Country Visits

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Work Package 5

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TRIPLE S
Syndromic Surveillance Systems in Europe

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Contents

Abbreviations

ASTER	Alerte et surveillance en temps réel
CDC	Centers for Disease Control and Prevention
DMOS	Danish medical on-call service
ED	Emergency department
EDSSS	Emergency Department Syndromic Surveillance System
EU	European Union
GETWELL	Generating Epidemiological Trends from Web Logs, Like
GIS	Geographic Information System
GP	General Practitioner
ICARES	Integrated Crisis Alert and Response System
IT	Information Technology
KIzSS	Kinderdagverblijven Infectieziekten Surveillance Systeem
n.a.	not applicable
NHS	National Health System
n.i.	no information
OOH	Out-of-hours
PIPeR	Pandemic Influenza Primary Care Reporting
RCGP	Royal College of General Practitioners
SAM@EMR	Surveillance, Assurance, and Monitoring in the Euregio Maas-Rhine
SIDARTHa	European Emergency Data-based System for Information on, Detection and Analysis of Risks and Threats to Health
SISRS	Scottish Influenza Surveillance Reporting Scheme
SURSAUD	Surveillance sanitaire des urgences et des décès
SyS	Syndromic surveillance
Triple-S-AGE	Syndromic Surveillance Survey, Assessment towards Guidelines for Europe
UK	United Kingdom
WP	Work Package
WRS	Weekly Returns Service

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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) reviewed European syndromic surveillance (SyS) systems. Co-financed by the European Commission through the Executive Agency for Health and Consumers, the project encompassed an inventory of existing and proposed SyS systems across the European Union (EU). Knowledge exchange between member states interested to setup or improve SyS systems complemented the inventory through visits of SyS systems in different EU countries. The final aim was to establish guidelines to implement SyS systems in Europe.

As part of Work Package (WP) 5, visits of SyS systems in eight EU member states and of one European project, European Emergency Data-based System for Information on, Detection and Analysis of Risks and Threats to Health (SIDARTHa), were organised between June 2011 and June 2012 for project partners and external participants. The purpose of these site visits was to facilitate knowledge exchange between representatives of existing, pilot, planned or expired SyS systems in Europe who are interested to setup, improve or re-establish a SyS system. During the visits, strengths and weaknesses of SyS systems, good practices, experiences and lessons learnt, and the importance of different determinants of SyS were to be discussed. The information obtained during the site visits also provided one basis for developing guidelines for implementing SyS systems in Europe in the future (one main objective of the Triple S project). The site visits did not intend to assess or evaluate the visited systems but were for mutual learning and capacity building for improving SyS in Europe.

The site visits were coordinated by the leaders of WP 5, Alexandra Ziemann and Thomas Krafft, Maastricht University, and for each visit two rapporteurs were nominated who took part in all visits, Alexandra Ziemann, Maastricht University and Marta Sala Soler, French Institute for Public Health Surveillance. To structure the visits and make the obtained information comparable, WP 5 developed scientific visit guidelines which also form the basis for structuring this report.[1]

For each visit, there was a package of information on the visited SyS systems comprising Briefing Documents (compiled in preparation of the visits comprising next to administrative documents also background reading material on the SyS systems such as scientific articles), presentations (major means of knowledge transfer providing information on the SyS systems following the scientific visit guidelines), and visit minutes (summarising the content of presentations and discussions during the visits based on the rapporteur's notes and voice recordings). Based on this information package for each visit, this country visits report provides a comparative description of the visited SyS systems.

[1] Ziemann A, Krafft T: Visit Guidelines. Scientific guidelines for knowledge exchange on syndromic surveillance in Europe. Triple S Project; 2011.

2. Objectives of the visit report

This report provides a comparative summary description of information obtained during the visits on the different components of SyS systems, experiences and lesson's learned, following the structure given by the scientific visit guidelines. It aims at providing information regarding the following questions:

Which SyS activities exist in Europe?

How are the SyS systems characterised?

What are advantages and disadvantages and added value of SyS systems?

3. Methodology

Between June 2011 and 2012 country visits of SyS activities of the following eight countries were accomplished:

1. June 2011: United Kingdom (UK) (England & Scotland)
2. September 2011: France
3. November 2011: Denmark
4. November 2011: Sweden
5. December 2011: Hungary
6. March 2012: Italy
7. June 2012: Belgium
8. June 2012: Netherlands

Further, in May 2012 a visit of the European SyS project SIDARTHa was conducted.

The objectives of the visits were primarily exchange of knowledge and experience on one hand. On the other hand, the visits were used to gain insight knowledge on good practices, strengths and weaknesses of the visited systems and experiences and lessons learned, beyond what is published in the scientific literature. This information was of particular interest as one component for the formulation of the Triple-S guidelines for implementing SyS in Europe.

The visits were structured by the Administrative[2] and Scientific Visit Guidelines.[3] Information was retrieved through different sources such as publications and material provided by visited sites, presentations and discussions during the site visit, and visits to external stakeholders (e.g., data providers). The visits covered characteristics and quality indicators of SyS systems (figure 1).

[2] Ziemann A, Krafft T: Visit Guidelines. Administrative guidelines for country visits of syndromic surveillance systems in Europe. Triple S Project; 2011.

[3] Ziemann A, Krafft T: Visit Guidelines. Scientific guidelines for knowledge exchange on syndromic surveillance in Europe. Triple S Project; 2011.

Although all characteristics of SyS systems were described in the scientific visit guidelines, the visits might not have provided information on every characteristic of a SyS system. The major aim of the visits was not gathering/providing information on all characteristic of each visited SyS system. The focus of the visits could follow the specific interests of the visitors, certain strengths and weaknesses or problems the system operators faced and issues of special relevance to other SyS system users and for the development of the Triple-S guidelines for implementing SyS in Europe.

The rapporteurs had the responsibility to coordinate the knowledge exchange and collate relevant information to ensure a sufficient basis for writing the visit minutes and this visit report. Visitors were asked to actively engage in the knowledge exchange and to obtain relevant information during the site visits by asking questions or taking part in discussions.

The description of characteristics of visited systems (and the scientific visit guidelines) follows the logic model of SyS systems starting with the context of the system, the system's input (data sources), the system's throughput in the sense of information technology (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. Relevant quality indicators to assess advantages and disadvantages of SyS systems were oriented at the guidelines for evaluation of early outbreak detection systems of the Centers for Disease Control and Prevention (CDC)[4]. Evidence in form of examples, facts and figures was to be provided by the visited sites.

