QResearch advisory board meeting

March 2012, Nottingham

Agenda

- Welcome to new members
- Minutes last meeting
- Terms of reference
- Examples of new research
- Data linkage project
- Patient Information & Practice notice
- Benefits back to contributing practices
- General discussion and advice
- AOB

Terms of Reference

- To oversee the general working of QResearch data handling, the type of analyses and access to the database.
- To oversee communication with and benefits back to contributing practices
- To agree and update the criteria and principles for access to the database and oversee their application.
- To advise on policy for accessing data
- To offer advice on professional issues

Terms of reference

- Is there anything else to add to TOR
- other groups which should be represented?
- Currently have
  - NUG
  - BMA & GPC
  - RCGP
  - Patient representative
  - UoN and EMIS
  - Scientific representative

Criteria for projects

1. Researcher employed by UK university
2. Research original and capable of publication
3. Independence and free to publish
4. Scientifically robust
5. Ensure outputs publically available
6. Acknowledge database & EMIS practices
7. NOT to attempt to identify patient(s) or practice(s)?
8. Only use data for specific project

Ethics approval

- Generic agreement with Trent REC
- Covers all research using database
- Requires scientific review
- Risk assessment wrt patient and practice confidentiality
- Annual report.

Update on QResearch

- Now about 680 current practices
- 5 million current, 14 million ever patients
- Ongoing linkage to linked to ONS cause of death
- Focus more on academic service
- Now up to about 120 project/programmes since 2003
- Wide range of researchers many universities
- MREC approval process working well
- No security breaches or complaints

Consent and confidentiality

- Practices all opt into QResearch either by
- - activating system
- - notifying me in writing
- All data pseudonymised BEFORE leaves practice. No strong identifiers
- Patients can ask to be opted out
- Software in system enables this.

Research funding

- Still no infrastructure funding for research
- Ad hoc research grants
  - MRC
  - HTA
  - NIHR
  - Dept Health
  - HPA
  - National School for Primary Care Research

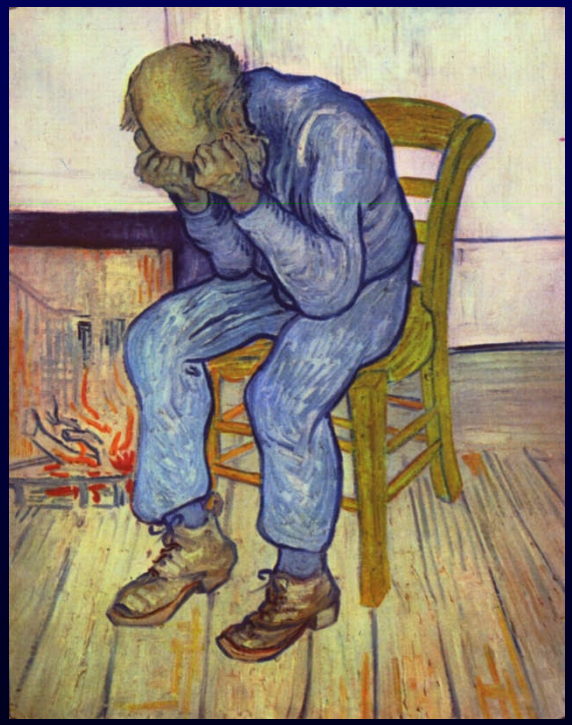
Research outputs

- All research publications on website
- http://www.qresearch.org/public/publications.aspx
- >110 papers in total
- Good number in high ranking
- Some very high profile papers
- Wide authorship range universities
- International reputation

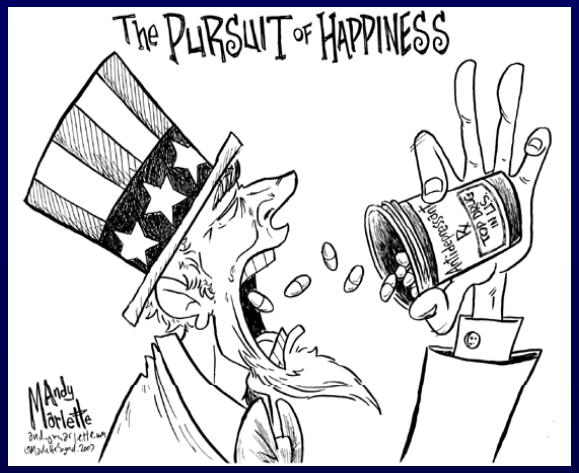
EXAMPLES NEW RESEARCH

Depression in older people

- Depression is a common condition in older people (around 15%)
- It is associated with increased rates of morbidity and mortality
- It is mainly treated in primary care, frequently with antidepressants



