

## **THOR**The Health and Occupation Research network



# 21<sup>st</sup> Century Occupational Health Reporting and Surveillance

Report of a workshop on The Health and Occupation Research network reporting schemes 29 March 2018, Manchester, UK

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http://www.coeh.man.ac.uk/thor

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#### **EXECUTIVE SUMMARY**

Reliable data on occupational ill-health is important for identifying priorities in policy interventions as well as assessing the effectiveness of such interventions. One source of occupational ill-health data is The Health and Occupation Research (THOR) network, hosted by the Centre for Occupational and Environmental Health (COEH) at the University of Manchester. A workshop was held on 29 March 2018 to bring together experts in the field of health surveillance, digital data collecting and data mining techniques to explore opportunities for innovations in data collection, data analysis and data insights which could provide the UK with a cost effective, sustainable model to enable evidence based policy decisions in the area of work and health. Following a number of plenary presentations, breakout discussion sessions were held on 'Technological advances and data linkage' and 'Physician engagement'. Various opportunities were identified to improve the current reporting schemes, which ranged from relatively minor changes (eg improvement of feedback to reporters) to more substantial activities (developing an accessible database, utilising mobile technologies, and using routine health data records). Following the outcomes of this workshop, a joint team from the Health and Safety Executive (HSE) and COEH will meet to develop one or more joint proposals to develop methods to improve occupational ill-health data in the UK.

#### **BACKGROUND**

Vital to the prevention of ill-health associated with work, as well as the promotion of health at work and the maintenance of 'work ability' is the availability of good quality data regarding work-related ill-health (WRIH) burden and risks. Such data are critical in risk assessment central to preventing WRIH as enshrined in regulatory guidance, as they inform the risk assessments and management process.

A key source of WRIH data in the UK is The Health and Occupation Research (THOR) network<sup>1</sup>, hosted by the Centre for Occupational and Environmental Health (COEH) at the University of Manchester and partially funded by the Health and Safety Executive (HSE). Having commenced with chest physician reporters in 1989 THOR, as it is now known, comprises a number of schemes to enable different groups of physicians (chest physicians, dermatologists, occupational physicians and general practitioners) to voluntarily report incident cases of WRIH throughout the UK (Carder et al., 2017). THOR is an important source of data for HSE, contributing to the HSE Annual Health and Safety Statistics publication (THOR ill-heath statistics have been granted National Statistics status by the UK Statistics Authority) and being HSE's preferred data source for asthma and dermatitis<sup>23</sup>. In general, THOR data are one of the main sources of statistical information with which HSE (and others) determine their priorities and work programmes on occupational health (Money et al., 2015).

Central to the longevity of THOR is the loyalty of the participating physicians coupled with an established reporting structure and well developed methodologies for determining incidence, trends in incidence and identifying novel causes. It is therefore important to ensure that the necessary steps are taken for THOR to continue as a valuable WRIH resource into the future. However, as THOR is a voluntary reporting scheme and physicians do not get paid to participate, there are some problems in terms of recruitment of physicians to the schemes, and reporting fatigue.

In addition, the rapid increase of digitisation in the health domain and the increased

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http://www.coeh.man.ac.uk/thor

http://www.hse.gov.uk/statistics/preferred-data-sources.pdf

http://www.hse.gov.uk/statistics/tables/index.htm

availability of a range of communications channels available to citizens and practitioners, has greatly enhanced availability of health related data. These developments, taken together, provide an environment in which the opportunities for future occupational health surveillance and reporting look different to current practices. This workshop aims to explore these.

Within the University of Manchester there are several other reporting schemes (e.g. TARN – Trauma Audit and Research Network<sup>4</sup>; and NDEC – National Drug Evidence Centre<sup>5</sup>). In addition, the University of Manchester leads the Health e-Research Centre<sup>6</sup>, which specifically aims to improve the collection and use of health data, and has expertise in health informatics<sup>7</sup>. Hence, there is a wide and high level of expertise in the area of collection and use of health data. We intended to bring together a group of interested scientists from University of Manchester as well as HSE to discuss the future need for occupational ill-health data and how to best collect these, making best use of existing data sources, whilst also making sure that we can continue to monitor trends in occupational ill-health over time.

#### AIM OF THE WORKSHOP

The aim of the workshop was to bring together experts in the field of health surveillance, digital data collecting and data mining techniques to explore opportunities for innovations in data collection, data analysis and data insights which could provide the UK with a cost effective, sustainable model to enable evidence based policy decisions in the area of work and health.

Specific objectives included:

- Exploration of opportunities for innovations in the occupational health reporting schemes, including digital methods for data recording, use of social media, data mining, clinic practices etc.,
- 2) Prioritisation of potential innovations in the context of impact (both negative and positive) on tracking of occupational ill-health and the ability to compare with

https://www.tarn.ac.uk/

http://research.bmh.manchester.ac.uk/epidemiology/NDEC

<sup>6</sup> https://www.herc.ac.uk/

http://research.bmh.manchester.ac.uk/healthinformatics

#### historic data

3) Draft plan for developing and implementing innovations.

#### PROGRAMME OF THE WORKSHOP

The workshop consisted of a number of plenary presentations in the morning followed by a break out session to discuss different themes. The programme of the workshop is provided on the Page 7. The presentations provided an overview of the THOR reporting schemes as well as a presentation on current approaches to engage with physicians. There was also a presentation on HSE's priorities for occupational health data, while two presentations provided insights into some ongoing work at the University of Manchester in relation to novel methods for data collection and the availability and use of databases with routinely collected health data.

The afternoon session involved two discussion groups discussing the following themes:

#### Group 1

- Technological advances,
- Data linkage and data mining, and

#### Group 2

Physician engagement.

LOCATION - Roo	m 2.05
9.45-10.00	Welcome and introduction
	(Professor Martie Van Tongeren)
10.00-10.30	History of THOR
	(Dr Melanie Carder)
10.30-11.00	Novel methods for data collection (Prof Niels Peek)
11.00-11.15am	Coffee break (room G.33)
11.15-11.45	Health and Safety Executive priorities and needs (Professor Andrew Curran)
11.45–12.15	Physician engagement (Dr Dil Sen and Dr Martin Seed)
12.15-13.15	Lunch (room G.33)
13.15-13.45	Databases of electronic health records in the UK (Professor Evangelos Kontopantelis)
13.45-14.00	Introduction to breakout groups
14.00-15.00	Breakout group discussions
	Breakout group 1 Technological advances and data linkage (led by Prof
	Andrew Curran)
	Breakout group 2 Physician engagement (led by Dr Dil Sen/Martin Seed)
3-3.15pm	Coffee break (Room G.33)
LOCATION - Roo	m 2.05
3.15-4pm	Report back from breakout groups and discussion
4-4.15pm	Conclusion and follow up plan

#### **CHARGES FOR THE BREAKOUT GROUPS**

#### Theme 1 Technological advances

The importance of making the reporting task as simple as possible and not over-burdening the physician is well recognised. THOR reporting originated with a postal report card but since 2007 the option to report via a web form has also been introduced (with newer schemes such as THOR-GP being exclusively electronic reporting). However, uptake of electronic reporting methods has been relatively low (approximately one third of non-GP reporters) with physicians citing barriers such as multiple work-places and the lack of a designated work-station. Within this theme we aimed to identify likely barriers to reporting within the existing methods, how they may be overcome, and the potential role of alternative reporting methods such as the use of a mobile phone app. We also explored the role of social media and other technological advances in surveillance schemes such as THOR, [or as complementary approaches?].

#### **Questions for discussion**

- How can we encourage physicians to submit their case information using online platforms such as a web-form? What are the barriers preventing them from doing so?
- Would a mobile-phone app be a viable reporting option? Have such methods been applied successfully elsewhere?
- Are there any other technological advances that could make reporting easier for physicians participating in surveillance schemes such as THOR?
- What is the role, if any, of social media in occupational health surveillance (e.g. in relation to physician participation, reporting, dissemination of information)?

#### Theme 2 Data linkage and data mining

The first aim of this theme was to explore the potential of linking THOR with other extant databases. Advantages of data linkage could include the refinement of estimates of WRIH burden (for example by increasing the accuracy of numerators/denominators) or improvement of the data collection process (for example by exporting data to THOR from existing clinician based databases). The theme explored what other databases are available, what data are collected, whether occupational data are collected (and if not, whether there is the scope for it to be collected) and the feasibility of data linkage with THOR. The second

aim of this theme explore the role of data mining techniques in surveillance systems such as THOR.

#### Questions for discussion

- What database with electronic health records current exists that could be used for OH surveillance or research?
- Could any of these databases be used in conjunction with THOR data and what would be the benefits of such data linkage for occupational disease surveillance?
- What is the role of data mining in occupational disease surveillance?
- Are their opportunities to include occupational data in electronic health records in future? If so, what are these and what needs to be done to include such information?