This country visit report is divided into the following sections, following the logic model of SyS:

- Introduction and overview of visited systems
- Context of SyS systems
- Partnership
- Data collection & preparation
- IT infrastructure of the SyS system
- Data analysis methods
- Output (of analysis)
- Reporting (of output)
- Response procedures (after reporting)
- Costs and funding sources
- Evaluation
- Synthesis: Added value, advantages and disadvantages

[4] 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;

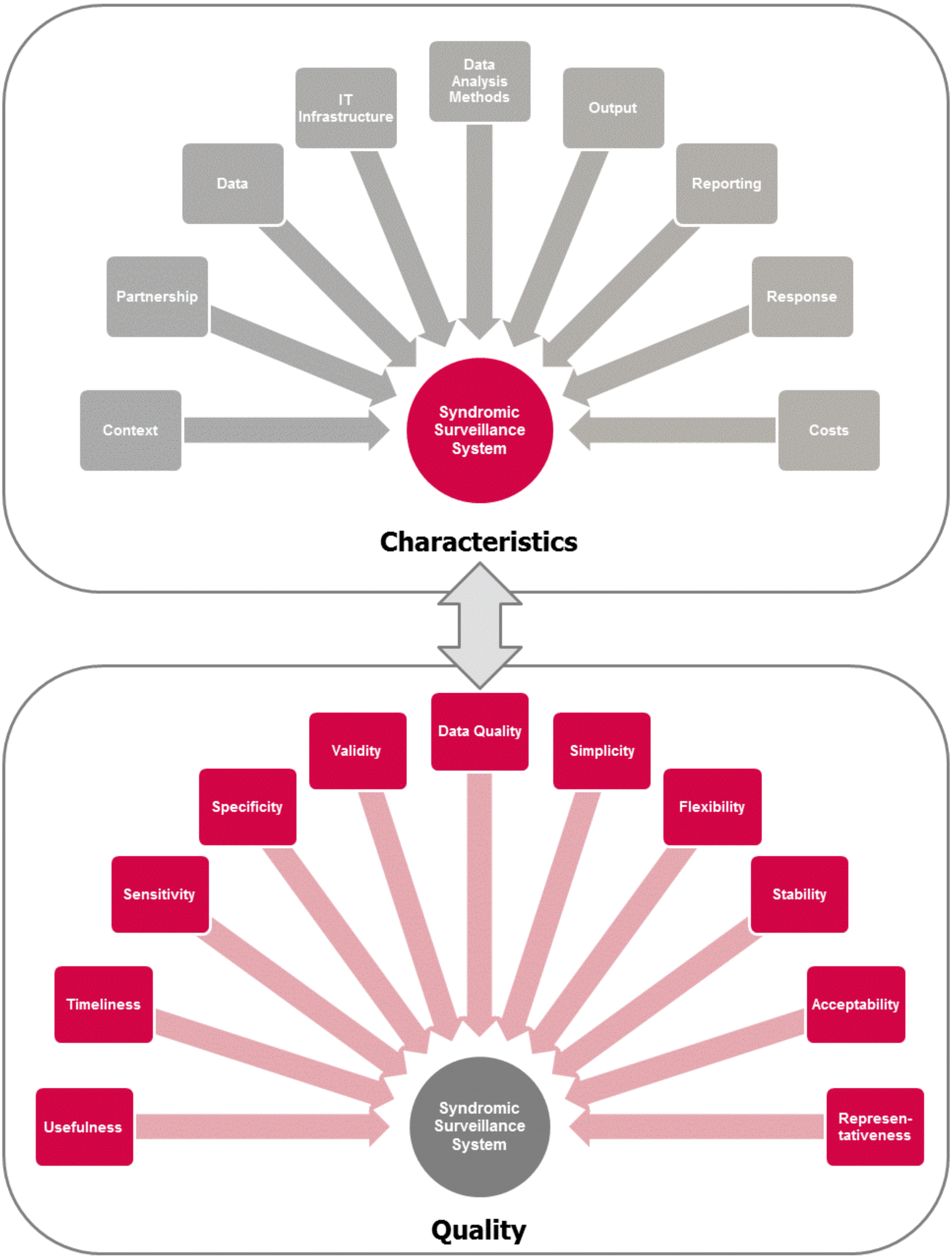

Figure 1: Framework for knowledge exchange on SyS systems during Triple-S visits

4. Results of visits to syndromic surveillance systems in Europe

4.1. Introduction

The 36 visited SyS systems ranged from purely planned activities such as in Hungary via systems in a test or pilot phase to long established systems such as in France or the UK. A specialty is the visit of the European initiative SIDARTHa which comprises regional level SyS systems, currently established as active, pilot and planned systems in five countries. Table 1 provides an overview of the visited systems, their underlying data source and status at the time of the visit

Table 1: Visited systems

Visited country	Number of visited SyS systems	Name/description SyS system	Data source	Status
Belgium	2	SAM@EMR	Emergency medical dispatch centre	Planned
		SIDARTHa Leuven	Emergency department	Pilot
Denmark	2	DMOS surveillance	Primary care	Active
		BioAlarm	Emergency medical dispatch centre	Active
England	5	EDSSS	Emergency Department	Active
		OOH/Unscheduled care surveillance system	Primary care	Active
		QSurveillance	Primary care	Active
		NHS Direct	Telephone helpline	Active
		RCGP Weekly Returns Service	Primary care	Active
France	3	SurSaUD – OSCOUR	Emergency department	Active
		SurSaUD – SOS Médecins	Primary care	Active
		ASTER	Military health services of deployed forces	Active
Hungary	2	Emergency department surveillance	Emergency department	Planned
		Emergency dispatch surveillance	Emergency medical dispatch centre	Planned
Italy	4	Migrant influx surveillance	Health services at migrant centres	Temporary
		National emergency department surveillance	Emergency department	Active
		Genoa SyS system	Emergency department	Active
		Lazio Region SyS system	Emergency department	Active

Visited country	Number of visited SyS systems	Name/description SyS system	Data source	Status
Netherlands	7	Retrospective feasibility analysis	Emergency department/hospitalisation, primary care, laboratory requests, pharmacy prescriptions , work absenteeism	Temporary
		National primary care monitoring	Primary care	Active
		Zuid-Holland H1N1 surveillance	Primary care	Temporary
		KIzSS	Child day care centre absenteeism	Pilot
		ICARES	Emergency department/ICU, primary care	Pilot
		SAM@EMR	Emergency medical dispatch centre	Planned
		Lab request surveillance	Laboratory test requests	Pilot
Scotland	4	NHS24	Telephone helpline	Active
		Antiviral prescribing data	Primary care prescriptions	Active
		PIPeR	Primary care	Active
		SISRS	Primary care	Active
SIDARTHa	5	SIDARTHa-Tirol	Emergency medical dispatch centre, Ambulance service staffed with emergency physicians, emergency department	Active (dispatch) Pilot (ambulance, emergency department)
		SIDARTHa-Cantabria	Emergency department	Active
		SIDARTHa-Belgium	Emergency department, Ambulance service staffed with emergency physicians	Pilot
		SIDARTHa-Göppingen	Ambulance service staffed with emergency physicians	Pilot
		SIDARTHa-Denmark	Emergency medical dispatch centre, Ambulance service	Planned
Sweden	2	GETWELL	Web queries	Active
		1177 call surveillance	Telephone helpline	Pilot-active
TOTAL	**36**			

4.2. Syndromic surveillance system characteristics

4.2.1. Context

The **health system organisation** has an impact on the organisation of SyS systems (Table 2). The longest established systems have been established in centralised health systems with a long tradition such as in the UK and France. Also the Hungarian systems will be established at the national level in a centralised health system. The recent health reform of 2011 which includes a restructuring of health services provides the opportunity to influence data collection and provision of health care institutions to fit also the necessities of surveillance including SyS. In more decentralised health care systems there is a mix of centralised and decentralised SyS systems. The mix might be explained by a changing or recently changed health system organisation, as e.g., in the Netherlands, by a mix of centralised and decentralised health system organisation, as e.g., in Italy, and the fact that in every country there is a system of local/regional and national authorities dealing with surveillance and being a potential setting to develop a system.

