# Learning Health Systems

*The System Awakens*

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# Agenda

- Who are we?
- Some musings about learning health systems
- The state of play in the UK
- A couple of examples of our work
- Questions?

## Who are we?

- Academic unit, mostly funded by research income (various)
- Part of Swansea University Medical School but increasingly working in social sciences
- Almost entirely self funding (within a University context)
- Major research funding via most of the UK's major research funders
- Working in the field for more than 10 years
- 180+ staff, with backgrounds in: epidemiology, statistics, health service research, public health science, clinicians (multiple specialties), geography, demography, social science, economics, information governance and IA, law, project management, public engagement, genetics, bioscience, computer science, maths, physics and hardcore IT.

## Our Focus

- Linking together highly sensitive personal datasets to form new powerful data resources for use in pubic benefit research
- Responding robustly to citizen and data guardian concerns about privacy and organisational interests
- Developing large scale technology platforms to for safe data reuse and sharing
- Expertise in working with data at national scales (billions of rows, thousands of columns).
- Deeply understanding difficult, error prone data, not collected for secondary use
- Hardcore analyses using cutting edge approaches
- Full accountability and auditability throughout, strong public engagement
- **Working closely with practitioners and policymakers**

# How do health organisations learn and decide?

- Do the same as last year, adjust a little and hope. **Not really learning**
- Adopt evidence, science, guidelines and protocols. **Doing as they are told**
- Findings from catastrophic calamities – **Knee-jerk changes**
- Hearing about something going on elsewhere and copying it: **Is copying learning?**
- Thinking hard about "the right thing to do" and doing it. **What has been learned? How do you know you are right?**
- Much rarer **- Plan – Do – Study - Act**

# Further observations / hypotheses. . .

- The demand for healthcare is rising faster than society's ability to pay
- Health systems are under increasing pressure to improve efficiency and effectiveness
- LHS can drive such improvements BUT . .
- It is unlikely that future demand can be coped with solely though improvements in efficiency
- Only by "turning off the tap" - reducing the demand for healthcare, will healthcare systems cope
- **Almost all ill health is either socially generated or socially mediated**
- **Social circumstances significantly affects responses to treatment**

# Further observations / hypotheses. . .

- Therefore, a healthcare systems need not only to be self aware and able to improve itself

BUT ALSO

- To understand how ill health is generated and to be able to interact with society more generally to reduce the demand for healthcare in meaningful ways
- So, a LHS needs to be able to understand and influence the mechanisms that generate ill health (or improve health)

And

- Be able to tailor (stratify) care to accommodate a patient's social circumstances
- To do this, they need data . . .

