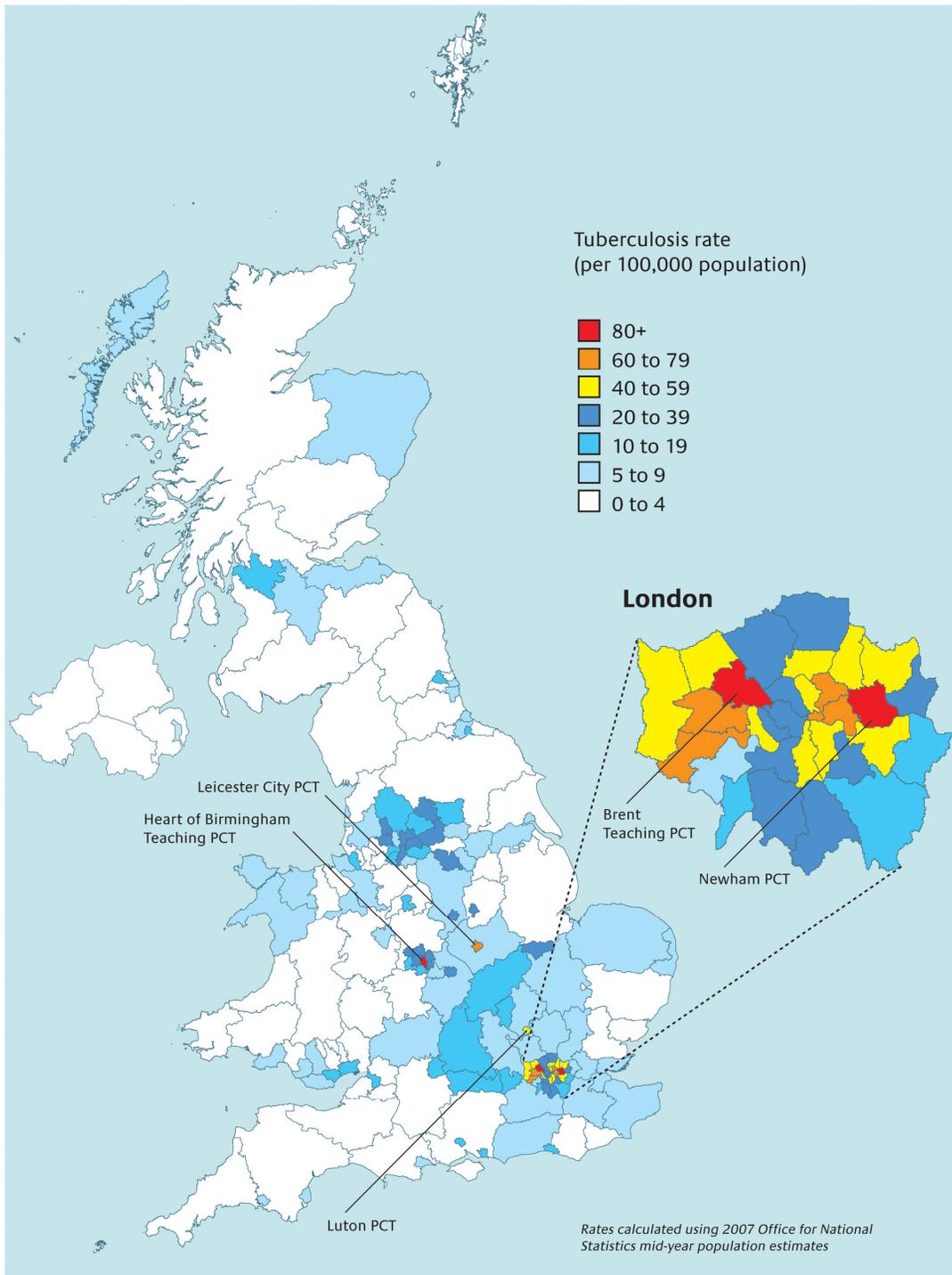


TB Data Quality Assurance: United Kingdom

Ibrahim Abubakar, MBBS, PhD, FFPH

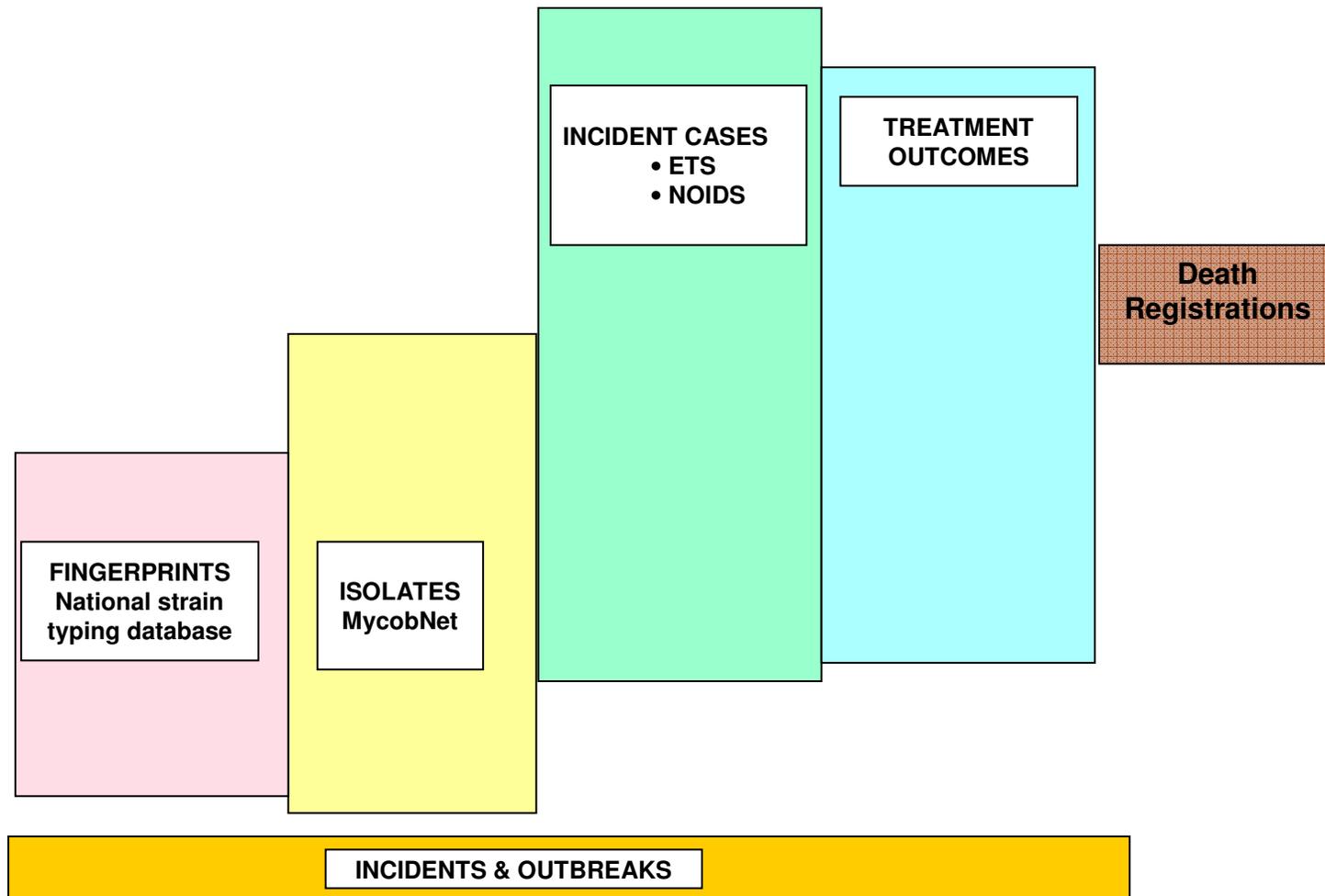
Tuberculosis Section

HPA Centre for Infections

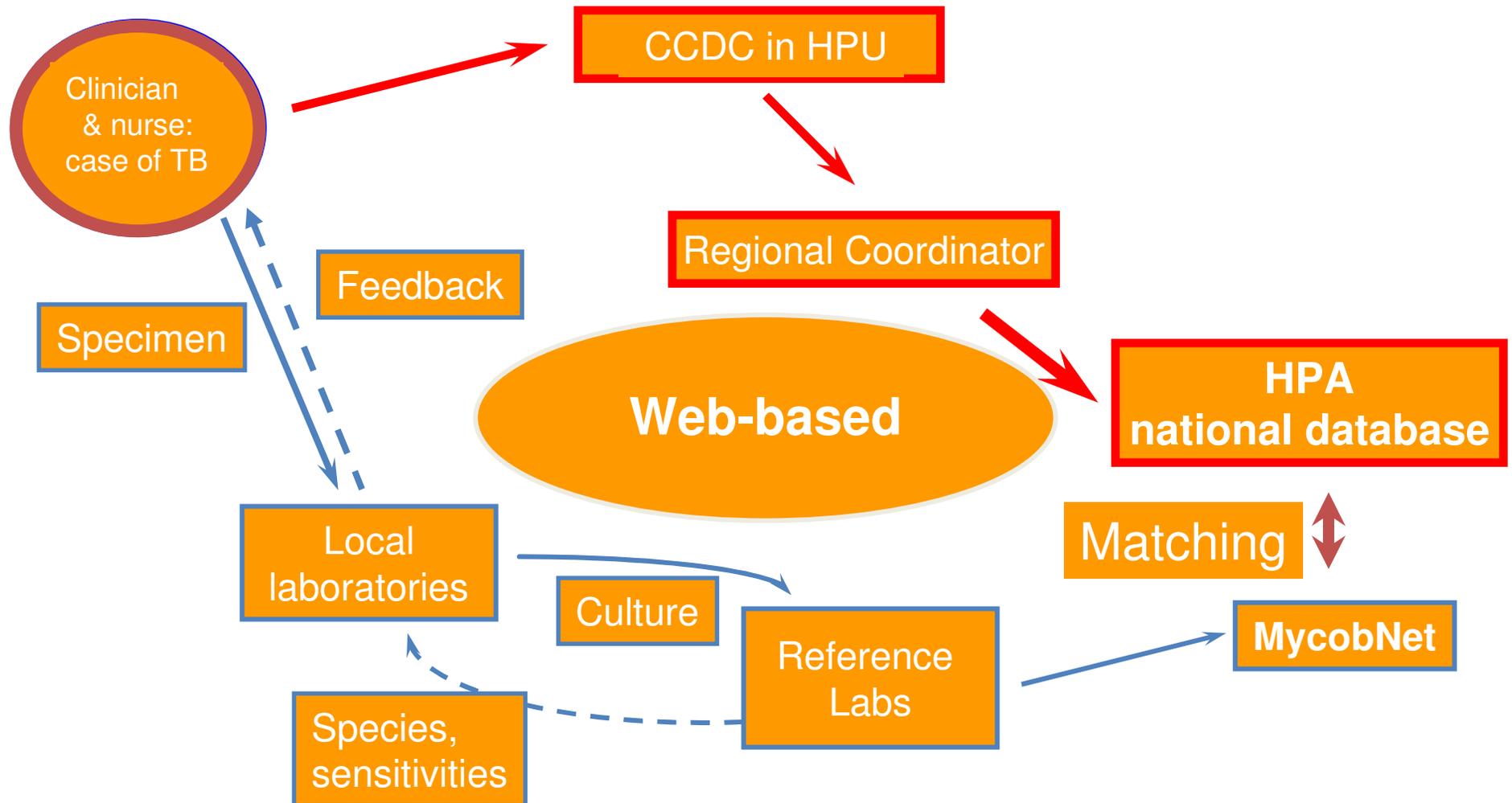


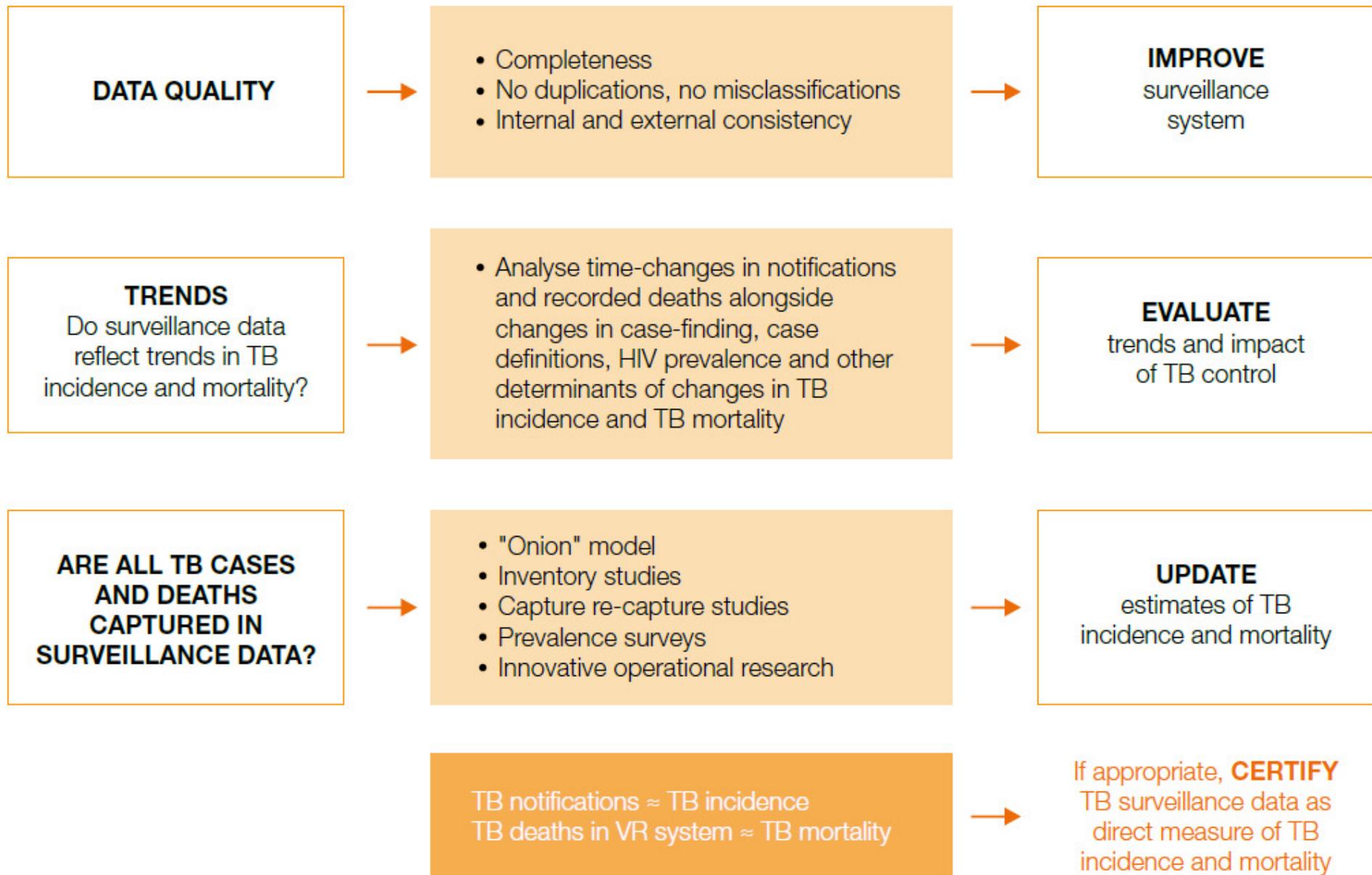
- 8,655 cases in 2008
- 14.1 per 100,000
- Increase over last 2 decades

TB Surveillance systems



TB surveillance – data flow





Quality Scheme

- Components
 - Completeness
 - Accuracy
 - Validity
 - Timeliness
- Single Quality System - QPulse

Assessing completeness

- “Inventory Method”
 - Comparison of laboratory and clinical reports
 - TB-HIV matching
 - Bespoke audits: British Paediatric Surv Unit
- Capture Recapture
 - Overall data