Antidepressant safety

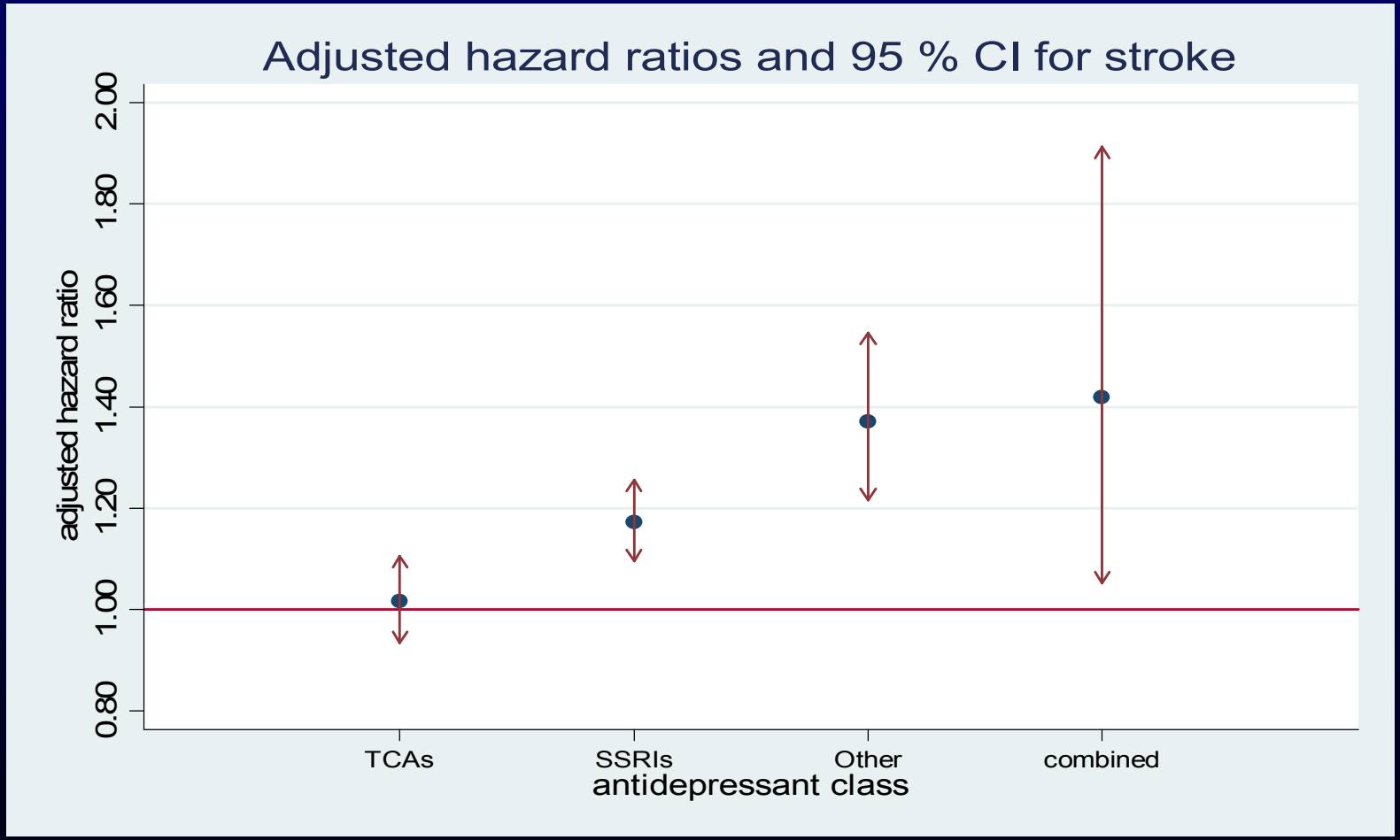


- Very little known about safety of antidepressants in elderly
- But important to know what adverse effects might occur
- Which are safest in elderly patients in real world setting