# LHS: the UK

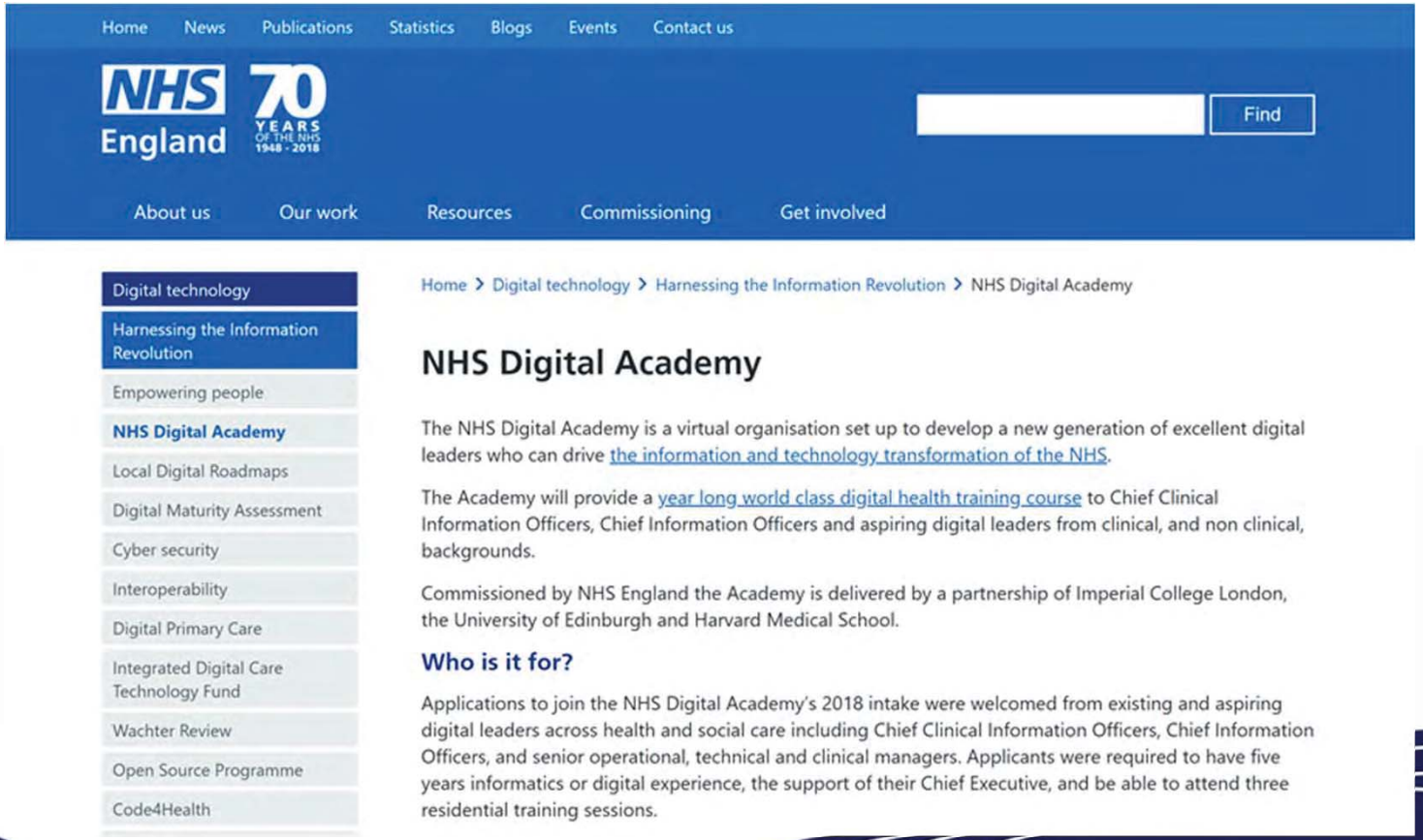
# And so - in the UK . . . .

- Background
  - NHS not one organisation any more
  - 4 separate countries (England, Scotland, Wales, Northern Ireland)
  - “The NHS” is really only a brand, with some commonalities (for the moment!)
  - Fragmentation via autonomy in England, less so in the other countries of the UK
  - National policy set in jurisdictions – different approaches in each
  - Each of the 4 NHSs under extreme pressure
  - Fire fighting, survival and avoiding collapse uses all resources in operational settings
  - System boundaries a challenge

# And so - in the UK . . . .

- Within the (fragmented) English NHS, things are very variable
  - Some hospitals doing great work with data and decisions (dashboards, patients pathways, quality feedback, performance monitoring)
  - Outcome data sometimes collected, but rarely
  - Whole system policies to improve outcome data collection do exist, but progress is slow
- Some key investments are being made within the NHS, centrally driven. Such as:
  - CCIO Training and development programme to lead the charge within NHS E (PICTURE)

# And so - in the UK . . . .



# Academic / NHS collaborations

- Large investments in academic health informatics, in partnership with NHS
  - Farr Institute (until end 2018), then becoming . . .
  - Health Data Research UK
  - Medical Bioinformatics investments
  - SAIL Databank (Wales)
  - Scottish NHS / Government
  - Administrative Data Research Network
  - Other local initiatives

