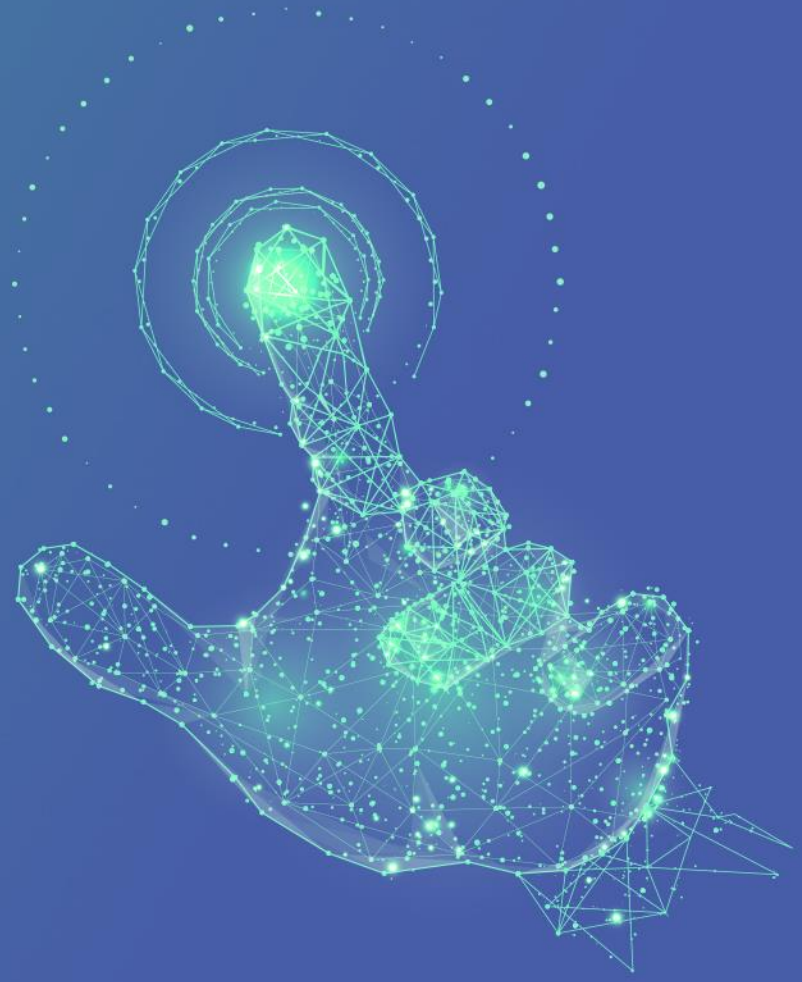
Embedding into clinical practice:
- Evidence of real-world implementation into routine clinical care
- Application of discovery/innovation from other HDRUK themes
- Anticipatory discussions with regulators

Scaling:
- Plans for scaling and sustaining outputs and impacts

HDRUK
Health Data Research UK

Computable clinical guidelines for Better care

09:05-10:35



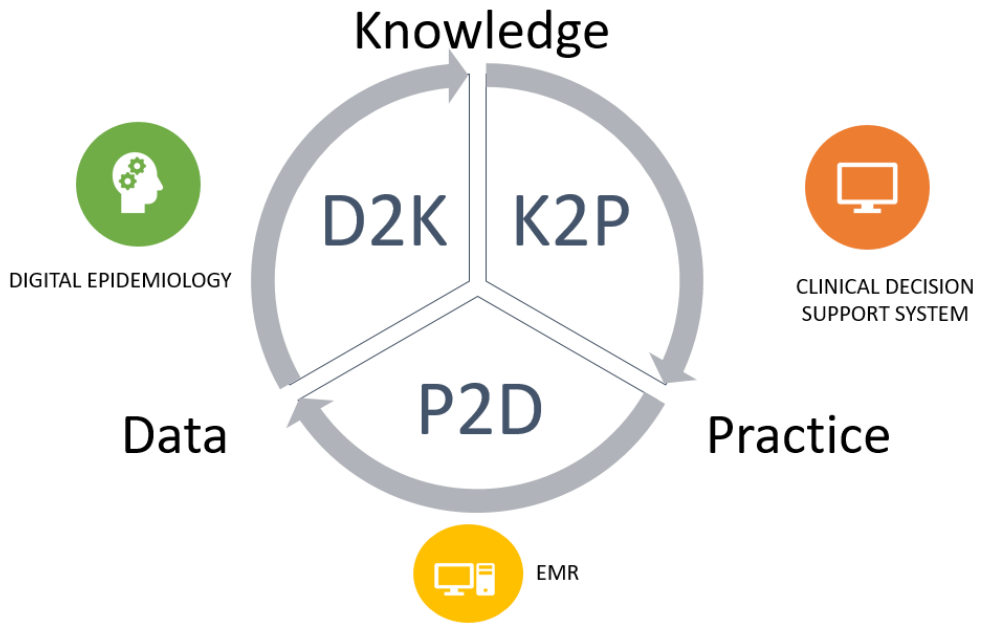
Learning Health System for National Health Service (LHS4NHS)

Computable Guidelines

Dr Krish Nirantharakumar MBBS MPH MD MFPH MRCP
Senior Clinical Lecturer & Honorary Consultant in Public Health Medicine
University of Birmingham & HDRUK
University Hospitals Birmingham & PHE

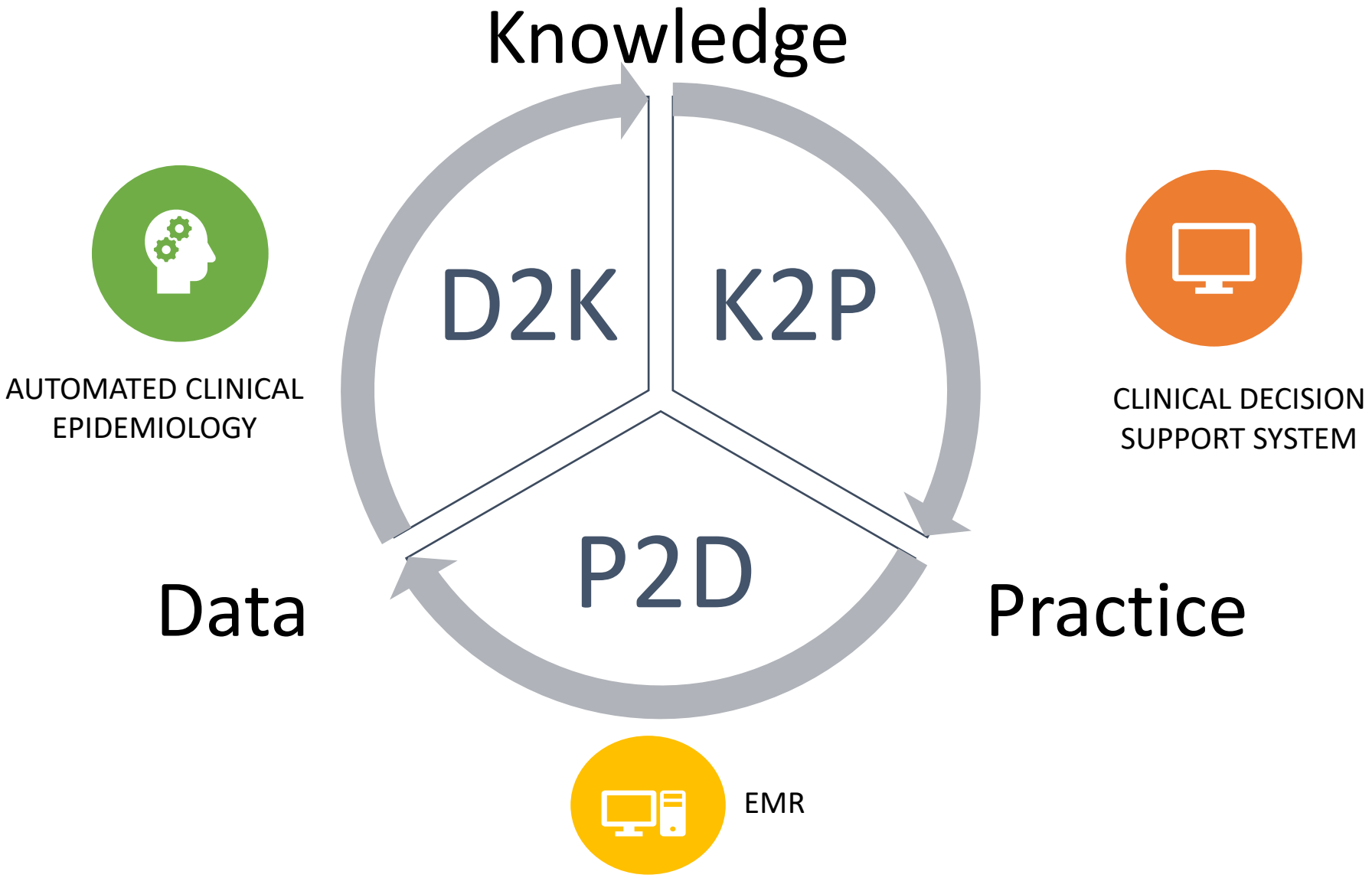
Learning Health Systems

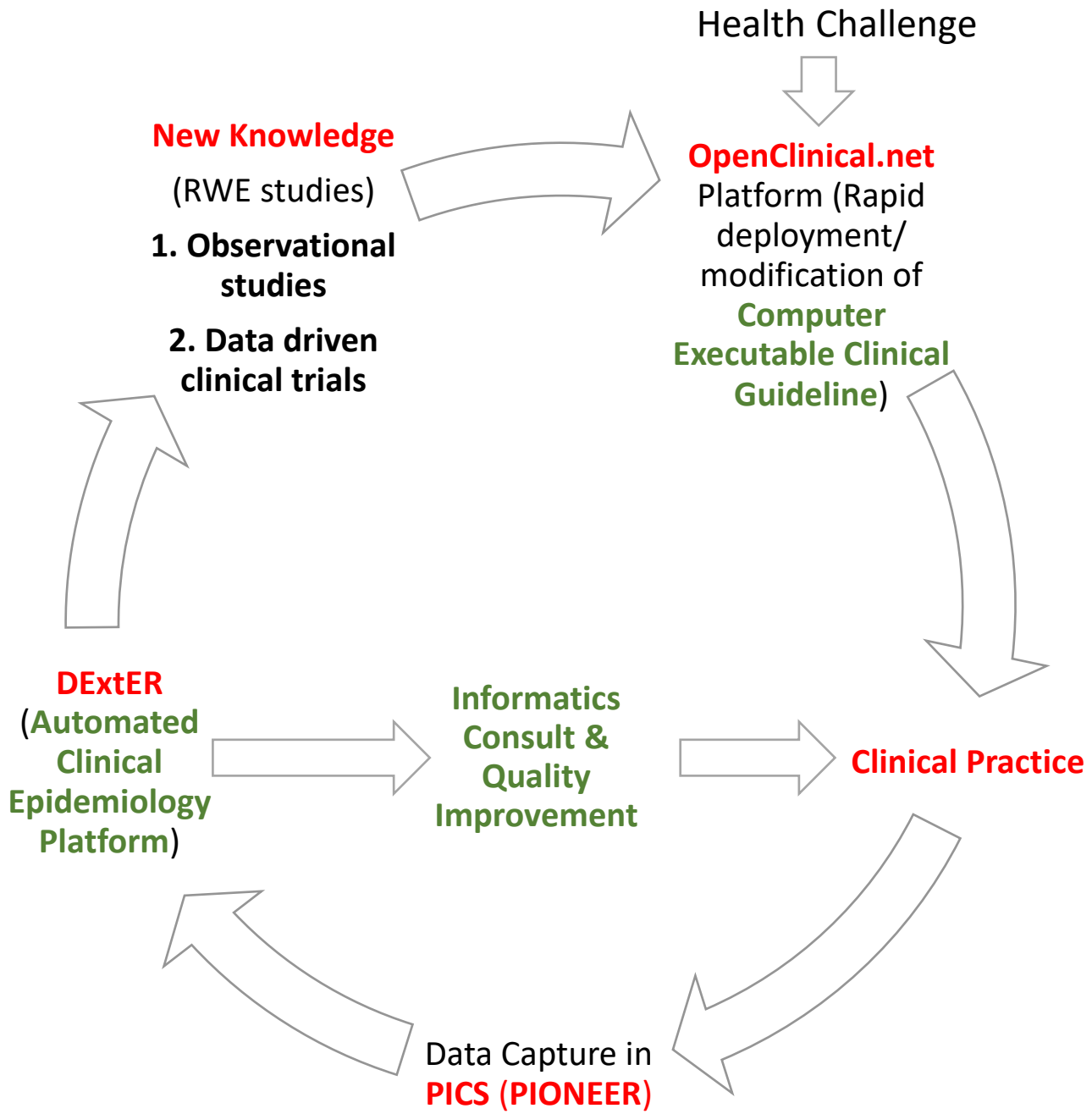
"The LHS focusses on approaches to ***capture data from clinical encounters*** *and other health-related events,* ***analyse the data to generate new knowledge****, and then* ***apply this knowledge*** *to continuously inform and improve health decision making and practice"*



Nwaru, B.I., Friedman, C., Halamka, J. *et al.* Can learning health systems help organisations deliver personalised care?. *BMC Med* **15,** 177 (2017). https://doi.org/10.1186/s12916-017-0935-0

Learning Health Systems





Learning Health System @ UHB: Demonstrator

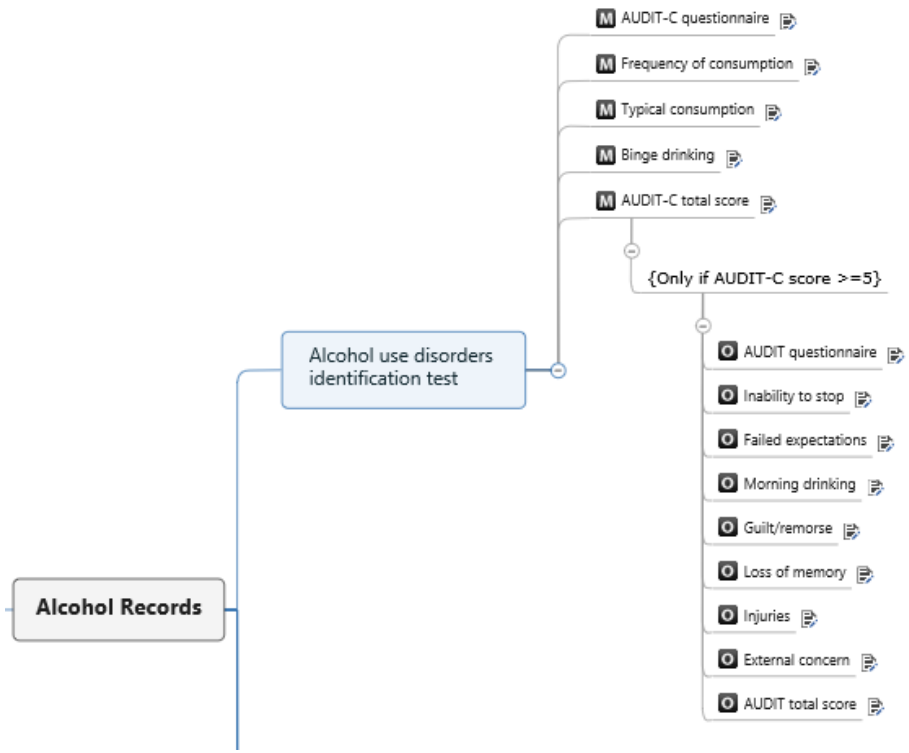
J. Smith is a 68 year old man with well controlled type 2 diabetes and hypertension. He deteriorates after an initial antibiotic prescription in the community and tests positive for Sars-Cov-2. He is admitted to UHB.

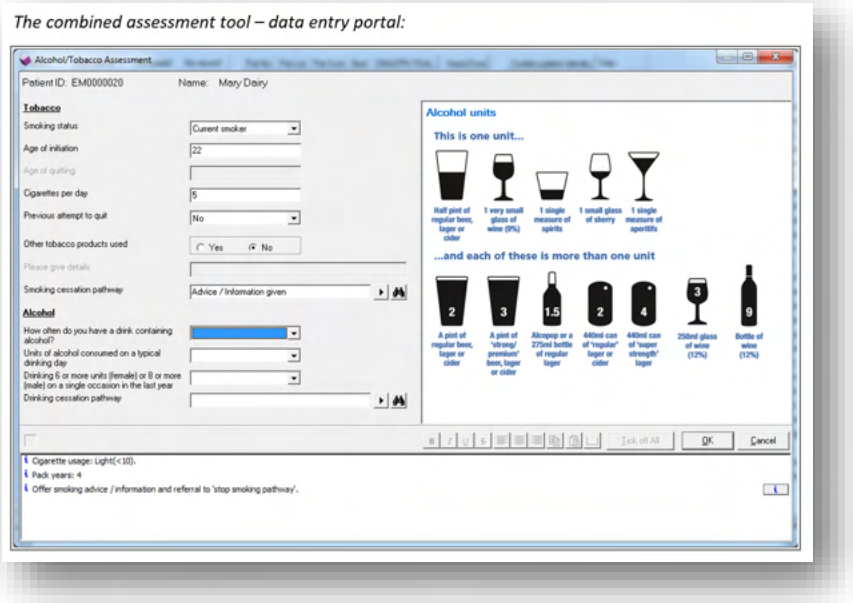
He has a history of excess alcohol intake.

Learning Health Systems: EHR (Capture data)

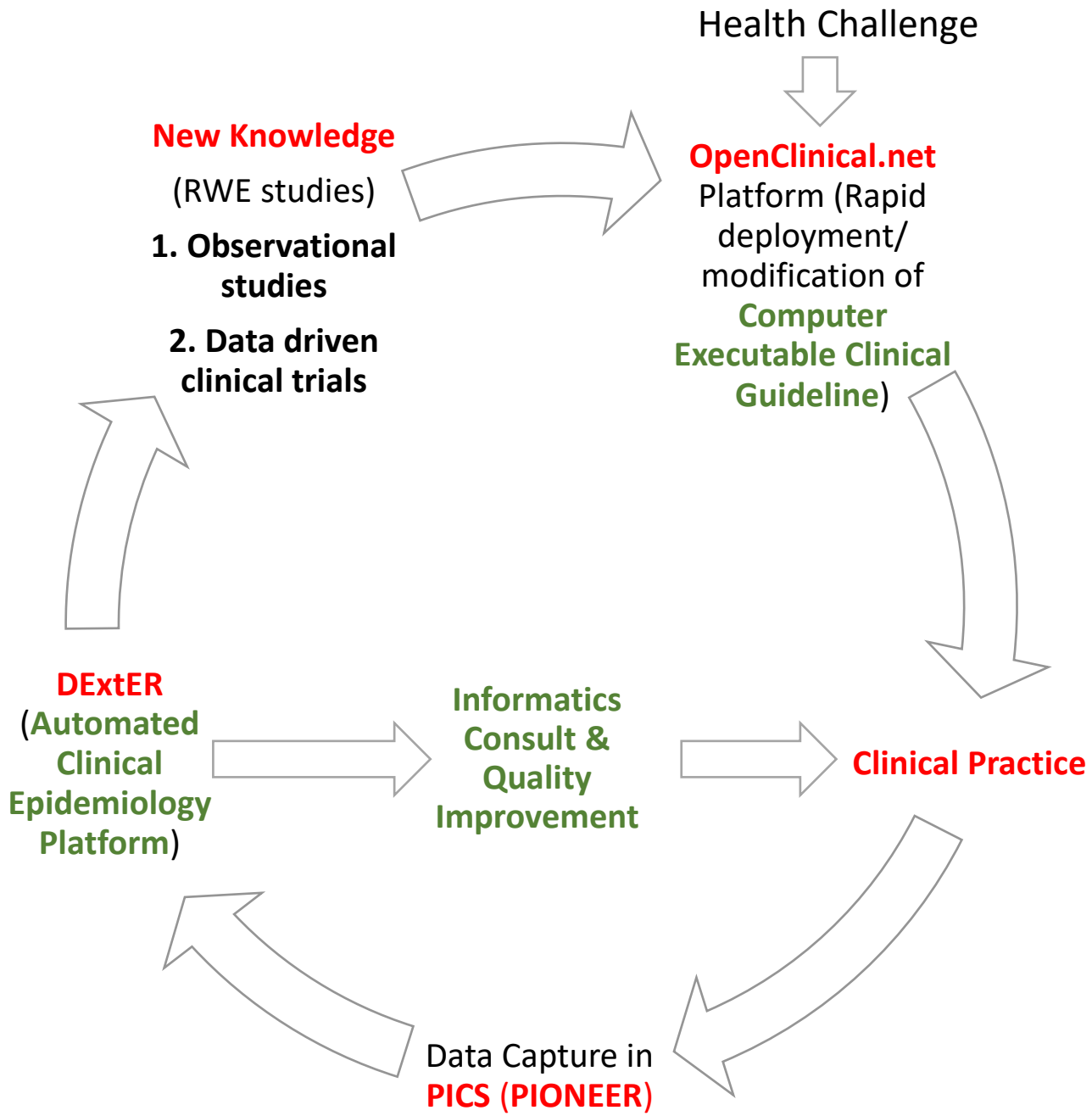
ELECTRONIC HEALTH RECORDS / REGISTRIES

- **Standards for structure and content**
  - **Professional record standards: e.g. RCP record standards**
  - **Formal coding and classification systems: e.g. SNOMED CT**





Haroon S, Wooldridge D, Hoogewerf J, Nirantharakumar K, Williams J, Martino L, Bhala N. Information standards for recording alcohol use in electronic health records: findings from a national consultation. BMC Med Inform Decis Mak. 2018 Jun 7;18(1):36.



Learning Health System @ UHB: Demonstrator

J. Smith is a 78 year old man with well controlled type 2 diabetes and hypertension. He deteriorates after an initial antibiotic prescription in the community and tests positive for Sars-Cov-2. He is admitted to UHB

He is hypoxic on arrival with Sats 86 % in air and a respiratory rate of 34

➡ *He is started on Dexamethasone*

He is found to have an AKI

➡ *His metformin and SGLT2i are stopped*

His capillary blood glucose is 18

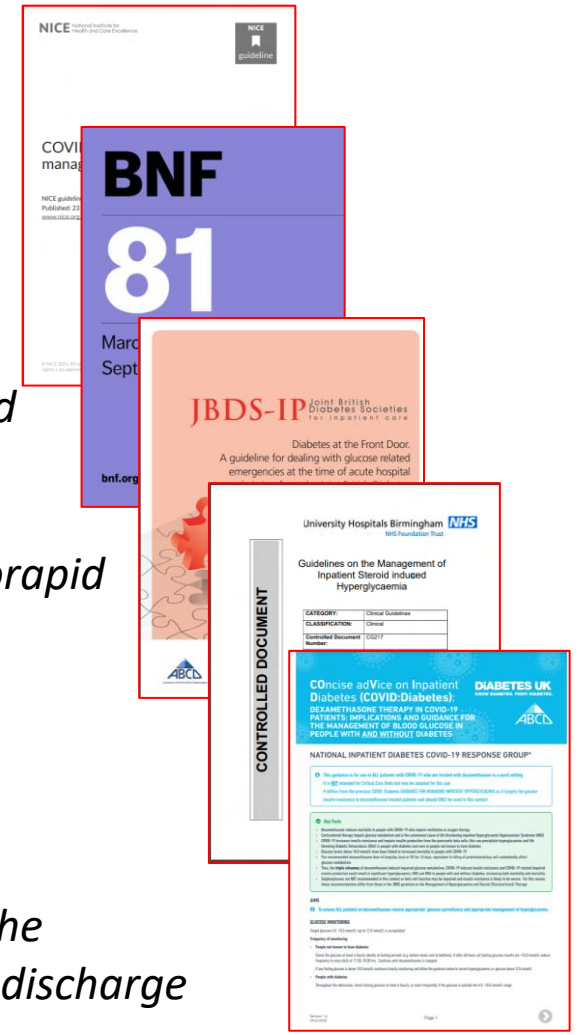
➡ *He receives a correction dose of Novorapid and is started on Humulin I*

His capillary blood glucose is 18 despite the Humulin I

➡ *His Humulin I is adjusted*

He improves and the dexamethasone is stopped

➡ *The Humulin I is further reduced and he is reviewed by the diabetes team for discharge to community*



Learning Health Systems: CDSS (Applying knowledge)

CLINICAL DECISION SUPPORT SYSTEM

CLINICAL DECISION SUPPORT SYSTEM

*"A computer system that uses two or more patient data to generate case specific or encounter specific advice" **

Key steps:

- **Knowledge engineering:** computable guidelines
- **Implementation of CDSS**

*Wyatt JC, Liu JLY. Basic concepts in medical informatics. *Journal of Epidemiology & Community Health* 2002;**56:**808-812.

Languages

Implementation Software

Arden Syntax → Arden2ByteCode

Drools → Drools Engine

PROforma → OPS, Talis, Deontics, Arezzo

Gello → MOWGLI

Asbru → Spock, Picard

Gaston → Gastonsuite

J. Smith is a 78 year old man with well controlled type 2 diabetes and hypertension. He deteriorates after an initial antibiotic prescription in the community and tests positive for Sars-Cov-2. He is admitted to UHB

He is hypoxic on arrival with Sats 86 % in air and a respiratory rate of 34

➡ *He is started on Dexamethasone*

He is found to have an AKI

➡ *His metformin and SGLT2i are stopped*

His capillary blood glucose is 18

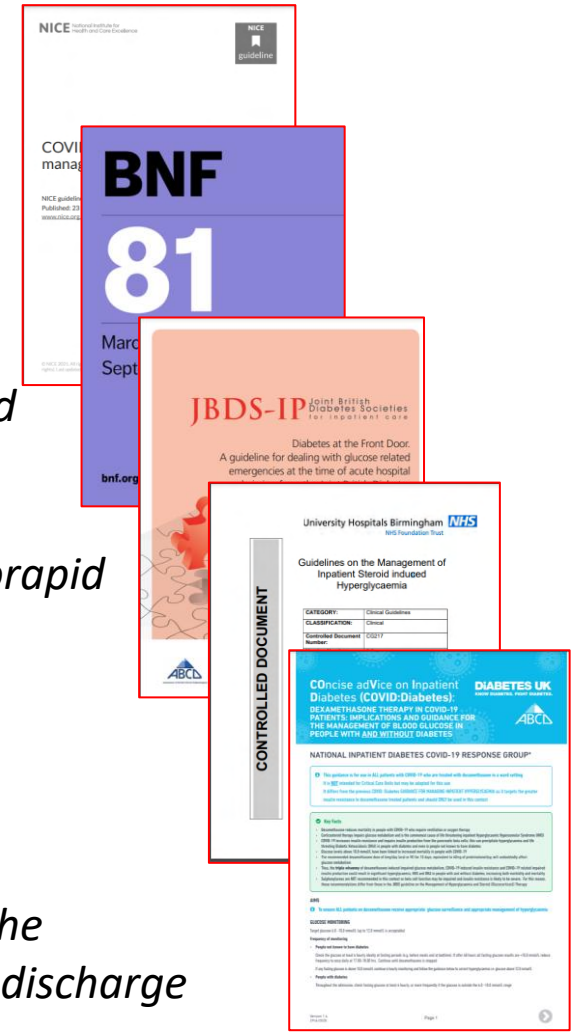
➡ *He receives a correction dose of Novorapid and is started on Humulin I*

His capillary blood glucose is 17 despite the Humulin I

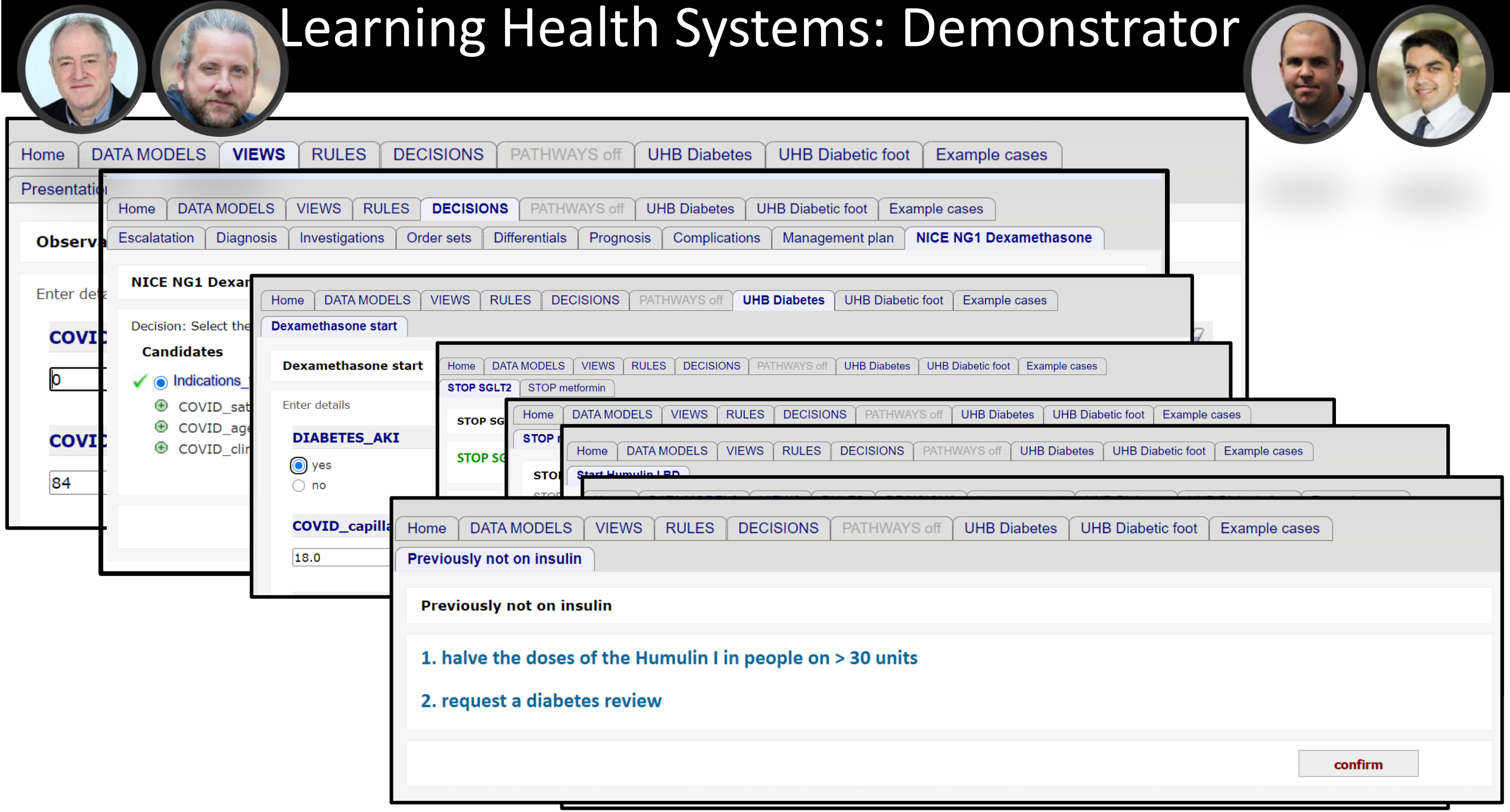
➡ *His Humulin I is adjusted*

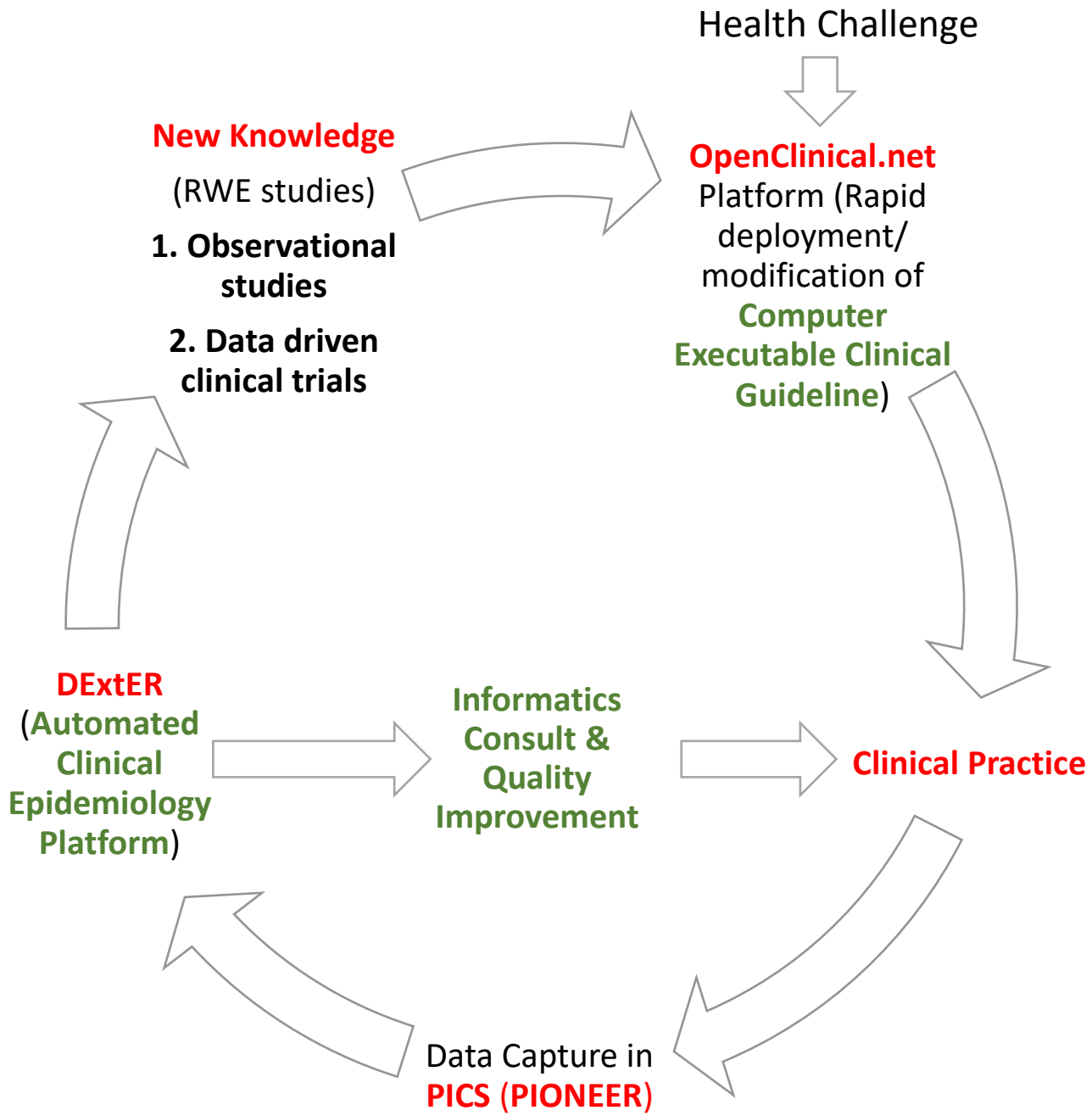
He improves and the dexamethasone is stopped