#### Theme 3 Physician engagement

Participation in THOR is voluntary so both recruitment and retainment of physicians in THOR can be challenging, particularly in times of increased workload, changing work patterns and reduced resources. In addition to minimising the burden of reporting it is important to provide meaningful benefits to the physicians for participating. Existing benefits of THOR participation include regular feedback in the form of quarterly and annual reports, access to an ad hoc enquiry service as well as opportunities to attend meetings, and collaborate with colleagues and THOR researchers to publish work based on collected data. We have also developed an online THOR related educational initiative, EELAB (Zhou et al., 2017), which (for some of THOR schemes) has been accredited for CPD purposes. The aim of this theme was to explore barriers to physician participation/engagement and possible future innovative methods to increase physician engagement/participation.

#### **Questions for discussion**

- What are the likely barriers to physicians participating in surveillance schemes such as THOR?
- What are the main incentives for physicians to participate and how can these be improved?

- What steps could be taken to reduce reporter 'fatigue', increase recruitment and retainment?
- How could we improve the value of educational tools such as EELAB?

#### **WORKSHOP NOTES**

#### Breakout Session 1 & 2 – Data linkage / technological advances

Led by Andrew Curran

Members included: Martie Van Tongeren; Annemarie Money; Melinda Lyons; Donald Cairns; Andy Darnton; Ian Hall; Laura Adelman; Yiqun Chen; Nick Warren; Tom Lawrence; Evangelos Kontopantelis; Andy Jones; Andy Povey.

Much of the discussion focussed on linkage possibilities with databases such as CPRD, electronic health record, injury data, DWP databases etc. THOR does not collect any identifiable data such as NHS number or national insurance number, therefore, although theoretically the consensus was that being able to link was the ideal scenario, there were too many practical / ethical issues to overcome this.

Would geographical data linkage be possible? This was also problematic given the fact that often, especially for the clinical schemes, the cases reported were those at the top of the surveillance pyramid, so there would be difficulties in identifying these cases.

The discussion moved onto whether it was worth pursuing consent from the patients via the reporting physicians; this would entail a different level of engagement from the physicians which could bring its own problems, i.e. over-burdening the physicians and whether this would have an impact of cases reported.

#### Actions:

Martie and team to produce a document mapping existing databases and possibilities and limitations of linking to THOR.

Discussion around technological developments highlighted that any advances need to always be user dependent and that what was developed for clinicians would not necessarily be applicable for patients. If the evidence from the clinical schemes is that card based

reporting is the preferred method, then web based reporting should not be forced on the reporters to the detriment of the scheme.

Practical considerations around ease of access for reporters were discussed; participating physicians noted that usernames and passwords were sometimes difficult to remember, so were there alternative ways that the doctors could log on? Ways to simplify the system without compromising security?

Advice from the group on developing an app for reporting was that it was preferable to ensure that the website was mobile enabled, rather than offer an app – but again, the user of the service should be taken into account in the development of any technology.

Social media presence was discussed in terms of ways to improve this and possibly to redirect the focus to identifying new hazards / jobs / industry sectors etc. Noted that we have a centre twitter and Facebook account, consensus was that there should be a THOR surveillance twitter account.

#### **Actions:**

- THOR web developer to investigate alternative / easier ways for reporters to log onto the THOR portal
- **THOR** team to consider setting up THOR surveillance twitter account

#### Breakout Session 3 – Physician participation, engagement and retainment

Led by Dil Sen

Members included: Martin Seed, Jenny Hoyle, Chris Barber, David Fishwick, Maria Panagioti, Ian Lambert, Siti Rusdhy, Nazia Zarin, Melanie Carder

Two main themes were discussed centred on barriers to reporting and recruiting:

#### Barriers to reporting

Ease of reporting - the ability to be able to report there and then i.e. immediately after seeing patient or at the end of clinic (when have access to clinical records) was considered important.

The general assumption that electronic reporting is always easier is not correct – especially if reporters have to find web-page, remember username and password etc.. It would be useful if the electronic reporting forms would automatically store username and passwords (i.e. reporters stay logged in unless explicitly log out). Similarly if certain fields could be autocompleted (unless specifically told otherwise) e.g. whether physician is full-time or part-time. The development of a mobile phone app for reporting cases was encouraged, although the uptake amongst physicians is likely to be mixed.

However, some reporters will prefer using the cards as it is often quicker to write on details on a reporting card. For some, the reporting card also acts as a prompt to remember to report.

The development of a desktop app is probably not feasible for practical and logistical reasons and the need to get permission to install such software on NHS computers.

#### Recruitment/retainment of reporters

The group emphasised the need to endorse THOR/engage with the reporters more as to why it is important to participate in schemes such as THOR. Most physicians have very little time, time allowed per consultation decreased, need to feel it's a worthwhile exercise.

More personalised feedback would be useful – e.g. a signed pdf saying thank-you for reporting, this is what you've reported, this is what others have reported etc. Electronic reporters can currently get a print-out of previously reported cases (but this doesn't include a thank-you etc) but card reporters don't get anything (other than the quarterly and annual reports).

Suggested we could survey reporters to ask them how they would like to report (app, web, card etc). Are younger reporters more likely to use electronic methods?

The issue of duplicate reporting was discussed – physician won't always report the case at first visit as might want to wait for test results etc. Sometimes they forget whether a case has already been reported. Could there be a prompt (e.g. if report same age, gender, postcode) saying 'you've recently reported something similar, is this a different case?).

EELAB, which provides opportunities to earn CPD points, is currently only available for GP and OP reporters via the reporting websites. It may be beneficial to extend this to SWORD and EPIDERM to incentivise reporting. This might require additional specialty specific learning modules to be created although it was commented that the existing modules on occupational asthma and contact dermatitis, that are currently available to OPRA and THOR-GP reporters, might also have educational value to sample SWORD and EPIDERM reporters respectively.

The development of a tool available for reporters to allow them to interrogate the THOR database (in real time) could be a useful addition.

In general, it was advised that engagement with professional societies is important e.g. BTS, SOM, BAD etc and to have a presence at the various meetings in order to publicise THOR – link into courses (e.g. BTS short course) to recruit physicians during their training stage

#### **Actions**

- Enable reporting forms to automatically store username and passwords
- > Autocomplete of fields
- > Thank-you pdf of reported cases
- Prompt for duplicate reporting
- Survey of reporters as to preferred reporting methods
- Develop mobile reporting app
- Continue to develop EELAB for chest physicians and dermatologists
- Investigate possibility of enabling physicians to interrogate THOR database
- Improve THOR endorsement (e.g. via recruitment information/methods, engagement with societies, presence at meetings etc)

#### **CONCLUSIONS**

This workshop was organised to develop ideas for improving the reporting mechanisms, incentivise physicians to report voluntarily and identify other sources of information that could be used, in conjunction with the current reporting scheme, to increase the usefulness of the data.

It was clear from the discussions during the workshop that various opportunities exist for making improvements in these areas. A number of these are relatively minor and could, with a modest level of resources, be implemented in the current reporting schemes. For example, these would include the development of mobile phone app and extending EELAB to chest physicians and dermatologists.

Other areas for development require further exploration, possibly in the form of one or more research projects. For example, the systematic review of electronic health records on the presence of occupational data would be a useful activity, and could form the basis of small joint project between HSE and the University of Manchester. This project should aim to determine i) if useful information is currently being collected; ii) if so, how can these electronic records be mined to extract the occupational data; and iii) how can occupational data collection be improved within routine health records. In addition, the development of a database that could be viewed interrogated by reporters and other stakeholders, and would improve the dissemination and use of the data, would require more substantial resources.

Specifically, the following specific actions were identified

- COEH to produce a document mapping existing databases and possibilities and limitations of linking to THOR.
- COEH web developer to investigate alternative / easier ways for reporters to log
  onto the THOR portal and make some modifications to increase user friendliness.
   This will also include ensuring that the website is mobile phone friendly. We will also
  consider including automatic thank you letters.
- COEH to consider setting up THOR surveillance twitter account
- We will consider carrying out a survey of reporters as to preferred reporting methods
- COEH will continue to develop EELAB for chest physicians and dermatologists
- COEH to improve THOR endorsement (e.g. via recruitment information/methods, engagement with societies, presence at meetings etc)

In addition, HSE and COEH (within the Thomas Ashton Institute) will meet during the summer months of 2018 to develop a detailed plan for continued funding for the THOR schemes. This will include:

- Continued data collection to ensure that HSE can use the occupational health data to track progress on current programmes (through HSE funding).
- A proposal for innovations in occupational ill-health data collection and dissemination. This proposal will include development of new and additional data collection methods that will improve our knowledge on occupational ill health incidence and trends in the UK. The proposal will also include development of methods to use existing data sources (if appropriate) and development of improved data dissemination of data (e.g. through accessible database).

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- Money A, Carder M, Hussey L, Agius RM. The utility of information collected by occupational disease monitoring systems. Occup Med (Lond) 2015;65:626-631
- Zhou Y, Dodman J, Hussey L, Sen D, Rayner C, Zarin N, Agius RA. Electronic, Experiential, Learning, Audit and Benchmarking (EELAB): An innovative educational resource in occupational medicine. Occup Med (Lond) 2017 Jul 1;67(5):363-370.