Farr The Farr Institute of Health Informatics Research

HDRUK Health Data Research UK

Administrative Data Research Centre Wales

SAIL DATABANK

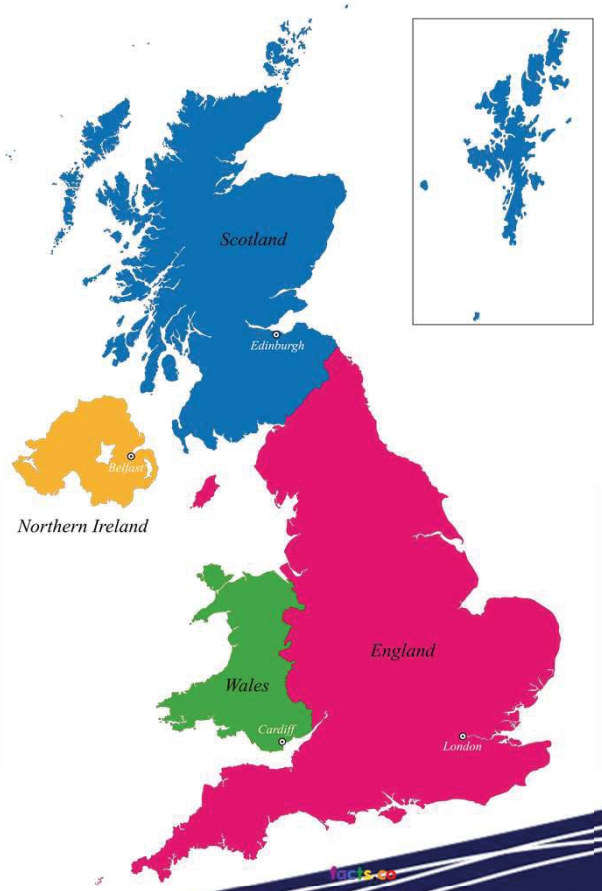
eDRIS

# Academic / NHS collaborations

- Each has within it an aspiration to co-work with the NHS and governmental agencies to improve data feedback loops and change processes (LHS and Actionable Analytics)
- Progress has been slow to date – quality engagement with the health system under intense stress is hard
- Back again the wall mentality only allows for (potential) cost saving activity
- Business case development process a hurdle
- Very little capacity to deliver change within NHS – at any scale

# Wales:

# UK and the Devolved Administrations



# NHS Wales

- Despite operating under a national “brand” (NHS Wales), hospitals and primary clinics are still almost totally autonomous.  Government has very few levers to compel them to work together or share
- There is a national programme of IT for NHS Wales, but it is largely optional and progress towards a national single EMR and/or interoperability is slow
- Understanding who the “whole system” works is important but challenging in distributed and semi-autonomous systems
- Also, data is the lifeblood of research – high quality patient data can support a wide range of clinical, health service and public health research
- In 2005, before the SAIL Databank existed, little progress had been made – an opportunity!

# SAIL DataBank

- National system for Wales.  Strong collaboration with NHS Wales and Welsh Government
- Monthly feeds from over 500 different sources across NHS, government and public agencies
- Building (from data) the richest possible picture of individuals in society
- Data from healthcare, education, social care, housing, transport, policing, fire services, +++
- Data refreshed regularly, increasingly in near real time (depending on source)
- >19 billion recordings going back c.25 years on 5million+ lives
- Access open to all
- Used widely by health researchers and social scientists and, increasingly, service managers and policymakers

