



Royal College of  
General Practitioners



# English data – State of the Art?

Using routine clinical data for surveillance, quality  
improvement & research

*Royal College of General Practitioners (RCGP)*

*Health and Surveillance Centre (RSC) @ 50*

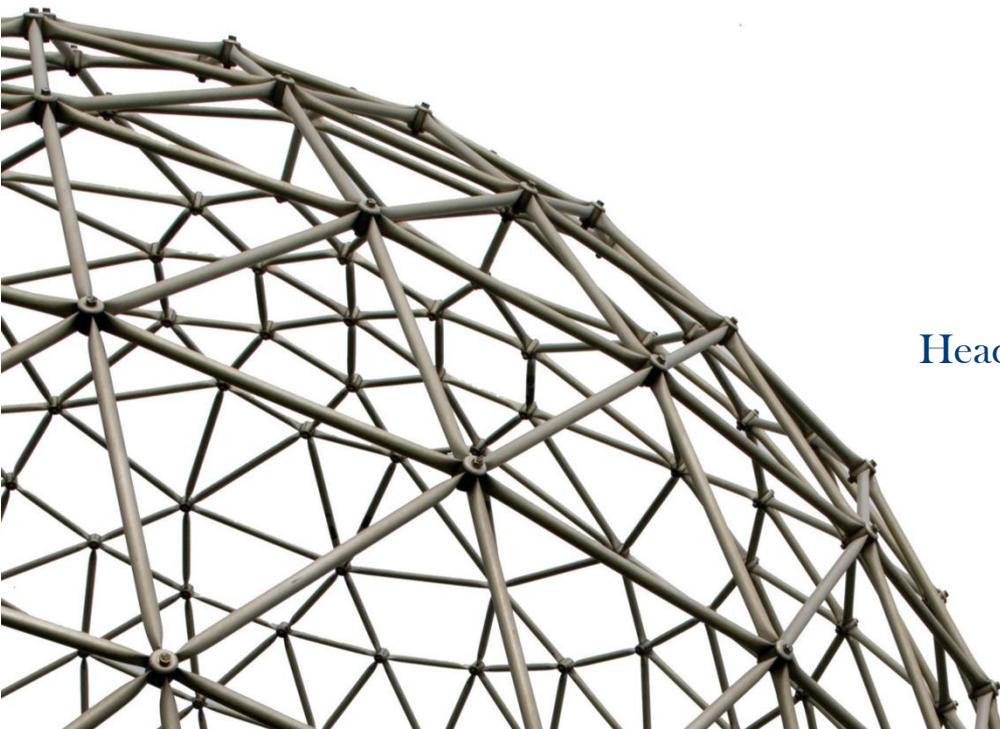
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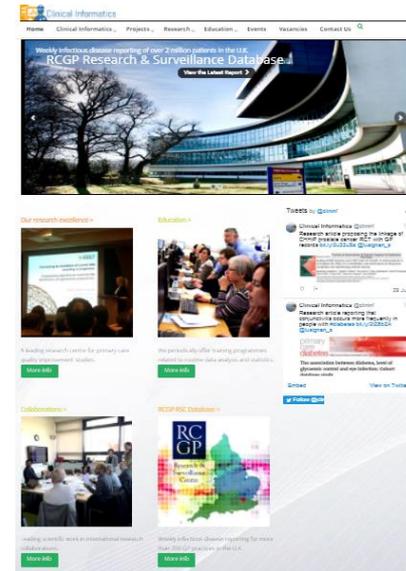
[www.surrey.ac.uk](http://www.surrey.ac.uk)



# My practice & academic work



[www.woodbridgehillsurgery.co.uk](http://www.woodbridgehillsurgery.co.uk)



[www.clininf.eu](http://www.clininf.eu)



- GP in Guildford >30years

- 12,000 patient practice - 10 GPs - 4 partners
- Computerised since 1988 - EMIS brand since 1994

- Professor of Primary Care & Clinical Informatics

- Head of Dept Clinical & Experimental Medicine

- Clinical Informatics & Health Outcomes Research Group:  
*How IT can be used to improve quality*
- Caldicott Guardian for University

- (1) Routine data for surveillance

- (2) Using Real World Evidence (RWE)

- (3) Scholarship:

- Chair PCI WG, UK Rep & Publications officer EFMI Board member & Chair IMIA PCI WG
- Editor of Journal of Innovation in Health Informatics

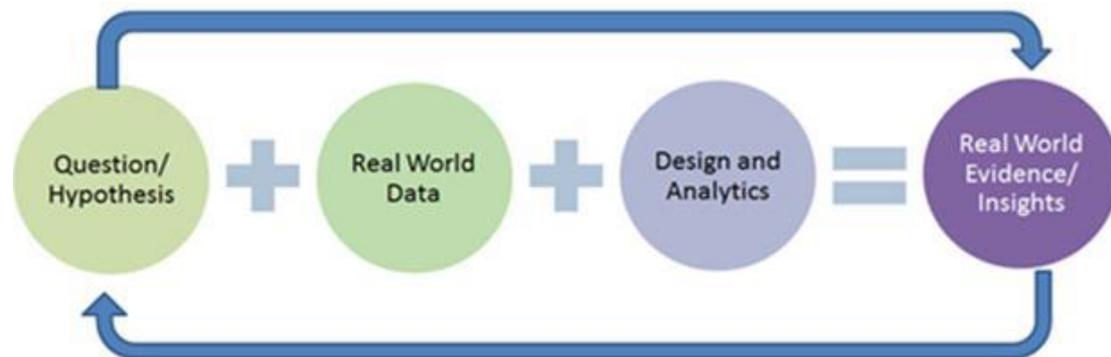
# Diabetes data in England & RCGP RSC



- **Real world evidence (RWE)**
- Nationally available data for RWE studies
- RCGP RSC
  - History & Role
  - Structure & Capability for linkage
  - Dataset & representativeness
- Diabetes - Quality Improvement & Research
- Conclusion:
  - Scope for collaborative research

# Scope of my RWE research:

- **CMR contain useful data for:**
  - **Epidemiology**
  - **Medication use & Effectiveness**
  - **Trials in routine practice**
- **Other big data**
  - **Social Media (Twitter)**
  - **IoT (Older people)**
  - **Device data**
- **We need to better define real world evidence (RWE) studies**



- Real world evidence (RWE)
- Nationally available data for RWE studies (UK)
- RCGP RSC
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# National & service data sources

- National data

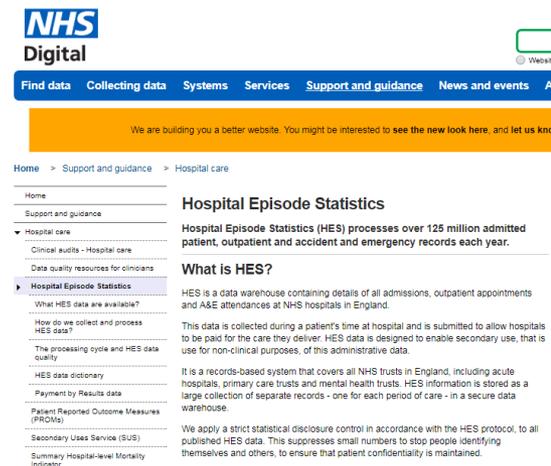
- NHS Digital <https://digital.nhs.uk/>
- National Statistics [www.gov.uk](http://www.gov.uk)
- Neighbourhood statistics [www.neighbourhood.statistics.gov.uk/](http://www.neighbourhood.statistics.gov.uk/)

- General Practice / Primary Care

- Single brand of GP computer systems
- *EMIS - QResearch; Vision (& EMIS) - CPRD & THIN; TPP - ResearchOne*
- All brands of GP CMR
- *Royal College of General Practitioners (RCGP) Research & Surveillance Centre (RSC)*

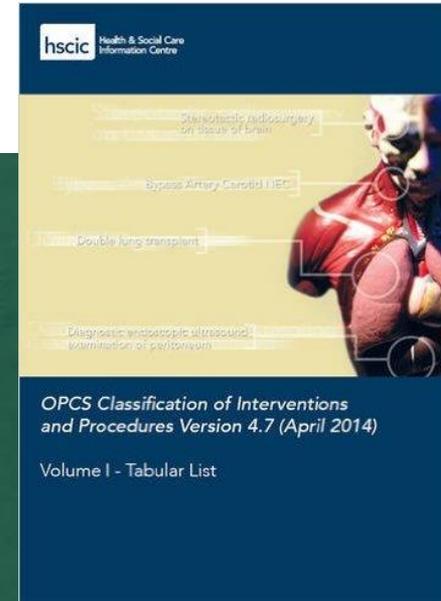
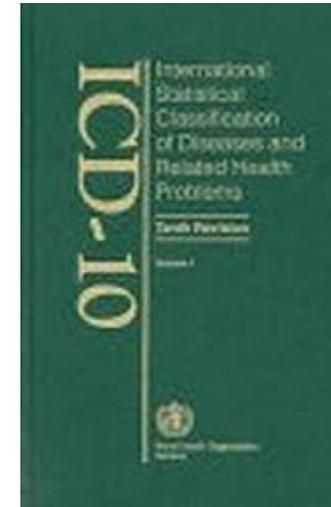
- Secondary care /Hospital data:

- Acute hospitals - Hospital Episode Statistics (HES) <http://content.digital.nhs.uk/hes>
- Mental Health <http://content.digital.nhs.uk/mentalhealth>



# How data are recorded

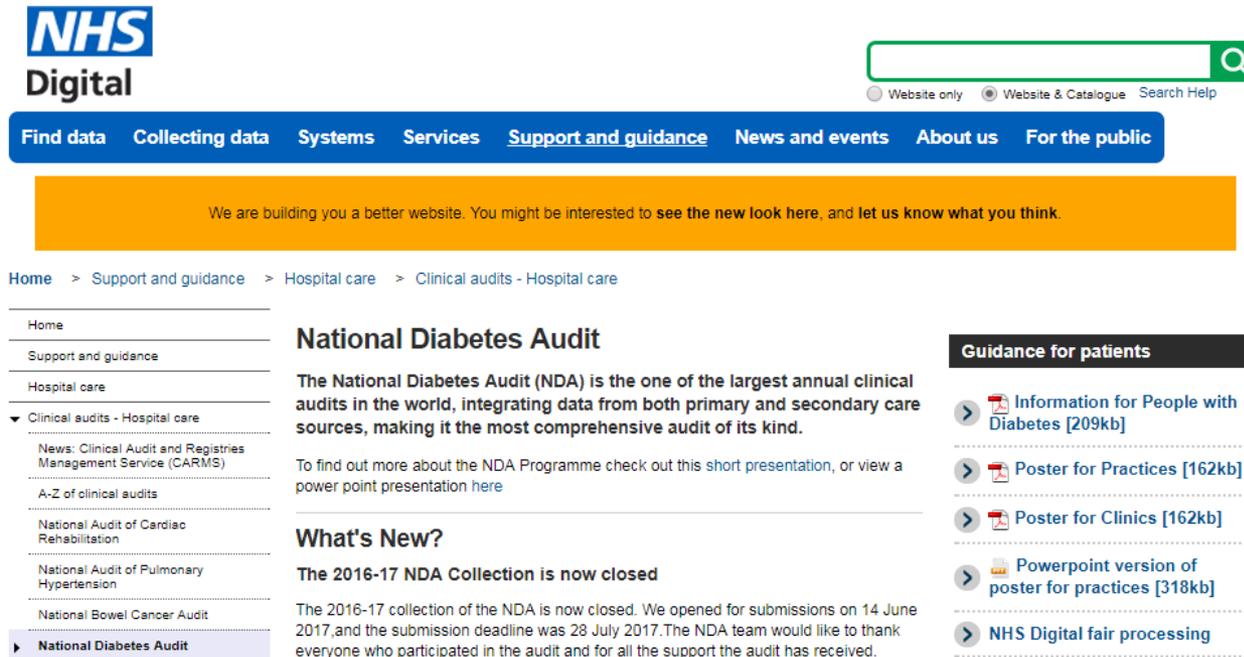
- Hospital data (Episodes)
  - ICD-10 for diseases
  - OPCS-4 for procedures
- Primary care data (Encounters)
  - Read codes
    - Version 2 hierarchical
    - CTv3
- Move to implement a comprehensive coding system
  - SNOMED CT
  - DM+D UK Drug Extension or Dictionary of Medicines <https://www.nhsbsa.nhs.uk/>



**SNOMED CT**  
The global language of healthcare

# Other UK Diabetes data

- **National Diabetes Audit** <http://content.digital.nhs.uk/nda>



The screenshot shows the NHS Digital website interface. At the top left is the NHS Digital logo. To the right is a search bar with a magnifying glass icon and radio buttons for 'Website only', 'Website & Catalogue', and 'Search Help'. Below the search bar is a blue navigation menu with links: 'Find data', 'Collecting data', 'Systems', 'Services', 'Support and guidance' (highlighted), 'News and events', 'About us', and 'For the public'. A yellow banner below the menu reads: 'We are building you a better website. You might be interested to see the new look here, and let us know what you think.' The main content area has a breadcrumb trail: 'Home > Support and guidance > Hospital care > Clinical audits - Hospital care'. On the left is a sidebar menu with 'Clinical audits - Hospital care' expanded to show 'National Diabetes Audit' as the selected item. The main content area features a heading 'National Diabetes Audit' followed by a paragraph: 'The National Diabetes Audit (NDA) is the one of the largest annual clinical audits in the world, integrating data from both primary and secondary care sources, making it the most comprehensive audit of its kind.' Below this is a link to a short presentation. A 'What's New?' section states 'The 2016-17 NDA Collection is now closed' and provides details about the submission deadline. On the right, a 'Guidance for patients' section lists links to 'Information for People with Diabetes [209kb]', 'Poster for Practices [162kb]', 'Poster for Clinics [162kb]', 'Powerpoint version of poster for practices [318kb]', and 'NHS Digital fair processing'.

- **Ambulance data**

- Real world evidence (RWE)
- Nationally available data for RWE studies
- **RCGP RSC**
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# RCGP RSC @50 years



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- One of the longest established primary care sentinel network
- Since 2015, new data & analytics hub at University of Surrey
- Data is extracted on a weekly basis from a network of  
    >170 GP practices comprising >2 million patients.
- Principal output:
  - Weekly surveillance report of infectious and respiratory diseases -
  - Used by Public Health England
  - Data informs the Chief Medical Officer when flu is circulating
- The practices in the network receive continuous feedback - Audit Based education
- Online at: [www.rcgp.org.uk/rsc](http://www.rcgp.org.uk/rsc)
- Sign up to receive our “Weekly Return” produced for >50-years

# RCGP RSC History



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- RCGP founders (1952)
  - embedded research ethos at the core of RCGP
- RCGP Research Committee (1953)
  - Dr Robin Pinsent
- 1957 first research centre:
  - Records and Statistical Unit
- Birmingham Research Unit (BRU)
  - “Weekly returns” since 1967
  - Founder Dr Donald Crombie
- Dr Douglas Fleming - Director from 1989
  - Gold standard sentinel network
- 25 years later 2013 - change in Director
- Data & analytics hub @ University of Surrey since March 2015



BIRMINGHAM  
RESEARCH UNIT

# Weekly report on surveillance of communicable and respiratory diseases



- [www.rcgp.org.uk/rsc](http://www.rcgp.org.uk/rsc)

RCGP Research & Surveillance Centre - Weekly Returns Service



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Research and Surveillance Centre

## RSC Communicable and Respiratory Disease Report for England

### Key Statistics:

Week Number/Year.....37/2017  
Week Starting - Ending.....11/09/2017 - 17/09/2017  
No. of Practices.....159  
Population.....1618960