Table 2: Administrative level at which the 36 SyS systems are setup and health system organisation in visited countries

Visited country	National system	Local/ Regional system	Health system organisation	Total number of SyS systems
Belgium	1	1	Decentralised	2
Denmark	2	0	Decentralised	2
England	5	0	Centralised	5
France*	2	0	Centralised	3
Hungary	2	0	Centralised	2
Italy	2	2	Decentralised	4
Scotland	4	0	Centralised	4
Netherlands	4	3	Centralised	7
SIDARTHa	0	5	Decentralised (Austria, Belgium, Germany, Denmark, Spain)	5
Sweden	2	0	Decentralised	2
TOTAL	**24**	**11**		**36**

* Alerte et surveillance en temps réel (ASTER) is for deployed overseas military personnel and is not included in this overview

Another factor affecting SyS systems which is inherent to its context is the **organisation of data collection** and especially **data ownership**. Data collection for SyS systems usually is not done for the purpose of surveillance and it can often not be influenced by the institutions running a SyS system. Ownership of data is a major factor impeding access to data especially if there is a third party involved next to the actual data provider and the SyS system organiser, usually a software provider. In the UK this is a major factor challenging data access, prolonging system setup and roll-out to the whole country. Also in the Netherlands, the different softwares used in general practices are a challenge.

Treatment seeking behaviour of people is another context factor influencing SyS systems. These are factors inherent in the data source used for SyS. For example, primary care data sources are covering the general population and common population health issues with mainly mild symptoms such as influenza. Another examples are opening hours of general practitioners (GP), thus general practice based SyS data is only covering the time the general practice is open. Further, absenteeism data for children which are collected in schools or child day care centres are not available during weekends and holidays. Media effects are mainly affecting SyS based on data sources covering people not seeking care, e.g., telephone helplines and web queries.

Reasons for setting up a SyS system

All visited SyS systems were developed in order to provide an **added value to the existing traditional surveillance systems**. The major reason for setting up SyS systems was for detecting **influenza or common infectious disease outbreaks** earlier or over the whole year (England, Scotland, Denmark, Italy, Sweden, Netherlands). In a couple of cases **health crises or special events** were the major reason for setting up SyS systems: the heat wave 2003 in France, the G8 summit and various serious infectious disease outbreaks in Scotland, the Olympic Games in England, the H1N1 pandemic 2009 in the Netherlands, the influx of migrants from North Africa in Italy. The BioAlarm system in Denmark was setup aiming at detecting **bioterrorist attacks**. The ASTER system in France was setup due to a **ministerial directive** calling for better health surveillance of military forces. Testing the **feasibility of data sources** and as a **proof of concept for SyS** were the major driving forces for the retrospective study in the Netherlands, the SIDARTHa project, and the SAM@EMR (Surveillance, Assurance and Monitoring in the Euregio Maas-Rhine) project in the cross-border area of Germany, Belgium and the Netherlands.

Purpose of the system

Table 3 provides an overview on the health threat groups targeted by the visited SyS systems. Most SyS systems focus on monitoring **common communicable diseases**, especially influenza-like illness (24 of 36 systems) and gastrointestinal illness (13 of 36 systems). **Other communicable diseases** covered are for example Legionnaires disease in the Netherlands or Dengue fever in deployed French forces (7 of 36 systems).

Many SyS systems are used to provide **reassurance or risk assessment** during events with potential public health impact (14 of 36 systems). This was a trend seen in many visited countries: the use of SyS for assessing the health impact or absence of a health impact of various kinds of unexpected, potentially health threatening events (also: situational awareness). Examples are ranging from large-scale fires at the local level (UK) to events threatening various countries in Europe, such as heat waves or the volcanic ash cloud in 2010 (surveillance for example in the UK and in SIDARTHa SyS systems). Also the influx of migrants from North Africa in Italy is an example for a temporary risk assessment SyS. This group also includes the monitoring of mass gatherings such as the Olympic Games 2012 in the England or the political summits in the UK, Denmark or France.

Table 3: Surveillance fields of visited SyS systems[5]

Visited country	Influenza-like illness or respiratory outbreaks	Gastrointestinal outbreaks	Reassurance/risk assessment of potentially health threatening events*	Other communicable disease outbreaks
Belgium	1	1	0	0
Denmark	2	1	1	0
England	5	2	5	0
France	2	1	2	2
Hungary	n.a.	n.a.	n.a.	n.a.
Italy	3	0	2	1
Netherlands	3	2	0	3
Scotland	4	0	1	0
SIDARTHa	3	4	3	0
Sweden	1	2	0	1
TOTAL	**24**	**13**	**14**	**7**

* includes situational awareness of potentially health threatening events such as heat waves, industrial accidents, mass gatherings; excludes surveillance of purely communicable disease outbreaks covered in the other categories
n.a.= not applicable

4.2.2. Partnership

Figure 2 is depicting the usual SyS system **partners**. The basic partners in a SyS system are a public health authority, often running the SyS system, and a data provider, often a health service provider or a representative thereof (e.g., regional/national network of data providers). A strong collaboration between data providers and public health authorities including feedback loops are a key success factor. In some systems additional partners are involved such as a data owner and/or someone responsible for the data analysis (e.g., Netherlands, UK, the ASTER system in France). Depending on the administrative level at which the system is set up, there are health authorities and data providers at subordinate or superordinate levels who could be involved receiving output from the SyS system.

[5] Systems can cover more than one threat, not syndromes but events for which the system was used

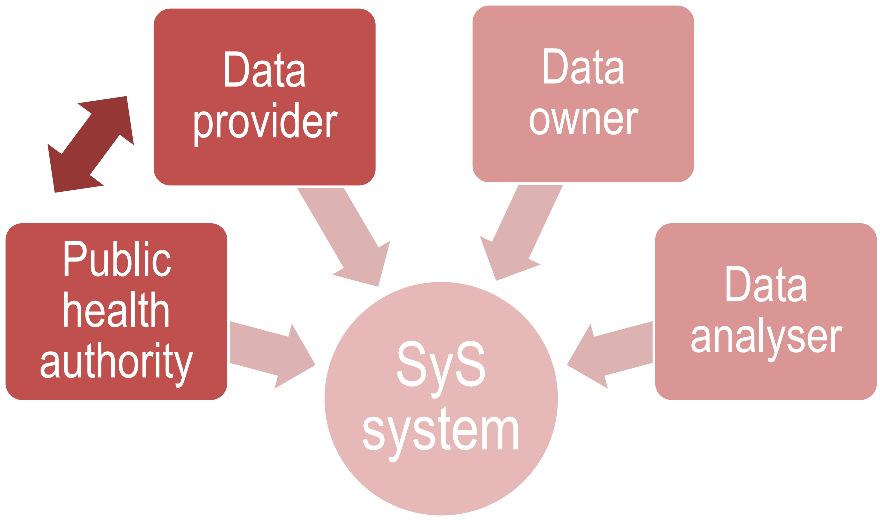

Figure 2: Partnership in SyS systems

Recruitment of data providers was a challenge seen in many visited surveillance systems prolonging the system setup or impeding data quality. This is especially the case if the system is not based on a centralised database but single data providers have to be approached, if data collection is voluntary and if data collection provides an extra workload for the data provider. In the national and regional primary care surveillance systems in the Netherlands, these were challenges to setup and maintain the system. The regional system setup benefitted from the threat of the pandemic to motivate data providers to notify cases. However, the burden of data collection in this system was depending on the busiest staff members (practice assistants). Further, the data analysis was putting extra burden on municipal health services. Also in the BioAlarm system in Denmark, additional manual data collection among ambulance personal was resulting in low data quality.

