
Visit Guidelines

Scientific guidelines for knowledge exchange on
syndromic surveillance in Europe

Version 1.2, November 2011

Work Package 5

Deliverable 2 - Part 2



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1. Introduction

The Public Health Action Programme Triple-S-AGE (Syndromic Surveillance Survey, Assessment towards Guidelines for Europe, Grant Agreement No. 20091112) will review European syndromic surveillance systems. Co-financed by the European Commission through the Executive Agency for Health and Consumers, the project encompasses an inventory of existing and proposed syndromic surveillance systems across the European Union (EU). Knowledge exchange between member states interested to setup or improve syndromic surveillance systems will complement the inventory through visits of syndromic surveillance systems in different EU countries. The final aim is to establish guidelines to implement syndromic surveillance systems in Europe.

As part of Work Package (WP) 5, eight country visits of syndromic surveillance systems in EU member states for project partners and external participants are organised between June 2011 and June 2012. The purpose of these site visits is to facilitate knowledge exchange between representatives of existing, pilot, planned or expired syndromic surveillance systems in Europe who are interested to setup, improve or re-establish a syndromic surveillance system. During the visits, strengths and weaknesses of syndromic surveillance systems, good practices, experiences and lessons learnt, and the importance of different determinants of syndromic surveillance shall be discussed. The information obtained during the site visits also provides the basis for developing guidelines for implementing syndromic surveillance systems in Europe in the future (one main objective of the Triple S project). The site visits are not for assessing or evaluating the visited systems but for mutual learning and improving syndromic surveillance in Europe.

The site visits are coordinated by the leaders of WP 5, Alexandra Ziemann and Thomas Krafft, Maastricht University (formerly GEOMED Research). Alexandra Ziemann functions as central contact point for all questions regarding the site visits. A special email address is established for all requests regarding the site visits: visits@syndromicsurveillance.eu.

2. Objectives of the scientific guidelines

This document aims at structuring the knowledge exchange process regarding the visited syndromic surveillance systems.¹ It supports the visited teams to prepare the site visit and the visiting team in retrieving relevant and comparable information on visited syndromic surveillance systems. The collected information will provide the basis for writing the country reports and for developing guidelines such as the Guidelines for Assessment of Data Sources.

This document constitutes the scientific part of the visit guidelines and forms part of Deliverable 2 prepared by WP5 at month 6 (February 2011) of the project, allowing the organisation of the first site visits in summer 2011. Nevertheless, it might be completed and adjusted after the experiences of the first two site visits.

¹ The term "system" is meant in a broad sense including any activity in syndromic surveillance.

3. Outline of the scientific guidelines

The main interest regarding the visited syndromic surveillance systems is the knowledge exchange regarding specific issues raised by the participants on one hand. On the other hand, good practices, strengths and weaknesses and experiences and lessons learnt are of specific interest in order to be able to formulate guidelines for future users of syndromic surveillance systems in Europe grounded in practice experience. It is relevant to understand the differences between syndromic surveillance systems in different countries and the different determinants of syndromic surveillance.

The guidelines are structuring the knowledge exchange process before, during and after the site visits. Knowledge exchange is facilitated through different sources such as publications, material provided by visited sites, presentations and discussions during the site visit, and visits to external stakeholders (e.g., data providers).

The rapporteurs (WP 5 leader and project leader) have the responsibility to coordinate the knowledge exchange and collate relevant information to ensure a sufficient basis for writing the country reports and formulating guidelines. Visitors are asked to actively engage in the knowledge exchange according to the contents of these guidelines to obtain relevant information during the site visits by asking questions or taking part in discussions.

The guidelines are listing all possible characteristics of a syndromic surveillance system but most probably information cannot be obtained on all items. It is not obligatory to gather/provide information on all items for each visited syndromic surveillance system. Rather, visited sites can focus on the specific interests of the visitors, and on certain strengths and weaknesses or problems they faced and the chosen solutions they think are of special relevance to other syndromic surveillance system users and for the development of guidelines.

The knowledge exchange covers characteristics and quality indicators of syndromic surveillance systems and also aims at exploring how characteristics determine quality (figure 1). The guidelines follow the logic model of characteristics of syndromic surveillance systems starting with the context of the system, the system's input (data sources), the system's throughput in the sense of IT infrastructure and data analysis, the system's output, e.g., reporting and response measures, and the outcome and impact of the system in the sense of usefulness. The quality indicators are oriented at the guidelines for evaluation of early outbreak detection systems of the Centers for Disease Control and Prevention². Evidence in form of examples, facts and figures should be provided by the visited sites.

² Centers for Disease Control and Prevention (CDC) (ed.) Framework for evaluating public health surveillance systems for early detection of outbreaks. Recommendations from the CDC Working Group. In: Morbidity and Mortality Weekly Report 2004 53(RR05): 1-11;

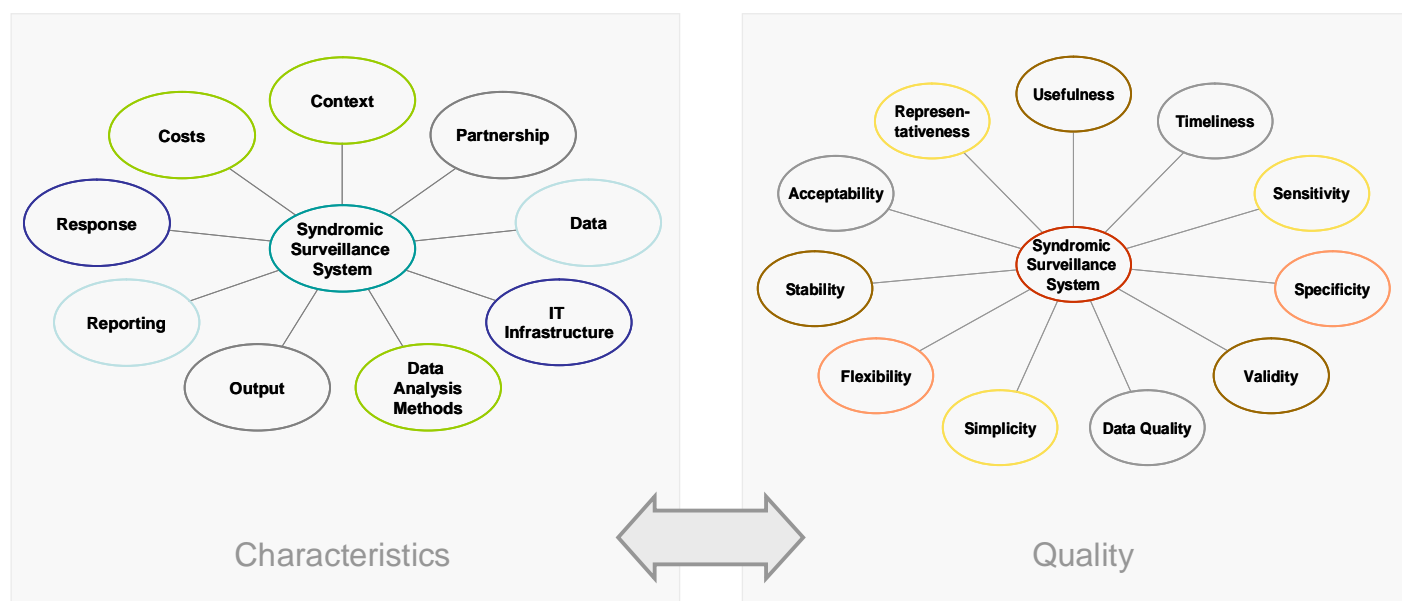


Figure 1: Framework for knowledge exchange on syndromic surveillance systems

The guidelines are divided into the following categories following the logic model of syndromic surveillance:

- I. Context
- II. Partnership at local/regional/national level & competencies
- III. Data collection & preparation
- IV. IT infrastructure of the syndromic surveillance system
- V. Data analysis methods
- VI. Output (of analysis)
- VII. Reporting (of output)
- VIII. Response procedures (after reporting)
- IX. Costs
- X. Impact/Usefulness

Each category is divided into sub items which are elaborated with questions, explanations or examples. The sub items follow this structure:

- Getting started: experiences during the preparatory phase
- Characteristics: description of the different syndromic surveillance system elements, experiences, examples
- Quality indicators: identifying strengths and weaknesses

The guidelines are adjusted to existing, pilot and expired and to planned systems and are targeted to the stakeholder groups (i) organisation operating the syndromic surveillance system, (ii) data providers, and (iii) public health authorities and policy representatives (table 1). This shall support the organising team and the stakeholders of a visited site to better prepare for the site visit presentations. The guidelines will also be included in the Briefing Documents.

Charac- teristics	Existing, Pilot, Expired Syndromic Surveillance Systems			Planned Syndromic Surveillance Systems		
	Organisation operating the system	Data provider	Public health authority & policy representatives	Organisation operating the system	Data provider	Public health authority & policy representatives
Context	x		x	x		x
Partnership	x	x	x	x	x	x
Data collection & data preparation	x	x		x	x	
IT infrastructure	x			x		
Data analysis	x			x		
Output	x			x		
Reporting	x	x	x	x	x	x
Response	x	x	x	x	x	x
Costs	x	x	x	x	x	x
Impact/ Usefulness	x	x	x	x	x	x

Table 1: Expertise of different stakeholder groups of syndromic surveillance

The agenda of a site visit and the setup of presentations and foci of discussions should be inspired by the guidelines to make the knowledge exchange process transparent and to give a common framework for each visit. External stakeholders, e.g., data provider, should be involved in sessions related to their area of expertise in order to provide different perspectives. This knowledge exchange with external stakeholders could also be organised in the form of visits to external sites, e.g., an emergency department. The last session of a site visit should be a synthesis session with the aim to highlight strengths and weaknesses, specific lesson's learned, and to explore the link between the system characteristics and quality indicators. Sessions should consist of presentations and enough time for questions and discussions.

The focus should be on experiences and lessons learnt that could support other syndromic surveillance users also by highlighting problems that were faced and to elaborate on solutions that worked to overcome these problems.

4. Guidelines for description of syndromic surveillance systems

4.1 Guidelines for existing, pilot, and expired systems

4.1.1 Stakeholder group: Organisation operating the syndromic surveillance system

- XI. Context
- XII. Partnership at local/regional/national level & competencies
- XIII. Data collection & preparation
- XIV. IT infrastructure of the syndromic surveillance system
- XV. Data analysis methods
- XVI. Output (of analysis)
- XVII. Reporting (of output)
- XVIII. Response procedures (after reporting)
- XIX. Costs
- XX. Impact/Usefulness

I - Context	
Organisational context (of health system)	<p>In each country (or region) the context of data collection and surveillance is different. Especially, when data from the health system is used its organisation substantially affects the way syndromic surveillance performs.</p> <p>Relevant issues can be for example:</p> <ul style="list-style-type: none"> - Legal context (e.g., ownership of data) - Centralised or decentralised health system organisation - Treatment seeking behavior - Opening hours <p>Please elaborate by data source.</p>
Reason for setting up a syndromic surveillance system	What was the reason for setting up a syndromic surveillance system, e.g., a specific health threat such as heat wave or the threat of bioterrorism?
Original purpose of the system	What was the intended advantage of setting up a syndromic surveillance system, e.g., an earlier detection or rapid availability of information on a health event?
Actual purpose of the system	For which purpose is the syndromic surveillance system used today? Was there a change or extension of utilisation, e.g., from early detection of pandemics to seasonal influenza surveillance?

