Investigación basada en registros electrónicos de salud

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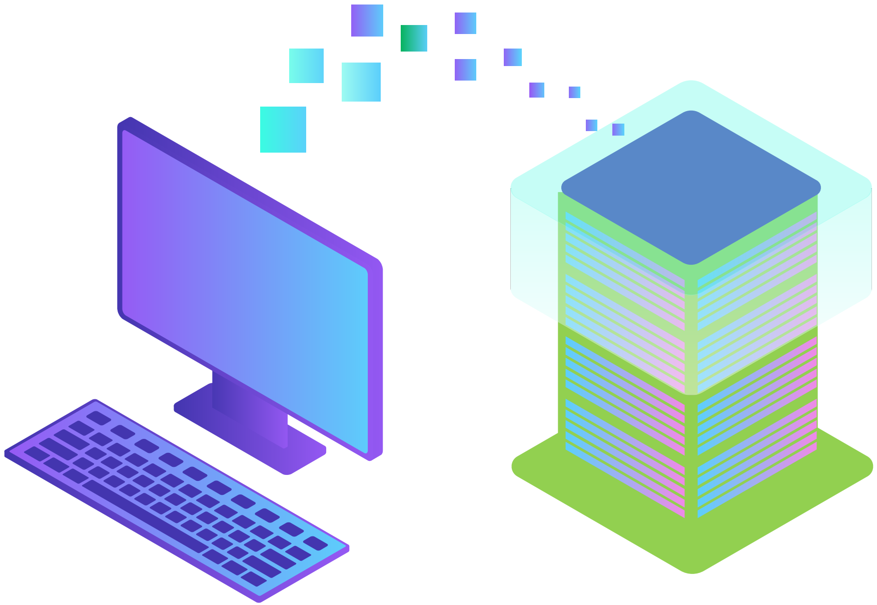
Hospital Rey Juan Carlos
Instituto Investigación Sanitaria FJD



Declaración de intereses

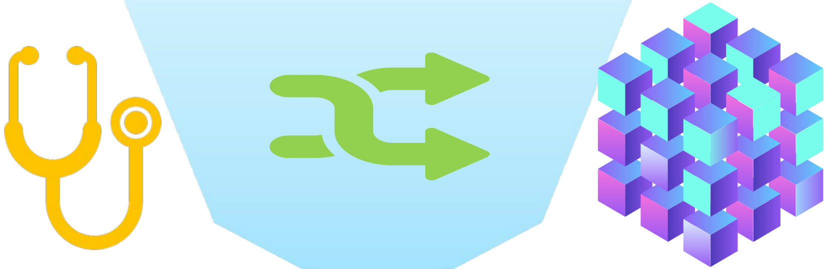
Interés	Organización
Rol y Filiación	• Doctora en Medicina. MPH. Especialista en MFyC. Hospital RJC, IIS-FJD • Honorary Senior Lecturer University of St Andrews (Escocia)
Becas y Premios	• Medical Research Council/HDRUK Fellowship 2018-2020 • Multimorbid Pregnancy: Determinants, Clusters, Consequences and Trajectories (MuM-PreDiCT). MRC. 2021-24 • OPTIMising therapies, discovering therapeutic targets and AI assisted clinical management for patients Living with complex multimorbidity (OPTIMAL study). NIHR. 2021-24
Honorarios	• Quiron Salud • University of St Andrews

Otras actividades profesionales	• Miembro de la Sociedad Española de Medicina Familiar y Comunitaria
	  • GdT Atención a la Mujer
	  • GdT Infecciosas
	• Vocalia investigación Junta SoMaMFyC 2014- 2018

Thompson DF. Understanding financial conflicts of interest. N Engl J Med. 1993 Aug 19;329(8):573–6.

¿Que es la investigación basada en registros electrónicos de salud?

