Infectious disease surveillance

Learn how infectious diseases are monitored

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2025-08-11

1 About the book

Learn how infectious diseases are monitored.

Whats in this book

This book is about infectious disease surveillance. It explains what surveillance ist, how it is related with other similiar concepts, what elements a surveillance system is build of and how to asses the quality of surveillance systems. The book is written for infectious disease experts in Europe, but can be used by anybody interested in the topic. It would be good to have some prior knowledge, but you dont need to.

The book consists of two parts

1. Presentation: This is meant for presenting
2. Detailed part: This highlights the cont

Learning objectives

- Surveillance is information for action
- Learn how to define a surveillance system
- Get to know types of surveillance systems
- Learn the steps of a surveillance system
- Find resources about the evaluation

Who writes this book

The contents of the book come form the “EPIET-World” - the european fellowship programm for applied epidemiology. Most content of the book is writtten by Jakob Schumacher, but its based upon the work of many collegues who taught the subject beforehand.

You would like to help this book - great! Here is how to do that:

1. You can go to Github issues of this repository and say what can be improved
2. You can clone, than write something yourself and then make a pull request.

Learn more

- ECDC Handbook: Data quality monitoring and surveillance system evaluation

Part I

Presentation

2 Intro

2.1 Definition

> Public health surveillance is the **systematic** and **ongoing** collection, collation and **analysis** of data for public health purposes and the **timely dissemination** of public health information for assessment and **public health response** as necessary. [1]

2.2 Other surveillance systems

1. Neighbourhood surveillance (People watching other people)
2. Rhizomatic surveillance (Unkown actors watching secretly)
3. Top-down-surveillance (State actors watching their people)

2.3 Objectives

Objective	Description
Action for cases	guidance/quarantine/isolation
Action for groups	lockdown/school closings
Action for medical professionals	substitute antibiotic in response to antibiotic resistance
Action for the comminity	mask, voluntary social distancing
Detect and alert	Serves as an early warning system for impending public health emergencies
Evaluate	Documents the impact of an intervention, or track progress towards specified goals
Describe	Monitors and clarify the epidemiology of health problems

[1] World Health Assembly 2005 (similar definition from Langmuir AD. William Farr: Founder of modern concept of surveillance. Int J Epidemiol 1973;5:13-8)

Objective	Description
Inform	Allows priorities to be set and to inform public health policy and strategies

2.4 Examples

2.4.1 Decision to lockdown on 28th of October 2020, Germany

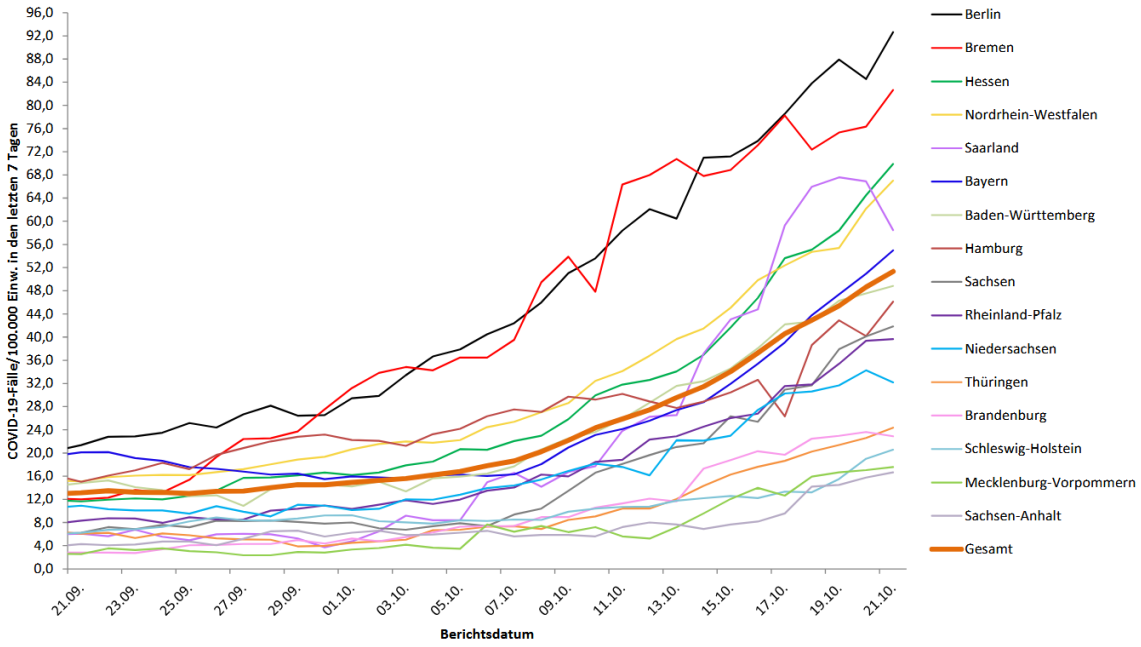


Figure 2.1: Picture taken from "Täglicher Lagebericht des RKI zur Coronavirus-Krankheit-2019 (COVID-19) 21.10.2020"