➡ *The Humulin I is further reduced and he is reviewed by the diabetes team for discharge to community*



Learning Health Systems: Demonstrator





Learning Health System @ UHB: Demonstrator

Learning Health Systems: Automated Epidemiology (Generating new knowledge)

AUTOMATED CLINICAL EPIDEMIOLOGY

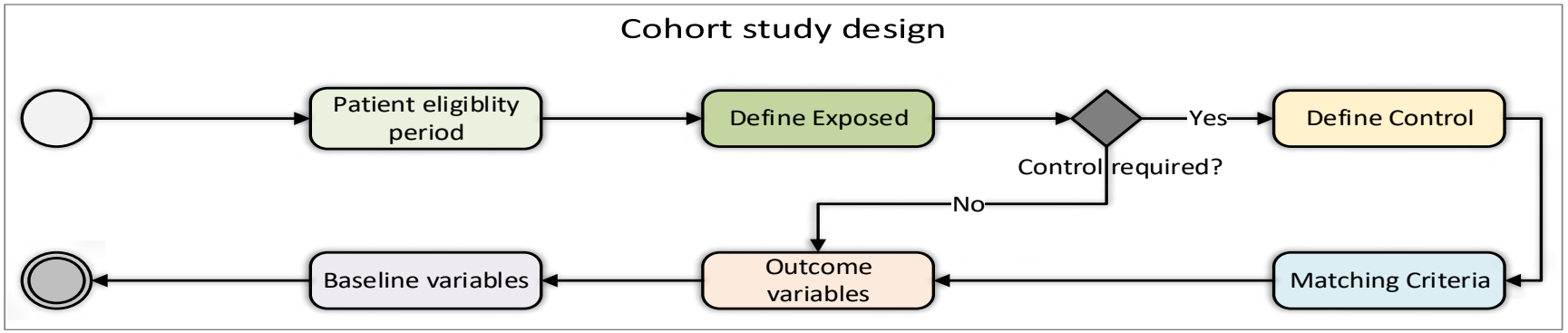
AUTOMATED CLINICAL EPIDEMIOLOGY STUDIES

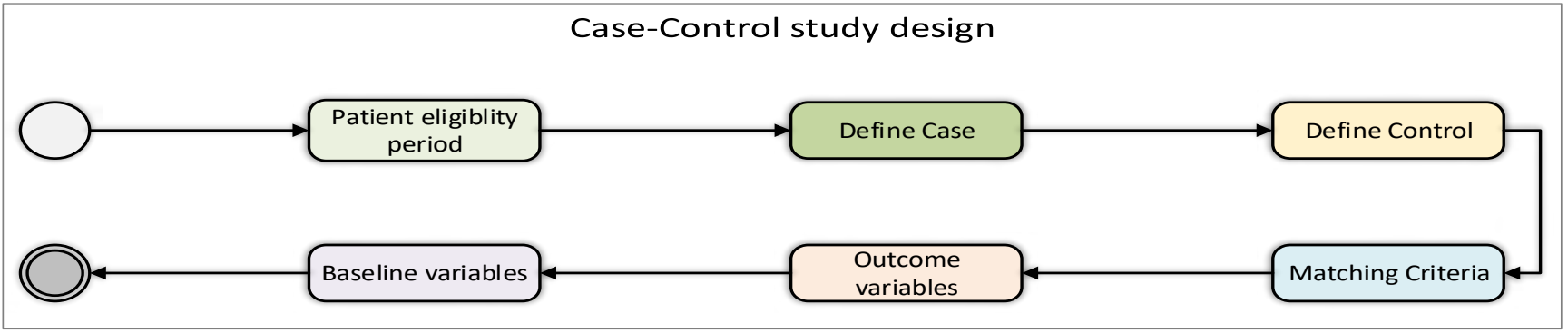
Key steps:

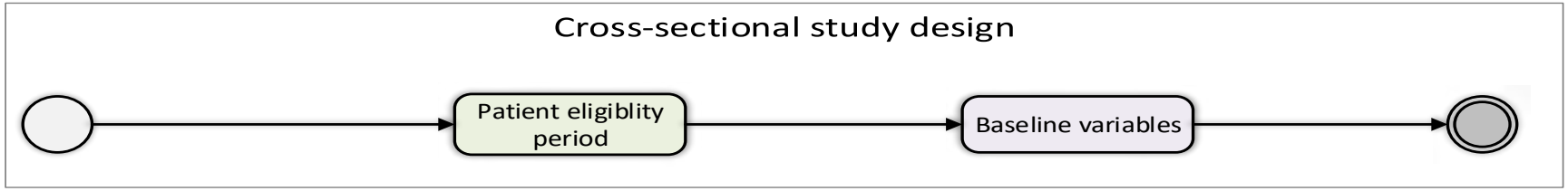
- **Knowledge engineering:** epidemiology study designs **(DExtER: Data Extraction for Epidemiology Research)**
- Analytics

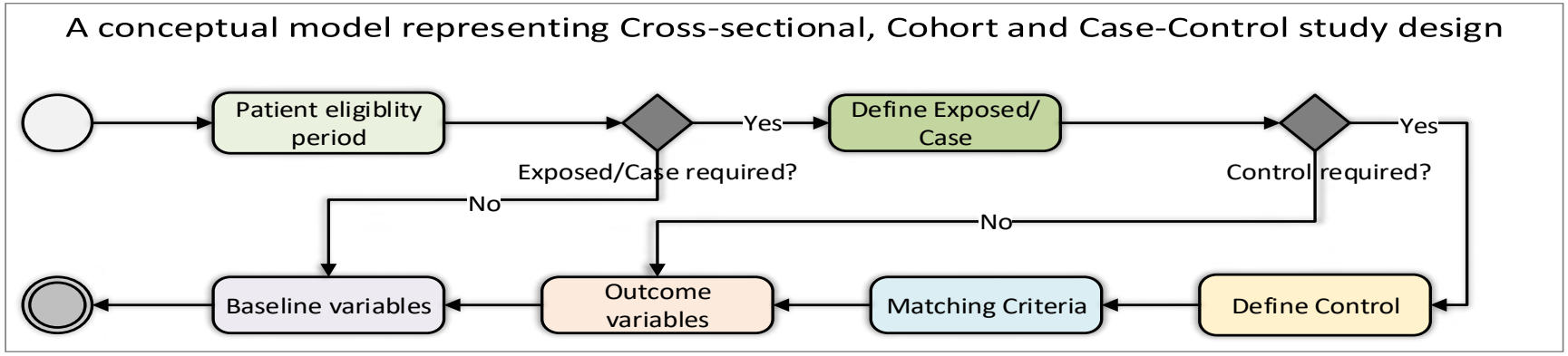
Informatics Consult

- Executing studies within short time periods & Real Time









Data Extraction steps for Cohort, Case-Control study & Cross-sectional designs

Architecture of DExtER

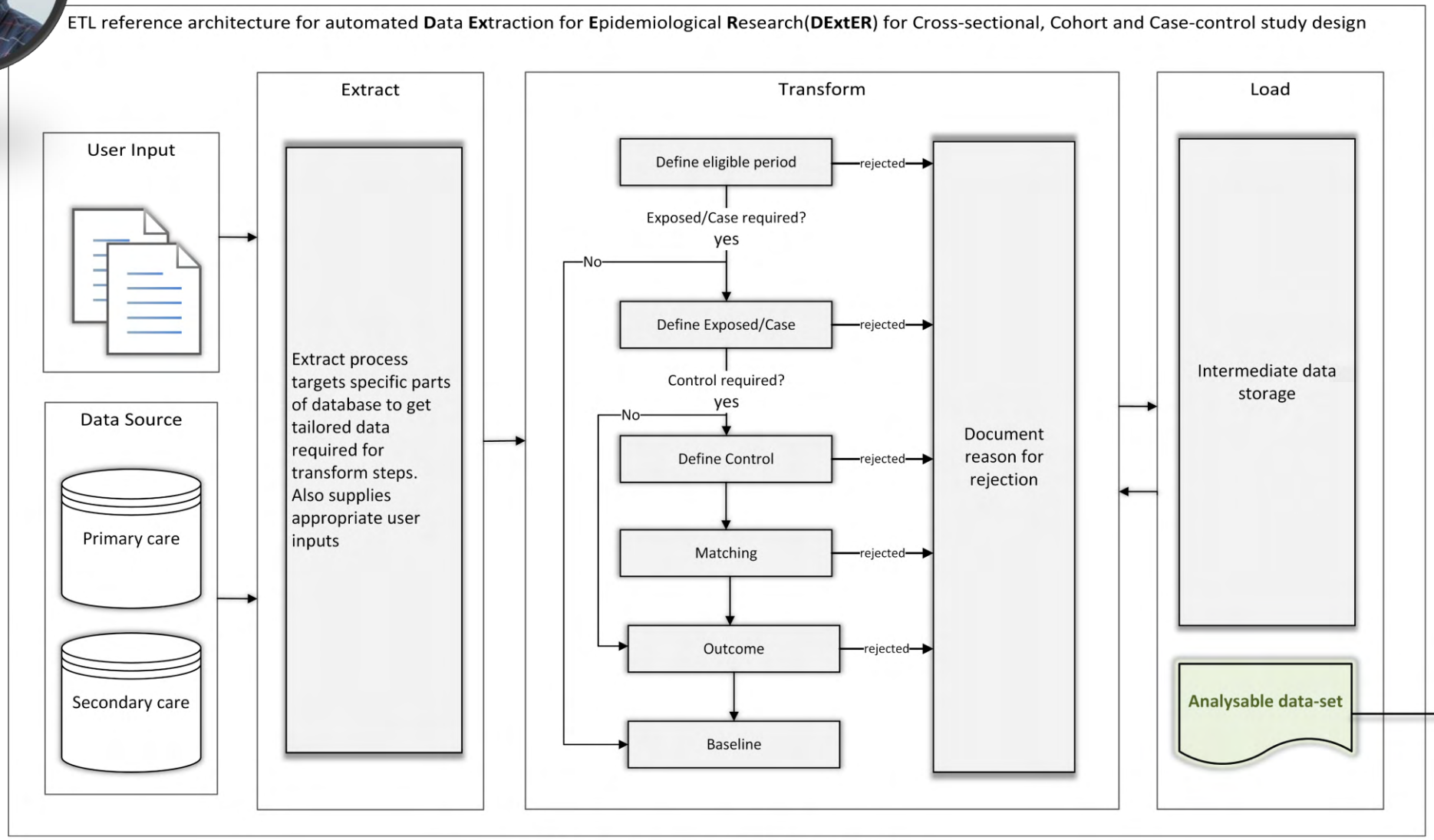


Figure1: Reference architecture for DExtER

Gokhale, K.M., Chandan, J.S., Toulis, K. *et al.* Data extraction for epidemiological research (DExtER): a novel tool for automated clinical epidemiology studies. *Eur J Epidemiol* (2020). https://doi.org/10.1007/s10654-020-00677-6

ACES24: Answering Clinical Enquiries in 24 Hours

Welcome to the world of instant bedside evidence-based medicine

Q: In wave 2 are hospitalised patients for COVID19 with pre-existing diabetes more likely to meet criteria for Dexamethasone treatment?

Informatics Consult

ACES24: Answering Clinical Enquiries in 24 Hours

Welcome to the world of instant bedside evidence-based medicine

DExtER

Data Extractor for Epidemiological Research

Baseline characteristics

Before matching | After matching

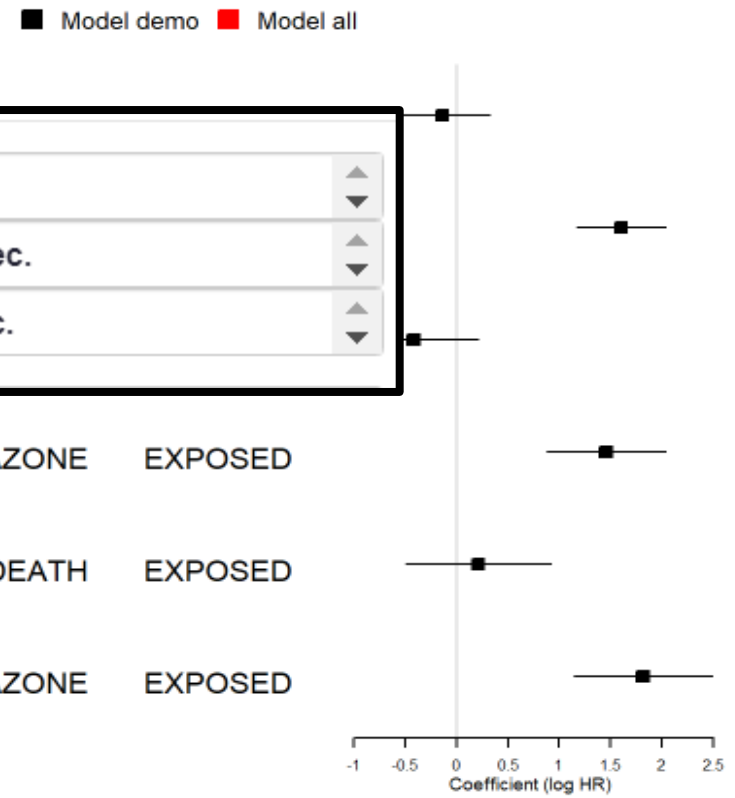
Covariate	
n	
AGE_AT_INDEX (	

Job submitted on:	2021-04-21 20:45:35.038	Wait time:	13 sec.
Extraction started on:	2021-04-21 20:45:48.337	Run time:	3 min & 53 sec.
Extraction completed on:	2021-04-21 20:49:41.708	Total time:	4 min & 6 sec.

Before matching | After matching

Covariate	Stratum	Overall	EXPOSED0	EXPOSED1
n		1036	518	518
AGE_AT_INDEX (mean (sd))		69.5 (15.8)	70.1 (16.3)	69 (15.1)

Cox regression coefficients for exposures



Informatics Consult (Advanced Patient Similarity Tool)

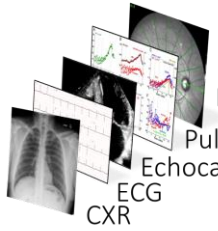
Patients like “Mary”

DATA

CPRD

PIONEER Health Data Research Hub

Validation data



Retina Scan

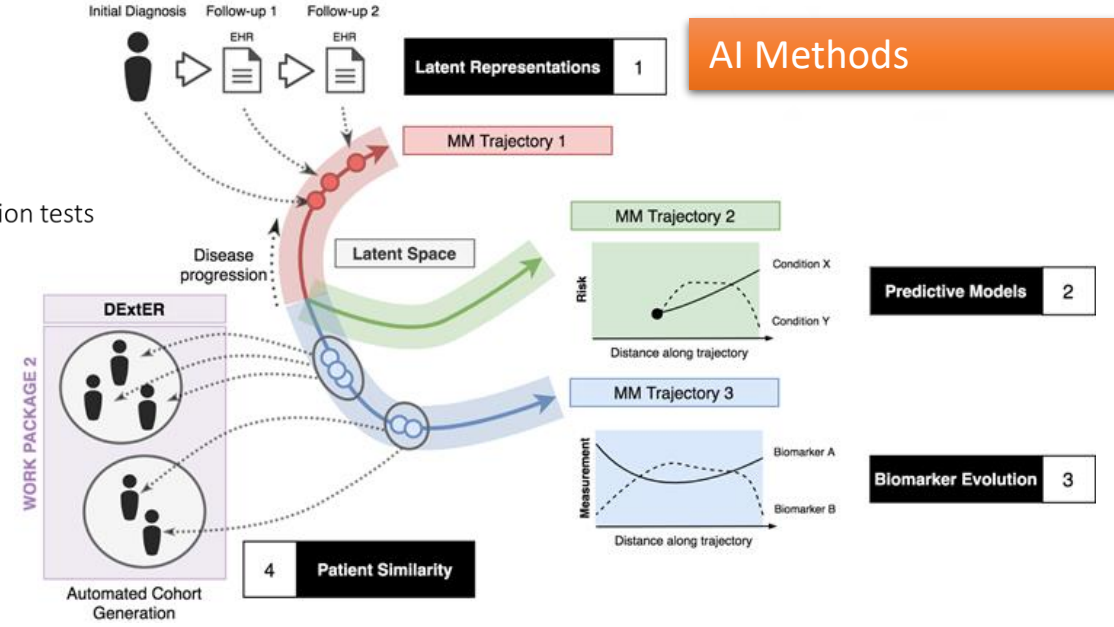
Pulmonary function tests

Echocardiogram

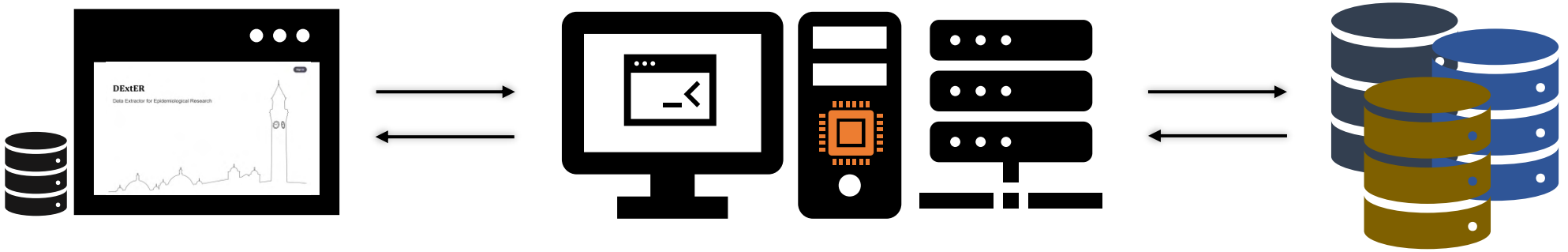
ECG

CXR

AI Methods



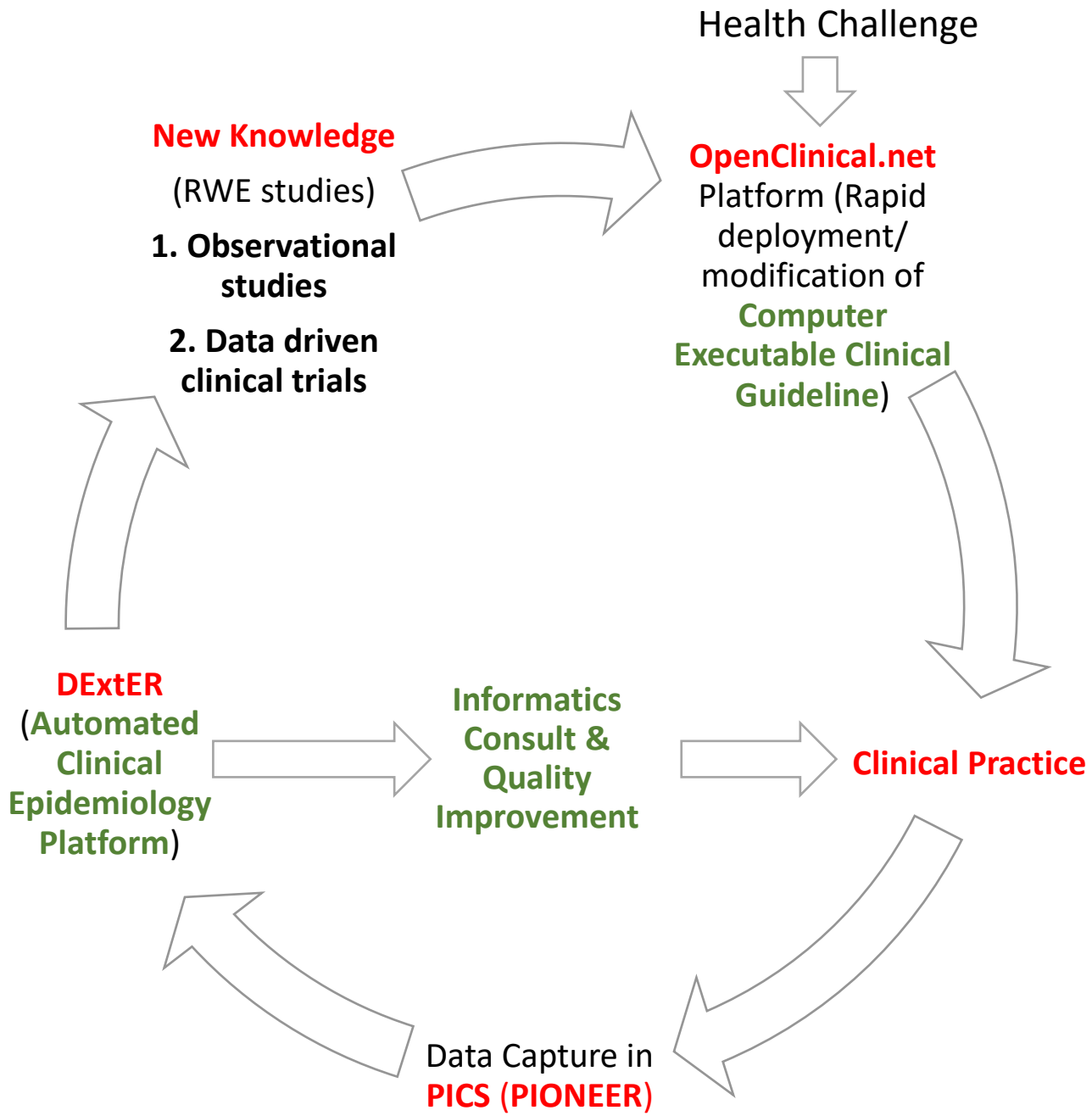
DExtER



Web-apps

Data extractor and analytics engine

Primary & Secondary care databases


Health Challenge
OpenClinical.net Platform (Rapid deployment/ modification of Computer Executable Clinical Guideline)
Clinical Practice
Data Capture in PICS (PIONEER)
DExtER (Automated Clinical Epidemiology Platform)
Informatics Consult & Quality Improvement
New Knowledge
(RWE studies)
1. Observational studies
2. Data driven clinical trials

Thank you

Computer Interpretable Clinical Guidelines:
Research Opportunities and Challenges

Professor Theodoros N. Arvanitis, RT, DPhil, CEng, FRSM, FGBHI
Chair in Digital Health Innovation &
Director of the Institute of Digital Healthcare, WMG, University of Warwick

Associate Director, HDR UK - Midlands

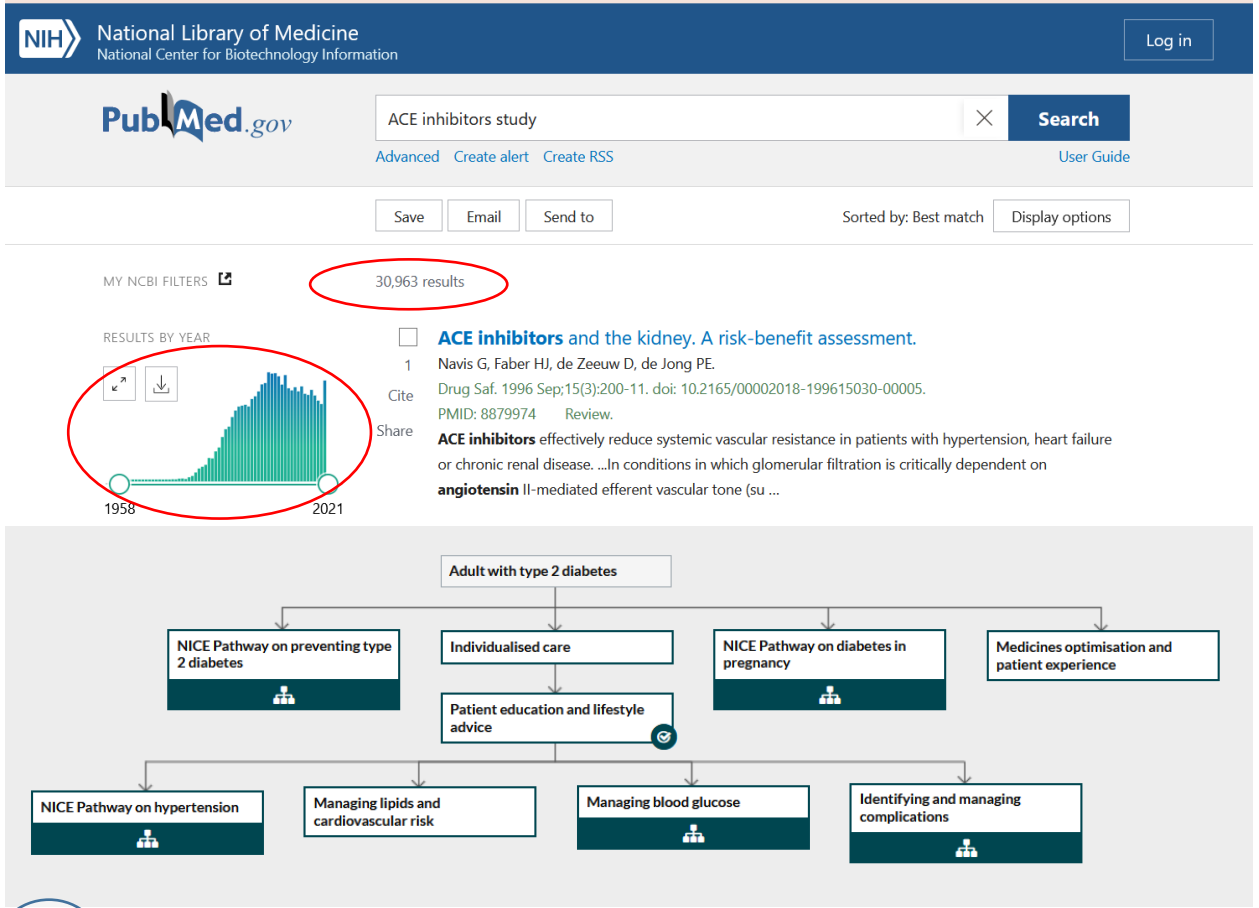
Better Care Insight Sharing Day – 22 April 2021

Overview

- Modelling EBM: Clinical Guidelines
- CPGs in context: Digital Health
- Computer Interpretable Clinical Guidelines (CIGs)
- Unambiguous Modelling of CIGs
- Representation of Information - Ontological Modelling
- Execution of CIGs
- V& V of CIGs
- Deployment of CIGs
- Research at IDH

Modelling Evidence Based Medicine

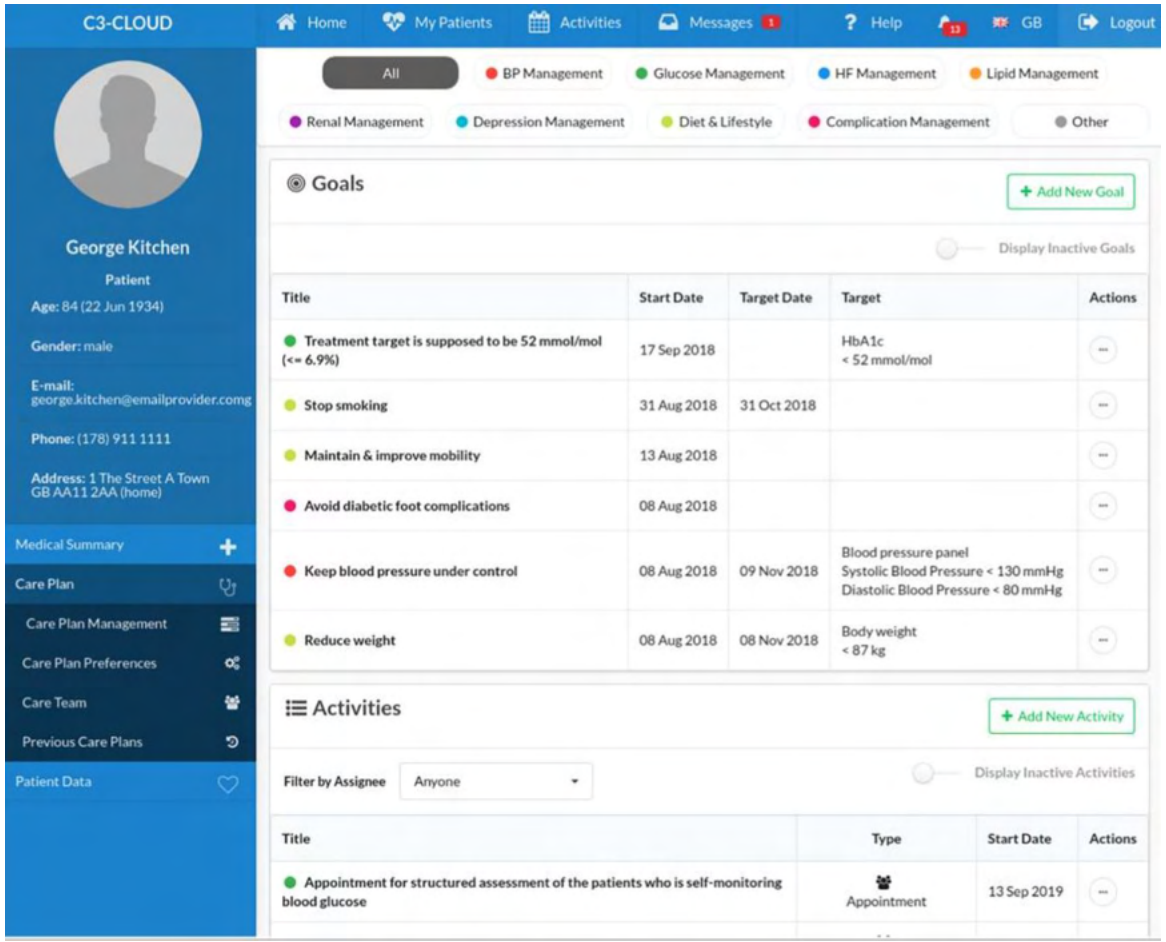
- Aim to incorporate clinical evidence into practice
- Body of evidence on a topic captured as a guideline
  - Clinical Practice Guidelines (CPGs)
- Instructions, recommendations, criteria
  - Presented as a care model



The UK National Institute for Health and Care Excellence (NICE) provides recommendations based on reviews of available evidence.