Independent study undertaken

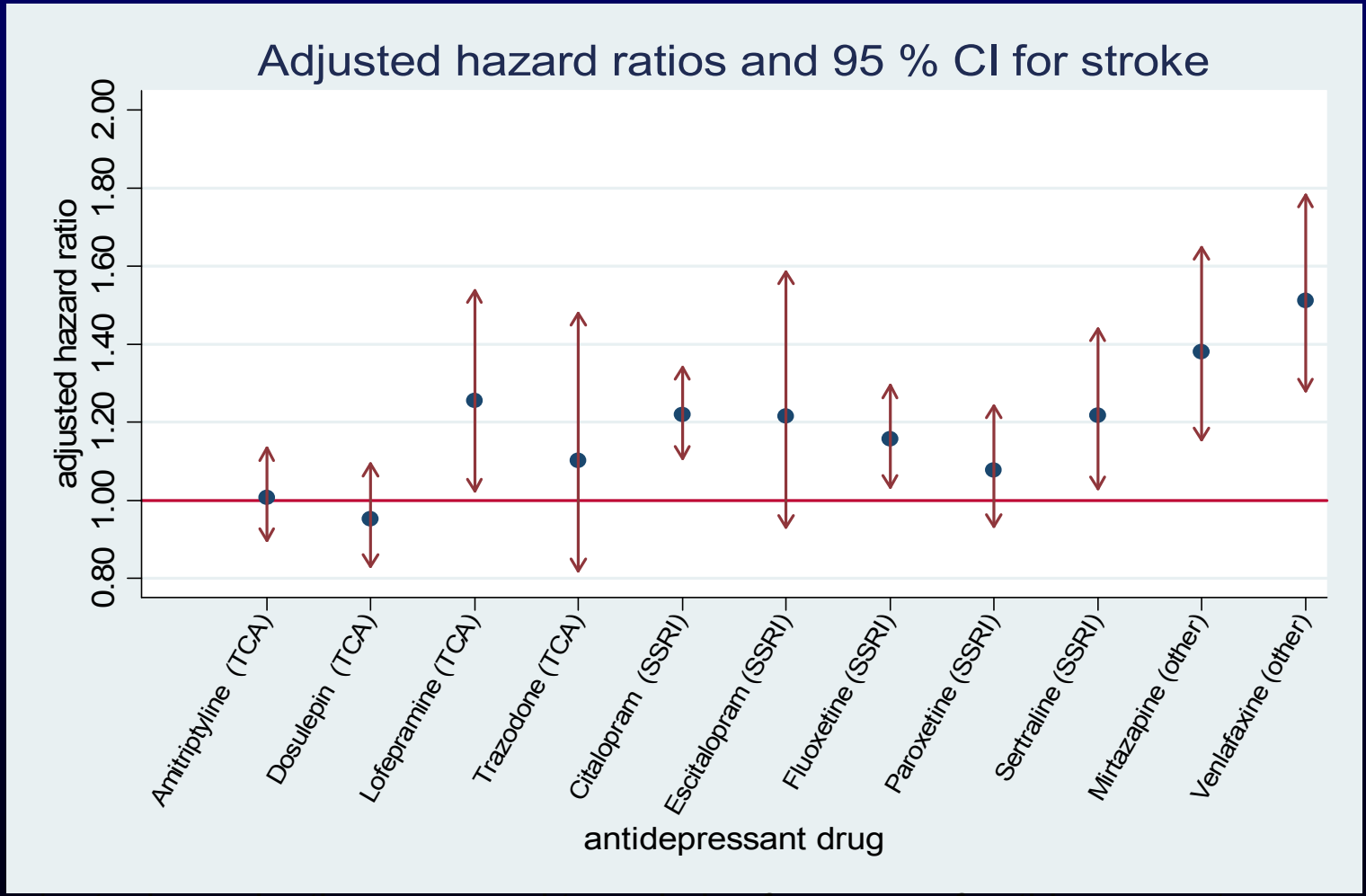
- Identified 60,000 elderly on antidepressants
- Followed up for range of effects over 10 years for different drugs including
  - Death
  - Suicide
  - Stroke
  - Hip fracture
  - Fits/seizures
  - Blood problems

Risks by type of antidepressant



*note: hazard ratios compared to periods of non-use of antidepressants

Risks by individual drugs



1 *note: hazard ratios compared to periods of non-use of antidepressants*

Excess stroke risks

For each 10,000 patients treated with:

- SSRIs - 38 additional people would have a stroke in one year compared with no treatment
- other antidepressants - 81 additional people would have a stroke in one year compared with no treatment

QScores – risk prediction tools

QScores – Family of Risk prediction tools

- Individual assessment
  - Who is most at risk of preventable disease?
  - Who is likely to benefit from interventions?
  - What is the balance of risks and benefits for my patient?
  - Enable informed consent and shared decisions