### National (England)

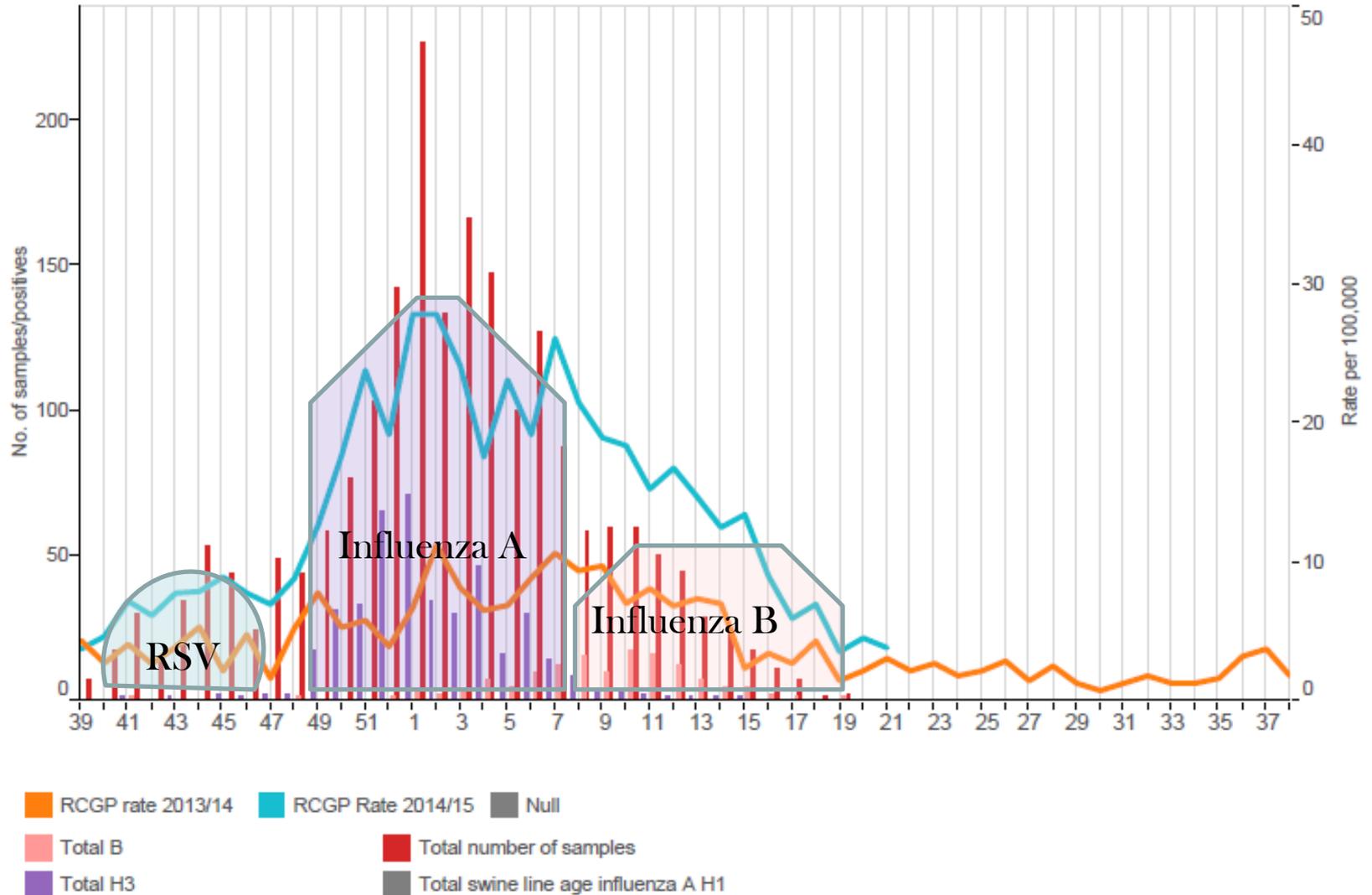
- **Allergic Rhinitis** : decreased a little from **6.0** in week 36 to **5.8** in week 37.
- **Asthma** : increased from **12.5** in week 36 to **13.8** in week 37.
- **Common Cold** : increased from **45.2** in week 36 to **57.4** in week 37.
- **Infectious Intestinal Diseases (IID)** : decreased a little from **8.7** in week 36 to **8.3** in week 37.
- **Respiratory System Diseases** : increased from **189.4** in week 36 to **213.8** in week 37.

### Regional (North, South, London and Midlands and East)

- **Allergic Rhinitis** : was unchanged at **9.8** in week 36 compared with **10.0** in week 37 in the London region, decreased from **6.5** in week 36 to **3.7** in week 37 in the North region, increased from **4.2** in week 36 to **5.5** in week 37 in the South region, and increased from **3.5** in week 36 to **4.8** in week 37 in the Midlands And East region.

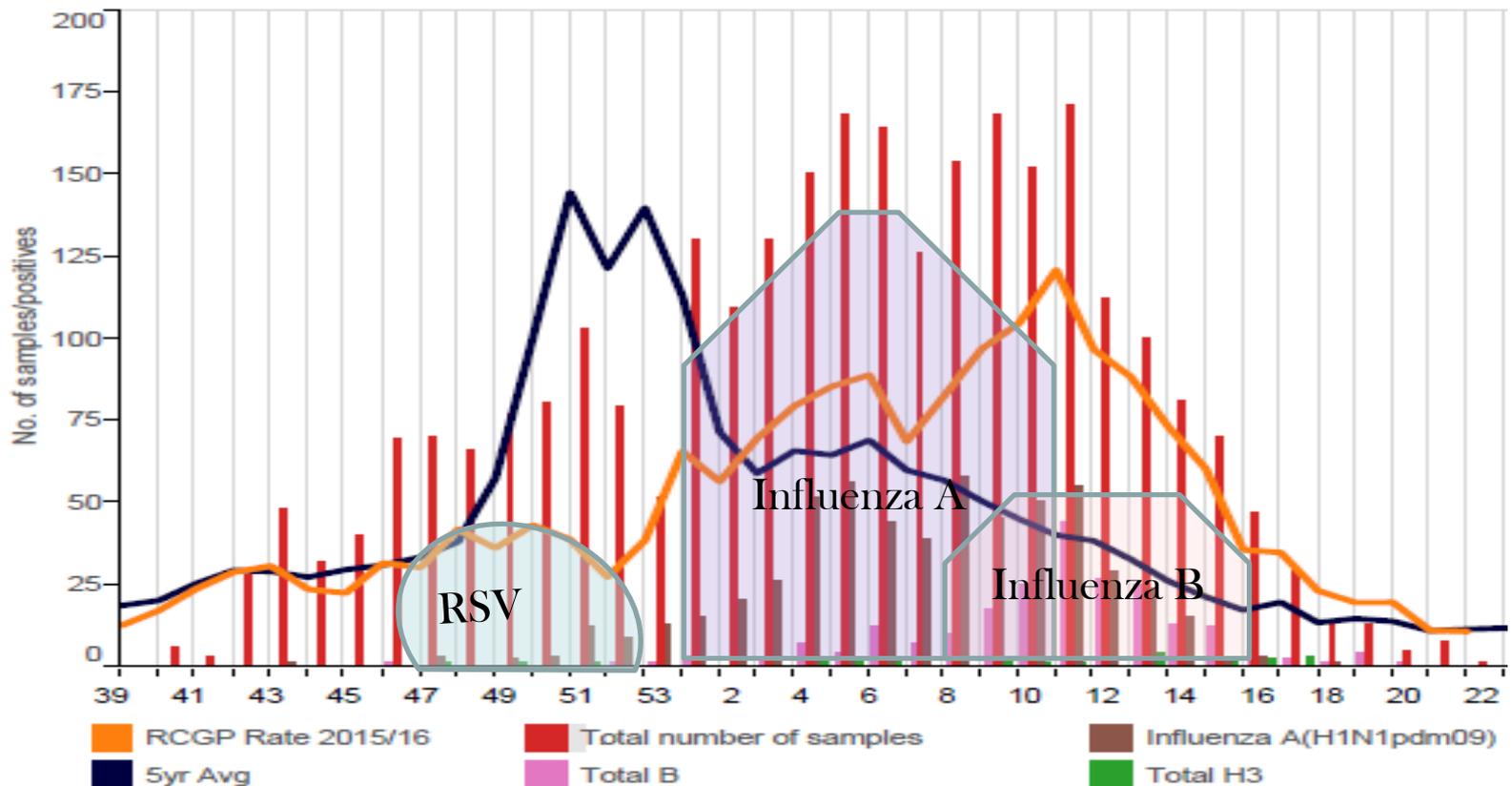
[www.clininf.eu](http://www.clininf.eu)  
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# Surveillance of influenza: 2014/2015