Existing, pilot, and expired systems

Stakeholder group: Organisation operating the syndromic surveillance system

II - Partnership at local/regional/national level & competencies	
Getting started	<p>How were partnerships built in the start phase of the syndromic surveillance system?</p> <p>Who was planned to be involved and why are the current partnerships chosen?</p> <p>Which experiences were made – which partnerships were easy or difficult to establish?</p> <p>Which strategy worked to overcome problems in partnerships?</p> <p>Were there major changes in partnerships and why?</p>
Partners	<p>Who is involved in syndromic surveillance in the institution operating the system and beyond (e.g., data provider, public health authorities) and at which administrative level (national, regional, local)?</p> <p>Which partners are necessary from your experience for successful of syndromic surveillance and why?</p> <p>If possible, please provide an organizational graph of the partnerships (figure, sketch).</p>
Roles	Which roles do the different involved partners take over in the process of syndromic surveillance?
Access to syndromic surveillance system and competencies	Which stakeholders have access to the syndromic surveillance system, the data, the results, etc. and which competencies, rights and duties do the different partners have in accessing and using the syndromic surveillance system and the output?
Impact of syndromic surveillance on your partnerships	<p>In which way are partnerships to stakeholders influenced by working together in syndromic surveillance? Are you working more closely now in other areas, e.g., joint response to an event? Was awareness raised to the aims, backgrounds and tasks of the different stakeholders?</p> <p>What was important to strengthen or enhance the partnership – what worked well and why?</p>
Dissemination activities, measures to maintain partnership	<p>Are there special measures or activities taken to maintain or foster partnership to stakeholders participating in syndromic surveillance, e.g., joint publications, joint workshops, regular feedback measures?</p> <ul style="list-style-type: none"> • How often are activities performed? • How is the attendance rate? • What kind of activities work well and why?

Existing, pilot, and expired systems

Stakeholder group: Organisation operating the syndromic surveillance system

II - Partnership at local/regional/national level & competencies contd.	
Acceptability of syndromic surveillance	<p>How do you rate the acceptability of the syndromic surveillance activities among the different stakeholders at local/regional/national level?</p> <p><u>Indicators:</u></p> <ul style="list-style-type: none"> • Level of utilization by stakeholders; • Level of use of syndromic surveillance results for primary work (e.g., during health events, every day); • No. of stakeholders and users per year or for the last three years; • Linkages to other surveillance systems; • Extension of syndromic surveillance system to cover additional syndromes, diseases, events or other data sources since establishment/during the last three years; • Impact and relevance of syndromic surveillance during public health events; • Flexibility to respond to specific user/stakeholder enquiries; • Responsiveness to suggestions and comments from stakeholders; • Ease and cost of data collection for data providers; • Ease and cost of reporting (accessing/receiving syndromic surveillance system results) for stakeholders; • Level of assurance of privacy and confidentiality regarding data provided for syndromic surveillance and if the system is IT-based regarding personal information of stakeholders accessing the data via the IT system; • Level of representativeness of syndromic surveillance results (i.e., coverage of population/area, data sources: percentage of participating institutions providing data, e.g., no. of emergency departments providing data of all emergency departments in an area, no. of public health events of which syndromic surveillance made a contribution).

Existing, pilot, and expired systems

Stakeholder group: Organisation operating the syndromic surveillance system

III - Data collection & preparation	
Getting started	<p>How was access to data sources gained in the start phase of the syndromic surveillance system?</p> <p>Which data sources did you try to access?</p> <p>Which experiences were made - which data sources were easy/difficult to access and why?</p> <p>Which strategy worked to overcome problems in accessing data sources?</p> <p>Were there major changes in data sources during the last years and why?</p>
Data sources	Which data sources are providing data of the syndromic surveillance system, (i.e., emergency department, telephone helpline)?
Do you trust one data source more than another?	Which one? Why? Which are the main factors for you to trust this data source?
Purpose of data collection	Is the data collected for another purpose than syndromic surveillance or is (any part of) the data only collected for syndromic surveillance purposes and if so which?
Data collection process	<p>How is the data collection process? Electronic or paper-based</p> <ul style="list-style-type: none"> • When is data collected, e.g. while patient is treated, within 24 hours after treatment of a patient, etc. • Who collects the data in the data providing institutions? • Which level of training do the staff have that collect the data, especially diagnostic information, i.e. ICD codes, regarding the different levels in the institution, e.g., in an emergency department: nurses, physicians, or administrative staff. • Did the staff of the data provider collecting the data receive specific training or information for collecting data for syndromic surveillance purposes? <ul style="list-style-type: none"> • What kind of training/information? • Which effect did the training/information have on data quality? • What kind of training/information worked well and why?
Data provision process	<p>How often is data provided to the syndromic surveillance system (covering which period of time)?</p> <p>How is data provided, i.e.,</p> <ul style="list-style-type: none"> • Automatic (continuous connection between data base of data provider and institution operating the syndromic surveillance system) or manually • Push or pull (i.e., institutions operating the syndromic surveillance system ask for data or data provider provides data (either automatically or manually)?

Existing, pilot, and expired systems

Stakeholder group: Organisation operating the syndromic surveillance system

III - Data collection & preparation contd.	
Indicators/variables	<p>Which indicators or variables are provided that are used in the syndromic surveillance system (by data source), i.e.,</p> <ul style="list-style-type: none"> • Date • Place (geographic data) • Age, Gender, • Severity • Diagnostic information: chief complaint, working diagnosis, final diagnosis, etc. • Etc. • Other (external) data variables, e.g., temperature (meteorological)?
Format	<p>In which format is the data, especially diagnostic information, provided by the data provider to the institution operating the syndromic surveillance system, i.e.,</p> <ul style="list-style-type: none"> • Internationally used code (e.g., ICD) • Nationally, regionally or locally used code • Free-text • Aggregated data (i.e., cases per day) or case specific data
Data preparation for syndromic surveillance	<p>In which way does the provided data have to be prepared (e.g., missing values, seasonal variation, change of data format, generation of new variables, natural language processing, aggregation) before it can be analysed for syndromic surveillance?</p> <p>Were analyses of long-term historical data necessary?</p> <p>How often does preparation have to be done, i.e., every time data is provided or once before data is used for the first time?</p> <p>Which effort does this preparation take (time, costs)?</p>
Adjustment of collected data	<p>Is adjustment of collected data possible or necessary, e.g., new syndrome/case definition?</p> <ul style="list-style-type: none"> • On which occasion? • For which purpose? • By whom? • Which effort?
Public health events	<p>Which data source is used to cover which public health problem, i.e., heat waves, influenza outbreak, unknown health threat?</p>
Syndromes	<p>Which syndromes, e.g., Influenza-like-illness, gastrointestinal syndrome, are covered with the syndromic surveillance system?</p> <p>How are syndromes defined based on which variables from which data source, i.e. (i.e., influenza-like-illness = working diagnosis in emergency department, ICDx-y, symptom x + age y)</p>

Existing, pilot, and expired systems

Stakeholder group: Organisation operating the syndromic surveillance system

III - Data collection & preparation contd.	
Data quality	<p>Data quality reflects the completeness and validity of the data provided to the syndromic surveillance system, e.g.,</p> <ul style="list-style-type: none"> • missing values; • accuracy of data collection, i.e., ICD is reported with one digit and not of three; • variety of data, i.e., only few ICD codes are collected; <ul style="list-style-type: none"> • divided by data source and variable (if there are differences between variables provided for syndromic surveillance, e.g., if new variables have to be generated); • divided by syndrome; • divided by analysis method. <p>How is data quality measured, i.e., which reference data and variables are used for comparison?</p>
Costs	<p>What are the costs per year related to the data collection and data preparation process?</p>

Existing, pilot, and expired systems

Stakeholder group: Organisation operating the syndromic surveillance system

IV - IT infrastructure of the syndromic surveillance system	
Getting started	<p>How was the IT infrastructure setup in the start phase of the syndromic surveillance system?</p> <ul style="list-style-type: none"> • Which IT system were discussed and why was the currently used one chosen? • Which experiences were made - which parts of the IT infrastructure were easy/difficult to setup and why? • Which strategy worked to overcome problems in setting up the IT infrastructure? • Were there major changes in the IT infrastructure during the last years and why?
IT infrastructure	Please describe the IT infrastructure components, data flow, communication channels/interfaces, features, etc. and provide a sketch/flow chart if possible.
Automatic or manual system	Which parts of the system work automatically and which manually?
Location & access	<p>In which institution is the IT infrastructure or different components located?</p> <p>Who has access to which parts of the IT infrastructure?</p> <p>Who has the responsibility for service/maintenance of the (different parts of the) IT infrastructure?</p>
Costs	What are the costs per year related to setting up and maintaining the (different parts of the) IT infrastructure?
Simplicity	<p>Simplicity refers to both the structure of the syndromic surveillance system and its ease of operation. Syndromic surveillance systems should be as simple as possible while still meeting their objectives.</p> <ul style="list-style-type: none"> • Level of integration with existing surveillance systems; • Time and resources spent to collect, transfer, analyse data, maintain and update the system and disseminate reports/alerts using the IT infrastructure; • Staff training requirements for syndromic surveillance; • Easily applicable case definitions and indicator rationales; • Output, reports, interface that is easy to understand and easy to use.
Flexibility	<p>Flexibility refers to the syndromic surveillance system's ability to change as needs change. A flexible syndromic surveillance system can adapt to changing information needs or operating conditions with little additional time, personnel, or allocated funds.</p> <ul style="list-style-type: none"> • Easy integration in existing surveillance systems; • Easy integration in new regions; • Easy adaptation to new case definitions/rationales and additional or new data sources and incorporation of other information technology; • Dependence on funding; • Dependence on no./variety of. reporting sources; • Flexibility to respond to specific user enquiries.

Existing, pilot, and expired systems

Stakeholder group: Organisation operating the syndromic surveillance system

IV - IT infrastructure of the syndromic surveillance system contd.	
Stability	<p>Stability refers to the reliability (i.e., the ability to collect, manage, and provide data properly without failure) and availability (the ability to be operational when it is needed) of the syndromic surveillance system?</p> <ul style="list-style-type: none">• Ability to collect, manage and provide data properly without failure;• Ability to adapt to changes (i.e., new coding);• Ability to be operational when necessary;• No. of unscheduled outages and down times of the system;• Amount of costs involved in repairing the system;• Percentage of time that the syndromic surveillance system is fully operating;• Difference between estimated and actual amount of time required to manage data and release results with the IT infrastructure.

Existing, pilot, and expired systems

Stakeholder group: Organisation operating the syndromic surveillance system

V - Data analysis methods	
Getting started	<p>How were the data analysis methods chosen in the start phase of the syndromic surveillance system?</p> <ul style="list-style-type: none"> • Which analysis methods were discussed and why were the currently used ones chosen? • Which experiences were made - which analysis methods were easy/difficult to apply and why? • Which strategy worked to overcome problems in applying analysis methods? • Were there major changes during the last years to data analysis methods and why?
Analysis methods	<p>Which analysis methods are applied in the syndromic surveillance system, (e.g., cumulative sums, moving averages, modelling, spatial-temporal methods, etc.)?</p> <p>Please provide the specific mathematical connotation including your adaptations if possible.</p>
Analysis process	<p>How is the process of analysing data?</p> <ul style="list-style-type: none"> • Automatically or manually? • If manually, <ul style="list-style-type: none"> • who analyses the data (training, function)? • which software is used? • which analysis steps are taken (e.g., preparatory analysis, e.g., statistical tests, actual analysis, visualisation of results, etc.) • How often are analyses done? • How long does the analysis process take? • Which effort does the analysis process take (workload)?
Adjustment of analysis methods	<p>Did you had to adapt the analysis methods before or while applying them in your syndromic surveillance system, i.e., thresholds, certain variables?</p> <p>How big was the effort for that?</p>
Costs	What are the costs per year related to the data analysis?