Criteria for chosing clinical outcomes

- Major cause morbidity & mortality
- Represents real clinical need
- Related intervention which can be targeted
- Related to national priorities (ideally)
- Necessary data in clinical record
- All then available as Open Source software
- Ideally integrated back into system for use by practices

Current algorithms

scores	outcome	Web link
QRISK	CVD	www.qrisk.org
QDScore	Type 2 diabetes	www.qdsore.org
QKidney	Moderate/severe renal failure	www.qkidney.org
QThrombosis	VTE	www.qthrombosis.org
QFracture	Osteoporotic fracture	www.qfracture.org
Qintervention	Risks benefits interventions to lower CVD and diabetes risk	www.qintervention.org
QCancer	Detection common cancers	www.qcancer.org

Cancer: The problem of diagnosis

- Some cancers diagnosed very late when curative Rx not possible
- Symptoms very common in general practice
- Single symptoms not very specific
- Earlier diagnosis improves options & outcome
- NICE guidelines
  - Complicated
  - Miss patients & false positive
  - No indication of risk of patient having cancer

QCancer scores – what they need to do

- Accurately predict level of risk for individual based on risk factors and symptoms
- Discriminate between those with and without cancer
- Help guide decision on who to investigate and degree of urgency.
- Educational tool for sharing information with patient. Sometimes will be reassurance.

Results – the algorithms/predictors

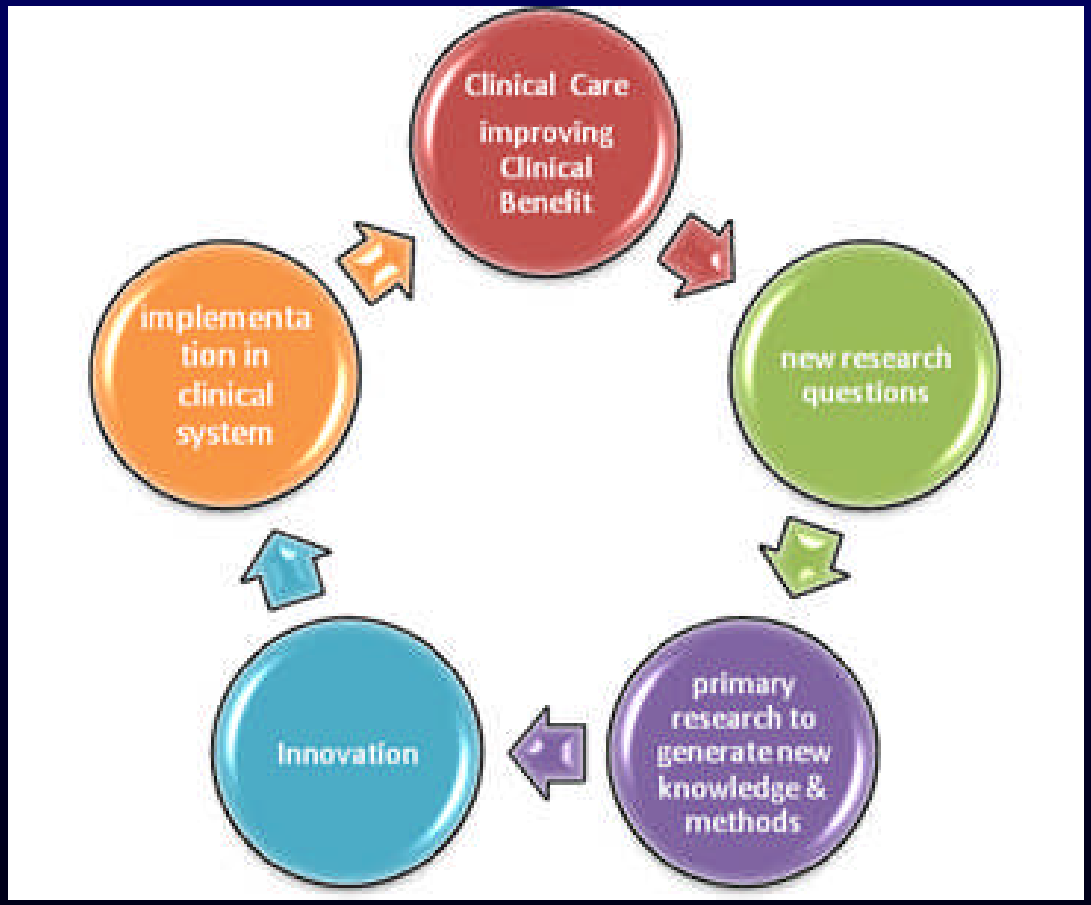
Outcome	Risk factors	Symptoms
Lung	Age, sex, smoking, deprivation, COPD, prior cancers	Haemoptysis, appetite loss, weight loss, cough, anaemia
Gastro-oeso	Age, sex, smoking status	Haematemsis, appetite loss, weight loss, abdo pain, dysphagia
Colorectal	Age, sex, alcohol, family history	Rectal bleeding, appetite loss, weight loss, abdo pain, change bowel habit, anaemia
Pancreas	Age, sex, type 2, chronic pancreatitis	Dysphagia, appetite loss, weight loss, abdo pain, abdo distension, constipation
Ovarian	Age, family history	Rectal bleeding, appetite loss, weight loss, abdo pain, abdo distension, PMB, anaemia
Renal	Age, sex, smoking status, prior cancer	Haematuria, appetite loss, weight loss, abdo pain, anaemia