CPGs in Digital Health

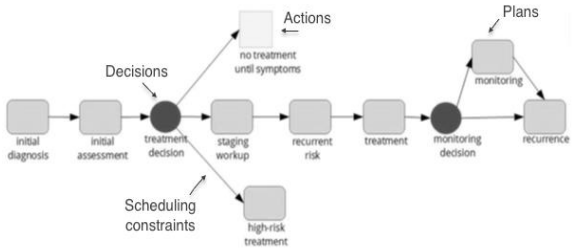
- Digital health systems provide capabilities for continuous (self) monitoring
  - Chronic conditions
  - Patient empowerment
  - Early warning of trends (prevention)
- Clinical Decision Support Systems
- Need to incorporate CPGs in the algorithms of the systems
- Computer Interpretable Guidelines (CIGs)

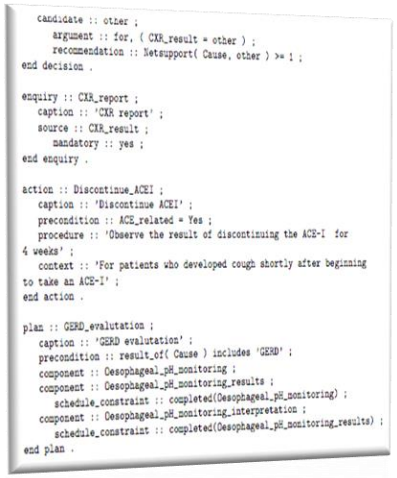


The C3-Cloud Project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 689181

CIGs and CIG Research Aspects

- Coding of clinical practice guidelines into a format that is understandable and executable by computer based systems
- Guidelines converted in programmable models and code: specific semantics and syntax



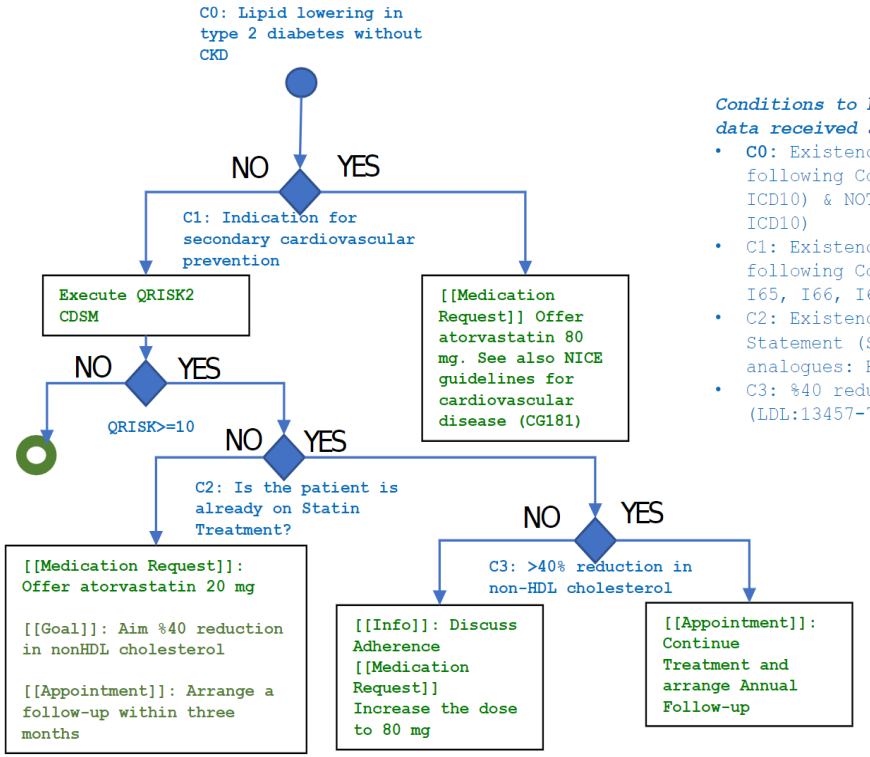


```
   candidate :: other ;
      argument :: for, ( CXR_result = other ) ;
      recommendation :: Notsupport( Cause, other ) >= 1 ;
end decision .

enquiry :: CXR_report ;
   caption :: 'CXR report' ;
   source :: CXR_result ;
      mandatory :: yes ;
end enquiry .

action :: Discontinue_ACEI ;
   caption :: 'Discontinue ACEI' ;
   precondition :: ACE_related = Yes ;
   procedure :: 'Observe the result of discontinuing the ACE-I  for
4 weeks' ;
   context :: 'For patients who developed cough shortly after beginning
to take an ACE-I' ;
end action .

plan :: GERD_evalutation ;
   caption :: 'GERD evalutation' ;
   precondition :: result_of( Cause ) includes 'GERD' ;
   component :: Oesophageal_pH_monitoring ;
   component :: Oesophageal_pH_monitoring_results ;
      schedule_constraint :: completed(Oesophageal_pH_monitoring) ;
   component :: Oesophageal_pH_monitoring_interpretation ;
      schedule_constraint :: completed(Oesophageal_pH_monitoring_results) ;
end plan .
```

- Modelling of guidelines
- Representation of information
- Coding: Languages
- Execution of CIGs
- Validation and verification of CIGs
- Deployment of CIGs

Modelling of Guidelines

- Unambiguous models that can be understood by people (e.g., flow charts, UML-based models)
- Discussion viewpoint between clinical and IT/Software Engineering staff
- Specification of the algorithms
- Model-Driven Software Engineering
- Example: A sample flowchart for lipid management CDS in C3-Cloud Project



Conditions to be checked on Patient data received as FHIR resources:

- **C0**: Existence of one of the following Conditions: (T2D:E11 - ICD10) & NOT (CKD:N18.0-N18.9 - ICD10)
- C1: Existence of one of the following Conditions: (I20-I25, I63, I65, I66, I67.2, I70 - ICD10)
- C2: Existence of Medication Statement (Somatostatin and analogues: H01CB- ATC)
- C3: %40 reduction in Observation (LDL:13457-7, LOINC)

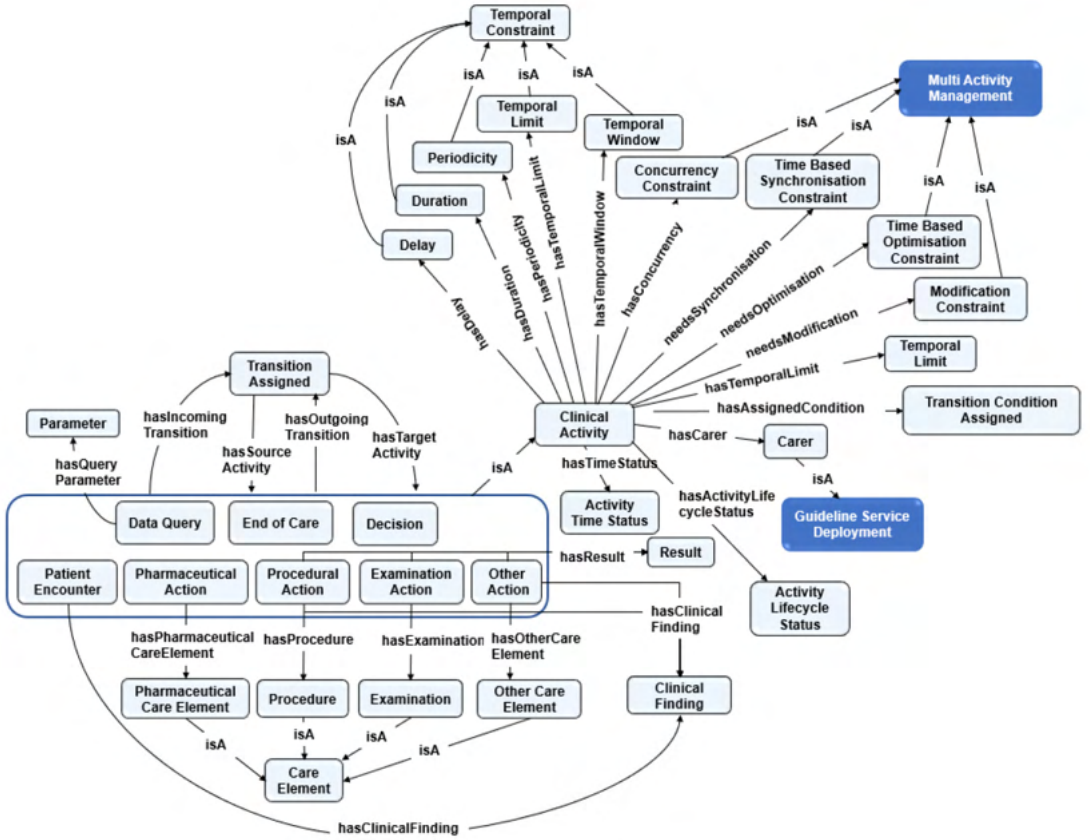
G. B. Laleci Erturkmen, M. Yuksel, B. Sarigul, T. N. Arvanitis, P. Lindman, R. Chen, L. Zhao, E. Sadou, J. Bouaud, L. Traore, A. Teoman, S. N. Lim Choi Keung, G. Despotou, E. de Manuel Keenoy, D. Verdoy, A. de Blas, N. Gonzalez, M. Lilja, M. von Tottleben, M. Beach, C. Marguerie, G. O. Klein, and D. Kalra, A Collaborative Platform for Management of Chronic Diseases via Guideline-Driven Individualized Care Plans, *Computational and Structural Biotechnology Journal*, 2019; 17: 869-885.

CIG Formalisms

	Type	Guideline basic elements	Creation & editing tool	Execution engine
Arden Syntax	Rule-based language	Medical logic modules: Data slot, Event slot, logic slot and action slot	Arden syntax IDE	Arden syntax rule engine
GLIF3 (Guideline interchange format)	Task-network model	Steps: decision, action, patient state, branch, synchronization, action	Protégé	GLEE (Guideline execution engine)
PROforma	Task-network model	Tasks: plan, action, decision, enquiry	Arezzo	Arezzo, **Tallis**
Asbru	Task-network model	Roles: preferences, intentions, conditions, effects, plan body	Asbru view	DeGeL Spock engine
SAGE (Standards-based sharable active guideline environment)	Task-network model	Nodes: context, action, decision, routing nodes	SAGE workbench	SAGE execution engine
GLARE (Guideline acquisition, representation and execution)	Task-network model	Actions: query, work, decision, conclusion	GLARE	GLARE Acquisition module
…	….	….	….	….

Representation of Information - I

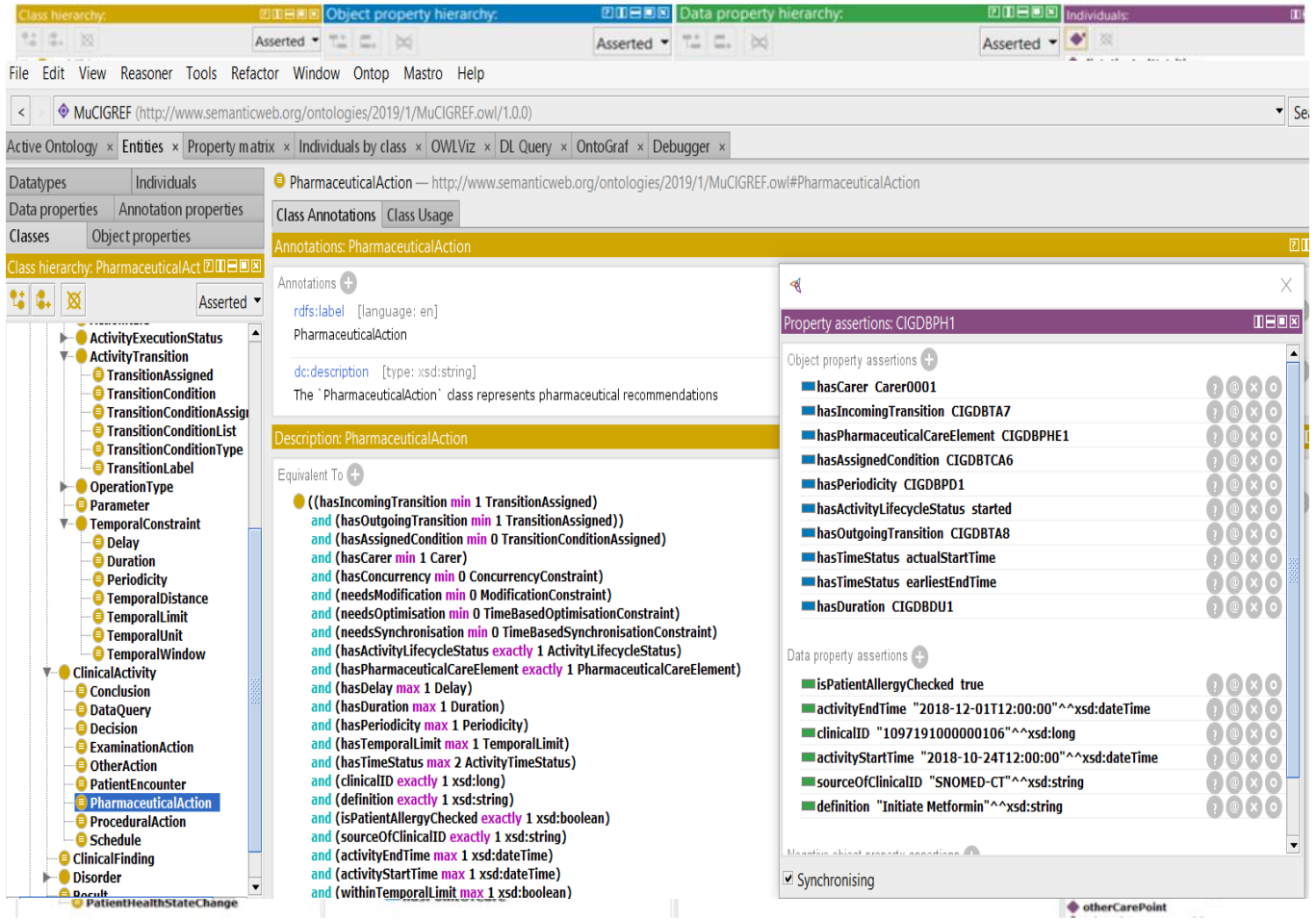
- Concepts that will capture the information in a guideline
  - Unambiguously
  - Understandable by computers
  - E.g. patient, observation, prescription
- Ontologies
  - and computer representation
- Association of multiple guidelines is a challenge



PhD of Eda Bilici Özyiğit: MuCIGREF: multiple computer-interpretable guideline representation and execution framework for managing multimorbidity care, 2020

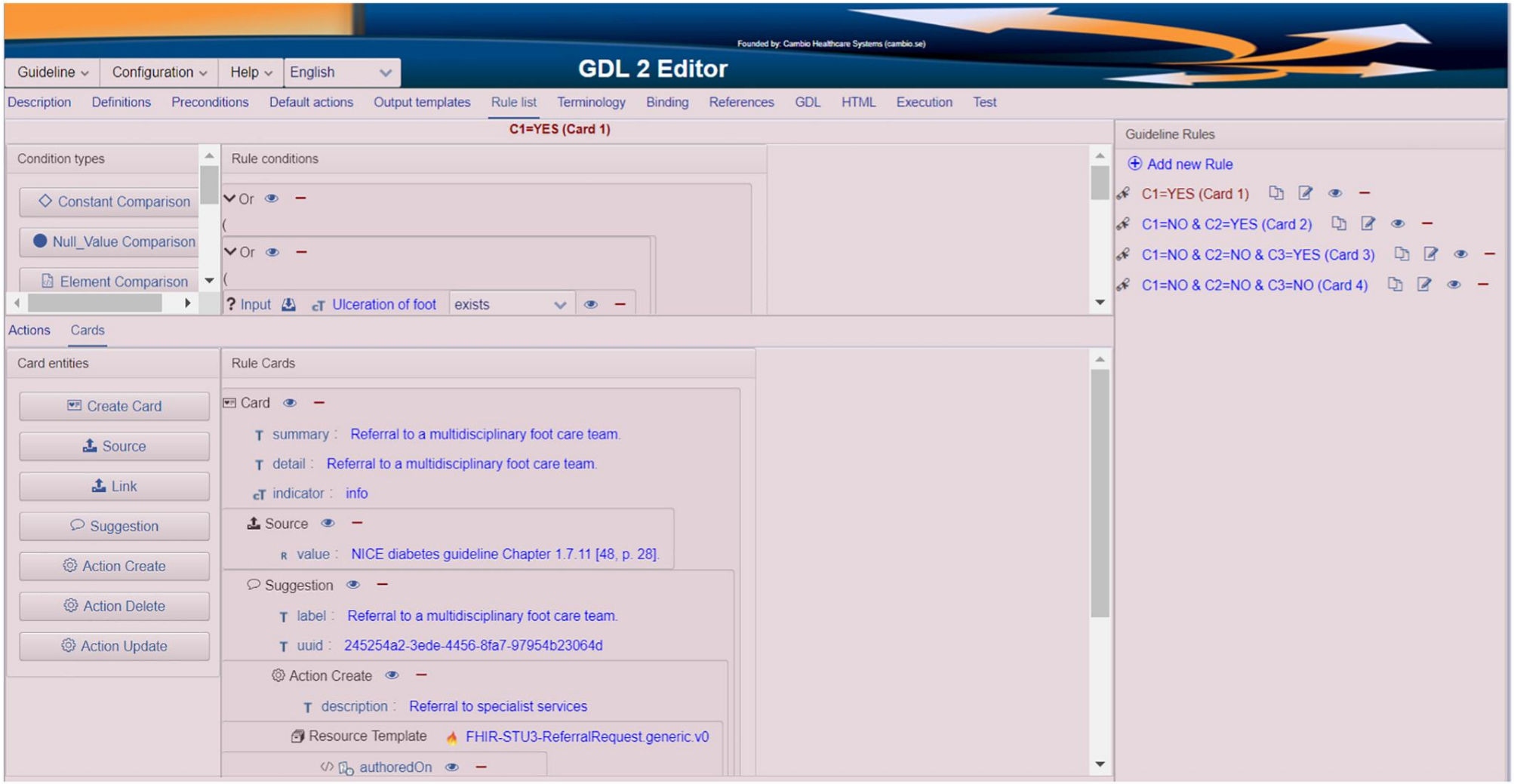
Representation of Information - II

- Multiple CIG Ontology
  - 72 classes, 74 object properties, 127 data properties, and 132 individuals (instances) of the enumerated classes
  - 4 conceptual groups
    - » Guideline Service Deployment (GSD)
    - » Patient Care Personalisation (PCP)
    - » HEalthcare Service (HES)
    - » Multi-Activity management (MAN)



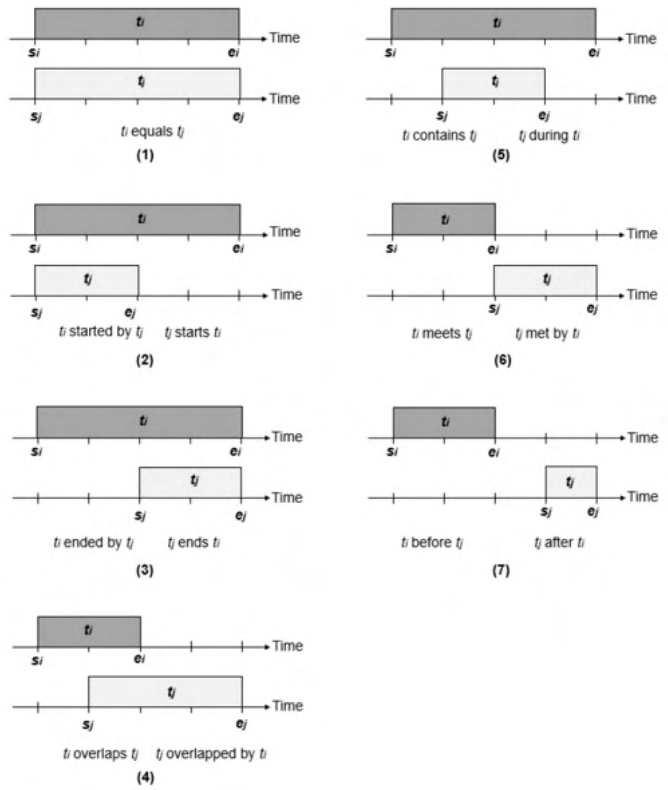
PhD of Eda Bilici Özyiğit: MuCIGREF: multiple computer-interpretable guideline representation and execution framework for managing multimorbidity care, 2020

Coding of CIGs - II



Execution of Information

- Needs to consider numerous aspects
  - Parallel activities
  - Conflicting activities
  - Dependencies
  - Temporal requirements
  - Invariants
- CIGs become invaluable when considering the parallel execution of multiple guidelines
  - Allows a profound transformation of the model of care that we can offer



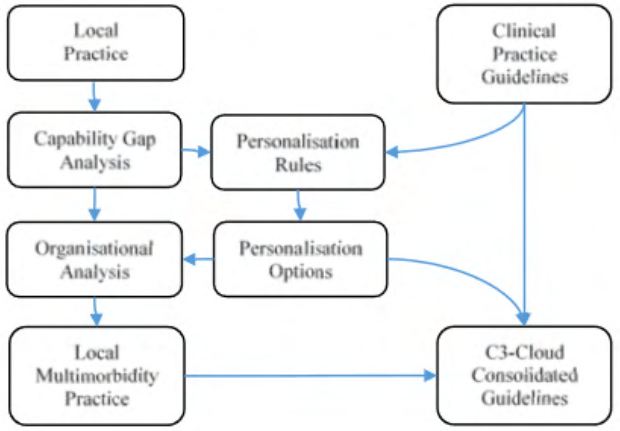
E. Bilici, G. Despotou, and T. N. Arvanitis, Concurrent execution of multiple computer-interpretable clinical practice guidelines and their interrelations, *Studies in Health Technology and Informatics*, 262: 7-10, 2019

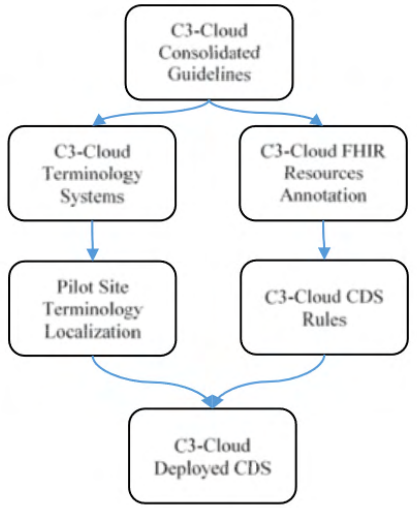
```
context Prescription inv correctDosage:
    self.content.oclAsType(MedicationPrescription).dosageInstructions->forAll( i | i.dose ->
forAll(d | oclAsType(DoseQuantity).type = 'mg' and
d.oclAsType(DoseQuantity).oclAsType(Quantity).value <200))
```

G. Despotou, M. Yuksel, B. Sarigul, and T.N. Arvanitis, Drug Interaction Advisory Service for Clinical Decision Support of Multimordity Patient Centric Care Plans in the C3-Cloud System, tudies in Health Technology and Informatics, 262: 388-391, 2019

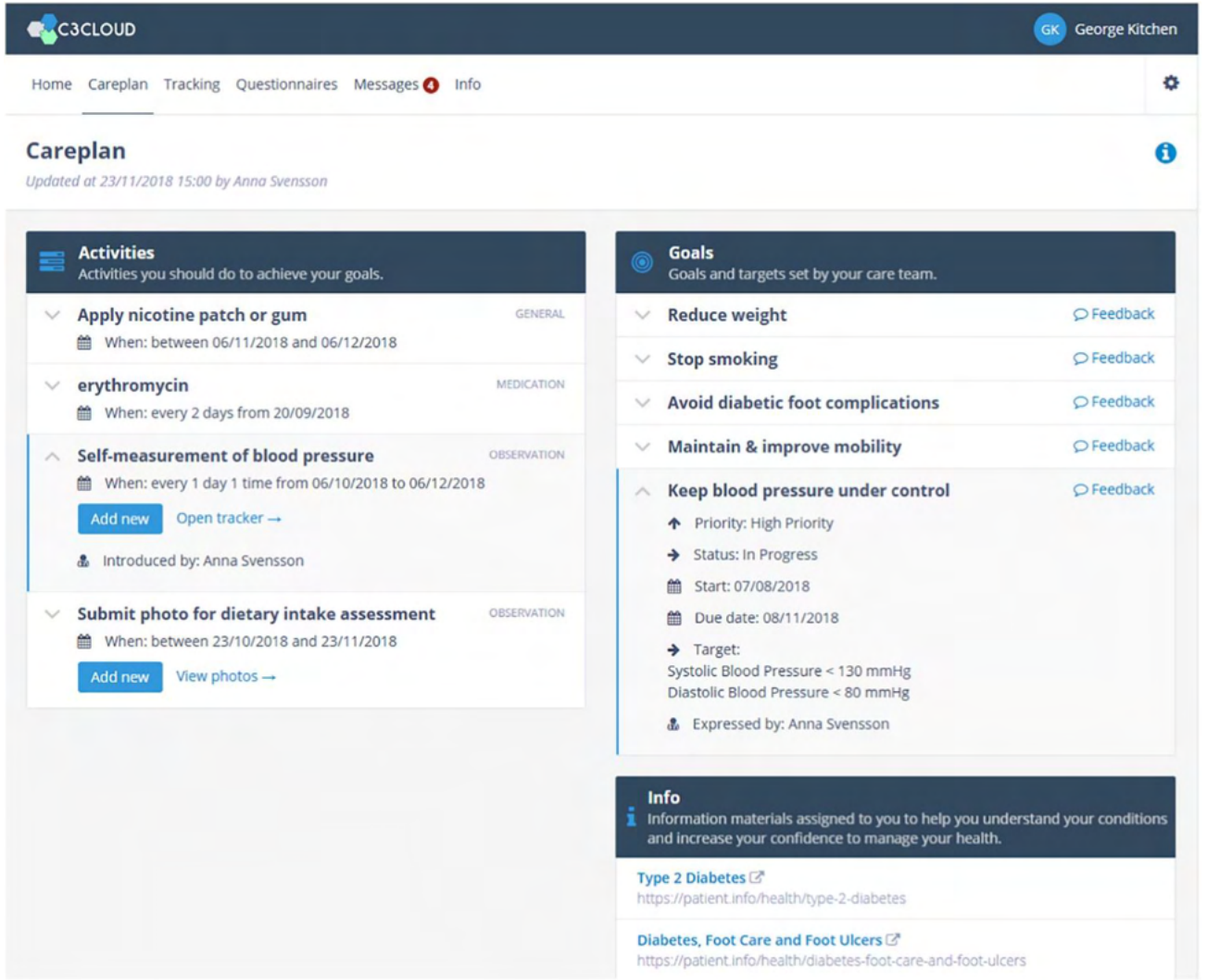
V&V of CIG

- Need to ensure that we implement the correct and intended guidelines
  - Clinical acceptance
  - Co-production
- Need to ensure that we have implemented the intended guidelines correctly
  - Requirements traceability
  - Test cases
- Through-life maintenance





Deployment of CIGs



CIG Research in IDH

- European (Horizon 2020) Consortia
  - C3-Cloud
  - ADLIFE
  - CAREPATH
- HDR UK: Ontological Framework for CIGs and Associated Tools
  - Ontology on Multimorbidity Related Guidelines
    - » PhD Research: **Eda Bilici Özyiğit:** MuCIGREF: multiple computer-interpretable guideline representation and execution framework for managing multimorbidity care, 2020
  - OWL and EMF Modelling, GDL2, Execution Engines, Clinical Validation
  - NLP-based Evaluation of the Fitness of UMLS as a semantic source for a CIG Ontology

  - IDH HDR UK Team members in CIG research: O. Khan, G. Despotou and T. N. Arvanitis
  - Past member: E. Bilici Özyiğit

IDH Publications on CIG/CDS related work

- A Collaborative Platform for Management of Chronic Diseases via Guideline-Driven Individualized Care Plans, DOI: 10.1016/j.csbj.2019.06.003
- Localisation, Personalisation and Delivery of Best Practice Guidelines on an Integrated Care and Cure Cloud Architecture: The C3-Cloud Approach to Managing Multimorbidity, DOI 10.3233/SHTI200235
- The use of computer-interpretable clinical guidelines to manage care complexities of patients with multimorbid conditions: A review, DOI: 10.1177/2055207618804927
- Structuring Clinical Decision Support Rules for Drug Safety Using Natural Language Processing, DOI 10.3233/978-1-61499-880-8-89
- Concurrent Execution of Multiple Computer-interpretable Clinical Practice Guidelines and Their Interrelations, DOI: 10.3233/SHTI190003
- Drug Interaction Advisory Service for Clinical Decision Support of Multimordity Patient Centric Care Plans in the C3-Cloud System, DOI 10.3233/SHTI190100

HDRUK
Health Data Research UK

Institute of Digital Healthcare

Thank you

t.arvanitis@warwick.ac.uk

WMG
THE UNIVERSITY OF WARWICK

Interoperable and computable clinical guidelines

Dr Philip Scott
Reader in Health Informatics, University of Portsmouth
Chair, BCS Health & Care
Co-chair, FCI-BCS working group on computable biomedical knowledge

FACULTY OF CLINICAL INFORMATICS

bcs The Chartered Institute for IT

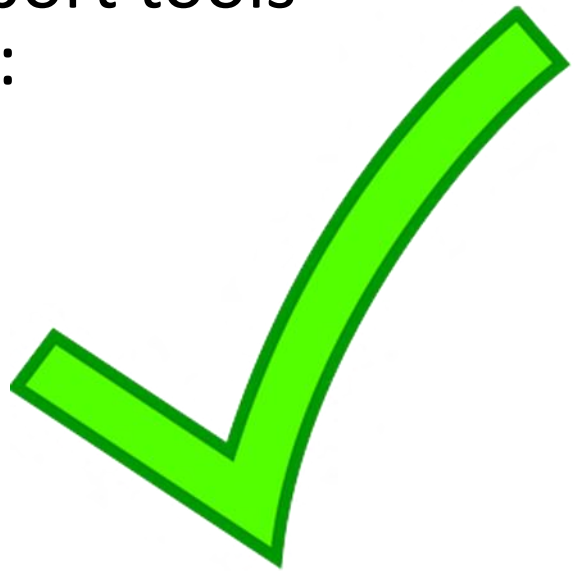
Contents

- Focus
- Context
- UoP MONAD project
- MCBK-UK
- HDR UK computable knowledge collaborathon
- NHS Scotland project

Focus

- **NOT** knowledge production (clinical trials, systematic reviews, guideline development, data science).