Uso con fines de investigación de datos recogidos por otros motivos



El Club
Carrefour
www.carrefour.es
El Club
Carrefour
www.carrefour.es

Sistema Nacional de Salud

Registros específicos de enfermedad

Servicios sociales

Datos demográficos

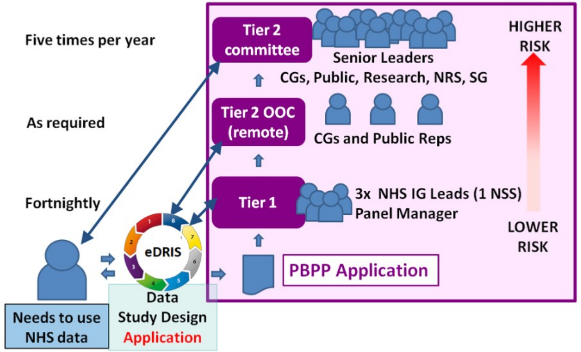
HDRUK
Health Data Research UK

HDRUK
Health Data Research UK

Public Health Scotland

PBPP Approval process

NHS National Services Scotland



Five times per year

As required

Fortnightly

Tier 2 committee
Senior Leaders
CGs, Public, Research, NRS, SG

Tier 2 OOC (remote)
CGs and Public Reps

Tier 1
3x NHS IG Leads (1 NSS)
Panel Manager

HIGHER RISK

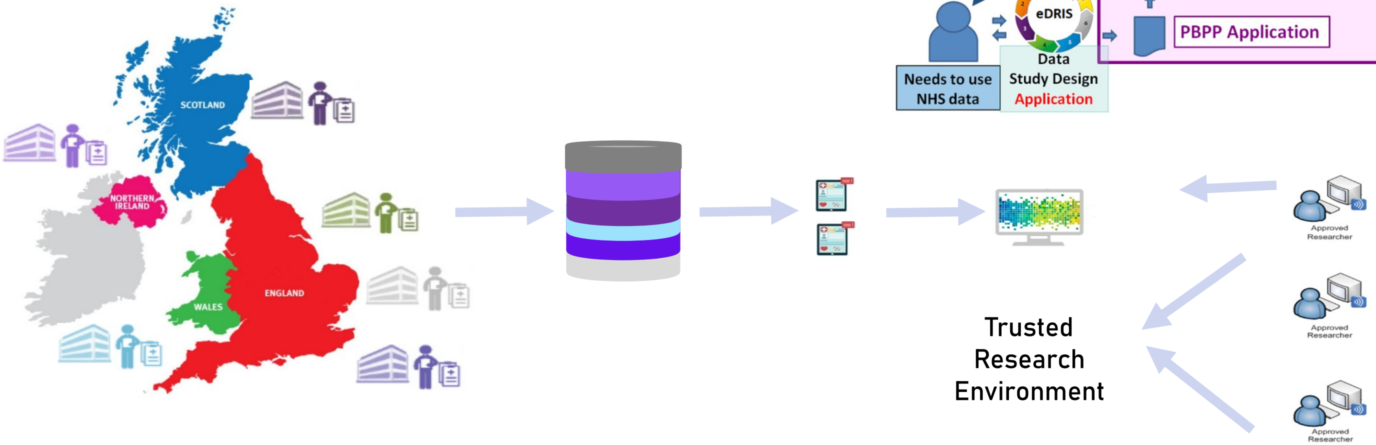
LOWER RISK

eDRIS

PBPP Application

Needs to use NHS data

Data
Study Design
Application


SCOTLAND
NORTHERN IRELAND
WALES
ENGLAND
Approved Researcher
Approved Researcher
Approved Researcher

Trusted Research Environment

SAIL DATABANK

NHS Digital

Data linkage

CIE-10
RED CODEs
BNF

coded event
information

Remove Personal Identifiable data

NHS Number →
Anonymised Unique ID
Date of Birth → Few weeks
added or subtracted anonymously

Information combined to form:
Hospitalisation data
Maternity records
A&E data
or other national datasets

National
Safe
Haven

Linked data held in study area
Trusted Research Environment

All identifiable data is encrypted and anonymised, with each person assigned a unique id.

What is a TRE?

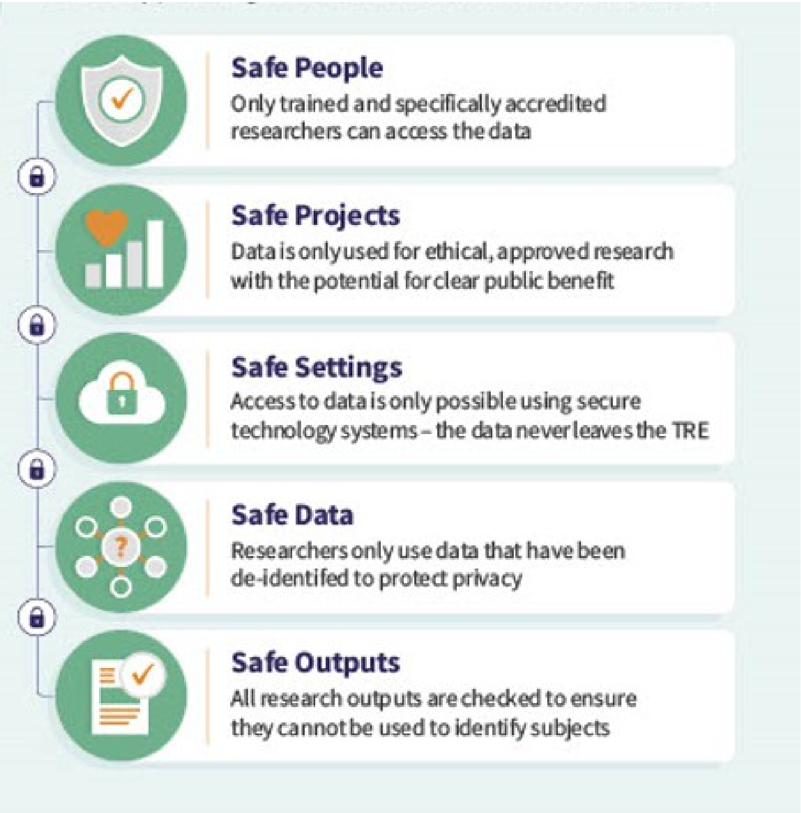
Trusted Research Environments (TREs) are **highly secure** computing environments that provide **remote access** to health data for approved research that can **save and improve lives.**

HDRUK
Health Data Research UK

What is a TRE?

Why are they important?

Trusted Research Environment.



Safe People
Only trained and specifically accredited researchers can access the data

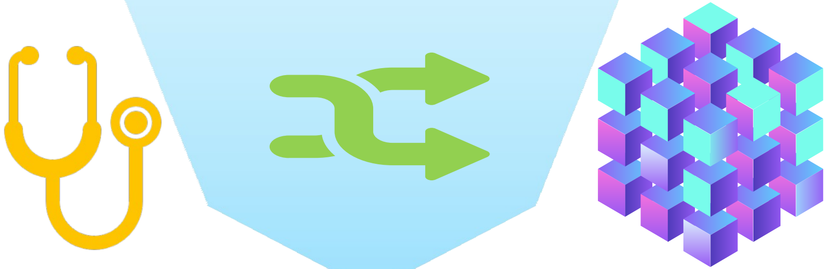
Safe Projects
Data is only used for ethical, approved research with the potential for clear public benefit

Safe Settings
Access to data is only possible using secure technology systems – the data never leaves the TRE

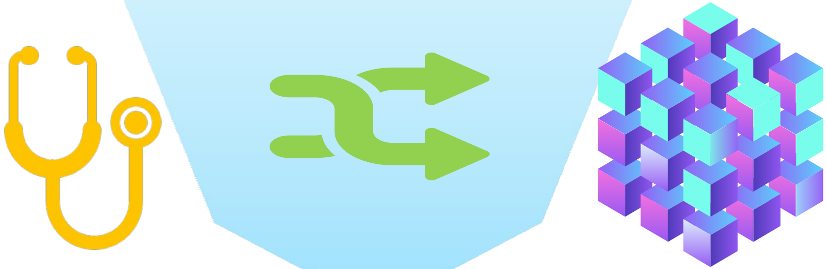
Safe Data
Researchers only use data that have been de-identifed to protect privacy

Safe Outputs
All research outputs are checked to ensure they cannot be used to identify subjects

¿ Que preguntas podemos responder?