The SurSaUD system in France are generally using data from regional data bases so individual data providers are rarely directly involved. However, **feedback to data providers** was seen as a critical tool for motivating high quality and continuous data collection. This was also a critical point raised during the visit of a data provider for the ED-based system which made clear that an individual emergency physician might not know about the involvement in the SyS system and cannot use the results for own work. This will be changed in the future. In the SOS médecins system the feedback loop to individual physicians is already established.

The **close collaboration with data providers or experts from the field** in which the data is collected was experienced as crucial in the UK for setup of the system and later on for interpreting signals. Also the BioAlarm system in Denmark and the Integrated Crisis Alert and Response System (ICARES) system in the Netherlands established a link to the health care institutions providing data for support in interpreting signals. This was also a driving force for the SIDARTHa project which is an initiative of emergency data providers in close collaboration with public health authorities. The emergency care providers in the SIDARTHa network saw the potential of their data for timely information on public health issues and the necessity to be prepared themselves if a crisis arises. During the SIDARTHa project it also became clear that the connection between emergency care and public health authorities is weak and that setting up a SyS system helped building a network with regular contacts on interpreting signals together (SIDARTHa systems in Spain and Austria).

Another point raised earlier in this report is the sometimes necessary involvement of an intermediary who owns the data, e.g., a data collection **software provider**. This can result in extra costs or exclusion of regions/data providers who are not collaborating with the intermediary who is collaborating with the SyS system (e.g., UK, Netherlands).

Partnership depends also on the kind of data source. Mostly health services are data providers with the above mentioned partnership challenges. This is less a problem in web query based systems such as the Generating Epidemiological Trends from Web Logs, Like (GETWELL) system in Sweden. Here, the health website used for analysing queries belongs to the city of Stockholm, one public partner to be approached by another public agency. And thinking of Google searches, this data source is available immediately at any time and all the time without having to build a partnership with anyone. Of course, the specificity and level of detail of this data source compared to health services data sources is weaker.

4.2.3. Data collection

Data sources

Table 4 shows the different data sources used in the visited SyS systems. In seven countries, 11 SyS systems based on ED data were presented: England (n=1), France (n=1), Hungary (n=1), Italy (n=3), Belgium (n=1), Netherlands (n=2), and in two SIDARTHa systems. ED data is therefore the most used data source in the visited systems, closely followed by primary care sources (n=10) in 5 countries. Primary care data sources are diverse and comprise out-of-hours (OOH), on-call and usual in-hours GP services. Other emergency care data sources (dispatch centre, ambulance service) are used in 6 countries including the SIDARTHa project which focused on emergency care data only. Ambulance service data was first and is only used in four SIDARTHa systems until now. Telephone helplines are used in 3 countries which can be explained by the fact that such services are not available in many countries in Europe. Laboratory requests, absenteeism information and prescription information from pharmacies were explored as data source in feasibility studies in the Netherlands. Prescriptions retrieved from GP are also explored in a system in Scotland. Health services of armed forces and in immigration centres and web queries were used as data source in one system respectively.

Two systems in the Netherlands use/used multiple data sources: (i) a retrospective feasibility study analysing work absenteeism, GP-consultations, prescriptions from pharmacies, lab requests, emergency department (ED)/hospital admissions and mortality data, and (ii) the ICARES system using ED, intensive care unit, in-hours and OOH GP services.

Choice of and accessing data source

It becomes clear from the visits that the choice of data source is often one of practicability. For example, access to the data source of the National Health System (NHS) telephone helplines systems in the UK was easier compared to any health services based data source. This is moreover the reason for ad-hoc established systems, as e.g., in the regional Dutch system for the pandemic.

In Sweden, the choice for web-based data was based on trying to cover a part of the population that is not yet covered by other surveillance systems and the fact that the quality of the traditional surveillance systems was assessed as sufficiently high. This holds also true for the migrant monitoring system in Italy which had to be setup at refugee camp health services in order to cover this population.

A trend seen in many countries was the inclusion of more and more data sources over time such as in the UK, the planned comprehensive system in Hungary or the ICARES system in the Netherlands.

Problems with accessing data sources were mainly because of data ownership as described further above.

Table 4: Number of SyS systems in visited countries and SIDARTHa project by data source (planned, pilot, active, expired systems)

Visited countries	Data Source										
	Emergency department	Primary care	Emergency medical dispatch	Ambulance service	Telephone helpline	Laboratory requests	Absenteeism	Prescriptions	Armed forces	Web queries	Immigration centres	TOTAL
Belgium	1	0	1	0	0	0	0	0	0	0	0	**2**
Denmark	0	1	1	0	0	0	0	0	0	0	0	**2**
England	1	3	0	0	1	0	0	0	0	0	0	**5**
France	1	1	0	0	0	0	0	0	1	0	0	**3**
Hungary	1	0	1	0	0	0	0	0	0	0	0	**2**
Italy	3	0	0	0	0	0	0	0	0	0	1	**4**
Netherlands	2	3	1	0	0	2	2	1	0	0	0	**11**
Scotland	0	2	0	0	1	0	0	1	0	0	0	**4**
SIDARTHa	2	0	2	4	0	0	0	0	0	0	0	**8**
Sweden	0	0	0	0	1	0	0	0	0	1	0	**3**
TOTAL	**11**	**10**	**6**	**4**	**3**	**2**	**2**	**2**	**1**	**1**	**1**	**44**

Purpose of data collection

Data collection in the majority of the visited systems was not for the purpose of surveillance but different other purposes, mainly patient records. Data collection in the Danish DMOS, the Italian migrant SyS system, the Dutch KizSS network and the French ASTER system were setup for SyS.

Data collection and transfer process

Table 5 shows information on the art and frequency of data collection and transfer. Most data is collected electronically (n=34/36). Systems based on manual data collection are the Italian temporary system for monitoring of influx of migrants from North Africa and the Kinderdagverblijven Infectieziekten Surveillance Systeem (KIzSS) system in the Netherlands. Furthermore, most data is collected daily (or in few cases in real-time, i.e. after a data set is created) (n=31/36). In the other systems data is collected once or twice a week: in the English Royal College of General Practitioners Weekly Returns Service (RCGP WRS) and QSurveillance, the Dutch national primary care SyS and lab request feasibility study, and the national ED SyS system in Italy. Around 55% of systems are based on automatic transfer of data which can be explained by the temporary/pilot/planned character of many systems.

Table 5: Art and frequency of data collection and transfer in visited systems

Visited country	Electronic data collection	Daily data transfer	Automatic data transfer
Belgium	2	2	0
Denmark	2	2	2
England	5	3	5
France	3	3	2
Hungary	2	2	2
Italy	3	3	2
Netherlands	6	5	1
Scotland	4	4	4
SIDARTHa	5	5	2
Sweden	2	2	0
TOTAL	**34**	**31**	**20**

Indicators/variables

In all visited systems temporal information is available (table 6). Also a sort of information for generating syndromes is available in all systems, mostly these are diagnostic information from health services. Geographic information is not available in all systems (31/36), e.g., not in the web query based GETWELL system in Sweden. Geographic information might be of different detail from health boards in the UK to x/y coordinates in the SIDARTHa-Tyrol system. Mainly postal codes or truncated postal codes are used. Age is important for differentiating analyses as only certain age groups might be affected by an event. This indicator is collected in 29 of 36 systems. Severity is often inherent in data sources, e.g., in the level of response, which a caller to a telephone helplines receives. The amount of systems collecting this information (13/36) is likely to be underrepresenting the availability and use of this indicator in the visited systems. However, analyses for severity were not highly featured during the visits despite the availability and potential relevance of this indicator.