 - Mortality
- Modelling from mortality

Completeness method 1: Matching Clinical and Lab Register, by region, 2003 and 2004

	2003		2004	
	n	%	n	%
East Midlands	19/290	7	45/317	14
East of England	28/229	12	52/313	17
London	356/2131	17	264/2068	13
North East	16/104	15	19/115	17
North West	90/360	25	125/424	29
South East	139/387	36	160/424	38
South West	16/132	12	18/165	11
Wales	24/140	17	9/102	9
West Midlands	58/510	11	54/582	9
Yorkshire & the Humber	58/332	17	62/368	17
Total	804/4615	17	808/4878	17

Completeness Method 1: Reasons for not matching and solutions implemented

Shouldn't be on Laboratory Register (MycobNet)

- False positives (cross contamination) – not denotified
- Not UK resident
- Non-human isolate

Solution: Automated identification of such isolates

In Clinical Register (ETS) but not matched successfully

- Case report more than 1 year from specimen date
- Missed by matching method (misspelt, insufficient completed variables to match etc.)

Solution: Improve matching algorithm with stochastic modelling, use of Soundex codes, local responsibility for matching

Should be on Clinical Register (ETS), but isn't

- Treatment started but ETS not completed
- Patient lost to follow up (Treatment never started despite +ve culture)
- Patient died and ETS never completed

Solution: Identification of districts with particular issues, local audits

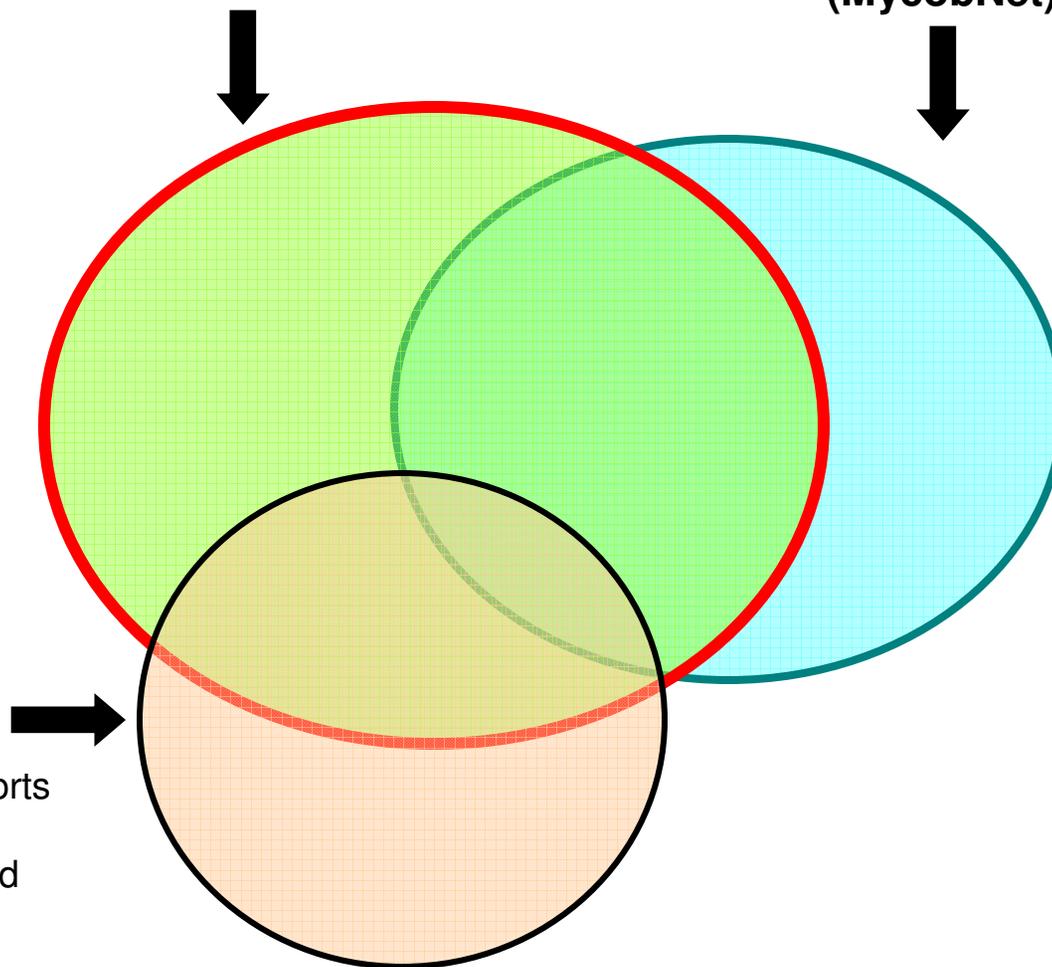
Completeness Method 2: Source of information on TB/HIV co-infection England and Wales