Integration back into GP system

- Publically available websites
- Where possible resulting tools integrated back into GP system for practices to use
- Discussion on how this is working

The Research Cycle

'clinically useful epidemiology - new knowledge & utilities to improve patient care'



QResearch Data Linkage Project

QResearch Data Linkage Project

- QResearch database already linked to
  - deprivation data
  - cause of death data
- Very useful for research
  - better definition & capture of outcomes
  - Health inequality analysis
  - Improved performance of QRISK and similar scores

QResearch Linkage Project

Data source	Content
• Hospital Episode Statistics	• Inpatient, outpatient, A&E, maternity
• Cancer registry	• Cancer type, grade stage
• MINAP 'Myocardial Infarction National Audit Project'	• Heart attack type and treatment

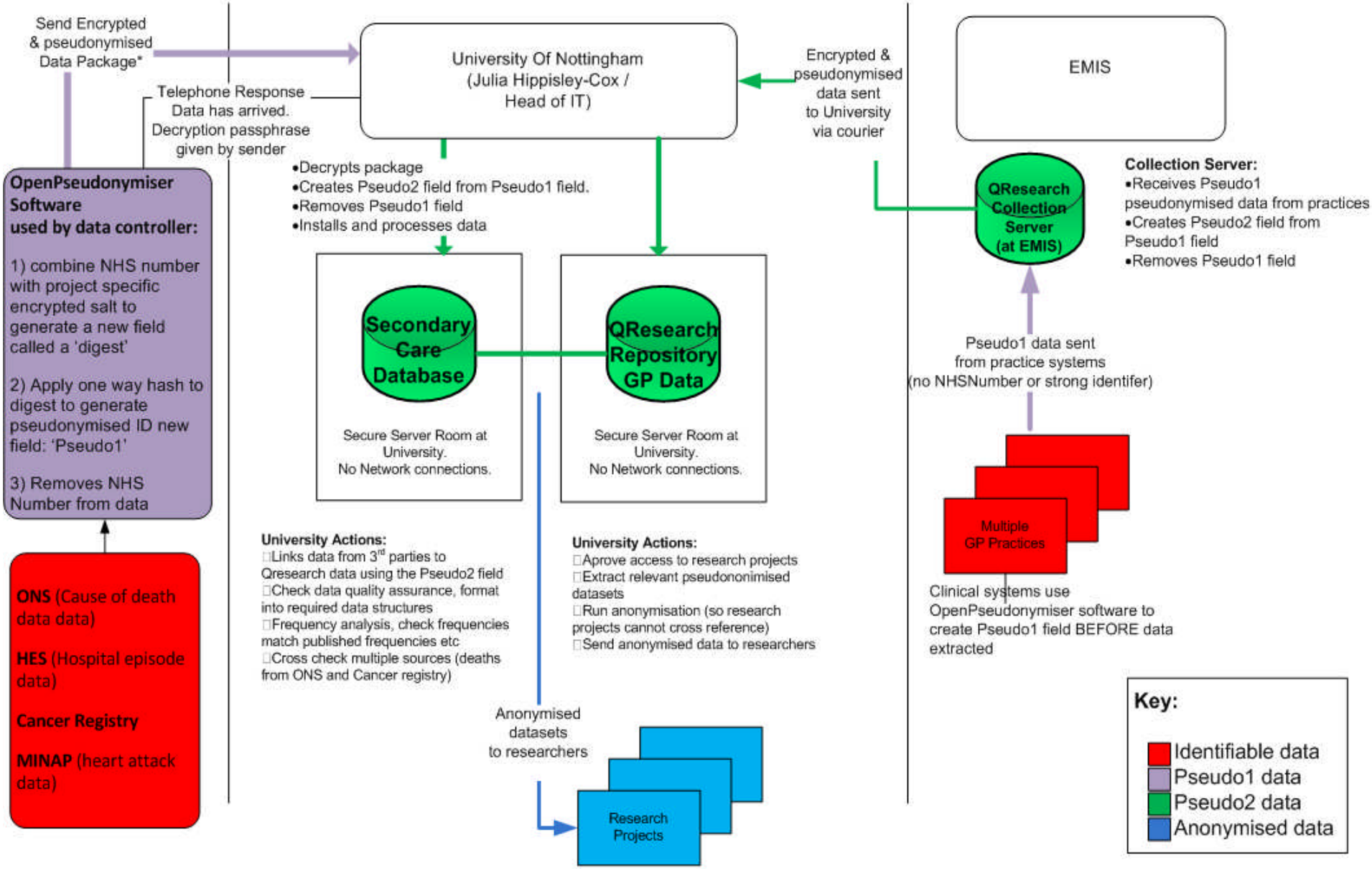
New approach pseudonymisation

- Need approach which doesn't extract identifiable data but still allows linkage
  - Legal, ethical and NIGB approvals
  - Secure, Scalable
  - Reliable, Affordable
  - Generates ID which are Unique to Project
  - Applied within the heart of the clinical system
  - Minimise disclosure

Pseudonymisation: method

- Scrambles NHS number BEFORE extraction from clinical system
- Takes NHS number + project specific encrypted ‘salt code’
- One way hashing algorithm (SHA2-256)
- Cant be reversed engineered
- Applied twice in to separate locations before data leaves EMIS
- Apply identical software to external dataset
- Allows two pseudonymised datasets to be linked

Data Flow Diagram illustrating the OpenPseudonymiser process to enable linkage secondary care data to the QResearch database



Practice notice

- This goes up in waiting rooms
- System allows opt out for individual patients
- Any changes needed?

THIS SURGERY IS A QRESEARCH PRACTICE.

As you know GPs keep information, notes, about all patients so that each patient can receive the appropriate care and treatment. We may also ask you for information about yourself. We may use this information for other reasons, for example, to plan future health services, to train staff or to carry out medical and other health research for the benefit of everyone.