Some GP data based systems comprise also information on prescriptions and vaccinations, e.g., in the UK. In few systems additional data is collected, mainly environmental measures such as temperature, pollen or air pollution level, e.g., in Hungary.

Table 6: Collected indicators/variables in visited SyS systems

Visited country	Temporal information	Syndromic information*	Geographic information	Age	Severity
Belgium	2	2	2	1	2
Denmark	2	2	2	1	0
England	5	5	5	5	1
France	3	3	3	2	1
Hungary	2	2	2	2	0
Italy	4	4	4	4	3
Netherlands	7	7	4	6	1
Scotland	4	4	3	2	0
SIDARTHa	5	5	5	5	5
Sweden	2	2	1	1	0
TOTAL	**36**	**36**	**31**	**29**	**13**

*in the multiple data-source analysis Netherlands: diagnostic information not available for absenteeism

Format

The format of data is especially important for diagnostic information in order to assess the comparability and transferability of syndrome generation and analysis. The majority of systems are based on diagnostic coding systems which are specific to the country or the region (17/36), only in 10 of 36 systems an international coding system such as International Classification of Diseases was used in the underlying data source (table 7). 7 of 36 systems are analysing free-text which is usually connected to a high workload for syndrome generation and analysis. Also 7 systems are using another sort or no coding system but for example a tick-box as in the Danish DMOS system or an own coding system developed for the SyS system such as in the Italian migrant SyS system. Few systems simply use case counts without further diagnostic differentiation, e.g., the Danish BioAlarm and the Dutch regional pandemic SyS system.

Table 7: Format of diagnostic information collected in visited SyS systems (multiple codes per system possible)

Visited country	International code	National, regional, local code	Free text	Other
Belgium	0	1	1	0
Denmark	0	1	0	1
England	1	6	0	0
France	1	1	1	1
Hungary	n.i.	n.i.	n.i.	n.i.
Italy	2	0	2	1
Netherlands	3	2	0	3
Scotland	0	3	2	0
SIDARTHa*	3	2	0	0
Sweden	0	1	1	0
TOTAL	**10**	**17**	**7**	**7**

*Not yet known for SIDARTHa planned system in Denmark
n.i. = no information provided during visit

Adjustment of collected data

In general, it is important to note that in most SyS systems the underlying data source cannot be changed for the purpose of SyS.

Flexibility in terms of adjusting or generating new syndromes based on the underlying data source is an important characteristic of SyS systems. Examples were provided during the visits in various countries. One example is the adjustment of the free-text analysis algorithms in the Scottish telephone helpline based SyS system to search for "swine" during the 2009 influenza pandemic. Another example is using further information which is provided by a data source for other SyS applications or for setting up a whole new SyS. This was done for the Scottish antiviral prescribing data based SyS for which the data is coming from the GP data which is already used in the Pandemic Influenza Primary Care Reporting (PIPeR) and Scottish Influenza Surveillance Reporting Scheme (SISRS) systems.

If data sources are changed this can cause problems to SyS as the analyses have to be adjusted and the baselines are interrupted which can cause delays until the SyS is operational again. This is currently happening on a large scale in England. Here, the 111 telephone helpline is introduced which is supposed to replace the existing NHS Direct system. This will mean that the whole SyS based on NHS Direct will have to be setup in a new form for the 111 system. Smaller changes are experienced when data sources are enhanced to cover other populations or regions. This was the case for example in the SIDARTHa system in Tirol. Here, more and more districts are covered by the state dispatch centre providing the data for the SyS system.

Public health events

Which data source is used to cover which public health problem, i.e., heat waves, influenza outbreak or an unknown health threat? As table 3 shows, SyS is most often applied to common or **seasonal infectious disease events** such as influenza or gastrointestinal disease outbreaks. Here, the added value to traditional systems is mainly availability of timelier information during the whole year. Further, SyS is also used to cover populations not monitored by traditional health care or laboratory surveillance systems, i.e., populations calling a telephone helpline or searching the web for advice. The same syndromes analysed for expected seasonal events are also used to detect/assess **unexpected outbreaks** or cover **events with potential health impact that cause similar symptoms as those already analysed in a SyS system**. This way, many SyS systems are more and more used for monitoring and assessing various kinds of health threats such as rare infectious disease outbreaks, e.g., Legionnaires disease or Q-Fever outbreaks in the Netherlands, mass gatherings (e.g., Olympic Games in England, G8 summits in Scotland and France), local fires in England and in an industrial plant in France, or the volcanic ash cloud in 2010 (e.g., UK, SIDARTHa).

Many SyS systems firstly used for monitoring one syndrome were enhanced and used also during **other situations and for other syndromes**, mainly for **situational awareness** to assess if an event has a health impact or reassurance that it has no health impact. Examples are the Danish DMOS system which was developed to monitor influenza but was also used to retrospectively analyse if contaminated water supply had an impact on population health. The SurSaUD system in France was used to monitor a drug overdose cluster and a mushroom poisoning outbreak. The gastrointestinal syndrome in the SurSaUD system was also adjusted to specifically cover bloody diarrhoea.

Another important area of application in Europe is monitoring **heat waves** as earlier heat waves caused a huge public health impact in many European countries. Heat impact is monitored by SyS in the UK, France, and Hungary.

Syndromes

Next to influenza-like illness or respiratory syndrome (24/36 systems) and gastrointestinal syndrome (13/36 systems) which are the most common syndromes (table 3), table 8 shows other syndromes monitored in the visited SyS systems. Only in Sweden and Denmark, no additional syndromes are currently monitored. Most common additional syndromes are neurological symptoms, skin problems, heat-related symptoms, fever, cardio-vascular problems, eye problems, and poisoning. Trauma is less often monitored.

In some systems, not syndromes or symptoms but working diagnoses for specific diseases are monitored, e.g. measles, otitis media, jaundice, or meningitis. These will be based on signs and syndromes but are monitored as specific diagnoses. Examples are the ED-based systems in Italy or the primary care based systems in England.

Table 8: Monitored syndromes and symptoms in visited SyS systems (except influenza-like-illness/respiratory syndrome and gastrointestinal syndrome)

Visited country	Neurological	Skin problems	Heat-related	Fever	Cardio-vascular	Eye problems	Poisoning	Trauma
Belgium	0	0	1	0	0	0	0	0
Denmark	0	0	0	0	0	0	0	0
England	1	1	2	0	2	1	0	1
France	3	1	2	2	2	2	2	1
Hungary*	1	1	1	0	1	0	0	0
Italy	3	4	0	4	0	1	0	0
Netherlands	2	1	0	0	0	1	0	0
Scotland	0	1	0	1	0	1	0	0
SIDARTHa	0	0	1	0	2	0	4	1
Sweden	0	0	0	0	0	0	0	0
TOTAL	**10**	**9**	**7**	**7**	**7**	**6**	**6**	**3**

*planned for both systems, not clear yet if both systems can provide information on all syndromes

4.2.4. IT infrastructure of the syndromic surveillance system

IT infrastructure

The visited systems use IT infrastructure for all parts of data transfer, analysis, output generation and reporting (figure 3).