# Two simple examples

# The Housing Regeneration and Health Study

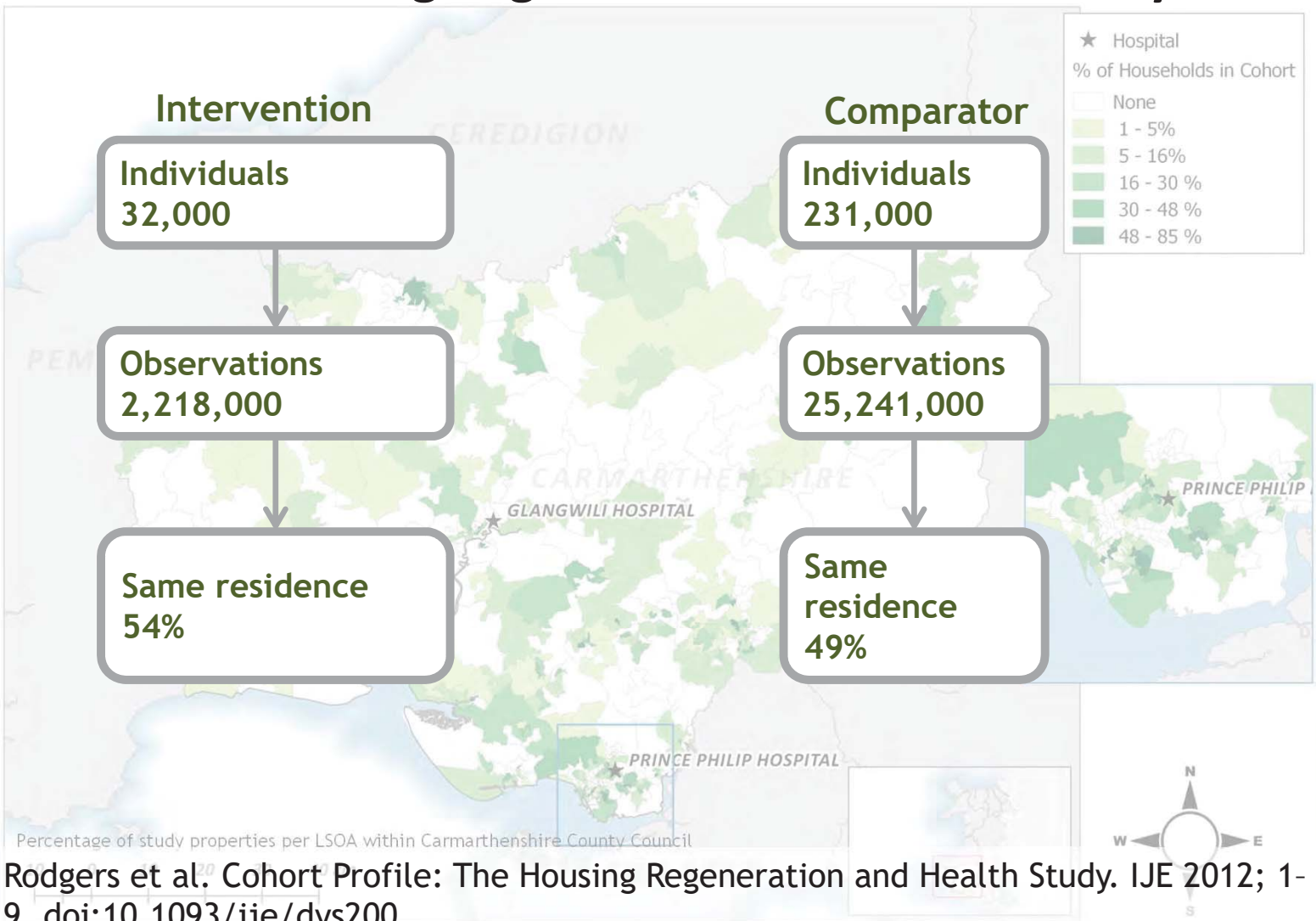
Observational studies show strong housing/health effects but few large scale evaluation of interventions.

NIHR funded evaluation of an (un)natural experiment through multiple linked study specific and routine datasets

- Investment of £204 million in Carmarthenshire social housing improvements; 9,256 homes (2008 – 2015)