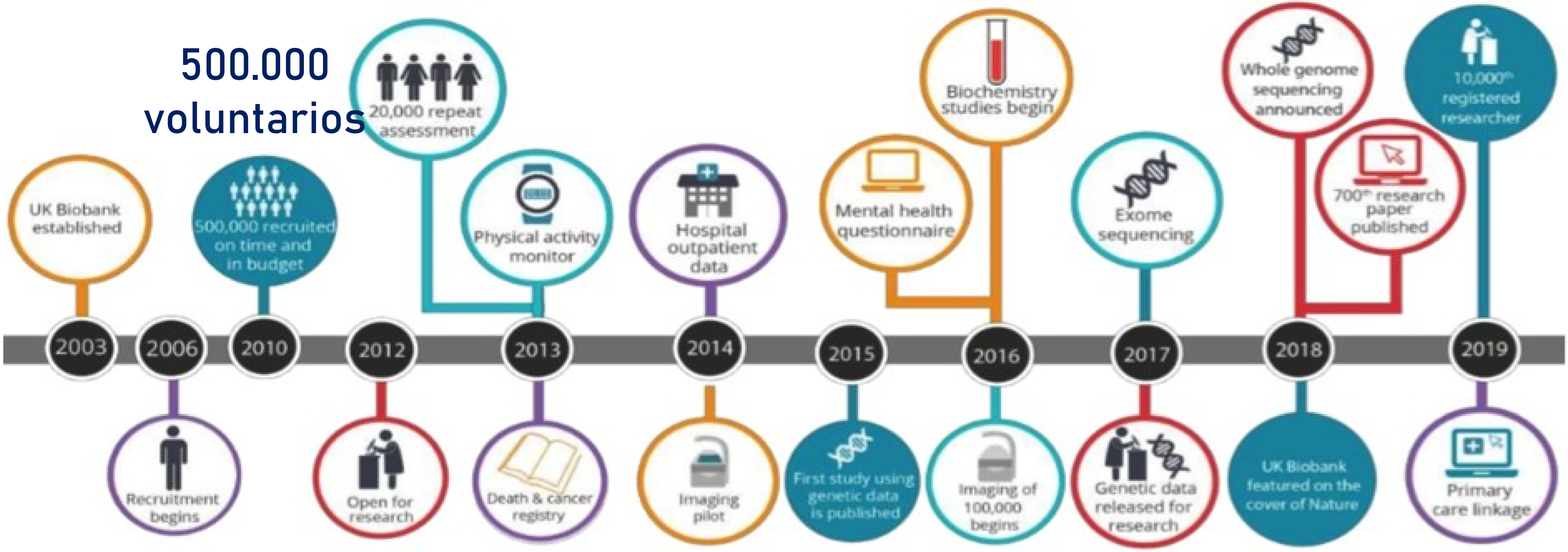


Validación de los registrsde consumo de alcohol en Atención Primaria en Escocia

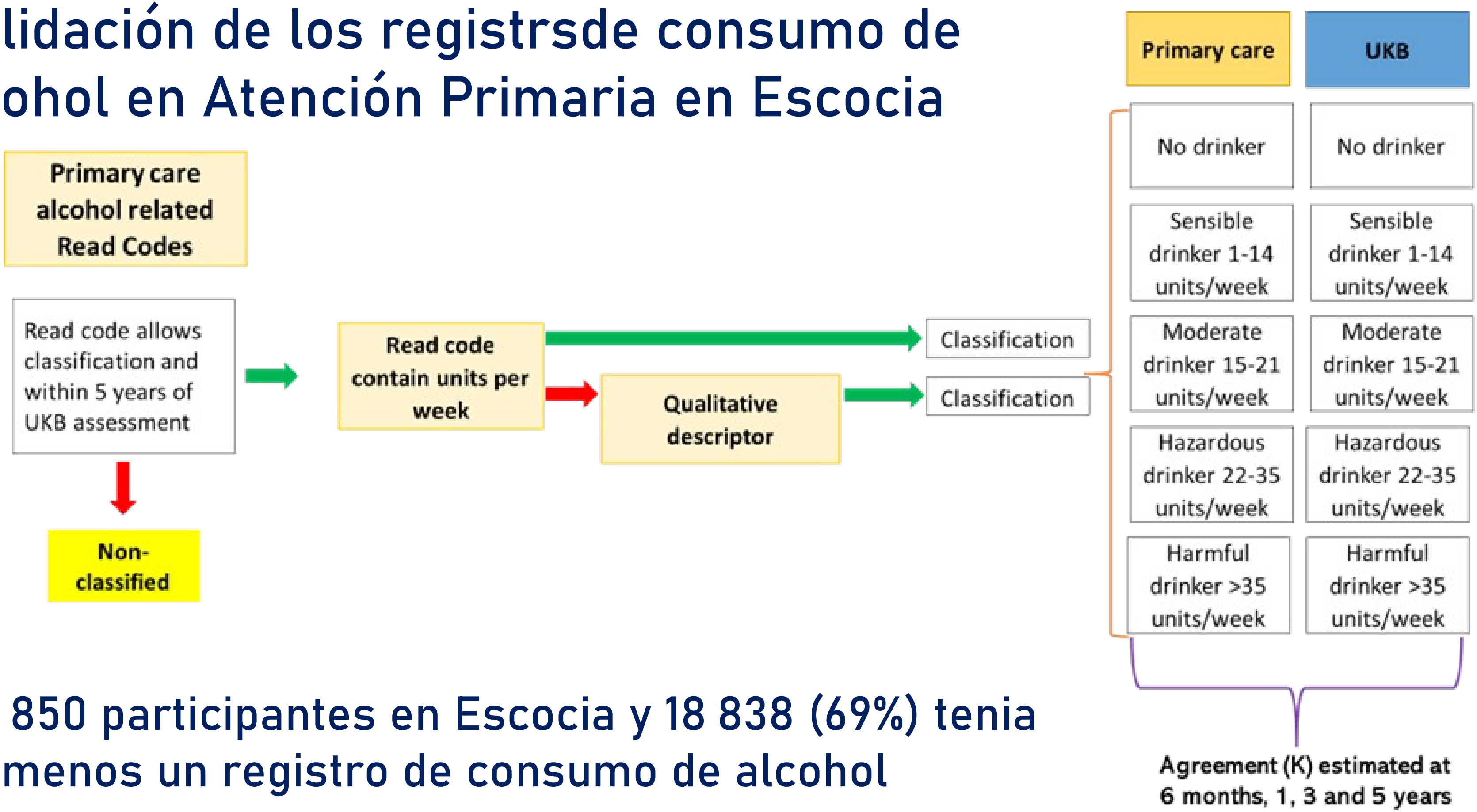


biobank uk

500.000
voluntarios


UK Biobank established
2003
2006
Recruitment begins
500,000 recruited on time and in budget
2010
2012
Open for research
20,000 repeat assessment
Physical activity monitor
2013
Death & cancer registry
Hospital outpatient data
2014
Imaging pilot
2015
First study using genetic data is published
Mental health questionnaire
Biochemistry studies begin
2016
Imaging of 100,000 begins
Exome sequencing
2017
Genetic data released for research
Whole genome sequencing announced
700th research paper published
2018
UK Biobank featured on the cover of Nature
10,000th registered researcher
2019
Primary care linkage

Validación de los registrsde consumo de alcohol en Atención Primaria en Escocia



Primary care alcohol related Read Codes

Read code allows classification and within 5 years of UKB assessment

Non-classified

Read code contain units per week

Qualitative descriptor

Classification

Classification

Primary care	**UKB**
No drinker	No drinker
Sensible drinker 1-14 units/week	Sensible drinker 1-14 units/week
Moderate drinker 15-21 units/week	Moderate drinker 15-21 units/week
Hazardous drinker 22-35 units/week	Hazardous drinker 22-35 units/week
Harmful drinker >35 units/week	Harmful drinker >35 units/week

Agreement (K) estimated at 6 months, 1, 3 and 5 years

35 850 participantes en Escocia y 18 838 (69%) tenia al menos un registro de consumo de alcohol

XLI

CONGRESO DE LA SEMFYC

DEL 7 AL 9 DE OCTUBRE DE 2021

PALMA DE MALLORCA

Transformando
la Atención Primaria

ID: 5073

Autores: Amaya Azcoaga Lorenzo [1], David Fraile Navarro, [1,2], Utkarsh Agrawal [1] Frank M Sullivan[1] Alexander M Baldacchino[1].

1. University of St Andrews, School of Medicine, Medical and Biological Sciences, North Haugh, St Andrews, KY16 9TF, United Kingdom