- Knowledge **deployment** into clinical decision support tools (apps, electronic health records, medical devices):
  - Standards
  - Ecosystem
  - Governance
  - Curation
  - Policy



Context

- “t
  w
  to
- “I
  o

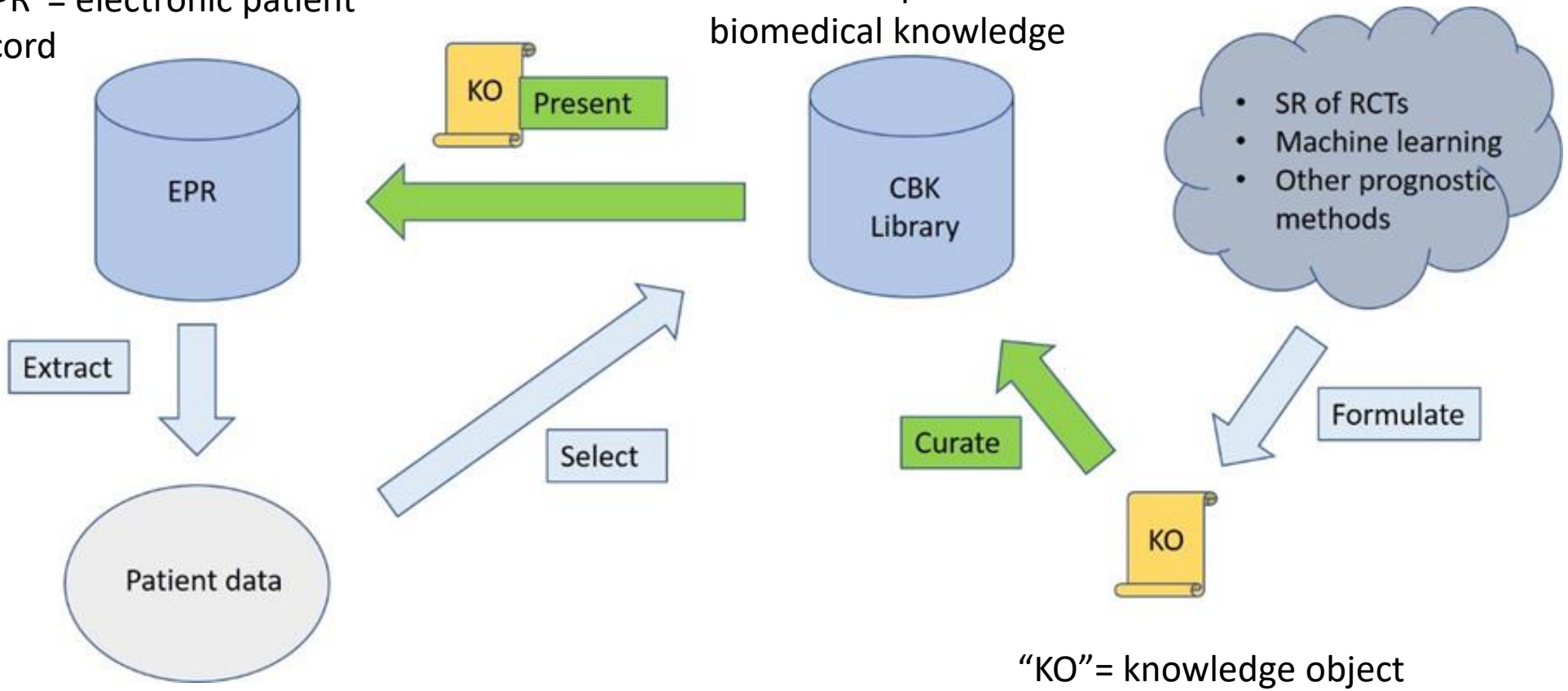
Co

SH...)

UoP MONAD project

"EPR"= electronic patient record

"CBK"= computable biomedical knowledge



"SR"= systematic review
"RCT" = randomised controlled trial

"KO"= knowledge object

MOdelling Next-generation heAlthcare Decision support

MONAD

UNIVERSITY OF PORTSMOUTH

RAMSEY SYSTEMS

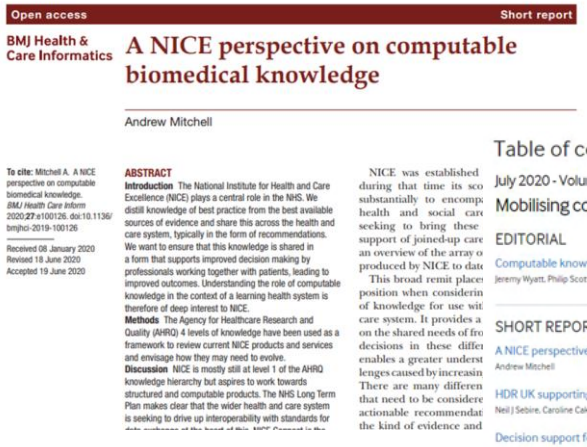
PRSB Professional Record Standards Body

UoP MONAD project

- Technical
  - Prototype software developed to demonstrate EPR interaction.
  - Showed feasibility of CQL knowledge objects in FHIR Libraries, executed on FHIR data.
  - Basis for HL7 UK educational competition.
- Policy
  - Focus group on trust and governance issues held Dec 2019.
  - Abstract published in *Learning Health Systems.*
- Sustainability and leadership
  - Formed MCBK-UK working group between BCS and Faculty of Clinical Informatics.
  - Also involves NICE and Health Education England.

MCBK-UK

- First discussions June 2019, first conference October 2019.
  - Reports and editorial in special issue of *BMJ Health & Care Informatics*: https://informatics.bmj.com/content/27/2
  - Videos on YouTube: https://www.youtube.com/playlist?list=PLn7CfTWFFBSzTZtK4bTpo7Q2kBLjr0RUM


Open access Short report

BMJ Health & Care Informatics

A NICE perspective on computable biomedical knowledge

Andrew Mitchell

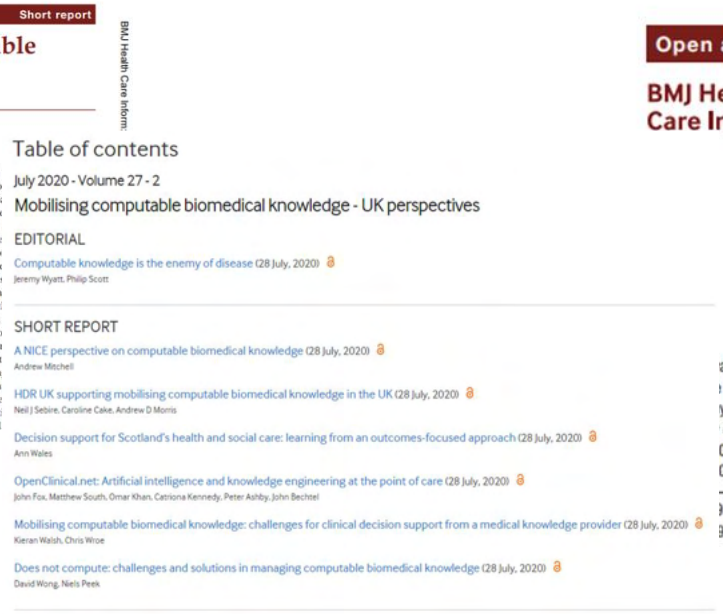


Table of contents

July 2020 - Volume 27 - 2

Mobilising computable biomedical knowledge - UK perspectives

EDITORIAL

Computable knowledge is the enemy of disease (28 July, 2020)

Jeremy Wyatt, Philip Scott

SHORT REPORT

A NICE perspective on computable biomedical knowledge (28 July, 2020)

Andrew Mitchell

HDR UK supporting mobilising computable biomedical knowledge in the UK (28 July, 2020)

Neil J Sebire, Caroline Cake, Andrew D Morris

Decision support for Scotland's health and social care: learning from an outcomes-focused approach (28 July, 2020)

Ann Wales

OpenClinical.net: Artificial intelligence and knowledge engineering at the point of care (28 July, 2020)

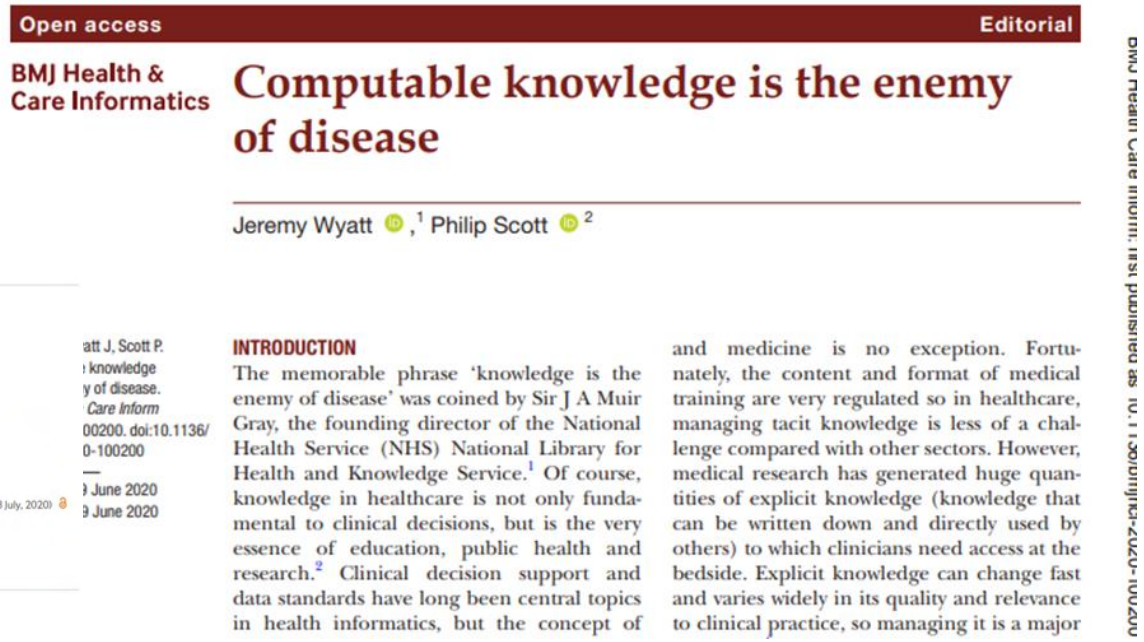
John Fox, Matthew South, Omar Khan, Catriona Kennedy, Peter Ashby, John Bechtel

Mobilising computable biomedical knowledge: challenges for clinical decision support from a medical knowledge provider (28 July, 2020)

Kieran Walsh, Chris Wroe

Does not compute: challenges and solutions in managing computable biomedical knowledge (28 July, 2020)

David Wong, Niels Peek


Open access Editorial

BMJ Health & Care Informatics

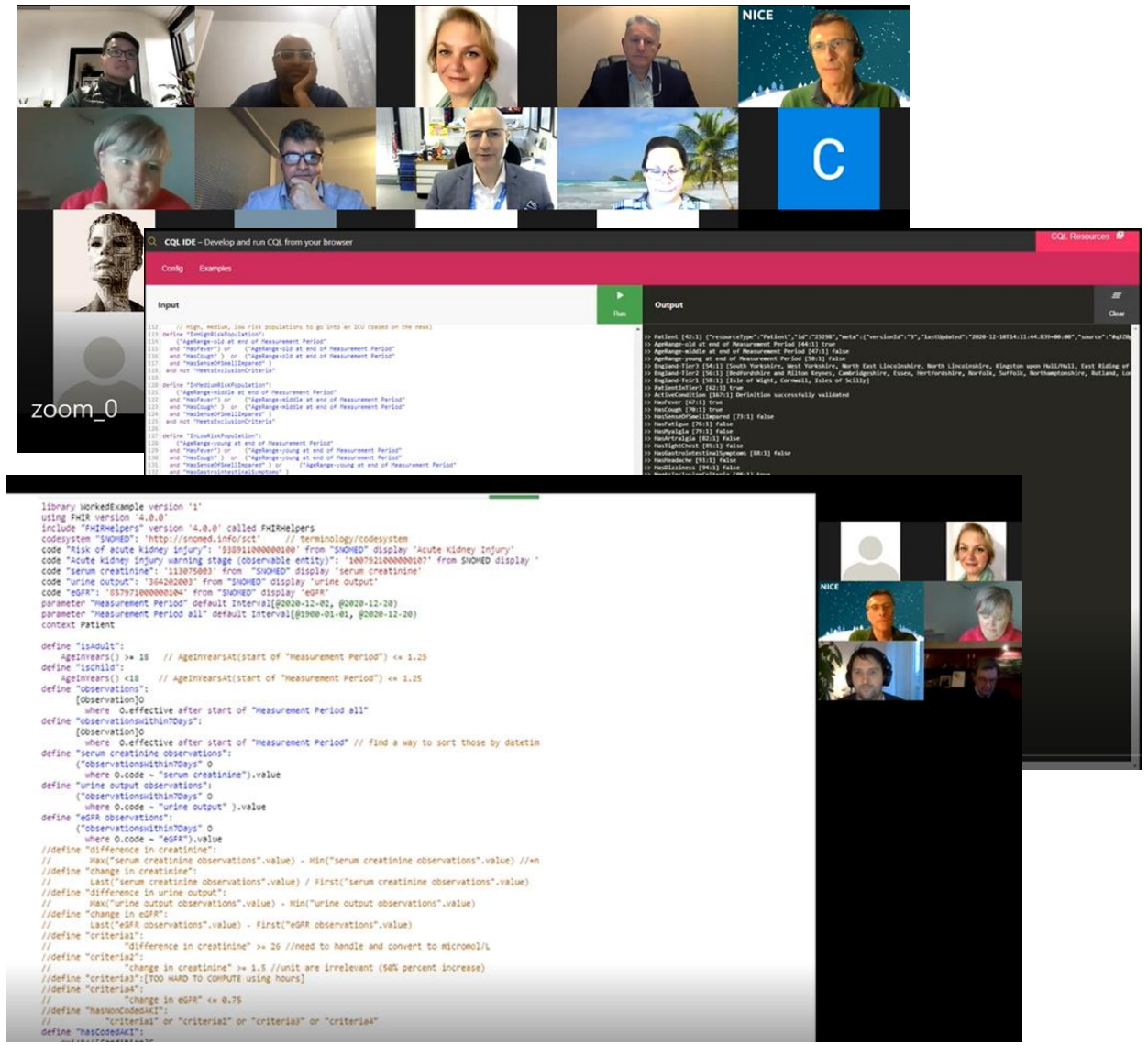
Computable knowledge is the enemy of disease

Jeremy Wyatt [1], Philip Scott [2]

INTRODUCTION

The memorable phrase 'knowledge is the enemy of disease' was coined by Sir J A Muir Gray, the founding director of the National Health Service (NHS) National Library for Health and Knowledge Service.[1] Of course, knowledge in healthcare is not only fundamental to clinical decisions, but is the very essence of education, public health and research.[2] Clinical decision support and data standards have long been central topics in health informatics, but the concept of and medicine is no exception. Fortunately, the content and format of medical training are very regulated so in healthcare, managing tacit knowledge is less of a challenge compared with other sectors. However, medical research has generated huge quantities of explicit knowledge (knowledge that can be written down and directly used by others) to which clinicians need access at the bedside. Explicit knowledge can change fast and varies widely in its quality and relevance to clinical practice, so managing it is a major

HDR UK Computable Knowledge Collaborathon



- 10 December 2020 virtual event.
- Four teams, 11 participants from 7 organisations.
- Judges from PRSB, HDR UK, NICE and NHS Wales / FCI.
- Total 35 including observers.
- Teams produced computable algorithms of NICE guidance using Clinical Quality Language (CQL): https://cql.hl7.org/

HDR UK Computable Knowledge Collaborathon

- Difficult to get **computable** artefacts from HDR UK projects, focus seems mainly on traditional publication.
- NICE supports the vision of computable knowledge, but narrative content is still predominant.
- Research mindset seems mostly about knowledge production rather than knowledge deployment at scale in routine practice.
- Deploying someone else's knowledge artefact is more challenging than building your own (especially without an ecosystem and standards).
- Computable knowledge teams **must** include both clinical & technical.
- There is an enthusiastic community that wants this kind of event.

NHS Scotland technical review

- Review of current products
- International context
- Market capabilities
- GP system implications
- Potential standards-based approach

Potential standards-based approach

- Background
  - Numerous guideline formalisms developed over several decades, e.g. Proforma, Arden Syntax, GELLO, GLIF, ASBRU and many more.
- Future
  - HL7® FHIR® is anticipated to become the *lingua franca* for health and care **data**.
  - US federal projects on CDS are mostly using HL7 Clinical Quality Language (CQL, https://cql.hl7.org/), which is being co-developed with FHIR.
  - Some US projects are using Business Process Modelling+ from the Object Management Group® (BPM+, https://www.bpm-plus.org/) with CQL.

Potential standards-based approach

	CQL & BPM+
Advantages	Co-developed with HL7 FHIR. Considerable US support, including federal agencies. Large development communities (OMG, HL7). Likely strong influence on industry roadmaps. Some UK national infrastructure uses or plans FHIR interoperability. GP systems suppliers starting to support FHIR interoperability
Disadvantages	No prior experience in UK. CQL immature and incomplete. Separation of concerns between CQL and BPM+ still emerging.

Thank you for your attention

- Philip.Scott@port.ac.uk
- https://www.hdruk.ac.uk/news/computable-knowledge-part-1-of-2-what-is-it-and-why-do-we-need-it-to-build-a-learning-health-system/
- https://www.hdruk.ac.uk/news/computable-knowledge-part-2-of-2-learning-from-the-hdr-uk-collaborathon-make-it-fair/

Computable guidelines: how psychology can help

Prof Jeremy Wyatt DM(Oxon) FRCP(Lon) ACMI Fellow, FCI Founding fellow

Co-lead, FCI-BCS group on Mobilising Computable Biomedical Knowledge

Emeritus Professor of Digital Healthcare, University of Southampton

j.c.wyatt@soton.ac.uk

Do guidelines change clinical practice ?

Guidelines alone ***rarely*** change clinical behaviour (Grimshaw ’92, 2002, 2004 systematic reviews)

A psychological explanation is **poor wording**:

- Using specific, concrete statements helps people understand & remember (Ley ’97)
- Study of 10 Dutch guidelines: GPs followed guideline twice as often (on 67% of occasions) when wording was concrete as when wording was vague (36%) - Grol R, 1998

A practical challenge is **finding the right guideline** (and the recommendation in it) at the right time…

Hibble A et al. Guidelines in general practice: the new Tower of Babel? *BMJ* 1998; 317 doi: https://doi.org/10.1136/bmj.317.7162.862

Improving guideline wording

The more precisely the desired behaviour is specified, the more likely it is to be carried out

To increase “behavioural specificity”**,** we need to state:

- **what action**
- **who does it**
- **when, where,** and **how**

Rewriting reminders & alerts like this may be the simplest, most effective way to increase the uptake of advice

(Susan Michie, BMJ 2004)

The practical problem: finding the right guideline and recommendation when you need it

Challenges:

- Many guidelines, and many recommendations per guideline (30-150)
- Many different guideline users (GP, practice nurse, therapist, hospital doctor, social worker...) and clinical settings
- Pressures of time, interruptions (Tonks '99) and data overload make clinical work "***a humanly impossible task***" (Rector 1991)

However, decision support systems & reminders based on computable guidelines may help

Decision support systems

"A knowledge-rich system that uses two or more items of patient data to generate encounter-specific advice or interpretation" (Wyatt & Spiegelhalter 1991)

ACORN chest pain adviser in use in Westminster Hospital A&E, 1989

Meta analysis of the impact of decision support

122 RCTs studying impact on clinical practice in 1.2M patients managed by 11,000 care providers
Small effect sizes (4%
Large heterogeneity (

Type of outcome	No of trials
Prescribing	68
Test ordering	30
Documentation	25
Vaccination	12
Other*	35
All	122

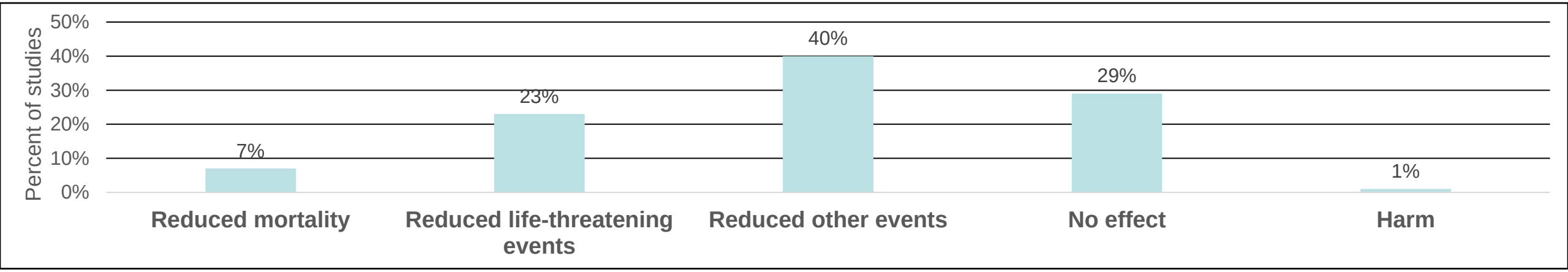
Feature (no. of studies)	Effect size (CI)
Paediatric setting (9)	**14.7% (8.4 to 21)**
Acknowledgement required (20)	**4.8% (0.1 to 9.6)**
Execute the action via DSS (58)	**4.4% (0.9 to 7.9)**
Targeted under-used behaviour (82)	**4% (0.1 to 7.9)**
Based on EPIC platform (25)	3.8% (-0.5 to 8.2)
Interruptive (55)	3.2% (-0.4 to 6.7)
Push vs. pull advice (90)	2.4% (-3.5 to 8.2)
Other DSS active at the time (14)	2.1% (-3.4 to 7.6)
Appearance differed if urgent (3)	-0.5% (-11.4 to 10.4)
Included supporting information (53)	-1.1% (-4.7 to 2.5)
Requires input of patient information (9)	-1.9% (-8.8 to 4.9)
Outpatient care setting (90)	-3.7% (-7.8 to 0.5)
Includes patient-specific information (107)	-4.4% (-9.8 to 1.0)

* Diagnosis, guideline adherence, specialty referral etc.

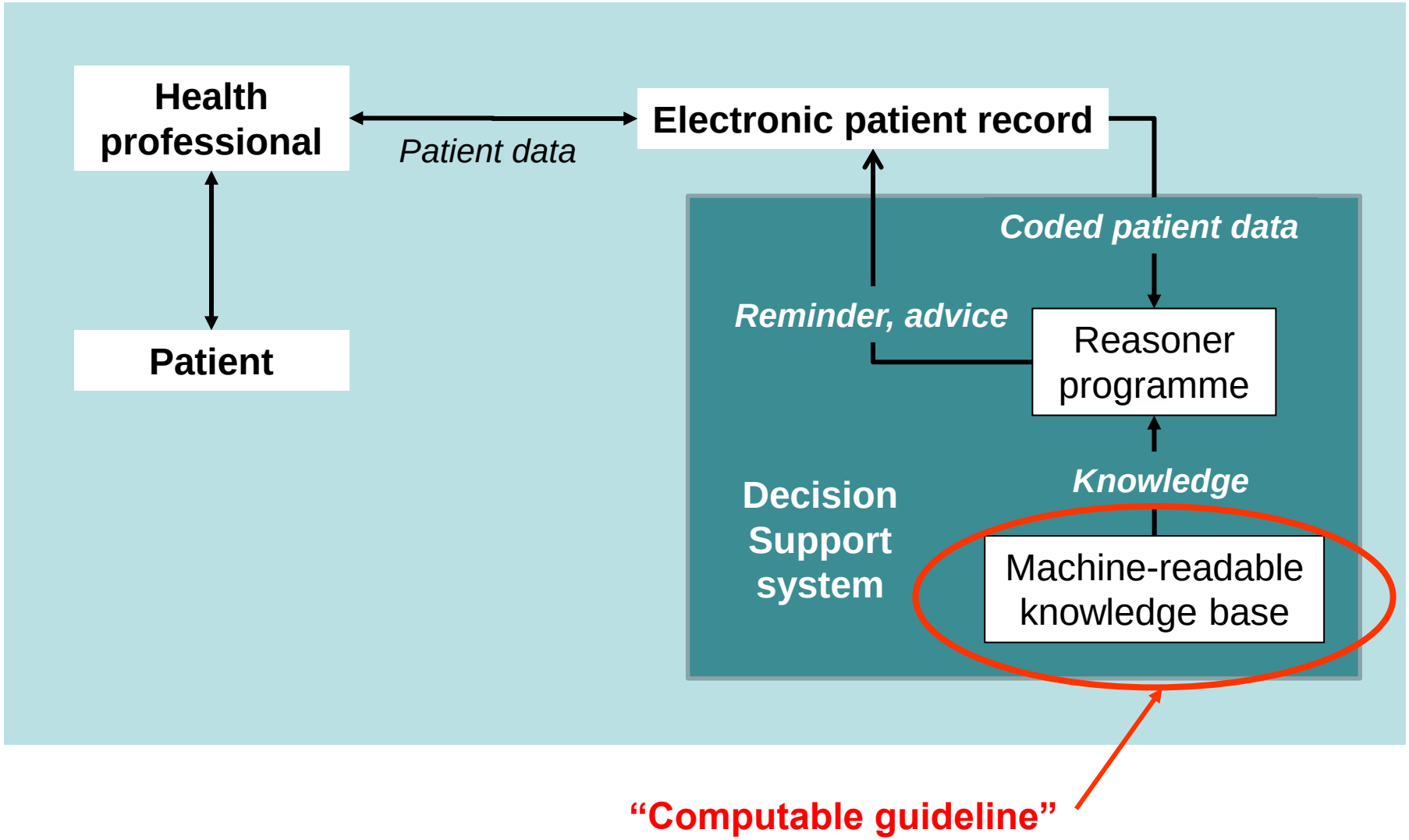
Evidence: decision support systems benefit patients

Systematic review of 70 patient outcome studies (Varghese et al. JAMIA 2018):

- 33 prospective nonrandomized studies with pre/post analysis or cohort studies (47%), 20 randomized controlled studies (28%), 18 retrospective studies (25%)
- 70% of the studies showed patient benefit (**graph**); 29% no patient benefit, 1 showed harm (blood glucose system ***increased*** hypoglycaemic events)
- High effect scores & medium or low risk of bias for DSS in 6 of 24 disease / care groups: managing blood glucose or blood transfusion & preventing physiological deterioration, pressure ulcers, AKI or VTE
- 72% of algorithms were rule-based, 6% were Bayesian nets, 22% not stated



How do decision support systems work ?



Capturing the computable guideline knowledge base

Most computable guideline languages & tools (eg. GEM, GLIF, Protégé, Proforma) help user to capture the entire guideline from a PDF version

Issues:

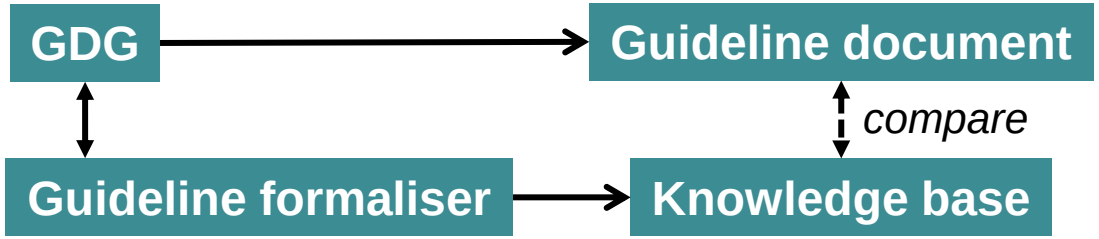
- Little chance of guideline development groups using such tools
- Most tools fail to specify **who / when / where / how**
- It takes much work to capture & formalise an entire guideline
- When the same computable guideline was captured independently by several authors, there was large variation in the results (Ohno-Machado, JAMIA 99)

From Guideline Development Group (GDG) to knowledge base

Now – sequential, retrospective process:

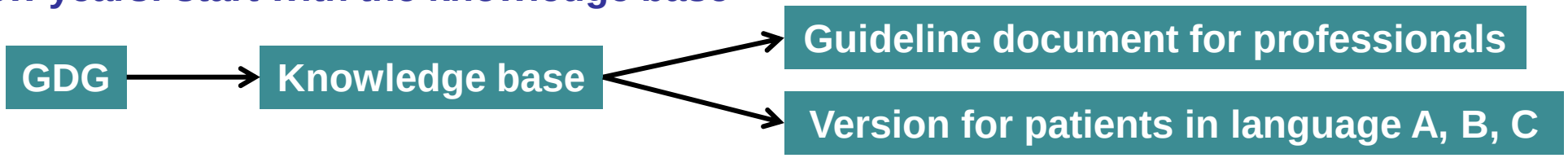
Result: reminder incomplete (lacks who, when, where) & inaccurate, so less likely to change behaviour

Soon – parallel, prospective process (Goud R et al, IJMI 2008):



Result: guideline more complete & consistent & reminder more accurate, so more likely to be followed

In a few years: start with the knowledge base



Draft web form to capture a reminder

Name of reminder			
Reminder text to be displayed to user			
List of potential actions that user can carry out following reminder:			
Describe the logic of the reminder			
Other information: eg. reference, help text			
List of contexts when the reminder can appear:			
Clinical setting (primary / secondary care etc.)	Health prof.	Type of clinical task	
Status of the reminder (select one box):			
For information			
Advice that can be overruled			
Advice that cannot be overruled			
Information user needs to provide if they wish to overrule advice:			
Reason for overruling			
Role of person with whom user has checked			
Other – specify:			
List of data items needed to prompt the reminder:			
Data item name	SNOMED code	Threshold value	Relevant time

(Jeremy Wyatt for SIGN, 2007)

Results of computable guideline RCT

Cluster RCT of impact of computable guideline (captured prospectively by guideline formaliser Rick Goud working with Netherlands Heart Foundation / Cardiology Society using GASTON toolkit) on cardiac rehabilitation decisions in 21 centres, studying 2787 post-MI patients

Results:

- Computerised guideline increased concordance with guideline-recommended decisions for:
  - Education therapy - by 26% (above baseline of 64%)
  - Relaxation therapy - by 26% (baseline 34%)
  - Exercise therapy - by 8% (baseline 85% - ceiling effect ?)
- Computerised guideline also reduced over- and under-treatment

(Goud R et al. BMJ 2009)

Conclusions

- Much guideline development activity, but modest impact on clinical practice & patient outcomes
- We need to:
  - Structure guideline advice more clearly, including **who, when, where, how**
  - Help users find & apply recommendations using automatic reminders
  - Capture the reminders prospectively, in structured format
  - Build tools that guideline development groups can use to do this
- We demonstrated the feasibility of this in the Netherlands in 2009

Email: J.C.Wyatt@soton.ac.uk

HDRUK
Health Data Research UK

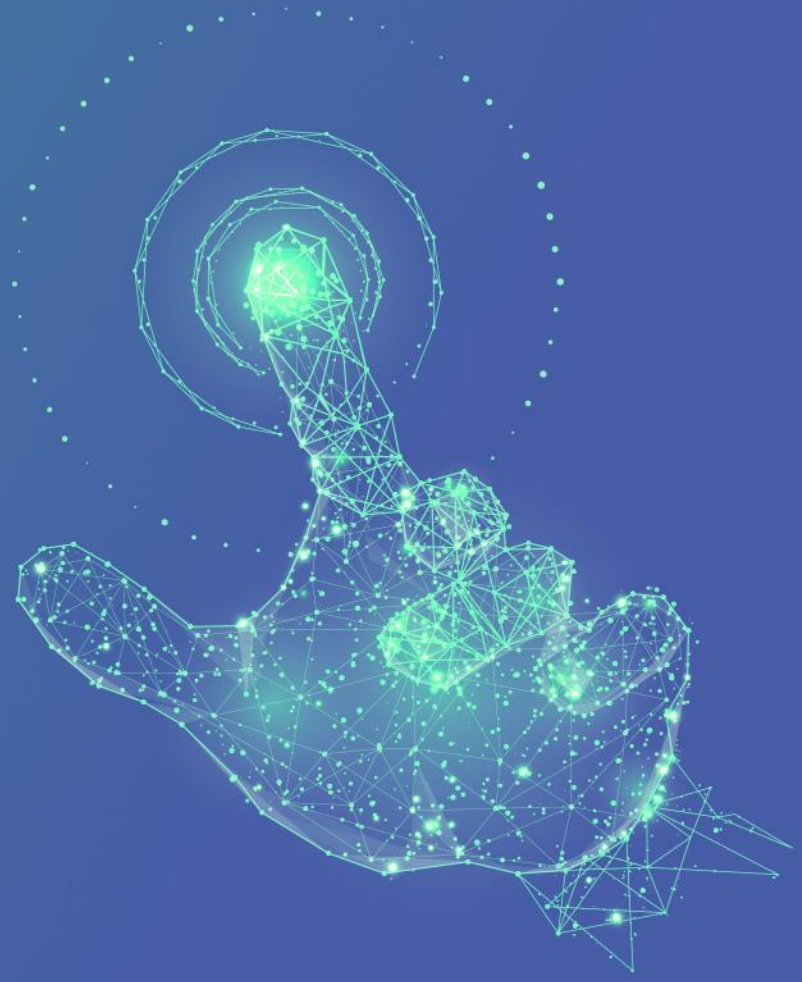
BREAK

The next session will start at 10:45

HDRUK
Health Data Research UK

PPIE for Better Care

10:45-11:45



HDRUK
Health Data Research UK

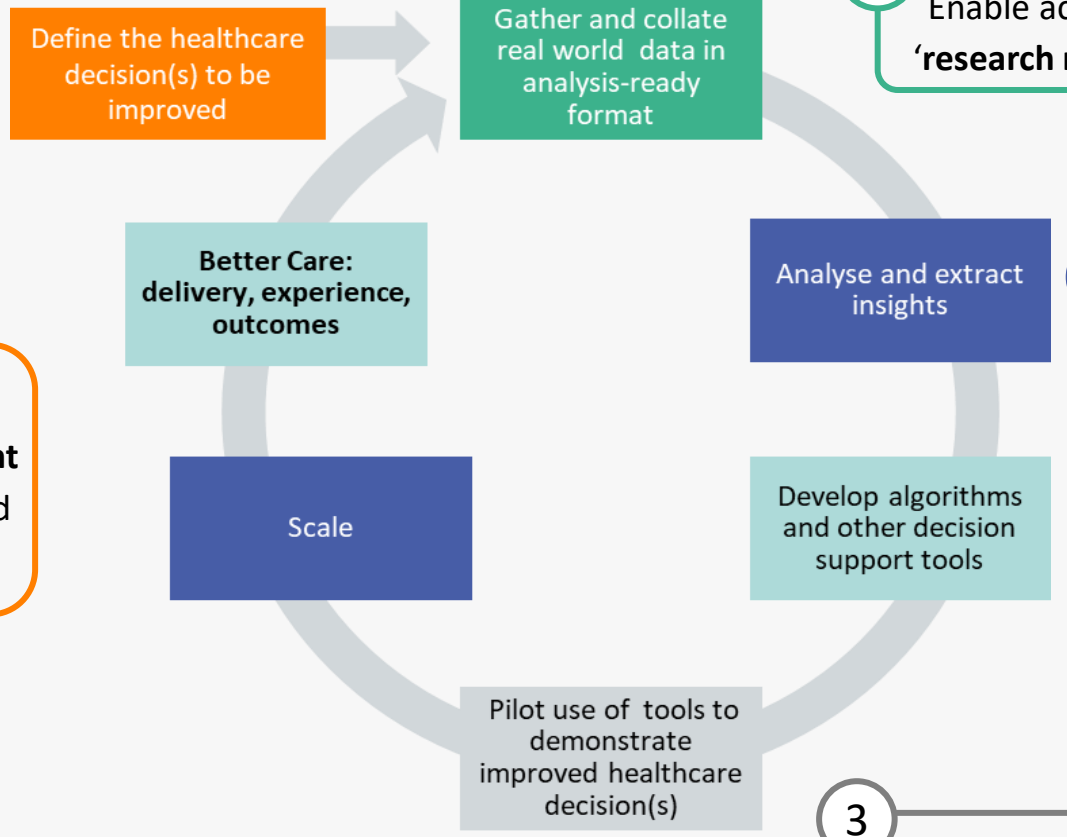
Better Care Programme:

Our vision is that by 2030, patients will benefit from healthcare decisions informed by large scale data and advanced analytics to identify what will work best for them

Improving people's lives by equipping clinicians and patients in the UK with the best possible data-based information to make decisions about their care:

HDRUK
Health Data Research UK

Implementing Better Care loops:



1 Enable access to large scale **'research ready' patient data**

2 Use this data to facilitate academic, industry and clinical innovators in developing **robust and regulated tools and algorithms**

3 Implement the tools to inform **real-world clinical practice**

4 Support a **cycle of continuous improvement to improve patient outcomes** by ongoing real-world evaluation

With a programme of work is aligned to our delivery priorities:

HDRUK
Health Data Research UK

Better Care delivery priorities:	Programme activity
1. Work with the NHS, industry, patients and researchers to deliver **research programmes which develop and exemplify the Better Care approach**	**HDR UK partnership sites** • 8 partnerships (running 24 Better Care projects • Developing solutions and methodologies to scale Better Care loops across multiple health and care settings and to transfer Better Care innovations across multiple health and care decisions **Catalyst projects** • 3 projects delivering rapid learnings about the Better Care Loop • Providing exemplar case studies for learning across the network • 12 months duration (end 01 May 2021)

2. Support the development of **data science & analysis skills** to enable the Better Care approach	**Catalyst workstreams**
	• Underlying needs to support the scalability and sustainability of the Better Care process:
	  • Knowledge management
	  • Training
	  • Policy and insight

3. Provide a **national forum** to accelerate the Better Care approach	**Quarterly insight sharing days** • Convening members of the HDR UK Better Care community and key external partners • Sharing progress and key barriers **Special interest groups** • Collaborations around key themes of interest (clinical and technical) to drive progress and address unmet need

Our goals for Patient, Public and Practitioner Involvement and Engagement (PPPIE) at Health Data Research UK

HDRUK
Health Data Research UK

01 Patients and the public are our partners in design and decision making

02 The needs and interests of the public are understood and embedded in our work

03 People have trust and confidence in the use of health data for research and innovation

04 People are excited about their data being used in research and innovation

DRAFT

Better Care - PPPIE strategy and priorities:

1. **Identify how and where patients, practitioners, carers and the public can most impactfully and meaningfully be involved in Better Care research.**
   - Through this we will ensure we deliver **patient informed research** to tackle the problems that matter most to patients, the public, carers and practitioners.

2. **Create an enabling environment for patients, practitioners, carers and the public to be involved in Better Care research**
   - Prioritise inclusivity to enable participation across diverse groups who may otherwise be excluded from Better Care research, considering digital exclusion, language, lifestyle and cultural barriers.
   - Embed research best practice which enables PPPIE, empowering a connected Better Care network to share knowledge, insights and expertise in PPPIE, and access tools and training to support delivery.

3. **Equip patients, practitioners, carers and the public to act as collaborative participants in research**
   - Support these groups to determine how their data should be collected, shared and used for Better Care research

Guiding Principles:

1. **Focus on impact** for patients, practitioners, carers and the public.
2. **Respond to our audience needs** to enable inclusive, impactful and implementable Better Care research.
3. **Learn and share experience and insights** to maximise patient, practitioner, carer and public engagement and involvement in Better Care research
4. Prioritise patient, practitioner, carer and public views to enable research which considers **real world implementation.**
5. Draw on patient, practitioner, carer and public insights to identify how Better Care research can be **transferred and scale.**

Identify how and where patients, practitioners, carers and the public can most impactfully and meaningfully be involved in Better Care research.

Approach	Outcomes
a) Identify how and where patients, practitioners, carers and the public can offer greatest impact at different stages of the Better Care loop.	Better Care research which makes best use of patient, public, carer and practitioner insights to deliver maximum impact.
b) Proactively seek to understand from the user perspective where issues lie in different care pathways and use these insights to identify research priorities and impacts.	User-led Better Care research which addresses the real-world problems which matter most to patients, practitioners, carers and the public.
c) Stretch goal: Review and identify lessons learnt from approaches to PPPIE in research during the COVID-pandemic and use this insight to inform best practice for Better Care research moving forwards.	Better Care research which continuously learns from our own experience, and that of others to deliver improvements for patients, practitioners, carers and the public.

Create an enabling environment for patients, practitioners, carers and the public to be involved in Better Care research

HDRUK
Health Data Research UK

Approach	Outcomes
a) Review "Better Care Communications Plan" and key messages and revise to ensure we communicate in a way which resounds with a diverse audience.	• Better Care vision, outputs and impacts shared in a way which enables inclusive understanding and engagement. • An empowered, informed and engaged user audience to take an active role in both Better Care research and champion the value of delivering care informed by large scale data and advanced analytics.
b) Collaborate with partners and engage with national, regional and local networks.	• Better Care research which builds trust and awareness by making use of respected and effective networks to access hard to reach groups and a broader audience. • An open, collaborative Better Care community which recognises the expertise of others to increase outreach and impact.
c) Use events (for example Quarterly Insight Sharing days) to connect our broader PPPIE and research communities.	• A connected community with channels available to build collaboration and share insights and expertise across disciplines, geographies and organisations.
d) Identify a network of engaged Better Care PPPIE champions	• A Better Care approach which builds on existing PPPIE expertise and interest to inform how PPPIE can most effectively enhance our work. • A collaborative network with support channels and routes for contact and connection clearly signposted.
e) Provide the tools to evaluate and measure impact of PPIE in BC research	• PPPIE delivering measurable impact throughout Better Care research which is captured and communicated.

Equip patients, practitioners, carers and the public to act as collaborative participants in research, determining how their data should be collected, shared and used for Better Care research

Approach	Outcomes
a) Establishing a PROs Special Interest Group to focus on how patients and the public engage with PROs	Develop solutions which can be implemented in the real-world

All supported by an implementation plan outlining key events and activities.

Measures of success:

Key Performance Indicators

- Number of patients and members of the public participating in Better Care events and consultation (in person and remote) during the reporting period *(new, repeat, TOTAL)*

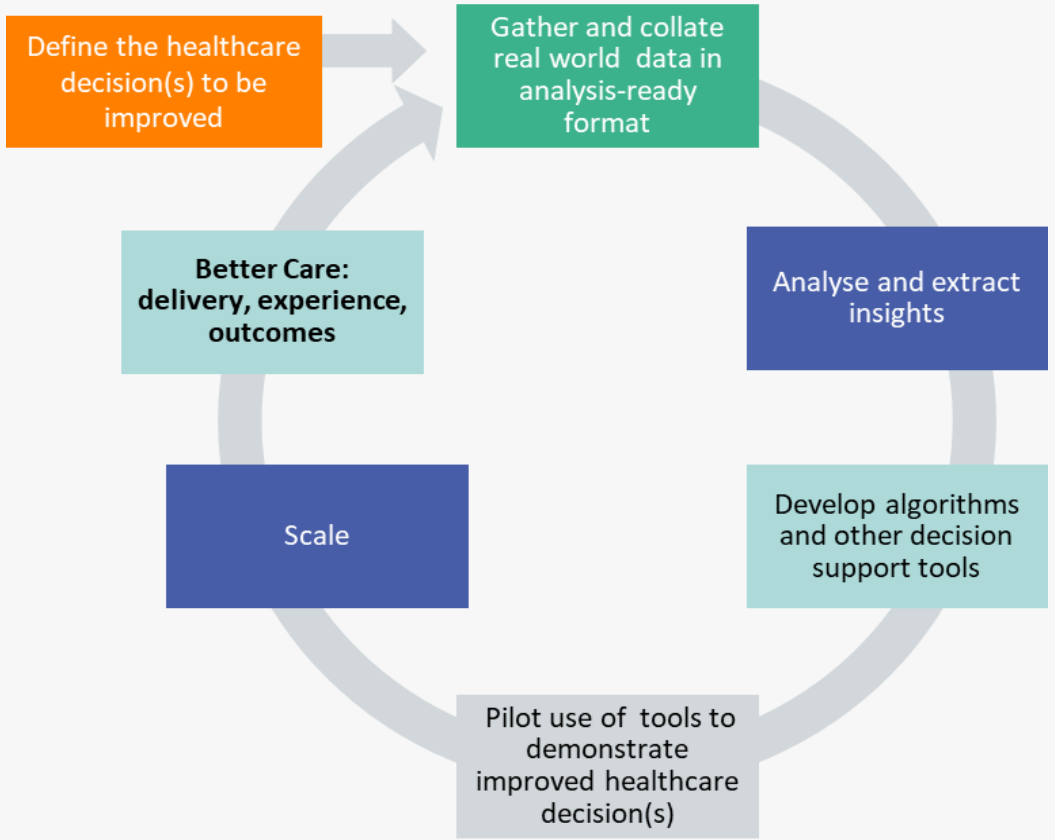
Qualitative Evaluation

Simple evaluation questionnaire after any PPPIE activity to determine:

- Impact on patient, public, practitioner contributors
- Impact on HDR UK staff involved

Breakout groups to discuss:
How can patients, carers, the public and practitioners provide the greatest impact within Better Care research?

1. How can we ensure we're delivering research that tackles problems that matter most to patients, the public, carers and practitioners?
2. How can patients, carers, the public and practitioners be involved in all stages of the Better Care loop?
   - If we had to prioritise where could they have the greatest impact?
3. What support would you need to enable this to happen?



HDRUK
Health Data Research UK

Any questions?

HDRUK
Health Data Research UK

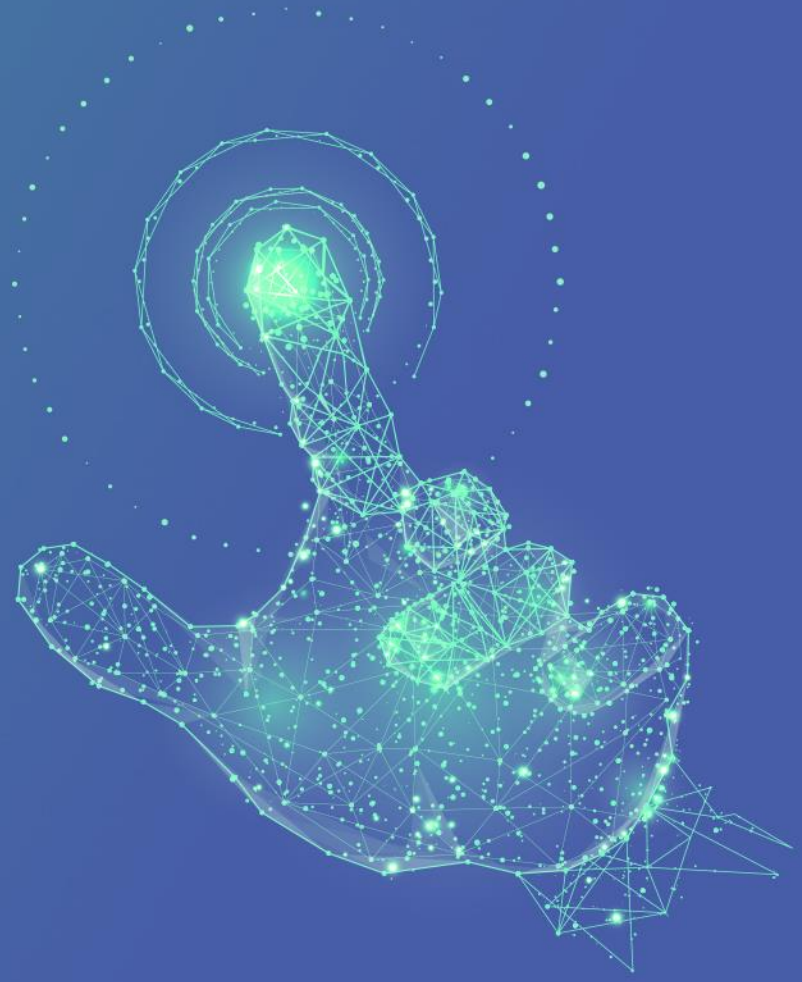
BREAK

The next session will start at 11:55

HDRUK
Health Data Research UK

Better Care Lightning talks - insights from across the Better Care portfolio

11:55-12:55



Better Care Insight Day
RADAR
(Risk Algorithms for Decision support and Adverse outcomes Reduction)

Project Lead: Tony Willis, North West London Health and Care Partnership

Partnership Organisations: Imperial College Health Partners, Institute of Global Health Innovation at Imperial College London, MyWay Digital Health, Astra Zeneca, Imperial College Healthcare NHS Trust

Overview

- Project Recap
- Model revalidation overview
- Stakeholder engagement
- Changes to interfaces & technical work
- Evaluation plan
- Next steps

Background

- Diabetes is one of the greatest challenges currently facing the NHS. In North West London more than 150,000 people have been diagnosed with type 2 diabetes – excess mortality of 2,500 patients/year, over 25,000 admissions annually with CVD complications

- Evidence demonstrates that through assessing the risk of complications and providing targeted and early interventions to those at highest risk can reduce mortality, complications, and hospital admissions

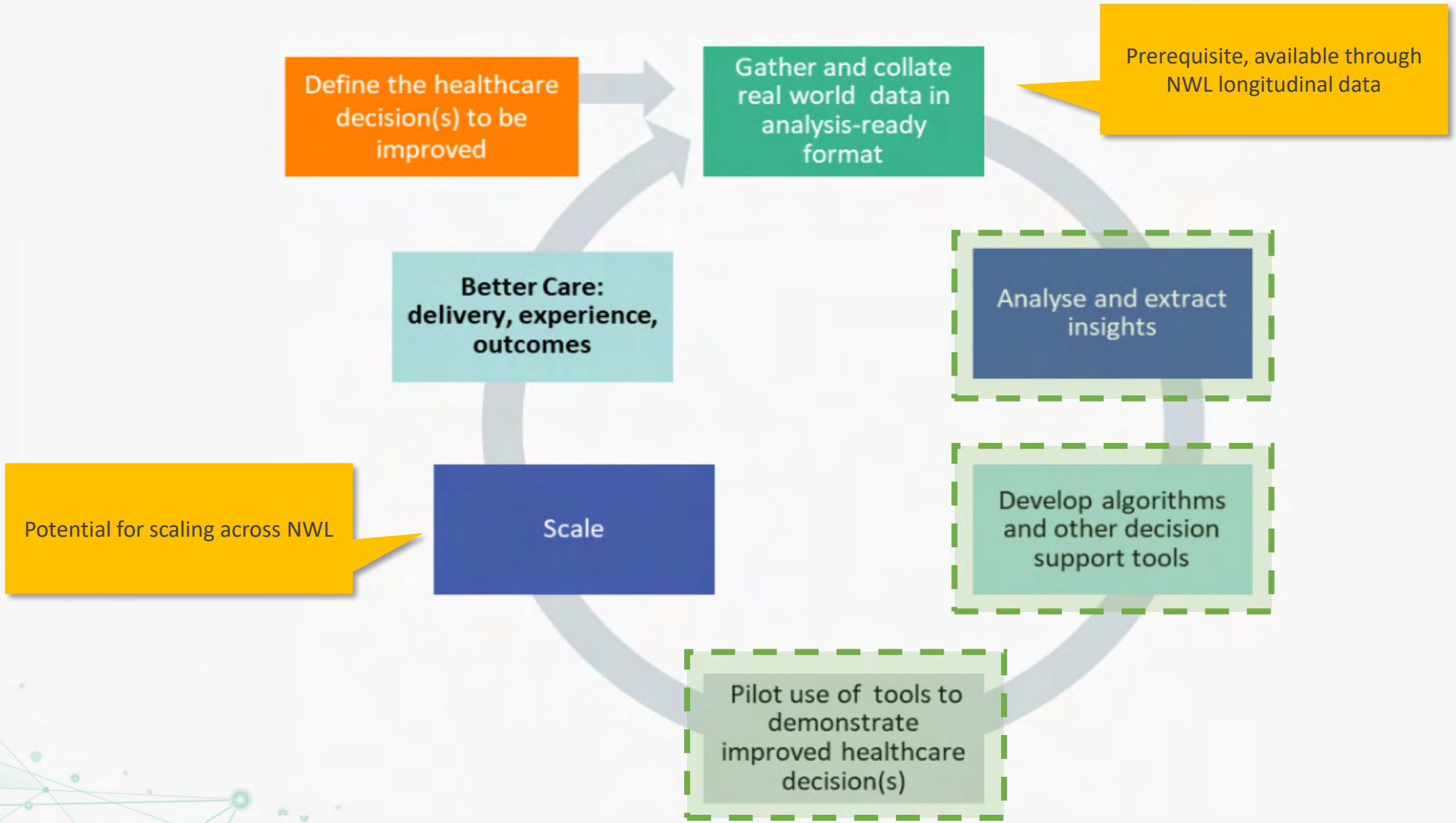
The North West London health and care partnership
IMPERIAL COLLEGE HEALTH PARTNERS
AstraZeneca
Imperial College London
myway digital health
Discover-NOW Health Data Research Hub for Real World Evidence
Imperial College Healthcare NHS Trust
Institute of Global Health Innovation

Project Objectives

- Make use of diabetes predictive AI models developed in Scotland (MWDH)
- Apply these to the Northwest London (NWL) population, by revalidating in NWL's longitudinally linked dataset ('Discover') and widening to incorporate new datasets where relevant
- Consider and develop prototypes for end-user interfaces that use risk prediction to drive clinician and patient behaviour change impacting on clinical decision making and patient self-management behaviour
- "Needs assess" end-user requirements, UX and UI requirements and wider facilitators and barriers to success adoption; and
- Test prototypes with clinicians and patients

The North West London health and care partnership
IMPERIAL COLLEGE HEALTH PARTNERS
AstraZeneca
Imperial College London
myway digital health
Discover-NOW Health Data Research Hub for Real World Evidence
Imperial College Healthcare NHS Trust
Institute of Global Health Innovation

Better Care Loop: Where RADAR Fits In



Key Milestones

- Revalidation of selected models: CVD, Mortality and Composite – supported using DataRobot machine learning tool in the NWL dataset
- Consideration of end user interfaces and needs assessment
- Workshops with patients and clinicians & user testing in which we gathered feedback for iterations to the end user interfaces
- Technical work to link models to end user interfaces
- Evaluation of interfaces with recommended changes incorporated underway

The North West London health and care partnership
IMPERIAL COLLEGE HEALTH PARTNERS
AstraZeneca
Imperial College London
myway digital health
Discover-NOW Health Data Research Hub for Real World Evidence
Imperial College Healthcare NHS Trust
Institute of Global Health Innovation

Model revalidation

- Literature based models (extracted and coded by Pharmatics) have previously been applied and performance validated/benchmarked in an NHS GGC SCI diabetes data extract.

- One of the aims of this project was to apply these models to NW London (NWL) diabetes data, assess their performance and then develop a number of metamodels, with the hypothesis being that these metamodels would outperform the individual literature-derived models in predicting identical outcomes.

- The models below were initially selected for revalidation using DataRobot, these models predict risk of complications in people with Type 2 Diabetes:

Algorithm	End User
Mortality	Individual clinicians
CVD	Individual clinicians
Composite	Individual patients Individual clinicians

The North West London health and care partnership
IMPERIAL COLLEGE HEALTH PARTNERS
AstraZeneca
Imperial College London
myway digital health
Discover-NOW Health Data Research Hub for Real World Evidence
Imperial College Healthcare NHS Trust
Institute of Global Health Innovation

Models developed and validated

Scottish (SCI Diabetes) dataset:

- literature-derived base models developed / internally validated
- metamodels developed and internally cross-validated

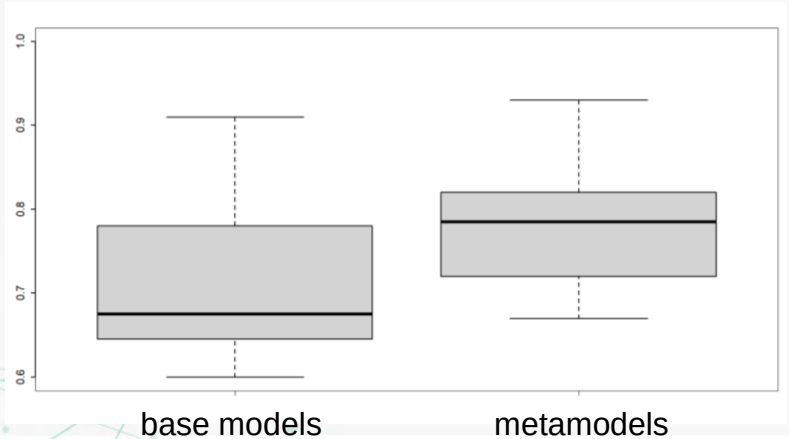
NW London dataset:

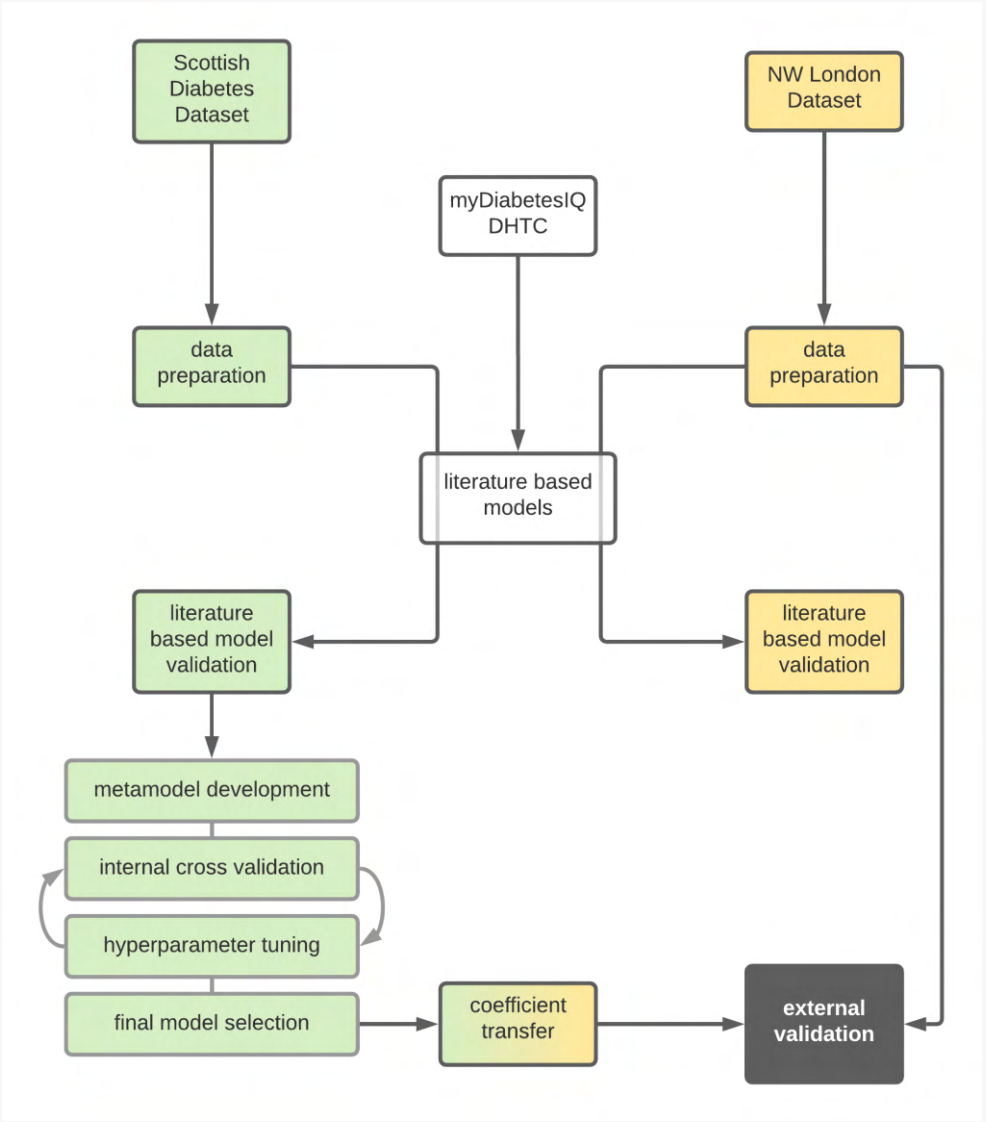
- individual base model performance validated
- metamodels performance externally validated

Prediction Targets:

macrovascular / microvascular complications of Type 2 Diabetes

Model performance / metamodel performance increment:





Development and external validation of literature derived metamodels

Stakeholder workshops

- A series of workshops and user testing was carried out with patients and clinicians to provide feedback on the tools

- This feedback was then reviewed by the team and prioritised, taking into consideration the timelines and scope of the project as well as feedback given in previous workshops held by the University of Dundee in Scotland

- The MWDH development team took this feedback and incorporated it into the latest iteration of the tools ahead of the final evaluation which is currently underway

The North West London health and care partnership
IMPERIAL COLLEGE HEALTH PARTNERS
AstraZeneca
Imperial College London
myway digital health
Discover-NOW Health Data Research Hub for Real World Evidence
Imperial College Healthcare NHS Trust
Institute of Global Health Innovation

Examples of feedback

Clinician Feedback

‘Beauty of the tool is simplicity - this will make information gathering/ processing easier & therefore empowering the patient much easier.’

‘I also really like the patient tool and can see how I could use this to motivate and empower patients to manage their care by supporting them’

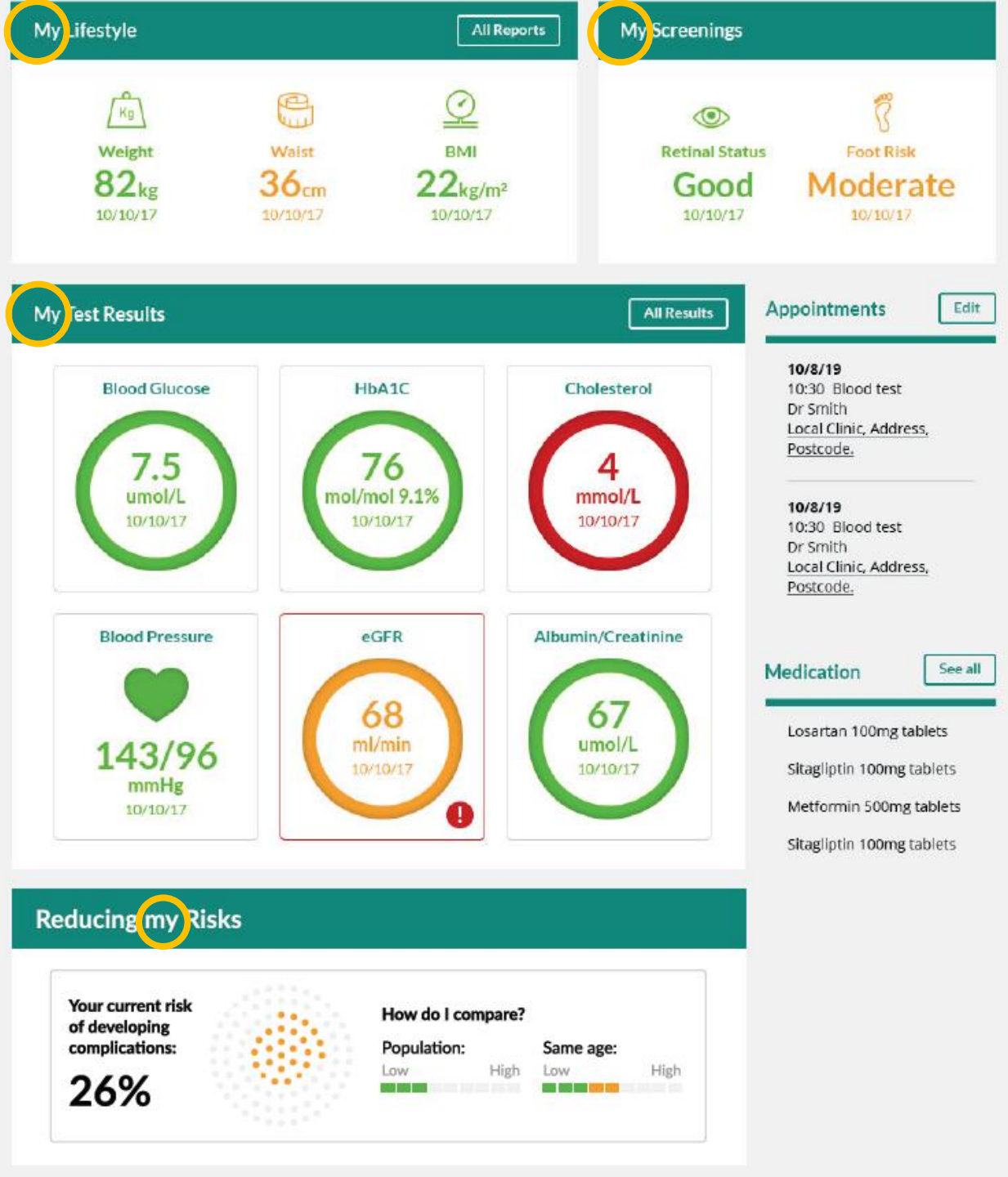
Patient feedback

‘Really good to have all of this information available for patients so that they are aware of the factors that contribute to their health/ take action. I also like that it can be used on a mobile, as that will suit the majority of users like me.’

