HDRUK
Health Data Research UK

Better Care Insight Sharing Day

14 July 2022

Introduction and welcome

Objectives for today

1. **Overview of ongoing work across the Better Care network and key partner initiatives**

2. **Update on HDR UK QQR process**

3. **Start to discuss how the Better Care Community will evolve as we move forwards**

Agenda:

Time	Session	Who	Aims
09.30	**Introduction and welcome**	Simon Ball, Executive Medical Director, University Hospitals Birmingham NHS Foundation Trust	• Introduction, welcome and overview of the day
09:40 (20 min)	**QQR Update**	**Rhos Walker,** Chief Science Strategy Office, HDR UK	• Update on the QQR process and key next steps
10:00 (60 min)	**Early Career Researcher Showcase**	**Chair: Kevin Dunn,** • **Adi Kale,** Clinical Research Fellow, AI and Digital Healthcare Research Team, Birmingham: *Clinical AI Safety: Developing our understanding of algorithmic errors and patient harms* • **Aseel Abuzour & Bethan Copsey,** Senior Research Fellows, University of Leeds: *Development of Anticholinergic Medication Index in Bradford* • **Alex Garner,** Senior Research Associate, University of Lancaster: *Analysing care sequences of care home residents during the pandemic* • **James Schmidt,** Biostatistical PhD Researcher, University of Leicester: *Patterns of rates of mortality in the Clinical Practice Research Datalink*	• Presentations from our Early Career Researchers across the HDR UK Better Care Community • Project overview, progress and opportunities for collaboration
11:00 (15 min)	**BREAK**		

Agenda:

Time	Session	Who	Aims
11:15 (60 mins)	**The Networked Data Lab**	**Fiona Grimm** and **Sebastien Peytrignet**, The Health Foundation **Jessica Butler**, University of Aberdeen	• Overview of the Networked Data Lab • Recent output, progress to date and lessons learned
12:15 (25 mins)	**Using regional networks to support the adoption and spread of data science innovations**	**Andy Clegg,** Professor of Geriatric Medicine, University of Leeds and Honorary Consultant Geriatrician, Bradford Royal Infirmary	• Consider, how can we maximise the impact of regional and national networks to support the adoption and spread of data science innovations? • Discuss, how the Better Care community interfaces with these networks
12:40 (20 min)	**Better Care within the HDR UK future strategy**	**Chair: Alastair Denniston,** Director of INSIGHT - the Health Data Research Hub for Eye Health, University of Birmingham, UK	• Explore, what do members of the Better Care Community value from being part of a national network • Discuss, what role can the Better Care community plan to enable the HDR UK future strategy • Consider additional opportunities for funding to embed the Better Care approach in the future and support research which enables implementation of research into practice
13:00	**MEETING CLOSE**		

Better Care Vision

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

Better Care 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

We deliver through*:

1. **Sharing and learning:** Sharing across a connected national network to transfer best practice and provide insights from experience and learning
2. **Embedding into clinical practice:** Engaging with practitioners and policy makers to address the barriers to real-world implementation into routine health and care
3. **Scaling:** Supporting the scaling and sustaining of outputs and impacts across geographies, specialties and time

*Ref: First Better Care Insight Day, July 2020

We have built a community to build on in the future

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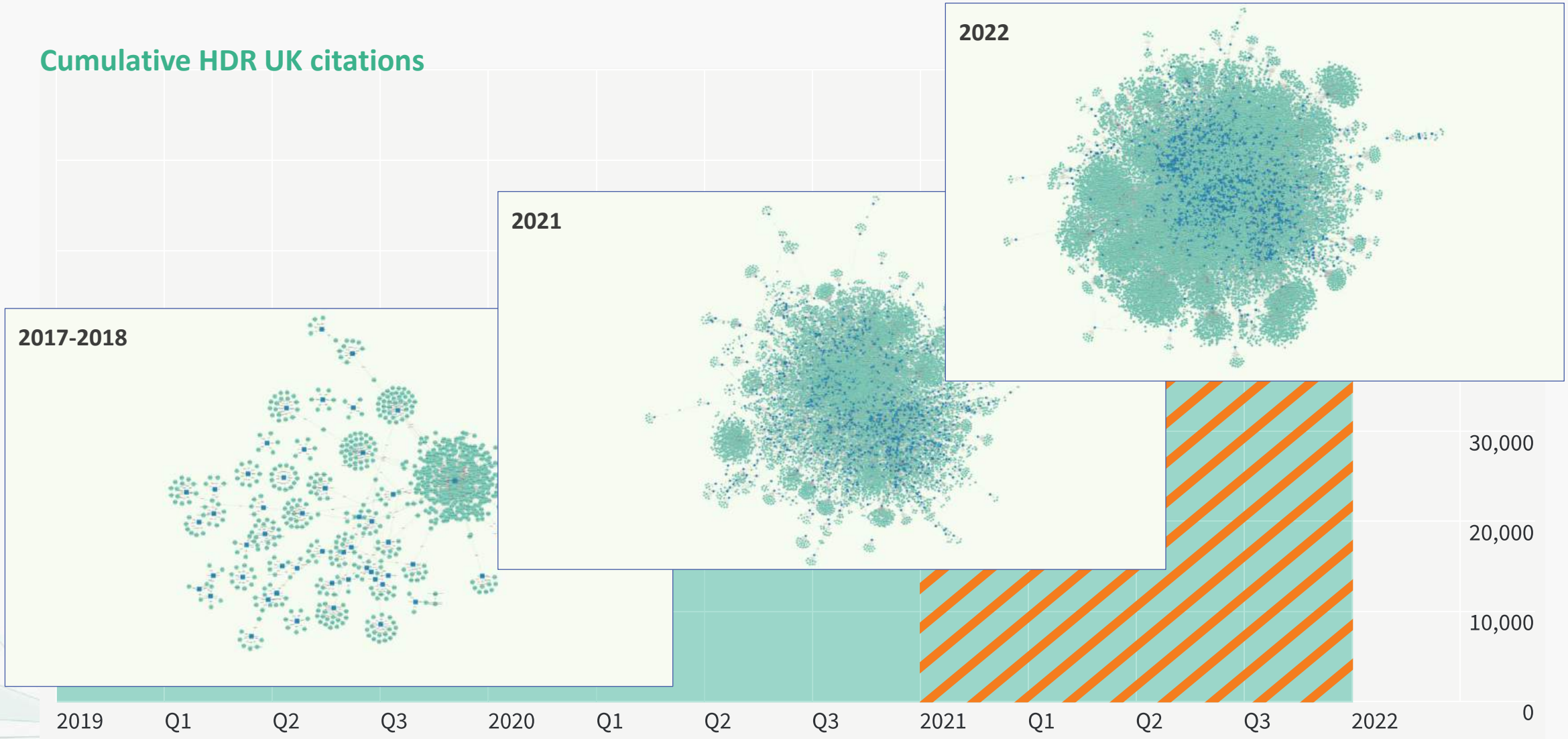
Cumulative HDR UK citations

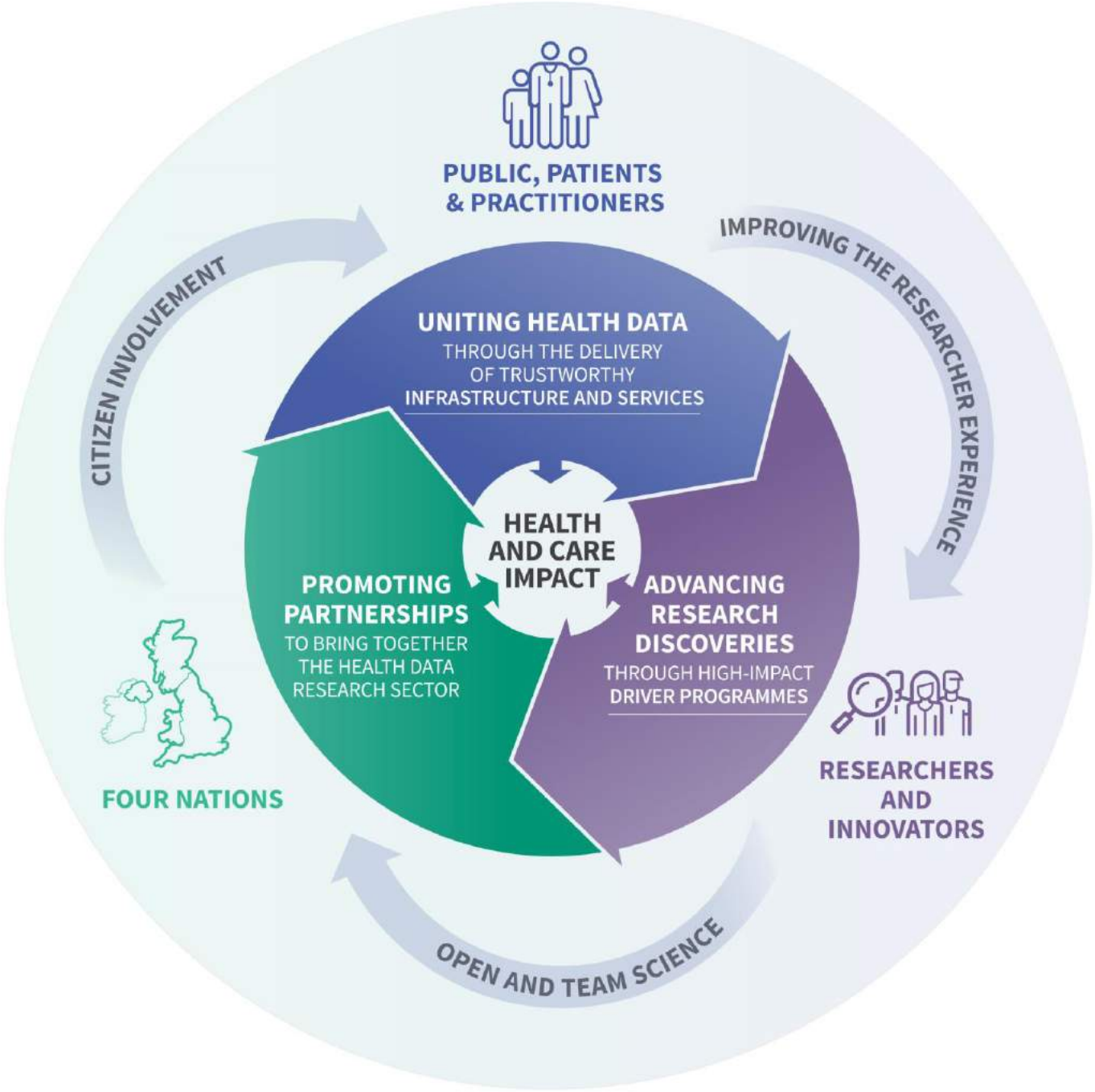


ResearchFish March 2022

QQR Update

Our refreshed strategy focusing on three integrated areas of activity

1. **Research Data Infrastructure and Services**
2. **Research Driver Programmes**
3. **One Institute Partnerships**



We have made lots of progress in the last 3 months...

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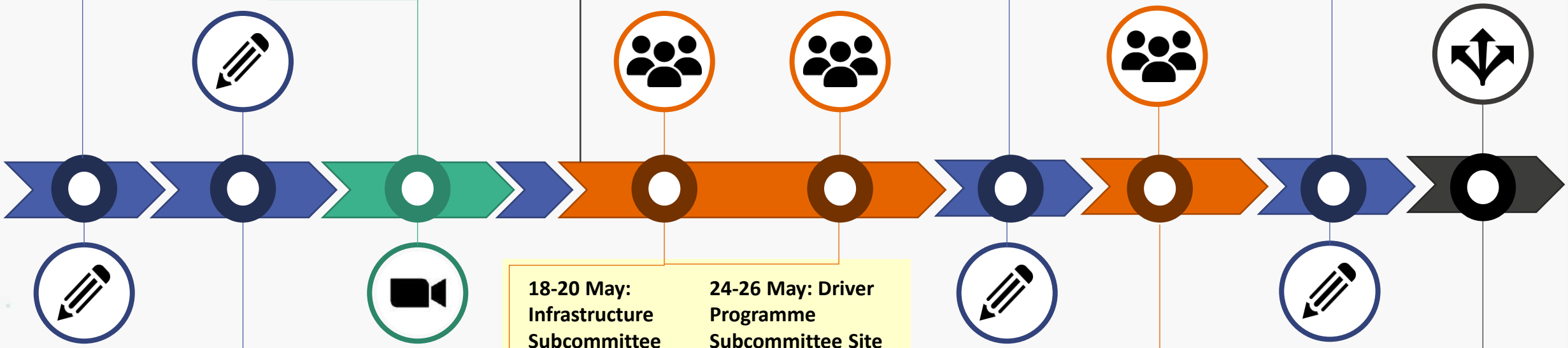
04 Feb: HDR UK Submit QQR Report

16 Mar: HDR UK QQR Board 1st Meeting
- Committee briefing attended by Institute Director and limited observers
- 10 min presentation to set out HDR UK unique model and vision

4-5 May: QQR Retreat, Bristol

19 Aug: Directors Response to Subcommittee Recommendations

27 Oct: Directors Response to Review Board



Mar-Apr: External Inputs and Peer review
- Peer review, core funder office assessment (PPIE, comms, KTE, training)
- Institute response to reviewer feedback

18-20 May: Infrastructure Subcommittee Site Visit
- *In person – London*

24-26 May: Driver Programme Subcommittee Site Visit
- *In person – Edinburgh*

- Set-out the vision and details of each programme
- Respond to Subcommittee questions
- Programme leadership attend

15-16 Sep: HDR UK QQR Board 2nd Meeting
- Final recommendations in light of Director's response
- Attended by Institute Director and limited observers
- HDR UK to make changes to the Institute Overview (if required)

Dec: Core Funders' Assessments and Decisions

Jan 2023: Core Funders' Committee Ratification

The process has been a testament to team science

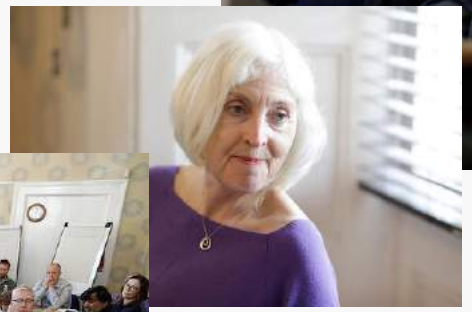
73 HDR UK members from across

28 Institutions presented to the panels








Feedback has been very positive and HDR UK's unique contribution has been recognised*

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Infrastructure and Services

(This is an) incredible achievement

HDR UK is providing a unique and critical contribution to the UK research ecosystem

HDR UK serves as a strong platform and example for other data initiatives around the world

Research

HDR UK is a world leader in this space

HDR UK, will offer substantial benefits over a piecemeal approach to ...individual studies

One Institute

Congratulations for setting up something unique

We are unhesitating in our support for what you do and the need of the country for HDR UK as the national Institute for health data research

		Score
Infrastructure and Services	Past	9/10
	Future	9/10
Research Driver Programmes	Past	9/10
	Future	9/10

9/10 = "Excellent - Internationally competitive and leading edge in most areas."

**QQR Independent review process feedback*

And accelerated key opportunities...

1. **NHS alignment** and **closer integration with the NHS Data for R&D investment**

- Ongoing discussions with NHS TD (led by David Seymour) to map out opportunities for collaboration
- Response to be provided to Review Board in September

2. **International Strategy**

- Integration of our work through HDR Global in the Global South and international collaborations across “Infrastructure and Services” and “Driver Programmes”
- To be discussed with HDR UK International Advisory Board (25 July) and at September Board meeting

What happens next?

July Formal feedback from review sub-committees confirming key strategic priorities to address

19 Aug: HDR UK Response to sub-committee feedback

15-16 Sept: Review Board to discuss final recommendations and outcomes of review process

Dec-Jan: Core Funder decisions

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Early Career Researcher Showcase

Clinical AI Safety (for all): Developing our understanding of algorithmic errors and patient harms

Dr Aditya Kale

Clinical Research Fellow

University Hospitals Birmingham & University of Birmingham

Health Data Research UK

University Hospitals Birmingham NHS Foundation Trust

UNIVERSITY OF BIRMINGHAM

Overview

Safety of Clinical Artificial Intelligence

Data curation and clinical evaluation

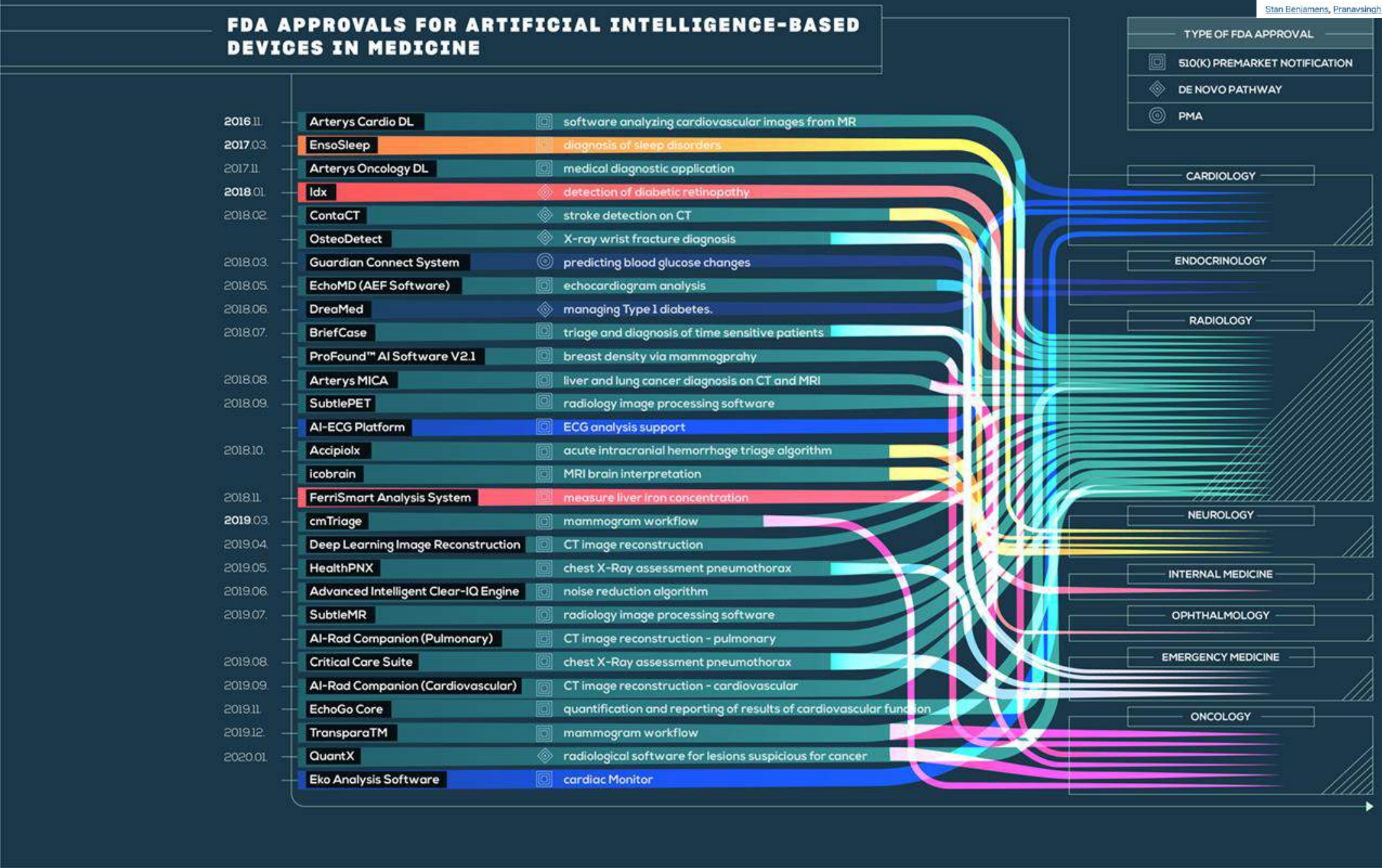
The Medical Algorithmic Audit

Monitoring the safety of deployed AI health technologies (Current focus of my research)

Article | Open Access | Published: 11 September 2020

The state of artificial intelligence-based FDA-approved medical devices and algorithms: an online database

Stan Benjamens, Pranavsingh Dhunnoo & Bertalan Meskó



The urgent need for AI safety frameworks

Routine Clinical Practice

- Screening and Triage
- Diagnosis
- Prognostication
- Decision support and treatment recommendation

The Fourth Industrial Revolution

AI Development and Evaluation

- Mammograms
- Eye imaging
- Skin cancer

Integration and Routine use of AI

Effective, safe and inclusive

Robust post-deployment safety monitoring

Scalable deployment in clinical setting

Preparation, collection and checking of data → Development of the AI model → Validation of the AI model → Development of the software application → Impact assessment → Implementation and use

Guidelines and quality criteria for artificial intelligence-based prediction models in healthcare: a scoping review