We are currently contributing to the QResearch database run by the University of Nottingham and EMIS, who are a computer supplier. We would like to involve all patients in the practice. The process requires taking anonymous information (ie ie information which cannot identify you) from individual patients' electronic health records which may then be linked to other health records such as hospital records. The information is then used for research. It is important to emphasise that neither you nor any other patient can be identified or recognised from the information that is taken from health records as it is anonymised before it is removed from the notes.

If you would like to know more or have any concerns about how we use information about you, please speak to your GP or our practice manager. If you would prefer that anonymised data about you is not included in the QRESEARCH data base, you can opt out by speaking to your GP. For more information on QRESEARCH please visit www.qresearch.org

EVERYONE WORKING FOR THE NHS HAS A LEGAL DUTY TO KEEP INFORMATION ABOUT YOU CONFIDENTIAL

Public benefits & engagement

- Practice notice
- Patient page on our website
- Press release all new research
- Leaflet to PPA conference
- Do radio shows – eg radio 4 and local radio
- Some discussion on research questions and results (eg drug safety)
- Answer many queries from public

Public benefit & engagement

- What other things can we do to
- - raise awareness of database
- - raise awareness results
- - increase public benefit

Practice benefits & engagement

- Presentation at annual conference
- Article for NUG user magazine
- Brochure on Q related projects
- Integration QScores into clinical system where possible
- QFeedback (also for QSurveillance)
-

Quote from GP from Oxford

- “My experience of teaching GPs throughout the country is the main thing they love about the Q tools is the sense of inclusivity that comes from knowing it is their EMIS data being used – they have a sense of ownership and trust its applicability. And, of course, that they are so simple to use! Qfracture, Qrisk, Qintervention etc are now part of daily practice helping GPs help patients in an evidence-based way that truly empowers them. Thanks for all the great work so far”

QFeedback: update

ehi 2011 AWARDS FINALIST

- Interactive tool for QResearch and QSurveillance
- Allows practices to view own data compared
  - PCT, SHA, UK
  - Similar practices
- Graphs, Maps, Export data to excel
- Deployed to 3,400 EMIS LV sites
- Uptake 2885 practices in 1st 6 months
- Final of E Heath innovation awards