The North West London health and care partnership
IMPERIAL COLLEGE HEALTH PARTNERS
AstraZeneca
Imperial College London
myway digital health
Discover-NOW Health Data Research Hub for Real World Evidence
Imperial College Healthcare NHS Trust
Institute of Global Health Innovation

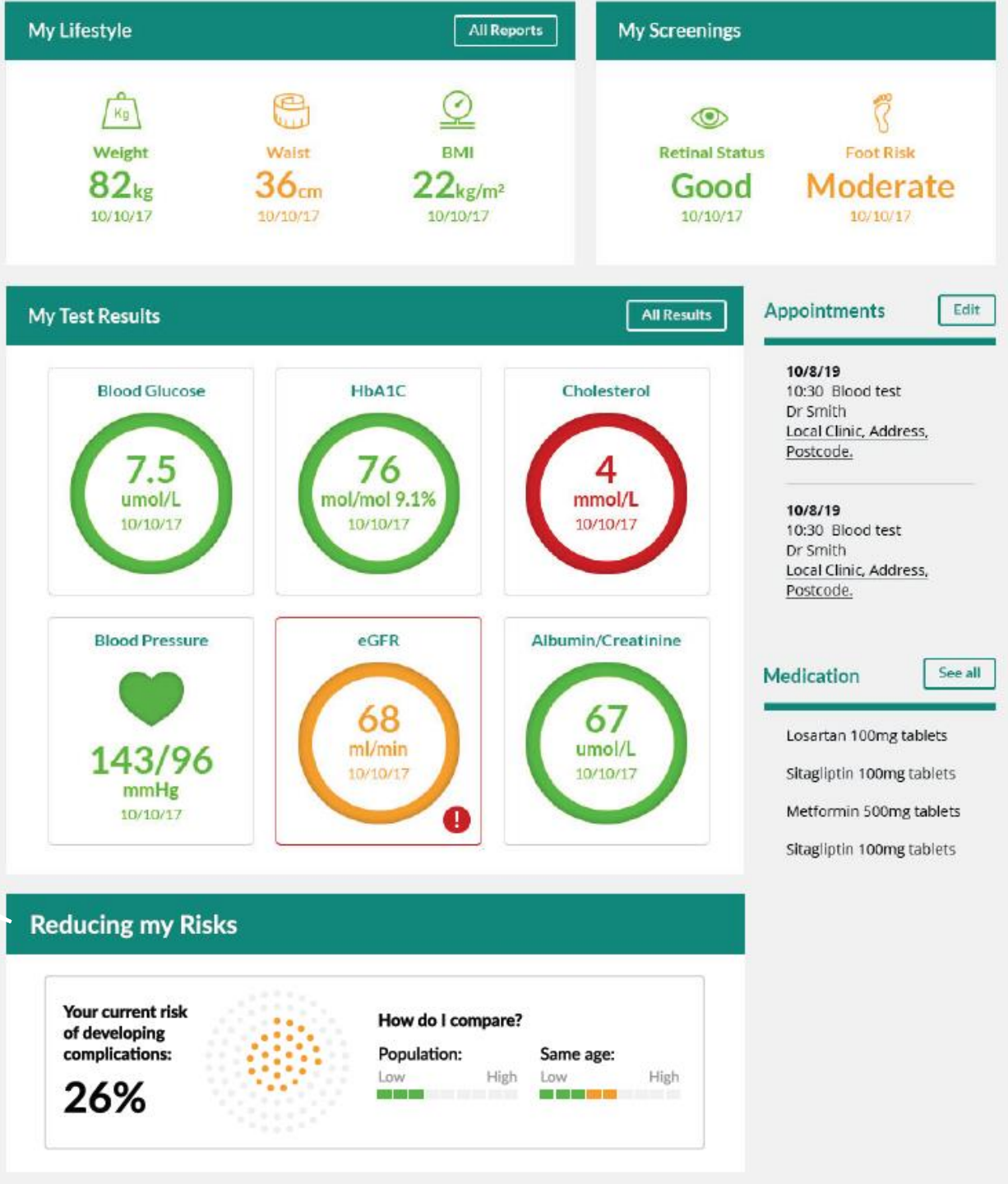
Example of changes

Use of consistent pronouns throughout the site



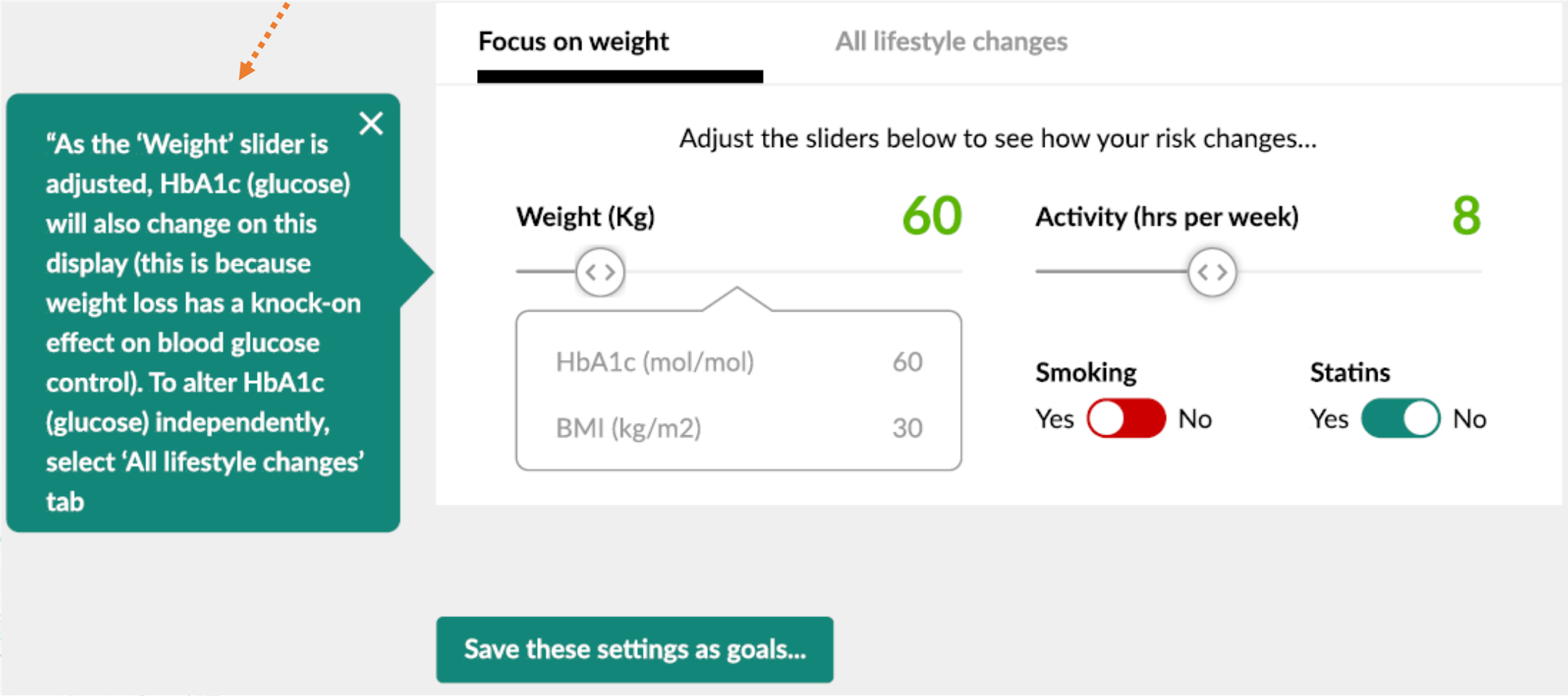
Example of changes

Banner added to ‘Reducing my risks’ block (to make consistent with other blocks)



Example of changes

Confusing text altered – this will appear once user starts to adjust the weight slider



Example of changes

To help explain probability of complications to he user, the <model score> will be inserted into the explanation (accessed via an info icon):

If there were 100 people with a similar health status to you, <model score> would be expected to develop a diabetes-related complication within the selected time period. This includes complications such as:

- Foot complications (ulcers/ amputations)
- Eye complications (blindness)
- Heart disease
- Kidney failure
- Severe low glucose event

Your current risk of developing complications:

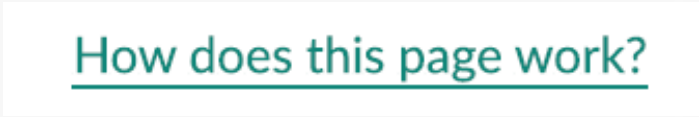
26%

Example of changes

Includes a ‘positive message’ that there are lots of simple things user can do to stay well

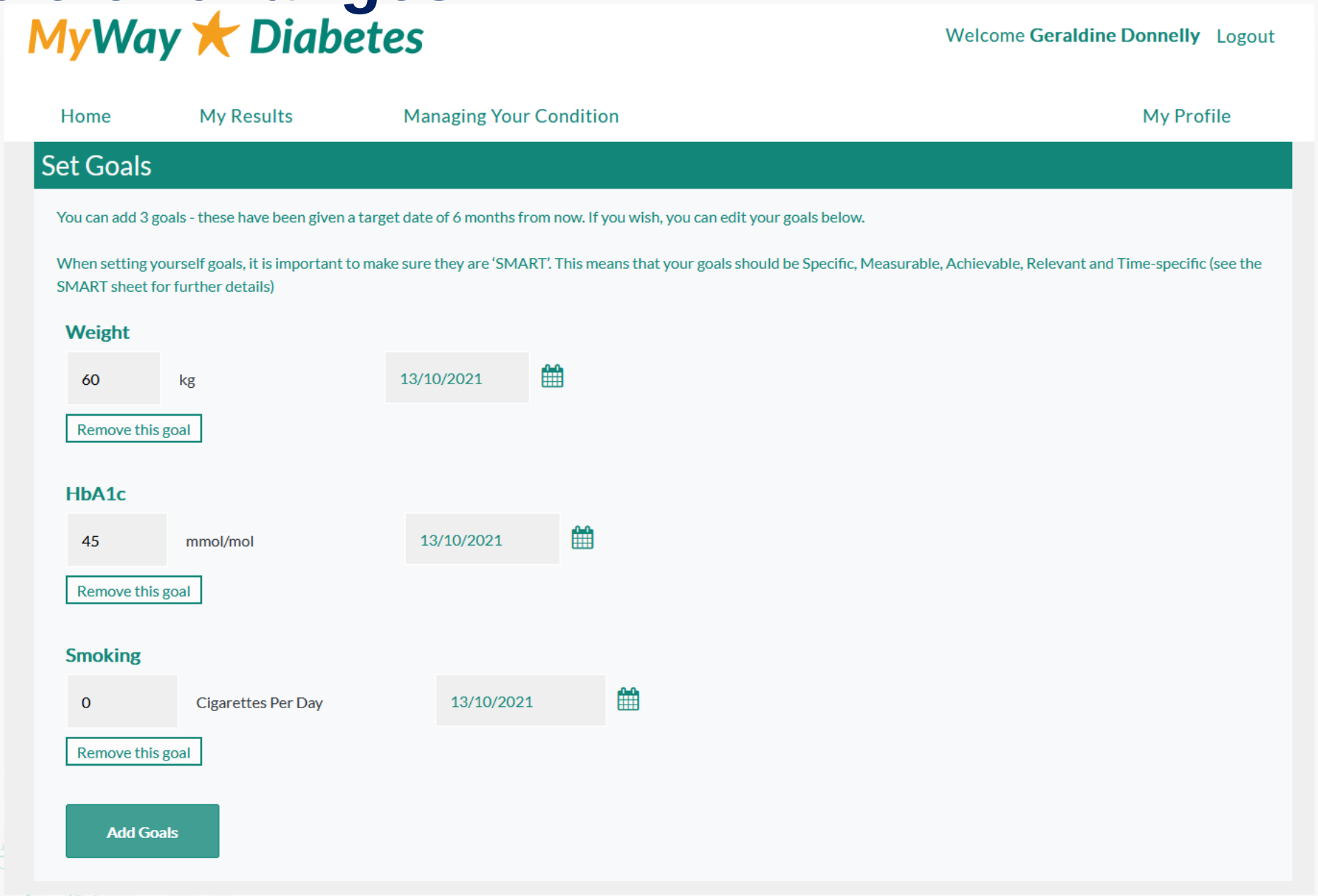
“There are lots of things you can do to stay well and reduce your risk of developing diabetes complications. Keeping active and eating well are really important. Both of these things will not only improve your mood and make you feel more energised in the short term, but will help you build towards a healthier future. The government recommends at least 150 mins of moderate intensity activity every week. Eating a varied and balanced diet and limiting salt, fat and sugar will help you to manage your blood sugar levels. Limiting portion sizes may help with maintaining a healthy weight.”

Will link to a page on how to use the tool, explanations of terms used, and instruction video

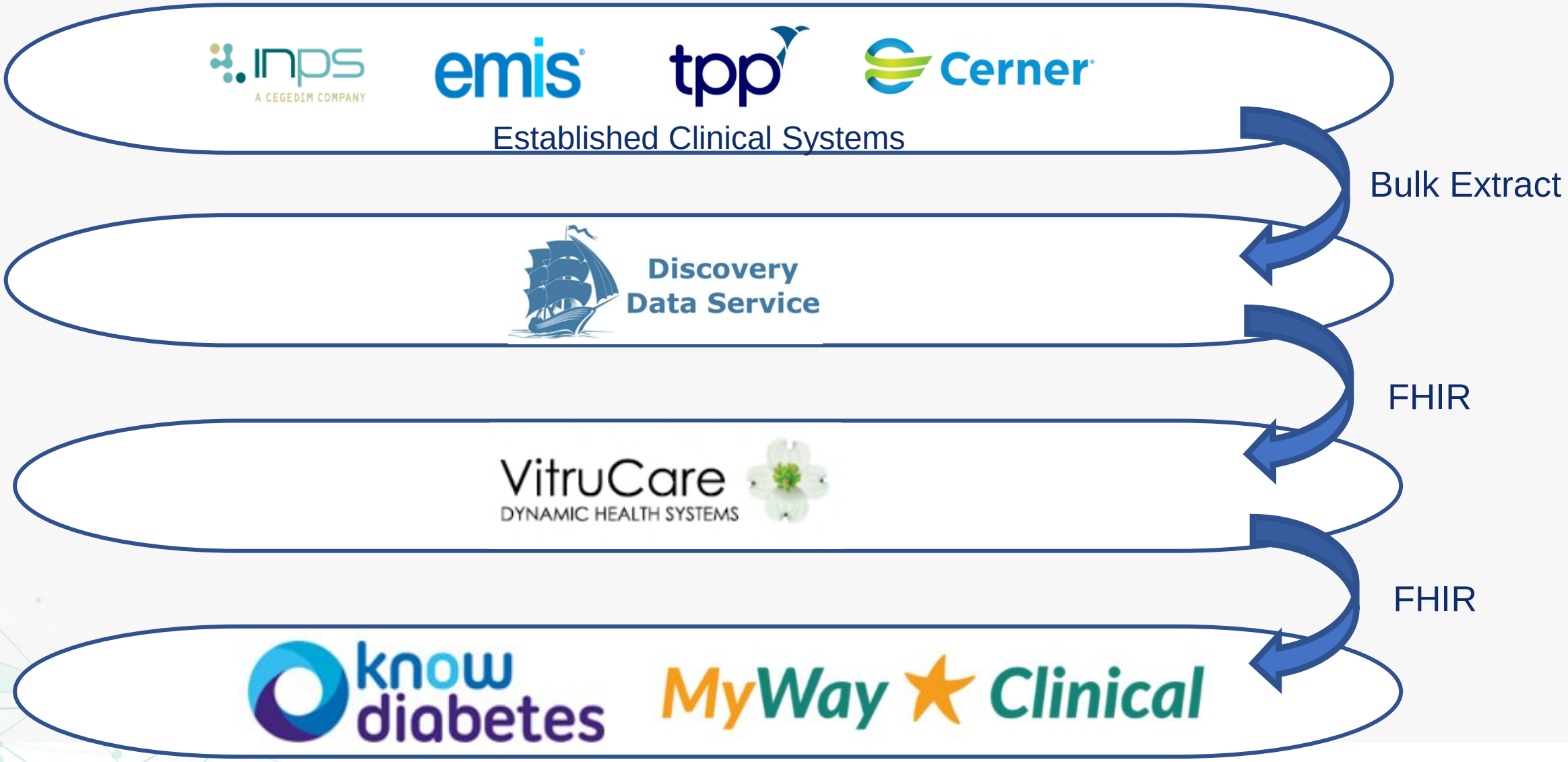


Further clarification of ‘how do I compare?’ gauge - inclusion of ‘average’ and ‘lower than average’ etc

Example of changes



Technical work – data flows



Evaluation

The evaluation of the prototype risk prediction tools is currently underway and is led by Imperial College London.

Objectives

1. To gather **feedback on the usability and acceptability** of risk prediction tools **amongst people with diabetes**.
2. To gather **feedback on the usability and acceptability** of risk prediction tools **amongst clinicians**.

Methods

The tools will be evaluated using a combination of:

- **"Think-aloud" sessions** with people with diabetes (x5) and with clinicians (x5)
- **Simulated consultations** between people with diabetes and clinicians (x5)

Recruitment

- Participants with Type 2 Diabetes recruited using the NWL Health Research Register.
- Clinicians recruited from the team's professional network

The North West London health and care partnership
IMPERIAL COLLEGE HEALTH PARTNERS
AstraZeneca
Imperial College London
myway digital health
Discover-NOW Health Data Research Hub for Real World Evidence
Imperial College Healthcare NHS Trust
Institute of Global Health Innovation

Next steps

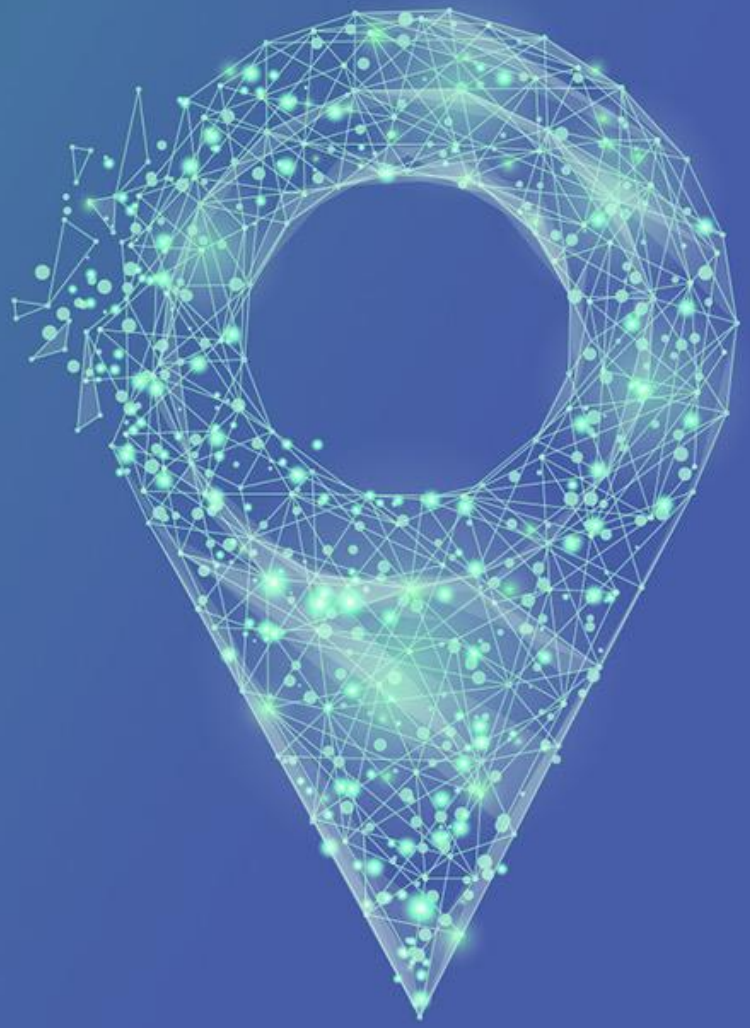
- Project completion at the end of this month
- Consolidation of the results of the evaluation into our final report
- Recommendations for wider rollout and seeking funding opportunities to support this

HDRUK
Health Data Research UK

Improving Anticholinergic Medication Prescribing for Older People with Frailty

Andy Clegg
Professor of Geriatric Medicine
Associate Director, HDRUK North
University of Leeds & Bradford Royal Infirmary
a.p.clegg@leeds.ac.uk
@drandyclegg

05/05/2021



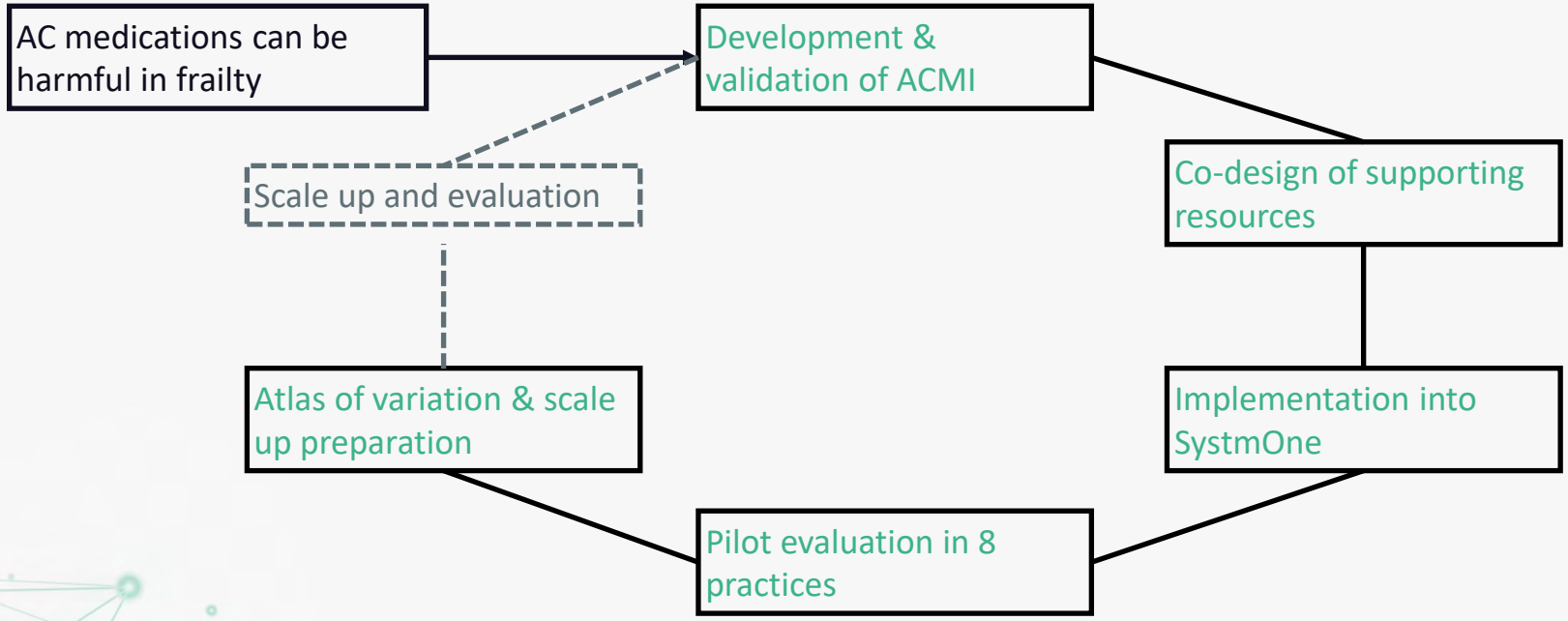
Optimising Anticholinergic Prescribing

We will develop, implement and pilot an Anticholinergic Medication Index (ACMI) and supporting resources to reduce potentially harmful anticholinergic medications for older people with frailty

CONNECTED BRADFORD

SAIL DATABANK

HEALTHY WIRRAL PARTNERS



Progress and next steps

- Jun 2020 – remote access to Connected Bradford dataset
- Jan 2021 – provisional ACMI model
- Feb-Apr 2021 – iterative model development & incorporation of medication doses
- Mar-Aug 2021 – Expert Reference Group meetings/co-design of supporting resources
- May 2021 – internal validation complete
- May-Jul 2021 – development of SystmOne algorithm
- Aug 2021 – evaluation work starts (multiple interrupted time series methods)

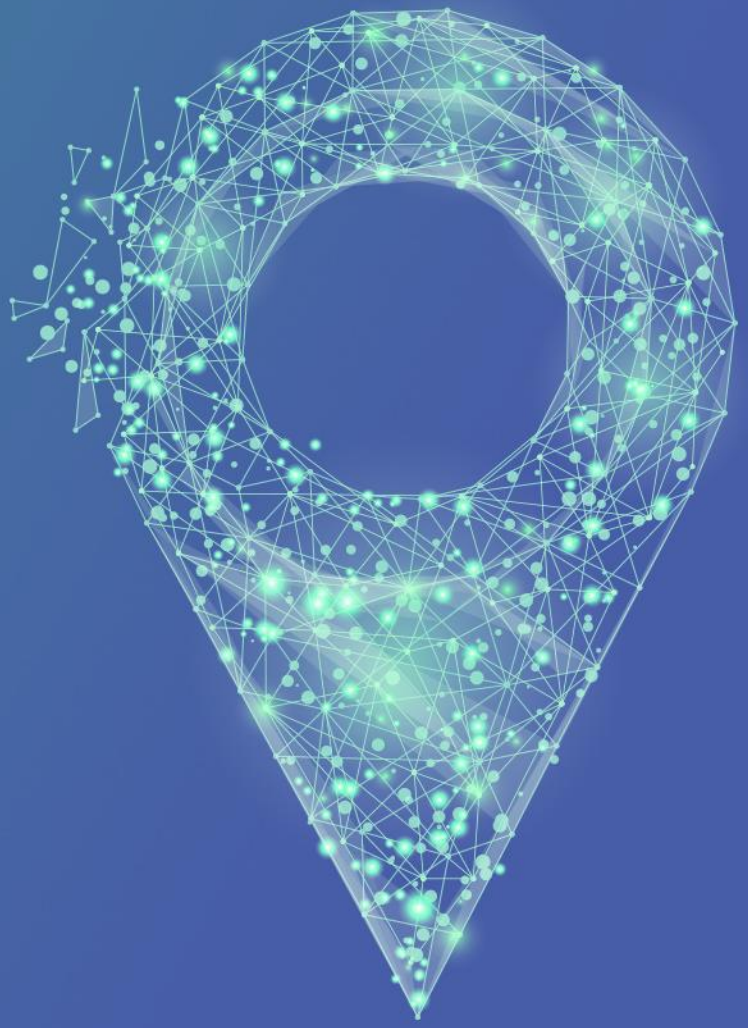
Challenges & learning

- COVID19 delay to co-design of supporting resources & evaluation work
- Complexity of routine data work with medications, particularly medication doses & frequency
- Considerable learning in this area, including development of a standardised approach to defining medication doses using routine data

HDRUK
Health Data Research UK

INDUSTRIAL STRATEGY | UK Research and Innovation

Learning Healthcare System in action: antibiotic prescribing in primary care



Tjeerd van Staa

Co-Director HDRUK North
Lead BetterRx
University of Manchester

ANATOMY OF A CYCLIST'S BRAIN

MANCHESTER 1824
The University of Manchester

Building Rapid Interventions to reduce antimicrobial resisTance and over-prescribing of antibiotics (BRIT)

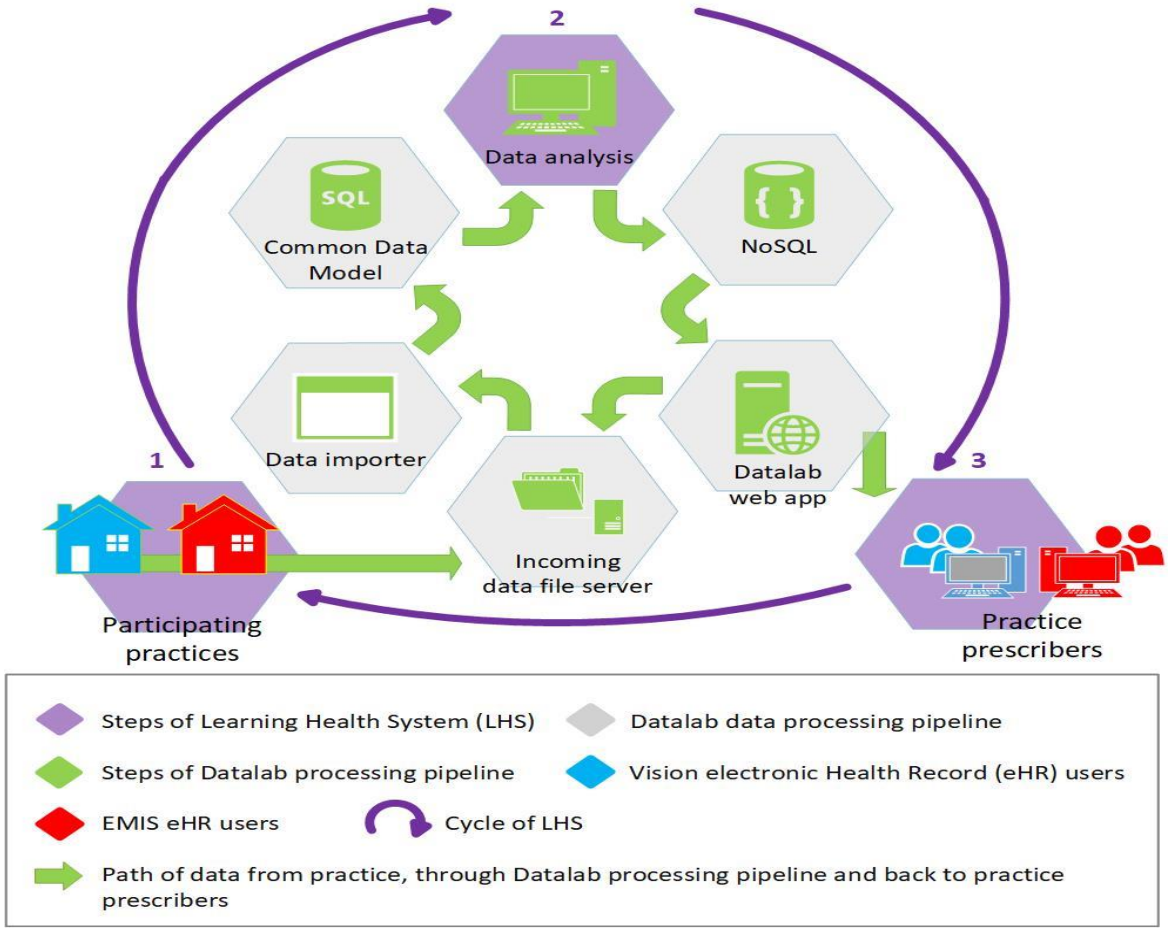
Aim: to implement digital and analytical tools to support effective stewardship of antibiotics and tailored feedback to clinicians on effective care

Approaches

1. Secure processing of GP data (> 70 practices)
2. Feedback to general practices
3. Advanced data analytics using large national datasets combined with participating practices (> 10 million records)

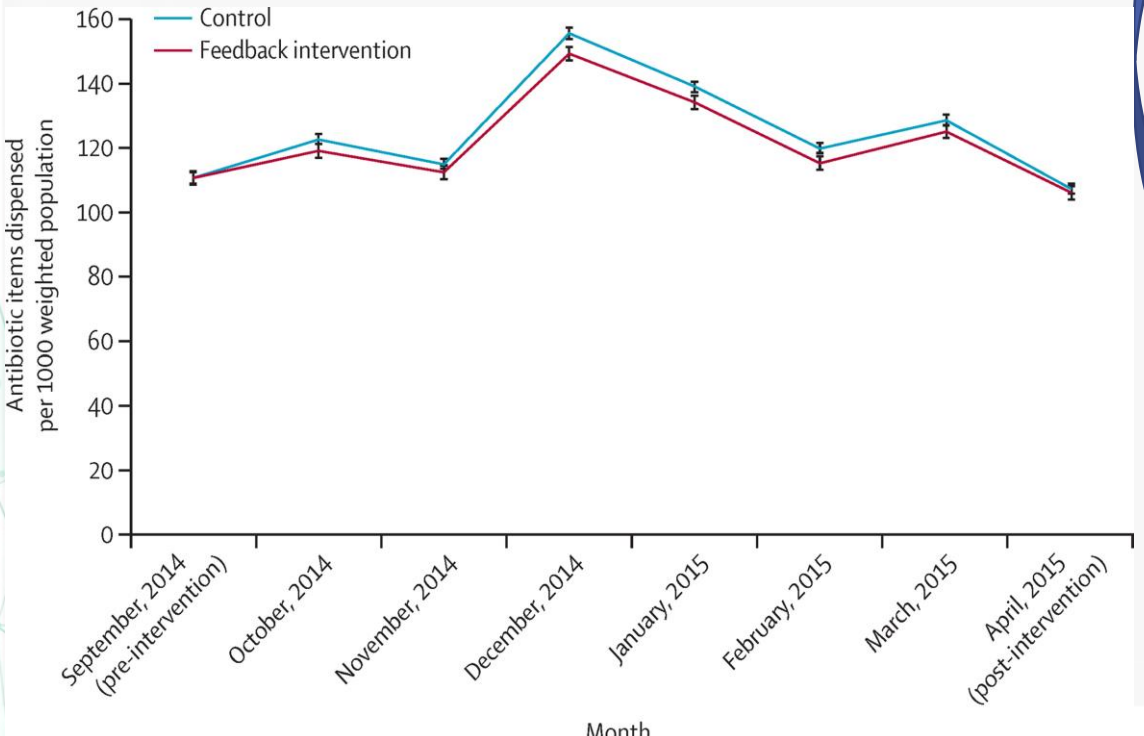
⇒ Partnership in design, roll-out, implementation and scalability assessment