Anne A. H. de Hond, Artuur M. Leeuwenberg, Lotty Hooft, Ilse M. J. Kant, Steven W. J. Nijman, Hendrikus J. A. van Os, Jiska J. Aardoom, Thomas P. A. Debray, Ewoud Schuit, Maarten van Smeden, Johannes B. Reitsma, Ewout W. Steyerberg, Niels H. Chavannes & Karel G. M. Moons

npj Digital Medicine **5**, Article number: 2 (2022) | Cite this article

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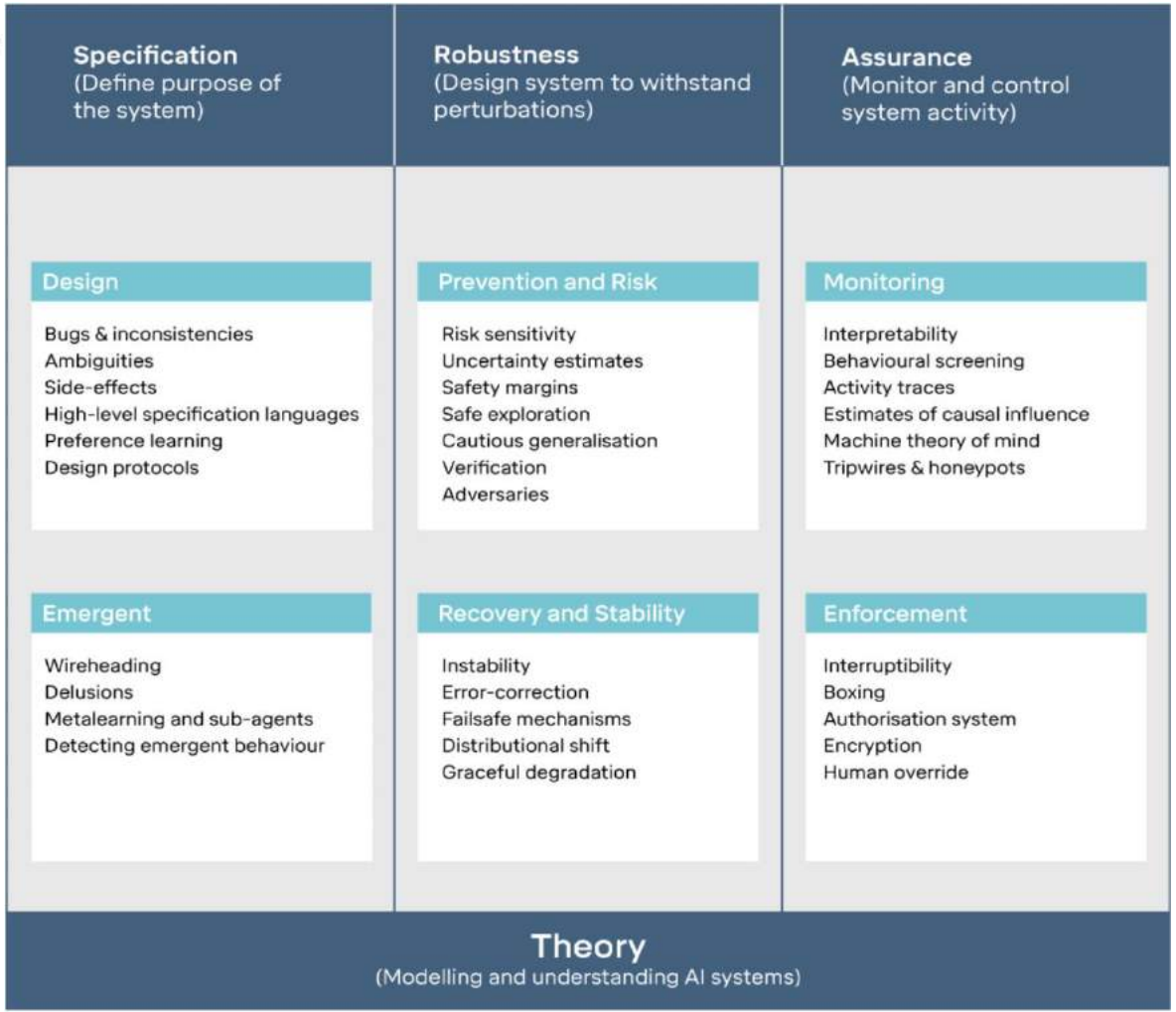
Building safe artificial intelligence: specification, robustness, and assurance

By Pedro A. Ortega, Vishal Maini, and the DeepMind safety team



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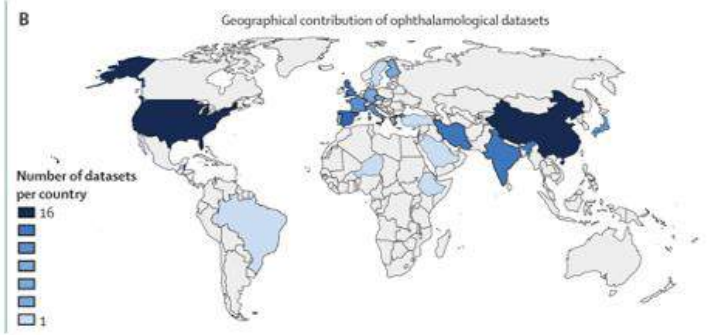
Standards for Datasets

THE LANCET
Digital Health

A global review of publicly available datasets for ophthalmological imaging: barriers to access, usability, and generalisability

Saad M Khan*, Xiaoxuan Liu*, Siddharth Nath, Edward Korot, Livia Faes, Siegfried K Wagner, Pearse A Keane, Neil J Sebire, Matthew J Burton, Alastair K Denniston

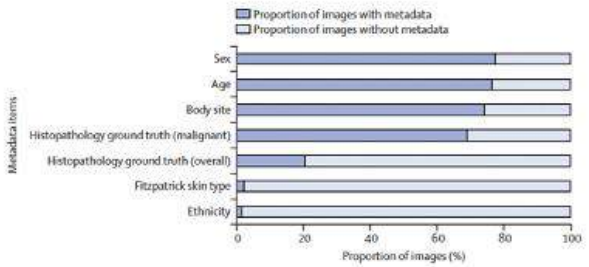


THE LANCET
Digital Health

Characteristics of publicly available skin cancer image datasets: a systematic review

David Wen, Saad M Khan, Antonio Ji Xu, Hussein Ibrahim, Luke Smith, Jose Caballero, Luis Zepeda, Carlos de Blas Perez, Alastair K Denniston, Xiaoxuan Liu*, Rubeta N Matin*

Publicly available skin image datasets are increasingly used to develop machine learning algorithms for skin cancer diagnosis. However, the total number of datasets and their respective content is currently unclear. This systematic review aimed to identify and evaluate all publicly available skin image datasets used for skin cancer diagnosis by exploring their characteristics, data access requirements, and associated image metadata. A combined MEDLINE,



THE LANCET
Digital Health

Health data poverty: an assailable barrier to equitable digital health care

Hussein Ibrahim, Xiaoxuan Liu, Nevine Zariffa, Andrew D Morris*, Alastair K Denniston*

The inability for individuals, groups, or populations to benefit from a discovery or innovation due to insufficient data that are representative of them

STANDING Together

The Health Foundation

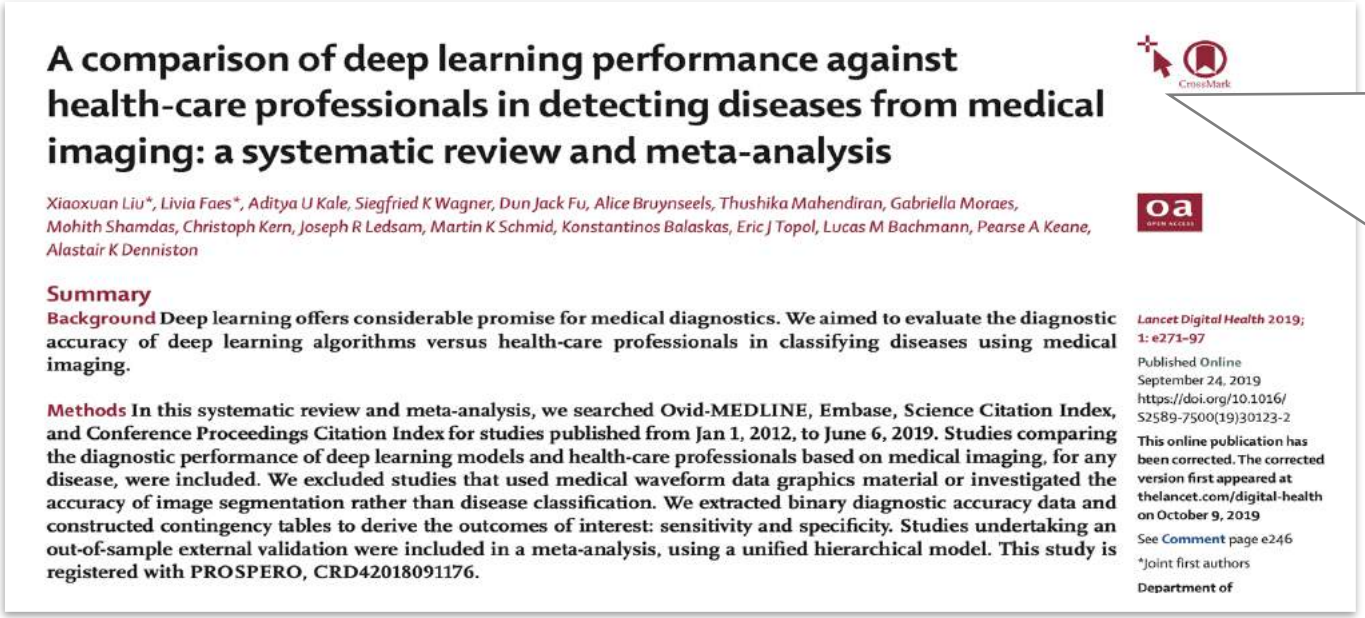
NHS X

NIHR | National Institute for Health Research

www.datadiversity.org

To ensure AI healthcare technologies are supported by adequately representative data, we are developing standards on how AI datasets should be composed (‘*who*’ is represented in the data) and transparency around the data composition (‘*how*’ they are represented).

Clinical Evaluation- Reporting of studies



A comparison of deep learning performance against health-care professionals in detecting diseases from medical imaging: a systematic review and meta-analysis

Xiaoxuan Liu*, Livia Faes*, Aditya U Kale, Siegfried K Wagner, Dun Jack Fu, Alice Bruynseels, Thushika Mahendiran, Gabriella Moraes, Mohith Shamdas, Christoph Kern, Joseph R Ledsam, Martin K Schmid, Konstantinos Balaskas, Eric J Topol, Lucas M Bachmann, Pearse A Keane, Alastair K Denniston

Summary

Background Deep learning offers considerable promise for medical diagnostics. We aimed to evaluate the diagnostic accuracy of deep learning algorithms versus health-care professionals in classifying diseases using medical imaging.

Methods In this systematic review and meta-analysis, we searched Ovid-MEDLINE, Embase, Science Citation Index, and Conference Proceedings Citation Index for studies published from Jan 1, 2012, to June 6, 2019. Studies comparing the diagnostic performance of deep learning models and health-care professionals based on medical imaging, for any disease, were included. We excluded studies that used medical waveform data graphics material or investigated the accuracy of image segmentation rather than disease classification. We extracted binary diagnostic accuracy data and constructed contingency tables to derive the outcomes of interest: sensitivity and specificity. Studies undertaking an out-of-sample external validation were included in a meta-analysis, using a unified hierarchical model. This study is registered with PROSPERO, CRD42018091176.

Lancet Digital Health 2019; 1: e271–97

Published Online September 24, 2019 https://doi.org/10.1016/S2589-7500(19)30123-2

This online publication has been corrected. The corrected version first appeared at thelancet.com/digital-health on October 9, 2019

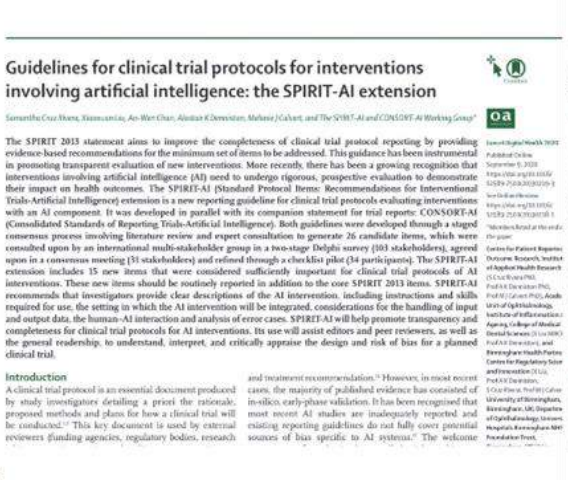
See Comment page e246

*Joint first authors

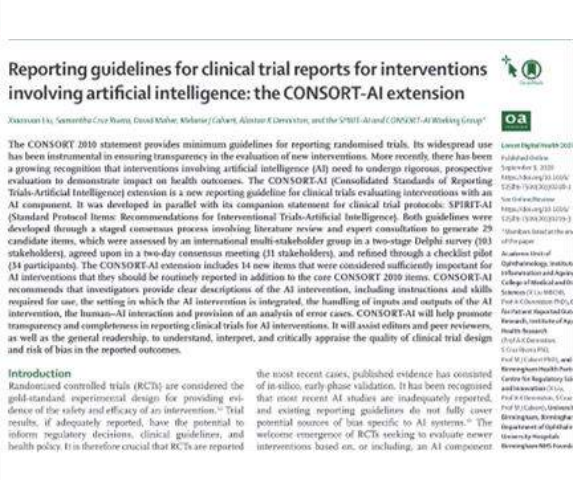
Department of

Inadequate Reporting

- Population characteristics for datasets
- Inclusion/exclusion criteria of participants
- Inclusion/exclusion criteria of images
- Methods for splitting the datasets
- Image preparation and pre-processing
- Procedures for poor quality images
- Provision of the full algorithm
- Instructions on how to use the algorithm
- Expertise of the human comparator



Guidelines for clinical trial protocols for interventions involving artificial intelligence: the SPIRIT-AI extension



Reporting guidelines for clinical trial reports for interventions involving artificial intelligence: the CONSORT-AI extension

nature medicine

THE LANCET Digital Health

thebmj

SPIRIT-AI

CONSORT-AI

Reporting of adverse events/AI errors/ patient harms

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The urgent need for AI safety frameworks

Routine Clinical Practice

- Screening and Triage
- Diagnosis
- Prognostication
- Decision support and treatment recommendation

The Fourth Industrial Revolution

AI Development and Evaluation

- Mammograms
- Eye imaging
- Skin cancer

Integration and Routine use of AI

Effective, safe and inclusive

Robust post-deployment safety monitoring

Scalable deployment in clinical setting

Problem:

- **Urgent need to establish methods for error detection, analysis and reporting (Safety Monitoring)**
- **Lack of understanding around what constitutes AI errors and patient harms**

First Do No Harm

The report of the Independent Medicines and Medical Devices Safety Review

Cumberlege First Do No Harm Report published

Regulatory Horizons Council Report on Medical Devices 19 August 2021

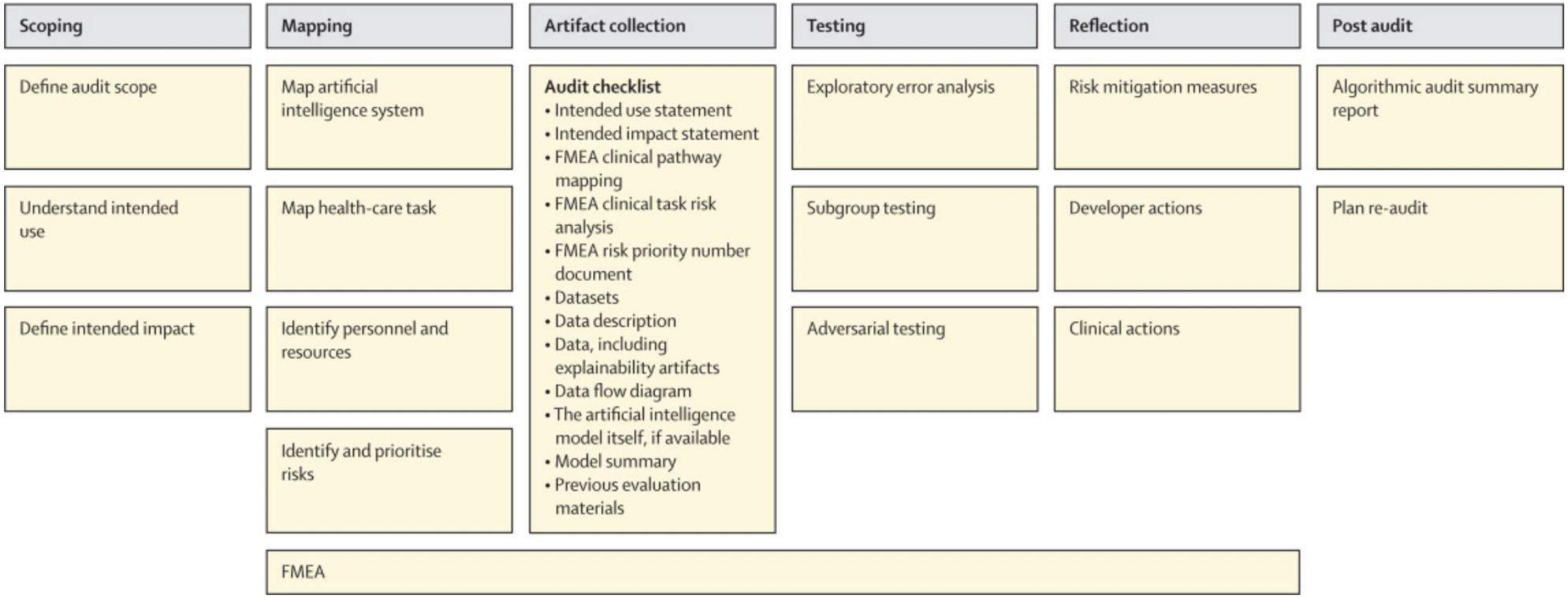
REGULATORY HORIZONS COUNCIL

Performance and safety monitoring of clinical AI

THE LANCET
Digital Health

The medical algorithmic audit

Xiaoxuan Liu, PhD • Ben Glocker, PhD • Melissa M McCradden, PhD • Marzyeh Ghassemi, PhD • Prof Alastair K Denniston, PhD † • Lauren Oakden-Rayner, MBBS † • Show footnotes



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Evaluating safety for Artificial Intelligence (AI) health technologies: improving the detection, analysis and reporting of AI errors and patient harms

Aim:
To improve the detection, analysis and reporting of errors and harms in the context of AI health technologies

Work Package Objectives

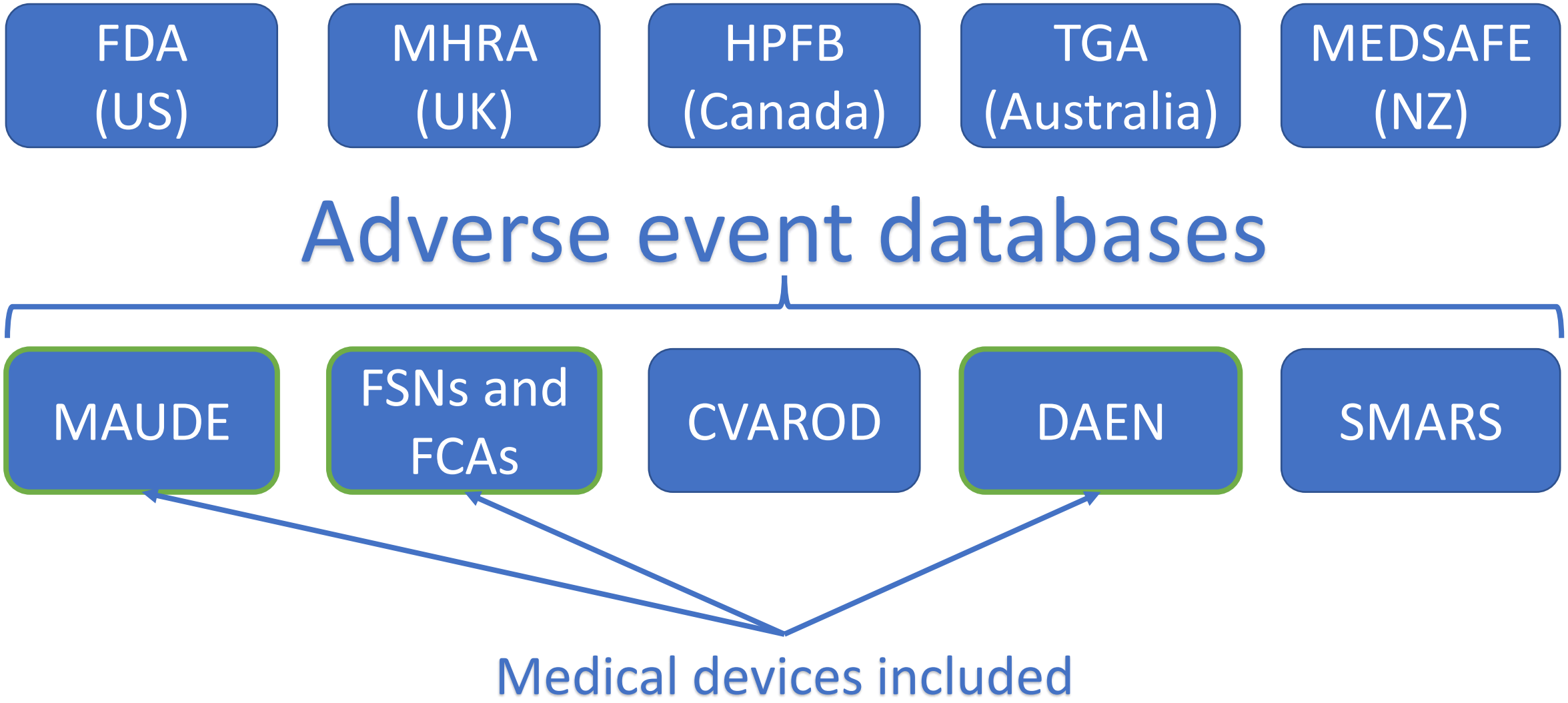
WP1: Identify and characterise AI errors and patient harms

WP2: Evaluate how errors and harms could be detected and reported in practice

WP3: Developing recommendations for a best practice safety monitoring framework to support safe AI deployment

Understanding how to detect, report and prevent errors

Adverse event reporting



Errors and failure modes

Insulin dose optimization using an automated artificial intelligence-based decision support system in youths with type 1 diabetes

Primary outcome: Time spent within target glucose range
Secondary outcome: Adverse events

6 month single blind, parallel RCT (non-inferiority).