2. Centre for Health Informatics, Australian Institute of Health Innovation, Macquarie University, Sydney, Australia.

Email: aalz2@standrews.ac.uk

¿ Cuánto bebemos?
Depende de quien pregunte…

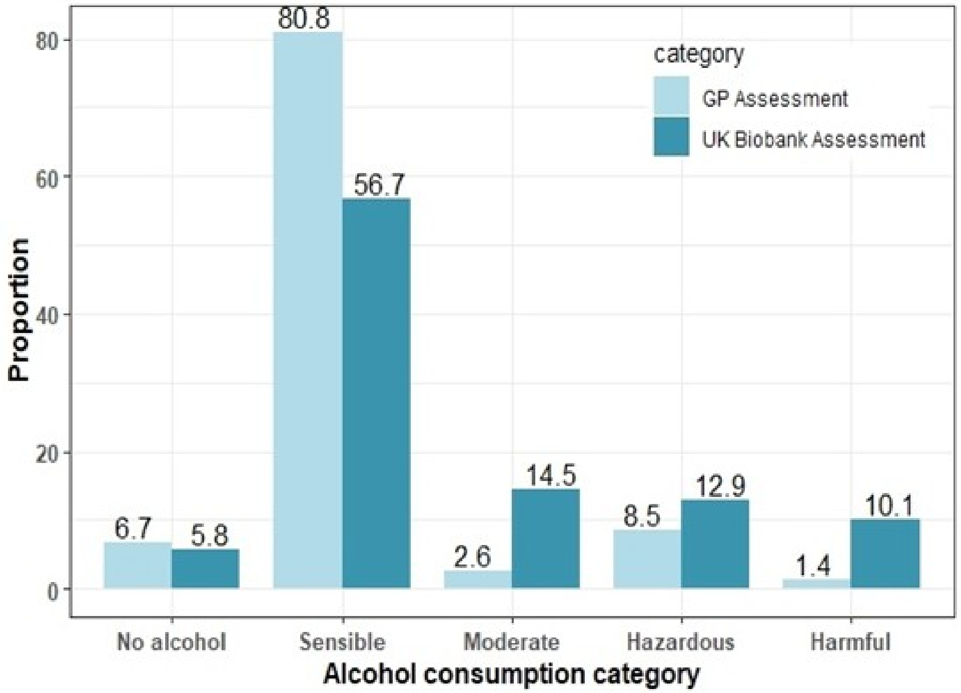
Open access Original research

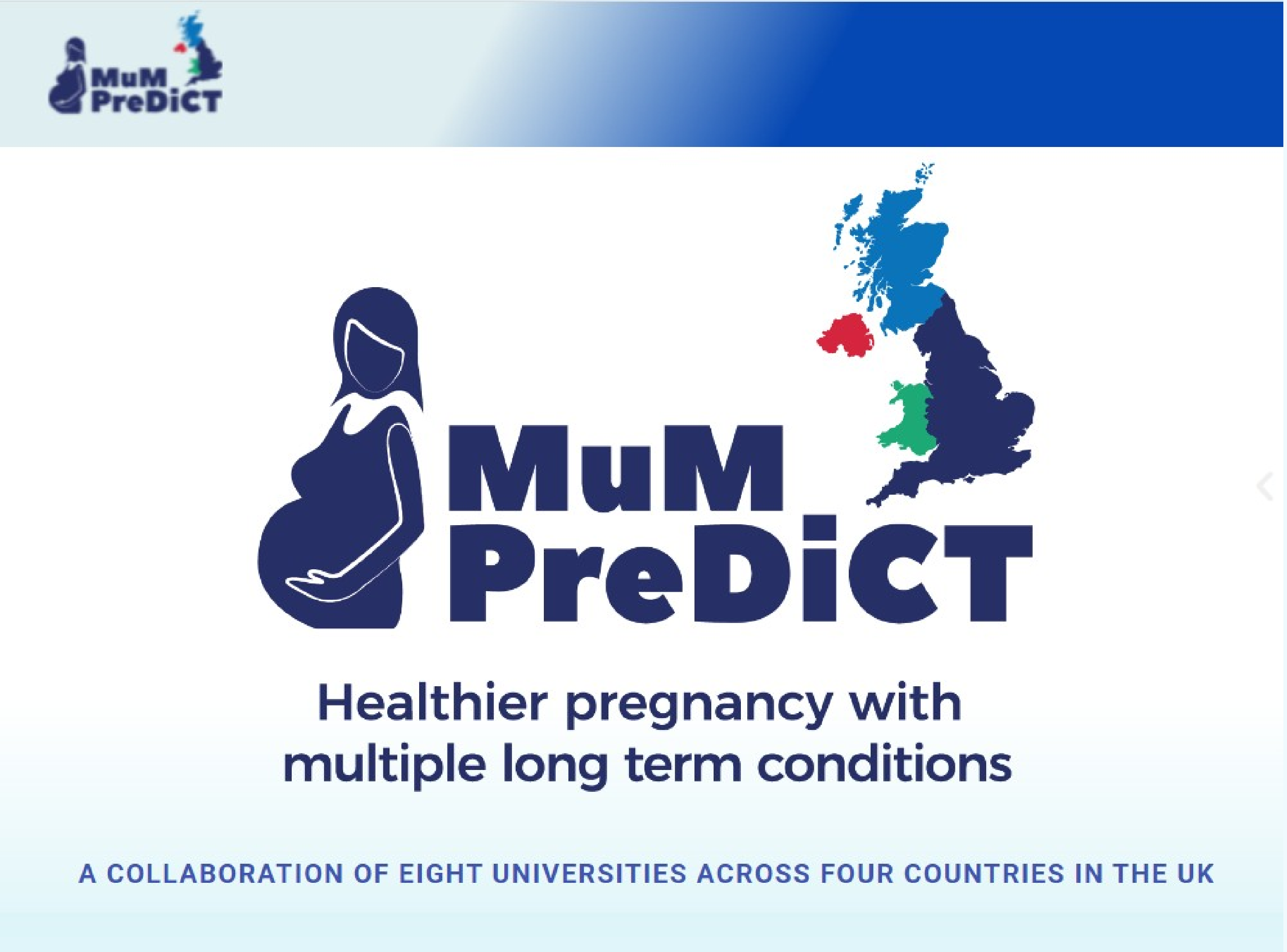
BMJ Open

Development of an algorithm to classify primary care electronic health records of alcohol consumption: experience using data linkage from UK Biobank and primary care electronic health data sources

David Fraile-Navarro [1,2] Amaya Azcoaga-Lorenzo [1]
Bhautesh Jani [3] Adeniyi Fagbamigbe [1] Dorothy Curr
Alexander Baldacchino [1] Frank Sullivan [1]