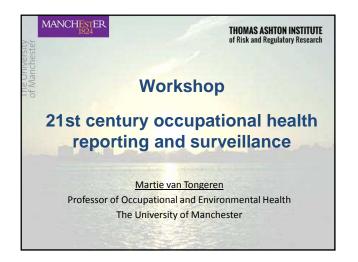
#### **ANNEX POWERPOINT PRESENTATIONS**

1.	Professor Martie Van Tongeren
	21st century occupational health reporting and surveillance

2. Dr Melanie Carder

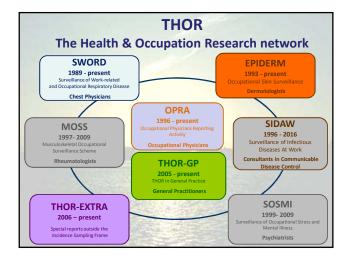
Overview of The Health and Occupation Research (THOR) surveillance scheme

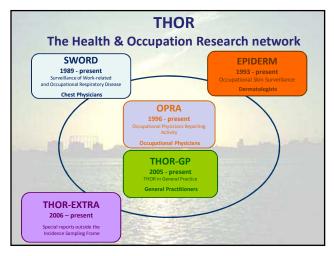
- 3. Professor Neils Peek21st century occupational health reporting and surveillance
- 4. Professor Andrew Curran21st Century Occupational Health Reporting and Surveillance
- Dr Dil Sen & Dr Martin Seed
   Physician engagement
- Professor Evangelos Kontopantelis
   Primary Care Databases Analysing Electronic Health Records

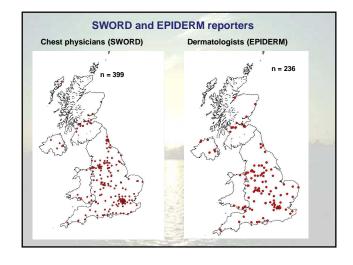


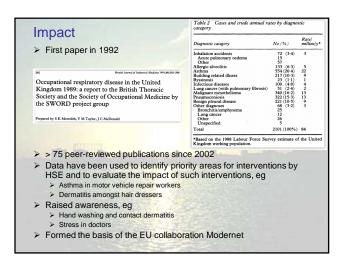
# The Health and Occupation Research (THOR) Network A research and surveillance programme, fulfilling a medical observatory function, for occupational disease, work related ill health and sickness absence Started in UK with 1st scheme in 1989: SWORD

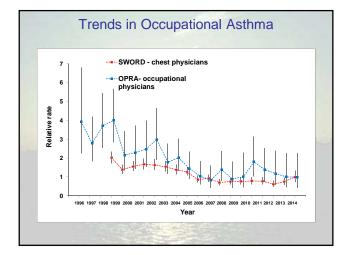
- > >1000 doctors participate
- > 1000 doctors participate
- Reports from clinical 'system' specialists account for an estimated 11,000 new UK cases of work-related ill-health per annum.
- Reports from OPs and GPs account for a further estimated 12,000 UK cases per year
- > THOR Ireland started in 2005











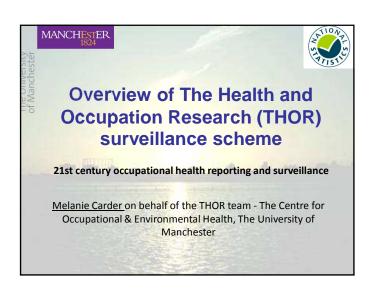
#### **Some problems THOR**

- Voluntary reporting:
  - Participating physicians do not receive payment
  - Recruitment/retainment
  - Reporting fatigue
  - Limited amount of data requested
- Accuracy of incidence rates
  - Lack of denominator information
  - Not all relevant physicians (chest physicians, dermatologists, occupational physicians, GPs) participate, hence underestimating of cases

#### **Aim of the Workshop**

- To explore opportunities for innovations in the occupational health reporting schemes, including digital methods for data recording, use of social media, data mining, clinic practices
- To prioritise potential innovations
  - According to requirements of HSE and other stakeholders
  - To study temporal and other trends in incidence
  - To evaluate effectiveness of interventions
  - To identify new causes of occupational disease
- The outcomes of the workshop should provide a platform to develop further proposals to implement innovations (if appropriate)

	Programme
9.45-10.00	Welcome and introduction (Professor Martie Van Tongeren)
10.00-10.30	History of THOR (Dr Melanie Carder)
10.30-11.00	Novel methods for data collection (Prof Niels Peek)
11.00-11.15	Coffee break
11.15-11.45	Health and Safety Executive priorities and needs (Prof Andrew Curran)
11.45-12.15	Physician engagement (Dr Dil Sen and Dr Martin Seed)
12.15-13.15	Lunch
13.15-13.45	Electronic health records in the UK (Prof Evangelos Kontopantelis)
13.45-14.00	Introduction to breakout groups
	Breakout group discussions Breakout group 1 Technological advances (led by TBC, rapporteur, Dr Annemarie Money) Breakout group 2 Data linkage and data mining (led by TBC, Dr Melanie Carder)
	Breakout group 3 Physician engagement (led by Dr Dil Sen, rapporteur Dr Martin Seed)
15.00-15.15	Coffee break
15.15-16.00	Report back from breakout groups and discussion
16.00-16.30	Conclusion and follow up plan



#### Structure of presentation

- 1. Background and overview of THOR
- 2. What gets reported
- 3. What the data are used for
- 4. The 'challenges'

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- 1. Background and overview of THOR
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- 3. What the data are used for
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### The need for data on incidence of occupational ill-health

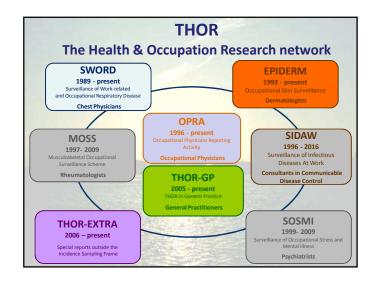
- Occupational diseases (ODs) and work-related injuries (WRI) impose a heavy burden on both workers and employers and represent enormous economic costs.
- In general the information on incidence and prevalence of occupational diseases is rather poor and fragmented.
- Statutory provisions are poor sources of work related disease data e.g. UK HSE no longer publishes occupational disease data from the Reporting of Injuries Diseases and Dangerous Occurrences Regulations (RIDDOR) on its website.

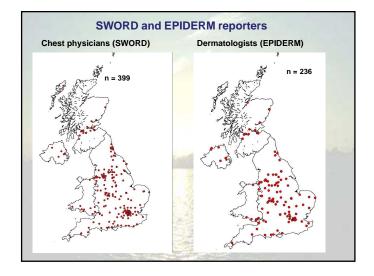
#### Instead it relies on THOR

- The Republic of Ireland has also been collecting data through THOR
- Similar schemes exist elsewhere e.g. The Netherlands, France (RNV3P)

#### **The Health and Occupation** Research (THOR) Network

- > A research and surveillance programme, fulfilling a medical observatory function, for occupational disease, work related ill health and sickness absence
- > Started in UK with 1st scheme in 1989: SWORD
- > >1000 doctors participate
- Reports from clinical 'system' specialists account for an estimated 11,000 new UK cases of work-related ill-health per
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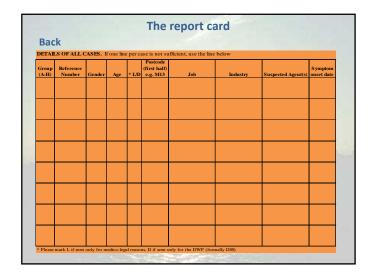


#### **THOR reporting**

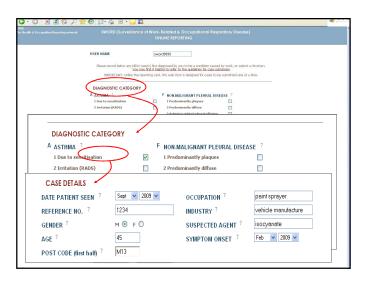
- Physicians participate on either a monthly basis (core reporters) or for one randomly selected month per year (sample reporters)
- Report cases seen during their usual clinical practice that they believe to have been 'caused or aggravated by work'
- Reporting options report card, web-form, 'group' reporting, delegating the task to another member of their clinical team (e.g. a specialist medical trainee or an OH nurse)
- Data collection includes
  - Demographic information
  - Employment occupation & industry
    Suspected causal agent/task/event

  - Sickness absence (GPs)
  - Patient referrals (GPs)

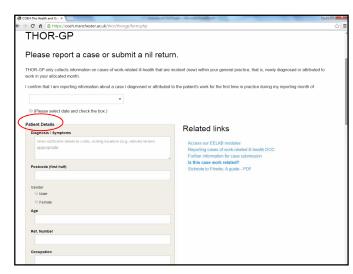
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	2 Irritant		F	NAIL	1 Dystrophy	
	3 Allergic and Irritant				2 Paronychia	
	4 Unclear		G	NEOPLASIA	1 Keratosis	
В	CONTACT URTICARIA				2 Basal Cell	
$\mathbf{c}$	FOLLICULITIS/ACNE				3 Squamous Cell	
D	INFECTIVE				4 Melanoma	
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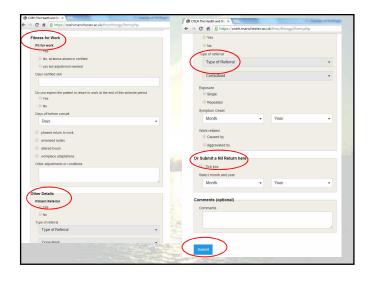