Dose adjustments at 3-week intervals using AI DSS vs Physicians

Table 2 | Adverse events

	AI-DSS arm (N = 60)	Physician arm (N = 62)
No. of severe hypoglycemic events[a]	0	2
No. of severe hyperglycemic event (diabetic ketoacidosis)	0	1
No. of severe AEs unrelated to diabetes[b]	2	1
Significant hyperglycemia[c] (due to pump malfunction)	2 (1)	8 (4)
Ketonuria	0	2
Significant hypoglycemia[d]	3	2
No. of device-related AEs		
Sensor-related contact allergic	1	0
Insulin pump site infection	0	4
No. of AEs not related to study interventions (sum)	44	55
Ear, throat and respiratory infections[e]	21	28
Gastrointestinal infections and inflammatory conditions[f]	8	8
Bone and muscle and joint injury or pain	3	7
Allergic conditions	3	0
Urinary infections	2	0
Conjunctivitis	0	2
Skin and subcutaneous tissue disorders	2	4
Neurologic (syncope/headache)	2	0
Other[g]	3	6

A total of 20 diabetes-related study adverse events (AEs) (AI-DSS arm, $n = 8$; physician arm, $n = 12$) were reported. Among these, there were three severe AEs (two severe hypoglycemia, one diabetic ketoacidosis), which were reported in the physician arm. All AEs are presented in Table 2.

Real-time automatic detection system increases colonoscopic polyp and adenoma detection rates: a prospective randomised controlled study

Pu Wang,[1] Tyler M Berzin,[2] Jeremy Romek Glissen Brown,[2] Shishira Bharadwaj,[2] Aymeric Becq,[2] Xun Xiao,[1] Peixi Liu,[1] Liangping Li,[1] Yan Song,[1] Di Zhang,[1] Yi Li,[1] Guangre Xu,[1] Mengtian Tu,[1] Xiaogang Liu[1]

False positives with the automatic polyp detection system

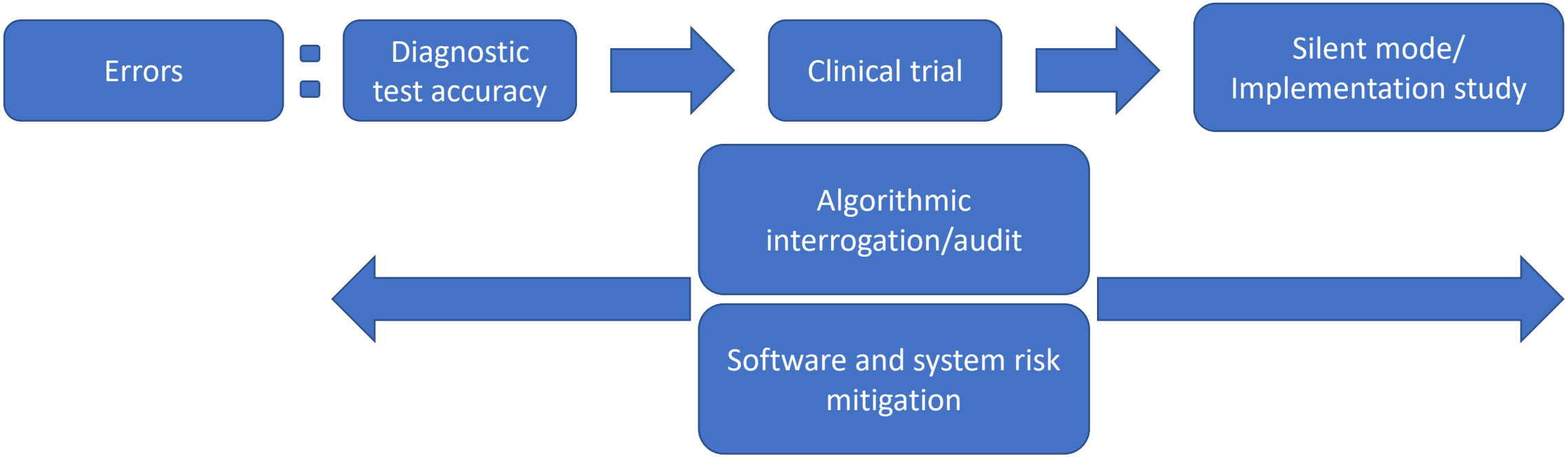
There was a total of 39 false alarms (false positives) in the CADe group, averaging at 0.075 false alarms per colonoscopy (table 5).

Of all the detected polyps in CADe group, none was missed by the automatic polyp detection system (table 5).

Table 5 Statistical results of false alarms and missed polyp

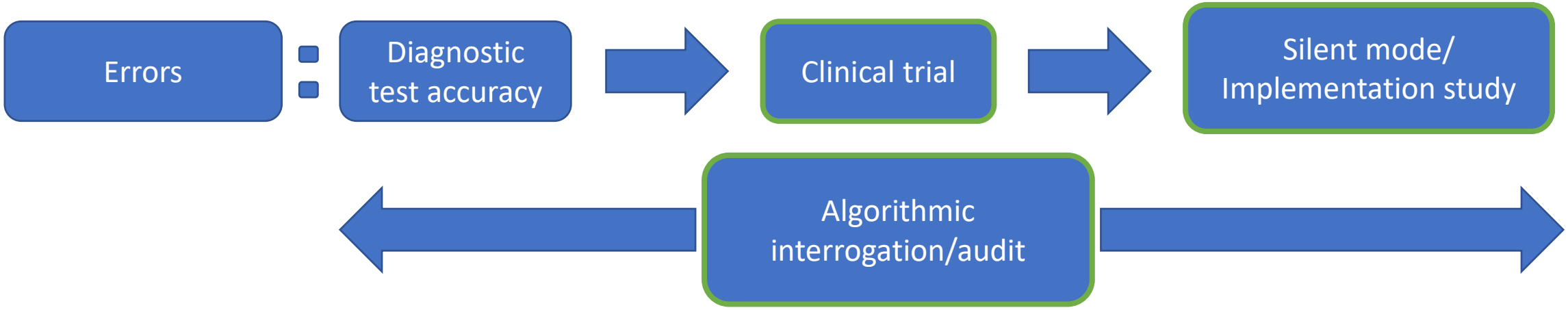
	CADe colonoscopy, n (%)
False alarm	39 (100.00)
Bubble	13 (33.33)
Faeces	5 (12.82)
Undigested debris	4 (10.26)
Wrinkled mucosa	7 (17.95)
Local inflammation	5 (12.82)
Local bleeding	1 (2.56)
Rounded drug capsules	4 (10.26)
Other (circular blood vessel, scar, diverticulum and so on)	0 (0.00)
Missed polyp	0 (0.00)

Errors and failure modes



If the error rate is within the performance claim, are there any failure modes and systematic biases that can be identified?

Summary



- Consideration of safety mechanisms at each stage of development
- Error and failure mode detection during development and implementation (and beyond)
- Collaborative multistakeholder AI safety and performance monitoring

Thank you

a.kale@bham.ac.uk @A_U_Kale

Evaluating safety for Artificial Intelligence (AI) health technologies: improving the detection, analysis and reporting of AI errors and patient harms

Why?

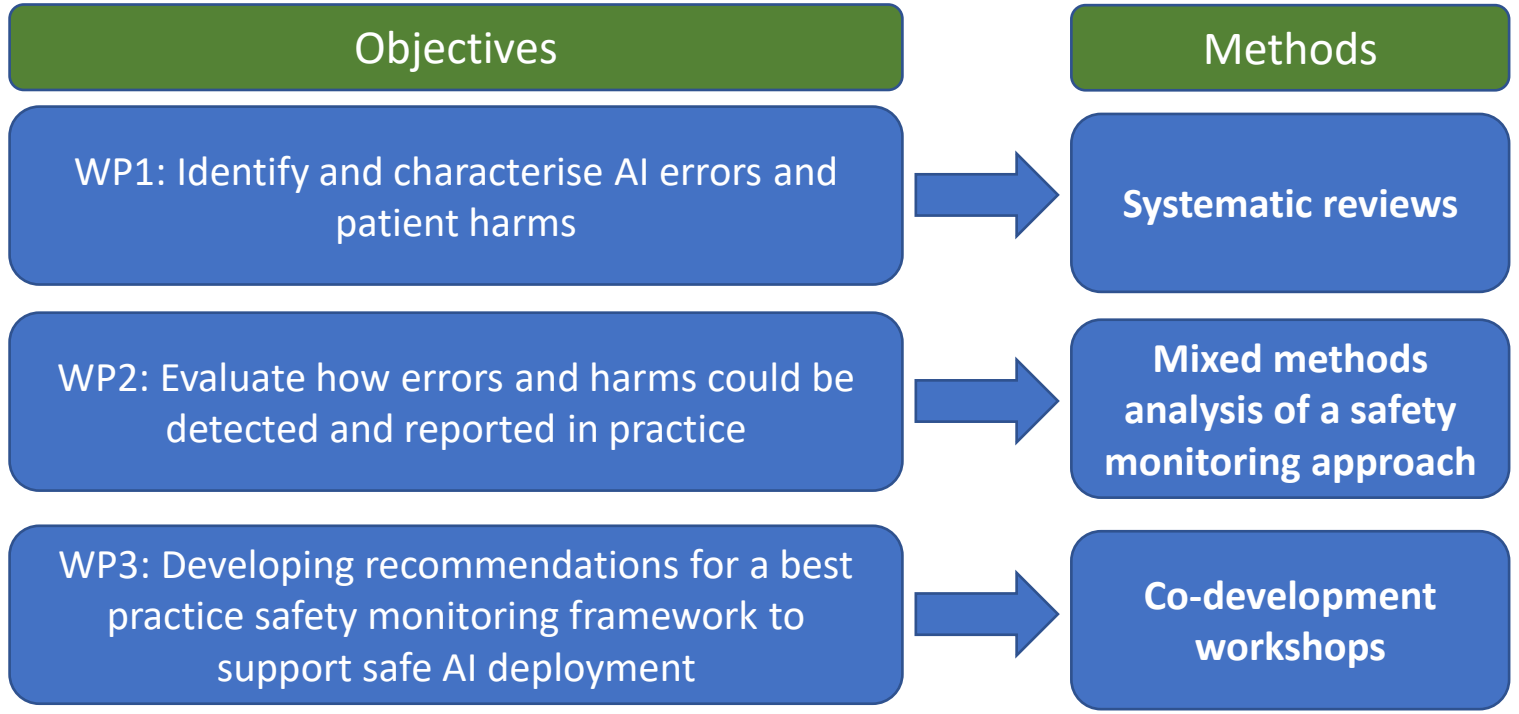
- *Novel AI health technologies are being developed for a range of different clinical tasks, however there is still a lack of robust safety monitoring processes*

Aim:

- *To improve the detection, analysis and reporting of errors and harms in the context of AI health technologies*

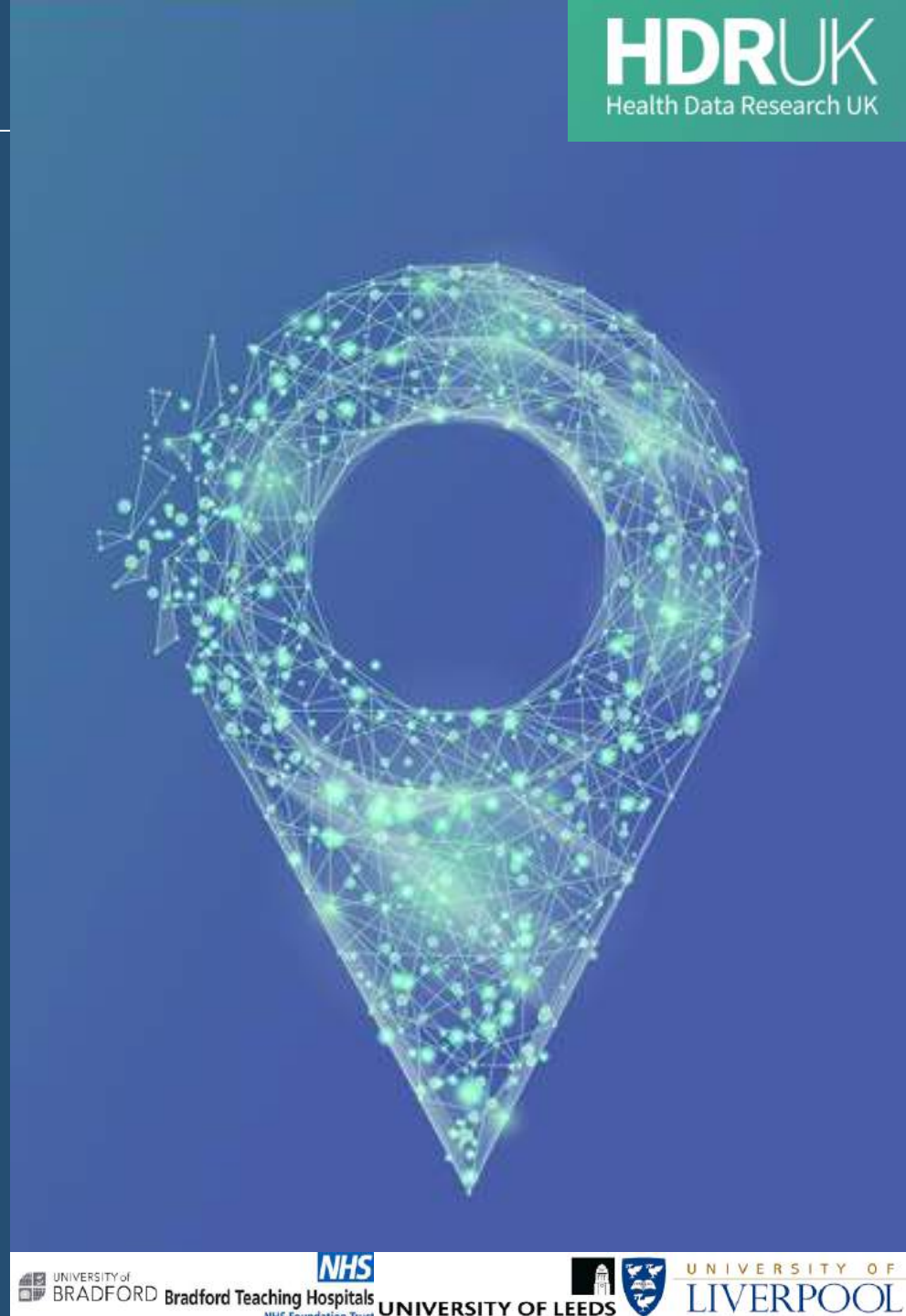
Outcome/Impact:

- *Operationalised safety monitoring tool for deployment in clinical settings, with an understanding of how a multi-stakeholder collaborative approach will assure safe, effective and inclusive integration.*



Improving anticholinergic medication prescribing for older people

Dr Aseel Abuzour
Dr Bethan Copsey



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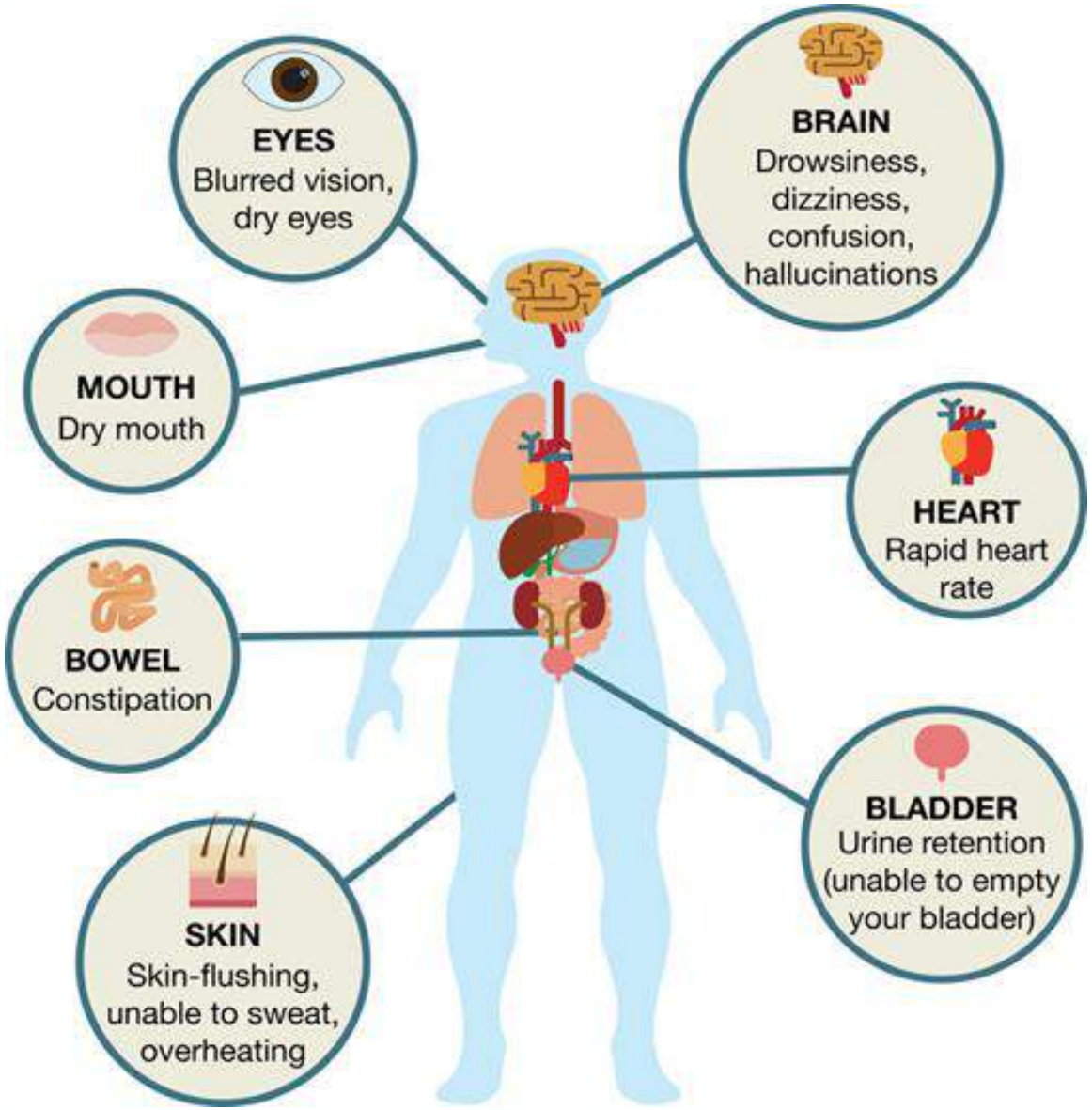
UNIVERSITY of BRADFORD
NHS Bradford Teaching Hospitals
UNIVERSITY OF LEEDS
UNIVERSITY OF LIVERPOOL



Background

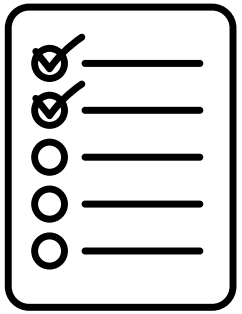
20% of older adults are prescribed anticholinergic medicines for various medical conditions.

Older people living with frailty are particularly sensitive to the adverse effects of AC medications.

Available tools that calculate AC medication burden have not been optimised to predict adverse outcomes, and are not freely/easily available across UK clinical information systems.