QFeedback dashboard

ehi 2011 AWARDS FINALIST

QSurveillance
QFeedback Practice Portal

Logged in: C84136 (CDB:123)
Data last aggregated: 05/09/2011 16:03

summary | reports | about

Report Options

Compare
- [x] UK
- [ ] SHA
- [x] PCT
- [x] Practices Like Mine

Indicator
- Chronic Heart Disease
- Diabetes
- Chronic Liver Disease
- Chronic Renal Disease
- Chronic Respiratory Disease

[add another indicator]

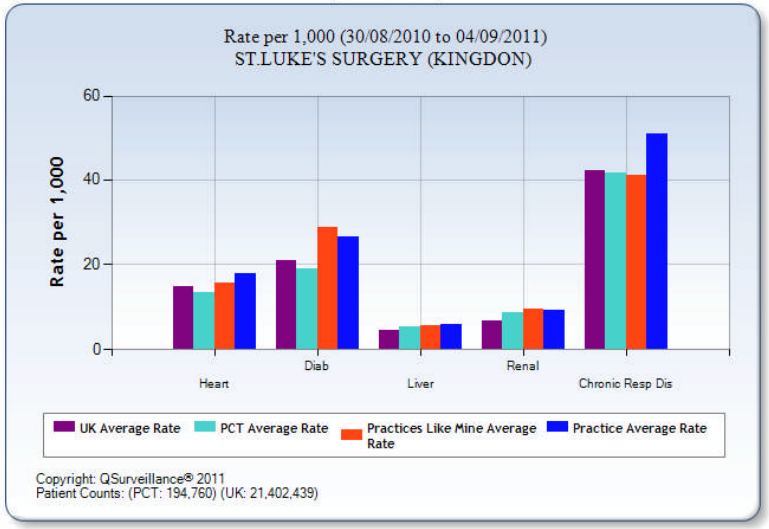
Period: Last Year

Baseline: Don't show previous year

Run Report

Results - Charts

[Trend] [Average]
[Practices Like Mine]



Results - UK Map

Results - SHA Map

Notes & Statistics

Practice Data Table

Export

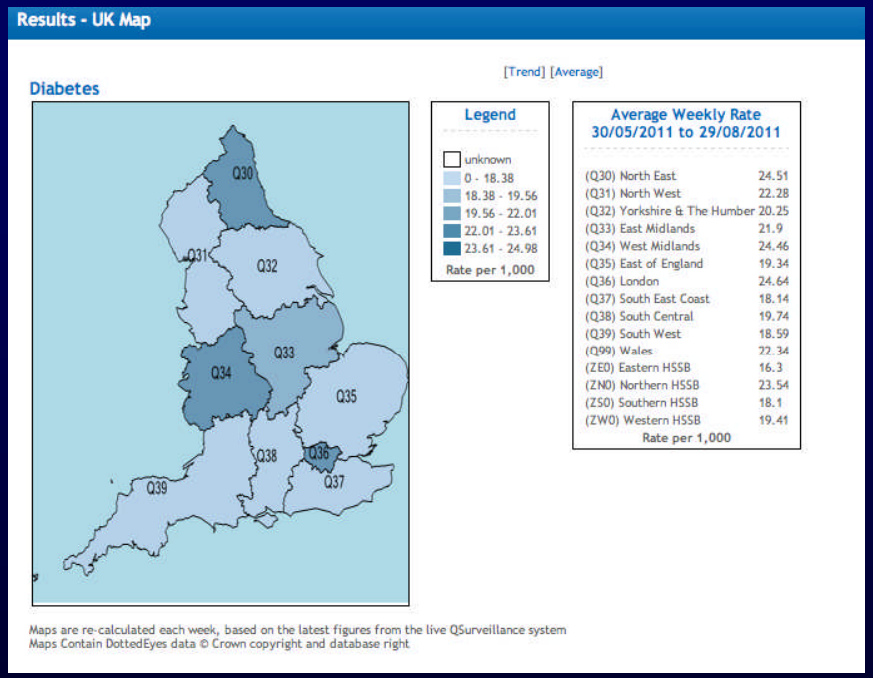
ST.LUKE'S SURGERY (KINGDON)(CDB: 123) : Chronic Heart Disease