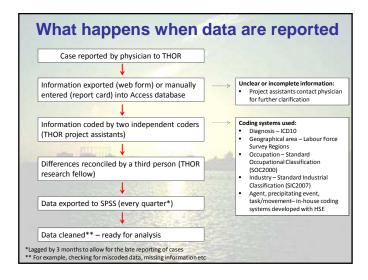


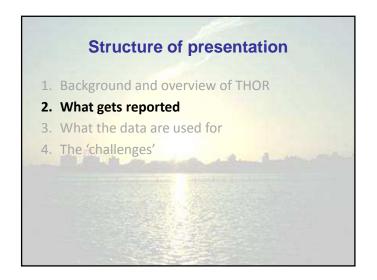


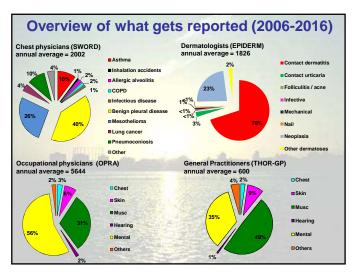


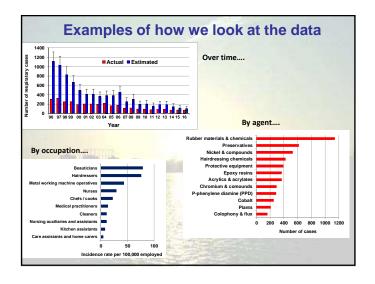


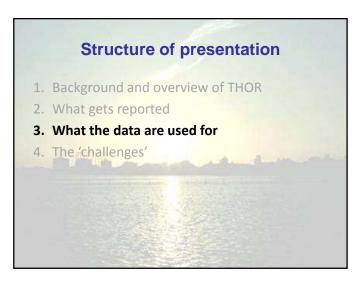












#### **Outputs from THOR**

#### Annual statistical provision for the Health and Safety Annual Statistics

- SWORD (respiratory physicians), EPIDERM (dermatologists)
- Cross-tabulations by diagnosis, year, region, age, gender, occupation, industry and agent

#### Annual trends in incidence report

Provide the change in incidence over specified periods for selected diagnosis including an overview of the statistical methodology.

#### Progress reports to HSE and the physicians

- Quarterly and annual reports to physicians and HSE (response rates, cases reported, features)
- Biannual progress reports to HSE –official THOR update to HSE; contractual milestones,

#### **THOR data and HSE**

- THOR is one of the main sources of information with which the HSE (and others) determine their priorities and work programmes on occupational health
- A search for THOR on the HSE's website will yield hundreds of documents which make substantial reference to THOR, and more than 50 tables of THOR data.
- > THOR has been assessed by the UK Statistics Authority in order to meet the required standard to be classified as 'national statistics'
- THOR data are also used regularly by the HSE to check anecdotal suspicions against a wider range of evidence.
- > This helps prioritise activity and provides an evidence base for the HSE's campaigns and interventions.

#### **Examples of THOR data informing policy**

- The HSE pocket book Bakers! Time to clear the air was developed in response to THOR data identifying bakers and confectioners as a high-risk group.
- The Asthma Workplace Charter, which was developed by Asthma UK in consultation with the HSE, uses THOR data as the basis for its list of the main occupations at risk from developing occupational asthma.
- > THOR data influenced the choice of trades and case studies highlighted on the HSE's asthma website.
- The House of Lords Science and Technology Committee inquiry into allergy cited THOR as a source for its statistics (RA expert witness)
- THOR data have helped identify HSE priorities for intervention, such as the Bad Hand Day campaign to raise awareness of, and prevent, work-related dermatitis in the hairdressing industry.
- The HSE 'Topic inspection pack on the Control of isocyanate exposure in motor vehicle repair bodyshops cites Epiderm data that vehicle paint sprayers are one of the top-10 occupations suffering occupational contact dermatitis.

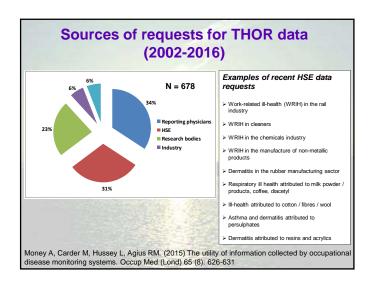
#### **Outputs from THOR**

#### Other ad-hoc reports

- In addition to the key recurring outputs, THOR generates occasional 'ad-hoc' reports, either requested by HSE and/or arising from issues identified by COEH researchers. For example:
  - the impact of reporter 'fatigue' on WRIH trends estimates,
     methodological issues associated with the calculation of THOR incidence rates).

#### Data enquiry service

- key strength of THOR is that its longevity has meant that, to date, in excess of 109,000 cases have been reported to the constituent schemes.
- Thus, a large database exists which can be interrogated to answer specific questions relating to WRIH and its determinants.



#### Structure of presentation

- 1. Background and overview of THOR
- 2. What gets reported
- 3. What the data are used for
- 4. The 'challenges'

#### Structure of presentation

- 1. Background and overview of THOR
- 2. What gets reported
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- 4. The 'challenges'
  - Physician recruitment and retainment

#### **THOR recruitment - ongoing**

- Identifying and approaching potential recruits (NHS choices, NHS Clinical excellence awards register, BMJ, specialist registrar)
- Publicising THOR-GP to COEH (GP) students undertaking postgraduate training to diploma level in occupational medicine (DOccMed)
- Ask physicians who decline to join/or withdraw for reason why (and whether replacement if latter) - advise of option for delegating and/or 'group' reporting
- Updating recruitment material
- Continue to assert our presence via the individual specialist societies e.g. recruitment material to new members
- Further presentations at relevant conferences/meetings
- preparation of articles publicising THOR for inclusion in relevant newsletters/journals

#### **Physician retainment**

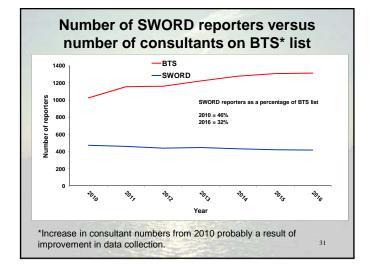
#### Reporting made easy as possible

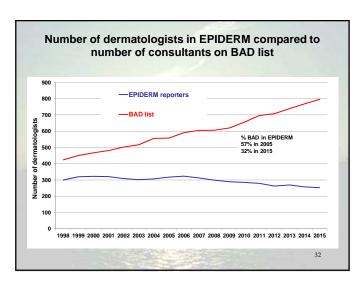
- Different methods (postal report card, web form)
- Developing new (more convenient) methods: exporting data from extant database, mobile phone app
- Reporting guidelines provided
- Reporting criteria not too stringent (inclusive)
- Group reporting
- Delegating the reporting task (e.g. to a clinical nurse specialist)
- Not asking for too much information/overburdening the physician

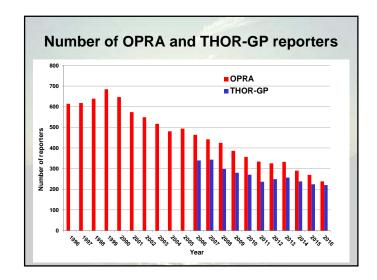
A survey of THOR participants in 2011 suggested that it took between two and five minutes to report a case to THOR, with a general consensus that the benefits obtained from participating in THOR far outweighed the time spent reporting.

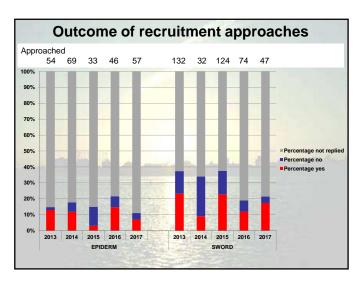
#### **Benefits of reporting to THOR**

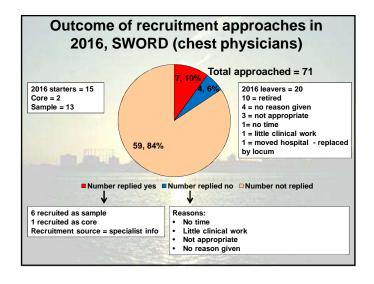
- Physicians provided with regular feedback about what they and others have reported
- Quarterly and annual reports (digest and interpretation of recent data, plans for future THOR activity, and occasional articles such as 'why I report to THOR')
- Ad-hoc enquiry service: typically cases of diagnosis 'x' in occupation 'y', attributed to agent 'z'.
- Over 600 enquiries (40% from THOR physicians)
- Annual advisory committee meetings and annual symposium: learn about recent research within their speciality, share ideas and inform and influence future plans for THOR
- > Encouraged to actively collaborate with THOR researchers to publish work based on THOR data
- ➤ EELAB (Electronic, Experiential Learning, Audit and Benchmarking)



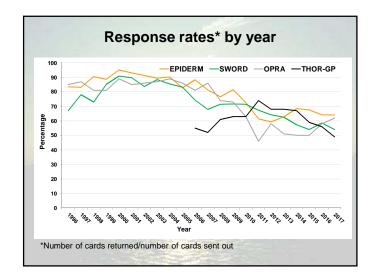




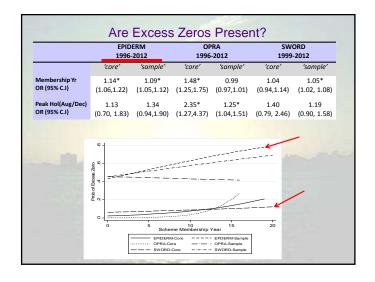












# Structure of presentation 1. Background and overview of THOR 2. What gets reported 3. What the data are used for 4. The 'challenges' Physician recruitment and retainment Reporter 'fatigue' Data representativeness

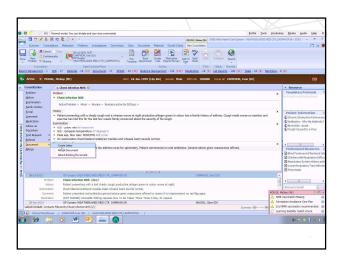
#### Some of the data issues..