# Surveillance of influenza: 2015/2016

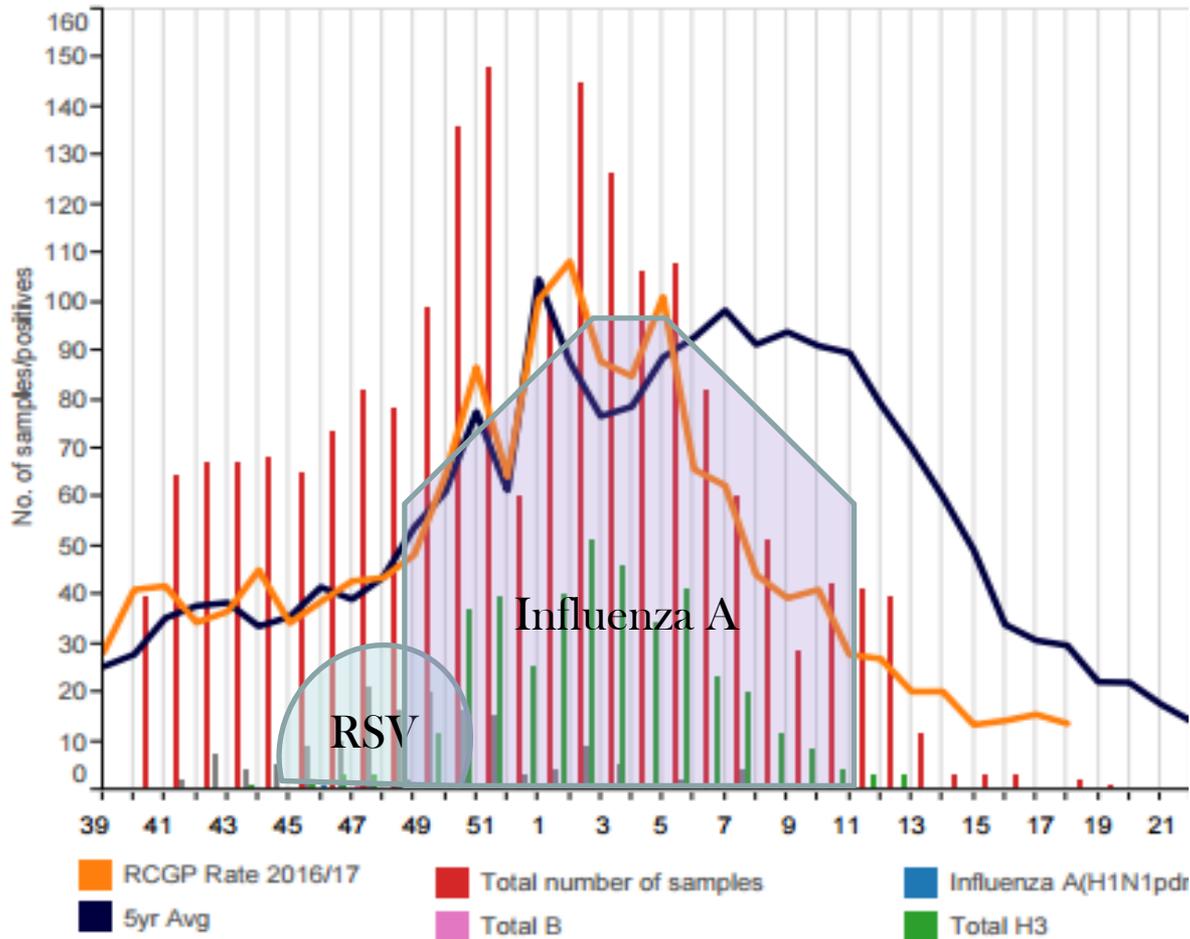
**(B) RCGP/PHE Influenza Swabbing Surveillance 2015/16 (all ages, gender,**



# RCGP RSC

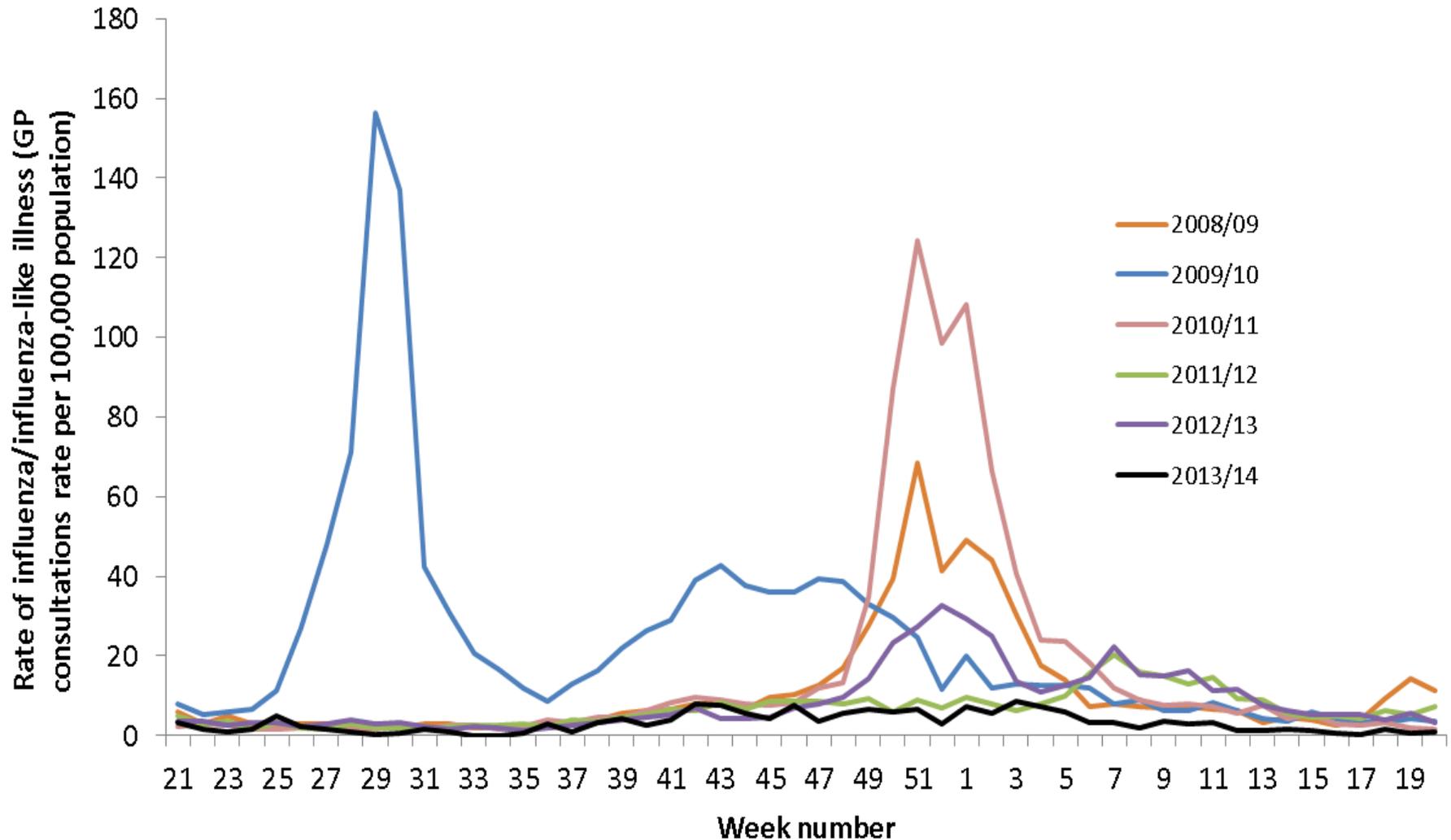
## - 50<sup>th</sup> influenza season

(B) RCGP/PHE RSV and Influenza Virology Swab Surveillance 2016/17



- Little influenza B this season!

# RCGP RSC spotted swine flu pandemic 2009/2010



- Real world evidence (RWE)
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  - **Structure & Capability for linkage**
  - Dataset & representativeness
- Diabetes - Quality Improvement & Research
- Conclusion:
  - Scope for collaborative research

