Results from the pilot of the checklist for TB surveillance standards and benchmarks:

Netherlands
Overview of surveillance system

TB Notification System
- OSIRIS = web based system for 42 compulsory notifiable infectious diseases
- Compulsory notification of (clinical) TB diagnosis AND laboratory isolation of \textit{M. tuberculosis} comp.
- OSIRIS NTR = TB specific module combining compulsory items and items registered on voluntary basis
- Case based recording in three phases:
  1. notification and demographic details,
  2. diagnostic details,
  3. outcome details (treatment, DNA cluster and contact investigation)
- 100% geographical coverage through 24 district public health services with TB department
- Anonymized case-based data available at national level
- There are automatic checks at data entry, automatic verification reports for some inconsistencies
- Checks for timeliness and completeness of reporting

Mortality Information System
- Nationwide system
- Anonymized record of cause of death for every citizen
- Coverage: death cause known in 98.6% of all recorded deaths
Main findings from pilot test (1): Essential Features - Table 1

- **Overall remarks:**
  - NL meets most standards for the benchmarks
  - 44% of central TB control budget is allocated for TB surveillance
  - TB surveillance activities also include monitoring and evaluation of TB screening and DNA-clustersurveillance

- **Problems identified:**
  - Explanation / guidance how to interpret the features is missing (e.g. M&E team including person in charge?)
  - % of total operational TB budget allocated for surveillance not known:
    - Difficulty to assess total budget TB control because funded through different financial mechanisms and administration levels
    - Definition of total operational TB control budget is missing
Main findings from pilot test (1):
Essential Features - Table 1 (cont.)

• S/B not adequately assessed:
  – % of total operational TB budget allocated for surveillance not known in NL

• S/B important but not in the checklist:
  – Discussion of TB report with users

• S/B unnecessary:
  – None
Main findings from pilot test (2): System coverage - Table 2

• **Overall remarks:**
  – Capture – recapture study published in 2008 was based on cohort 1998 (completeness 93%)
  – Since 1998 many changes to data collection methods: completeness is expected to have improved considerably
  – Notification data in NL are now based on different sources: health care providers / laboratory (real time linkage)
  – Results linkage with HIV-monitoring database (2011) pending

• **Problems identified:**
  – Underreporting generally difficult to assess through routine linkage of data sources
  – Demographic data in surveillance systems are anonymized due to privacy legislation, thus linking of systems is extremely troublesome, if not impossible.
  – Notification system and vital register use different time periods (date of diagnosis / date of death). Therefore comparison of aggregated data always show differences
Main findings from pilot test (2):
System coverage - Table 2 (cont.)

• **S/B not adequately assessed**
  – underreporting from all providers
  – proportion of undiagnosed cases

• **S/B important but not in the checklist:**
  – none

• **S/B unnecessary:**
  – none
Main findings from pilot test (3): Core data items

- **Overall remarks:**
  - Osiris - NTR meets most of the core data benchmarks
  - Registration in Osiris-NTR of risk factors includes both social risk factors, biological risk factors and exposure factors, except smoking

- **Problems identified:**
  - Demographic data in surveillance systems are anonimized due to privacy legislation.
  - Linking of anonimized systems is extremely troublesome, if not impossible.
  - Notification system and vital register use different time periods (date of diagnosis / date of death). Therefore comparison of aggregated data always show differences
Main findings from pilot test (3): Core data items (cont.)

• **S/B adequately assessed:**
  – None

• **S/B important but not in the checklist:**
  – Disaggregation of notification data by disease site (PTB/ETB)
  – Disaggregation MDR- cases by demographic status, previous treatment and risk factors
  – Treatment outcome disaggregated by risk groups / factors
  – Quality of diagnosis: bacteriological / culture confirmation and % DST done

• **S/B unnecessary:**
  – % retreatment cases (former treatment in NL) is low and high proportion of patients foreign born
  >> disaggregation by retreatment status not relevant in countries with 100% DST coverage (should be replaced by MDR).
Main findings from pilot test (4): Data quality and completeness

• Overall remarks:
  – Completeness core data in NL: 97-100%, except HIV-status (35% known)
  – NL is small country: (TB) surveillance of approx. 1000 annual cases is relatively easy and more efficient to manage on central level.
  – The central surveillance unit is supportive to subnational level in terms of monitoring timeliness of reporting, completeness and quality. The central unit provides quarterly reports disaggregated by TB region, which are discussed in quarterly meeting of with the TB regions in Central committee for Practical TB Control.
  – External consistency of rates for core data are not within range if ‘general’ expected rates. However, these rates are consistent with previous years and should be compared with rates in countries with a similar epidemiological situation and standard of health care services.

• Problems identified:
  – No central registration of TB suspects and laboratory diagnostics for TB
Main findings from pilot test (4):
Data quality and completeness (cont.)

• **S/B not adequately assessed**
  – Information of case records in notification system matches information in client registration system TB services. Central TB notification system also serves as TB register for TB service. Quality and data checks are only performed in notification system and not routinely double checked at TB service level (although this can be done by district TB service).
  – Smear/culture confirmed results TB suspects

• **S/B important but not in the checklist:**
  – Core variables quality of diagnosis (bacteriological / culture confirmation and DST)

• **S/B unnecessary:**
  – Quarterly reporting by subnational level: In NL quarterly reporting disaggregated by TB region is done centrally and communicated with the districts / TB regions
General comments/Lessons learned

• NL scores quite well with most of the criteria in the checklist;
• Quality of data were greatly enhanced by web based data collection system, linkage to laboratory results and regular feedback to users;
• Weak points are: financial structure is complicated, thus budget and expenditures are an educated guess;
• Evaluation of completeness of notification data is hampered by anonymized data in NTR and other systems such as VRS and HIV-register (PRIVACY LEGISLATION!);
• Internal consistency: complicated analysis – not sure if we made the right assumptions. What about autonomous external influences (e.g. immigration?)
• External consistency: criteria are not similar in various epidemiological situations. E.g. NL low prevalence-high income country, with large proportion foreign born patients and high level of diagnostic care;
• Comparison of completeness core variables (benchmarking) is helpful on subnational level to further improve quality of data / target training;
Recommendations

• Differentiate check list to suit different settings (high income-low prevalence vs low income – high prevalence) or differences in data collection (paper based, electronic based, central web based).

• Explanatory guideline how to calculate and interpret the items in the check-list (e.g. internal consistency, what is meant with ‘audit’?).

• Suggestions how to further engage users in surveillance processes