- > Data not representative of the (working) population as a whole
  - E.g. OPRA occupational physician coverage in the UK biased towards public sector and larger industries.
  - Applying national population estimates to estimate incidence inappropriate (carried out specific denominator surveys)
- Data incomplete
  - E.g. SWORD and EPIDERM cases under-reported because of physician non-participation, non-response, under-recognition,
  - Applying national population estimates to estimate incidence would lead to rates being underestimated (methods developed to adjust for some of these factors)
- The influence of changes in referral patterns on trends—THOR data may not be capturing certain diagnoses e.g. neoplasia, mesothelioma (cases increasingly seen by other specialists such as oncologists)

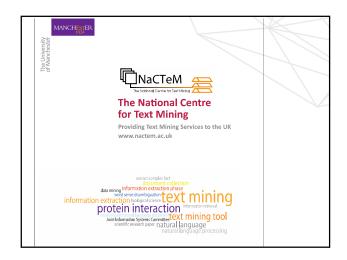
#### Structure of presentation

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- 2. What gets reported
- 3. What the data are used for
- 4. The 'challenges'
  - > Physician recruitment and retainment
  - Reporter 'fatigue'
  - Data representativeness
- 5. The solutions to discuss!

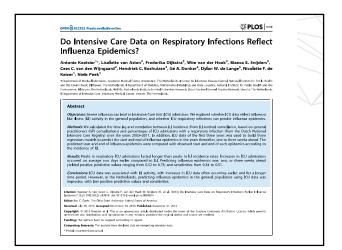


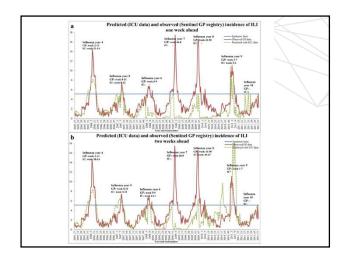




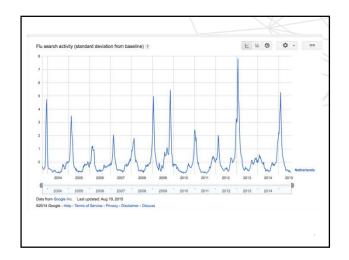


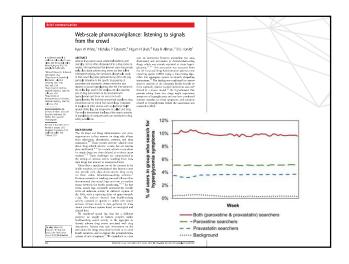


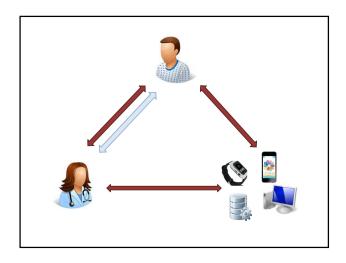


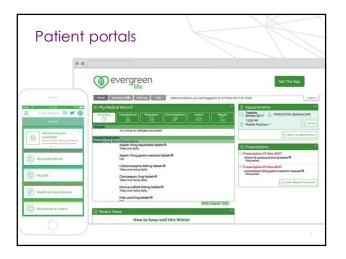


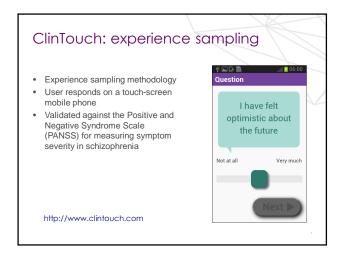


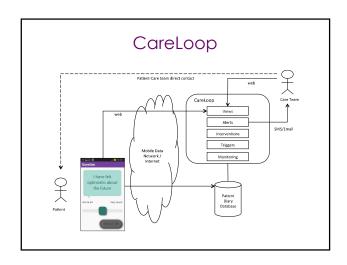


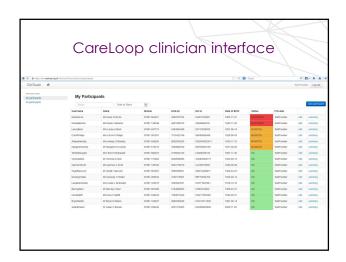


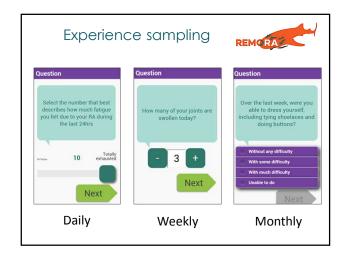




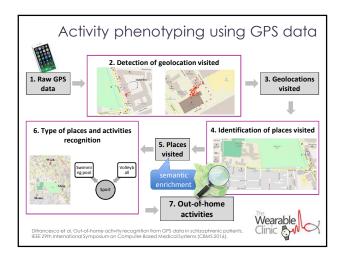




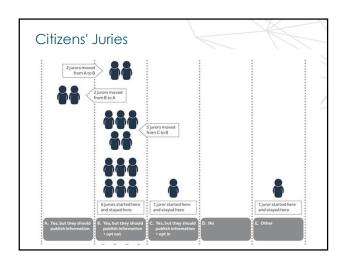


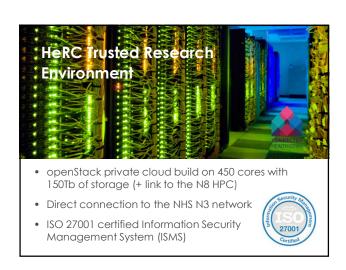


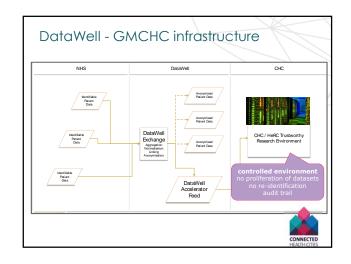








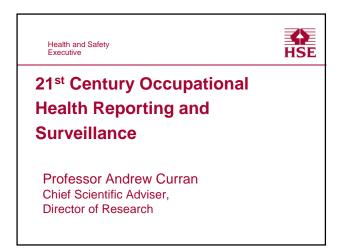


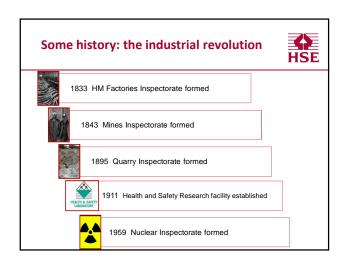


#### Summary

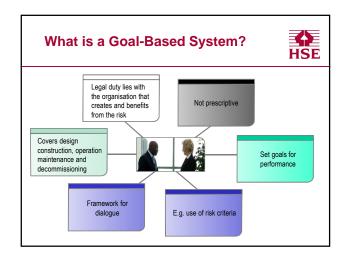
- Active reporting of incident cases by GPs through the EHR
- Recognition of incident cases through Machine Learning and text mining
- Estimation of incidence through other routine data sources
- Active data collection by patients
- Passive data collection by patients