Existing, pilot, and expired systems

Stakeholder group: Organisation operating the syndromic surveillance system

VI - Output (of analysis)	
Getting started	<p>How were design and functions of the direct output of the syndromic surveillance system chosen at the beginning?</p> <ul style="list-style-type: none"> • Which output design and functions were discussed and why were the currently used ones chosen? • Which experiences were made - which outputs were easy/difficult to apply and why? • Which strategy worked to overcome problems in the output? • Were there major changes in the output during the last years and why?
Output	<p>Which direct output does the syndromic surveillance system produce after analysis, i.e., report, alerts, electronic display (e.g., online interface)?</p> <p>Is the output stored for later analysis or interpretation? In which form, e.g., raw or aggregated data or analysis results or reports?</p>
Output process	<p>How is the output process?</p> <ul style="list-style-type: none"> • Is the output generated automatically or manually? • If manually, <ul style="list-style-type: none"> • Who produces or manipulates the output (training, function)? • Which software is used? • Which steps are taken (e.g., preparation of results for visualisation, etc.) • How often are outputs produced? • How long does the output process take? • Who receives the output for which purpose? • Can the output be changed by the user and by which user? • Which effort does the output production take (workload)?
Alert	<p>At which threshold does the syndromic surveillance system produce an alert, i.e., 3 standard deviations (by data source, syndrome and data analysis method)?</p> <p>How long must an alert period be to issue any kind of public health action, i.e., after three consecutive alert days?</p>
Interpretation	<p>Who interprets the results of the analyses?</p> <p>How are interpretation results used, e.g., in reports to stakeholder?</p> <p>Who receives interpretations of the results for which purpose?</p> <p>How long does the interpretation of output take?</p> <p>Which effort does the interpretation take (workload)?</p>
Costs	<p>What are the costs per year related to producing and interpreting output?</p>

Existing, pilot, and expired systems

Stakeholder group: Organisation operating the syndromic surveillance system

VII - Reporting (of output)	
Getting started	<p>How were the reporting mechanisms of the of the syndromic surveillance system chosen at the beginning?</p> <ul style="list-style-type: none"> • Which reporting mechanisms were discussed and why were the currently used ones chosen? • Which experiences were made - which reporting mechanisms were easy/difficult to apply and why? • Which strategy worked to overcome problems in the reporting mechanisms? • Were there major changes during the last years in reporting mechanisms and why?
Reporting	<p>Which mechanisms are used to report the analysis results and their interpretation (output) to users/stakeholders, i.e., email, fax, print-out, electronic interface (e.g., website) etc.?</p>
Reporting process	<p>How is the reporting process?</p> <ul style="list-style-type: none"> • Is the reporting done automatically or manually? • If manually, <ul style="list-style-type: none"> • Who produces the report (training, function)? • Which software is used? • Which steps are taken (e.g., preparation of output for reporting, etc.) • How often is reported? • How long does the reporting take? • Who receives the report for which purpose? • Can the report be changed (e.g., interactive) or further used by the user how and by which user? • Which effort does the reporting take (workload)?
Costs	<p>What are the costs per year related to reporting?</p>

Existing, pilot, and expired systems

Stakeholder group: Organisation operating the syndromic surveillance system

VIII - Response procedures (after reporting)	
Getting started	<p>How were the response procedures defined in the start phase of the syndromic surveillance system?</p> <ul style="list-style-type: none"> • Which response procedures were discussed and why were the currently used ones chosen? • Which experiences were made - which response procedures were easy/difficult to apply and why? • Which strategy worked to overcome problems in the response procedures? • Were there major changes in response procedures during the last years and why?
Response procedures	<p>How is the response process after reporting/alerting of the syndromic surveillance system?</p> <ul style="list-style-type: none"> • Is the response issued automatically or manually? • If manually, <ul style="list-style-type: none"> • Who initiates the response (training, function)? • Which steps are taken? • How often was a response initiated during the last year? • Who is involved in the response with which roles? • Which effort does the initial response take (workload)?
False alerts	<p>How many responses were issued based on the reports of the syndromic surveillance system although there was no health event?</p> <p>How many of these false alerts are avoidable?</p> <p>Which syndromic surveillance system characteristics needs to be changed to decrease the number of false alerts?</p>
Syndromic surveillance effect on response	<p>Which effect does syndromic surveillance have on the response procedures in the region/country, e.g., timelier response, discouragement due to false alerts?</p> <p>Which effect does syndromic surveillance have on the involvement of important/affected stakeholders in the response process, e.g., health care institutions, e.g., better cooperation, better management during public health event, awareness to public health relevance of their work during public health events?</p> <p>Please provide examples.</p>
Costs	<p>What are the costs per year related to response procedures that are based on syndromic surveillance alerts?</p>

Existing, pilot, and expired systems

Stakeholder group: Organisation operating the syndromic surveillance system

IX - Costs	
Costs	<p>If it is not possible to provide the costs per characteristic mentioned above maybe it is possible to provide overall costs for the syndromic surveillance system, if possible divided by year (or per year 1, 2, 3 etc.) or per phase (e.g., planning, setup, everyday use, maintenance/update) and divided by direct and indirect costs (e.g., workload) and internal and external costs (e.g., data provider).</p> <p>Did costs unexpectedly change and if so how and why?</p> <p>Did the amount of expected costs in the start phase of the syndromic surveillance system met the amount of real costs later on?</p>
Funding sources	<p>From which sources is the syndromic surveillance system funded, if possible divided by year 1, 2, 3, etc. or phase (setup, everyday use, maintenance), by direct and indirect funds and internal and external funds.</p> <p>How were the funding sources identified in the start phase of the syndromic surveillance system?</p> <p>Which funding sources were discussed and why were the currently used ones chosen?</p> <p>Which experiences were made - which funding sources were easy/difficult to access/use and why?</p> <p>Which strategy worked to overcome funding problems?</p>
Impact of syndromic surveillance on costs in other areas	<p>Did syndromic surveillance have an impact on the costs of other areas/processes, e.g., whole surveillance system in general, response procedures – which and to which amount?</p>

Existing, pilot, and expired systems

Stakeholder group: Organisation operating the syndromic surveillance system

X - Impact / Usefulness	
Timeliness	<p>Time intervals between different steps of syndromic surveillance:</p> <ul style="list-style-type: none"> • between onset of a health event and data collection; • between data collection and data provision to syndromic surveillance system; • between data provision to syndromic surveillance system and alert; • between alert and response/intervention by public health authority; <ul style="list-style-type: none"> • divided by data source and variable, • divided by analysis method. <p>How is timeliness measured, i.e., which reference data and variables are used for comparison?</p>
Sensitivity	<p>The sensitivity of a syndromic surveillance system can refer:</p> <ul style="list-style-type: none"> • at the level of case reporting to the proportion of cases of a disease (or other health-related event) detected by the syndromic surveillance system; • to the ability to detect outbreaks, including the ability to monitor changes in the number of cases over time; • proportion of cases of a health threat detected until an event is detected; • ability to monitor changes during an outbreak (temporal, spatial) <ul style="list-style-type: none"> • divided by data source; • divided by syndrome; • divided by analysis method. <p>How is sensitivity measured, i.e., which reference data and variables are used for comparison?</p>
Specificity	<p>The proportion of cases without the health condition under surveillance that are correctly identified,</p> <ul style="list-style-type: none"> • divided by data source; • divided by syndrome; • divided by analysis method. <p>How is specificity measured, i.e., which reference data and variables are used for comparison?</p>
Validity	<p>The degree to which the syndromic surveillance system measures what it is intended to measure, i.e., positive predictive value, negative predictive value,</p> <ul style="list-style-type: none"> • divided by data source; • divided by syndrome; • divided by analysis method. <p>How is validity measured, i.e., which reference data and variables are used for comparison?</p>

Existing, pilot, and expired systems

Stakeholder group: Organisation operating the syndromic surveillance system

X - Impact / Usefulness	
Representativeness	<p>A syndromic surveillance system that is representative accurately describes the occurrence of a health-related event over time and its distribution in the population by place and person,</p> <ul style="list-style-type: none"> • divided by data source; • divided by syndrome; • divided by analysis method. <p>How is representativeness measured, i.e., which reference data and variables are used for comparison?</p>
Value of syndromic surveillance	In which way is syndromic surveillance of value to your work?
Syndromic surveillance effect on disease burden	In which way did syndromic surveillance affect the disease burden of the population served by your organisation? Please provide examples and figures.
Good characteristics	Which of the aforementioned characteristics/items of your syndromic surveillance system work well and why?
Changes in characteristics	Which characteristic do you intend to change and why?
Changes in syndromic surveillance in general	<p>Which concrete developments are planned in syndromic surveillance by your organisation, e.g., developments of existing system, new syndromic surveillance activities, termination of syndromic surveillance activities?</p> <p>Why are these changes planned?</p>
Evaluation of the syndromic surveillance system	<p>Was your syndromic surveillance system evaluated and if so how and by whom?</p> <p>How was the outcome?</p> <p>What are strengths and weaknesses of your syndromic surveillance system?</p> <p>What are opportunities and threats of your syndromic surveillance system in the future?</p>
Major take home message for future users	Which take home message/recommendation/warning regarding any of the aforementioned characteristics would be the most important one that you would give to future users based on your experiences?

4.1.2 Stakeholder group: Data providers

- II. Partnership at local/regional/national level & competencies
- III. Data collection & preparation
- VII. Reporting (of output)
- VIII. Response procedures (after reporting)
- IX. Costs
- X. Impact/Usefulness

II - Partnership at local/regional/national level & competencies	
Getting started	How were partnerships built in the start phase of the syndromic surveillance system by the organisation operating the system? Which experiences were made?
Participants	Who is involved in syndromic surveillance in your organisation and at which administrative level?
Roles	Which roles do the different involved participants of your organisation take over in the process of syndromic surveillance?
Access to syndromic surveillance system and competencies	Which competencies, rights and duties does your organisation have in accessing and using the syndromic surveillance system and the output?
Impact of syndromic surveillance on your partnerships	In which way is the partnerships between your organisation and the organisation operating the syndromic surveillance system influenced by working together in syndromic surveillance? Are you working more closely now in other areas, e.g., joint response to an event? What was important to strengthen or enhance the partnership – what worked well and why?
Dissemination activities, measures to maintain partnership	Are there special measures or activities taken to maintain or foster partnership to your organisation, e.g., joint publications, joint workshops, regular feedback measures? <ul style="list-style-type: none"> • How often are activities performed? • What kind of activities worked well and why?

Existing, pilot, and expired systems
Stakeholder group: Data providers

II - Partnership at local/regional/national level & competencies contd.	
Acceptability of syndromic surveillance	<p>How do you rate the acceptability of the syndromic surveillance activities?</p> <p><u>Indicators:</u></p> <ul style="list-style-type: none"> • Level of utilization by your organisation; • Level of use of syndromic surveillance results for primary work of your organisation (e.g., during health events, every day); • Impact and relevance of syndromic surveillance during public health events; • Flexibility of the syndromic surveillance system to respond to specific enquiries from your organisation; • Responsiveness to suggestions and comments from your organisation; • Ease and cost of data collection for syndromic surveillance for your organisation; • Ease and cost of accessing/receiving syndromic surveillance system results for your organisation; • Level of assurance of privacy and confidentiality regarding data provided for syndromic surveillance by your organisation and if the system is IT-based regarding personal information of your organisation's staff accessing the information via the IT system; • Level of representativeness of syndromic surveillance results (i.e., coverage of population/area, no. of public health events of which syndromic surveillance made a contribution).