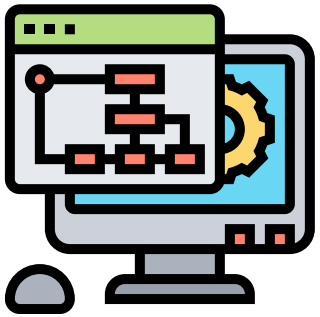
Anticholinergic medicines (ACM) literature search

ACM short-listed to 89 medicines



Connected Bradford dataset search for patients admitted to hospital

Prognostic model developed



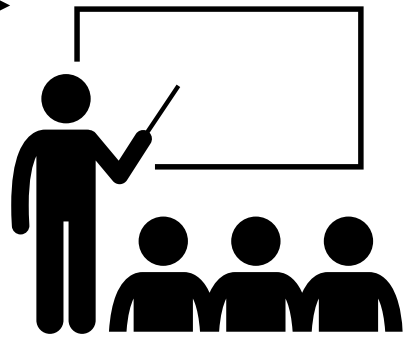
Development of Anticholinergic Medication Index (ACMI)

	What is the ACMI?	What is absolute risk?	Hide contributing medications	See less
NHS number	First name	Surname	Age	Sex	ACMI	Absolute risk	Drug Set
			91	Female	2.66	19.30%	, Digoxin, Furosemide
			97	Female	2.66	17.57%	, Digoxin, Furosemide
			82	Female	8.04	14.93%	, Dipyridamole, Furosemide, Mebeverine, Morphine, Solifenacin, Tramadol
			89	Male	0.00	14.56%	
			87	Female	2.53	14.19%	, Citalopram, Fetanyl
			86	Male	0.00	11.85%	
			81	Female	0.00	11.27%	
			86	Female	0.00	10.13%	
			78	Male	9.87	10.12%	, Digoxin, Furosemide, Hydrocortisone, Lorazepam, Mirtazapine, Morphine, P
			85	Male	9.40	10.10%	, Amitriptyline, Bendroflumethiazide, Chlorphenamine, Codeine, Digoxin, Mirt
			89	Female	0.00	10.04%	
			81	Male	4.11	9.04%	, Amitriptyline, Tramadol, Umeclidinium

Co-production of decision-support resources – clinicians & PPIE

Incorporated into GP electronic health records

Trained GP pharmacists



Patients identified using ACMI and invited for Structured Medication Review

Evaluation using interrupted time series

Anticholinergic Medication Index Calculator

					What is the ACMI?	What is absolute risk?	Hide contributing medications	See less
NHS number	**First name**	**Surname**	**Age**	**Sex**	**ACMI**	**Absolute risk**	**Drug Set**	
			91	Female	2.66	19.30%	, Digoxin, Furosemide	
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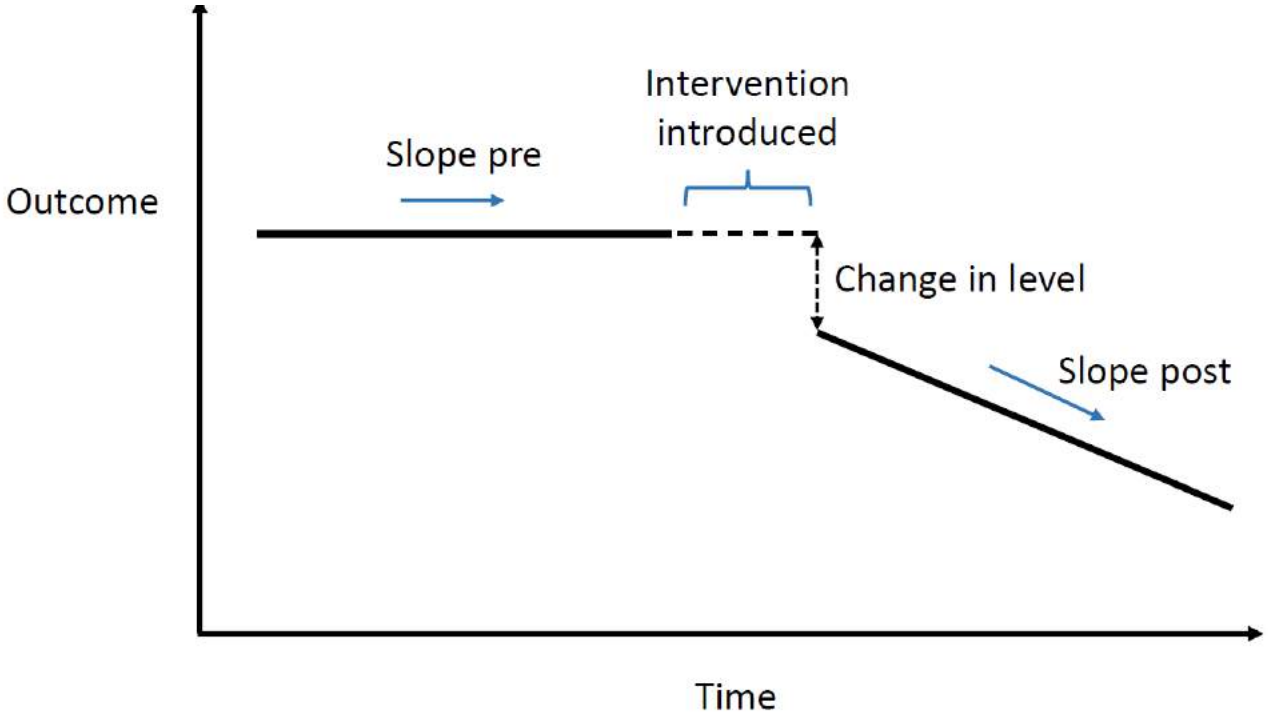
			89	Female	0.00	10.04%		
			81	Male	4.11	9.04%	, Amitriptyline, Tramadol, Umeclidinium	

Evaluation: Overview

- Data source: Connected Bradford – routine data on primary and secondary care
- Pilot evaluation on 4 GP practices
- Examine changes in ACMI score (primary), hospitalisations, dementia diagnoses, nursing home admissions
- Aims: Demonstrate feasibility, examine trends, justify large-scale study
- Analysis: Interrupted time series on aggregate data at GP practice level before and after ACMI medication review is implemented

Evaluation: Interrupted Time Series



Aims:

- Demonstrate feasibility of using data source and conducting analysis
- Examine trends in outcomes
- Provide evidence to justify large-scale study

Healthcare of Care Home Residents During the COVID-19 Pandemic

HDR UK Better Care Insight Sharing Day

Alex Garner - PhD Student, Lancaster University

a.garner2@lancaster.ac.uk

Co-authors:
Nancy Preston, Suzanne Mason, Camila Caiado, Barbara Hanratty, Catherine McShane and Jo Knight

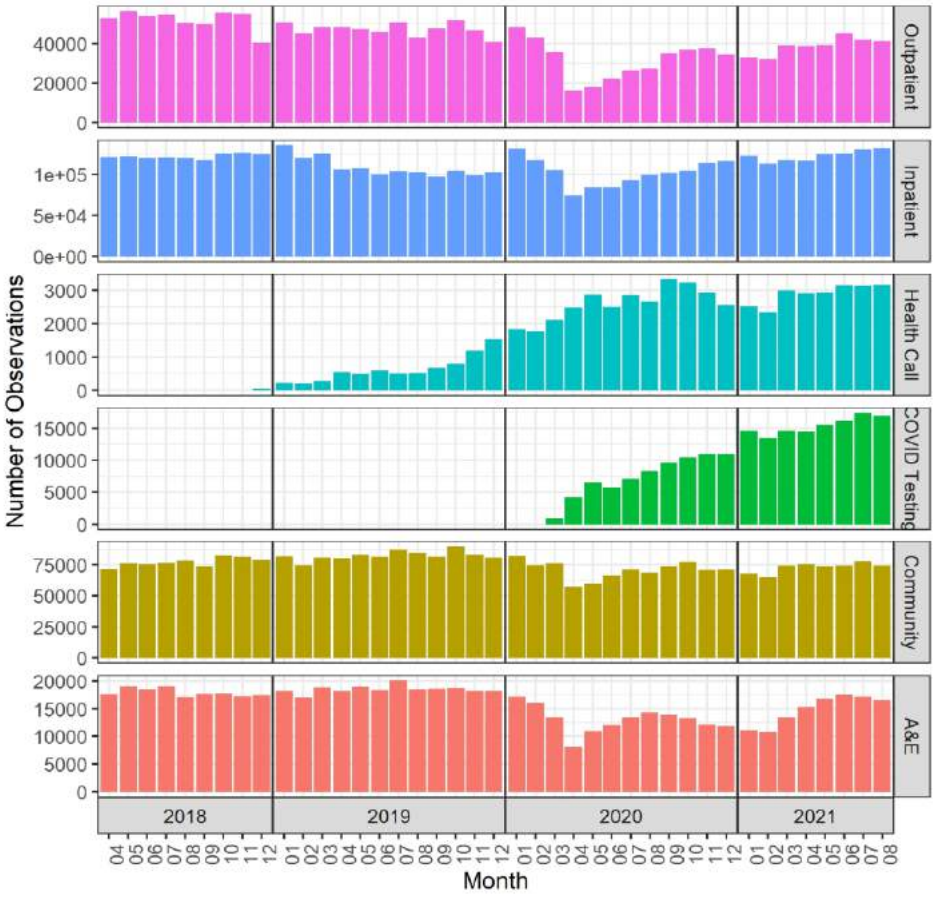
Background & Study Aims

- Care home residents' mortality risk increased disproportionately compared to older people in private homes during the first wave.
- NHS steps to 'free-up the maximum possible inpatient and critical care capacity'.
- Rapid policy changes during the first months of the pandemic.

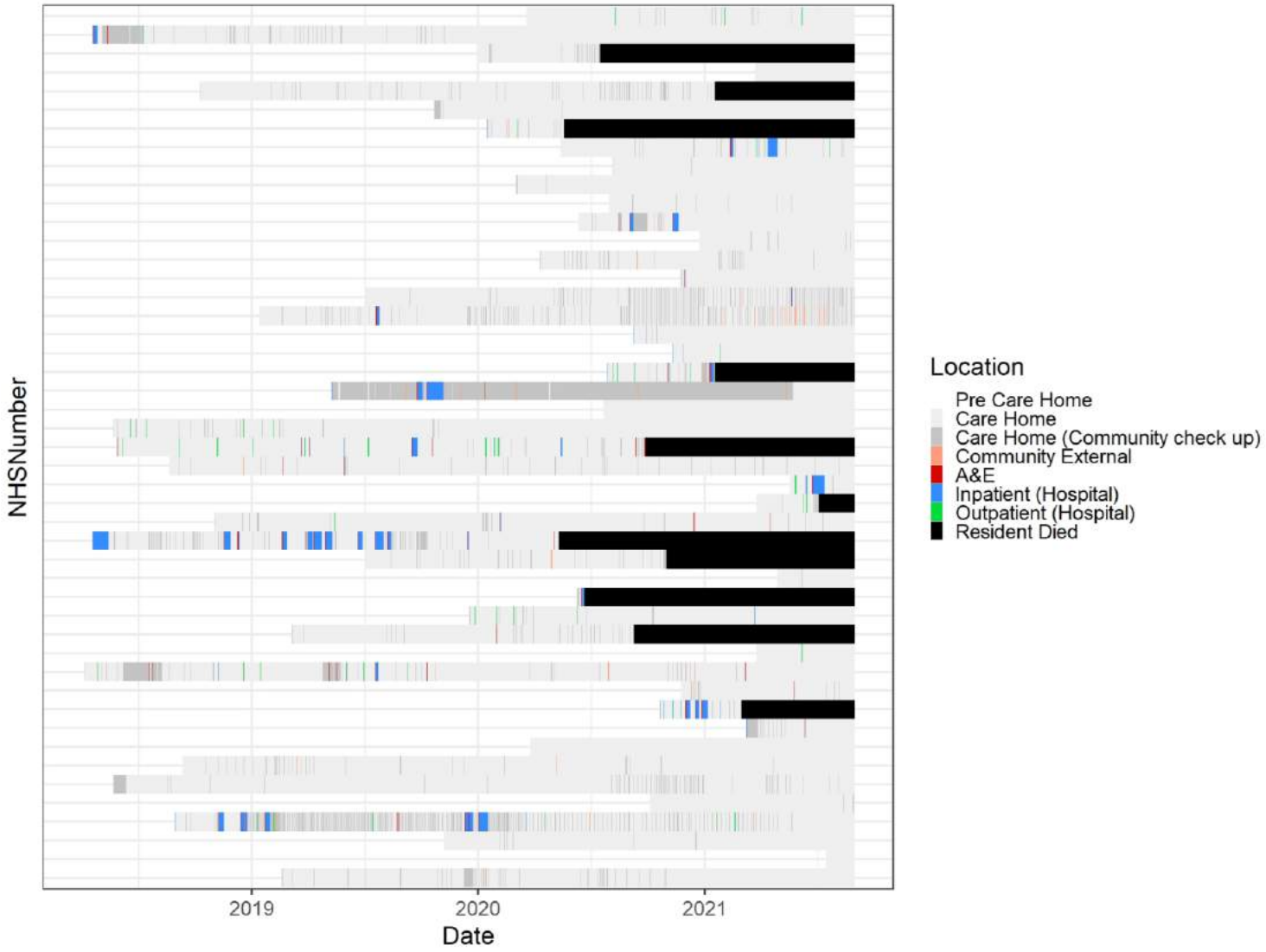
Aim: Descriptive analysis of how care home residents were treated during the pandemic.

Data

Data Set	No. of Observations	No. of Individuals
A&E	675,500	306,750
Inpatient	480,745	177,403
Inpatient Observations	3,726,105	177,825
Outpatient	1,770,173	328,638
Ward Episodes	550,358	186,885
Community	3,185,812	62,917
Health Call	72,261	6,318
COVID-19 Testing (P1)	240,805	94,531
Additional Data Sets		
Discharges	47,982	20,530
Health Call Referrals	15,936	8,785
Health Call Implementation	125	-
Total	10,701,759	612,408

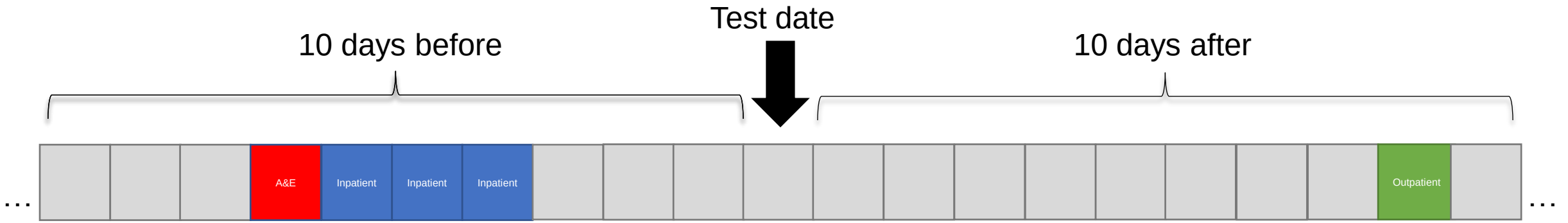


Defining Residents' Trajectories

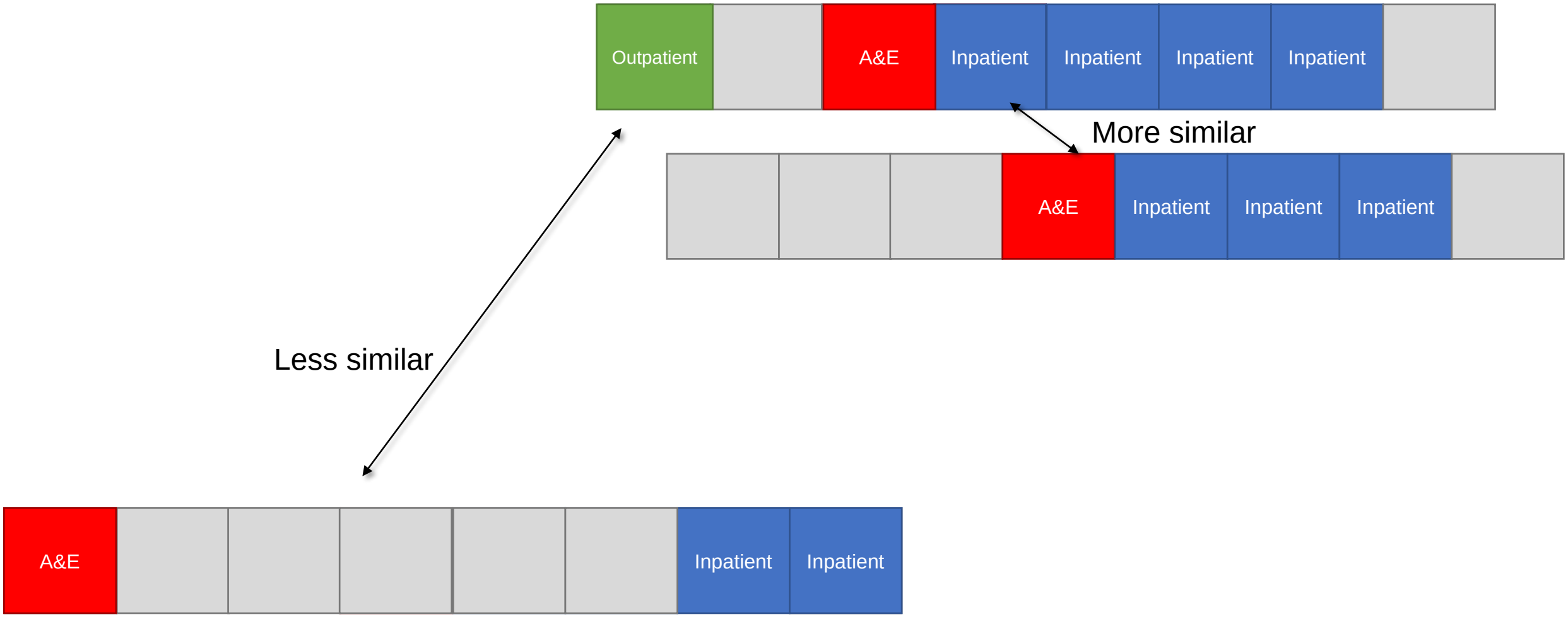


Sequences under Investigation

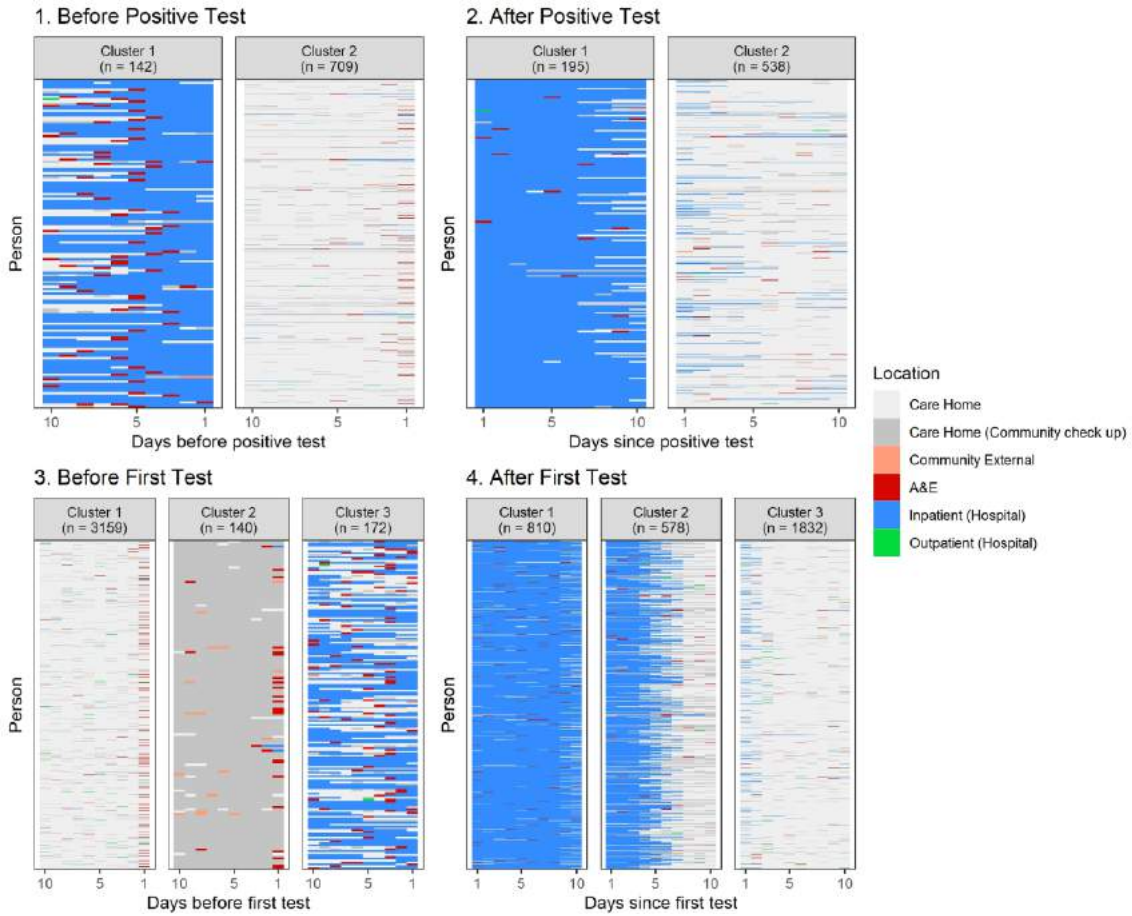
- 10 days before first positive test
- 10 days after first positive test
- 10 days before first test (any result)
- 10 days after first test (any result)



Comparing Residents' Trajectories



Results: Cluster Assignments & Associations



- Clusters driven by care received.
- Diabetes significantly associated with higher levels of care clusters.
- Residents with dementia more often in hospital after test event.
- Positive tests more common in home cluster.

Conclusion

- Application of State Sequence Analysis methodology.
- Clusters demonstrate typical healthcare patterns given the COVID-19 testing conditions.
- Investigated how characteristics impact care.
- Visualise how care changed in response to testing positive.

Thank you

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PATTERNS OF RATES OF MORTALITY IN THE CLINICAL PRACTICE RESEARCH DATALINK

James C. F. Schmidt, Paul Lambert, Clare Gillies and Michael Sweeting

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RESEARCH BACKGROUND

Using large scale electronic health records to adjust expected mortality rates in the form of published life tables.

Cohort of 1.8 million Clinical Practice Research Datalink (***CPRD***) GOLD subjects, alive and registered on CPRD from January 2000 to December 2018.

With research acceptable data and data linkages to the Office for National Statistics (***ONS***) and Hospital Episode Statistics Admitted Patient Care (***HES***).

Initial finding suggested some form of altered mortality.

Mortality rates were below the national English population.

INTRODUCTION

CPRD is one of the largest longitudinal datasets in the world.

Capturing primary care data from consenting GP practices.

Covering approx. 7% of the UK population.

CPRD is representative of ethnicity, sufficiently accurate in recordings of death and comparable to other populations with regards to age and sex distribution[1-4].

Aim 1:

How does mortality in selected CPRD cohorts compare with the general population?

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INTRODUCTION CONT.

Period of observation prior to the start of at-risk follow-up contribution (start of survival time, ***index date***).

Sometimes referred to as research-quality follow-up or a ***lookback window.***

Period of length W ends at the ***index date*** (baseline).

Uses: medication usage, procedure/diagnosis, comorbid condition identification etc.

Aim 2:

Does the use of lookback windows affect morality rates?

CPRD COHORT

Random sample of 1M CPRD GOLD patients with:

- *Research acceptable data*
- *Data linkages to HES and ONS*
- *18 years or older at index date*
- *Alive and with CPRD follow-up between January 2000 – December 2018*

Defined 3 dates:

Start date ($\boldsymbol{S}$) = last of first/current registration or practice up-to-standard date

Index date ($\boldsymbol{I}(\boldsymbol{w})$) = last of January 2000, 18th birthday or start date + w years lookback

End date ($\boldsymbol{E}$) = first of practice last collected, patient transfer out, death date or December 2018

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METHODS

Each subject had a start date, initial index date ($\boldsymbol{I(0)}$) and end date defined.