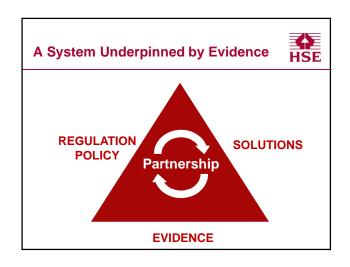


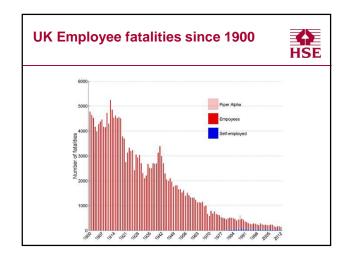


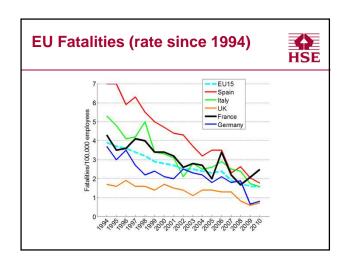










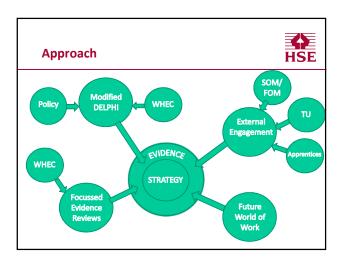


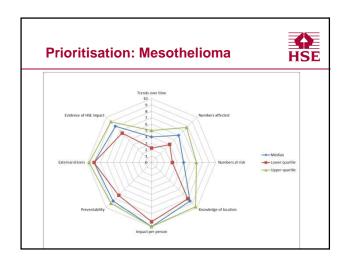


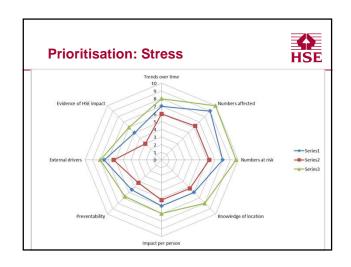


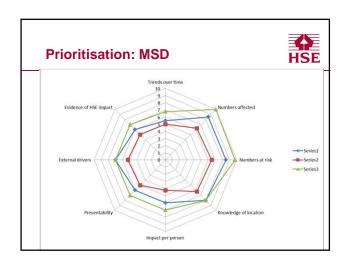


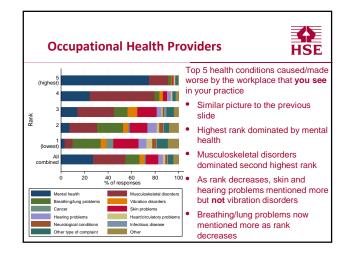


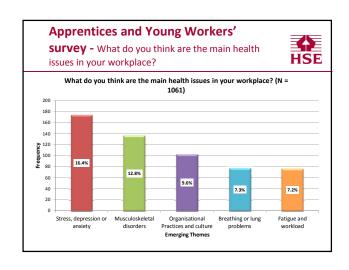


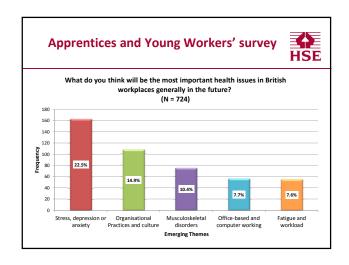


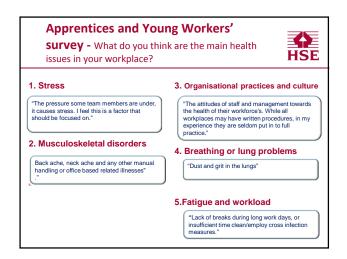






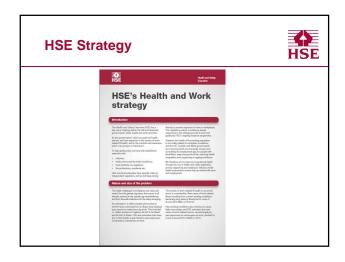




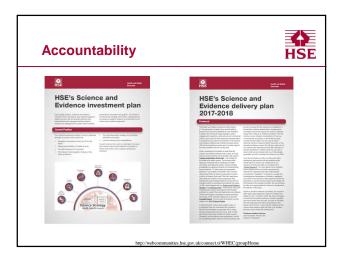




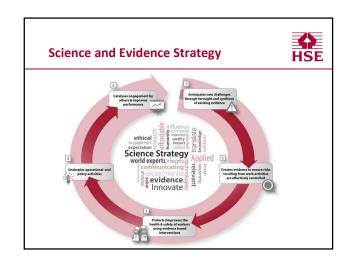




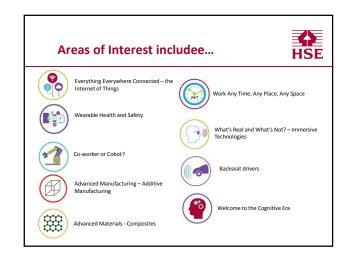


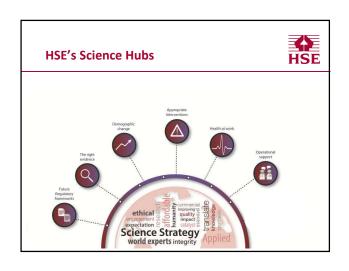




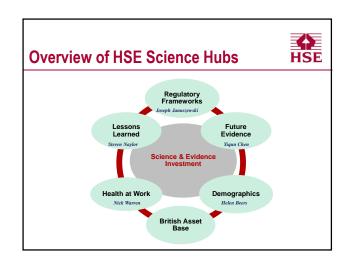




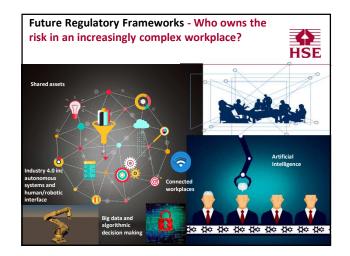


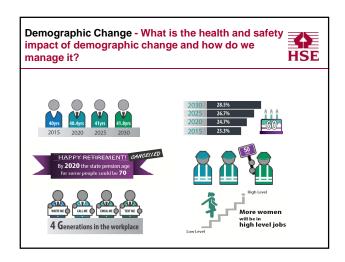






# 1. To provide technical leadership across HSE in the area identified 2. To identify research gaps and formulate research questions to address them 3. To ensure HSE priorities and regulatory context are reflected in the work of science hubs 4. To ensure our science and research meet the future challenges and opportunities 5. To identify commercial opportunities 6. To develop a programme of work and to evaluate the impact of the programme outcomes 7. To ensure the programme outcomes are communicated to HSE and the wider H&S system



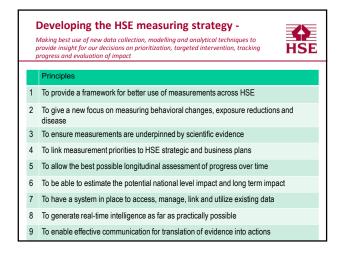


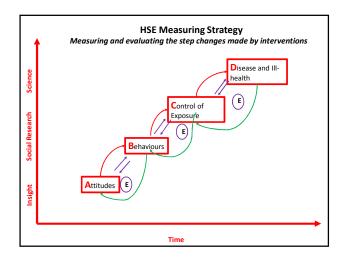




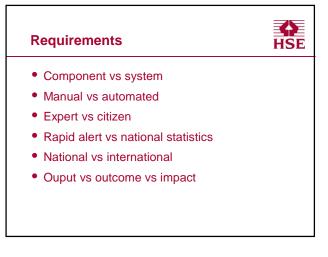
### The right evidence for the Future HSE Vision: To take a long term view in the development of the evidence base that can support HSE's long term strategic approach Supporting decisions on: Evidence will be: Credible Data collection systems Targeted intervention · Fit for purpose Analytical techniques • Prioritisation Development will be: Measurement strategy · Tracking progress Coherent · Evaluation of impact Strategic / future proofed · Identification of · Focused on priority areas

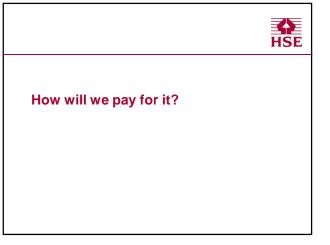
new/emerging risks













# **SHARED RESEARCH**

### **Shared Research**

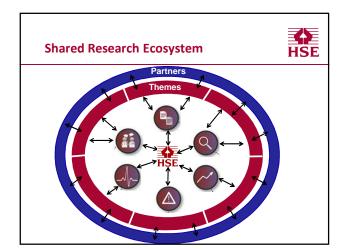


- Many problems to address
- Pace of change has increased
- HSE solutions vs system solutions
- Science hubs give focus: themes being developed

### **Shared Research**



- Public: private partnership
- From shared problems to shared solutions
- Unique insights
- Develops practical, real-world, evidence based solutions

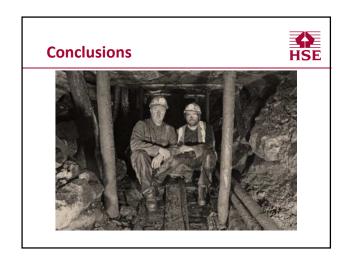


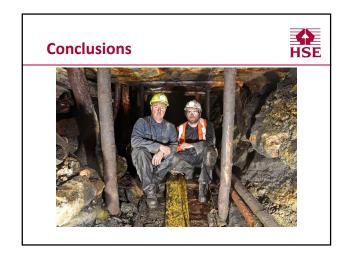
# Science and Evidence Strategy Antidipates new challenges through foreigness and synthesis of estimate professions and es

### Why?



What is the impact of work on health (health on work?) and do HSE's interventions have a positive impact on prevention?