DataLab infrastructure to securely analyse health data from practices



Reduce high levels of antibiotic prescribing in primary care: Cycle 1

Enhanced feedback on prescribing behaviours of general practices

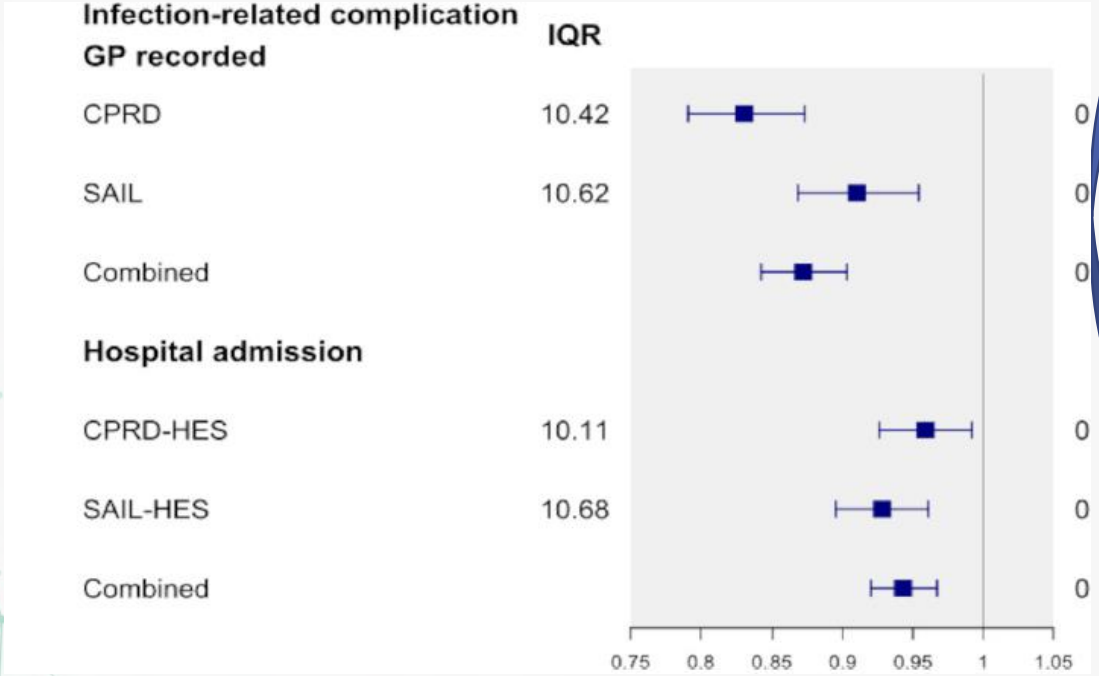


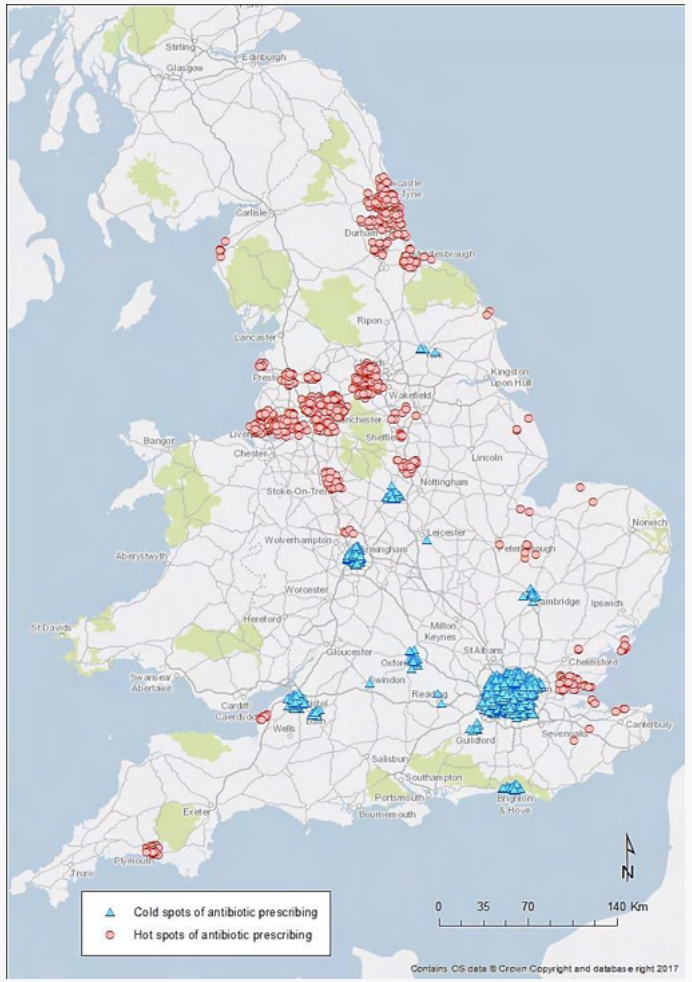
Provision of social norm feedback to high prescribers of antibiotics: a pragmatic national randomised controlled trial (Chadborn et al)

What are the limitations of practice–level feedback on antibiotic prescribing: Cycle 2 (BRIT)

HDRUK
Health Data Research UK

Need to optimise prescribing by targeting patients at high risk of complications





High antibiotic prescribing have better clinical outcomes (van Bodegraven)

Spatial pattern analysis: Hot and Cold spots (Molter A et al)

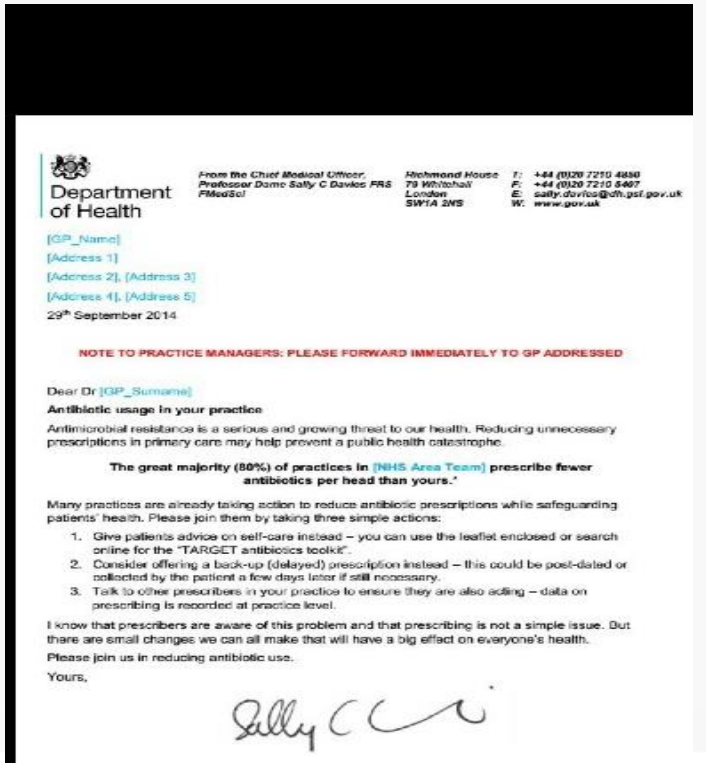
What are the limitations of practice–level feedback on antibiotic prescribing: Cycle 3 (BRIT)

HDRUK
Health Data Research UK

Practice antibiotic champion – tailored feedback

Improving Our Understanding and Practice of Antibiotic Prescribing (qualitative workshops Steels et al)

1.All participants spoke of the importance of having a personalised approach for each general practice and each GP. Participants discussed that it was not enough for the CMO or the CCG to send out an automated letter and expect action to be taken….
2.In providing further suggestions on presenting data within the letter, all participants agreed that a localised 'league table' would be better than the current graph that is used…
3.All participants felt that a much wider range of support was needed to change prescribing behaviours….
4.Prescribers discussed the shift needed by the CMO from 'telling off' to the 'empowerment and education' of GPs



Department of Health

From the Chief Medical Officer, Professor Dame Sally C Davies FRS FMedSci

Richmond House, 79 Whitehall, London, SW1A 2NS

T: +44 (0)20 7210 4850
F: +44 (0)20 7210 5407
E: sally.davies@dh.gsi.gov.uk
W: www.gov.uk

[GP_Name]
[Address 1]
[Address 2], [Address 3]
[Address 4], [Address 5]

29th September 2014

NOTE TO PRACTICE MANAGERS: PLEASE FORWARD IMMEDIATELY TO GP ADDRESSED

Dear Dr [GP_Surname]

Antibiotic usage in your practice

Antimicrobial resistance is a serious and growing threat to our health. Reducing unnecessary prescriptions in primary care may help prevent a public health catastrophe.

The great majority (80%) of practices in [NHS Area Team] prescribe fewer antibiotics per head than yours.'

Many practices are already taking action to reduce antibiotic prescriptions while safeguarding patients' health. Please join them by taking three simple actions:

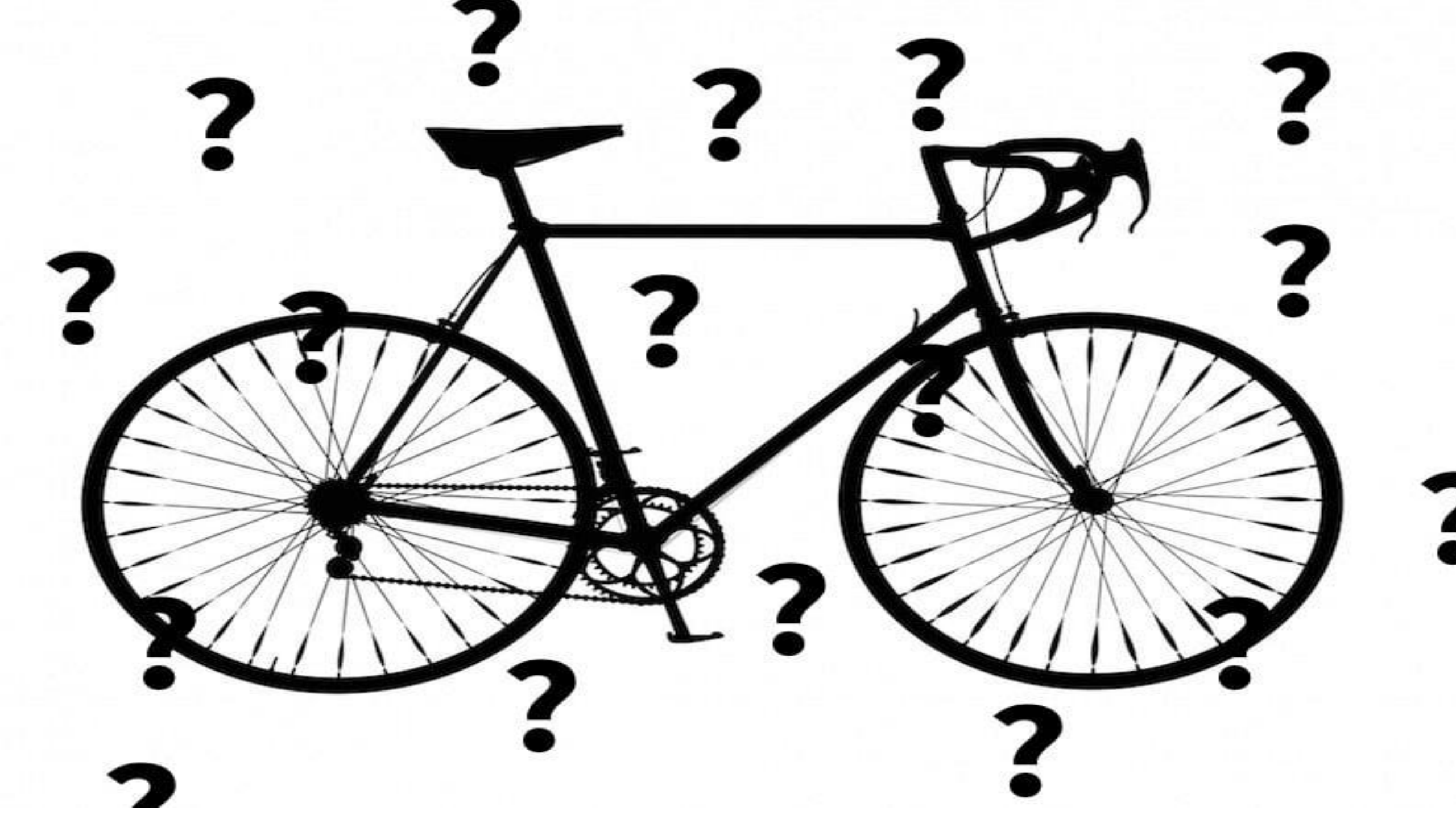
1. Give patients advice on self-care instead – you can use the leaflet enclosed or search online for the "TARGET antibiotics toolkit".
2. Consider offering a back-up (delayed) prescription instead – this could be post-dated or collected by the patient a few days later if still necessary.
3. Talk to other prescribers in your practice to ensure they are also acting – data on prescribing is recorded at practice level.

I know that prescribers are aware of this problem and that prescribing is not a simple issue. But there are small changes we can all make that will have a big effect on everyone's health.

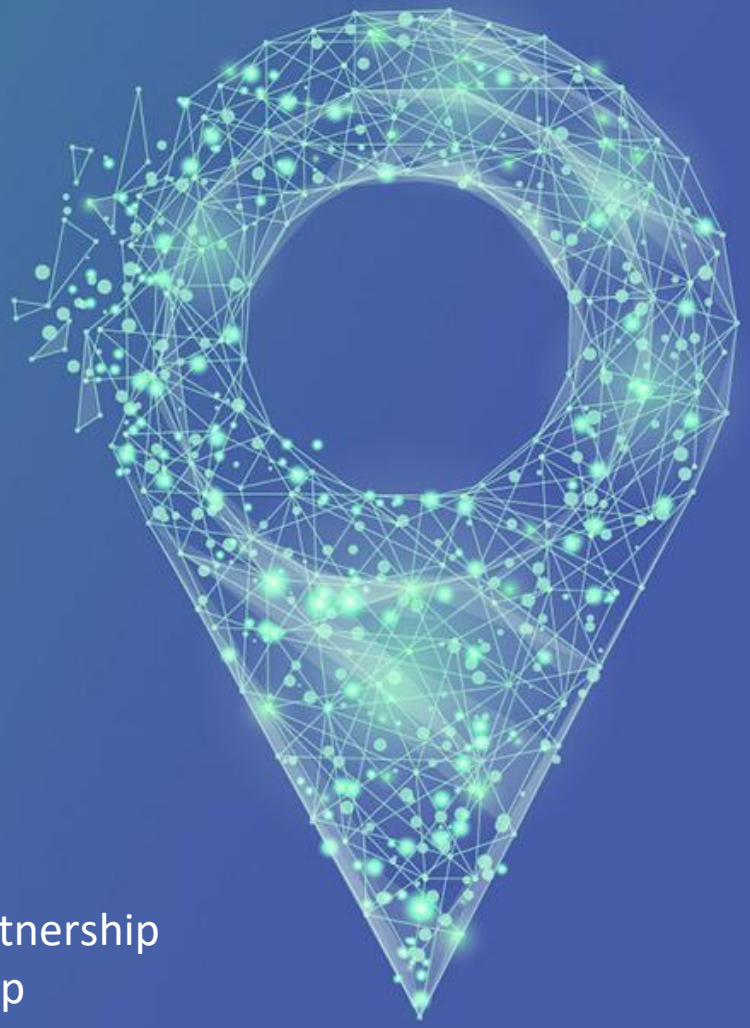
Please join us in reducing antibiotic use.

Yours,

Sally C Davies



HDRUK
Health Data Research UK



Better Care Northern Partnership

Learning Care Homes

Suzanne Mason, Associate Director, HDRUK Northern Partnership
Nancy Preston, Co-applicant, HDRUK Northern Partnership
Jo Knight, Associate Director, HDRUK Northern Partnership

22/04/21

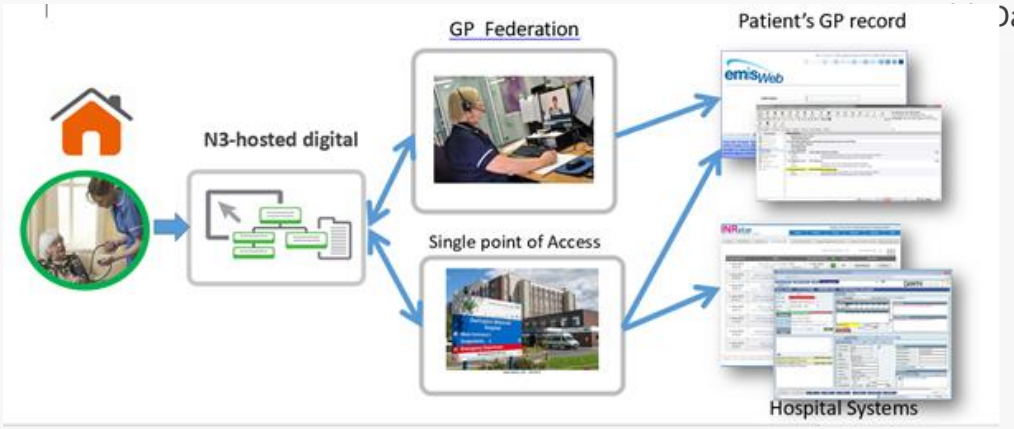
Learning Care Homes

WS1: Routine patient level data linkage; Analyse impact on residents, urgent care services & health service cost

WS2: Stakeholder consultation (residents, families, carers, healthcare professionals) identifying factors for evaluation in care homes / community; survey to explore experiences of using technology

WS3: scale up data linkage with ambulance data; evaluate & improve predictive accuracy of information gathered – esp NEWS; implementation work introducing technology to more care homes; design blue print for learning-loop to improve referrals

WS4: Synthesise findings, work with ARCs to disseminate; plan future work



- App or web portal
- Real time referral from care home to community team
- SBAR & NEWS2
- Pulled into clinical records
- Triage and actioned
- Care home informed

Recruitment to date

Organisation	Participant	Totals
Local HealthCall Team	Project Manager Clinical Trainers x 2 Administrator	4
Local Authority	Commissioning Manager	1
NHS/Clinical Staff	Team Leader, District Nursing x 3 Community Nurse 1 (and 1 pending) Assistant Community Nurse (pending)	4 (6)
Care Home Staff	Managers x 3 Deputy Managers x 3 Senior Carers x 8 (and 1 pending)	14 (15)
Care Home Residents and Relatives of Residents	Residents x 3 Relatives of Residents 0	3
	Total	26 (29)

Current gaps in recruitment: Care home nurses, GPs, relatives of residents

Care Home Characteristics

Care Home	Participants	Provider	Care provided	Beds
1	Seniors 1 & 2; Resident 1	Chain	Residential	~60
2	Deputy 1; Senior 3	Chain	Residential & nursing	~50
3	Deputy 2 ; Senior 4	Chain	Residential & nursing	~60
4	Manager 1	Independent	Residential	~25
5	Manager 2 ; Deputy 3 ; Senior 5	Chain	Residential	~50
6	Manager 3	Chain	Residential	~70
7	Seniors 6 & 7	Chain	Residential	~75
8	Senior 8; Residents 2 & 3	Independent	Residential	~20
9	Senior 9 (pending)	Chain	Residential & nursing	~40

Recruited from across Co. Durham and Darlington, including both rural and urban areas.

Care Quality Commission rating for all participating care homes is Good.

Key Tentative Findings: *HealthCall* Digital Care Homes App

Health Data Research UK

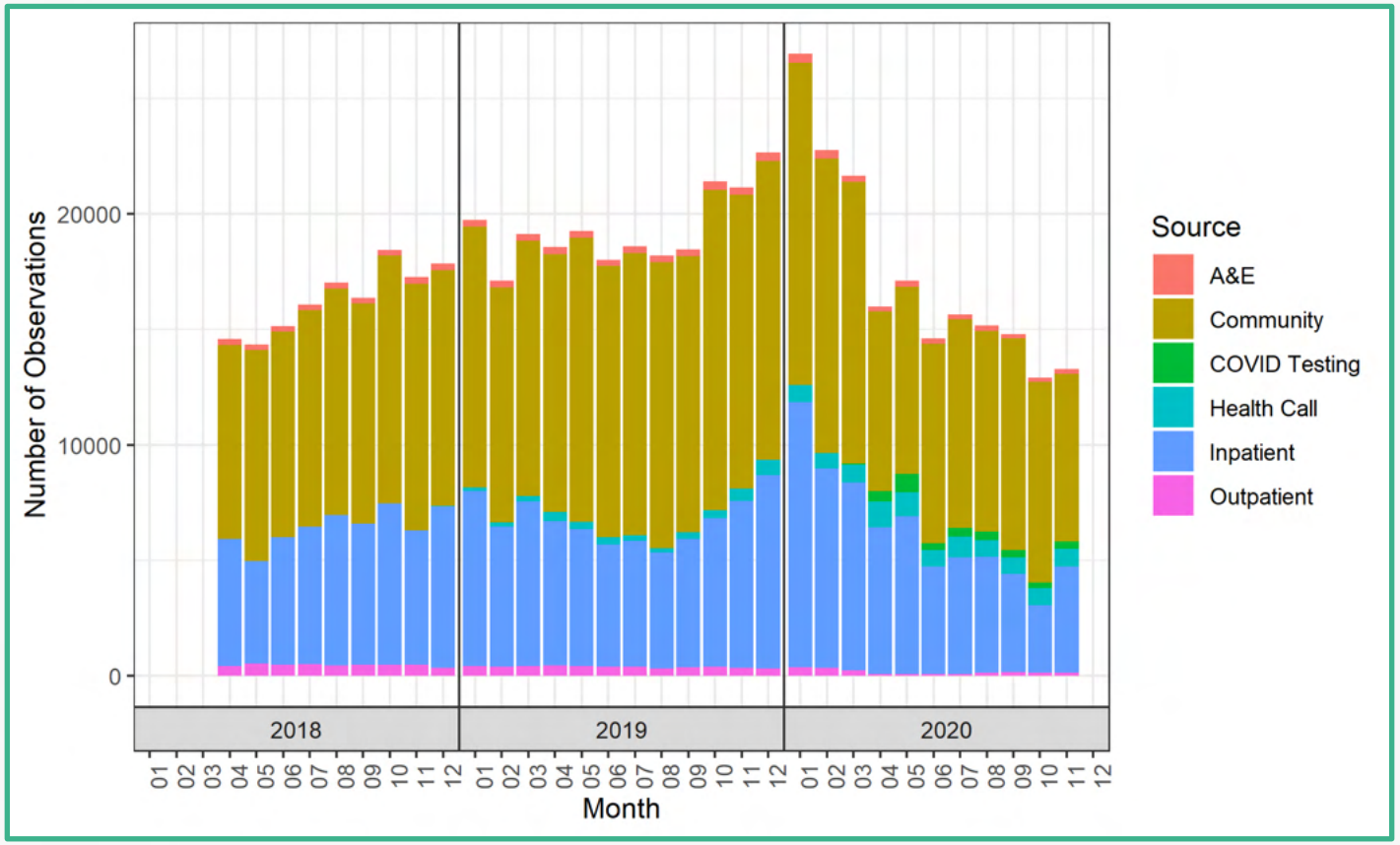
A Useful Tool	Relationships & Communication	Challenges to Implementation & Legitimation
Ease of use Improving efficiency Enhancing resident care Legitimising objective and subjective ("soft") signs of health and illness Risk and responsibility at the right level	Rapport and support Appropriacy of training Upskilling through interactions with each other and the technology Evolution of app and its implementation (Feedback loop)	Access (COVID-19) Resident challenges Skill set challenges Cultural challenges Operational/tech challenges
Manager 1: […] *we used to have to ring through to the nurses and it might be engaged. You might have one person to put through and then an hour later somebody else then becomes ill so you need to ring – so it took a lot of time,* ***so we were really excited just for the simplicity of it and I think just the reduction in our time as well.***	Clinical Trainer 1: *We give them our mobile numbers, our email addresses* […] ***give them a ring*** […] ***follow that up with regular visits*** […] *if homes are struggling post roll out they'll* ***need a lot more support and we'll pop back in and we'll ring them*** *and sort out issues on the fly type of thing.*	Clinical trainer 2: *Even though it's no different to some of the phones they're using,* ***some are very, very afraid of digital technology*** *so we have to spend time talking around that they can't make a mistake and if they do it doesn't matter because it will be seen by a human.*
Local Authority commissioner: *care home staff are trained how to the observations, trained how to complete the app* […] ***that information goes off to a clinician and they make the judgement***		Administrator: [some] ***would rather just pick up a phone up even though it's gonna take up more of their time*** *so we're still finding that happens in some areas but how we're trying to tackle that*

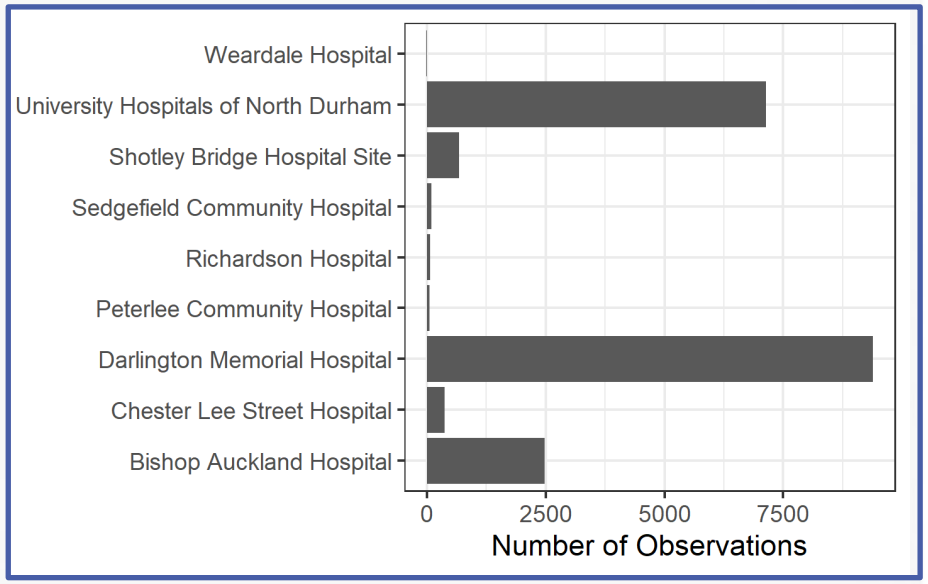
Things to explore further

Care home access to community healthcare services varies across County Durham and Darlington: does this variation influence the use of Digital Care Homes app?

Do views towards and use of the Digital Care Homes app vary between homes with existing, positive relationships with services (aligned GP) and those without?