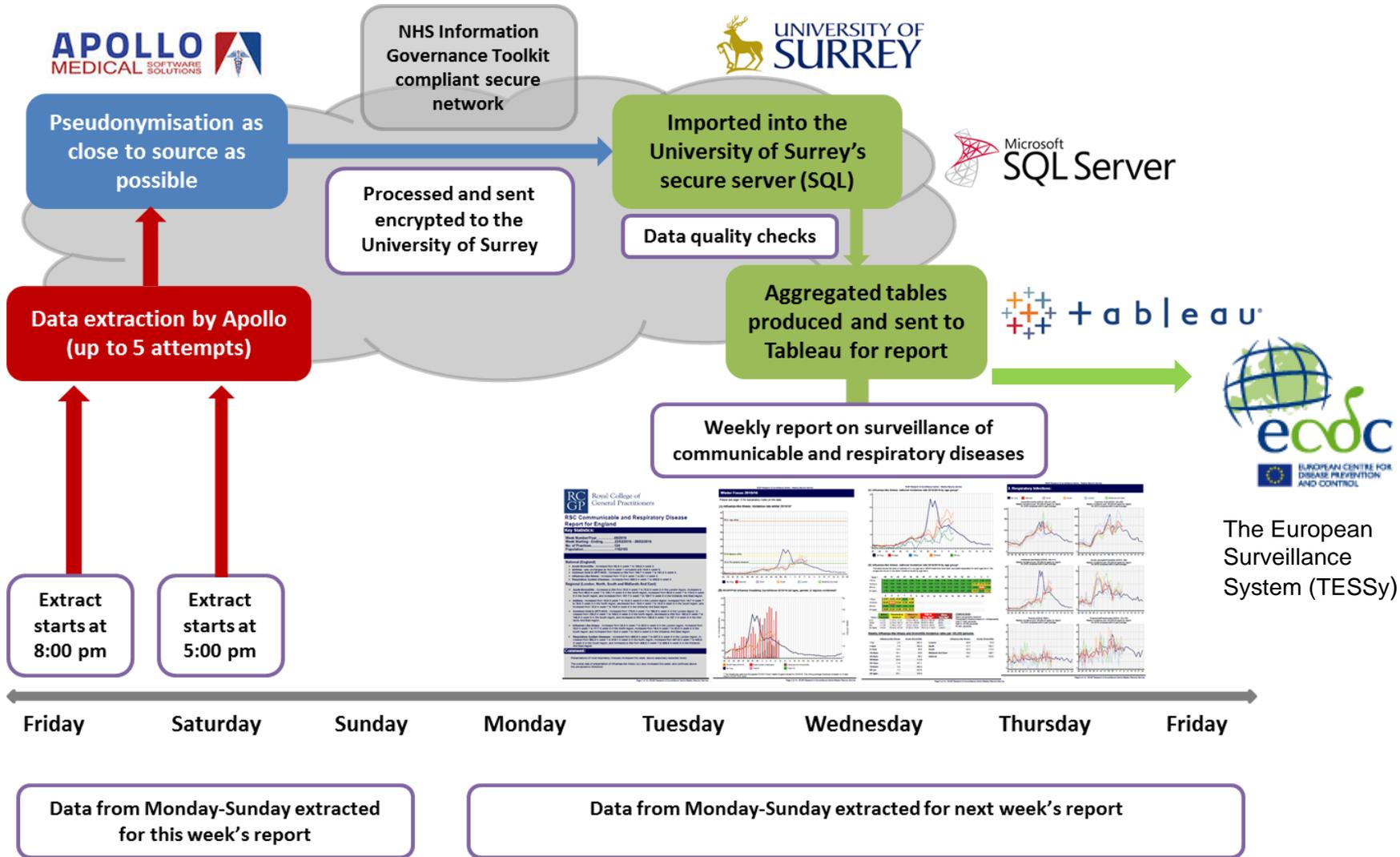
# Capability for data linkage:



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- The RCGP RSC is capable of “pseudonymised” linkage
- Links to other data – on project-by-project basis
  - Hospital Episode Statistics - HES
  - Cancer Registry
  - Mental Health data
- Capability within the group to link to other data sources
  - MINAP
  - SINAP
  - IAPT (where no NHS number))
  - Renal Registry

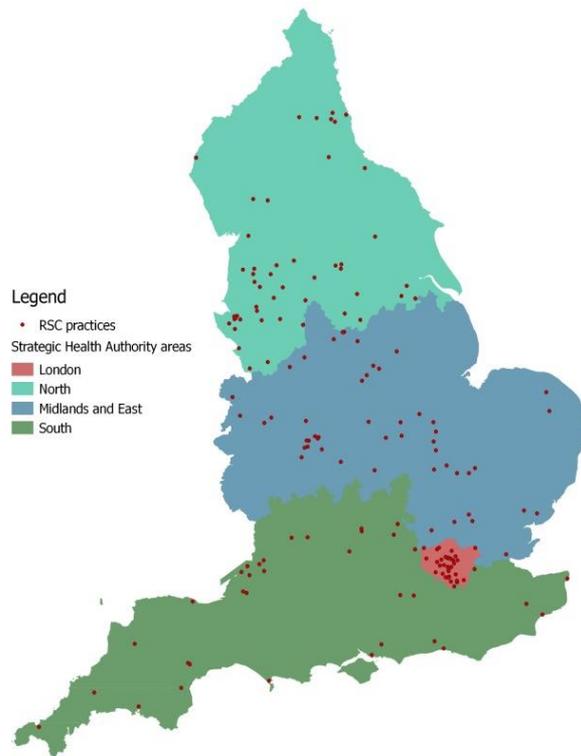
# Weekly data extraction process



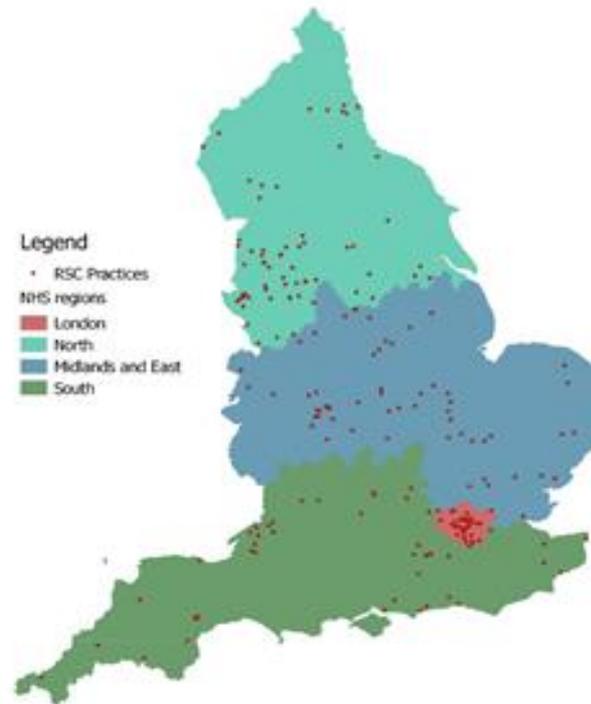
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# RSC geographical distribution