Existing, pilot, and expired systems
Stakeholder group: Data providers

III - Data collection & preparation	
Getting started	How was access to your data sources gained in the start phase of the syndromic surveillance system? Which experiences were made?
Data sources	From which data sources of your organisation is data provided to the syndromic surveillance system, (i.e., in the emergency department: working diagnosis, discharge diagnosis)?
Do you trust one data source more than another?	Which one? Why? Which are the main factors for you to trust this data source for syndromic surveillance?
Purpose of data collection	Is the data collected for another purpose than syndromic surveillance or is (any part of) the data only collected for syndromic surveillance purposes and if so which?
Data collection process	How is the data collection process? Electronic or paper-based <ul style="list-style-type: none"> • When is data collected, e.g. while patient is treated, within 24 hours of treatment of a patient, etc. • Who collects the data in your organisation? • Which level of training do the staff have that collect the data, especially diagnostic information, i.e. ICD codes, regarding the different levels in your organisation, e.g., in an emergency department: nurses, physicians, or administrative staff. • Did your staff collecting the data receive specific training or information for collecting data for syndromic surveillance purposes? <ul style="list-style-type: none"> • What kind of training/information? • Which effect did the training/information have on data quality? • What kind of training/information worked well and why?
Data provision process	How often is data provided to the syndromic surveillance system (covering which period of time)? How is data provided, i.e., <ul style="list-style-type: none"> • Automatic (continuous connection between data base of data provider and institution operating the syndromic surveillance system) or manually • Push or pull (i.e., institutions operating the syndromic surveillance system ask for data or your organisation provides data (either automatically or manually)?

Existing, pilot, and expired systems
Stakeholder group: Data providers

III - Data collection & preparation contd.	
Indicators/variables	<p>Which indicators or variables are provided by your organisation that are used in the syndromic surveillance system, i.e.,</p> <ul style="list-style-type: none"> • Date • Place (geographic data) • Age, Gender, • Severity • Diagnostic information: chief complaint, working diagnosis, final diagnosis, etc. • Etc. • Other (external) data variables, e.g., temperature (meteorological)?
Format	<p>In which format is the data, especially diagnostic information, provided by your organisation to the institution operating the syndromic surveillance system, i.e.,</p> <ul style="list-style-type: none"> • Internationally used code (e.g., ICD) • Nationally, regionally or locally used code • Free-text • Aggregated data (i.e., cases per day) or case specific data
Data preparation for syndromic surveillance	<p>Does the raw data have to be further prepared (e.g., missing values, seasonal variation, change of data format, generation of new variables, natural language processing, aggregation) before it is provided to the organisation operating the syndromic surveillance system?</p> <p>How often does preparation have to be done, i.e., every time data is provided or once before data is used for the first time?</p> <p>Which effort does this preparation take (time, costs)?</p>
Adjustment of collected data	<p>Is adjustment of collected data possible or necessary (for the purpose of syndromic surveillance), e.g., new case/syndrome definition?</p> <ul style="list-style-type: none"> • On which occasion? • For which purpose? • By whom? • Which effort?

Existing, pilot, and expired systems
Stakeholder group: Data providers

III - Data collection & preparation contd.	
Data quality	<p>Data quality reflects the completeness and validity of the data provided to the syndromic surveillance system (by data source), e.g.,</p> <ul style="list-style-type: none">• missing values;• accuracy of data collection, i.e., ICD is only reported with one digit instead of three;• variety of data, i.e., only few ICD codes are collected; . <p>How is data quality measured, i.e., which reference data and variables are used for comparison?</p>
Costs	<p>What are the costs per year related to the data collection and data preparation process in your organisation?</p>

Existing, pilot, and expired systems
Stakeholder group: Data providers

VII - Reporting (of output)	
Getting started	<p>How were the reporting mechanisms involving your organisation chosen at the beginning?</p> <ul style="list-style-type: none"> • Which experiences were made - which reporting mechanisms were easy/difficult to apply and why? • Which strategy worked to overcome problems in the reporting mechanisms? • Were there major changes during the last years in reporting mechanisms and why?
Reporting	<p>Which mechanisms are used to report the analysis results and their interpretation (output) to your organisation, i.e., email, fax, print-out, electronic interface (e.g., website) etc.?</p>
Reporting process	<p>How is the reporting process?</p> <ul style="list-style-type: none"> • Is the reporting done automatically or manually? • How often is reported? • How long does the reporting take? • Who receives the report in your organisation for which purpose? • Can the report be changed (e.g., interactive) or further used by your organisation and by whom? • Which effort does the reporting take (workload)?
Costs	<p>What are the costs per year related to reporting in your organisation?</p>

Existing, pilot, and expired systems
Stakeholder group: Data providers

VIII - Response procedures (after reporting)	
Getting started	<p>How were the response procedures involving your organisation defined in the start phase of the syndromic surveillance system?</p> <ul style="list-style-type: none"> • Which response procedures were discussed and why were the currently used ones chosen? • Which experiences were made - which response procedures were easy/difficult to apply and why? • Which strategy worked to overcome problems in the response procedures? • Were there major changes in response procedures during the last years and why?
Response procedures	<p>How is the response process after reporting/alerting of the syndromic surveillance system?</p> <ul style="list-style-type: none"> • Is the response issued automatically or manually? • If manually, <ul style="list-style-type: none"> • Who initiates the response (training, function)? • Which steps are taken? • How often was a response initiated during the last year? • Who is involved in the response in your organisation with which roles? • Which effort does the initial response take (workload)?
False alerts	<p>How many responses were issued based on the reports of the syndromic surveillance system although there was no health event? How many of these false alerts are avoidable?</p> <p>Which syndromic surveillance system characteristics on which your organisation can have an influence can be changed to decrease the number of false alerts?</p>
Syndromic surveillance effect on response	<p>Which effect does syndromic surveillance have on the response procedures in the region/country, e.g., timelier response, discouragement in responses due to false alerts?</p> <p>Which effect does syndromic surveillance have on the involvement of your organisation in the response process, e.g., better cooperation, better management during public health event, awareness of the relevance of your work during public health events?</p> <p>Please provide examples.</p>
Costs	<p>What are the costs per year related to response procedures that are based on syndromic surveillance alerts in your organisation?</p>

Existing, pilot, and expired systems
Stakeholder group: Data providers

IX – Costs	
Costs	<p>If it is not possible to provide the costs per characteristic mentioned above maybe it is possible to provide overall costs for your organisation related to syndromic surveillance, if possible divided by year (or per year 1, 2, 3 etc.) or per phase (e.g., planning, setup, everyday use, maintenance/update) and by direct and indirect costs (e.g., workload) and internal and external costs (e.g., IT support).</p> <p>Did costs unexpectedly change and if so how and why?</p> <p>Did the amount of expected costs in the start phase of the syndromic surveillance system met the amount of real costs later on?</p>
Funding sources	<p>From which sources are the costs of your organisation related to syndromic surveillance funded, if possible divided by year 1, 2, 3, etc. or phase (planning, setup, everyday use, maintenance), by direct and indirect funds and internal and external funds</p> <p>How were the funding sources identified in the start phase of the syndromic surveillance system?</p> <p>Which funding sources were discussed and why were the currently used ones chosen?</p> <p>Which experiences were made - which funding sources were easy/difficult to access/use and why?</p> <p>Which strategy worked to overcome funding problems?</p>
Impact of syndromic surveillance on costs in other areas	<p>Did syndromic surveillance have an impact on the costs of other areas/processes, e.g., management of everyday work/during health events, response procedures – which and to which amount?</p>

Existing, pilot, and expired systems
Stakeholder group: Data providers

X - Impact / Usefulness	
Timeliness	<p>Time intervals between different steps of syndromic surveillance:</p> <ul style="list-style-type: none"> • between onset of a health event and data collection; • between data collection and data provision to syndromic surveillance system; • between data provision to syndromic surveillance system and alert to your organisation; • between alert and response/intervention by public health authority involving your organisation divided by data source. <p>How is timeliness measured, i.e., which reference data and variables are used for comparison?</p>
Representativeness	<p>A data source that is representative accurately describes the occurrence of a health-related event over time and its distribution in the population by place and person (by data source).</p> <p>How is representativeness measured, i.e., which reference data and variables are used for comparison?</p>
Value of syndromic surveillance	In which way is syndromic surveillance of value to your work?
Syndromic surveillance effect on disease burden	In which way did syndromic surveillance affect the disease burden of the population served by your organisation? Please provide examples and figures.
Good characteristics	Which of the aforementioned characteristics/items of the syndromic surveillance system work well and why?
Future changes in characteristics	Which characteristic would you change and why?
Changes syndromic surveillance in general	<p>Which concrete developments are planned regarding syndromic surveillance involving by your organisation, e.g., developments of existing system, new syndromic surveillance activities, termination of syndromic surveillance activities?</p> <p>Why are these changes planned?</p>
Major take home message for future users	Which take home message/recommendation/warning regarding any of the aforementioned characteristics would be the most important one that you would give to future data providers to syndromic surveillance systems based on your experiences?

4.1.3 Stakeholder group: Public health authority & policy representatives

- I. Context
- II. Partnership at local/regional/national level & competencies
- VII. Reporting (of output)
- VIII. Response procedures (after reporting)
- IX. Costs
- X. Impact/Usefulness

I – Context	
Organisational context (of health system)	<p>In each country (or region) the context of data collection and surveillance is different. Especially, when data from the health system is used its organisation substantially affects the way syndromic surveillance performs.</p> <p>Relevant issues can be for example:</p> <ul style="list-style-type: none"> - Legal context (e.g., ownership of data) - Centralised or decentralised health system organisation - Treatment seeking behavior - Opening hours <p>Please elaborate by data source.</p>
Reason for setting up a syndromic surveillance system	What was the reason for setting up a syndromic surveillance system, e.g., a specific health threat such as heat wave or the threat of bioterrorism?
Original purpose of the system	What was the intended advantage of setting up a syndromic surveillance system, e.g., an earlier detection or rapid availability of information on a health event?
Actual purpose of the system	<p>For which purpose is the syndromic surveillance system used today?</p> <p>Was there a change or extension of utilisation, e.g., from early detection of pandemics to seasonal influenza surveillance?</p>

Existing, pilot, and expired systems

Stakeholder group: Public health authority & policy representatives

II - Partnership at local/regional/national level & competencies	
Getting started	How were partnerships built in the start phase of the syndromic surveillance system by the organisation operating the system? Which experiences were made?
Participants	Who is involved in syndromic surveillance in your organisation and at which administrative level?
Roles	Which roles do the different involved participants of your organisation take over in the process of syndromic surveillance?
Access to syndromic surveillance system and competencies	Which competencies, rights and duties does your organisation have in accessing and using the syndromic surveillance system and the output?
Impact of syndromic surveillance on your partnerships	In which way is the partnerships between your organisation and the organisation operating the syndromic surveillance system influenced by working together in syndromic surveillance? Are you working more closely now in other areas, e.g., joint response to an event? What was important to strengthen or enhance the partnership – what worked well and why?
Dissemination activities, measures to maintain partnership	Are there special measures or activities taken to maintain or foster partnership to your organisation, e.g., joint publications, joint workshops, regular feedback measures? <ul style="list-style-type: none"> • How often are activities performed? • What kind of activities worked well and why?