BMJ Open: first published as 10.1136/

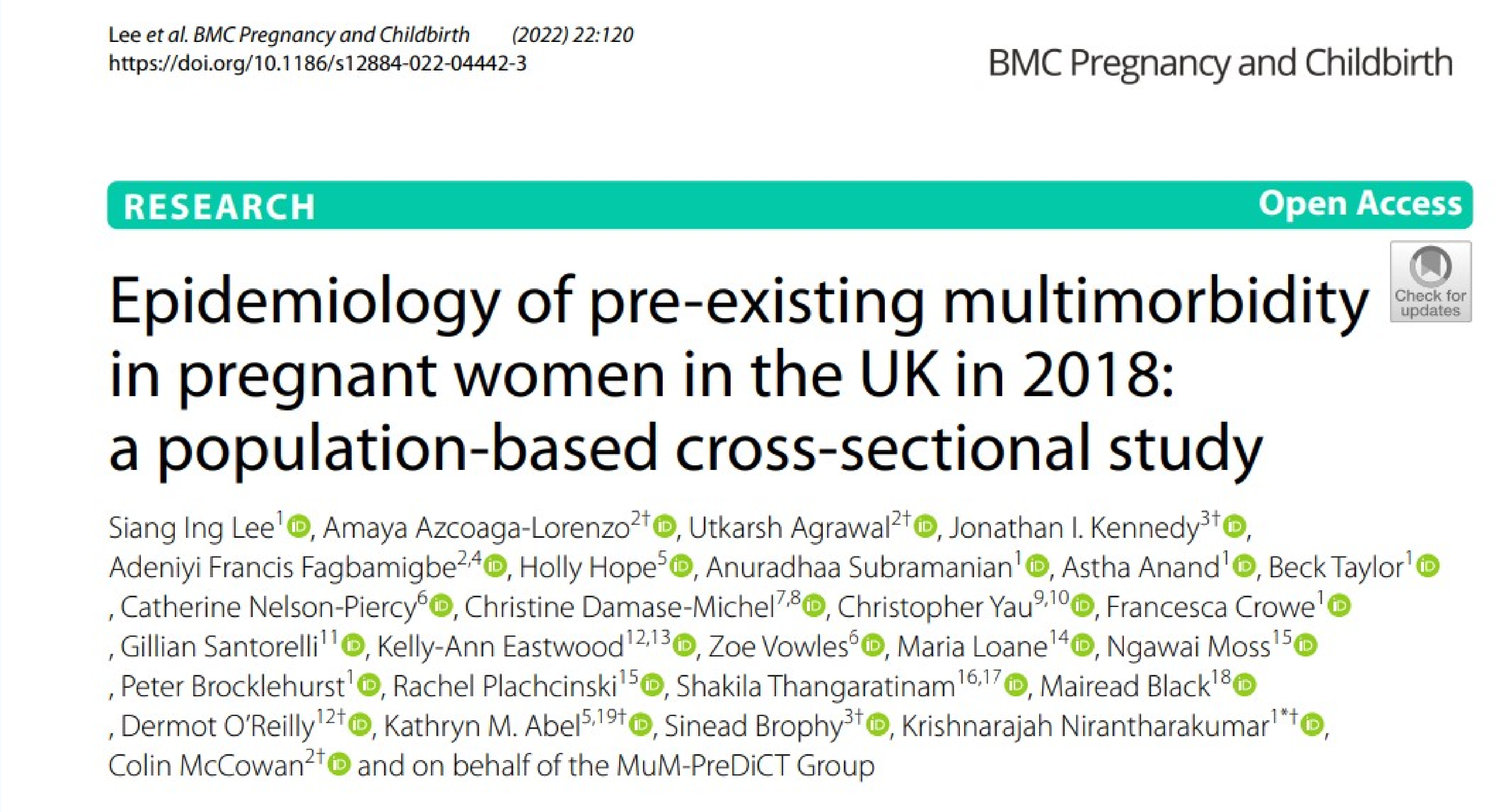




MuM PreDiCT

Healthier pregnancy with multiple long term conditions

A COLLABORATION OF EIGHT UNIVERSITIES ACROSS FOUR COUNTRIES IN THE UK



Lee *et al. BMC Pregnancy and Childbirth* (2022) 22:120
https://doi.org/10.1186/s12884-022-04442-3

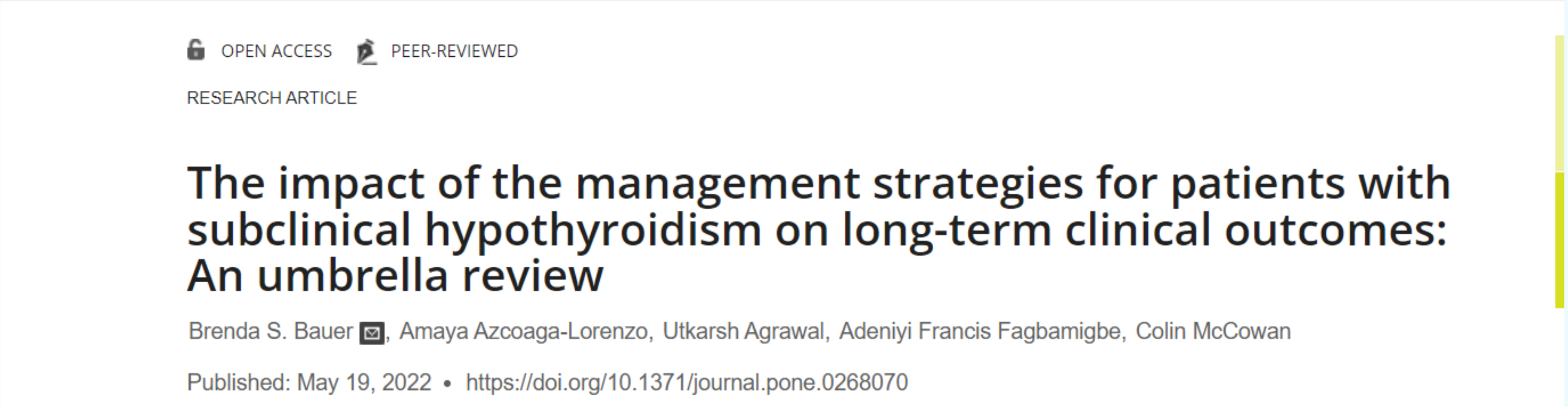
BMC Pregnancy and Childbirth

RESEARCH **Open Access**

Epidemiology of pre-existing multimorbidity in pregnant women in the UK in 2018: a population-based cross-sectional study

Siang Ing Lee[1], Amaya Azcoaga-Lorenzo[2†], Utkarsh Agrawal[2†], Jonathan I. Kennedy[3†],
Adeniyi Francis Fagbamigbe[2,4], Holly Hope[5], Anuradhaa Subramanian[1], Astha Anand[1], Beck Taylor[1]
, Catherine Nelson-Piercy[6], Christine Damase-Michel[7,8], Christopher Yau[9,10], Francesca Crowe[1]
, Gillian Santorelli[11], Kelly-Ann Eastwood[12,13], Zoe Vowles[6], Maria Loane[14], Ngawai Moss[15]
, Peter Brocklehurst[1], Rachel Plachcinski[15], Shakila Thangaratinam[16,17], Mairead Black[18]
, Dermot O'Reilly[12†], Kathryn M. Abel[5,19†], Sinead Brophy[3†], Krishnarajah Nirantharakumar[1*†],
Colin McCowan[2†] and on behalf of the MuM-PreDiCT Group