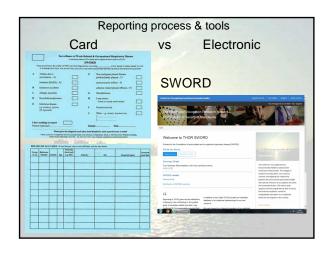


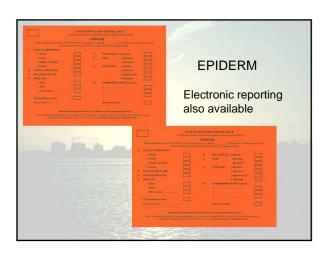


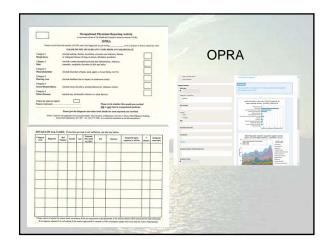


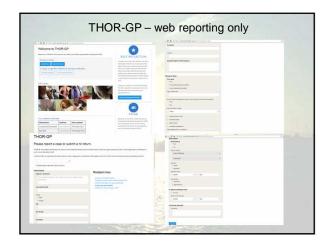
# Presentation outline Overview of current reporting processes Trends in reporter numbers and engagement Barriers to reporting Potential solutions for discussion



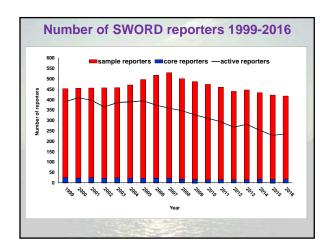


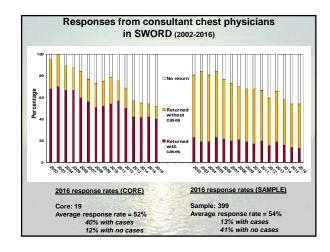


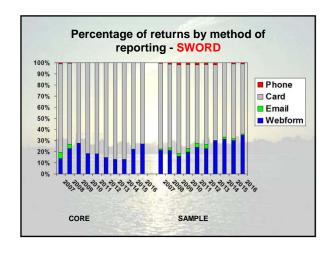


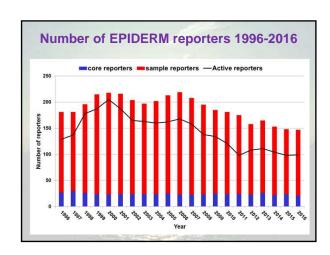


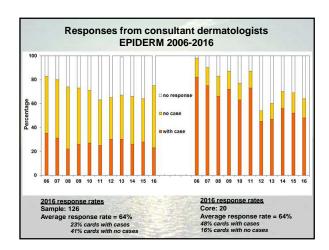


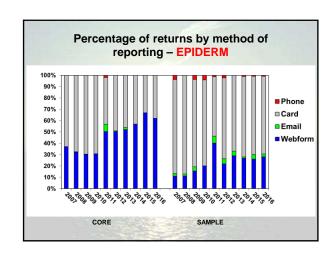


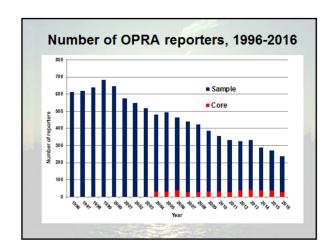


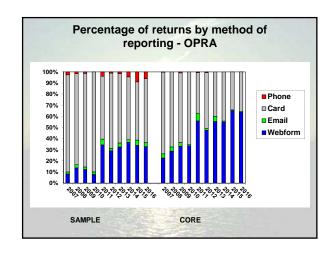












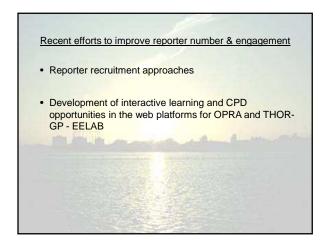


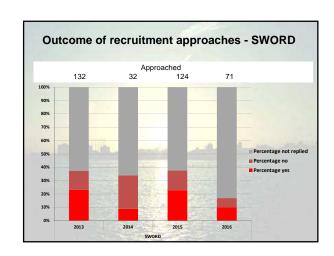
### Potential barriers to recruitment

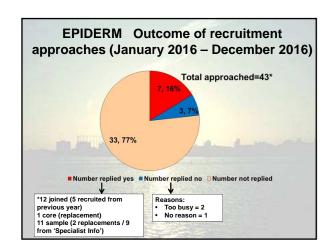
- Lack of publicity / awareness
- Possible lack of insight into occupational causation
- Yet another commitment for a new consultant take on
- · What's in it for me?
- Does the scheme result in any benefit to worker health?
- Likely other unrecognised barriers......

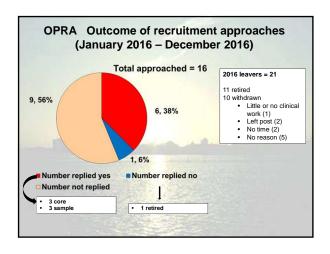
### Potential barriers to full engagement by existing reporters

- · Access to reporting tools
- Time commitment
- · Indecision on whether the case should be reported
- Fall in motivation with time 'reporter fatigue'
- Likely other factors......

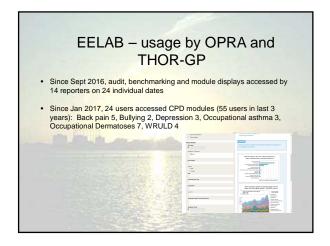






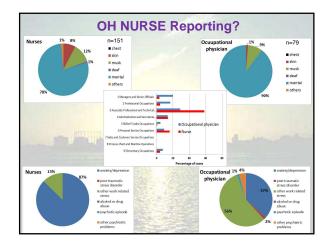






### Other possibilities to improve physician engagement in reporting

- Encouragement of electronic vs card reporting:
   'How to report to OPRA' article in preparation for Occupational Medicine
- If the majority continue to prefer card vs electronic should we develop adaptations to simple the paper based reporting?
- Survey reasons for 'zero returns'
- Given that most people carry a mobile phone these days is there scope for an 'app' to facilitate reporting and other web based interaction e.g. EELAB?
- Build on existing EELAB possible application to SWORD and EPIDERM?
- Further ideas to be discussed at this workshop.......



### Workshop discussion themes.....

- How to increase reporter numbers...using others eg. OHNs?
- How to improve engagement of existing reporters?
- How to increase transition from card to electronic reporting?
- Expanding on existing web features such as EELAB?
- Other technological innovations e.g mobile phone apps?



### Primary Care Databases Analysing Electronic Health Records

Evan(gelos) Kontopantelis

Division of Informatics, Imaging and Data Sciences Faculty of Biology, Medicine and Health University of Manchester

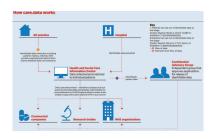
Manchester, 29 Mar 2018

# Electronic Health Records

- Have the potential to bring huge benefits to patients

  - can speed up clinical communication
     reduce the number of errors
     assist doctors in diagnosis and treatment

### What was supposed to happen



Kontopantelis (FBMH)	Primary Care Databases	29 Mar 2018	5/42
1824 ensity of Manchester		40148142142121	999

### Outline

- What is out there
- PCD Structure
- Examples
- So, Electronic Health Records (EHRs) then?
- Statistical analysis Methods
- Tools
- Summary

Electronic Health Records

- Have the potential to bring huge benefits to patients
  - · can speed up clinical communication

  - reduce the number of errors
    assist doctors in diagnosis and treatment
- Research quality augmented with added level of detail?
  - patient level factors can be taken into account
  - subgroup analyses are made easy
  - statistically, analyses can be more powerful

What happened



### Outline

- What is out there
- PCD Structure Examples
- So, Electronic Health Records (EHRs) then?
- 5 Statistical analysis Methods
- Tools
- Summary

# Electronic Health Records

- Have the potential to bring huge benefits to patients
  - can speed up clinical communication
  - reduce the number of errors
  - assist doctors in diagnosis and treatment
- Research quality augmented with added level of detail?
  - patient level factors can be taken into account
     subgroup analyses are made easy
  - statistically, analyses can be more powerful
- But...
  - (even more) confidentiality issues arise
  - much work and advanced computer skills
    usually no randomisation...