The difference lies in the level of automatisation and the kind of software that is used (table 9). 6 of 36 systems are fully automated from data retrieval to reporting (Bioalarm in Denmark, ASTER for French armed forces, ICARES in the Netherlands, and the SIDARTHa systems in Tirol, Cantabria and the planned system in Denmark). In 10 of 36 systems, a new software or a new system infrastructure based on existing software was setup for the SyS system. Two of the French SyS systems are run on the same new analysis system (SurSaUD), ASTER is based on its own new infrastructure. The Dutch ICARES system will be a new component of a widely used software for data management in Dutch health authorities. The SIDARTHa system in Spain runs on a newly developed software, while the Austrian and Danish systems are/are supposed to be implemented based on existing business intelligence software available at the data providers. As part of these new systems or as stand-alone software applications for analysing and visualising data, Microsoft Excel (including macros) and Geographic Information Systems (GIS) are applied in around 40% of systems, statistical programmes such as SPSS or STATA are used in one third of the systems. Other programmes such as the free spatial-temporal cluster detection software SaTScan and the open source statistical package R are less common.

Depending on the partner structure, IT infrastructure might be based solely at the organisation running the SyS system (e.g., France) or the part around data analysis might be outsourced to a third institution (e.g., Scotland).

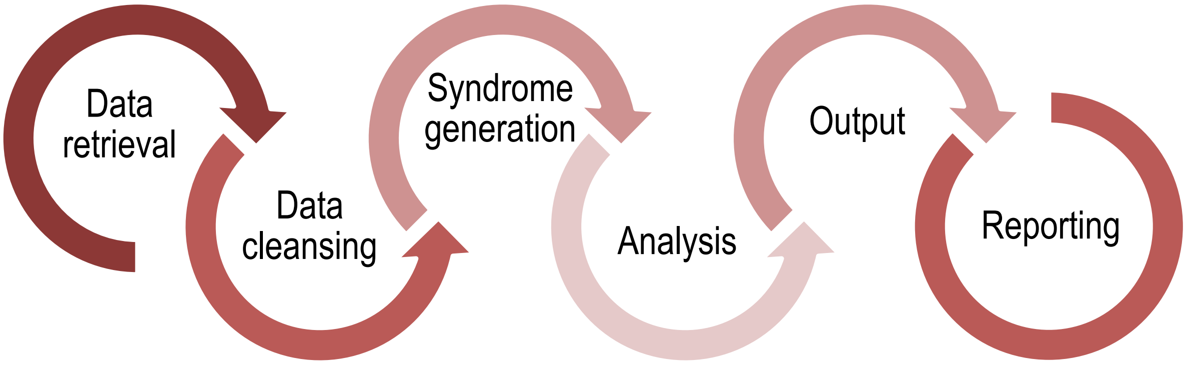

Figure 3: Components of SyS systems for which IT infrastructure is used (after data collection)

Table 9: IT infrastructure and software characteristics of visited systems (multiple characteristics per system possible)

Visited country	Fully automated	Own new software/ system	GIS	Excel	Statistical programmes	SaTScan	R	Google Maps
Belgium	0	0	1	1	1	1	0	1
Denmark	1	0	2	0	1	0	1	1
England	0	0	3	5	2	0	0	0
France	1	3	1	0	0	0	1	0
Hungary	n.i.	2	2	n.i.	n.i.	2	n.i.	n.i.
Italy	0	n.i.	n.i.	2	n.i.	n.i.	n.i.	n.i.
Netherlands	1	1	1	2	1	1	1	0
Scotland	0	0	3	1	3	0	1	0
SIDARTHa*	3	3	2	4	4	4	0	1
Sweden	0	1	1	1	1	0	1	0
TOTAL	**6**	**10**	**16**	**16**	**13**	**8**	**5**	**3**

*one fully automated system using own software is planned (SIDARTHa-Denmark)

4.2.5. Data analysis methods

25 of 36 systems apply no statistical detection algorithm to their data but just analyse for aberrations by **descriptive statistics and visual assessment** (table 10). Often, 95% or 99% confidence intervals are defined as thresholds. **Cumulative sums and control chart methods** are used in one third of systems. More complex **regression models** and **spatial or spatial-temporal cluster detection** methods are applied in 10 and 8 systems respectively.

The **alert threshold** depends on the chosen statistical algorithm/method. These can be a confidence interval or standard deviations, for example, in systems using descriptive statistics. In systems using aberration detection algorithms such as CUSUM or SaTScan, the method to calculate the alert threshold is included in the algorithm. Thresholds can be adjusted after a fine tuning process to the data source and the syndrome.

It seems necessary to allow for a **test and fine-tuning** period of the detection algorithms to the data sources to obtain better results (bigger feasibility studies for testing different methods were accomplished, e.g., in the SurSaUD and ASTER systems in France, in SIDARTHa and is currently ongoing for the ICARES system in the Netherlands).

Table 10: Analysis methods in visited SyS systems

Visited country	Descriptive statistics	Cumulative Sums / control charts	Regression analysis	Spatial or spatial-temporal cluster analysis	Other
Belgium	2	2	0	2	0
Denmark	2	1	0	0	1
England	5	2	1	0	0
France	2	2	0	0	1
Hungary	2	2	2	2	0
Italy	2	1	1	0	1
Netherlands	2	0	2	1	0
Scotland	4	0	2	0	1
SIDARTHa*	4	3	0	3	0
Sweden	0	0	2	0	0
TOTAL	**25**	**13**	**10**	**8**	**4**

*not yet known for planned system in Denmark

4.2.6. Output (of analysis)

Output

As table 11 shows, not all SyS systems rely on statistical alerts produced by algorithms or exceedance of defined thresholds (24 of 36 systems). All systems produce graphical representations of their results (temporal analysis, time series) while more than half show results in maps. Eight systems chose to have a separate graphical representation of statistical alerts such as in the alert clocks of the UK bulletins (see further below), the French ASTER system or in the active SIDARTHa systems in Austria and Spain and planned for the SIDARTHa system in Denmark. 6 of 36 systems are providing an online accessible dashboard as output which includes the graphical representation of results and alerts: Bioalarm in Denmark, ICARES in the Netherlands (planned), the French systems and three SIDARTHa systems in Austria, Denmark (planned) and Spain.

Table 11: Output of analysis results in visited SyS systems

Visited country	Statistical alert	Dashboard (online)	Graphical representation Graph	Graphical representation Map	Graphical representation alerts
Belgium	2	0	2	1	0
Denmark	1	1	2	2	0
England	3	0	5	2	1
France	3	3	3	3	1
Hungary	2	n.a.	2	2	n.a.
Italy	4	0	4	0	0
Netherlands	2	1	6	1	0
Scotland	2	0	4	3	3
SIDARTHa	5	3	6	5	3
Sweden	0	0	2	1	0
TOTAL	**24**	**8**	**36**	**20**	**8**

Interpretation of signals

Interpretation of signals or the definition when a statistical signal becomes an alert that should result in public health action was an important question during the visits as SyS systems are per se unspecific and produce many signals (high sensitivity, low specificity, signal-to-noise problem). Some systems have established **indicators**, for example, in England and Scotland and in the Genoa SyS system in Italy. Such indicators can be consecutive days with signals or the magnitude of the aberration, or a signal in more than one SyS system/data source.