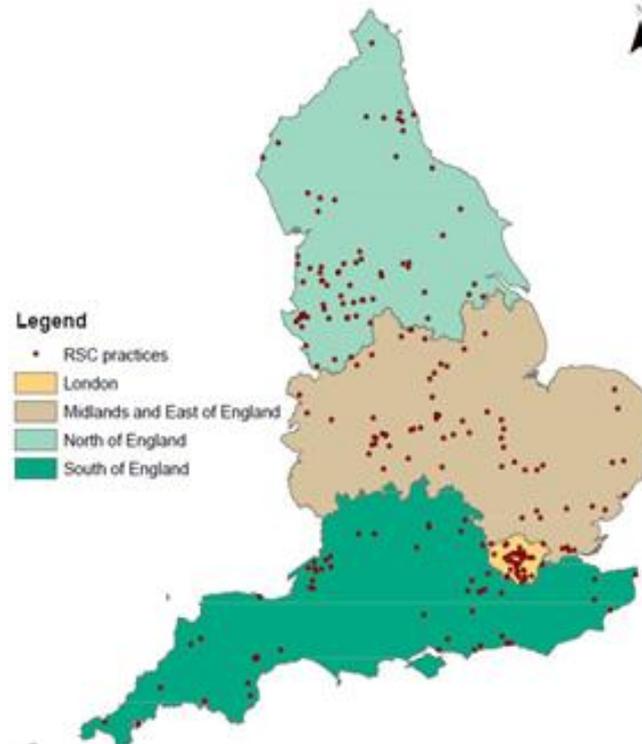
2015



2016



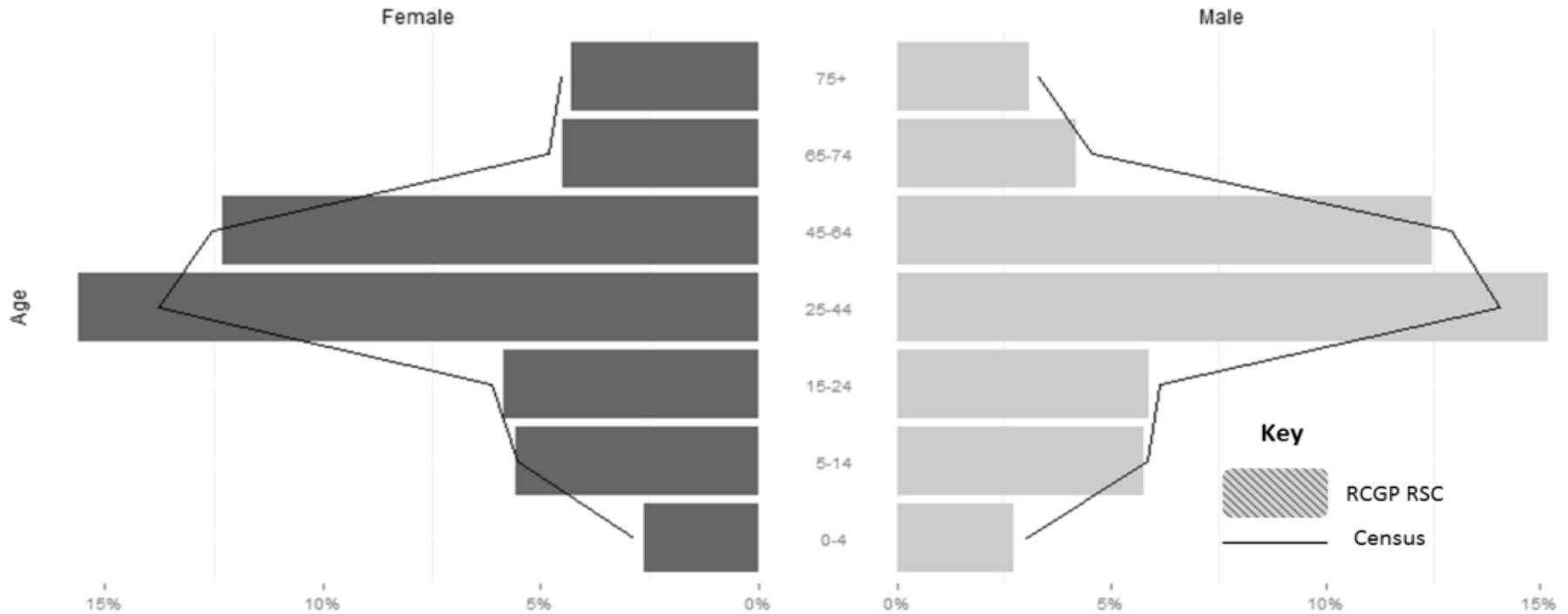
2017



# RCGP RSC Demographics: Age-sex profile of the network population

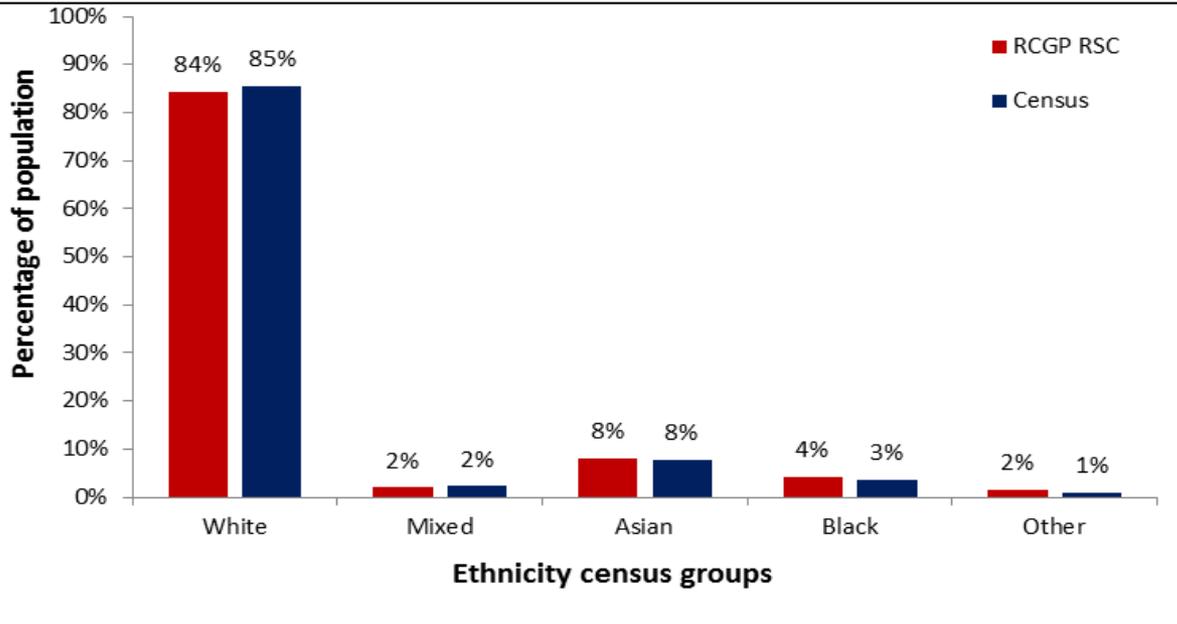


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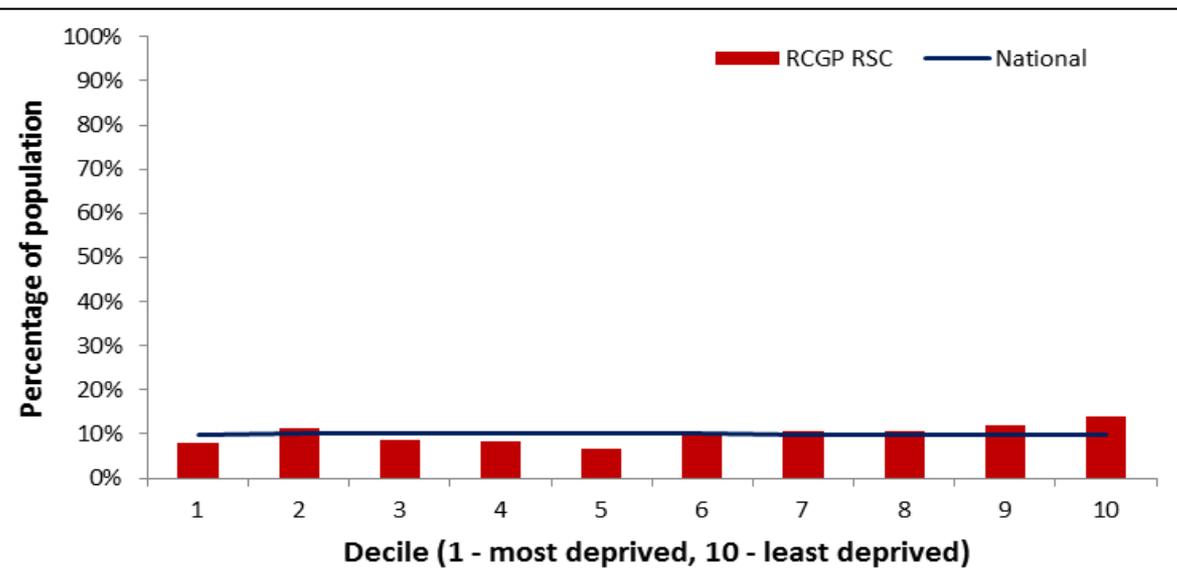


- Age-sex profile representative of the English population
- Higher proportion of both males and females in the 25 to 44 age band ( $p < 0.00015$ )