Existing, pilot, and expired systems

Stakeholder group: Public health authority & policy representatives

II - Partnership at local/regional/national level & competencies contd.	
Acceptability of syndromic surveillance	<p>How do you rate the acceptability of the syndromic surveillance activities?</p> <p><u>Indicators:</u></p> <ul style="list-style-type: none"> • Level of utilization by your organisation; • Level of use of syndromic surveillance results for primary work of your organisation (e.g., during health events, every day); • Linkages to other surveillance systems; • Extension of the syndromic surveillance system to cover additional syndromes, diseases, events or other data sources since establishment/during the last three years; • Impact and relevance of syndromic surveillance during public health events; • Flexibility of the syndromic surveillance system to respond to specific enquiries from your organisation; • Responsiveness to suggestions and comments from your organisation; • Ease and cost of accessing/receiving syndromic surveillance system results for your organisation; • Level of assurance of privacy and confidentiality regarding personal information of your organisation's staff accessing the information via the syndromic surveillance system's IT system; • Level of representativeness of syndromic surveillance results (i.e., coverage of population/area, data sources: percentage of participating institutions providing data, e.g., no. of emergency departments providing data of all emergency departments in an area, no. of public health events to which syndromic surveillance made a contribution).

Existing, pilot, and expired systems

Stakeholder group: Public health authority & policy representatives

VII - Reporting (of output)	
Getting started	<p>How were the reporting mechanisms of the syndromic surveillance system chosen at the beginning?</p> <ul style="list-style-type: none"> • Which reporting procedures were discussed and why were the currently used ones chosen? • Which experiences were made - which reporting mechanisms were easy/difficult to apply and why? • Which strategy worked to overcome problems in the reporting mechanisms? • Were there major changes during the last years in reporting mechanisms and why?
Reporting	<p>Which mechanisms are used to report the analysis results and their interpretation (output) to your organisation, i.e., email, fax, print-out, electronic interface (e.g., website) etc.?</p>
Reporting process	<p>How is the reporting process?</p> <ul style="list-style-type: none"> • Is the reporting done automatically or manually? • How often is reported? • How long does the reporting take? • Who receives the report in your organisation for which purpose? • Can the report be manipulated (e.g., interactive) or further used by the user and by which user? • Which effort does the reporting take (workload)?
Costs	<p>What are the costs per year related to reporting in your organisation?</p>

Existing, pilot, and expired systems

Stakeholder group: Public health authority & policy representatives

VIII - Response procedures (after reporting)	
Getting started	<p>How were the response procedures defined in the start phase of the syndromic surveillance system?</p> <ul style="list-style-type: none"> • Which response procedures were discussed and why were the currently used ones chosen? • Which experiences were made - which response procedures were easy/difficult to apply and why? • Which strategy worked to overcome problems in the response procedures? • Were there major changes in response procedures during the last years and why?
Response procedures	<p>How is the response process after reporting/alerting of the syndromic surveillance system?</p> <ul style="list-style-type: none"> • Is the response issued automatically or manually? • If manually, <ul style="list-style-type: none"> • Who initiates the response (training, function)? • Which steps are taken? • How often was a response initiated during the last year? • Who is involved in the response in your organisation with which roles? • Which effort does the initial response take (workload)?
False alerts	<p>How many responses were issued based on the reports of the syndromic surveillance system although there was no health event?</p> <p>How many of these false alerts are avoidable?</p> <p>Which syndromic surveillance system characteristics needs to be changed to decrease the number of false alerts?</p>
Syndromic surveillance effect on response	<p>Which effect does syndromic surveillance have on the response procedures in the region/country, e.g., timelier response, discouragement, in responses due to false alerts?</p> <p>Which effect does syndromic surveillance have on the involvement of your organisation in the response process, e.g., better cooperation, better management during public health event, awareness of the relevance of their work during public health events at other levels?</p> <p>Please provide examples.</p>
Costs	<p>What are the costs per year related to response procedures that are based on syndromic surveillance alerts?</p>

Existing, pilot, and expired systems

Stakeholder group: Public health authority & policy representatives

IX – Costs	
Costs	<p>If it is not possible to provide the costs per characteristic mentioned above maybe it is possible to provide overall costs for your organisation related to syndromic surveillance, if possible by year (or per year 1, 2, 3 etc.) or per phase (e.g., planning, setup, everyday use, maintenance/update) and divided by direct and indirect costs (e.g., workload) and internal and external costs (e.g., IT support).</p> <p>Did costs unexpectedly change and if so how and why?</p> <p>Did the amount of expected costs in the start phase of the syndromic surveillance system met the amount of real costs later on?</p>
Funding sources	<p>From which sources are the costs of your organisation related to syndromic surveillance funded, if possible divided by year 1, 2, 3, etc. or phase (planning, setup, everyday use, maintenance), direct and indirect funds and internal and external funds</p> <p>How were the funding sources identified in the start phase of the syndromic surveillance system?</p> <p>Which funding sources were discussed and why were the currently used ones chosen?</p> <p>Which experiences were made - which funding sources were easy/difficult to access/use and why?</p> <p>Which strategy worked to overcome funding problems?</p>
Impact of syndromic surveillance on costs in other areas	<p>Did syndromic surveillance have an impact on the costs of other areas/processes, e.g., whole surveillance system in general, response procedures – which and to which amount?</p>

Existing, pilot, and expired systems

Stakeholder group: Public health authority & policy representatives

X - Impact / Usefulness	
Value of syndromic surveillance	In which way is syndromic surveillance of value to your work?
Syndromic surveillance effect on disease burden	In which way did syndromic surveillance affect the disease burden of the population served by your organisation? Please provide examples and figures.
Good characteristics	Which of the aforementioned characteristics/items of your syndromic surveillance system work well and why?
Changes in characteristics	Which characteristic would you change and why?
Changes in syndromic surveillance in general	Which concrete developments are planned in syndromic surveillance by your organisation, e.g., developments of existing system, new syndromic surveillance activities, termination of syndromic surveillance activities? Why are these changes planned?
Evaluation of the syndromic surveillance system	Was your syndromic surveillance system evaluated and if so how and by whom? How was the outcome? What are strengths and weaknesses of your syndromic surveillance system? What are opportunities and threats of your syndromic surveillance system in the future?
Major take home message for future users	Which take home message/recommendation/warning regarding any of the aforementioned characteristics would be the most important one that you would give to future users based on your experiences?

4.2 Guidelines Planned Systems

4.2.1 Stakeholder group: Organisation operating the syndromic surveillance system

1. Context
2. Partnership at local/regional/national level & competencies
3. Data collection & preparation
4. IT infrastructure of the syndromic surveillance system
5. Data analysis methods
6. Output (of analysis)
7. Reporting (of output)
8. Response procedures (after reporting)
9. Costs
10. Impact/Usefulness

I - Context	
Organisational context (of health system)	<p>In each country (or region) the context of data collection and surveillance is different. Especially, when data from the health system is used its organisation substantially affects the way syndromic surveillance performs.</p> <p>Relevant issues can be for example:</p> <ul style="list-style-type: none"> - Legal context (e.g., ownership of data) - Centralised or decentralised health system organisation - Treatment seeking behavior - Opening hours <p>Please elaborate by data source.</p>
Reason for setting up Syndromic surveillance system	What is the reason for setting up a syndromic surveillance system, e.g., a specific health threat such as heat wave or the threat of bioterrorism?
Original purpose of the system	What is the intended advantage of setting up a syndromic surveillance system, e.g., an earlier detection or rapid availability of information on a health event?

Guidelines Planned Systems

Stakeholder group: Organisation operating the syndromic surveillance system

II - Partnership at local/regional/national level & competencies	
Getting started	<p>How are partnerships built for the syndromic surveillance system?</p> <p>Who is planned to be involved and why?</p> <p>Which experiences are made – which partnerships are easy or difficult to establish and why?</p> <p>Which strategy worked to overcome problems in partnerships?</p>
Partners	<p>Who will be involved in syndromic surveillance in the institution operating the system and beyond (e.g., data provider, public health authorities) and at which administrative level (national, regional, local)?</p> <p>If possible, please provide an organizational graph of the partnerships (figure, sketch).</p>
Roles	Which roles will the different involved partners take over in the process of syndromic surveillance?
Access to syndromic surveillance system and competencies	Which stakeholders will have access to the syndromic surveillance system, the data, the results, etc. and which competencies, rights and duties will the different partners have in accessing and using the syndromic surveillance system and the output?
Dissemination activities, measures to maintain partnership	<p>Are there special measures or activities planned to maintain or foster partnerships to stakeholders participating in syndromic surveillance, e.g., joint publications, joint workshops, regular feedback measures?</p> <p>How often are activities planned?</p>

Guidelines Planned Systems

Stakeholder group: Organisation operating the syndromic surveillance system

II - Partnership at local/regional/national level & competencies contd.	
Acceptability of syndromic surveillance	<p>How do you rate the acceptability of the planned syndromic surveillance activities among the different stakeholders at local/regional/national level?</p> <p><u>Indicators:</u></p> <ul style="list-style-type: none"> • Level of utilization by stakeholders; • No. of stakeholders and users; • Level of use of syndromic surveillance results for primary work of your organisation (e.g., during health events, every day); • Linkages to other surveillance systems; • Extension of syndromic surveillance system to cover additional syndromes, diseases, events or other data sources; • Flexibility to respond to specific user/stakeholder enquiries; • Planned responsiveness to suggestions and comments from stakeholders; • Ease and cost of data collection for data providers; • Ease and cost of reporting (accessing/receiving syndromic surveillance system results) for stakeholders; • Level of assurance of privacy and confidentiality regarding data provided for syndromic surveillance and if the system is IT-based regarding personal information of stakeholders accessing the data via the IT system; • Level of representativeness of syndromic surveillance results (i.e., coverage of population/area, data sources: percentage of participating institutions providing data, e.g., no. of emergency departments providing data of all emergency departments in an area, no. of public health events to which syndromic surveillance made a contribution).

Guidelines Planned Systems

Stakeholder group: Organisation operating the syndromic surveillance system

III - Data collection & preparation	
Getting started	<p>How is access to data sources gained? Which data sources are you trying to access and why? Which experiences are made - which data sources are easy/difficult to access and why? Which strategy worked to overcome problems in accessing data sources?</p>
Data sources	Which data sources are planned to provide data to the syndromic surveillance system, (i.e., emergency department, telephone helpline)?
Do you trust one data source more than another?	Which one? Why? Which are the main factors for you to trust this data source?
Purpose of data collection	Is the data collected for another purpose than syndromic surveillance or will (any part of) the data only collected for syndromic surveillance purposes and if so which?
Data collection process	<p>How is the data collection process?</p> <ul style="list-style-type: none"> • electronic or paper-based; • When is data collected, e.g. while patient is treated, within 24 hours after treatment of a patient, etc. • Who collects the data in the data providing institutions? • Which level of training do the staff have that collects the data, especially diagnostic information, i.e. ICD codes, regarding the different levels in the institution, e.g., in an emergency department: nurses, physicians, or administrative staff. • Will the staff of the data provider collecting the data receive specific training or information for collecting data for syndromic surveillance purposes? What kind of training/information?
Data provision process	<p>How often will data be provided to the syndromic surveillance system (covering which period of time)? How will data be provided, i.e.,</p> <ul style="list-style-type: none"> • Automatic (continuous connection between data base of data provider and institution operating the syndromic surveillance system) or manually • Push or pull (i.e., institutions operating the syndromic surveillance system ask for data or data provider provides data (either automatically or manually)?