A **decision tree** helps to define which steps are taken after a signal occurred. At this point, human input is necessary. The UK provided a good example of involving at first an information manager doing the analysis and looking at the analysis output. Should a signal occur, an epidemiologist or scientist is involved in interpreting the data and taking decisions about any further action. Such first actions include additional analyses, e.g., per age group or post code, informing further stakeholders in the organisation running the SyS system, contacting data providers to help interpreting a signal, or cross-checking with organisations/departments running other (traditional specific) surveillance systems.

4.2.7. Reporting (of output)

Reporting

Reporting in the visited systems can be through various ways. Table 12 shows the reporting ways for SyS which are used on a regular basis. During the visits mainly national public health institutes were visited who are running SyS systems. These institutes have already established reporting procedures as part of their routine, traditional surveillance work. The SyS results are often incorporated into the existing reporting structures, e.g., bulletins produced during the influenza season such as in Denmark or surveillance information posted on the institute's website. Other countries such as England produce bulletins only based on SyS results. Different reporting ways are often used in parallel and reports in the form of a bulletin or report can be distributed in various ways (by email, website posting, in print). During special events or for case studies, often special reports are produced in addition to regular reporting. In planned or pilot systems, reporting might not yet be established and the SyS results are reported only in special reports. Table 12 only lists a SyS system in the category of "special reports" if these are the primary way of reporting SyS results in a country/system (9 of 36 systems). Online dashboards are often used in automated systems and are providing reports on a daily basis. These systems are rather standing alone next to traditional reporting procedures (e.g., Bioalarm in Denmark, the French ASTER, SIDARTHa). Usually, reporting is done on a weekly or monthly basis, often connected to the frequency of traditional reporting. Figure 4 shows examples of a bulletin and a dashboard.

Table 12: Characteristics of regular reporting procedures in visited SyS systems

Visited country	Bulletin	Only Special report(s)*	Website*	Dashboard	Daily reporting	Automated reporting
Belgium	0	1	0	0	0	0
Denmark	1	0	1	1	1	1
England	3	0	0	0	0	0
France	2	0	3	1	3	1
Hungary	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
Italy	2	1	2	0	0	0
Netherlands	0	3	0	1	1	1
Scotland	4	0	0	0	0	0
SIDARTHa	1	2	0	1	2	2
Sweden	0	2	0	0	0	0
TOTAL	**13**	**9**	**6**	**4**	**7**	**5**

*reporting is primarily or only done this way

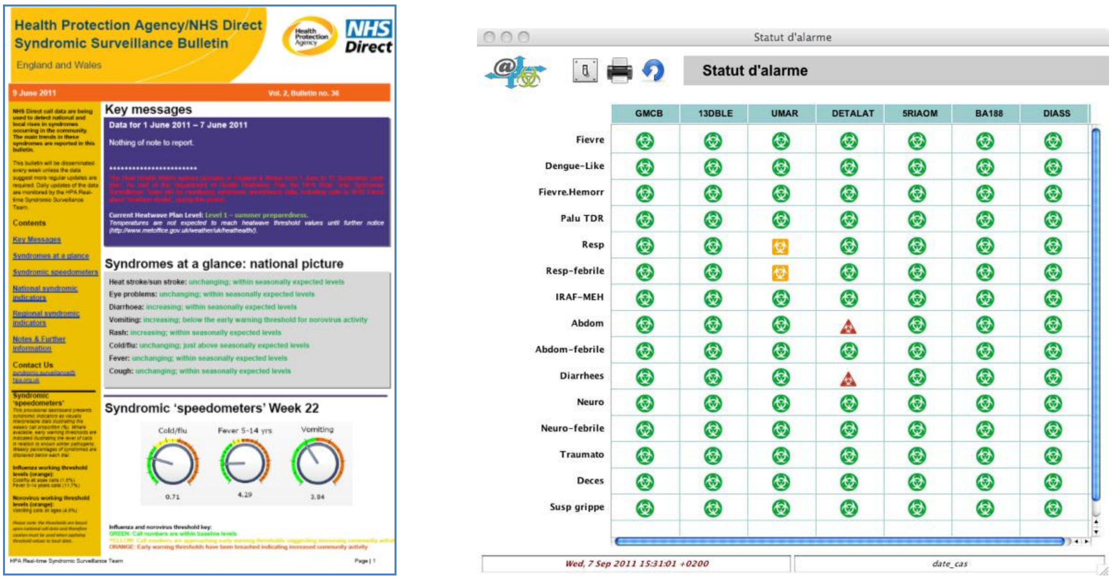

Figure 4: Example of a SyS bulletin from England and a dashboard from the French ASTER system

4.2.8. Response procedures (after reporting)

Response procedures

The visited systems are either based at public health institutes or provide information to be used by public health institutes. There are response procedures based on surveillance results which are already established at these institutions. SyS results do not trigger a different or separate response to that based on traditional surveillance. Thus, during the visits, there was little information about response procedures. SyS results are rather used as additional or sole information on an event but the response does not change. This is especially the case in SyS systems used for common or seasonal disease outbreaks such as influenza but also for unexpected events.

SyS effect on response

The SyS effect on response was only indirectly reported during the visits when SyS provided timelier information, e.g., on the onset of the influenza season, or valuable additional or sole information during unexpected events. For unexpected events, it was highlighted that it was important that SyS systems already existed to provide information and no new systems had to be established in short time. Such ad-hoc established systems were experienced as being difficult to setup and of insufficient quality (e.g., England). Another important point was the ability of having daily data available using SyS which is important to be able to inform policy makers or the public in a timely fashion, e.g., during the influenza pandemic 2009. SyS can be used for many different kinds of events which is enabling responses where traditional surveillance systems cannot.

One point especially raised in the UK was the use of syndromic information by health care data providers for their responses: The data provider NHS24 use the SyS output to adjust their resource management for securing service provisions during busy periods.

False alerts

Despite being a common problem with SyS, false alerts were no focus reported during the visits. This might be explained with the fact that this inherent weakness of SyS is accepted and dealt with as e.g., through the development of interpretation protocols and decision trees (from signal to alert). Responses are not issued based on single SyS signals.

4.2.9. Costs and funding sources

Costs for a SyS system are difficult to establish. Often SyS are run by institutions running other surveillance systems and staff who are working on SyS are employed in that institution anyways, so it is difficult to differentiate costs for a SyS from other costs. However, SyS are usually considered cost-effective compared to other surveillance tasks as the data sources are already existing, are electronic and are used “as they are”, standard statistics and software can be used, and the general knowledge, experience or training necessary for setting up and running a surveillance system is already available (through already employed epidemiologists, statisticians). In addition, the philosophy behind SyS is a pragmatic one which does not and cannot strive for perfection in terms of specificity or data quality.