2.4.2 Campylobacter

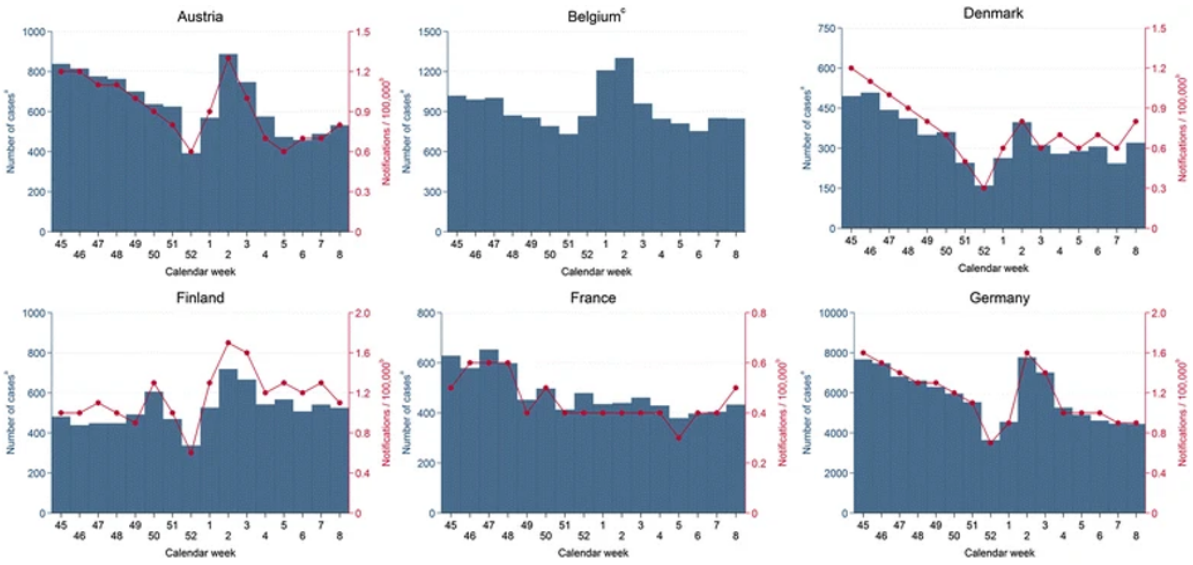


Figure 2.2: Bless, Schmutz, Mäusezahl: The recurrent campylobacteriosis epidemic over Christmas and New Year in European countries, 2006-2014 https://pubmed.ncbi.nlm.nih.gov/28693589/