Guidelines Planned Systems

Stakeholder group: Organisation operating the syndromic surveillance system

III - Data collection & preparation contd.	
Indicators/variables	<p>Which indicators or variables will be provided that are used in the syndromic surveillance system (by data provider), i.e.,</p> <ul style="list-style-type: none"> • Date • Place (geographic data) • Age, Gender, • Severity • Diagnostic information: chief complaint, working diagnosis, final diagnosis, etc. • Etc. • Other (external) data variables, e.g., temperature (meteorological)?
Format	<p>In which format will the data, especially diagnostic information, be provided by the data provider to the institution operating the syndromic system, i.e.,</p> <ul style="list-style-type: none"> • Internationally used code (e.g., ICD) • Nationally, regionally or locally used code • Free-text • Aggregated data (i.e., cases per day) or case specific data
Data preparation for syndromic surveillance	<p>In which way will the provided data have to be prepared (e.g., missing values, seasonal variation, change of data format, generation of new variables, natural language processing, aggregation) before it can be analysed for syndromic surveillance?</p> <p>Will analyses of long-term historical data be necessary?</p> <p>How often will preparation have to be done, i.e., every time data is provided or once before data is used for the first time?</p> <p>Which effort will this preparation take (time, costs)?</p>
Adjustment of collected data	<p>Will adjustment of collected data be possible or necessary, e.g., new syndrome/case definition?</p> <ul style="list-style-type: none"> • On which occasion? • For which purpose? • By whom? • Which effort?
Public health events	<p>Which data source will be used to cover which public health problem, i.e., heat waves, influenza outbreak, unknown health threat?</p>
Syndromes	<p>Which syndromes, e.g., Influenza-like-illness, gastrointestinal syndrome, will be covered with the syndromic surveillance system?</p> <p>How will syndromes be defined based on which variables from which data source, i.e. (i.e., influenza-like-illness = working diagnosis in ED, ICDx-y, symptom x + age y)</p>

Guidelines Planned Systems

Stakeholder group: Organisation operating the syndromic surveillance system

III - Data collection & preparation contd.	
Data quality	<p>What is the estimated data quality, i.e., the completeness and validity of the data provided to the syndromic surveillance system, e.g.:</p> <ul style="list-style-type: none"> • missing values; • accuracy of data collection, i.e., ICD is reported with one digit and not with three; • variety of data, i.e., only few ICD codes are collected; <ul style="list-style-type: none"> • divided by data source and variable (if there are differences between variables provided for syndromic surveillance, e.g., if new variables have to be generated); • divided by syndrome; • divided by analysis method? <p>How will data quality be measured, i.e., which reference data and variables are used for comparison?</p>
Costs	What are the estimated costs per year related to the data collection and data preparation process?

Guidelines Planned Systems

Stakeholder group: Organisation operating the syndromic surveillance system

IV - IT infrastructure of the syndromic surveillance system	
Getting started	<p>How is the IT infrastructure setup planned?</p> <ul style="list-style-type: none"> • Which IT system setup is planned to be used and why? • Which experiences are made - which parts of the IT infrastructure are easy/difficult to setup and why? • Which strategy worked to overcome problems in setting up the IT infrastructure?
IT infrastructure	Please describe the planned IT infrastructure components, data flow, communication channels/interfaces, features, etc. and provide a sketch/flow chart if possible.
Automatic or manual system	Which parts of the system will work automatically and which manually?
Location & access	<p>In which institution will the IT infrastructure or different components be located?</p> <p>Who will have access to which parts of the IT infrastructure?</p> <p>Who will have the responsibility for service/maintenance of the (different parts of the) IT infrastructure?</p>
Costs	What are the estimated costs per year related to setting up and maintaining the (different parts of the) IT infrastructure?
Simplicity	<p>What is the estimated simplicity, referring to both the structure of the syndromic surveillance system and its ease of operation. Syndromic surveillance systems should be as simple as possible while still meeting their objectives.</p> <ul style="list-style-type: none"> • Level of integration with existing surveillance systems; • Time and resources spent to collect, transfer, analyse data, maintain and update the system and disseminate reports/alerts using the IT infrastructure; • Staff training requirements for syndromic surveillance; • Easily applicable case definitions and indicator rationales; • Output, reports, interface that is easy to understand and easy to use.
Flexibility	<p>What is the estimated flexibility referring to the syndromic surveillance system's ability to change as needs change. A flexible syndromic surveillance system can adapt to changing information needs or operating conditions with little additional time, personnel, or allocated funds.</p> <ul style="list-style-type: none"> • Easy integration in existing surveillance systems; • Easy integration in new regions; • Easy adaptation to new case definitions/rationales and additional or new data sources and incorporation of other information technology; • Dependence on funding; • Dependence on no./variety of. reporting sources; • Flexibility to respond to specific user enquiries.

Guidelines Planned Systems

Stakeholder group: Organisation operating the syndromic surveillance system

IV - IT infrastructure of the syndromic surveillance system contd.	
Stability	<p>What is the estimated stability, referring to the reliability (i.e., the ability to collect, manage, and provide data properly without failure) and availability (the ability to be operational when it is needed) of the syndromic surveillance system?</p> <ul style="list-style-type: none">• Ability to collect, manage and provide data properly without failure;• Ability to adapt to changes (i.e., new coding);• Ability to be operational when necessary;• No. of unscheduled outages and down times of the system;• Amount of costs involved in repairing the system;• Percentage of time that the syndromic surveillance system is fully operating;• Difference between estimated and actual amount of time required to manage data and release results with the IT infrastructure.

Guidelines Planned Systems

Stakeholder group: Organisation operating the syndromic surveillance system

V - Data analysis methods	
Getting started	<p>How are the data analysis methods chosen?</p> <ul style="list-style-type: none"> • Which analysis methods are discussed and why? • Which experiences are made - which analysis methods are easy/difficult to apply and why? • Which strategy worked to overcome problems in applying analysis methods?
Analysis methods	<p>Which analysis methods will be applied in the syndromic surveillance system, (e.g., cumulative sums, moving averages, modelling, spatial-temporal methods, etc.)?</p> <p>Please provide the specific mathematical connotation including your adaptations if possible.</p>
Analysis process	<p>How will be the process of analysing data be?</p> <ul style="list-style-type: none"> • Automatically or manually? • If manually, <ul style="list-style-type: none"> • who will analyse the data (training, function)? • which software will be used? • which analysis steps will be taken (e.g., preparatory analysis, e.g., statistical tests, actual analysis, visualisation of results, etc.) • How often will analyses be done? • How long will the analysis process take? • Which effort will the analysis process take (workload)?
Adjustment of analysis methods	<p>Will you have to adapt the analysis methods before applying them in your syndromic surveillance system, i.e., thresholds, certain variables?</p> <p>How big is the estimated effort for that?</p>
Costs	<p>What are the estimated costs per year related to the data analysis?</p>

Guidelines Planned Systems

Stakeholder group: Organisation operating the syndromic surveillance system

VI - Output (of analysis)	
Getting started	<p>How are design and functions of the direct output of the syndromic surveillance system chosen?</p> <ul style="list-style-type: none"> • Which output design and functions are discussed and why? • Which experiences are made - which outputs are easy/difficult to apply and why? • Which strategy worked to overcome problems in the output?
Output	<p>Which direct output will the syndromic surveillance system produce after analysis, i.e., report, alerts, electronic display (e.g., online interface)?</p> <p>Will the output be stored for later analysis or interpretation? In which form, e.g., raw or aggregated data or analysis results or reports?</p>
Output process	<p>How will be the output process?</p> <ul style="list-style-type: none"> • Will the output be generated automatically or manually? • If manually, <ul style="list-style-type: none"> • Who will produce or manipulate the output (training, function)? • Which software will be used? • Which steps will be taken (e.g., preparation of results for visualisation, etc.)? • How often will outputs be produced? • How long will the output process take? • Who will receive the output for which purpose? • Will the output be changeable by the user and by which user? • Which effort will the output production take (workload)?
Alert	<p>At which threshold will the syndromic surveillance system produce an alert, i.e., 3 standard deviations (by data source, syndrome, analysis method)?</p> <p>How long will an alert period be to issue any kind of public health action, i.e., after three consecutive alert days?</p>
Interpretation	<p>Who will interpret the results of the analyses?</p> <p>How will interpretation results be used, e.g., in reports to stakeholders?</p> <p>Who will receive interpretations of the results for which purpose?</p> <p>How long will the interpretation of output take?</p> <p>Which effort will the interpretation take (workload)?</p>
Costs	<p>What are the estimated costs per year related to producing and interpreting output?</p>

Guidelines Planned Systems

Stakeholder group: Organisation operating the syndromic surveillance system

VII - Reporting (of output)	
Getting started	<p>How are the reporting mechanisms of the syndromic surveillance system chosen?</p> <ul style="list-style-type: none"> • Which reporting mechanisms are discussed and why? • Which experiences are made - which reporting mechanisms are easy/difficult to apply and why? • Which strategy worked to overcome problems in the reporting mechanisms?
Reporting	<p>Which mechanisms will be used to report the analysis results and their interpretation (output) to users/stakeholders, i.e., email, fax, print-out, electronic interface (e.g., website) etc.?</p>
Reporting process	<p>How will be the reporting process?</p> <ul style="list-style-type: none"> • Is the reporting done automatically or manually? • If manually, <ul style="list-style-type: none"> • Who will produce the report (training, function)? • Which software will be used? • Which steps will be taken (e.g., preparation of output for reporting, etc.) • How often will be reported? • How long will the reporting take? • Who will receive the report for which purpose? • Will the report be manipulable (e.g., interactive) or further used by the user, how and by which user? • Which effort will the reporting take (workload)?
Costs	<p>What will be the costs per year related to reporting?</p>

Guidelines Planned Systems

Stakeholder group: Organisation operating the syndromic surveillance system

VIII - Response procedures (after reporting)	
Getting started	<p>How are the response procedures defined?</p> <ul style="list-style-type: none"> • Which response procedures are discussed and why? • Which experiences are made - which response procedures are easy/difficult to apply and why? • Which strategy worked to overcome problems in the response procedures?
Response procedures	<p>How will be the response process after reporting/alerting of the syndromic surveillance system?</p> <ul style="list-style-type: none"> • Is the response issued automatically or manually? • If manually, <ul style="list-style-type: none"> • Who will initiate the response (training, function)? • Which steps will be taken? • Who will be involved in the response with which roles? • Which effort will the initial response take (workload)?
Syndromic surveillance effect on response	<p>Which effect might syndromic surveillance have on the response procedures in the region/country, e.g., timelier response, discouragement in responses due to false alerts?</p> <p>Which effect might syndromic surveillance have on the involvement of important/affected stakeholders in the response process, e.g., health care institutions, e.g., better cooperation, better management during public health event, awareness to public health relevance of their work during public health events?</p>
Costs	<p>What are the estimated costs per year related to response procedures that are based on syndromic surveillance alerts?</p>

Guidelines Planned Systems

Stakeholder group: Organisation operating the syndromic surveillance system

IX - Costs	
Costs	If it is not possible to provide the cost estimation per characteristic mentioned above maybe it is possible to provide overall estimated costs for the syndromic surveillance system, if possible divided by year (or per year 1, 2, 3 etc.) or per phase (e.g., planning, setup, everyday use, maintenance/update) and by direct and indirect costs (e.g., workload) and internal and external costs (e.g., data provider).
Funding sources	From which sources will the syndromic surveillance system be funded, if possible divided by year 1, 2, 3, etc. or phase (planning, setup, everyday use, maintenance), by direct and indirect funds and internal and external funds How are the funding sources identified? Which funding sources are discussed and why? Which experiences are made - which funding sources are easy/difficult to access/use and why? Which strategy worked to overcome funding problems?
Impact of syndromic surveillance on costs in other areas	Is it anticipated that syndromic surveillance will have an impact on the costs of other areas/processes, e.g., whole surveillance system in general, response procedures – which and to which amount?