# RCGP RSC Demographics: Ethnicity and deprivation

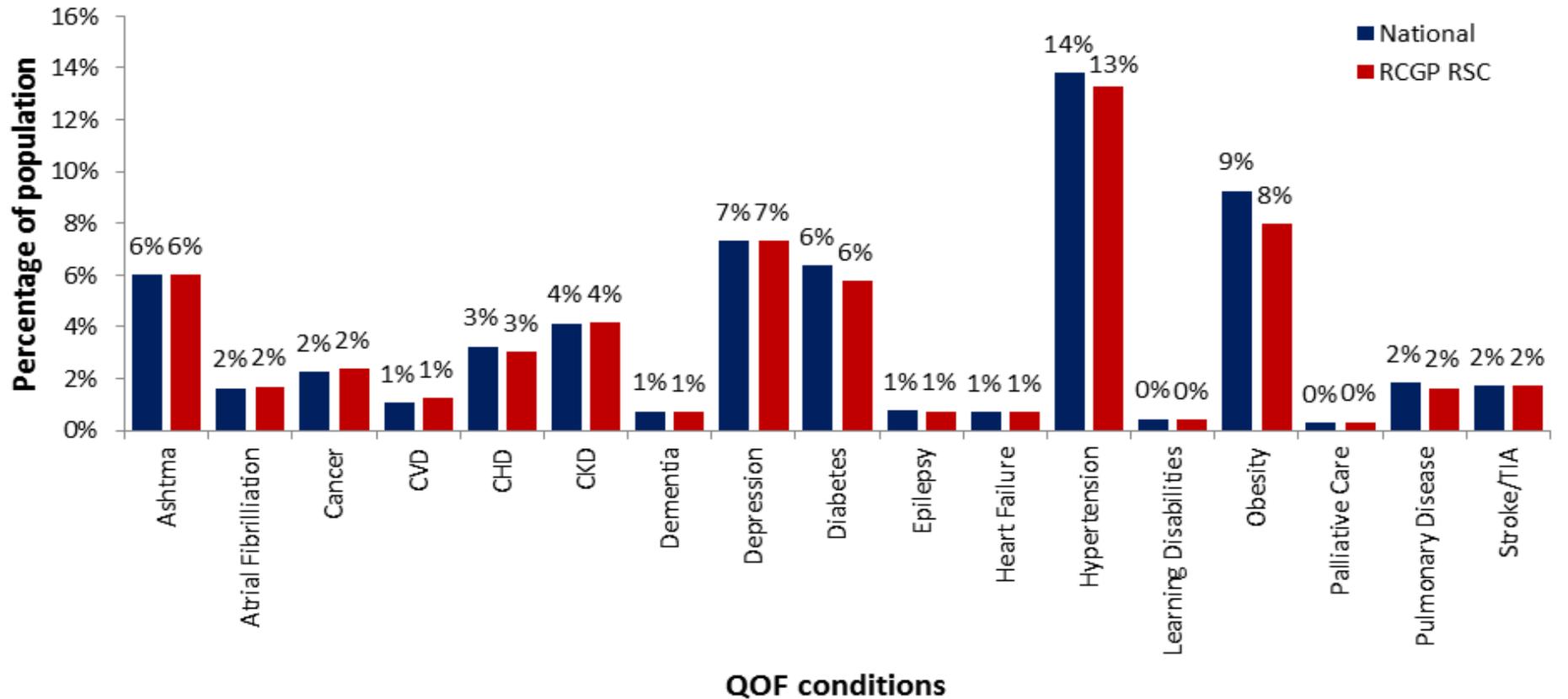


- The majority white ethnicity (84.4%), similar to the census population (85.4%)
- The mean IMD score for the RCGP RSC population was 19.8 (SD 0.00682), which was less deprived than the English population (mean 21.8; SD 0.00050)



# Chronic conditions: Prevalence

Prevalence of chronic conditions (QOF): National and RCGP RSC

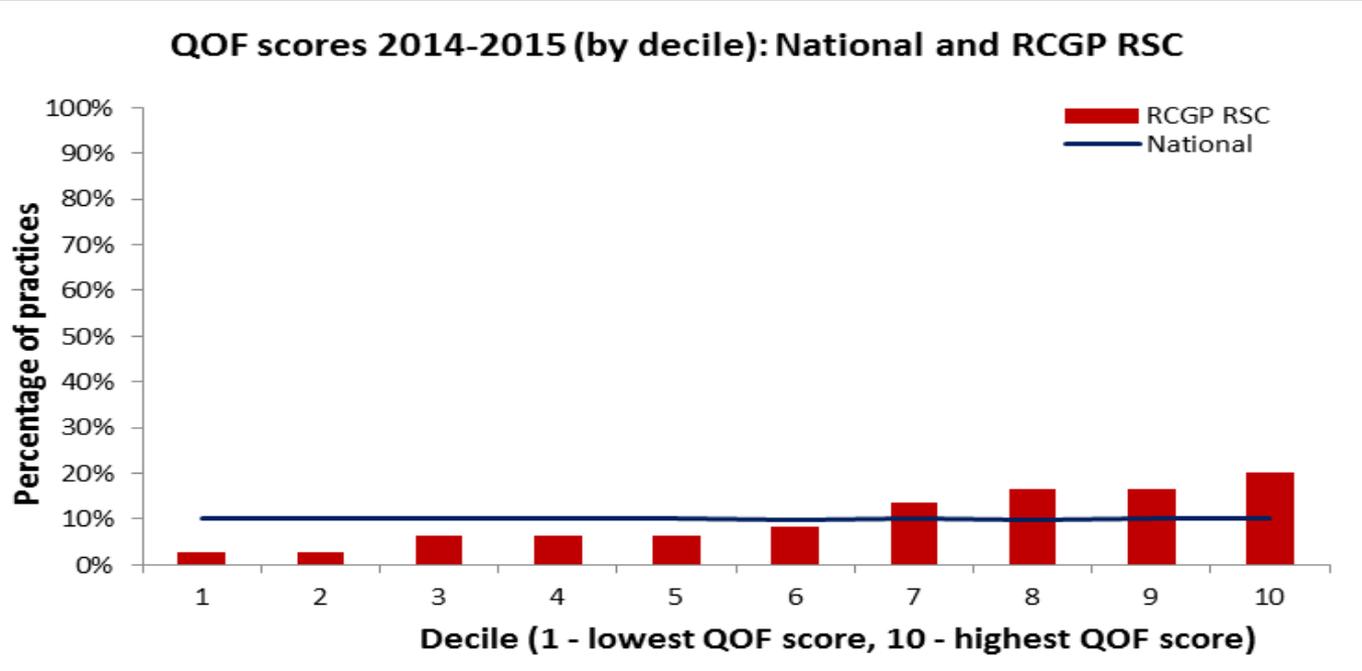


- The prevalence of common chronic diseases was similar to that reported nationally in the P4P/QOF scheme for chronic disease management.
- Underrepresented: Diabetes, learning disabilities, obesity, and pulmonary disease
- Overrepresented: Cardiovascular diseases

# Chronic conditions: QOF scores & completeness

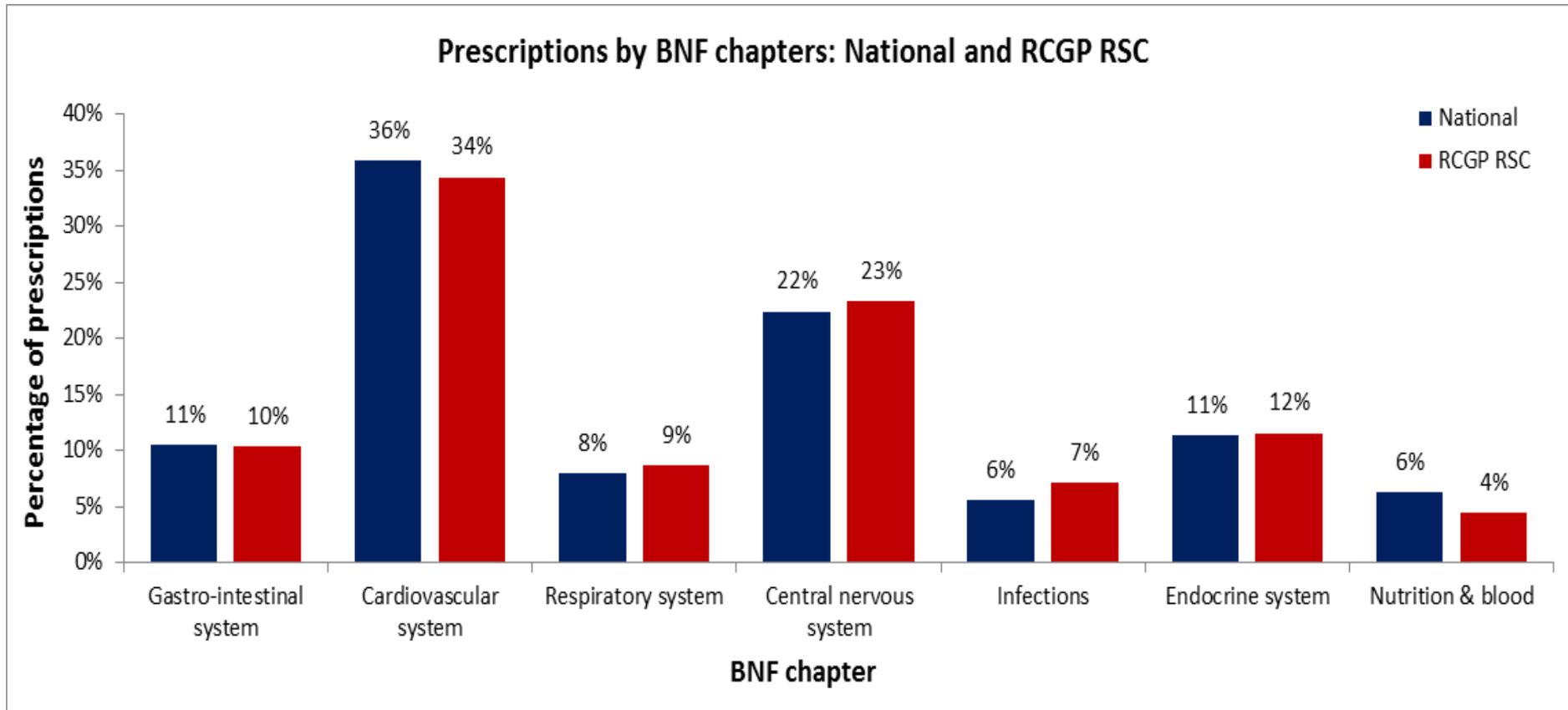
Variables	Diabetes		Non-Diabetes	
	Count	%	Count	%
Age	39,559	100%	977,445	100%
Gender	39,559	100%	977,445	100%
Deprivation score	38,312	97%	935,128	96%
Smoking status	38,928	98%	669,874	69%
Blood pressure (Systolic)	38,935	98%	502,188	51%
BMI (or Height and Weight)	38,225	97%	524,384	54%
Ethnicity	30,409	77%	585,279	60%
Cholesterol (HDL, LDL, other)	37,386	95%	293,082	30%
Glycaemic control (blood glucose/HbA1c)	39,244	99%	253,532	26%