Trial emulation



OPEN ACCESS PEER-REVIEWED

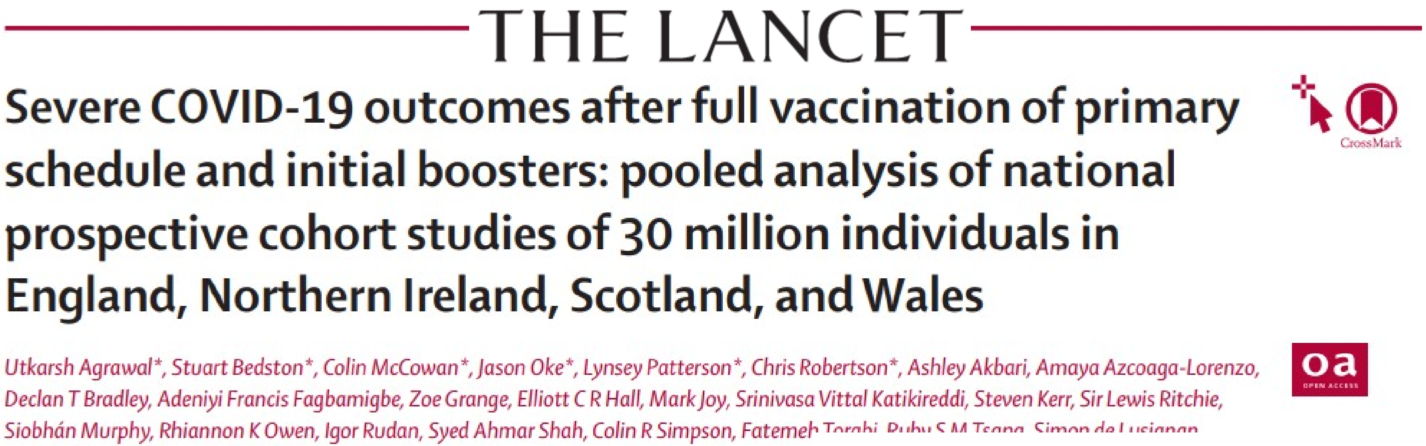
RESEARCH ARTICLE

The impact of the management strategies for patients with subclinical hypothyroidism on long-term clinical outcomes: An umbrella review

Brenda S. Bauer, Amaya Azcoaga-Lorenzo, Utkarsh Agrawal, Adeniyi Francis Fagbamigbe, Colin McCowan

Published: May 19, 2022 • https://doi.org/10.1371/journal.pone.0268070

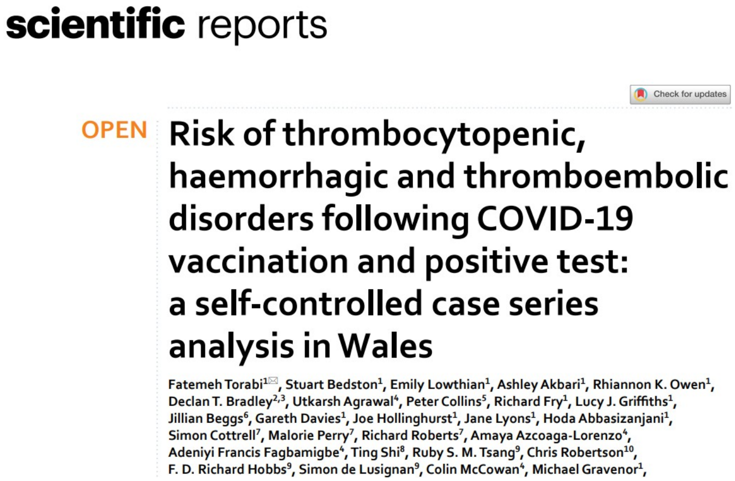
- SAIL Databank
- Emulating a hypothetical pragmatic randomized trial
- Specify the causal question, the study population and eligibility criteria, the exposure and reference groups, and start and end of follow-up.



THE LANCET

Severe COVID-19 outcomes after full vaccination of primary schedule and initial boosters: pooled analysis of national prospective cohort studies of 30 million individuals in England, Northern Ireland, Scotland, and Wales

Utkarsh Agrawal, Stuart Bedston*, Colin McCowan*, Jason Oke*, Lynsey Patterson*, Chris Robertson*, Ashley Akbari, Amaya Azcoaga-Lorenzo, Declan T Bradley, Adeniyi Francis Fagbamigbe, Zoe Grange, Elliott C R Hall, Mark Joy, Srinivasa Vittal Katikireddi, Steven Kerr, Sir Lewis Ritchie, Siobhán Murphy, Rhiannon K Owen, Igor Rudan, Syed Ahmar Shah, Colin R Simpson, Fatemeh Torabi, Ruby S M Tsang, Simon de Lusignan, Ronan A Lyons, Dermot O'Reilly, Sir Aziz Sheikh*



scientific reports

OPEN

Risk of thrombocytopenic, haemorrhagic and thromboembolic disorders following COVID-19 vaccination and positive test: a self-controlled case series analysis in Wales

Fatemeh Torabi[1], Stuart Bedston[1], Emily Lowthian[1], Ashley Akbari[1], Rhiannon K. Owen[1], Declan T. Bradley[2,3], Utkarsh Agrawal[4], Peter Collins[5], Richard Fry[1], Lucy J. Griffiths[1], Jillian Beggs[6], Gareth Davies[1], Joe Hollinghurst[1], Jane Lyons[1], Hoda Abbasizanjani[1], Simon Cottrell[7], Malorie Perry[7], Richard Roberts[7], Amaya Azcoaga-Lorenzo[4], Adeniyi Francis Fagbamigbe[4], Ting Shi[8], Ruby S. M. Tsang[9], Chris Robertson[10], F. D. Richard Hobbs[9], Simon de Lusignan[9], Colin McCowan[4], Michael Gravenor[1],

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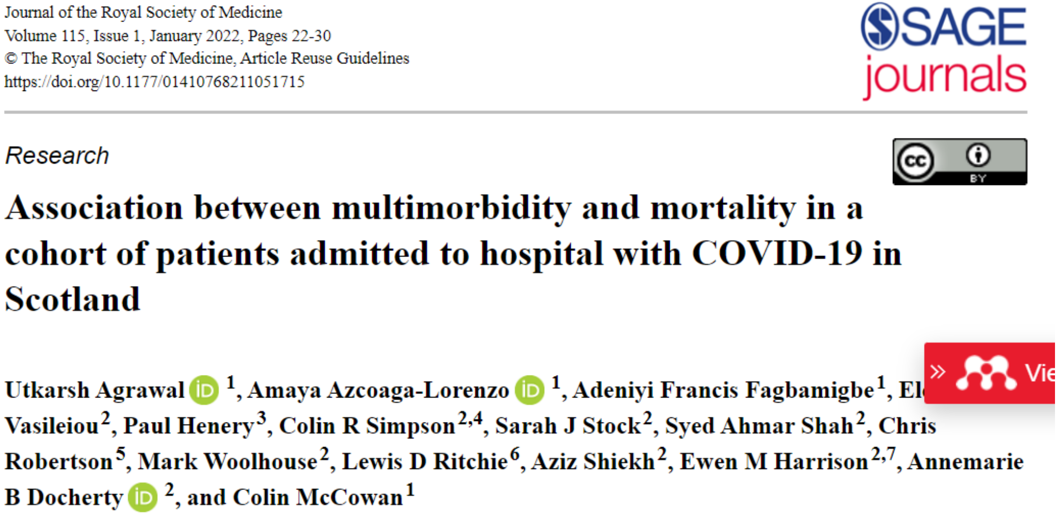