Guidelines Planned Systems

Stakeholder group: Organisation operating the syndromic surveillance system

X - Impact / Usefulness	
Timeliness	<p>Estimated time intervals between different steps of syndromic surveillance:</p> <ul style="list-style-type: none"> • between onset of a health event and data collection; • between data collection and data provision to syndromic surveillance system; • between data provision to syndromic surveillance system and alert; • between alert and response/intervention by public health authority; <ul style="list-style-type: none"> • divided by data source; • divided by syndrome; • divided by analysis method. <p>How will timeliness be measured, i.e., which reference data and variables will be used for comparison?</p>
Sensitivity	<p>What is the estimated sensitivity of the syndromic surveillance system? Sensitivity can refer:</p> <ul style="list-style-type: none"> • at the level of case reporting to the proportion of cases of a disease (or other health-related event) detected by the syndromic surveillance system; • to the ability to detect outbreaks, including the ability to monitor changes in the number of cases over time; • proportion of cases of a health threat detected until an event is detected; • ability to monitor changes during an outbreak (temporal, spatial) <ul style="list-style-type: none"> • divided by data source; • divided by syndrome; • divided by analysis method. <p>How will sensitivity be measured, i.e., which reference data and variables are used for comparison?</p>
Specificity	<p>What is the estimated specificity of the syndromic surveillance system, i.e., the proportion of cases without the health condition under surveillance that are correctly identified,</p> <ul style="list-style-type: none"> • divided by data source; • divided by syndrome; • divided by analysis method? <p>How will specificity be measured, i.e., which reference data and variables are used for comparison?</p>

Guidelines Planned Systems

Stakeholder group: Organisation operating the syndromic surveillance system

X - Impact / Usefulness	
Validity	<p>What is the estimated validity of the syndromic surveillance system, i.e. the degree to which the syndromic surveillance system measures what it is intended to measure, i.e., positive predictive value, negative predictive value,</p> <ul style="list-style-type: none"> • divided by data source; • divided by syndrome; • divided by analysis method? <p>How will validity be measured, i.e., which reference data and variables are used for comparison?</p>
Representativeness	<p>What is the estimated representativeness of the syndromic surveillance system, i.e., accurate description of the occurrence of a health-related event over time and its distribution in the population by place and person,</p> <ul style="list-style-type: none"> • divided by data source; • divided by syndrome; • divided by analysis method. <p>How will representativeness be measured, i.e., which reference data and variables are used for comparison?</p>
Value of syndromic surveillance	In which way is syndromic surveillance anticipated to be of value to your work?
Syndromic surveillance effect on disease burden	In which way is syndromic surveillance anticipated to affect the disease burden of the population served by your organisation? Please provide examples and figures.
Good characteristics	Which of the aforementioned characteristics/items of your syndromic surveillance system might work well and why?
Changes in characteristics	Which characteristic do you intend to further adjust and why?
Changes in syndromic surveillance in general	<p>Which concrete developments are planned in syndromic surveillance by your organisation, e.g., setup of system, new syndromic surveillance activities, termination of syndromic surveillance activities?</p> <p>Why are these changes planned?</p>
Evaluation of the syndromic surveillance system	<p>Do you intend to evaluate your syndromic surveillance system and if so how and by whom?</p> <p>What could become strengths and weaknesses of your syndromic surveillance system?</p> <p>What could become opportunities and threats of your syndromic surveillance system?</p>
Major take home message for future users	Which take home message/recommendation/warning regarding any of the aforementioned characteristics would be the most important one that you would give to future users based on your experiences?

4.2.2 Stakeholder group: Data providers

- II. Partnership at local/regional/national level & competencies
- III. Data collection & preparation
- VII. Reporting (of output)
- VIII. Response procedures (after reporting)
- IX. Costs
- X. Impact/Usefulness

II - Partnership at local/regional/national level & competencies	
Getting started	How are partnerships built by the organisation operating the system? Which experiences are made?
Participants	Who will be involved in syndromic surveillance in your organisation and at which administrative level?
Roles	Which roles will the different involved participants of your organisation take over in the process of syndromic surveillance?
Access to syndromic surveillance system and competencies	Which competencies, rights and duties will your organisation have in accessing and using the syndromic surveillance system and the output?
Impact of syndromic surveillance on your partnerships	In which way might the partnerships between your organisation and the organisation operating the syndromic surveillance system be influenced by working together in syndromic surveillance, e.g., working more closely in other areas, e.g., joint response to an event? What might be important to strengthen or enhance the partnership?
Dissemination activities, measures to maintain partnership	Will there special measures or activities taken to maintain or foster partnership to your organisation, e.g., joint publications, joint workshops, regular feedback measures? How often will activities be performed?

Guidelines Planned Systems
Stakeholder group: Data providers

II - Partnership at local/regional/national level & competencies contd.	
Acceptability of syndromic surveillance	<p>How do you estimate the acceptability of the syndromic surveillance activities?</p> <p><u>Indicators:</u></p> <ul style="list-style-type: none"> • Level of utilization by your organisation; • Level of use of syndromic surveillance results for the primary work of your organisation (e.g., during health events, every day); • Flexibility of the syndromic surveillance system to respond to specific enquiries from your organisation; • Responsiveness to suggestions and comments from your organisation; • Ease and cost of data collection for syndromic surveillance for your organisation; • Ease and cost of accessing/receiving syndromic surveillance system results for your organisation; • Level of assurance of privacy and confidentiality regarding data provided for syndromic surveillance by your organisation and if the system is IT-based regarding personal information of your organisation's staff accessing the information via the IT system; • Level of representativeness of syndromic surveillance results (i.e., coverage of population/area, no. of public health events to which syndromic surveillance made a contribution).

Guidelines Planned Systems
Stakeholder group: Data providers

III - Data collection & preparation	
Getting started	How is access to your data sources gained by the organisation operating the syndromic surveillance system? Which experiences were made?
Data sources	From which data sources of your organisation will data be provided to the syndromic surveillance system, (i.e., in the emergency department: working diagnosis, discharge diagnosis)?
Do you trust one data source more than another?	Which one? Why? Which are the main factors for you to trust this data source for syndromic surveillance?
Purpose of data collection	Is the data collected for another purpose than syndromic surveillance or will (any part of) the data only be collected for syndromic surveillance purposes and if so which?
Data collection process	How is the data collection process? Electronic or paper-based <ul style="list-style-type: none"> • When is data collected, e.g. while patient is treated, within 24 hours of treatment of a patient, etc. • Who collects the data in your organisation? • Which level of training do the staff have that collect the data, especially diagnostic information, i.e. ICD codes, regarding the different levels in your organisation, e.g., in an emergency department: nurses, physicians, or administrative staff. • Will your staff collecting the data receive specific training or information for collecting data for syndromic surveillance purposes? What kind of training/information?
Data provision process	How often will data be provided to the syndromic surveillance system (covering which period of time)? How will data be provided, i.e., <ul style="list-style-type: none"> • Automatic (continuous connection between data base of data provider and institution operating the syndromic surveillance system) or manually • Push or pull (i.e., institutions operating the syndromic surveillance system ask for data or your organisation provides data (either automatically or manually)?

Guidelines Planned Systems
Stakeholder group: Data providers

III - Data collection & preparation contd.	
Indicators/variables	<p>Which indicators or variables will be provided by your organisation that are to be used in the syndromic surveillance system, i.e.,</p> <ul style="list-style-type: none"> • Date • Place (geographic data) • Age, Gender, • Severity • Diagnostic information: chief complaint, working diagnosis, final diagnosis, etc. • Etc. • Other (external) data variables, e.g., temperature (meteorological)?
Format	<p>In which format will the data, especially diagnostic information, be provided by your organisation to the institution operating the syndromic surveillance system, i.e.,</p> <ul style="list-style-type: none"> • Internationally used code (e.g., ICD) • Nationally, regionally or locally used code • Free-text • Aggregated data (i.e., cases per day) or case specific data
Data preparation for syndromic surveillance	<p>Will the raw data have to be further prepared (e.g., missing values, seasonal variation, change of data format, generation of new variables, natural language processing, aggregation) before it is provided to the organisation operating the syndromic surveillance system?</p> <p>How often will preparation have to be done, i.e., every time data is provided or once before data is used for the first time?</p> <p>Which effort will this preparation take (time, costs)?</p>
Adjustment of collected data	<p>Will adjustment of collected data possible or necessary (for the purpose of syndromic surveillance), e.g., new case/syndrome definition?</p> <ul style="list-style-type: none"> • On which occasion? • For which purpose? • By whom? • Which effort?

Guidelines Planned Systems
Stakeholder group: Data providers

III - Data collection & preparation contd.	
Data quality	<p>What is the estimated data quality which reflects the completeness and validity of the data provided to the syndromic surveillance system,</p> <ul style="list-style-type: none"> • missing values; • accuracy of data collection, i.e., ICD is only reported with one digit instead of three; • variety of data, i.e., only few ICD codes are collected; <ul style="list-style-type: none"> • divided by data source and variable (if there are differences between variables provided for syndromic surveillance, e.g., if new variables have to be generated); <p>How will data quality be measured, i.e., which reference data and variables are used for comparison?</p>
Costs	<p>What are the estimated costs per year related to the data collection and data preparation process in your organisation?</p>

Guidelines Planned Systems
Stakeholder group: Data providers

VII - Reporting (of output)	
Getting started	<p>How are the reporting mechanisms of the of the syndromic surveillance system chosen?</p> <ul style="list-style-type: none"> • Which reporting mechanisms are discussed and why? • Which experiences were made - which reporting mechanisms were easy/difficult to apply and why? • Which strategy worked to overcome problems in the reporting mechanisms?
Reporting	<p>Which mechanisms will be used to report the analysis results and their interpretation (output) to your organisation, i.e., email, fax, print-out, electronic interface (e.g., website) etc.?</p>
Reporting process	<p>How will be the reporting process?</p> <ul style="list-style-type: none"> • Will the reporting be done automatically or manually? • If manually, <ul style="list-style-type: none"> • Who will produce the report (training, function)? • Which software will be used? • Which steps will be taken (e.g., preparation of output for reporting, etc.) • How often will be reported? • How long will reporting take? • Who will receive the report in your organisation for which purpose? • Will the report be changeable (e.g., interactive) or further used by the user in your organisaiton and by which user? • Which effort will the reporting take in your organisation (workload)?
Costs	<p>What are the costs per year related to reporting in your organisation?</p>

Guidelines Planned Systems
Stakeholder group: Data providers

VIII - Response procedures (after reporting)	
Getting started	<p>How will the response procedures involving your organisation be defined?</p> <ul style="list-style-type: none"> • Which response procedures are discussed and why? • Which experiences are made - which response procedures are easy/difficult to apply and why? • Which strategy worked to overcome problems in the response procedures?
Response procedures	<p>How will the response process after reporting/alerting of the syndromic surveillance system?</p> <ul style="list-style-type: none"> • Is the response issued automatically or manually? • If manually, <ul style="list-style-type: none"> • Who will initiate the response (training, function)? • Which steps will be taken? • Who will be involved in the response with which roles? • Which effort will the initial response take (workload)?
Syndromic surveillance effect on response	<p>Which effect might syndromic surveillance have on the response procedures in the region/country, e.g., timelier response, discouragement in responses due to false alerts?</p> <p>Which effect might syndromic surveillance have on the involvement of your organisation in the response process, e.g., better cooperation, better management during public health event, awareness of the relevance of your work during public health events?</p>
Costs	<p>What are the estimated costs per year related to response procedures that are based on syndromic surveillance alerts in your organisation?</p>

Guidelines Planned Systems
Stakeholder group: Data providers

IX – Costs	
Costs	If it is not possible to provide the estimated costs per characteristic mentioned above maybe it is possible to provide overall estimated costs for your organisation related to syndromic surveillance, if possible divided by year (or per year 1, 2, 3 etc.) or per phase (e.g., planning, setup, everyday use, maintenance/update) and by direct and indirect costs (e.g., workload) and internal and external costs (e.g., IT support).
Funding sources	From which sources will the costs of your organisation related to syndromic surveillance be funded, if possible divided by year 1, 2, 3, etc. or phase (planning, setup, everyday use, maintenance), by direct and indirect funds and internal and external funds How are the funding sources identified? Which funding sources are discussed and why? Which experiences are made - which funding sources are easy/difficult to access/use and why? Which strategy worked to overcome funding problems?
Impact of syndromic surveillance on costs in other areas	Will syndromic surveillance have an impact on the costs of other areas/processes, e.g., management of everyday work/during health events, response procedures – which and to which amount?