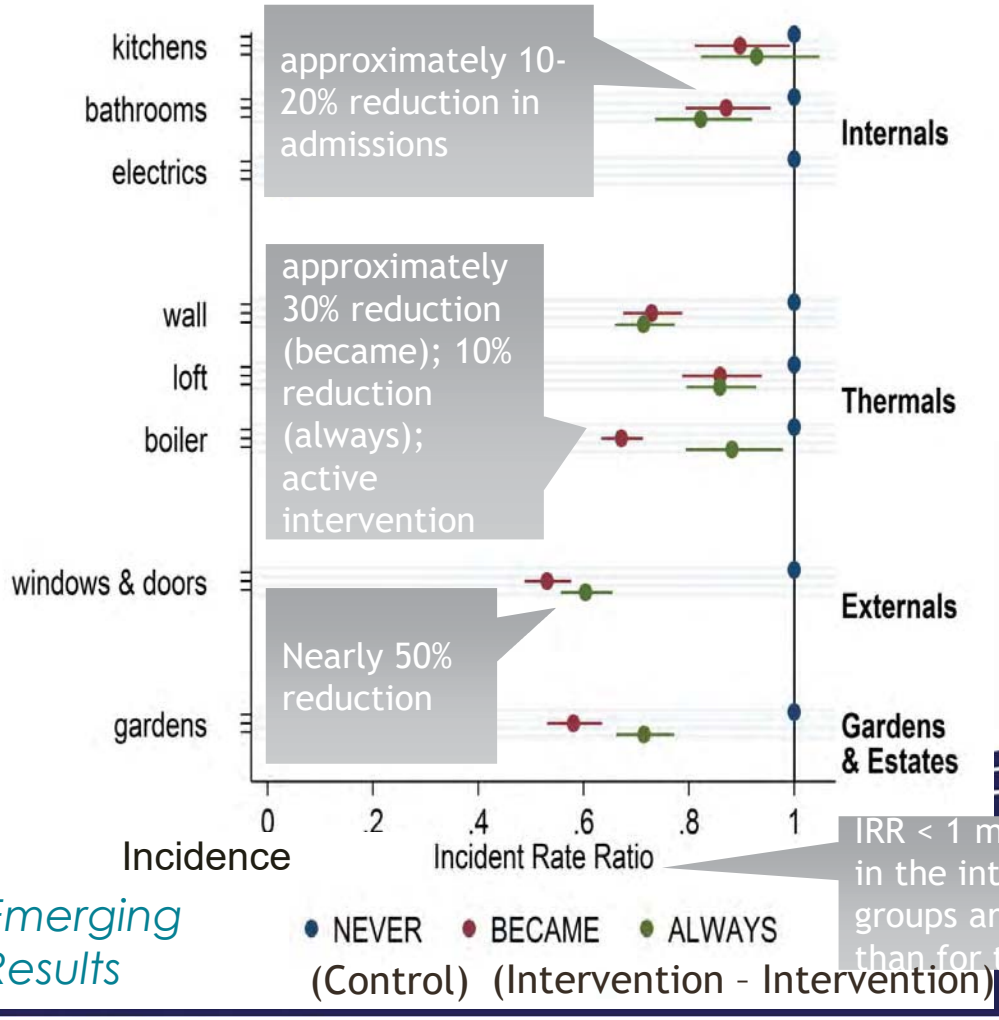
- internal works: kitchen units, bathroom suites, downstairs toilets, central heating, rewiring
- windows and doors: double-glazed, locks
- thermal insulation: walls and loft
- gardens and estate package: fencing, security lights, beautification

# The Housing Regeneration and Health Study




Rodgers et al. Cohort Profile: The Housing Regeneration and Health Study. IJE 2012; 1-9, doi:10.1093/ije/dys200

Respiratory, cardiovascular conditions, and injuries 60+ years




- Adjusted for: age, sex, deprivation, comorbidities, year, month, rurality, and the rest of Carmarthenshire rates

*Emerging Results*

# Air Aware Evaluation

- An evaluation of a Public Health Intervention using SAIL DataBank
- Based on COMEAP advice on air pollution warning
- Multi-disciplinary, multi-agency team

- Sara Thomas & Huw Brunt - Public Health Wales
- Rowena Bailey, Bridie Angela Evans, Sarah Rodgers, Dan Thayer, Ronan Lyons, Helen Snooks & Gwyneth Davies – Swansea University
- Geoff Marquis & Martin Hooper - Neath Port Talbot County Borough Council
- Paul Harold, Centre for Radiation Chemical & Environmental Hazards (Wales)
- Jonathan Bidmead & Jacqui McCarthy - Involving People