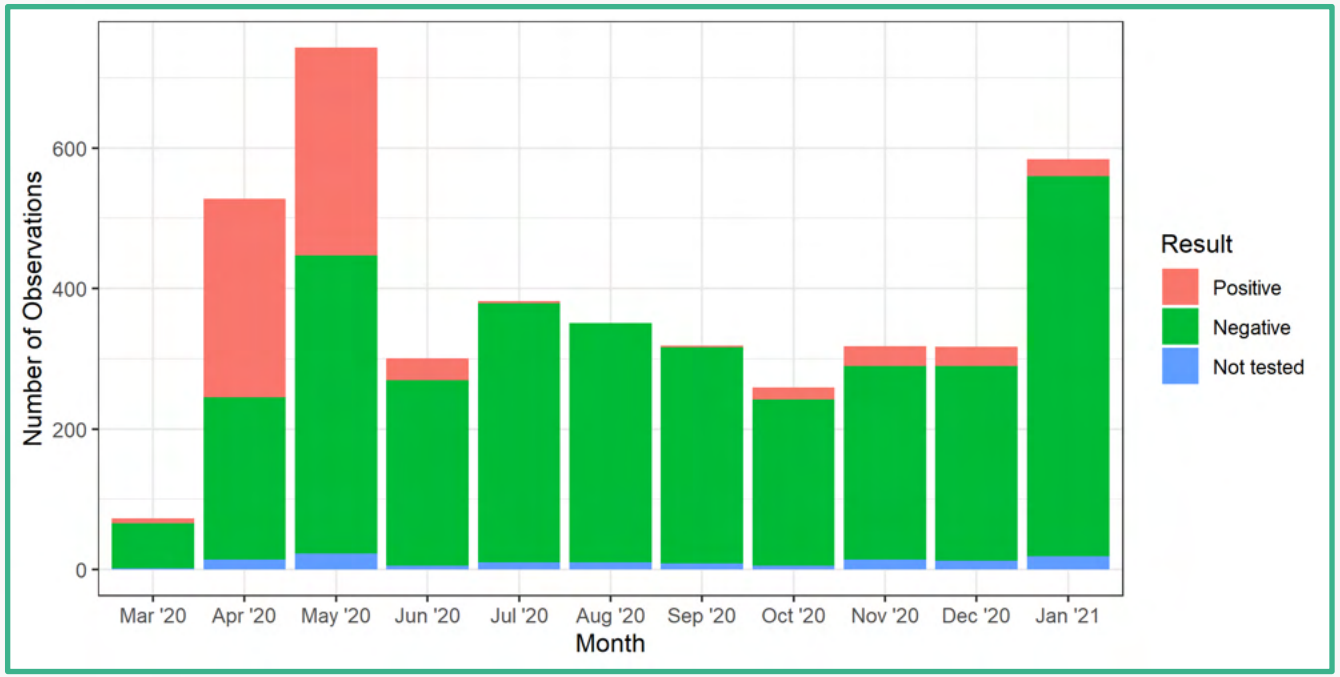
Data Sources

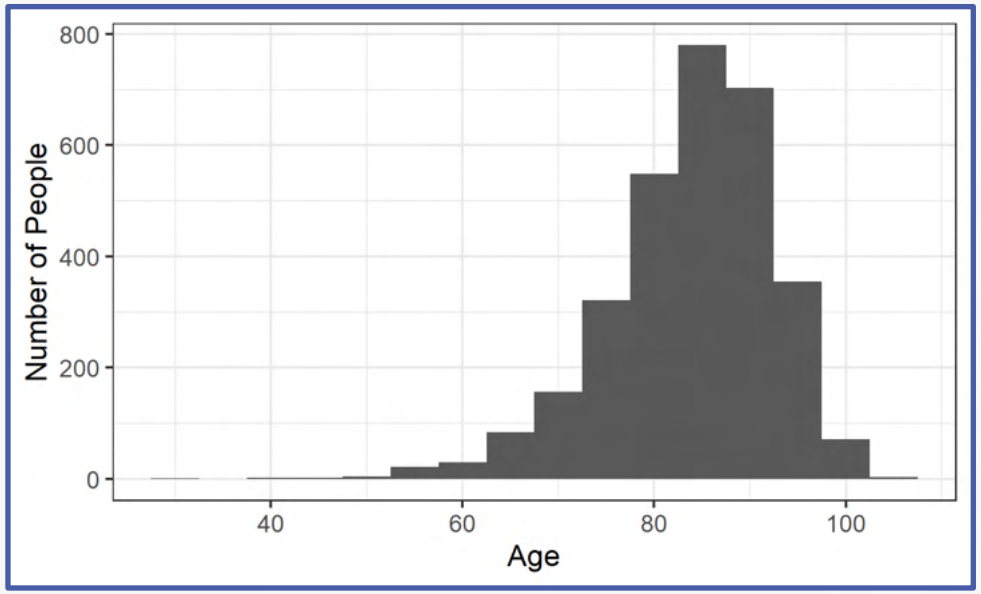




The sample

1.Health care interactions = 580,639
2.Individuals = 3591





Reason for Health Care interaction

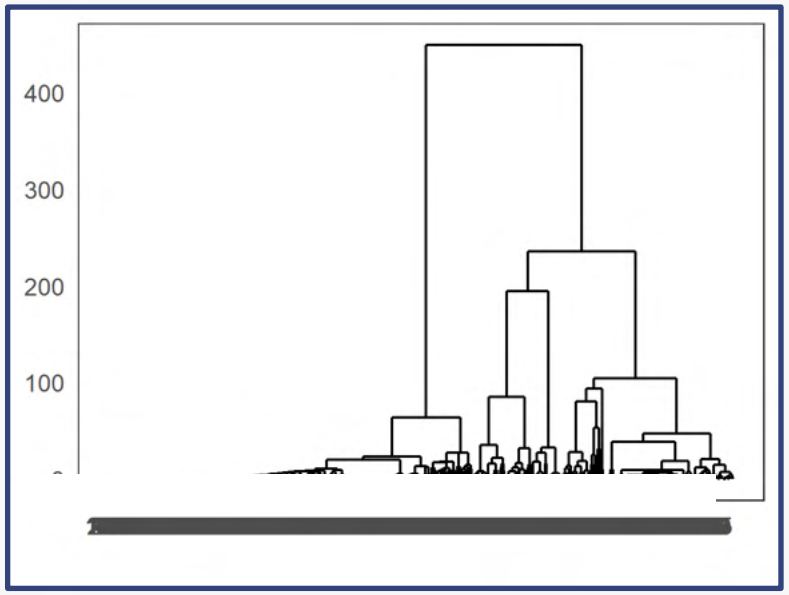
A&E: Diagnosis
1.Nothing abnormal detected
2.Urological conditions (including cystitis)
3.Dislocation fracture/joint injury/amputation
4.Respiratory conditions
5.Head injury

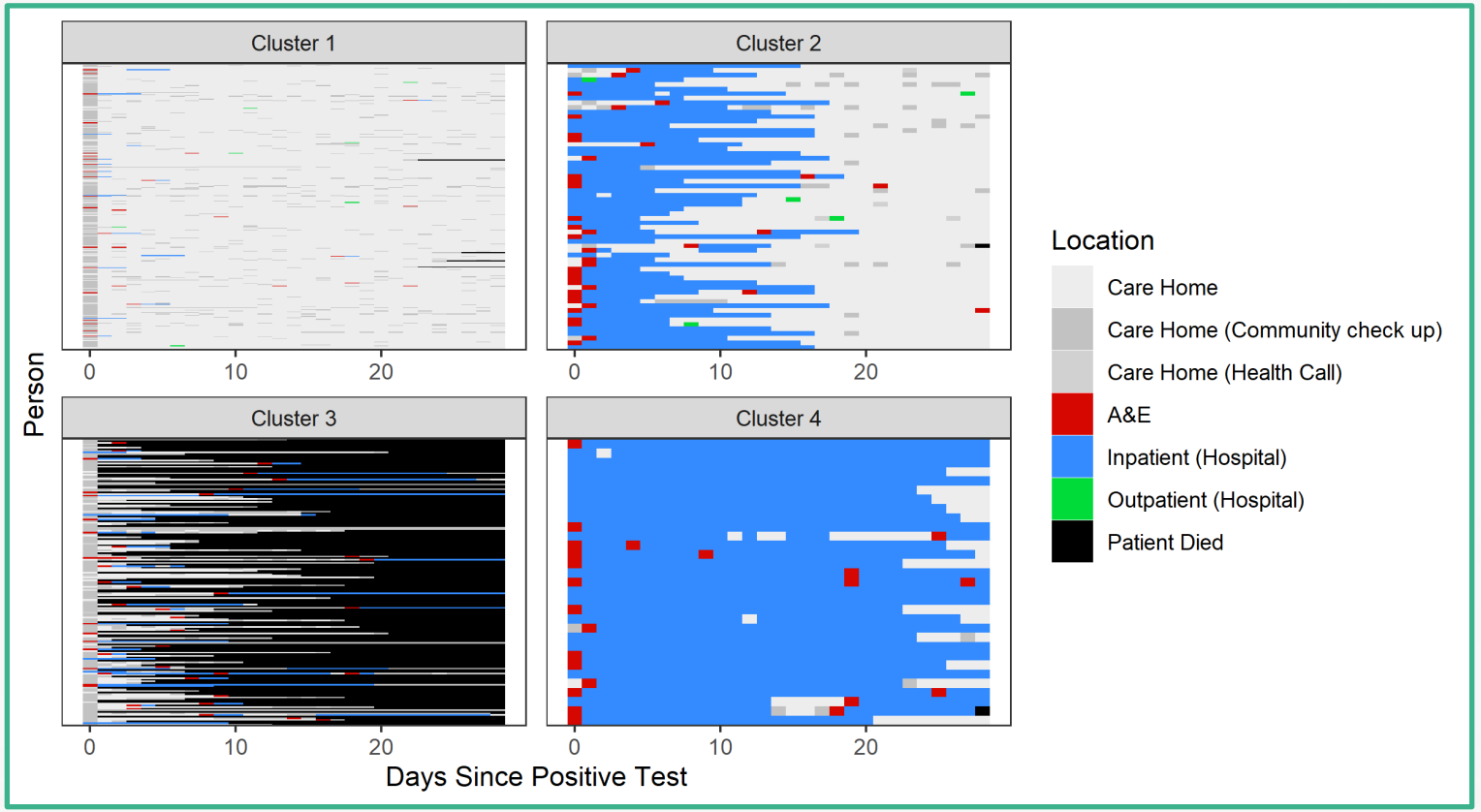
Community: Care plan categories and subcategories
1.Diabetes care and management ongoing
2.Simple wound management
3.Assessment
4.Complex wound management
5.Pressure ulcer prevention

Inpatient: ICD10 codes
1.(Other)
2.Essential (primary) hypertension
3.Renal failure
4.Organic, including symptomatic, mental disorders
5.Diabetes mellitus

Outpatient: Staff type
1.Ophthalmology
2.Traumatology
3.Geriatric
4.Cardiology
5.Pre-op assessment

Clustering of Health Service Provision

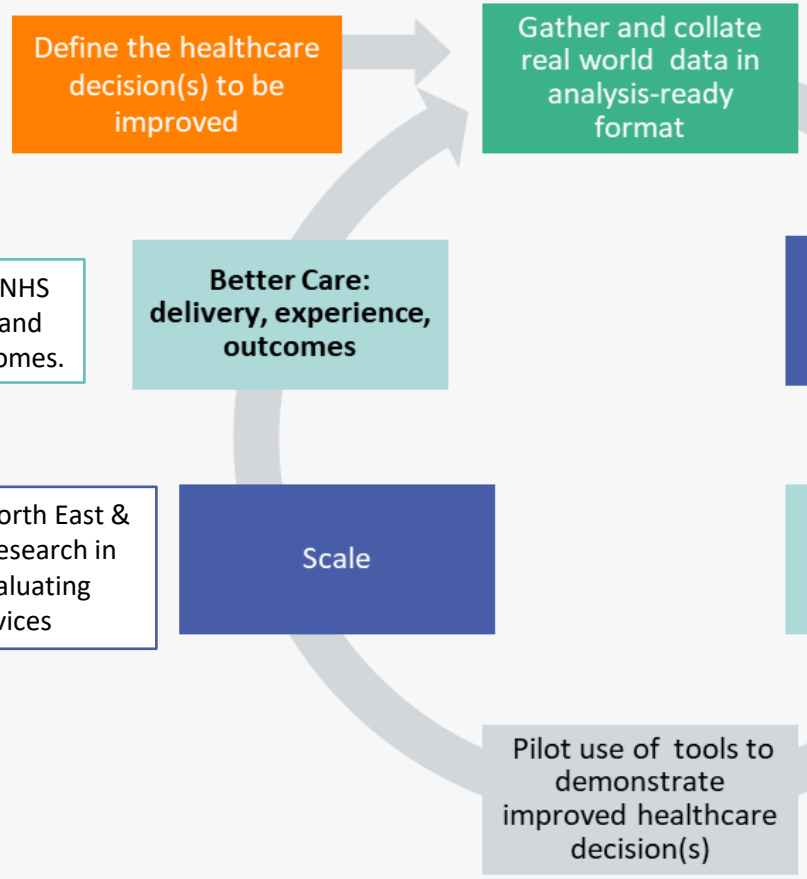




Learning care homes: Continuous improvement of structured referrals

HDRUK
Health Data Research UK

1. Deciding whether care home residents should be referred to hospital when they become unwell is challenging. It is often unclear what action will result in the best outcomes for the residents and care home staff may feel unsupported in the assessment.



2. Data from 60 care homes pre- and post-implementation of a computerized structured referral process (DCH app) which links with NHS community teams and primary health care records.
Data from app and acute hospital trusts

3. Analysis of the impact of the DCH app on NHS costs, patient outcomes and the experiences of care home staff and residents.

4. DCH app revised. Implementation approach recommendations developed

5. Revised DCH app piloted in ~10 care homes. Quantitative impact revisited

6. Expansion to further care homes across North East & Yorkshire. Comparator health informatics research in care home telecare projects in Wales. Evaluating additional impact on 111 and 999 services

7. Blueprint learning system for DCH-NHS referrals with validated quantitative and qualitative outcomes to optimise outcomes.

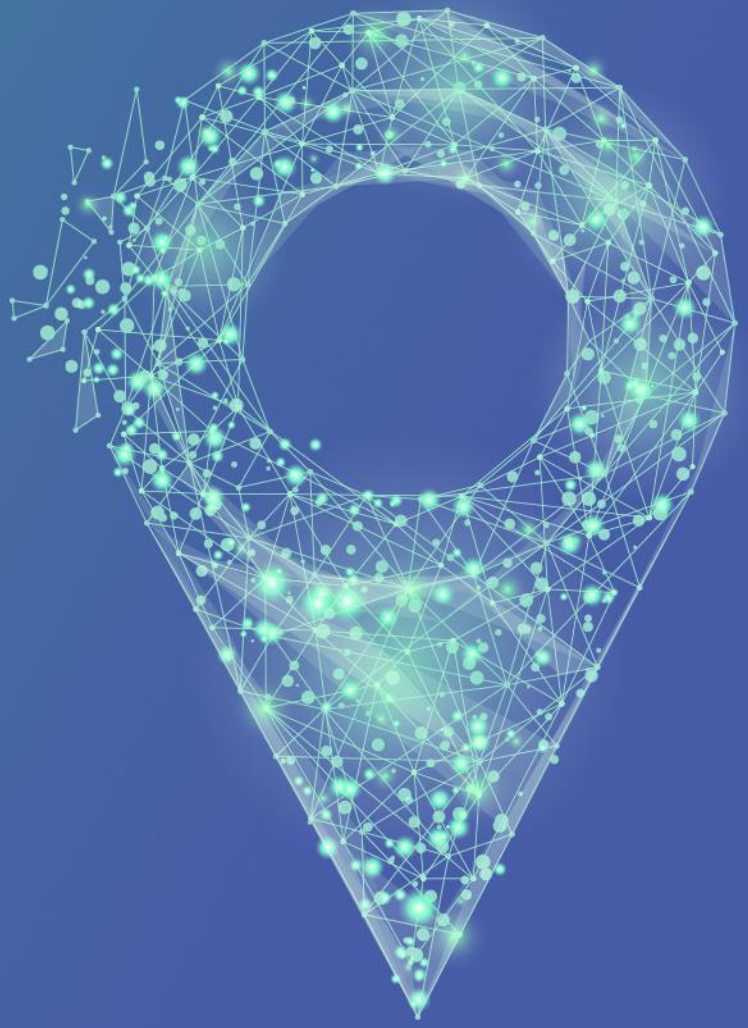
HDRUK
Health Data Research UK

Thank you & Questions

s.mason@sheffield.ac.uk
n.j.preston@lancaster.ac.uk
jo.knight@lancaster.ac.uk

HDRUK
Health Data Research UK

INDUSTRIAL STRATEGY | UK Research and Innovation



HDRUK North – Data Architecture and Governance

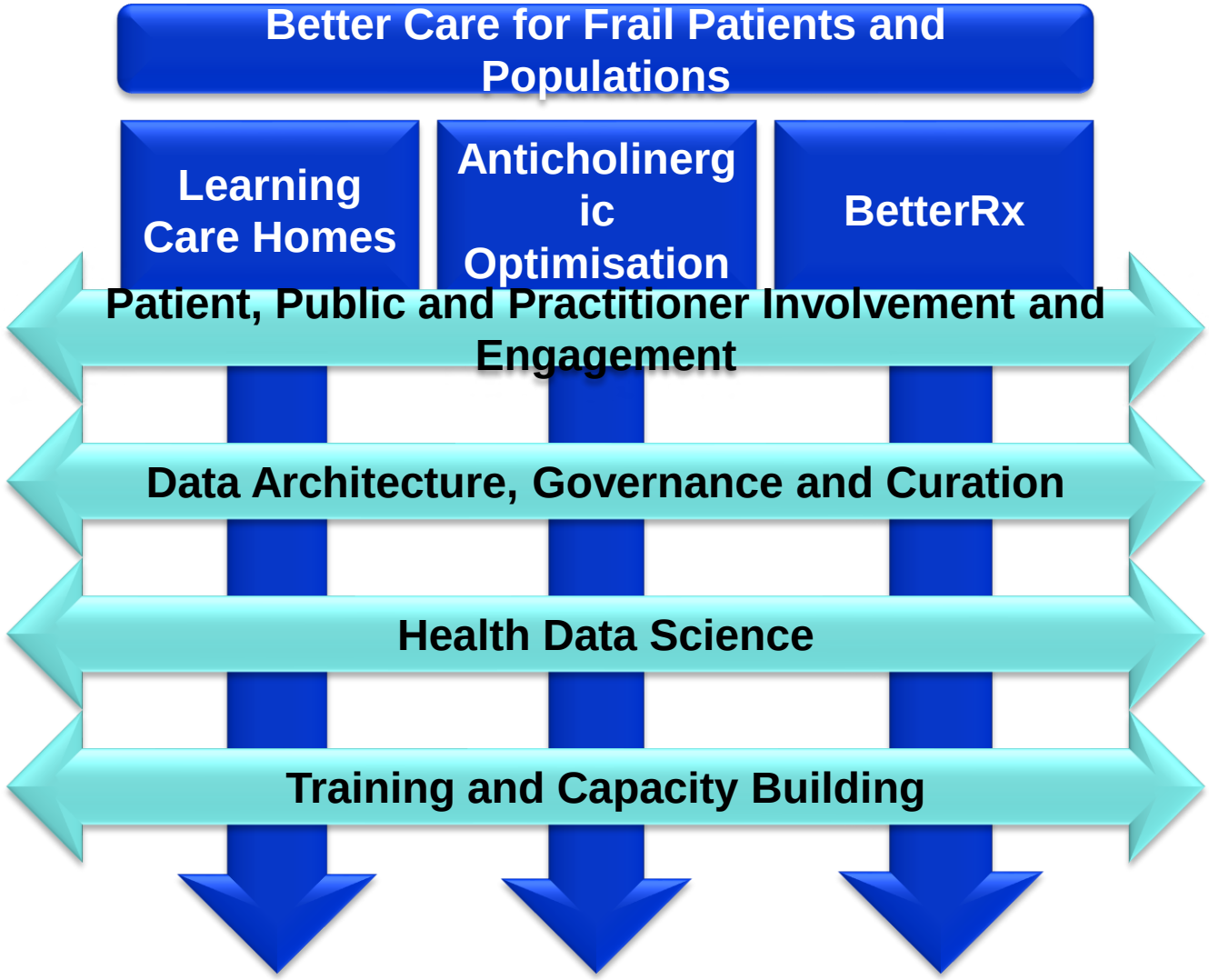
Monica Jones

Chief Data Officer – DATA-CAN
Associate Director – HDRUK North
Executive Lead - YHCR Population Health

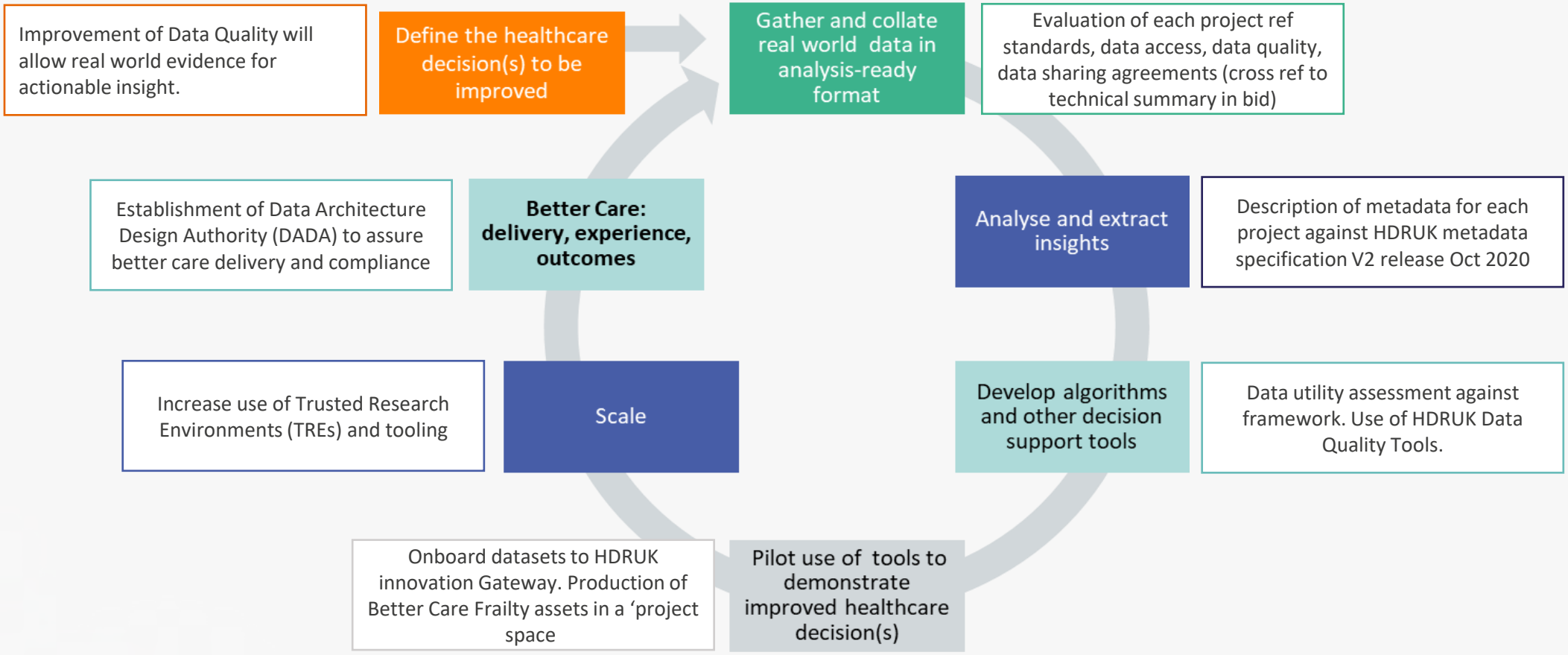
Cross-cutting themes ensure standardisation of approach

Critical Success Factors:

- Improvement of Data Quality
- Increased Membership of HDRUK Alliance
- Increased use of Innovation Gateway and all metadata readily accessible
- Improved access to data for research
- Extended use of Trusted Research Environments (TREs) for scalability and satisfying the ‘Five Safes’



HDRUK North - Data Architecture and Governance



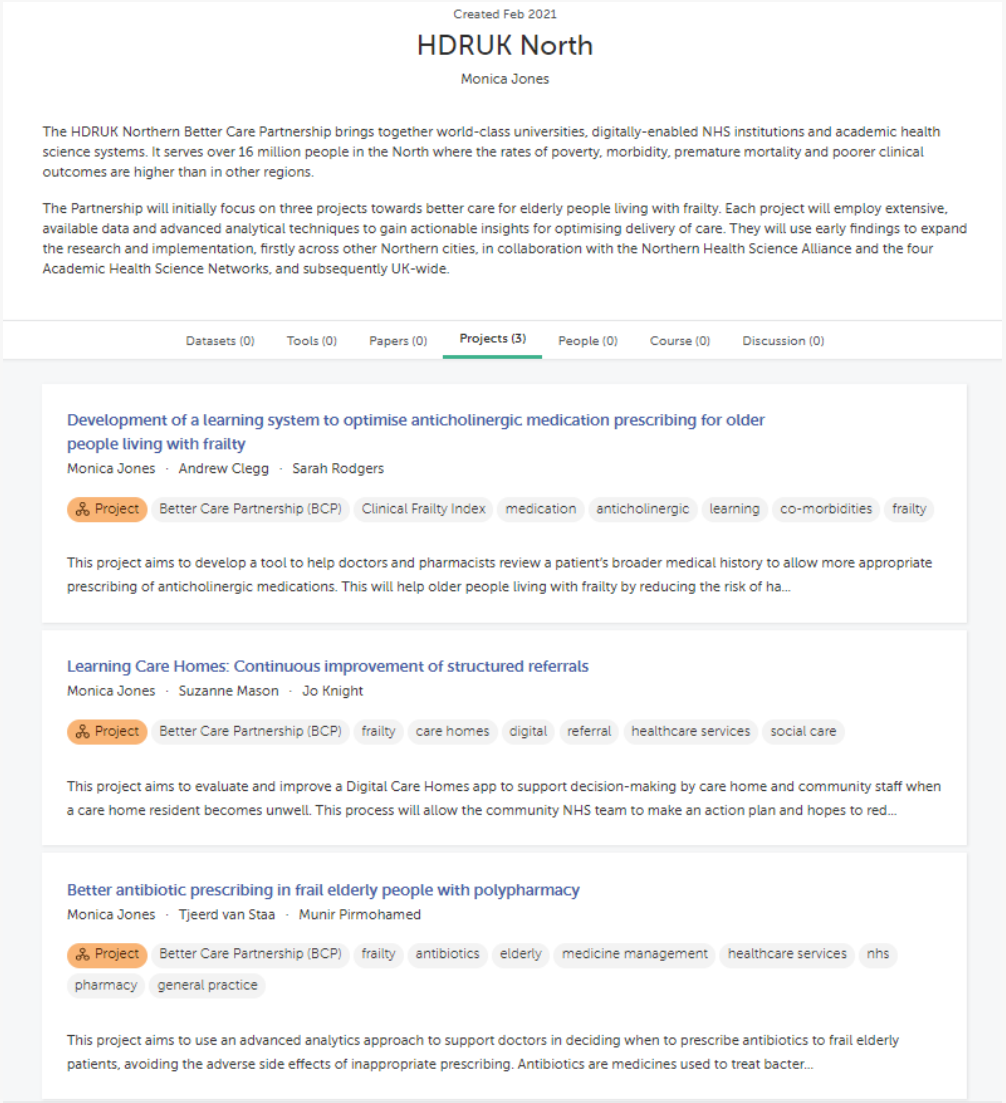
HDRUK North Gateway Collection

Onboard datasets to HDRUK innovation Gateway. Production of Better Care Frailty assets in a 'project space' - Complete

Description of metadata for each project against HDRUK metadata specification V2 – Underway

- Care Homes
- ACMI
- Better Rx

Data utility assessment against framework. Use of HDRUK Data Quality Tools – After 23 April 21



Description of metadata for each project against HDRUK metadata specification V2

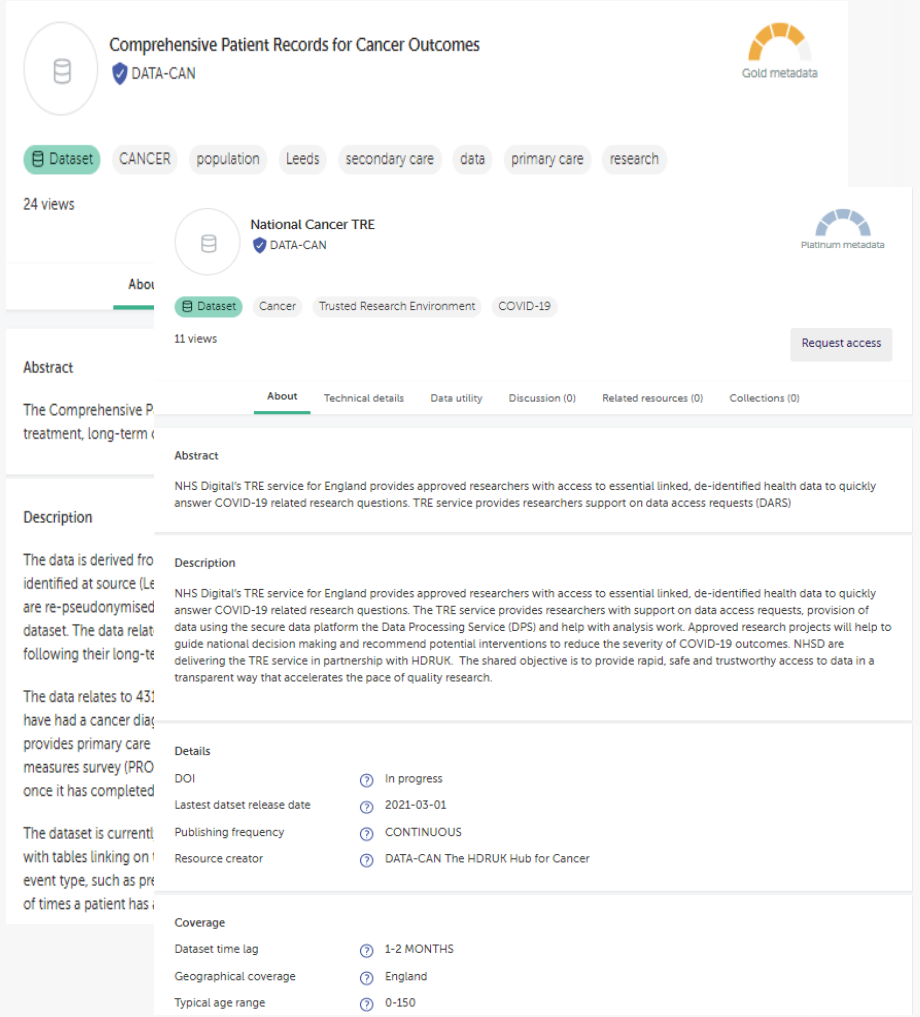
HDRUK
Health Data Research UK

Structural Metadata

We recommend that sites provide a data dictionary of structural metadata that includes the following information (please see the Structural Metadata Completion Guidance for full details including examples).

Metadata Field	Completion Guidance
Table Name *	Name of the table in the dataset. Use a fully qualified name if appropriate.
Table Description	Description of the table in the dataset.
Column Name *	Name of the column in the table dataset
Column Description *	Description of the column in the table dataset.
Data Type *	Type of data contained in the column.
Sensitive *	Please indicate (True / False) whether the information must be treated as sensitive and may need additional constraints / removal / anonymisation / masking through the data access request process. Definition: An ODRL conformant policy expressing the rights associated with the resource.

Further Information at:
Metadata Exchange Knowledge Base - Confluence (atlassian.net)

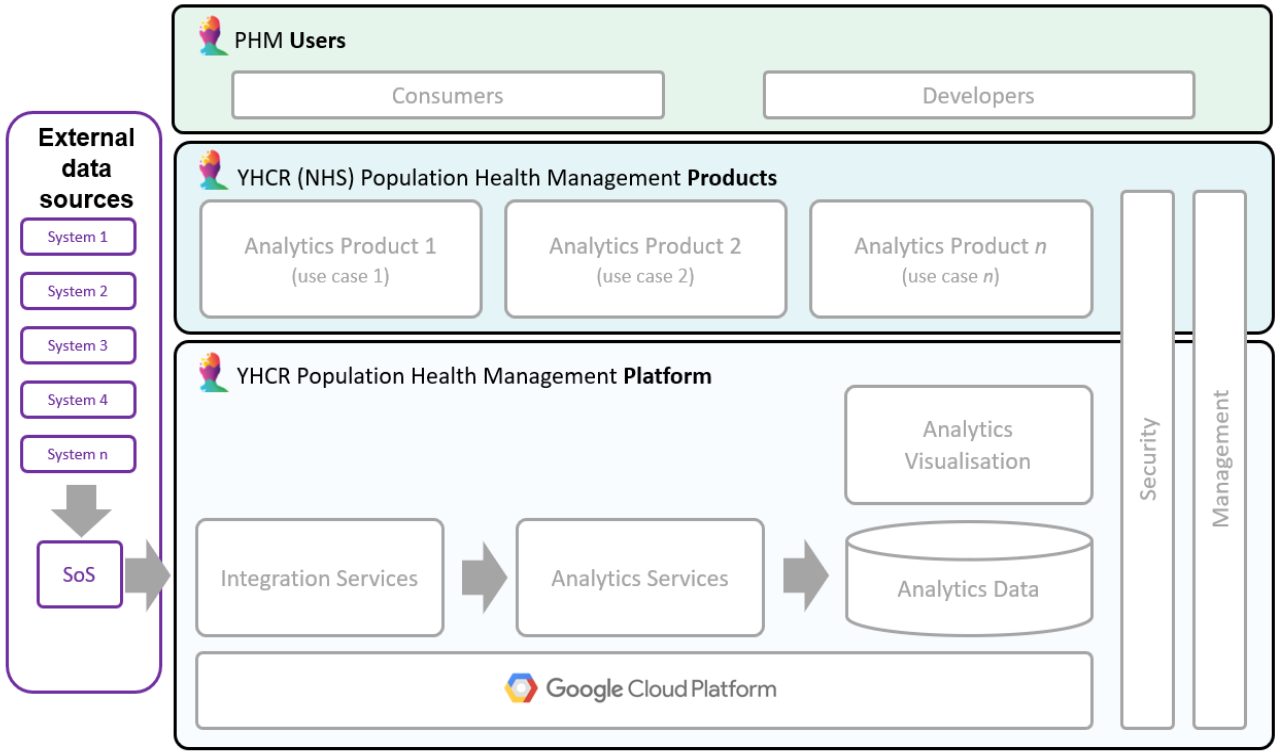


Increase use of Trusted Research Environments (TREs) and tooling

HDRUK
Health Data Research UK

A platform for analytics, predictive modelling, machine learning, artificial intelligence, visualisation and reporting

The solution, to be supported by Local Help Desks, the YH Central Service Management Team and suppliers, provides an advanced PHM platform which allows users to develop analytic products that use selected data to address the objectives of a particular use case.



Population Health Management Users consist of the following:
Consumers - The colleagues who will use the solutions to improve population health *e.g. Commissioners, Health Providers, Clinicians and Health & Social Care workers.*

Developers - The colleagues who will build analytics solutions using the platform *e.g. data engineers, data analysts, data scientists and visualisation developers.*

The **YHCR Population Health Management Products** are built on the Platform and address the objectives and challenges of a particular use case in an organisation.

Each Use Case utilises the capabilities of the PHM platform to develop a dashboard or similar product which meets the specific objectives of the users designing it.

The **YHCR Population Health Management Platform**, is built on Google Cloud technology and stores data that can be used to develop population health management products.

Integration Services gathers data from systems across the region using Systems of Systems (SoS).

Analytics Services enables the data to be processed and manipulated using advanced analytics tools and techniques.

Analytics Data store is the repository that securely stores the data.

Analytics Visualisation provides the tools to visualise the data.

Security and Management ensures that the access to and processing of data is protected.

Next steps

Meeting follow up

01

- If you have any other thoughts or would like to support as we develop the Better Care QQR proposal, please do get in touch: alice.turnbull@hdruk.ac.uk

Events

02

- **26 April 2021:** HDR UK Quinquennial Frontiers meeting 1
- **01 July 2021:** Better Care Insight Sharing Day

Stay in touch

03

- Get in contact **alice.turnbull@hdruk.ac.uk**
- Join the Better Care slack channel **#hdruk_bettercare**
- Visit the **Better Care webpage**
- Visit the **Gateway Better Care collection**
- Sign up to the **HDR UK mailing list**
- Follow us on LinkedIn and Twitter @HDR_UK

HDRUK
Health Data Research UK

THANK YOU