**TB reports from clinicians
(Enhanced TB surveillance)**

**TB reports from
laboratories
(MycobNet)**

**HIV/AIDS
patients
dataset**

Clinical HIV reports
collecting
demographic and
epidemiological
information



Completeness Method 2: Proportion of patients with active TB reported only to the HIV surveillance database

Year	Not reported as active cases of tuberculosis to tuberculosis surveillance database	Total co-infected
	Number (% of total co-infected)	
1999	40 (23.7)	169
2000	52 (20.6)	253
2001	54 (17.2)	314
2002	78 (17.0)	459
2003	99 (18.1)	548
Total	323 (18.5)	1,743

Completeness Method 3: Bespoke Paediatric TB Survey

- BPSU 320, ETS 446, Matched: 222
- Total: 557; 98 (18%) reported only to BPSU, and 237 (42%) reported only to ETS
- 19% under-reporting to ETS
- Matching on year, partial postcode, gender

BPSU – British Paediatric Surveillance Unit, ETS – Enhanced Tuberculosis Surveillance

Completeness Method 4: NATURALIST'S NOTEBOOK

Saturday

17 spotted butterflies caught, marked and released.

Monday

13 spotted butterflies caught, of which 3 have marks from Saturday.

Calculation

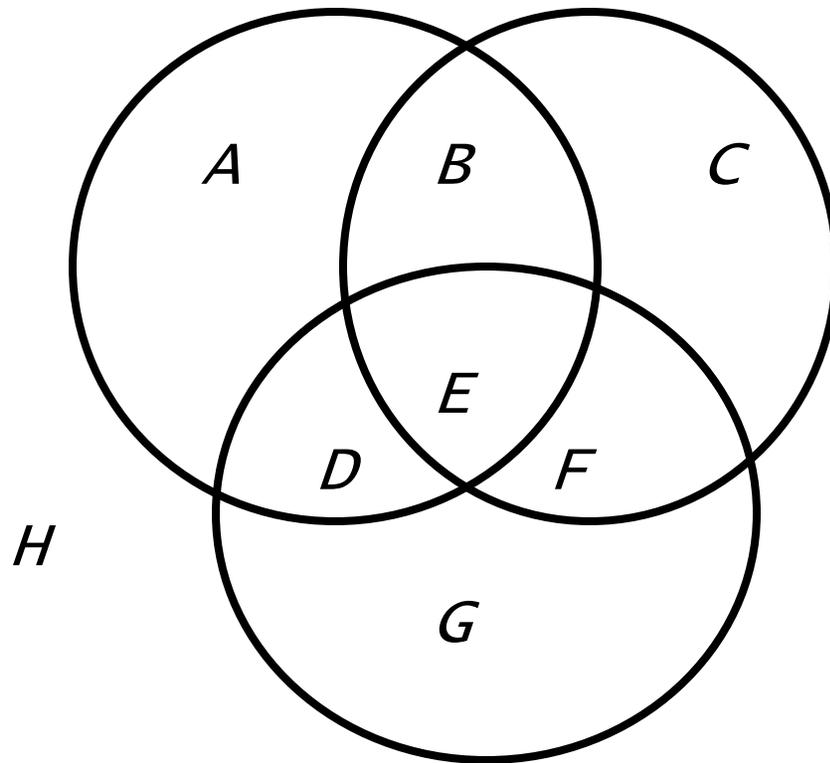
$3/13 = 23\%$ of all butterflies were caught and marked on Saturday.

$23\% = 17$, therefore $100\% = 17 \times 100 \div 23 = 74$.

There are 74 spotted butterflies in the neighbourhood.

Completeness Method 4: Capture-recapture estimation of TB in England, 1999-2002.

Enhanced
Surveil-
Lance



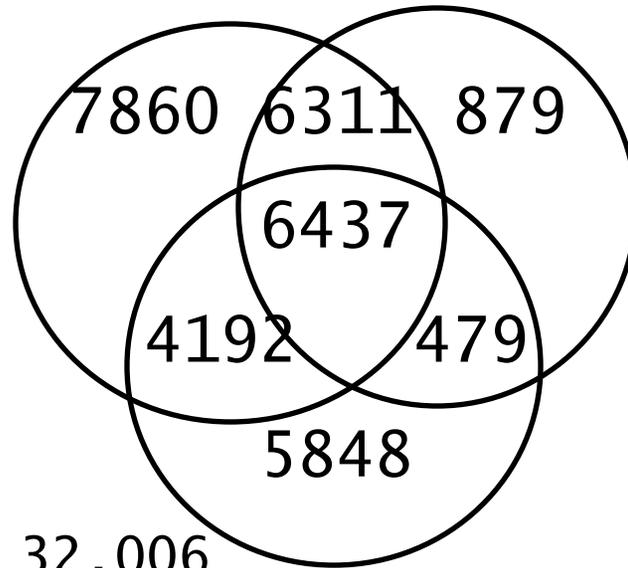
Mycobnet

Hospital
Episode
Statistics

Completeness Method 4: RESULTS

Four years' incidence of TB in England

Data:

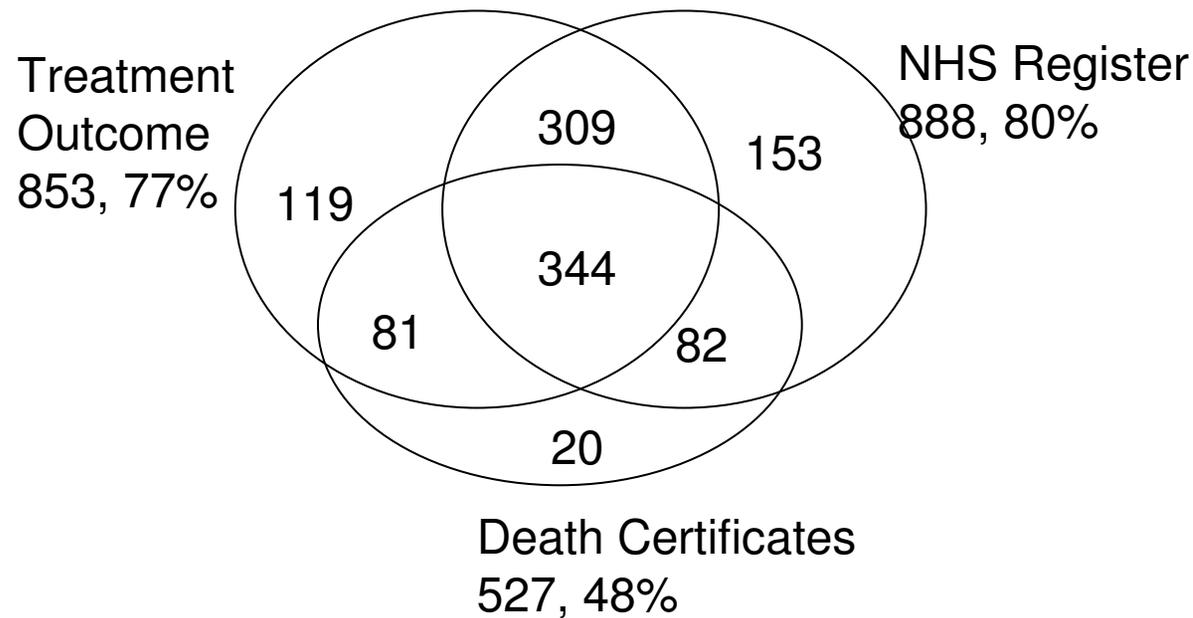


Results: $n = 32,006$

CRC $n_0 = 20,523$ (18,109, 23,259)

Under-notification = 15.9%

Completeness Method 4: Capture recapture - Mortality



61 additional deaths
estimated

PROBLEMS

List dependency: You are more likely to get on to Laboratory Register if you are on Hospital Admission Data (HES).

Case dependency: You are more likely to be listed if your mother is listed.

Case heterogeneity: You are less likely to be diagnosed if you have no GP.

Overcount: Some people listed do not meet the case definition.....especially true for Hospital Admission Data (HES)

Capture Recapture Recommendations

- Should never take precedence over routine surveillance strengthening
- Best when adequately resourced
- Should have at least three data sources
- May provide useful information on data sources and how they relate to each other
- Provides a broad estimate of under-notification that should always be interpreted with local knowledge

Assessing completeness estimates: modelling from mortality

- Back-calculation from mortality
- Bayesian approach allowing incorporation of prior knowledge on progression to death with and with/without treatment
- This combined with mortality data, hospital admissions, and surveillance data allows estimates of incidence and credible intervals to be produced.

Improving completeness: users are prompted to match isolates to case reports or to make new case reports

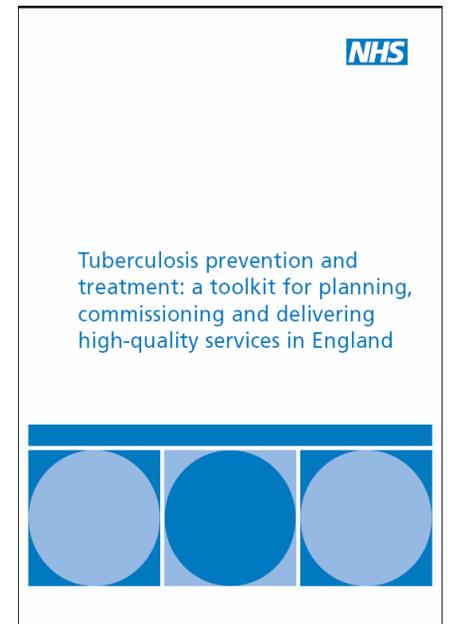
The screenshot shows a web browser window titled "Unmatched laboratory Isolate List - Microsoft Internet Explorer provided by Health Protection Agency". The address bar shows the URL "https://10.190.223.145/ETS.Site/Notification/LaboratoryIsolateList.aspx". The browser's menu bar includes "File", "Edit", "View", "Favorites", "Tools", and "Help". The page content features the Health Protection Agency logo and tagline: "Protecting people, Preventing harm, Preparing for threats". A navigation bar contains "Case Management", "Reports", "Administration", and "Help". A sidebar menu under "Case" lists options: "New case", "Search for case", "Treatment outcome result due", "Case transfers", and "Laboratory isolate matching" (which is selected). Below the sidebar, it says "Logged in as:" with a "Log Out" button and a list of links: "Download paper data collection form", "SitePrecompile-1.5.0.5", and "ServicePrecompile-1.5.0.6". The main content area is titled "Laboratory isolate matching" and contains the text: "Laboratory isolate reports from your area that are currently unmatched to an ETS case". Below this, a instruction reads: "Click on an isolate to see a list of ETS cases possibly matching the selected isolate". A table with the following headers is displayed: "Patient", "DOB", "Postcode laboratory", "Specimen", "Specimen date", and "OrganismName". The table body contains several empty rows.

Improving completeness

- Local audits in the South East region compared to prescription data and other sources
- Dedicated resources including additional staff
- New electronic system

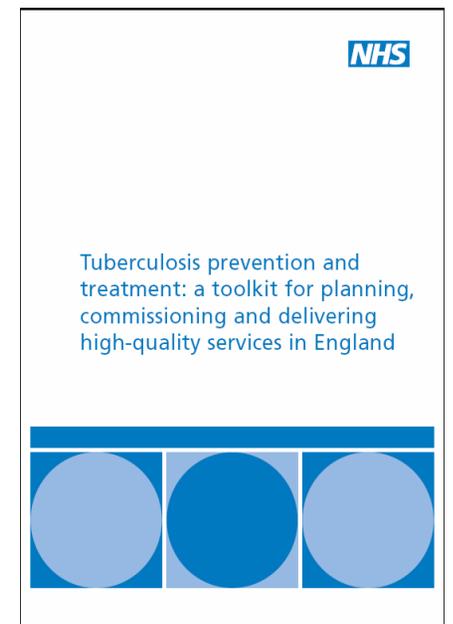
Assessing accuracy

- Annual audit of high priority fields
 - name;
 - date of birth;
 - sex;
 - ethnic group;
 - born/not born in the UK;
 - postcode (with option for 'no fixed abode');
 - date of notification;
 - previous TB treatment;
 - site of disease (pulmonary/extra-pulmonary); and
 - sputum smear status (only needs to be completed for pulmonary cases).