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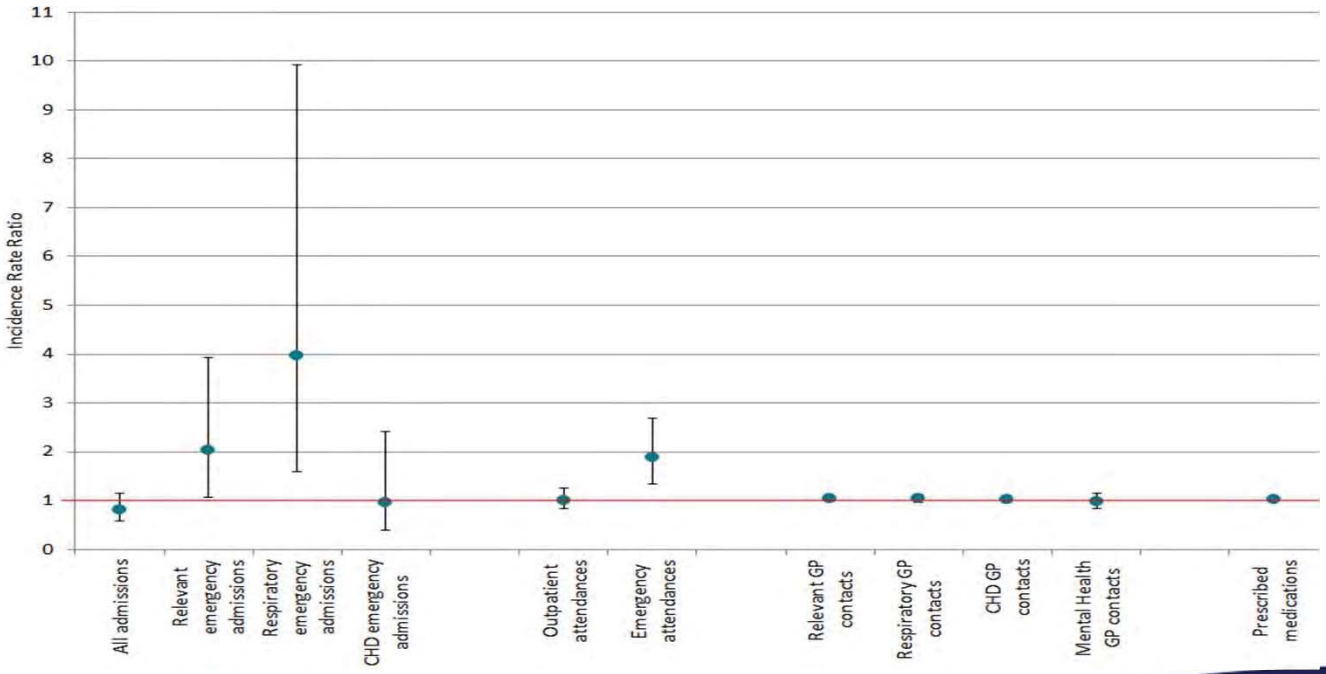
# Air quality bandings and health advice

| Air Quality Band | Public Health Message (Messages based on COMEAP advice) |
|---|---|
| **Green** | Enjoy your usual outdoor activities |
| **Yellow** | If you experience symptoms **consider reducing** strenuous physical activity, particularly outdoors |
| **Amber** | **Reduce** strenuous physical activity, particularly outdoors. Keep reliever inhaler with you. Follow doctor's usual advice about managing your condition |
| **Red** | **Avoid** strenuous physical activity, particularly outdoors. Keep reliever inhaler with you. Follow doctor's usual advice about managing your condition |

# Main result: IRRs for intervention vs control



# Results

- Doubling of emergency attendances and
- Quadrupling of respiratory admissions.
- Not a what was expected at all!

- Local Service Board immediately stopped the service

# Thank you

Questions?