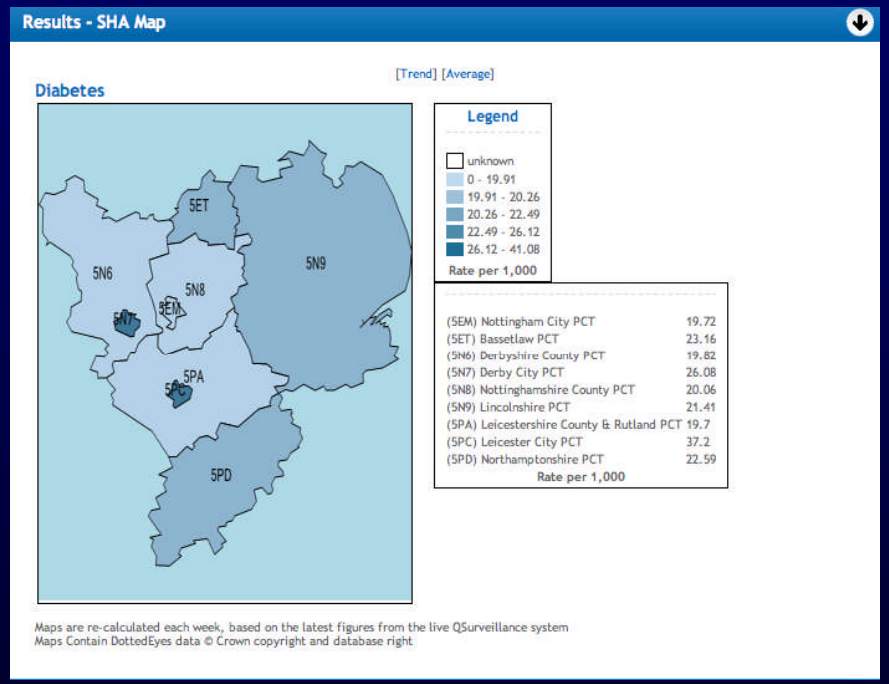
Week Commencing	Total Cases	Total Population	Weekly Rate	Prev Year Week Commencing	Prev Year New Cases	Prev Year Total Population	Weekly Rate
30/08/2010	54	3,354	16.10	31/08/2009	0	3,481	0.00
06/09/2010	54	3,360	16.07	07/09/2009	0	3,479	0.00

Advanced Options

Display Options

Example maps

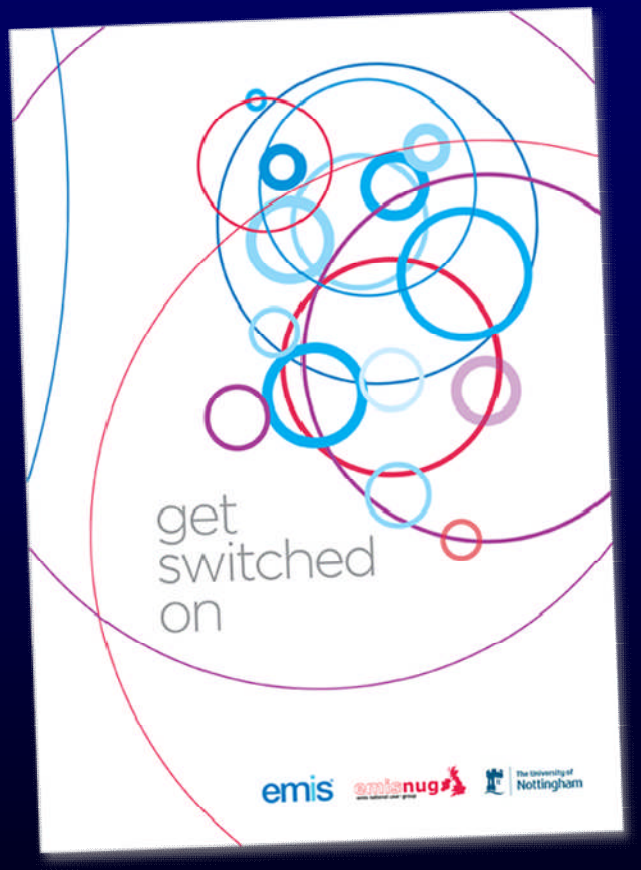




GP from Huntingdon on QFeedback

- *"This is a brilliant resource. I found it quick and easy to use and the results have been thought provoking for our practice. As well as giving us an insight into our own incidence of seasonal problems such as flu it also enables us to compare how we are doing on longer term issues such as heart disease"*

Get switched on



summaries for practices on various Q Projects and results of research

Practice benefits

- What other things can we do to
- - increase awareness of developments
- - increase recruitment to database
- - increase benefits back to practices

General Discussion

- Comments, questions, suggestions.