Four sub-cohorts were then defined where $\boldsymbol{W \geq w}$, $w = 1, 2, 5, 10$.

Five datasets: no lookback, 1, 2, 5 and 10 years lookback.

At-risk follow-up = end date - index date (in years).

Crude death rates calculated per cohort $\left(\frac{deaths}{follow-up} x1000\right)$.

Mean Charlson Comorbidity Index (***CCI***)[5] scores calculated per cohort, classified as CCI score 0, 1, 2 or 2+ score.

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METHODS CONT.

Standardised Mortality Ratios (**SMRs**) - indirect standardisation measure giving estimate of relative increase or decrease in mortality in study population compared to reference population.

Estimated over calendar year and follow-up.

Reference mortality rates derived from ONS life tables for England.

Life tables stratified by age, sex and calendar year.

RESULTS

	$W \geq 0$	$W \geq 1$	$W \geq 2$	$W \geq 5$	$W \geq 10$
Subjects[a]	1 000 000	876 048	771 175	568 114	370 780
Deaths[c]	78 729 (7.87)	67 540 (7.71)	60 929 (7.90)	46 058 (8.11)	27 626 (7.45)
Follow-up[d]	6 539 842 (6.54)	5 915 754 (6.75)	5 345 168 (6.93)	3 933 523 (6.92)	2 186 635 (5.90)
Crude Death Rate[e]	12.04	11.42	11.4	11.71	12.63
CCI Score[c]					
0	927 079 (92.71)	814 348 (92.96)	714 801 (92.69)	519 327 (91.41)	329 214 (88.79)
1	42 495 (4.25)	37 324 (4.26)	34 143 (4.43)	28 939 (5.09)	23 457 (6.33)
2	16 032 (1.6)	13 799 (1.58)	1 791 (1.66)	1 563 (2.04)	1 193 (2.75)
3+	14 394 (1.44)	1 577 (1.21)	9 440 (1.22)	8 285 (1.46)	7 916 (2.13)
Mean CCI Score[f]	0.14 (0.7)	0.13 (0.63)	0.13 (0.64)	0.16 (0.7)	0.22 (0.84)

Values reported are: a - N, b - mean (std. dev.) [min, max], c - N (%.), d – total (mean), e – (deaths/ follow-up)x1000 and f – mean (std. dev),

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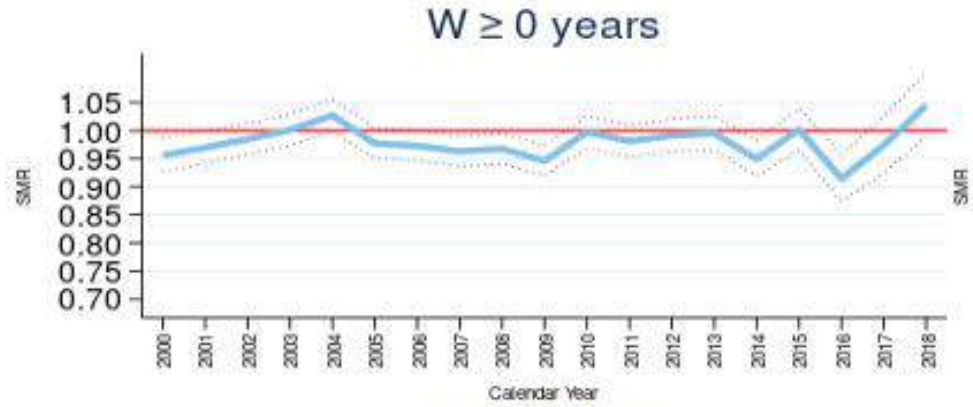
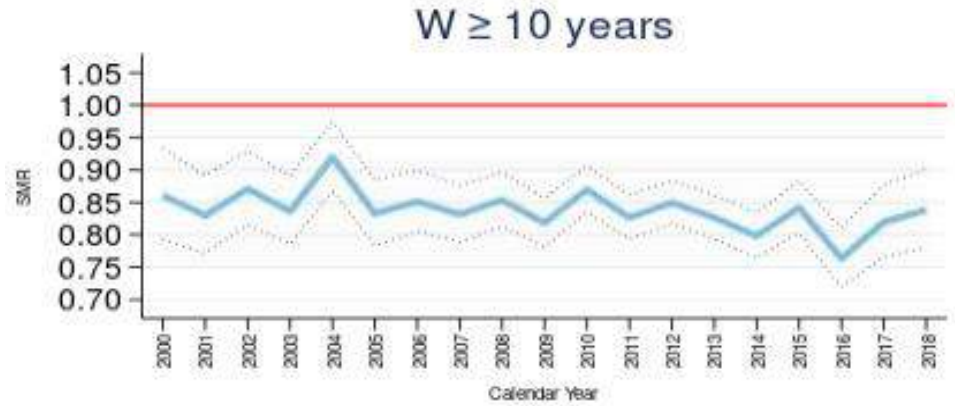
RESULTS
CONT.

SMRs and 95% CI for cohorts, over calendar year with reference line SMR=1





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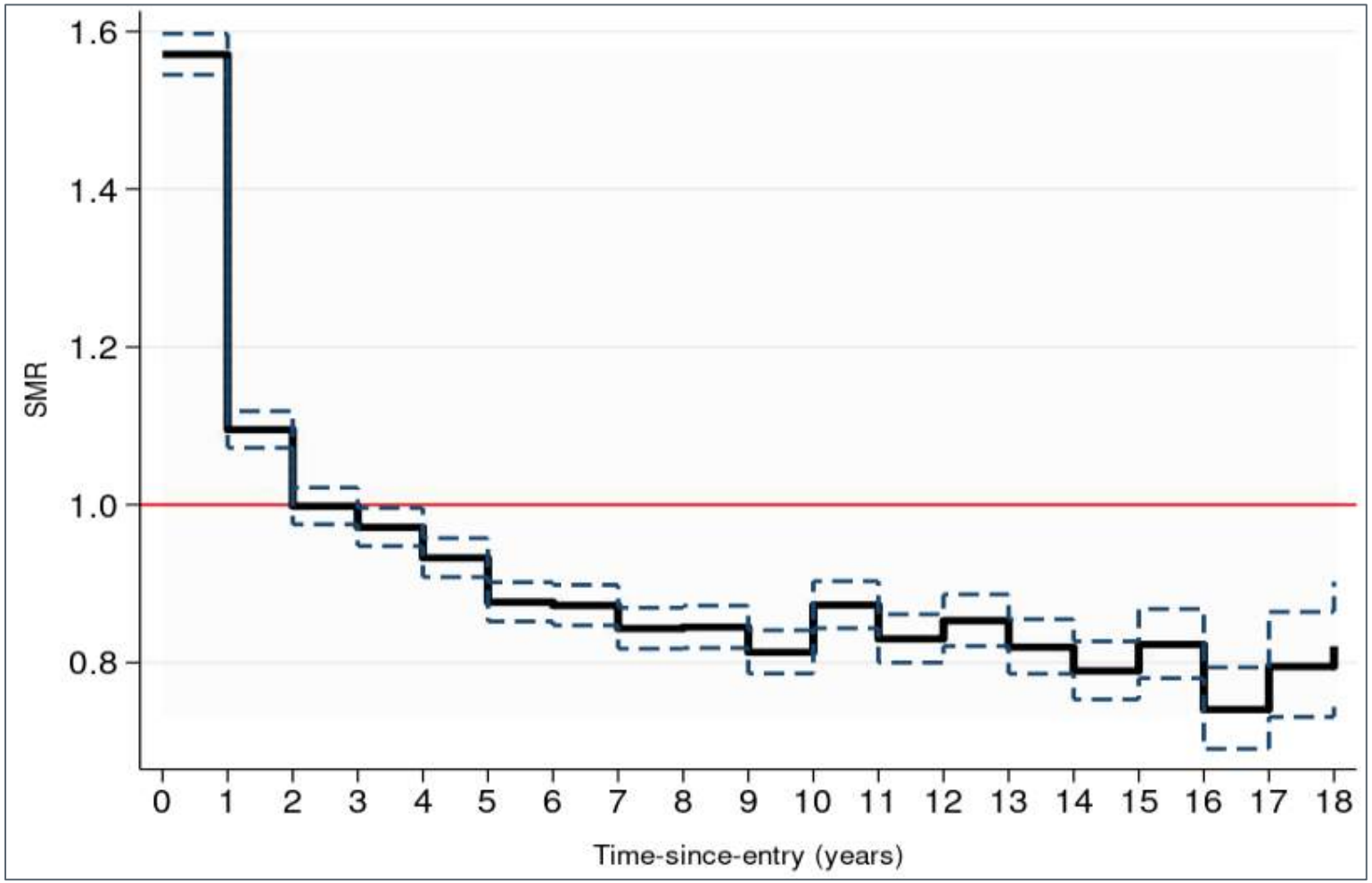
RESULTS
CONT.

SMRs and 95% CI over follow-up time-since-entry (in years), with reference line SMR=1



DISCUSSION

Mortality rates in unrestricted 1m random sample similar to general English pop.

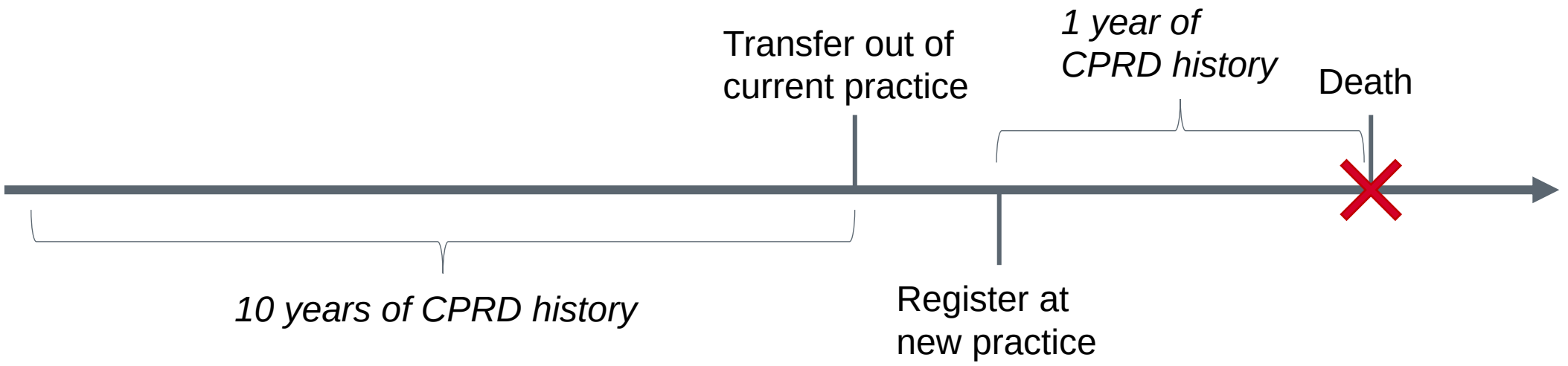
Inclusion of lookback = reduced mortality rates when compared to age-, sex- and calendar year match general pop.

Longer CPRD registration ≈ '*stable*' population, more medically vigilant, removes high risk patients??

Selection bias

DISCUSSION CONT.

High initial mortality ≈ patients are unique lines of data in CPRD.



Patient registered 10 years at GP, transfers out, joins new GP and dies
Seen as two separate individuals in CPRD.

CONCLUSION

Mechanism or reasoning for the selection effect or high initial mortality rates (when compared to the general population) unknown.

Reduced mortality rates with increased lookback window periods and high initial mortality rates in CPRD are significant and should be noted by all who use CPRD in the study of mortality.

The implicit assumption that CPRD is representative of mortality in the general population must be carefully considered.

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HDRUK
Health Data Research UK

The Networked Data Lab

Fiona Grimm and Sebastien Peytrignet, The Health Foundation

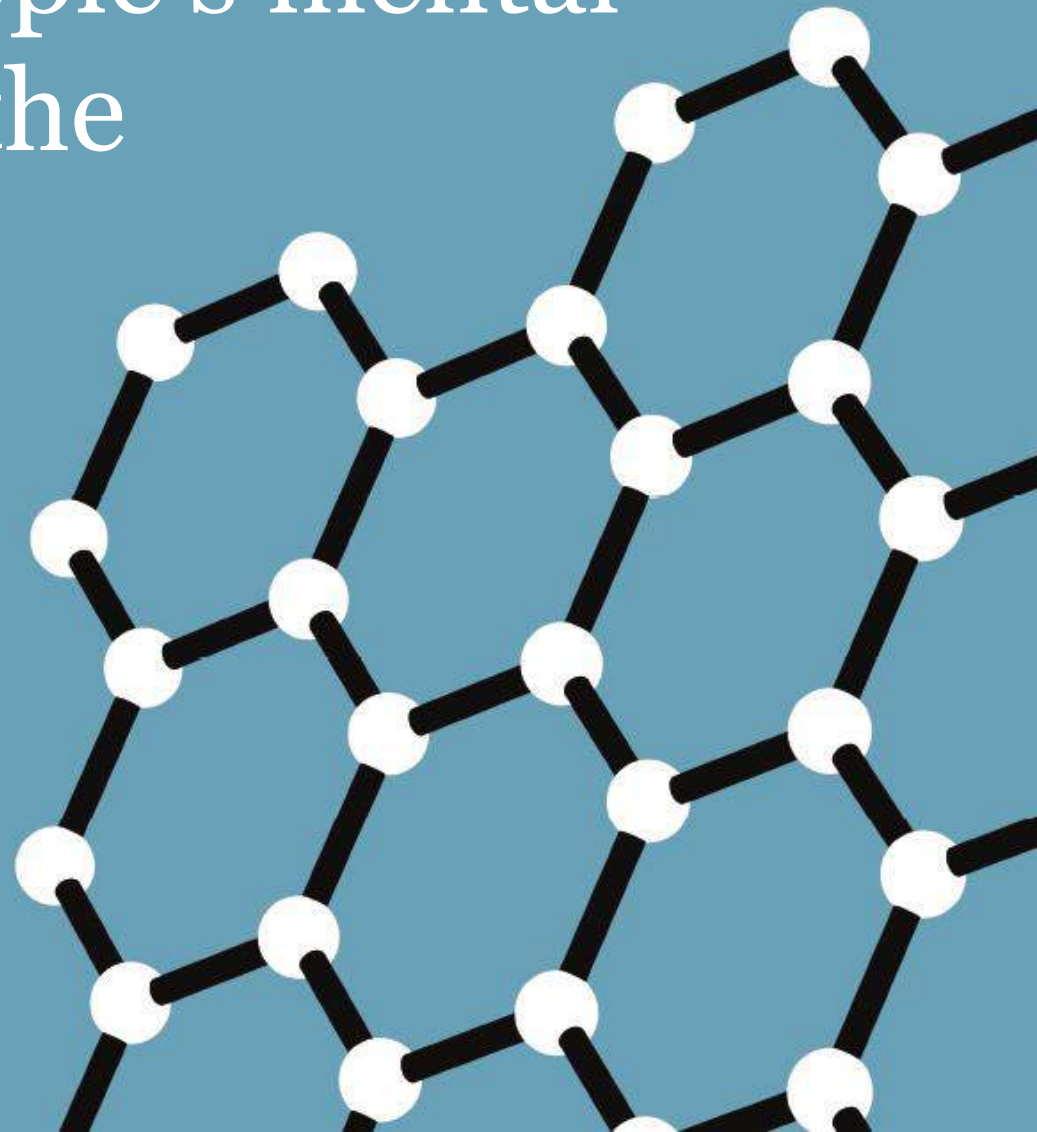
Jessica Butler, University of Aberdeen

Children and young people's mental health – findings from the Networked Data Lab

Fiona Grimm, Senior Analytical Manager
Sebastien Peytrignet, Senior Data Analyst

HDRUK Better Care Insight Sharing Day
14 July 2022

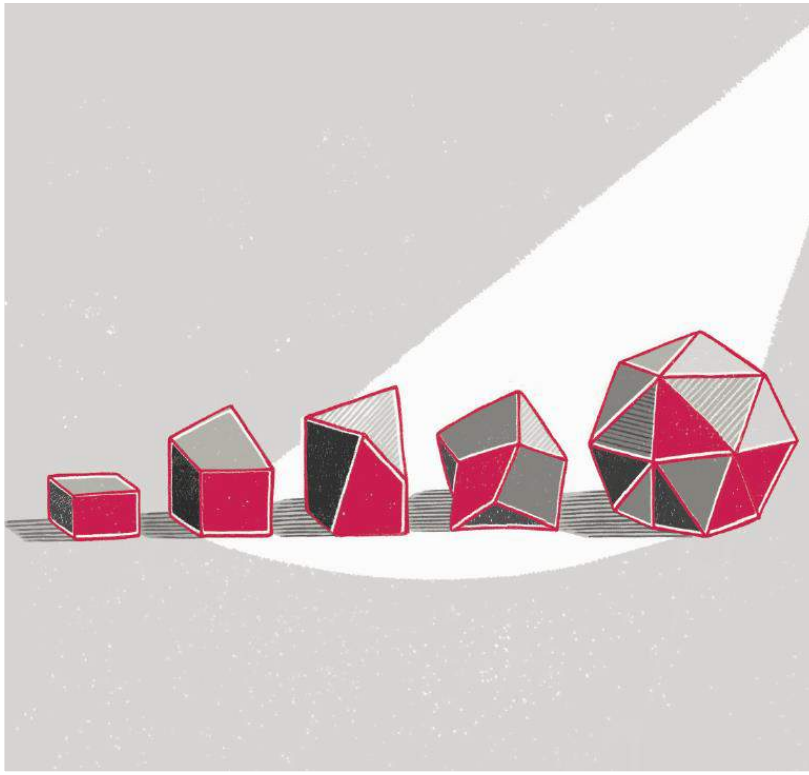
The Health Foundation



About us

The Health Foundation is an independent charity committed to bringing about better health and health care for people in the UK.

We connect what works on the ground with effective policymaking and vice versa.



We shine a light on how to make successful change happen

Network of analytical partnerships across the UK

https://www.health.org.uk/funding-and-partnerships/the-networked-data-lab

Why a network of existing teams?

Investment and support is needed to accelerate the development and use of linked datasets, especially beyond NHS services.

We support local partner sites to **accelerate data linkage across health and social care**, and data around the wider determinants of health. We invest in **developing analytical capability and reusable tools and resources.**

Those planning and delivering services need insights to help improve care and reduce inequalities.

The NDL **provides policy-relevant analysis** to support decision making at the local and national level and showcases the value of linked data.

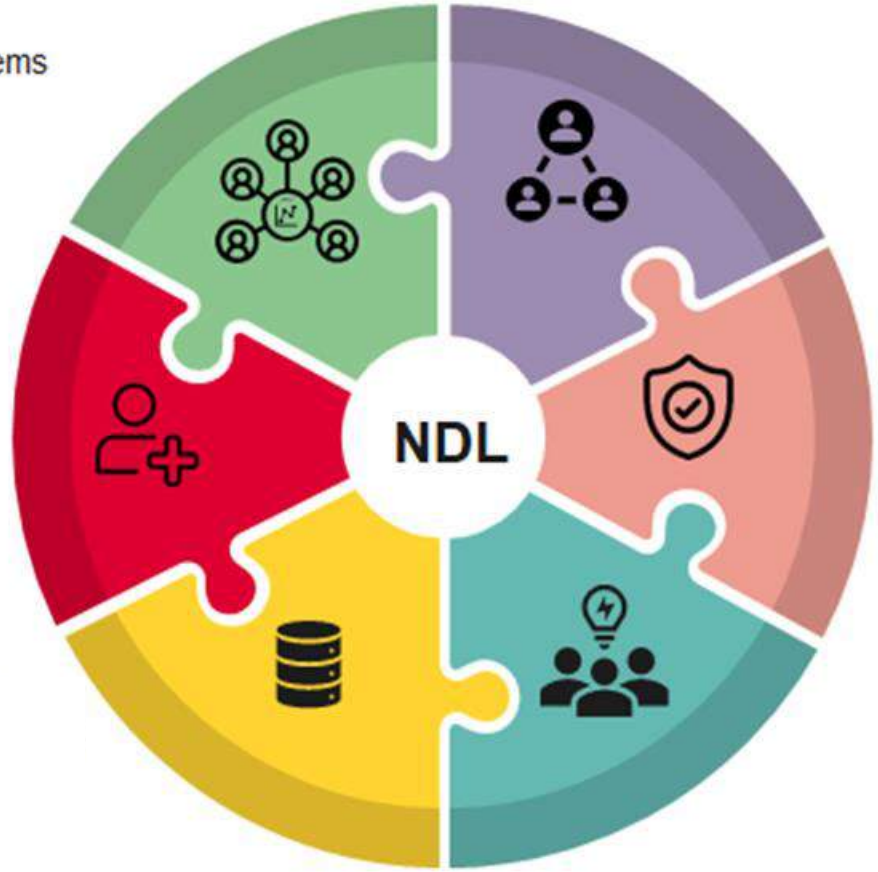
Privacy-preserving models of analysis are needed to preserve and build public trust.

Our **federated analysis approach** removes the need for patient data to ever leave secure local systems.