- Recording of cardiovascular risk factors 77%-99% for people with diabetes, and 26%-69% for the non-DM



- P4P/QOF targets achieved by the RCGP RSC network (97.4%; SD 0.0233%) was higher (94.7%; SD 0.0006%)

# Chronic conditions: Prescriptions



- The prescription rates in the network were in line with those reported at the national level
- Higher prescribing rates: **Infections chapter**
- Lower prescribing rates: **Nutrition and blood chapter**

- Real world evidence (RWE)
- Nationally available data for RWE studies
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- **Diabetes - Quality Improvement & Research**
- Conclusion:
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# Diabetes research:



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- **Dataset characteristics**

- Up to 50 years of infection data
- Every repeat prescription from late 1980s/1990s
- Some preventive data from 1991
- Pathology and chronic disease data from 2003/4
- Every prescription from 2015

- **Cohort profiles**

Correa A et al. BMJ Open. (2016)

[Royal College of General Practitioners Research and Surveillance Centre \(RCGP RSC\) sentinel network: a cohort profile.](http://bmjopen.bmj.com/content/6/4/e011092.long)

<http://bmjopen.bmj.com/content/6/4/e011092.long>

McGovern A et al. BMJ Open. (2016)

[Real-world evidence studies into treatment adherence, thresholds for intervention and disparities in treatment in people with type 2 diabetes in the UK.](http://bmjopen.bmj.com/content/6/11/e012801.long)

<http://bmjopen.bmj.com/content/6/11/e012801.long>

- Problem – with opaque case definitions and key outcomes
  - Codes selected to write papers was often opaque
  - Hard to reproduce internationally

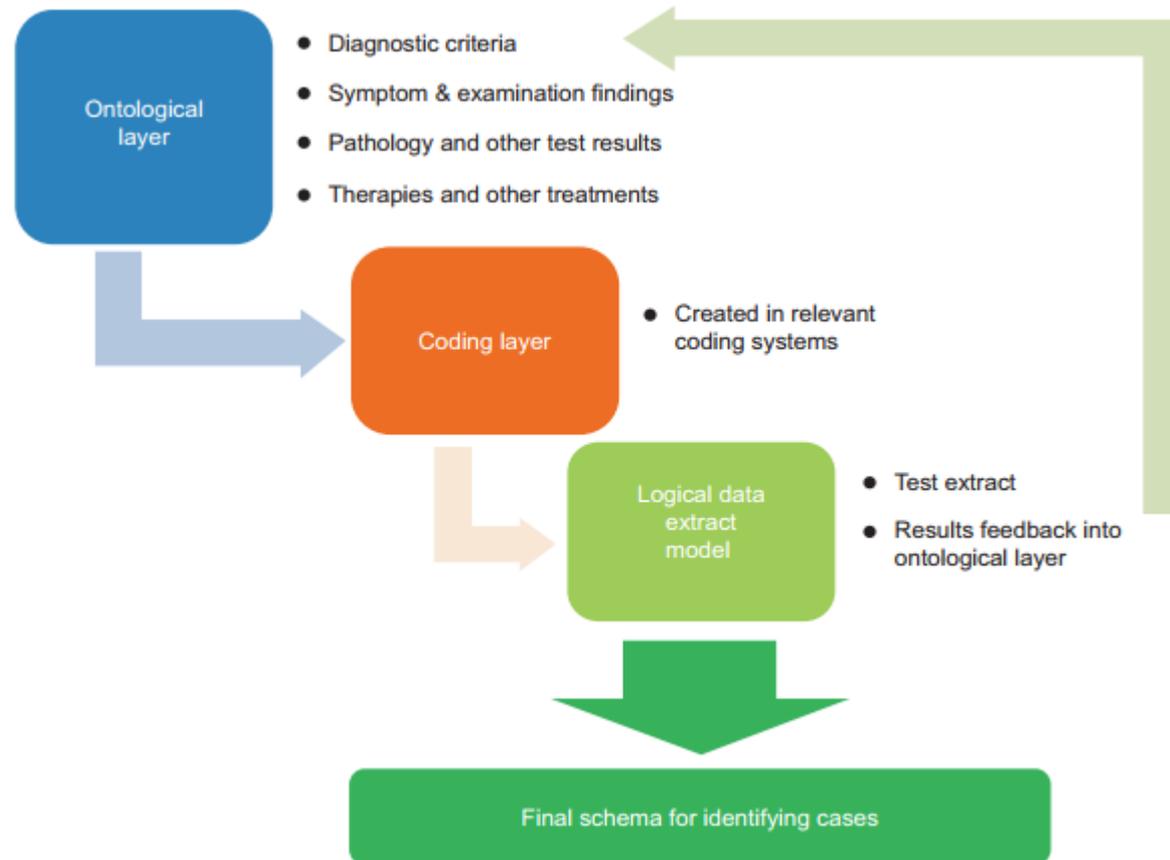
- “Solution”

- an ontological approach

- Transparent mapping from clinical concept to coding list

- Plus include and document testing

- Formal recording of ontology in OWL



# Recent publications - 2017 (1):



- Linking diabetes and infection data:
  - [The association between diabetes, level of glycaemic control and eye infection: Cohort database study.](#) *Prim Care Diabetes*. 2017 Oct;11(5):421-429. doi:
  - [Association Between Diabetes, Level of Glycemic Control, and Eye Infection: A Cohort Study.](#) *Diabetes Care*. 2017 Mar;40(3):e30-e31. doi: 10.2337/dc16-2320.
  - [Association between glycaemic control and common infections in people with Type 2 diabetes: a cohort study.](#) *Diabet Med*. 2017 Apr;34(4):551-557. doi: 10.1111/dme.13205.
- Diabetes and mental health data
  - [CHOICE: Choosing Health Options In Chronic Care Emergencies.](#) Southampton (UK): NIHR Journals Library; 2017 Jul.
- Is RW use of medications the same as trials
  - [Sodium-Glucose Co-transporter 2 \(SGLT2\) Inhibitor: Comparing Trial Data and Real-World Use.](#) *Diabetes Ther*. 2017 Apr;8(2):365-376. doi: 10.1007/s13300-017-0254-7.

# Recent publications – 2017 (2):



- Outcome measures/health care management
  - Measuring Quality of Healthcare Outcomes in Type 2 Diabetes from Routine Data: a Seven-nation Survey Conducted by the IMIA Primary Health Care Working Group. Primary Health Care Informatics Working Group Contribution to the Year Book of Medical Informatics 2017. Yearb Med Inform. 2017 May 8;26(1). doi: 10.15265/IY-2017-005
  - Glucose test provenance recording in UK primary care: was that fasted or random? Diabet Med. 2017 Jan;34(1):93-98. doi: 10.1111/dme.13067.
- Diabetes linked to pancreatic disease
- Incidence, Demographics, and Clinical Characteristics of Diabetes of the Exocrine Pancreas (Type 3c): A Retrospective Cohort Study. Diabetes Care. 2017 Aug 31. pii: dc170542. doi: 10.2337/dc17-0542
- Diabetes data and genetic data
  - Epigenome-wide association study of body mass index, and the adverse outcomes of adiposity. Nature. 2017 Jan 5;541(7635):81-86. doi: 10.1038/nature20784.

- Real world evidence (RWE)
- Nationally available data for RWE studies
- RCGP RSC
  - History & Role
  - Structure & Capability for linkage
  - Dataset & representativeness
- Diabetes quality Improvement & Research
- **Conclusion:**
  - There is greater capacity for collaborative research

# Future collaborations



- The RCGP RSC network is representative of the underlying English population, and key significant differences have been clearly quantified, making this database a rich source for health outcomes research. It is currently under used by the academic community
- There is potential for more collaboration – findings independent of health system context
- We would welcome opportunities, especially for strategic collaboration
- We encourage interested researchers to attend the short courses on how to analyse primary care data offered by the university twice a year:
  - Surrey Winter Statistics School (SWISS) January 2018: Date TBA
  - Surrey Informatics Summer School (SISS) July 2018: Date TBA



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Thank you for listening

Simon de Lusignan

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