Assessing accuracy

Name	100
Date of birth	99.9
Sex	99.8
Ethnic group	95.4
Born in UK	91
Postcode	99.4
Date of case report	100
Previous TB treatment	75
Site of disease	98.3
Sputum smear status	82
Treatment Outcome	95



Improving accuracy

- Training
 - Training event
 - Web-cast
- Automated checks in the web based system
 - NHS number validity
 - Minimum number of fields – trade off
 - Dates
 - Sites of disease
 - Derived fields from postcodes

Improving accuracy: Duplicates identified / Not TB denotified



Protecting people
Preventing harm
Preparing for threats

Case Management Reports Administration Help

Id: 127269, Case report date: 19/02/2010
John Smith
Sex: U

Demographics

Title	Forename	Surname
Unknown	John	Smith
NHS number	Sex	Date of birth
	Unknown	
Age at case report	Local Patient ID	
Address line 1	Address line 2	
Town or City	County	Postcode

No fixed abod

Patient's PCT or health board
Please Select

Local Authority
Please Select

Search ETS

Possible match found

Name	Address
John SMITH	
john smith	
JOHN SMITH	



Protecting people
Preventing harm
Preparing for threats

Case Management Reports Administration Help

Treatment Outcome Monitoring

Denotify Case

Did the patient complete a full course of therapy within 12 months of starting treatment?

- Yes, the patient completed a full course of therapy
- No, the patient did not complete a full course within 12 months
- The patient's care was transferred to another clinic
- The patient was lost to follow-up before the end of treatment
- Unknown (treatment details are unavailable for this patient)

Please identify the circumstances for incomplete treatment

- Treatment stopped - Patient subsequently found not to have TB (including atypical mycobacterial infection)
- Treatment stopped - but patient had TB
- Patient died before or while on treatment
- Planned course of treatment exceeds 12 months
- Planned course of treatment interrupted
- Planned course of treatment changed
- No treatment details available
- The patients care was transferred to another clinic

Please select as appropriate:
Atypical Mycobacterium identified.

<input type="checkbox"/> M. abscessus	<input type="checkbox"/> M. gordonae	<input type="checkbox"/> M. peregrinum
<input type="checkbox"/> M. avium-intracellulare	<input type="checkbox"/> M. kansasii	<input type="checkbox"/> M. xenopi
<input type="checkbox"/> M. chelonae	<input type="checkbox"/> M. malmoense	<input type="checkbox"/> Other atypical
<input type="checkbox"/> M. fortuitum	<input type="checkbox"/> M. marinum	

Other disease identified:

Please denotify this case by entering a date below and submitting the outcome.

Denotified date

Assessing validity

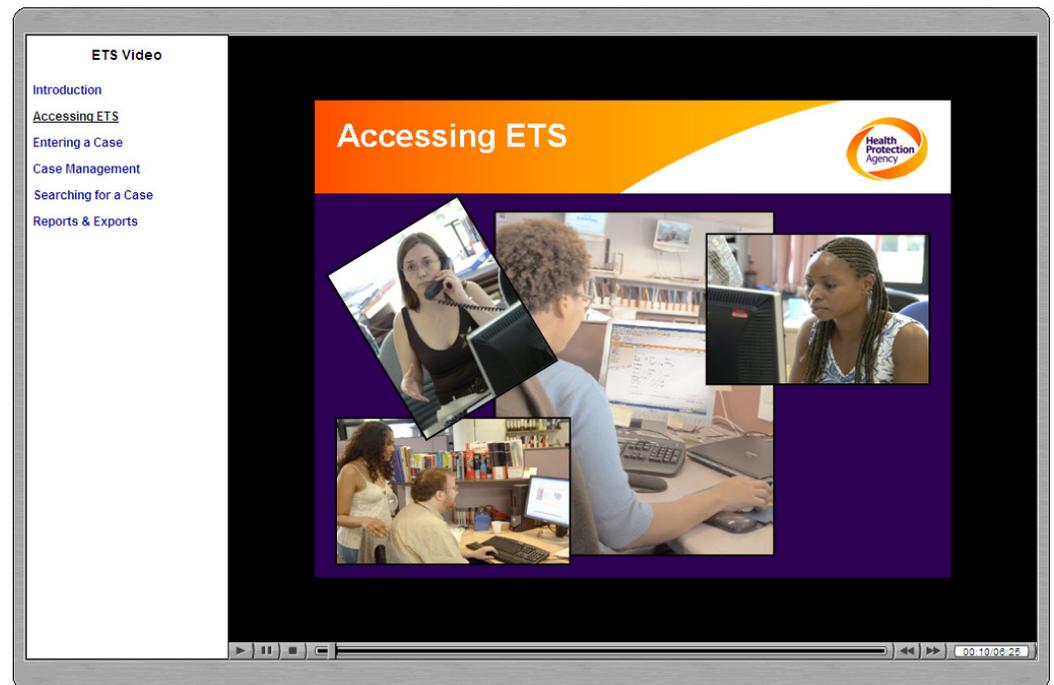
- Audit by national internal audit department comparing local, regional and national data
- Programme of audit by TB section
 - Matching audit
 - Next one will be on DOT

Improving validity

- Audit
- Data dictionary
- Training events
- Web casts



Health Protection Agency
User Manual
Web Based Enhanced Tuberculosis Surveillance (ETS)
Version: November-2008