During the visits, some information was provided on the **staff resources** necessary for surveillance. In France, the SurSaUD system is run by a coordinator, one project manager for each of the two systems (statistician, epidemiologist), and the team is supported by an IT project manager. This team is supported by one person in each regional team who is in charge of networking with data providers and data analysis at the regional level. For the planned systems in Hungary, no additional staff costs are planned for SyS. In the Italian migrant SyS, one person working at the national institute running the system was in charge of data entry, one statistician and two epidemiologists work on the system, all in part time. For the Italian national ED-based system, there are two employees at the national institute running the system and one employee in a regional office who are working on data analysis. In the SyS system in Genoa, one medical doctor who is already employed at the university is doing the free-text analysis every day, which takes around 90 minutes. In the Netherlands, one person is working on the national GP-based system in full-time, a coordinator was employed for recruiting the practices, and some IT staff is working in part-time on the system. In Sweden, the web query-based GETWELL system is run by one person in full-time with in-kind support from the national institute running the system in the form of statisticians and the company hosting the search engine. The visit to the long established and constantly growing SyS system landscape in the UK, run by national institutes, showed also the development in staff and resources: "we started with one system, one day per week, and one person doing it. It has taken opportunistic strategy to grow." They showed the usefulness of SyS for various kinds of health events and thus obtained more funds to further develop their systems. This makes clear also that not many resources are needed to start a SyS system. Also the French SurSaUD system started similarly with one person analysing data from one source against the background of a health crisis (heat wave 2003).

SyS systems are often run by institutions that are responsible for surveillance which causes them less costs for setting up a SyS system as the necessary resources and knowledge is already available. In the SIDARTHa project which was established by scientists not involved in routine surveillance and data providers, the resources for setting up the systems were comparably bigger: one scientist as project officer for 2.5 years, one scientific coordinator in part-time for 2.5 years, one epidemiologist in full-time for 2 years, one scientist for the spatial analyses in full-time for 2 years and part-time staff from the four implementing institutions. Funding for this effort came to a certain extent from the European Commission but a considerable amount was provided by the involved institutions themselves.

There are usually costs involved in the form of staff time for recruiting participants or accessing data sources in the setup phase of a system. Usually, the data providers do not receive any financial compensation but their costs are reimbursed in the form of feedback and information from the system that they can use for their work.

4.2.10. Evaluation

Evaluation in one form or another is done by the visited SyS systems if they are active or further developed in a pilot phase. As for tradtional surveillance systems there are a couple of evaluation indicators which are usually applied in an evaluation to assess the operation (e.g., validity, timeliness) and/or the experiece of the system (e.g., usefulness, acceptability), according to the objectives of the system. These indicators have been adjusted to early outbreak detection systems by the CDC[6] which can be seen as a reference framework for evaluating SyS systems and was used (in parts) by some of the visited systems, too. As table 13 shows, most visited systems use case studies to evaluate the performance of their system against a real health event, e.g., the 2009 influenza pandemic (24/36 systems). Only few systems used simulations or scenarios. The assessment of operation and/experience according to reference evaluation indicators, most often timeliness, sensitivity and specificity were accomplished in 13 of 36 systems. This can be part of case studies or an independent effort. Only one sixth of the visited systems have evaluated experience indicators. Many visited systems published their evalution results.

Table 13: Evaluation characteristics of visited SyS systems

Visited country	Evaluation by case studies	Evaluation by simulations, scenarios	Evaluation of the operation of the system*	Evaluation of the experience with the system*
Belgium	1	0	1	0
Denmark	1	1	1	0
England	3	0	1	1
France	3	0	3	1
Hungary	n.a.	n.a.	n.a.	n.a.
Italy	4	0	1	0
Netherlands	3	0	1	0
Scotland	3	0	0	0
SIDARTHa	4	1	4	4
Sweden	2	0	1	0
TOTAL	**24**	**2**	**13**	**6**

* according to Triple S Guidelines and Evaluation Framework for Early Outbreak Detection Systems by Centres for Disease Control and Prevention

[6] Buehler JW, Hopkins RS, Overhage JM, Sosin DM, Tong V. Framework for evaluating public health surveillance systems for early detection of outbreaks: recommendations from the CDC Working Group. MMWR Recomm Rep 2004;53(RR-5):1-11.

4.3. Synthesis: Added value, advantages and disadvantages

Advantages and disadvantages

Advantages and disadvantages of the visited systems depend a lot on the underlying **data source** and the applied general system setup. Typical weaknesses of data sources are insufficient representativeness and coverage, a missing denominator population, unavailability on certain days (e.g., weekends, holidays), differences in data quality of collected data, lack of historical data, difficulty in accessing data sources, insufficient data availability for small area analysis, low specificity and the dependence on changes in the underlying data source or way of data collection. Strengths of data sources are the opposite of the aforementioned weaknesses.

The main weakness in the **SyS system setup** is high workload either for collecting/reporting data on the data provider's side or for processing data in the institution running the SyS system. The strength of the SyS system setup is keeping the workload, especially for data providers, low.

Major advantages of SyS systems reported across all visited systems are **timeliness, flexibility** (use of different diseases and events, quickly adjustable during events) and **complementarity** to existing surveillance systems. The major reported challenge is **lack of funding**.

Added value of SyS

There are two trends which can be identified from the visits showing the added value of SyS: monitoring of seasonal infectious disease outbreaks and situational awareness during various kinds of potentially health threatening events. "SyS is an essential component of the national surveillance system […]. It is used for early recognition of trends and a key factor for description of the health burden." stated an Italian stakeholder of the SyS systems in the country.

Visited systems reported a special value of SyS for **seasonal influenza monitoring** as SyS is providing information quicker, earlier and on populations not covered by traditional influenza surveillance (Denmark, France, Italy, Sweden, SIDARTHa in Spain, Netherlands, England and Scotland). As a stakeholder in England described it: "a key component of routine influenza surveillance". Another seasonally occurring event for which SyS was providing added value for the same reasons was **winter vomiting disease** (England, Sweden). The fact that SyS information is available throughout the year and depending on the data source also during weekends and holiday seasons proved to be useful in a couple of cases, e.g., for seasonal influenza in Spain (the SIDARTHa SyS was the only information source available as the influenza season peaked during the Christmas holidays) or an out-of-season norovirus outbreak in England (here, a new norovirus strain was identified based on the detection of the outbreak by SyS). Also the 2009 influenza pandemic was starting out-of-season and in all visited countries (except the planned Hungarian systems) and the SIDARTHa system, SyS was used to monitor the onset and development of the pandemic.

During seasonal events, the SyS system output is also used by the data providing health care institutions to adjust their resources (Denmark, France, Italy, SIDARTHa in Spain, Netherlands, UK).

Situational awareness or reassurance of no health impact of potentially health threatening events was of special value of SyS as reported by the visited systems. Examples are extreme weather events (heat waves in France, flooding in the UK), mass gatherings (Olympic Games in England, G8/20 summits in France, Denmark and Scotland), industrial accidents (France, England), other infectious disease outbreaks (Legionnaires disease in Scotland and the Netherlands, Chikungunya outbreak in La Reunion (France), Dengue outbreak in deployed French forces (ASTER system), measles in Italy), or unexpected rare events such as a drug overdose cluster in France, the volcanic ash cloud covering Europe in 2010 (monitored by SyS in the UK and SIDARTHa) or the influx of migrants from North Africa to Italy. It was made clear, e.g., in Italy and England, that SyS played a crucial role of being a real-time information source to answer to questions from the public, policy makers and journalists during large-scale health crises such as the pandemic 2009 or the influx of migrants in Italy 2011.

No system reported having identified a previously unknown disease or that their systems were of particular value for detecting outbreaks but rather to assess the impact or absence of impact of an event on the health of the population.

A value of more mature SyS is provided by the fact that **multiple data sources/systems** are available that provide a more complete picture, covering different parts of the population, different severity levels or different syndromes, and for cross-check of signals. As a stakeholder in Scotland put it: “Blend of data is most powerful!”.