Guidelines Planned Systems
Stakeholder group: Data providers

X - Impact / Usefulness	
Timeliness	<p>What is the estimated timeliness, i.e., time intervals between different steps of syndromic surveillance (by data source):</p> <ul style="list-style-type: none"> • between onset of a health event and data collection; • between data collection and data provision to syndromic surveillance system; • between data provision to syndromic surveillance system and alert to your organisation; • between alert and response/intervention by public health authority involving your organisation; <p>How will timeliness be measured, i.e., which reference data and variables are used for comparison?</p>
Representativeness	<p>What is the estimated representativeness, i.e., accurately describes the occurrence of a health-related event over time and its distribution in the population by place and person (by data source)?</p> <p>How will representativeness be measured, i.e., which reference data and variables are used for comparison?</p>
Value of syndromic surveillance	In which way will syndromic surveillance be of value to your work?
Syndromic surveillance effect on disease burden	In which way will syndromic surveillance affect the disease burden of the population served by your organisation? Please provide examples and figures.
Good characteristics	Which of the aforementioned characteristics/items of the syndromic surveillance system might work well and why?
Changes in characteristics	Which characteristic do you intend to further adjust and why?
Changes in syndromic surveillance in general	<p>Which concrete developments are planned regarding syndromic surveillance in your organisation, e.g., setup of system, new syndromic surveillance activities, termination of syndromic surveillance activities?</p> <p>Why are these changes planned?</p>
Major take home message for future users	Which take home message/recommendation/warning regarding any of the aforementioned characteristics would be the most important one that you would give to future data providers to syndromic surveillance systems based on your experiences?

4.2.3 Stakeholder group: Public health authority & policy representatives

- I. Context
- II. Partnership at local/regional/national level & competencies
- VII. Reporting (of output)
- VIII. Response procedures (after reporting)
- IX. Costs
- X. Impact/Usefulness

I - Context	
Organisational context (of health system)	<p>In each country (or region) the context of data collection and surveillance is different. Especially, when data from the health system is used its organisation substantially affects the way syndromic surveillance performs.</p> <p>Relevant issues can be for example:</p> <ul style="list-style-type: none"> - Legal context (e.g., ownership of data) - Centralised or decentralised health system organisation - Treatment seeking behavior - Opening hours
Reason for setting up a syndromic surveillance system	What is the reason for setting up a syndromic surveillance system, e.g., a specific health threat such as heat wave or the threat of bioterrorism?
Original purpose of the system	What is the intended advantage of setting up a syndromic surveillance system, e.g., an earlier detection or rapid availability of information on a health event?

Guidelines Planned Systems

Stakeholder group: Public health authority & policy representatives

II - Partnership at local/regional/national level & competencies	
Getting started	How are partnerships built by the organisation operating the system? Which experiences are made?
Participants	Who will be involved in syndromic surveillance in your organisation and at which administrative level?
Roles	Which roles will the different involved participants in your organisation take over in the process of syndromic surveillance?
Access to syndromic surveillance system and competencies	Which competencies, rights and duties will your organisation have in accessing and using the syndromic surveillance system and the output?
Impact of syndromic surveillance on your partnerships	In which way might the partnerships between your organisation and the organisation operating the syndromic surveillance system be influenced by working together in syndromic surveillance? Will you work more closely in other areas, e.g., joint response to an event? What will be important to strengthen or enhance the partnership?
Dissemination activities, measures to maintain partnership	Will there be special measures or activities taken to maintain or foster partnership to your organisation, e.g., joint publications, joint workshops, regular feedback measures? How often will these activities be performed?

Guidelines Planned Systems

Stakeholder group: Public health authority & policy representatives

II - Partnership at local/regional/national level & competencies contd.	
Acceptability of syndromic surveillance	<p>How do you estimate the acceptability of the syndromic surveillance activities?</p> <p><u>Indicators:</u></p> <ul style="list-style-type: none"> • Level of utilization by your organisation; • Level of use of syndromic surveillance results for the primary work of your organisation (e.g., during health events, every day); • Linkages to other surveillance systems; • Extension of syndromic surveillance system to cover additional syndromes, diseases, events or other data sources since establishment/during the last three years; • Flexibility of the syndromic surveillance system to respond to specific enquiries from your organisation; • Responsiveness to suggestions and comments from your organisation; • Ease and cost of accessing/receiving syndromic surveillance system results for your organisation; • Level of assurance of privacy and confidentiality regarding personal information of your organisation's staff accessing the information via the syndromic surveillance system's IT system; • Level of representativeness of syndromic surveillance results (i.e., coverage of population/area, data sources: percentage of participating institutions providing data, e.g., no. of emergency departments providing data of all emergency departments in an area, no. of public health events to which syndromic surveillance made a contribution).

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VII - Reporting (of output)	
Getting started	<p>How will the reporting mechanisms of the of the syndromic surveillance system be chosen?</p> <ul style="list-style-type: none"> • Which reporting mechanisms are discussed and why? • Which experiences are made - which reporting mechanisms are easy/difficult to apply and why? • Which strategy worked to overcome problems in the reporting mechanisms?
Reporting	<p>Which mechanisms will be used to report the analysis results and their interpretation (output) to the users in your organisation, i.e., email, fax, print-out, electronic interface (e.g., website) etc.?</p>
Reporting process	<p>How will be the reporting process?</p> <ul style="list-style-type: none"> • Will reporting be done automatically or manually? • If manually, <ul style="list-style-type: none"> • Who will produce the report (training, function)? • Which software will be used? • Which steps will be taken (e.g., preparation of output for reporting, etc.) • How often will be reported? • How long will reporting take? • Who will receive the report in your organisation for which purpose? • Will the report be changeable (e.g., interactive) or further used by the user in your organisation and by which user? • Which effort will the reporting take (workload)?
Costs	<p>What are the estimated costs per year related to reporting in your organisation?</p>

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VIII - Response procedures (after reporting)	
Getting started	<p>How are the response procedures defined?</p> <ul style="list-style-type: none"> • Which response procedures are discussed and why? • Which experiences are made - which response procedures are easy/difficult to apply and why? • Which strategy worked to overcome problems in the response procedures?
Response procedures	<p>How will the response process after reporting/alerting of the syndromic surveillance system?</p> <ul style="list-style-type: none"> • Is the response issued automatically or manually? • If manually, <ul style="list-style-type: none"> • Who will initiate the response (training, function)? • Which steps will be taken? • How often will a response be initiated during the last year? • Who will be involved in the response in your organisation with which roles? • Which effort will the initial response take (workload)?
Syndromic surveillance effect on response	<p>Which effect might syndromic surveillance have on the response procedures in the region/country, e.g., timelier response, discouragement in responses due to false alerts?</p> <p>Which effect will syndromic surveillance have on the involvement of your organisation in the response process, e.g., better cooperation, better management during public health event, awareness of the relevance of their work during public health events at other levels?</p>
Costs	<p>What are the estimated costs per year related to response procedures that are based on syndromic surveillance alerts in your organisation?</p>

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IX – Costs	
Costs	If it is not possible to provide the estimated costs per characteristic mentioned above maybe it is possible to provide overall estimated costs for your organisation related to syndromic surveillance, if possible divided by year (or per year 1, 2, 3 etc.) or per phase (e.g., planning, setup, everyday use, maintenance/update) and by direct and indirect costs (e.g., workload) and internal and external costs (e.g., IT support).
Funding sources	From which sources will the costs of your organisation related to syndromic surveillance be funded, if possible divided by year 1, 2, 3, etc. or phase (planning setup, everyday use, maintenance), by direct and indirect funds and internal and external funds How are the funding sources identified? Which funding sources are discussed and why? Which experiences are made - which funding sources are easy/difficult to access/use and why? Which strategy worked to overcome funding problems?
Impact of syndromic surveillance on costs in other areas	Will syndromic surveillance have an impact on the costs of other areas/processes, e.g., whole surveillance system in general, response procedures – which and to which amount?

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X - Impact / Usefulness	
Value of syndromic surveillance	In which way will syndromic surveillance be of value to your work?
Syndromic surveillance effect on disease burden	In which way will syndromic surveillance affect the disease burden of the population served by your organisation? Please provide examples and figures.
Good characteristics	Which of the aforementioned characteristics/items of the syndromic surveillance system work well and why?
Changes in characteristics	Which characteristic would you change and why?
Changes in syndromic surveillance in general	Which concrete developments are planned in syndromic surveillance by your organisation, e.g., setup of the system, new syndromic surveillance activities, termination of syndromic surveillance activities? Why are these changes planned?
Evaluation of the syndromic surveillance system	Are you planning to evaluate the syndromic surveillance system and if so how and by whom? What might be strengths and weaknesses of your syndromic surveillance system? What might be opportunities and threats of your syndromic surveillance system in the future?
Major take home message for future users	Which take home message/recommendation/warning regarding any of the aforementioned characteristics would be the most important one that you would give to future users based on your experiences?

5. Synthesis of knowledge exchange

Experiences and lessons learnt gained in conceptualizing, setting up, operating, using and maintaining a syndromic surveillance provides very valuable knowledge to those who intend to implement or adjust a syndromic surveillance system and to enhance syndromic surveillance in general. Good practices and the determinants can be assessed in order to find out what can make syndromic surveillance systems useful.

The last session of a site visit could focus on summarizing specific strengths and weaknesses and specific lessons learnt. Based on this summary a synthesis could be drawn: which characteristics determine which quality indicator of the visited system to which extend.

The following framework could guide the discussions during this last session:

5.1.1. Strengths and weaknesses of the system regarding the following quality indicators

- Timeliness
- Sensitivity
- Specificity
- Validity – e.g., positive predictive value
- Data quality
- Simplicity
- Flexibility
- Stability
- Acceptability
- Representativeness

5.1.2. Determinants of strengths and weaknesses of the system by quality indicator taking into account the following factors

- Context
- Partnership
- Data
- IT infrastructure
- Data analysis
- Output
- Reporting
- Response
- Costs

5.1.3. Most important determinants (biggest influence on strength and weaknesses with biggest impact on usefulness of syndromic surveillance system).