Timeliness

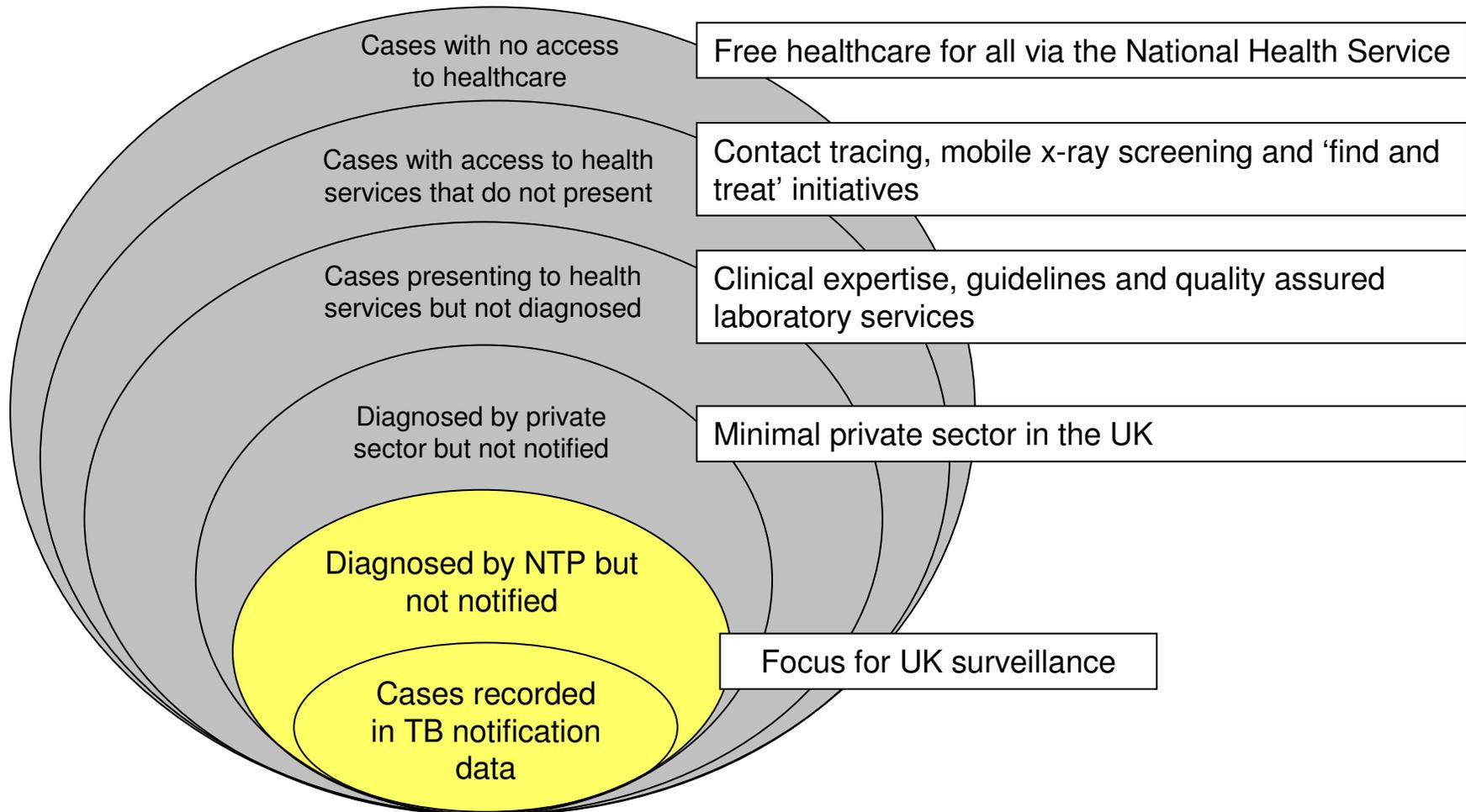
Reporting new cases by clinical teams/local TB services (case definitions are given in the appendix on page 39)

- All cases should be reported by the clinical team to the local health protection unit.
- At least 95% of cases should be reported within two weeks of diagnosis or decision to treat with a full course of anti-TB drugs.
- At least 95% of reported cases should include complete data for the key variables (see appendix on page 40 for the key variables).
- At least 95% of all originally notified cases of TB that are subsequently denotified, should be reported within two weeks of the date of the non-TB diagnosis.

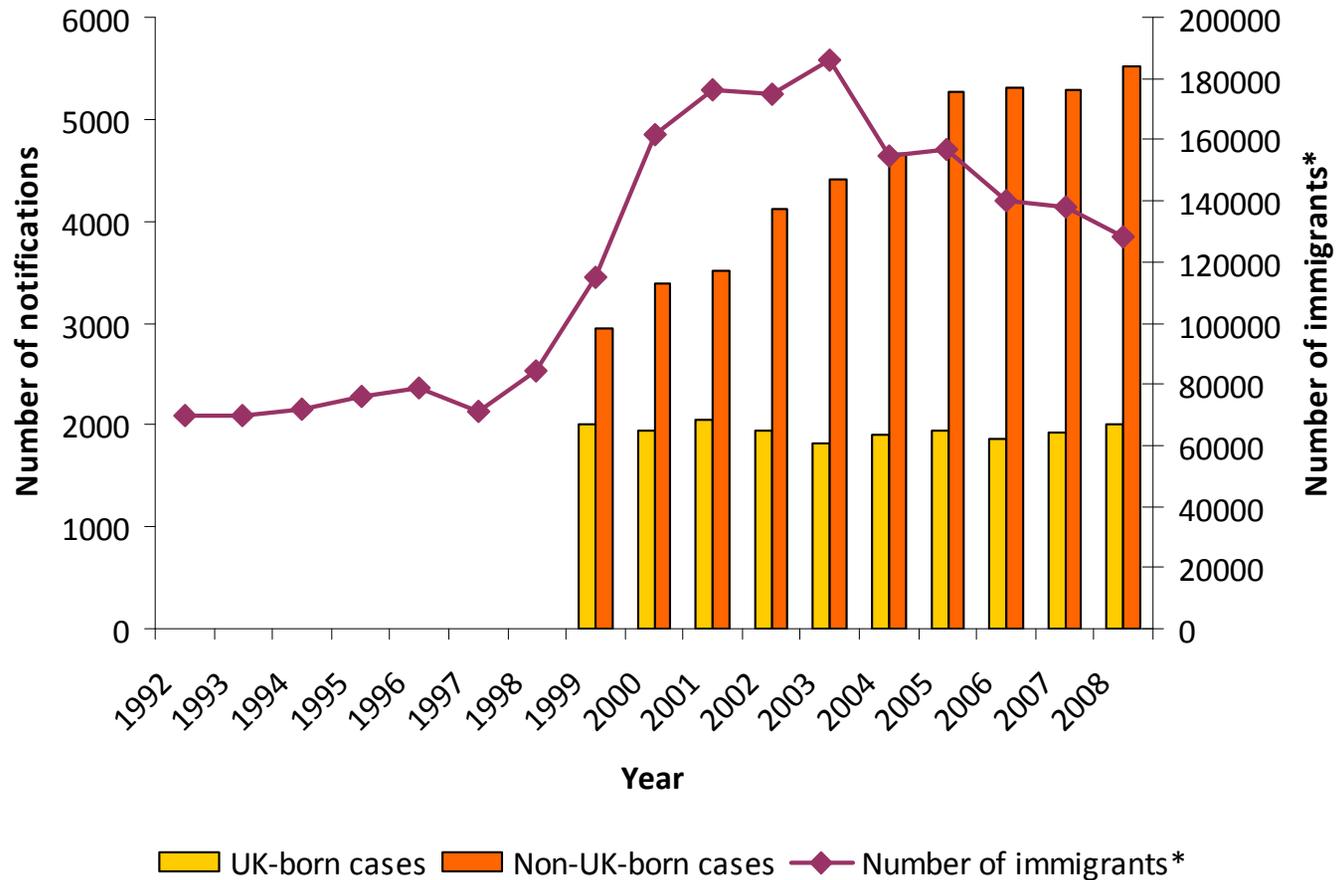
Timeliness

- Assessing timeliness: annual audit of reporting dates against national standards
- Improving timeliness
 - High priority identified nationally
 - Use of web-based system – however.....
 - Cleaning, validation, record linkage, audits take a lot of time