Ways of working with partners

COLLABORATIVE ANALYTICS

- Federated analysis between local systems
- Open code, open working
- Reproducible statistical models



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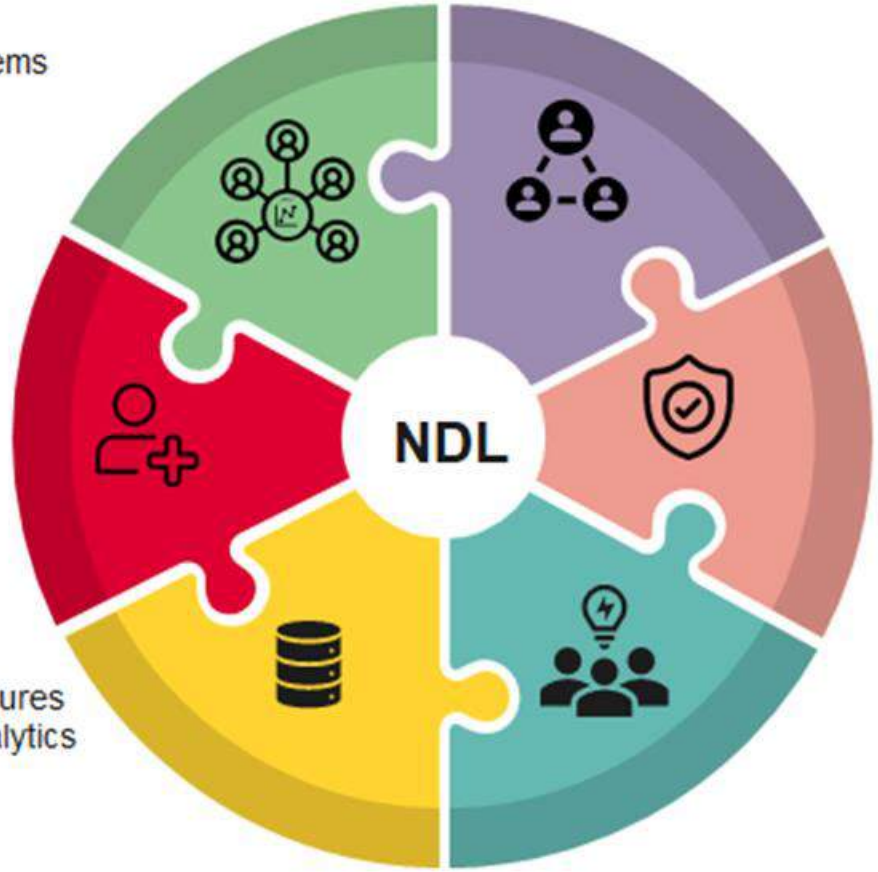

LOCAL DATA ACCESS

- Data resides in local secure infrastructures
- Analysts granted access to secure analytics areas according to local governance
- Summary statistics stored centrally

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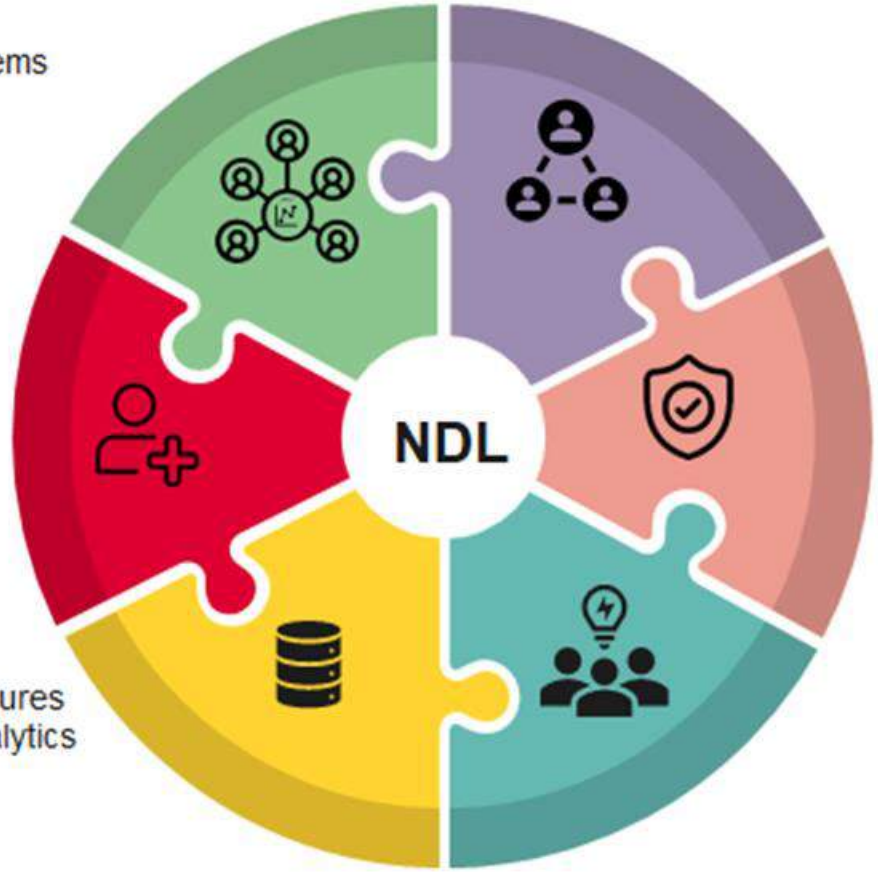

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BUILDING ANALYTICAL CAPABILITY

- Novel linkage of local datasets
- Build sustainable analytical capability in the local health and care service

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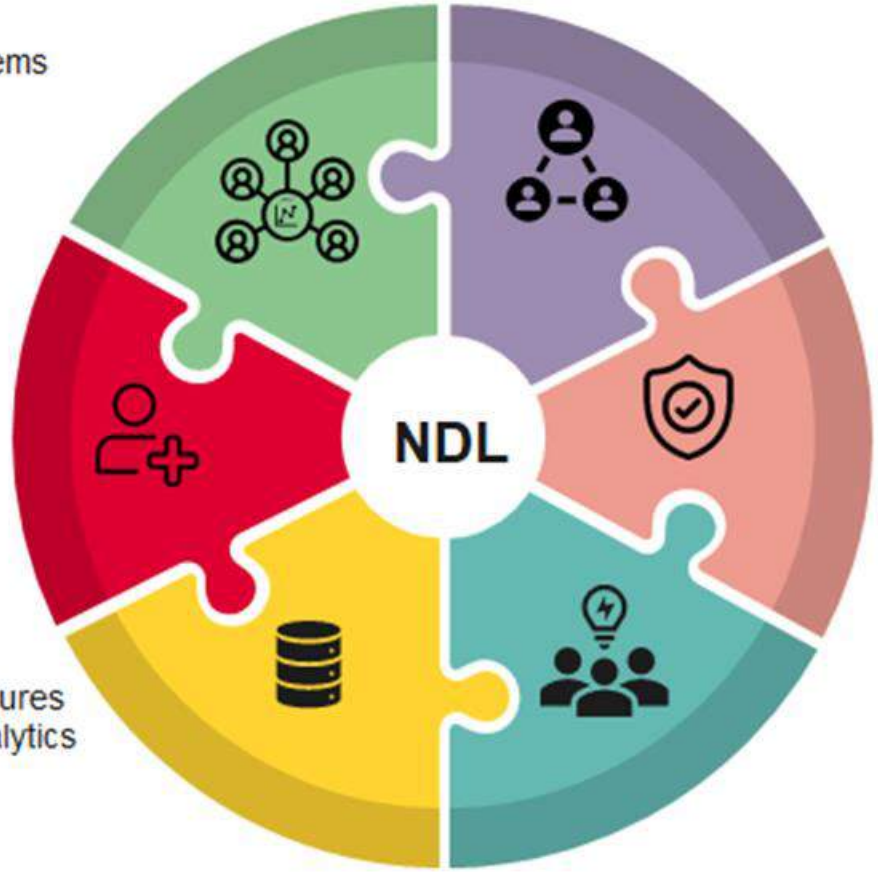

QUALITY ASSURANCE

- Internal/local QA of code
- Patient and public reviewers
- Statistical disclosure control
- Peer review

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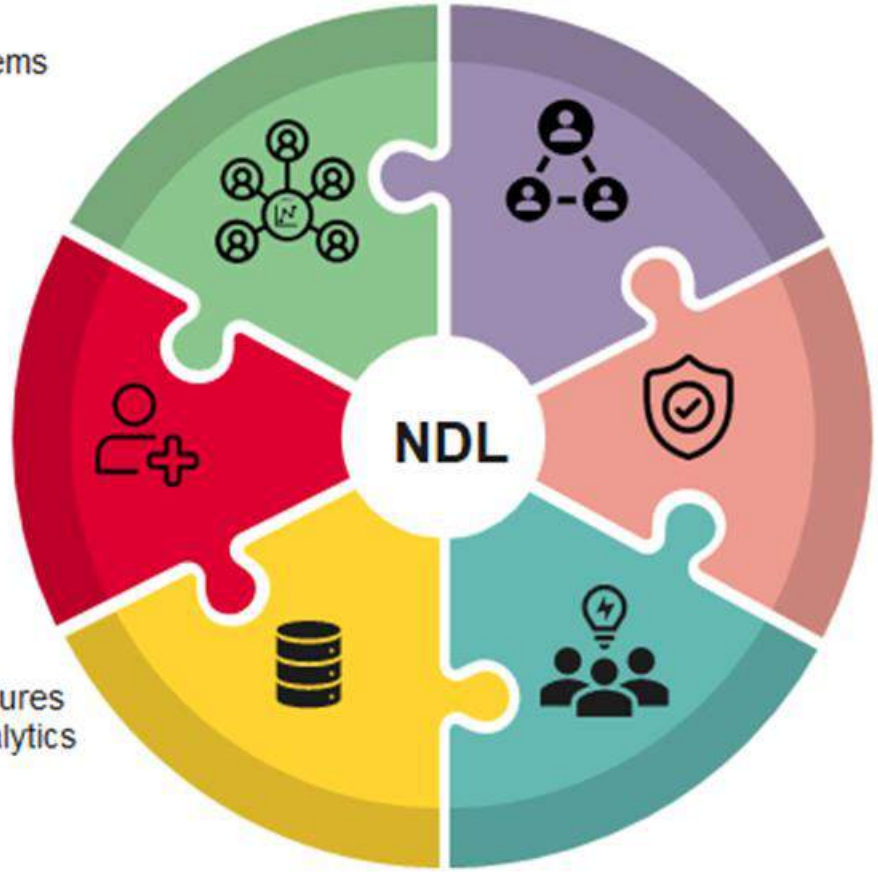

SHARED LEARNING

- Virtual and in-person workshops, huddles, events (internal/external)
- NDL Slack workspace
- 1-2-1 engagement between Labs

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PATIENT AND PUBLIC INVOLVEMENT & ENGAGEMENT

Involvement for better data – based on the principles of partnership, respect, inclusivity and transparency

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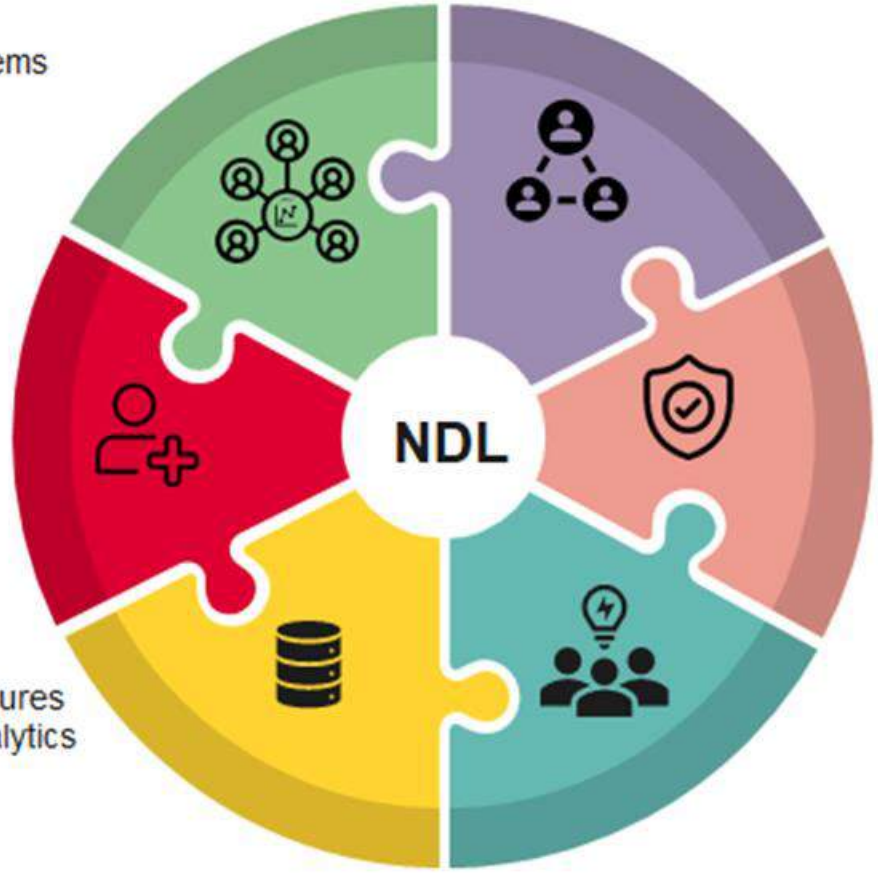

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https://link.medium.com/8IOOaF8Zurb

Embedding open analytics and ways of working

README.md

The Networked Data Lab on GitHub

Welcome to the Networked Data Lab's central landing page on GitHub, where we all our code repositor resources are referenced in one place.

2 Topic 2: Children and young people's mental health (2021-2022)

Resources for the analytical community

- A library of clinical code lists for mental health conditions - GitHub, Links to external code list repositories
- Data extraction and cleaning pipeline for the secure-access version of NHS Digital's Mental Health Services Dataset (MHSDS) - GitHub, SQL codes
- Web-scraping and data cleaning pipeline for NHS Digital's monthly MHSDS statistics - GitHub, R codes to extract monhtly data, compile into a longitudinal dataset and create a visualization dashboard

Open data analyses

- Children and young people's mental health: COVID-19 and the road ahead - analysis using open data from NHS Digital and Health Education England - GitHub, R analysis files - publication link

Satellite analyses by labs

These are analyses done independently by each of the labs.

- Grampian: Prescribing patterns of mental health medications and referrals to CAMHS - GitHub, Analysis plan, codes and report
- Leeds: Patterns in the use of mental health services among children and young people in Leeds - GitHub, Analysis plan, codes and report
- Liverpool and Wirral: Children and young people's mental Health in Liverpool and Wirral - GitHub, Analysis plan, codes and report
- Wales: Trends in mental health crisis events among children and young people across the acute health care system in Wales - GitHub, Analysis plan, codes and report
- North West London: Impact of the COVID-19 pandemic on the mental health of the children and young people population in North West London - GitHub, Analysis plan, codes and report

github.com/HFAnalyticsLab/networked_data_lab

Progress

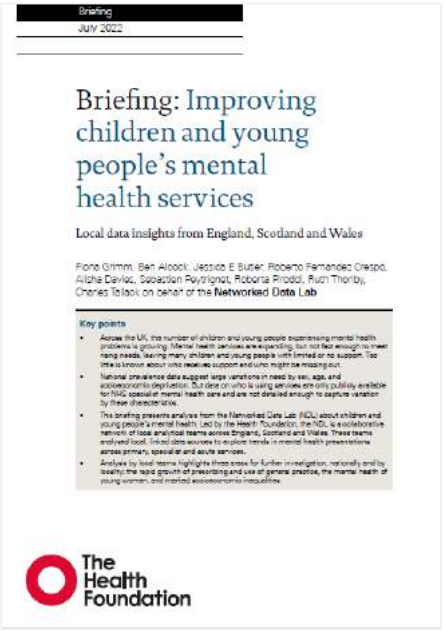
2019 — 2020 — 2021 — 2022 — 2023

Partner recruitment

Topic 1: Impact of shielding from COVID-19

Topic 3 & redesign

Topic 2: Children and young people's mental health



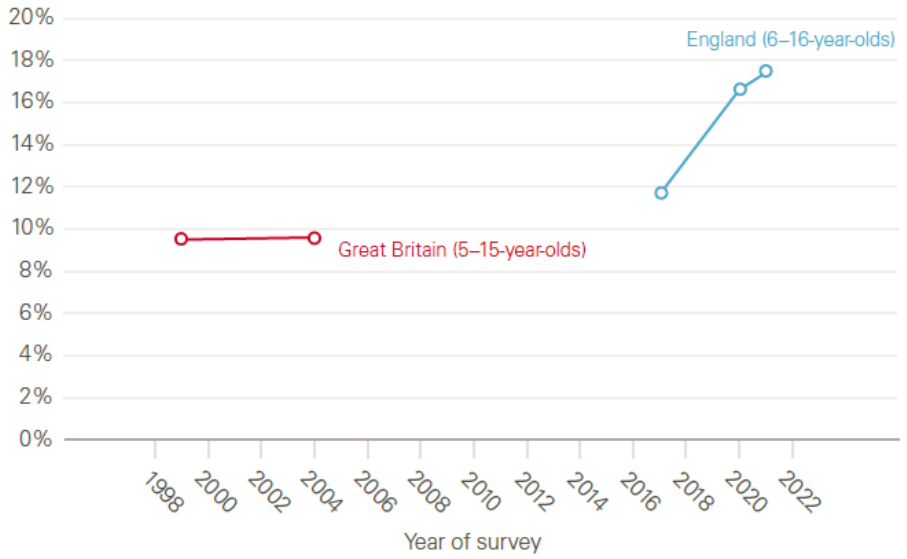
Learning from the pilot phase

- Embedded approach helps us to ask questions relevant to patients and local stakeholders, and helps drive local demand for analysis and use of insights
- A key challenge is to ensure that analysis meets the needs of national policy and local decision makers
- Time needed for stakeholder engagement and PPIE tends to be underestimated for capacity and resource planning
- Relationships and collaboration between partners are key – but finding the time to build them is not easy
- Being pragmatic about data harmonisation

Children and young people's mental health services

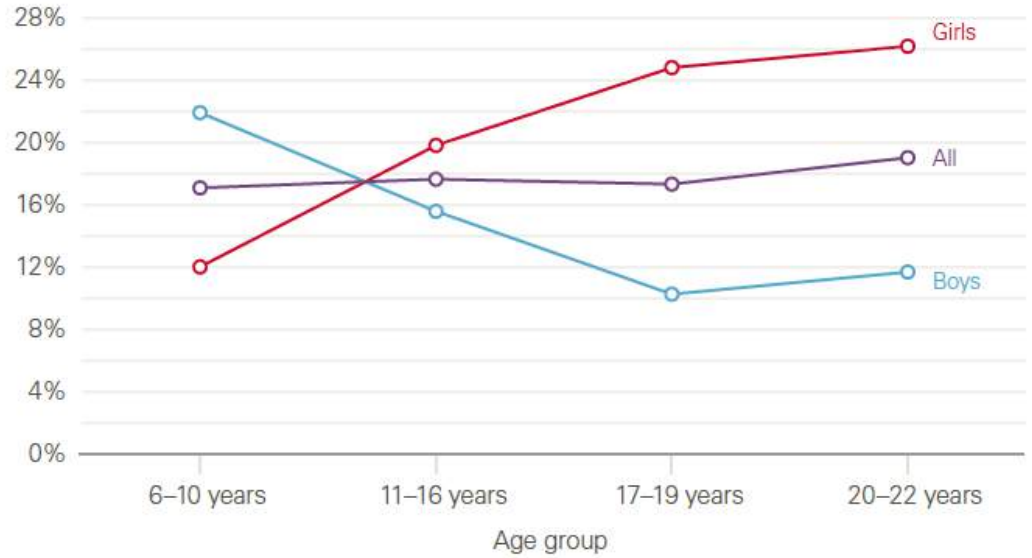
Mental health conditions among CYP

Figure 1: Percentage of children and young people with a probable mental health disorder in Great Britain in 1999 and 2004 and England in 2017, 2020 and 2021



Source: 2017–2021 Mental Health of Children and Young People in England Survey; 1999 The mental health of children and adolescents in Great Britain; 2004 Mental health of children and young people in Great Britain. Between 2017 and 2021, 6 to 16 year olds are considered to have a probable mental health condition based on answers to the Strengths and Difficulties Questionnaire. In 1999 and 2004, survey responses were analysed by clinicians using a case vignette approach.

Figure 2: Percentage of children and young people with a probable mental health disorder in England, 2021



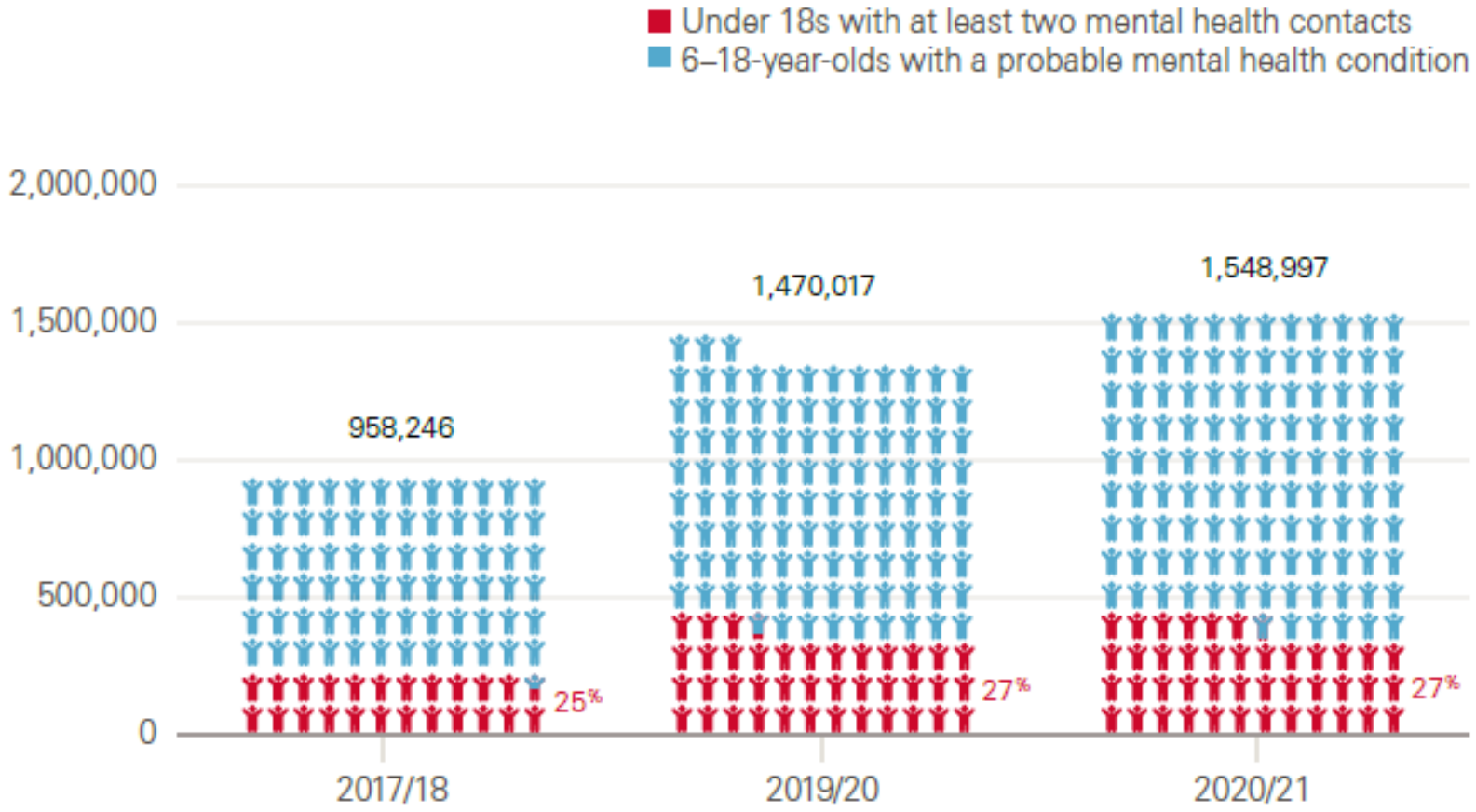
Source: 2021 Mental Health of Children and Young People in England Survey.