Journal of the Royal Society of Medicine
Volume 115, Issue 1, January 2022, Pages 22-30
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https://doi.org/10.1177/01410768211051715

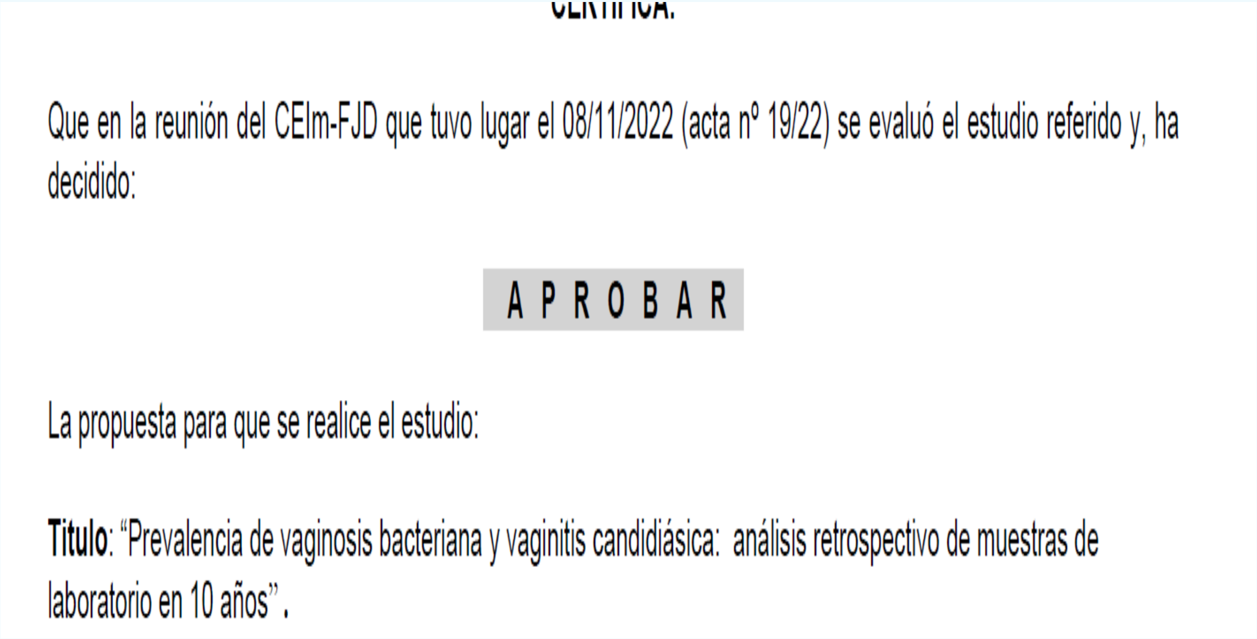
SAGE journals

Research

Association between multimorbidity and mortality in a cohort of patients admitted to hospital with COVID-19 in Scotland

Utkarsh Agrawal [1], Amaya Azcoaga-Lorenzo [1], Adeniyi Francis Fagbamigbe[1], El Vasileiou[2], Paul Henery[3], Colin R Simpson[2,4], Sarah J Stock[2], Syed Ahmar Shah[2], Chris Robertson[5], Mark Woolhouse[2], Lewis D Ritchie[6], Aziz Shiekh[2], Ewen M Harrison[2,7], Annemarie B Docherty [2], and Colin McCowan[1]

Prevalencia de vaginosis bacteriana y vaginitis candidiasica



CERTIFICA:

Que en la reunión del CEIm-FJD que tuvo lugar el 08/11/2022 (acta nº 19/22) se evaluó el estudio referido y, ha decidido:

APROBAR

La propuesta para que se realice el estudio:

Titulo: "Prevalencia de vaginosis bacteriana y vaginitis candidiásica: análisis retrospectivo de muestras de laboratorio en 10 años".

INSTITUTO DE INVESTIGACIÓN SANITARIA
FUNDACIÓN JIMÉNEZ DÍAZ

Prevalencia de vaginosis bacteriana y vaginitis candidiasica

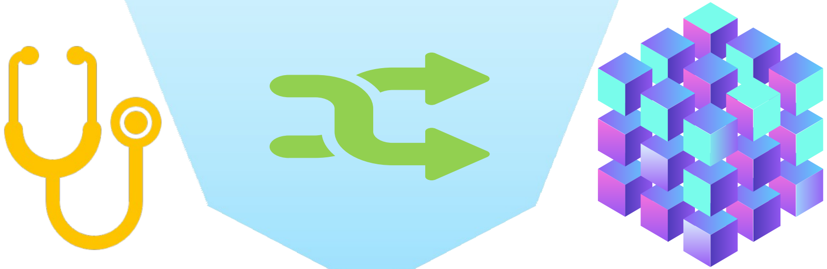
- Aproximadamente el 1% de todas las consultas de Atención Primaria en Madrid al año
  - 40-50 millones de consultas año
- 10 millones de consultas al año en EEUU
- Gran consumo de recursos por consultas, pruebas y tratamientos-mucho autotratamiento.
- Poco interés por ser patología considerada banal

Pros y contras de usar EHR

- Barato (mas barato)
- Actualización periódica de los datos
- Datos poblacionales
- Disminuye sesgo de selección
- Codificación de los datos
- Tiempo de seguimiento
- Tamaño de la muestra

- Acceso y aspectos éticos
- Consentimiento y anonimizacion
- Diferencias locales en registro
- Datos administrativos
- Calidad de las bases
- Datos perdidos
- Dificultades en la vinculación de las bases

iiS FJD
INSTITUTO DE INVESTIGACIÓN SANITARIA
FUNDACIÓN JIMÉNEZ DÍAZ

Gracias