Applying the Onion Model



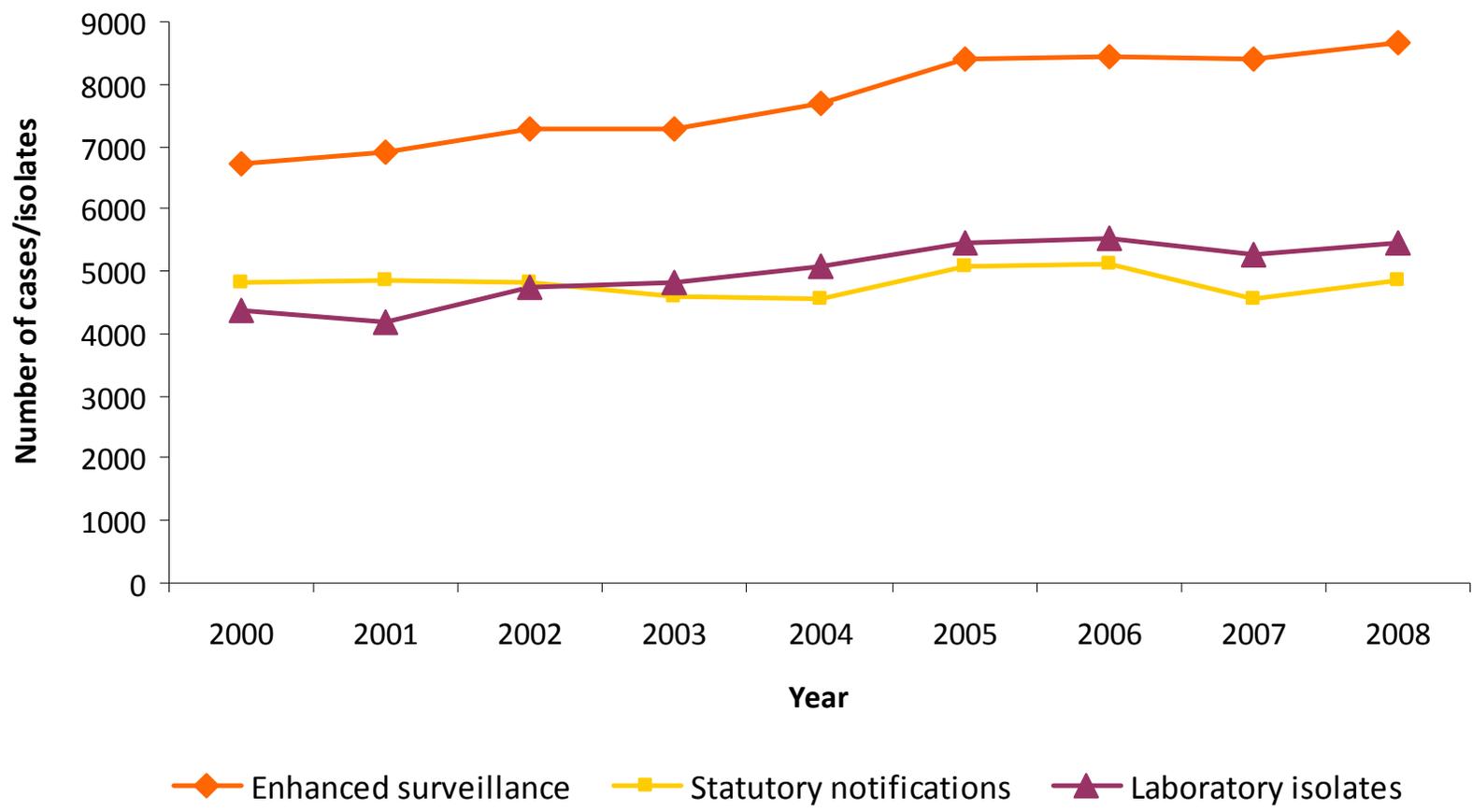
Trends show consistency with immigration patterns



*Immigrants from non-EU and non-commonwealth countries

Sources: Enhanced Tuberculosis Surveillance, Office for National Statistics Long-Term International Migration

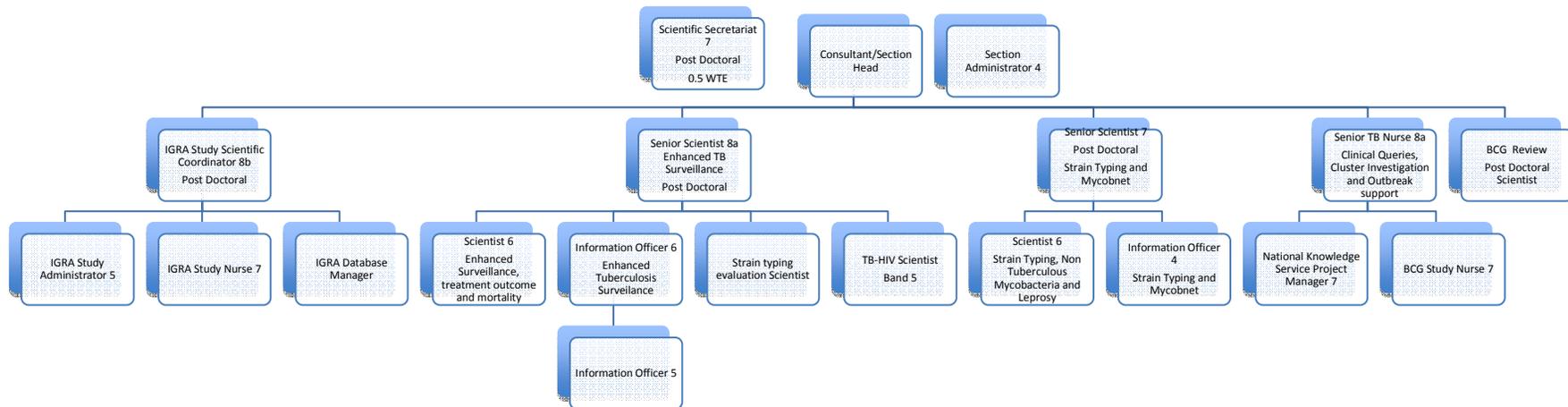
Trends show consistency across data sources



Sources: Enhanced Tuberculosis Surveillance, Enhanced Surveillance of Mycobacterial Infections, Statutory Notifications of Infectious Diseases (England and Wales only), UK Mycobacterial Surveillance Network

Resources

- Staff
 - National TB Epidemiology Unit (see organogram below)
 - Regional units (London *5, other units about 0.3 to 1 person per region)



Conclusion

- Complex national system for historical reasons
- Recent improvement in systems
- Trends reflect real changes over time
- Good routine surveillance requires resources