Policies in England, Scotland and Wales

Shared aims:

- more provision of mental health and wellbeing support in schools and the community outside the NHS, including a focus on prevention
- improving access to (and reducing waiting times for) specialist Children and Adolescent Mental Health Services (CAMHS)
- improved crisis care
- extending mental health services beyond age 18, to 25 or 26 (Scotland).

Access to specialist services remains low



Source: Networked Data Lab briefing

Rationale for this analysis

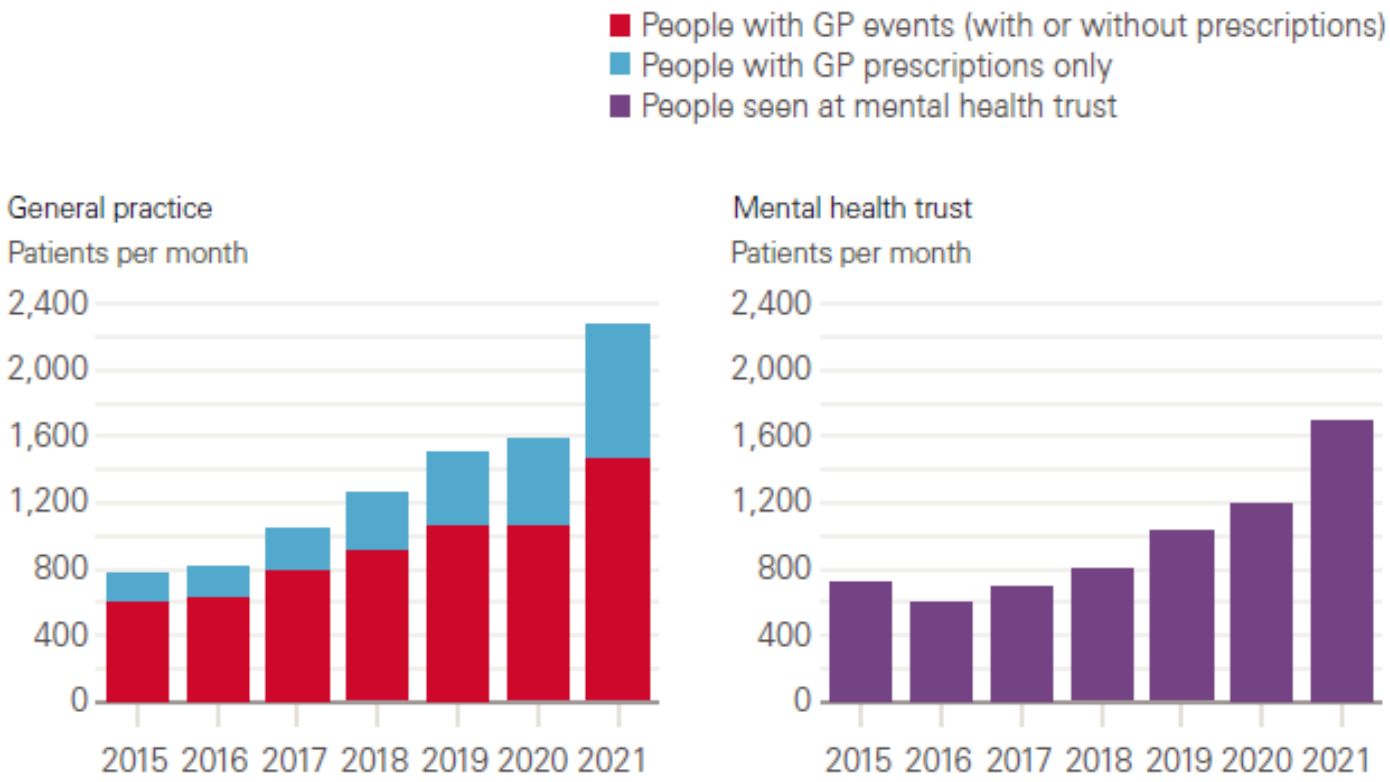
- Those planning and providing services having a clear understanding of who is using what kinds of services and how this compares with expected levels of need
- Routinely published data lacks granularity and mainly covers specialist NHS services

Aims:

- Local analysis of linked data to shed light on who is using services
- Test if observed patterns could inform service improvements in local areas

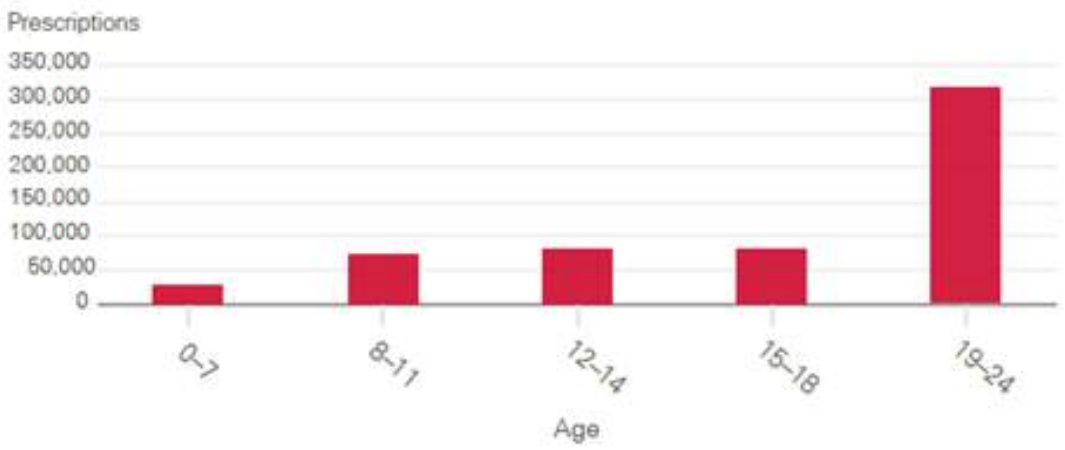
Findings from the Networked Data Lab

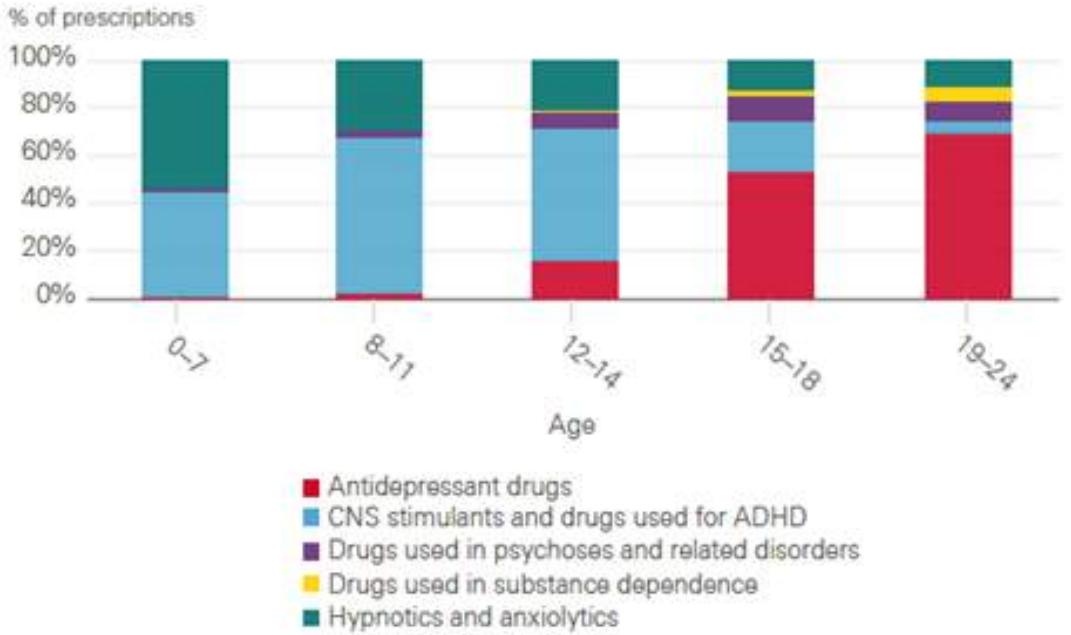
Mental health care in general practice



Source: Networked Data Lab briefing

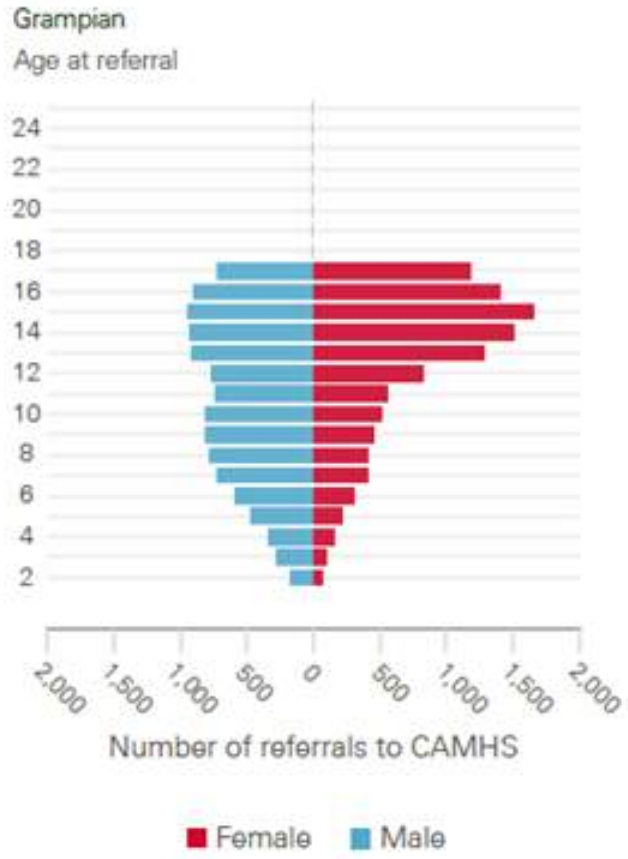
Mental health prescriptions

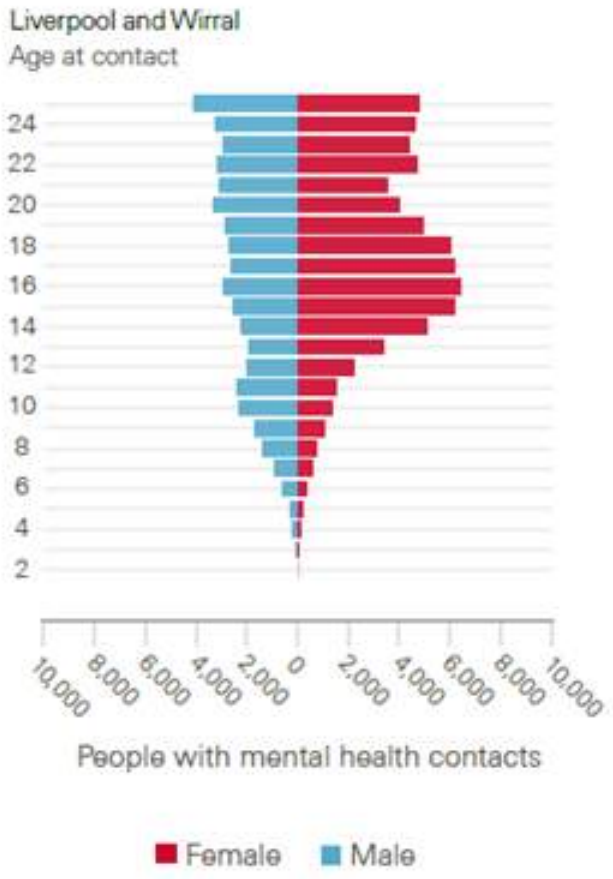




Source: Networked Data Lab briefing

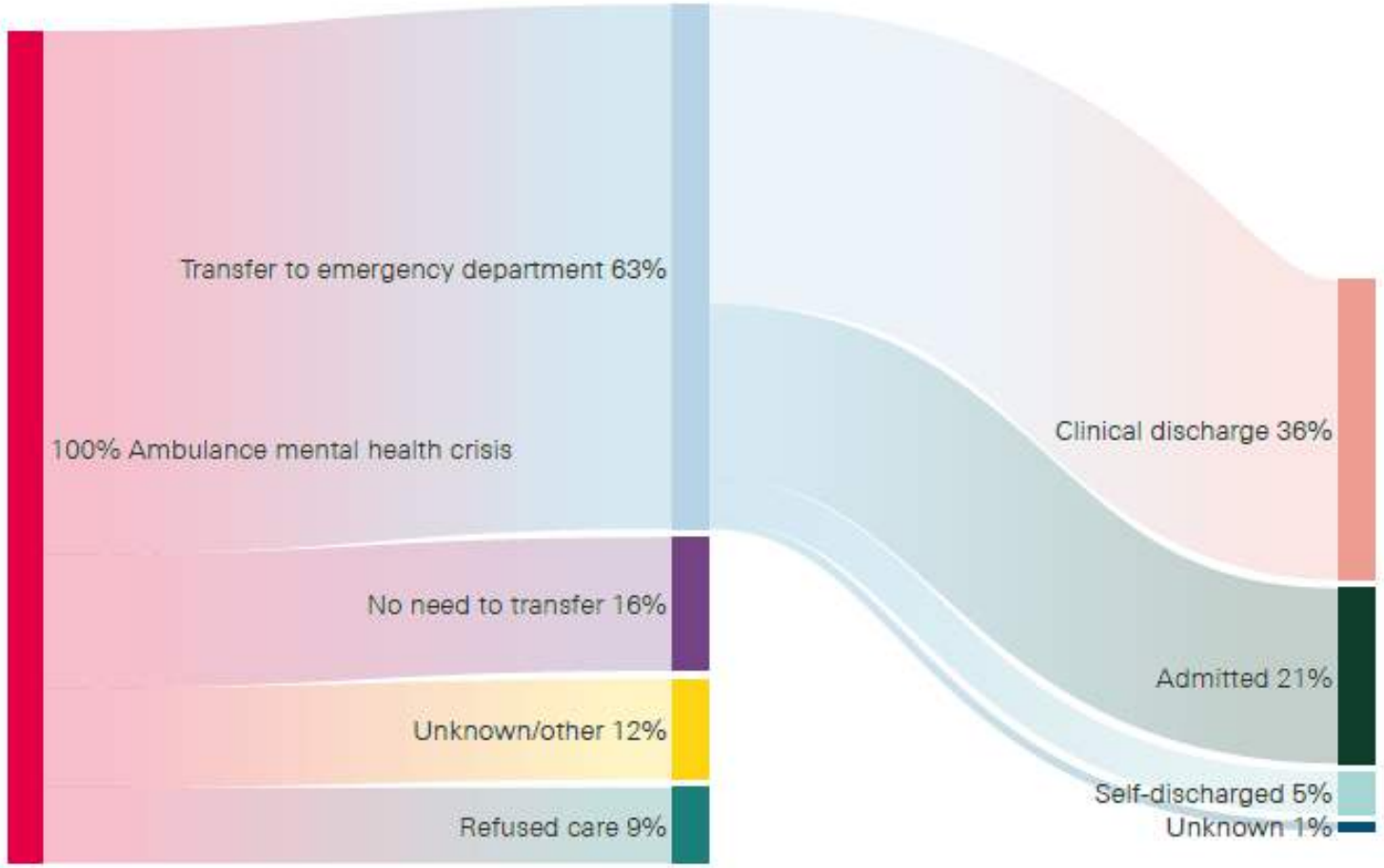
Referrals and contacts with specialist care





Source: Networked Data Lab briefing

Mental health crisis presentations



Source: Networked Data Lab briefing

Limitations

- The extent to which local results can be **generalised** beyond local areas will vary.
- No data were available on services accessed **outside the NHS** that often represent a significant part of mental health support, including in schools, or services funded by local government or the voluntary sector.
- No data was available on privately-funded mental health care, which may be used more often as NHS services have struggled to cope with demand.
- The data only captures those who sought and successfully gained access to services.
- These data often lack detailed **clinical information**, do not offer insights into how the **severity** and acuity of cases has changed (except for crises) and cannot shed light on the outcomes or experiences of care.

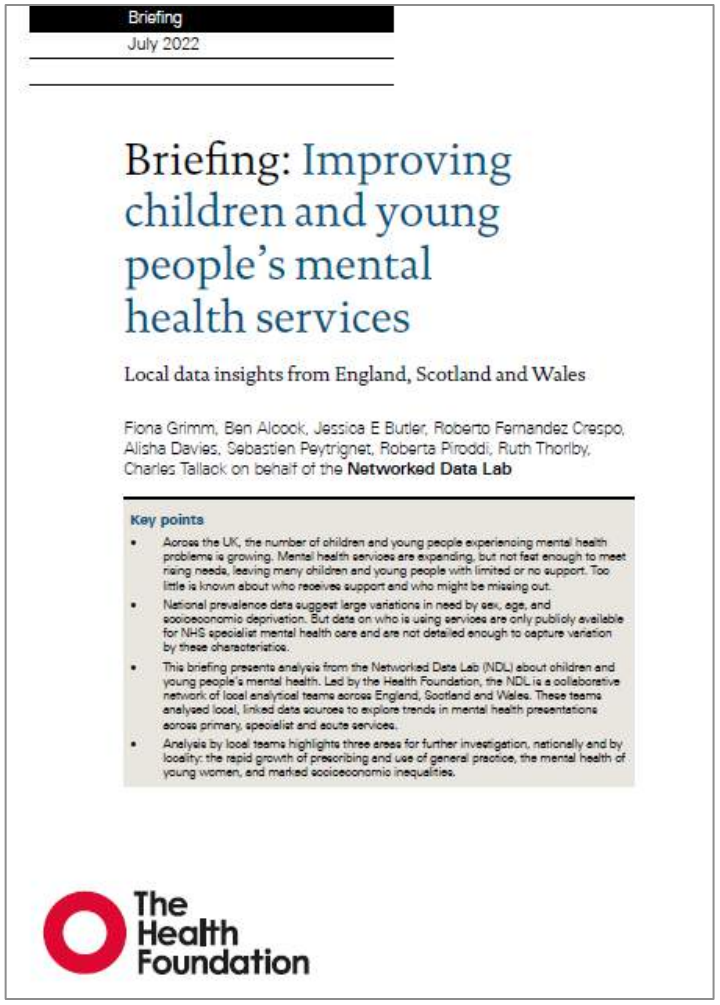
Implications

More resources need to be targeted at **prevention** for those at highest risk

Linked data sources and **data sharing** are vital to improve services.

More national action is needed to improve the **data quality** for NHS mental health services.

More regular collection of **prevalence** data would allow services to be expanded in line with need, with realistic targets.