### The unique UK Primary Care Databases

- The Clinical Practice Research Datalink (CPRD)
- The Health Improvement Network (THIN)
- QResearch
- ResearchOne

# The Clinical Practice Research Datalink

### • Established in 1987, with only a handful of practices

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- Since 1994 owned by the Secretary of State for Health
- In July 2012:
  - 644 practices (Vision system only: in Eng mainly London, SE, SC,
  - NW, WM; see /pubmed/23913774) 13,772,992 patients (≈5m active)
  - covering ≈7.1% of the UK population
- Access to whole database costs ≈£130,000 pa

# The Health Improvement Network database

- Established in 2003 as a collaboration between In Practice Systems Ltd and CSD Medical Research UK (EPIC)
- Now part and parcel of UCL

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- Access to whole database costs ≈£130,000 pa
- Offers the ability to extract anything adequately recorded in primary care and construct a usable dataset

In May 2014:

562 practices (Vision system, 50-60% overlap with CPRD)
11.1m patients (3.7m active)  $\bullet$  covering  ${\approx}6.2\%$  of the UK population

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- Usually 4-year license which costs £119,000
- Similar structure to CPRD and possibly more efficient patient matching for socio-demographic characteristics

### QResearch

- Collaboration with the University of Nottingham
- In May 2014 reports:
  - 754 practices (EMIS systems: biggest UK provider)
  - over 13m patients (??m active)
     covering ≈7% of the UK population?
- Datasets limited to 100k patients for
- externals



- Collaboration between TPP and the University of Leeds
- In May 2014 reports:
  - ??? practices (SystmOne: Yorkshire&H, East Mid, East Eng, NE) GP, Community Care, Hospital Care.
  - a 30m research records

  - covering ≈?% of the UK population
  - · costs?
- Uniformity of SystmOne and central databases for TPP systems







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- Publication list, 90-95%: Vinogradova, Coupland and/or Hippisley-Cox



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ResearchOne

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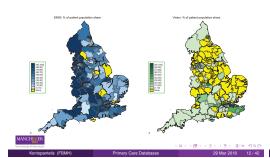
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     costs?
- New potentially important player
- Uniformity of SystmOne and central databases for TPP systems likely to provide better quality data at lower cost



### GP clinical systems



### Export format

### Broken down to numerous tables, due to data volume

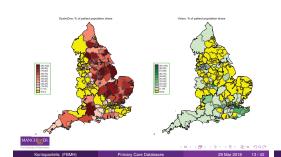
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# **Export format**

- Broken down to numerous tables, due to data volume
- Text files need to be imported into powerful analysis/database management software
- Some of the reliable information available:
  - Birth year, sex. BMI
  - Clinical, referral, therapy, test and immunisation events
- All events are entered in codes (lookup tables available)

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from SQL

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### Outline

- What is out there PCD Structure
- Examples
- So. Electronic Health Records (EHRs) then?
- Statistical analysis Methods
- Tools
- Summary

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- BUT a manual search on all the codes is not possible

# Primary Care Databases structure

- Event files
  - Clinical: all medical history data (symptoms, signs and diagnoses)
  - Referral: information on patient referrals to external care centres

  - Immunisation: data on immunisation records
     Therapy: data relating to all prescriptions issued by a GP
  - Test: data on test records

How to extract a cohort

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- Size of the tables prohibits looking at codes one by one
- Instead we use search terms to identify potentially relevant codes in the look-up tables and create draft lists

### Example (Search terms for diabetes)

- String search in Medical codes: 'diab' 'mell' 'iddm' 'niddm'
- Read code search in Medical codes file: 'C10' 'XaFsp'
- String search in Product codes file: 'insulin' 'sulphonylurea' 'chlorpropamide' 'glibenclamide'
- Clinicians go through draft lists and select relevant codes
- Using the finalised code lists we search for events in the Clinical, Referral, Immunisation, Therapy and Test files
- Process involves heavy code writing, hence use of an appropriate statistical package essential (Stata, R, SAS)

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  - a Immunisation: data on immunisation records
  - Therapy: data relating to all prescriptions issued by a GP
  - · Test: data on test records
- Look-up files
  - Medical codes: Read codes, ≈100k available
  - Product codes: ≈80k available
  - Test codes: ≈300 available

### How to extract a cohort

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### Additional data

=extra cost †=subset of  $\approx 60\%$  of practices that agreed to linkage

### Free-text\*

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  - Death (in addition to CPRD estimated death)
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### Occupational health

# Occupational health

- Possible to issue a questionnaire to GPs and health workers

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- Large cost; e.g. for the CPRD, per response:
  - Small questionnaire (1-4 questions) => £70
  - Medium questionnaire (5-9 questions) => £90
     Large questionnaire (10+ questions) => £120
- NIHR SPCR funded work on GP Burnout: drivers and variability
- Can calculate workload per practice or health worker and changes over time, as standard

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- Specific condition registries†
- - Cancer registry data (CPES, SACT)\*
     Cardiovascular disease registry data (MINAP)\*
     Mental Health Dataset (MHDS)\*

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### Outline

PCD Structure

Examples

Statistical analysis Methods

Tools

Summary

# Occupational health

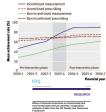
- Needlesticks/sharps injuries
- Manual handling
- · Slips, trips and falls
- Stress at work
- Pre-appointment checks
- Rehabilitation
- Immunisation
- Health monitoring
- Health promotion, education and training
- Substance misuse

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# Non-incentivised aspects of care

- Achievement rates improved for most indicators in the pre-incentive period
- Significant initial gains in incentivised indicators but no gains in later years
- By 2006-7 achievement rates significantly below those predicted by pre- trends



# Patient level diabetes care

- In 2004-5 quality improved over-and-above this pre-incentive trend by 14.2%
- By 2006-7 improvement above trend smaller at 7.3%
- Levels of care varied significantly for sex, age, years of previous care, number of co-morbid conditions



# **EHRs**

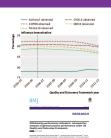
- Usually no randomisation ⇒ unmeasured confounding
- Association rather than causation
- Usually self-selected units contributing data
- Often regional hence generalisability questionable
- Anonymised higher-level units ⇒ how control or match?
- Observation bias: reliance on codes being used as they should
- Data quality varies: dependent on external pressures or incentives
- Much work and skill-mix teams needed: complex analyses
- Record of engagement with health service, not always of health

### EHRs

- Tobacco smoking and lung cancer
  - Smoking and Carcinoma of the Lung, BMJ 1950 (Richard Doll and Bradford Hill)
  - Causal role of smoking now universally accepted, even though based exclusively on observational data
  - . Sir Ronald A. Fischer most famous critic
- MMR vaccine controversy
  - Observational study on 12 children argued link between MMR vaccine and autism (Wakefield A. 1998. The Lancet)
  - Numerous large scale observational studies failed to replicate
  - Original paper retracted after fraud was identified

# Withdrawing incentives

- Financial incentives partially removed for aspects of care for patients with asthma, CHD, diabetes, stroke and psychosis
- Mean levels of performance generally stable after the removal of incentives
- Health benefits from incentive schemes may be increased by periodically replacing existing indicators with new ones



### **EHRs**

- Patient level data and subgroup analyses
- Able to extract data not available anywhere else
- Available now (with trustworthy data for a few years back)
- Real populations, not experimental settings (high external validity)
- Powered to detect almost anything
- Much cheaper than a trial
- Almost always possible and ethical
- Long-term effects and longitudinal analyses
- $\bullet$  In future, integrated in clinical systems  $\Rightarrow$  care improvements

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### Missing data MCAR, MAR or MNAR

- Missingness levels may be higher than in RCTs
- May lead to biased estimates
- Always use a multiple imputation framework:
  - include all covariates even if levels of missingness are very high

  - include all outcomes
    at least 5 datasets are recommended
- Do not use LOCF or complete case analyses

# Mainstream inference

- Linear regression for continuous outcomes
- Logistic regression for binary outcomes
- Cox-proportional hazards regression for time-to-event binary outcomes
  - for short term outcomes small differences to logistic regression
- Assumptions need to be met in all methods
- Easy to implement within a multiple imputation framework

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# EHRs tools

- Cleaning BMI

  - mibmi in Stata
     Cleaning and multiple imputation for missing BMI data
- Code lists

  - clinicalcodes.org
     Website with freely available developed code lists
  - Using Electronic Medical Records, PLOS ONE 2014

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### More advanced approaches for inference

- Competing risks regression for time-to-event
- Spline regression to model non-linear components
- Interrupted time-series (ITS) analysis
- Logit transformation for performance indicators
- Effect heterogeneity
- Propensity score matching

### EHRs tools

- Search commands
  - · pcdsearch in Stata and Rpcdsearch in R
  - code list extraction algorithm
  - Modelling conditions and health care processes in Ele Illness with the Clinical Practice Research Datalink, PLOS ONE 2016
- Representative sampling
  - · repsample in Stata
  - Select a representative sample (e.g. of practices)
  - A Greedy Algori
- Data extraction

  - rEHR (github.com)
     R package for manipulating and analysing EHR data

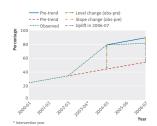
### Reporting guidelines

- <u>REporting of studies Conducted using Observational Routinely-collected Data</u>
   Based on STROBE (STrengthening the Reporting of OBservational
  - studies in Epidemiology)

    Unique features compared to other epidemiological studies

  - Often very hard to fully describe in a way that they are replicable

# ITS focus



### EHRs tools with a PCD focus

- Power calculations
  - · ipdpower in Stata
  - mixed-effects power calculation through simulations
- General Multiple imputation

- twofold in StataMultiple imputation for longitudinal datasets
- data. Stata Journal 2014

# Outline

What is out there

PCD Structure

3 Examples

So, Electronic Health Records (EHRs) then?

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### What to take home

- Complexity: not like pressing a button
- Unmeasured confounding and other biases
- 80% of the work if not more is creating a dataset to analyse
- Analyses options have similarities but are always more challenging than in RCTs
- Confidentiality and data linkages
- Quality varies between and within databases
- P-values often irrelevant



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Primary Care Databases

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