Briefing
July 2022

Briefing: Improving children and young people's mental health services

Local data insights from England, Scotland and Wales

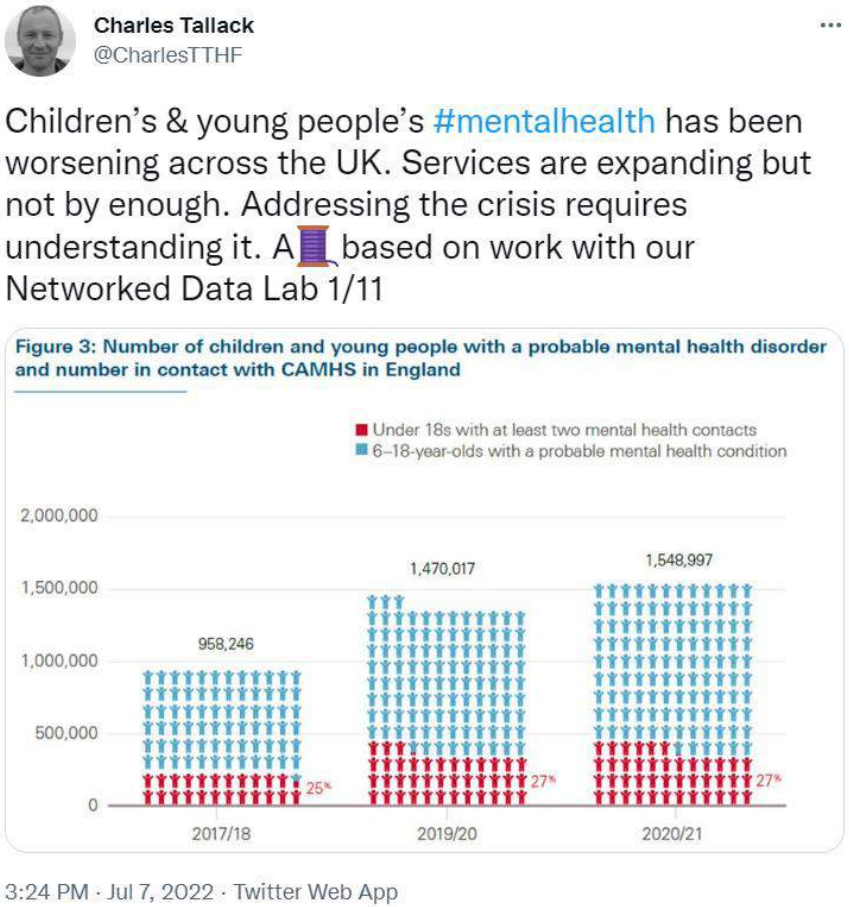
Fiona Grimm, Ben Alcock, Jessica E Butler, Roberto Fernandez Crespo, Alisha Davies, Sebastien Peytrignet, Roberta Piroddi, Ruth Thorlby, Charles Tallack on behalf of the **Networked Data Lab**

Key points

- Across the UK, the number of children and young people experiencing mental health problems is growing. Mental health services are expanding, but not fast enough to meet rising needs, leaving many children and young people with limited or no support. Too little is known about who receives support and who might be missing out.
- National prevalence data suggest large variations in need by sex, age, and socioeconomic deprivation. But data on who is using services are only publicly available for NHS specialist mental health care and are not detailed enough to capture variation by these characteristics.
- This briefing presents analysis from the Networked Data Lab (NDL) about children and young people's mental health. Led by the Health Foundation, the NDL is a collaborative network of local analytical teams across England, Scotland and Wales. These teams analysed local, linked data sources to explore trends in mental health presentations across primary, specialist and acute services.
- Analysis by local teams highlights three areas for further investigation, nationally and by locality: the rapid growth of prescribing and use of general practice, the mental health of young women, and marked socioeconomic inequalities.

The Health Foundation

health.org.uk/publications/reports/improving-children-and-young-peoples-mental-health-services



Charles Tallack
@CharlesTTHF

Children's & young people's #mentalhealth has been worsening across the UK. Services are expanding but not by enough. Addressing the crisis requires understanding it. A 🧵 based on work with our Networked Data Lab 1/11

Figure 3: Number of children and young people with a probable mental health disorder and number in contact with CAMHS in England

3:24 PM · Jul 7, 2022 · Twitter Web App

https://twitter.com/CharlesTTHF/status/1545051111345700867

Thank you

Get it touch: @fiona_grimm @SebastienPeytr2

The Health Foundation

Jessica Butler

Networked Data Lab Lead
NHS Grampian & University of Aberdeen
@JessButler284

Networked Data Lab Goals

Improve health
Reduce inequalities
Work quickly
Target policymakers

Real-world Integrated Care Systems

Networked Data Lab team is the silo bridge

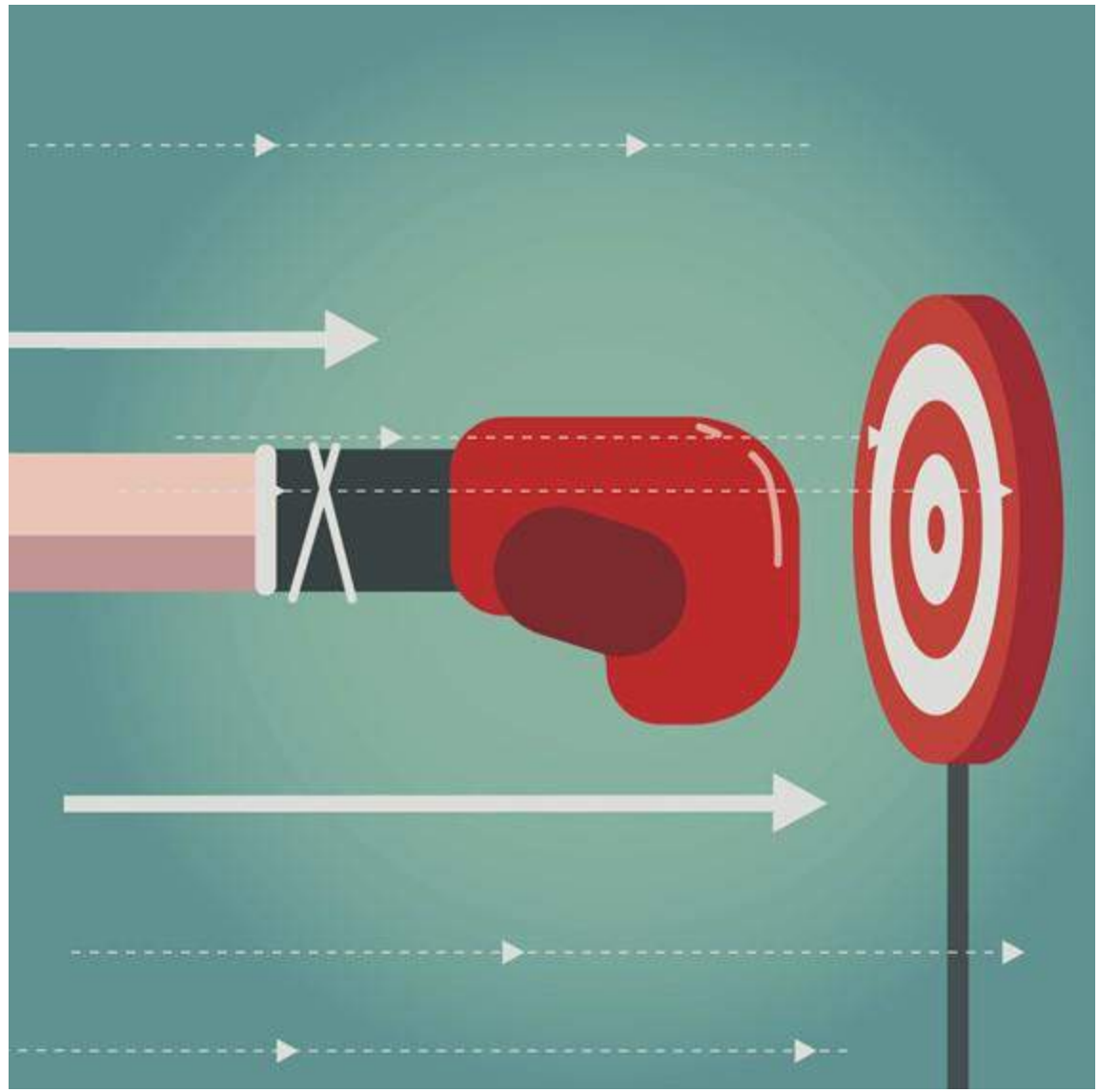
What do doctors want to know?

What are the data guardian’s worries?

What do the databases really contain?

What analysis can we do accurately?

How long is a policy maker’s attention span?



The data were not designed for research

The research was not designed for impact

Work local

Design for impact

Be rigorous

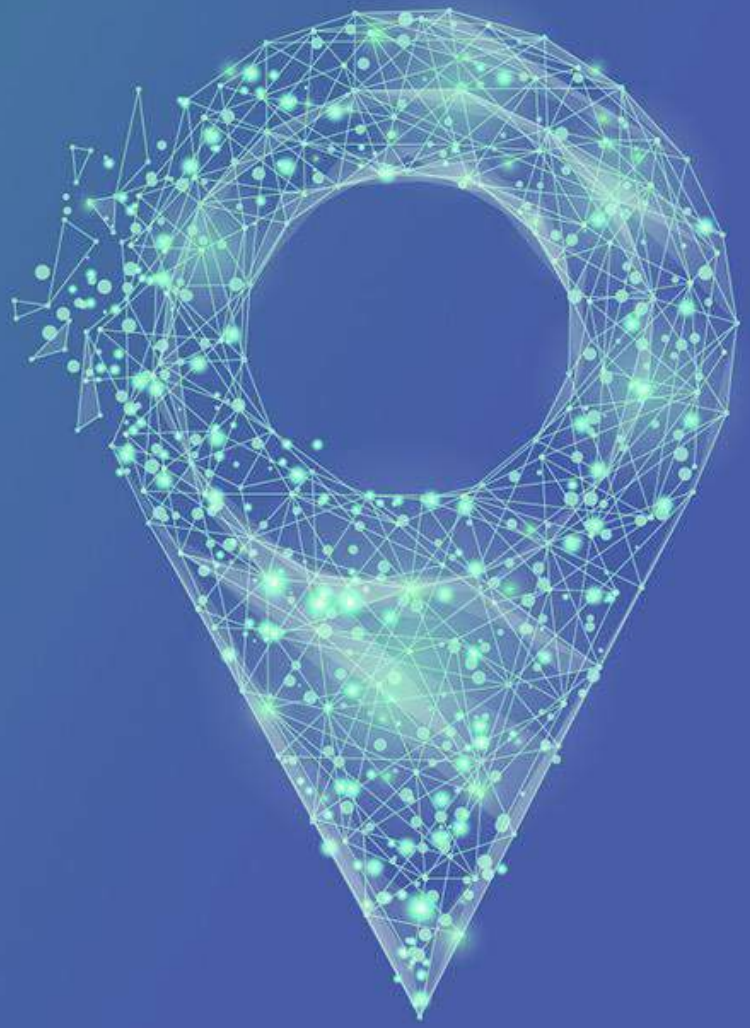
Return tools

Reward teams

Subvert publishers

HDRUK
Health Data Research UK

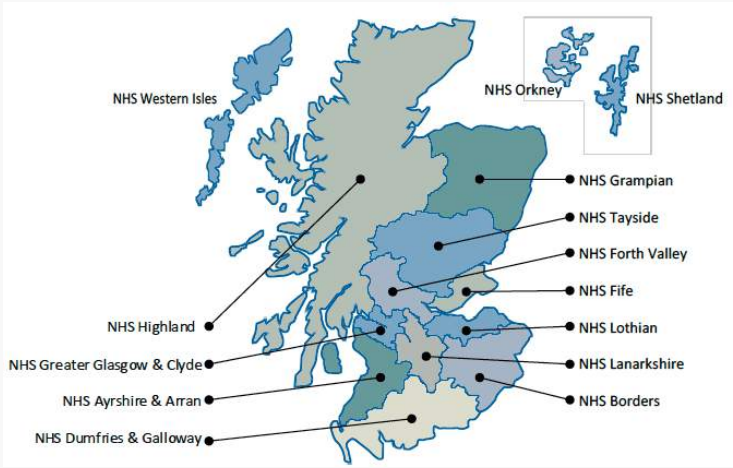
Using regional networks to support the adoption and spread of data science innovations

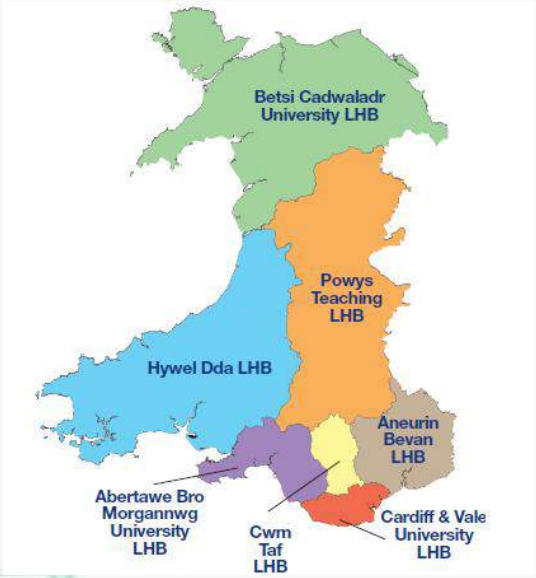


Andy Clegg
Professor of Geriatric Medicine
University of Leeds & Bradford Royal Infirmary
Associate Director, HDRUK North

18/07/2022

NHS structure



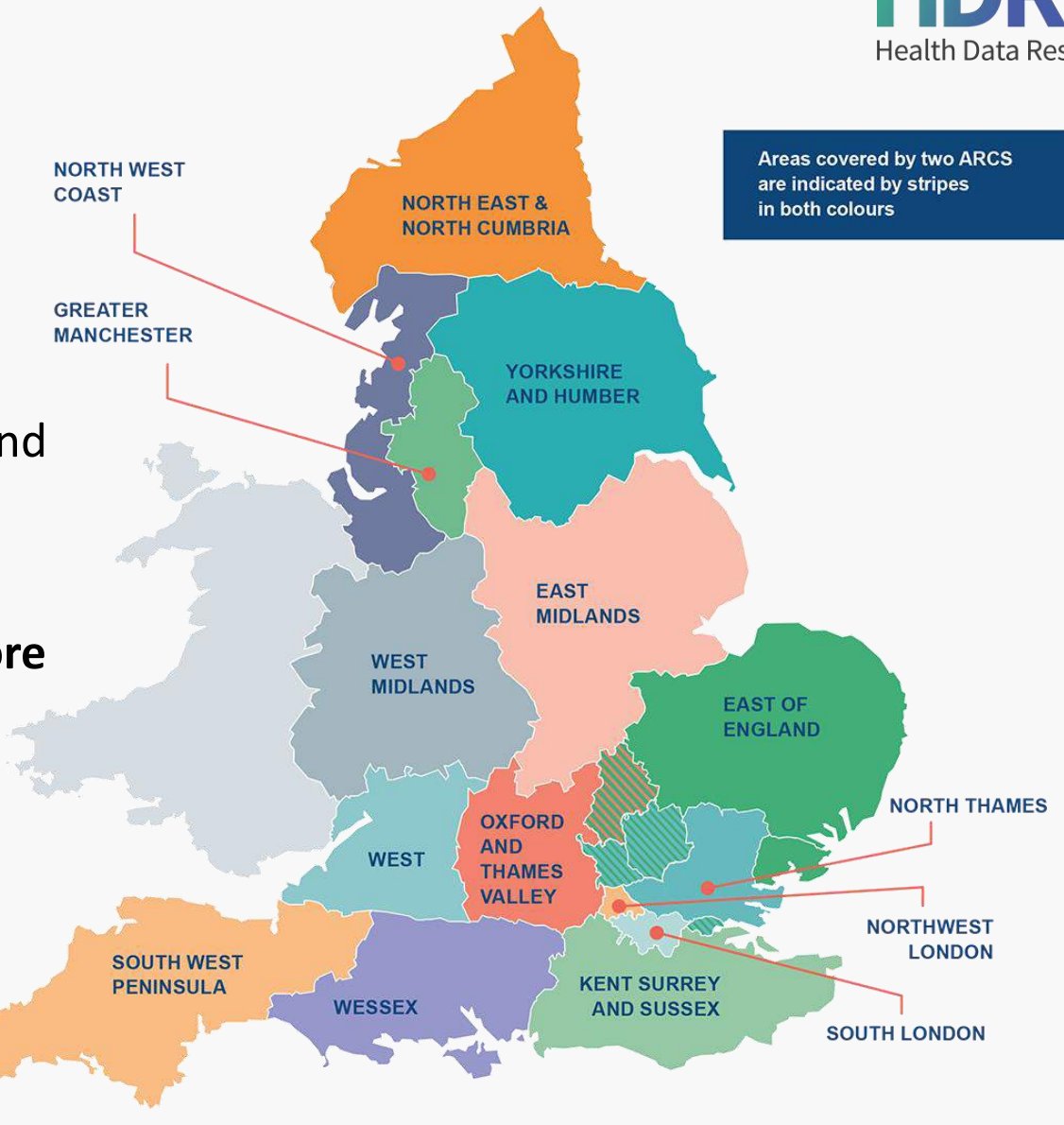


HDRUK structure

NIHR Applied Research Collaborations

Regional partnerships between NHS providers, universities, charities, local authorities, AHSNs that support applied health and care research and **implementation research to increase rate of adoption and spread of research findings**

Broad range of research themes, but map to core health and social care priorities (ageing population, MLTC, mental health, child health, etc)



Academic Health Science Networks

Regional bodies that connect NHS, universities, charities, local authorities, and industry to improve health and generate economic growth

Uniquely placed to identify and spread health innovation across large populations

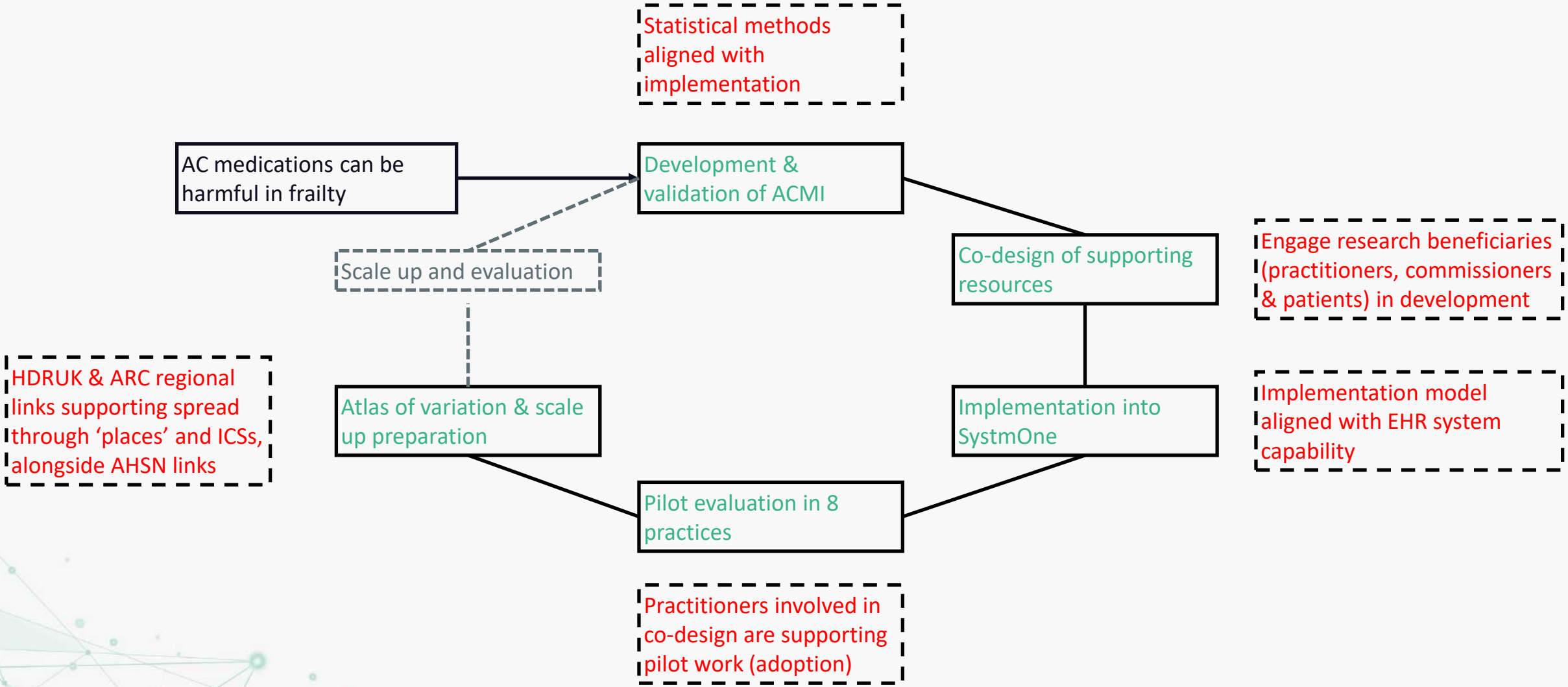
Share common priorities including optimizing medicine use, improving patient safety, translating research into practice

Collaborate on national programmes

HDRUK
Health Data Research UK

Adoption then spread

Optimising Anticholinergic Prescribing



Spread, then adoption

HDRUK
Health Data Research UK

Summary

- HDRUK regional networks well positioned to play a critical role in supporting adoption and spread of data science innovations
- To support adoption & spread, HDRUK regions should establish strong links with ICSs/health boards, NIHR ARCs, and AHSNs/Health Improvement bodies
- Individual HDRUK research teams should consider an implementation plan at outset of project that considers the role of the HDRUK regions in adoption and spread, in collaboration with other partners
- Critical question is ‘how will my innovation be used in practice’ as otherwise high risk that innovation will be developed that cannot be implemented in a way that is useful for end user
- Teams should involve potential research beneficiaries (patients, practitioners, commissioners, policymakers) from the outset to develop innovation aligned with needs of end user that will benefit patients
- These research beneficiaries can become your early adopters, who are your critical friends in driving spread
- EHR system suppliers are often crucial partners in adoption/spread, but have (many) other competing priorities

Better Care within the HDR UK future strategy

Alastair Denniston, Director of INSIGHT - the Health Data Research Hub for Eye Health, Consultant Ophthalmologist (Uveitis and Medical Retina), University Hospitals Birmingham NHSFT

Key questions

- **What do you value the most from the Better Care Community?**
  - E.g. Insight sharing days, access to national network, training, partnership opportunities

- **What is most important for HDR UK to retain from the Better Care Programme as we move into our next five years?**
  - E.g. Practitioner engagement in research

Closing remarks and next steps

Next steps

Meeting follow up

01

- Meeting slides and summary report will be circulated to all attendees
- Please let us know feedback for next time

Events

02

- **20 July:** BHF Data Science Centre monthly webinar
- **08 September:** HDR UK North Regional Meeting
- See the HDR UK website: Events - HDR UK

Stay in touch

03

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

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THANK YOU