2.4.3 Rotavirus

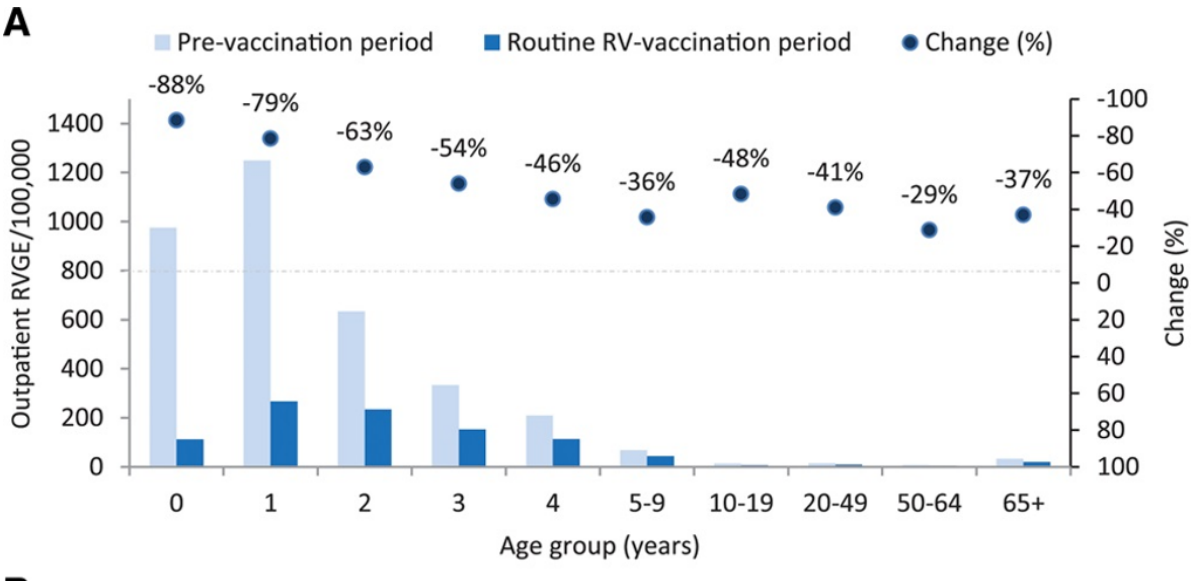


Figure 2.3: Marquis, Koch: Impact of Routine Rotavirus Vaccination in Germany: Evaluation Five Years After Its Introduction https://pubmed.ncbi.nlm.nih.gov/32187139/

2.4.4 SARS-CoV-2

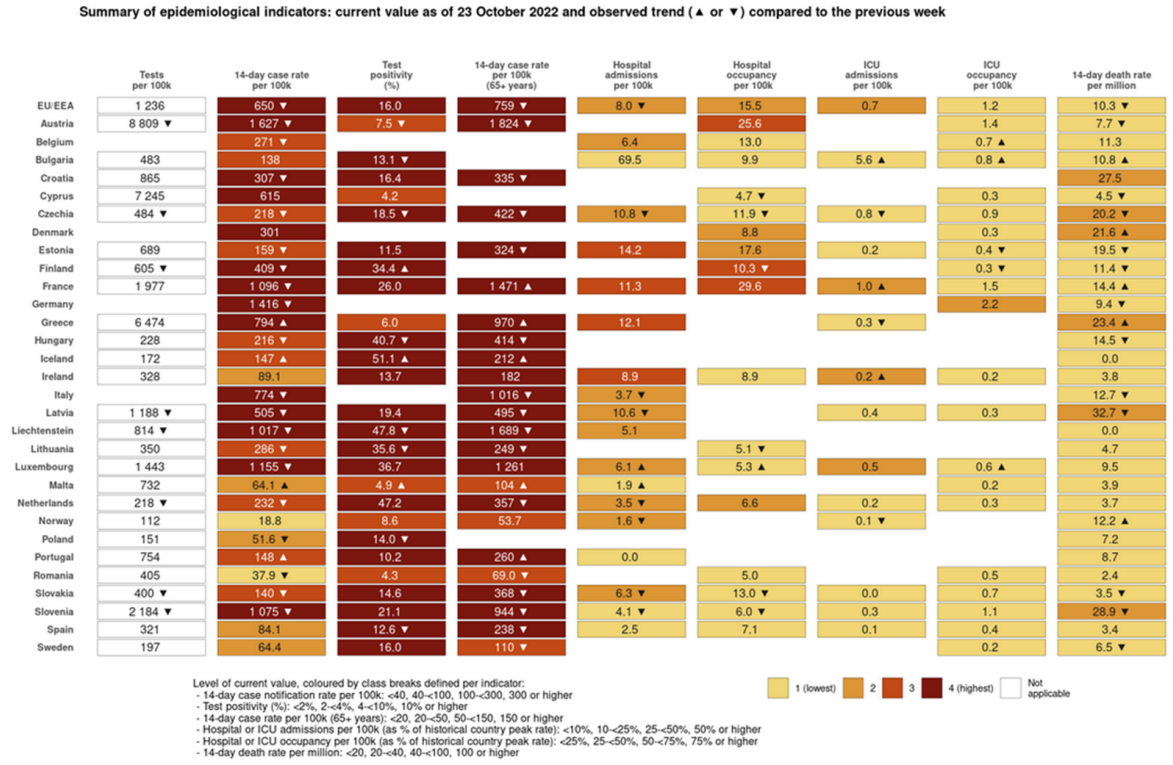


Figure 2.4: Summary of epidemiological indicators: current values as of 23 October 2022 and observed trend compared to the previous week. https://www.ecdc.europa.eu/en/covid-19/surveillance/weekly-surveillance-report

3 Steps

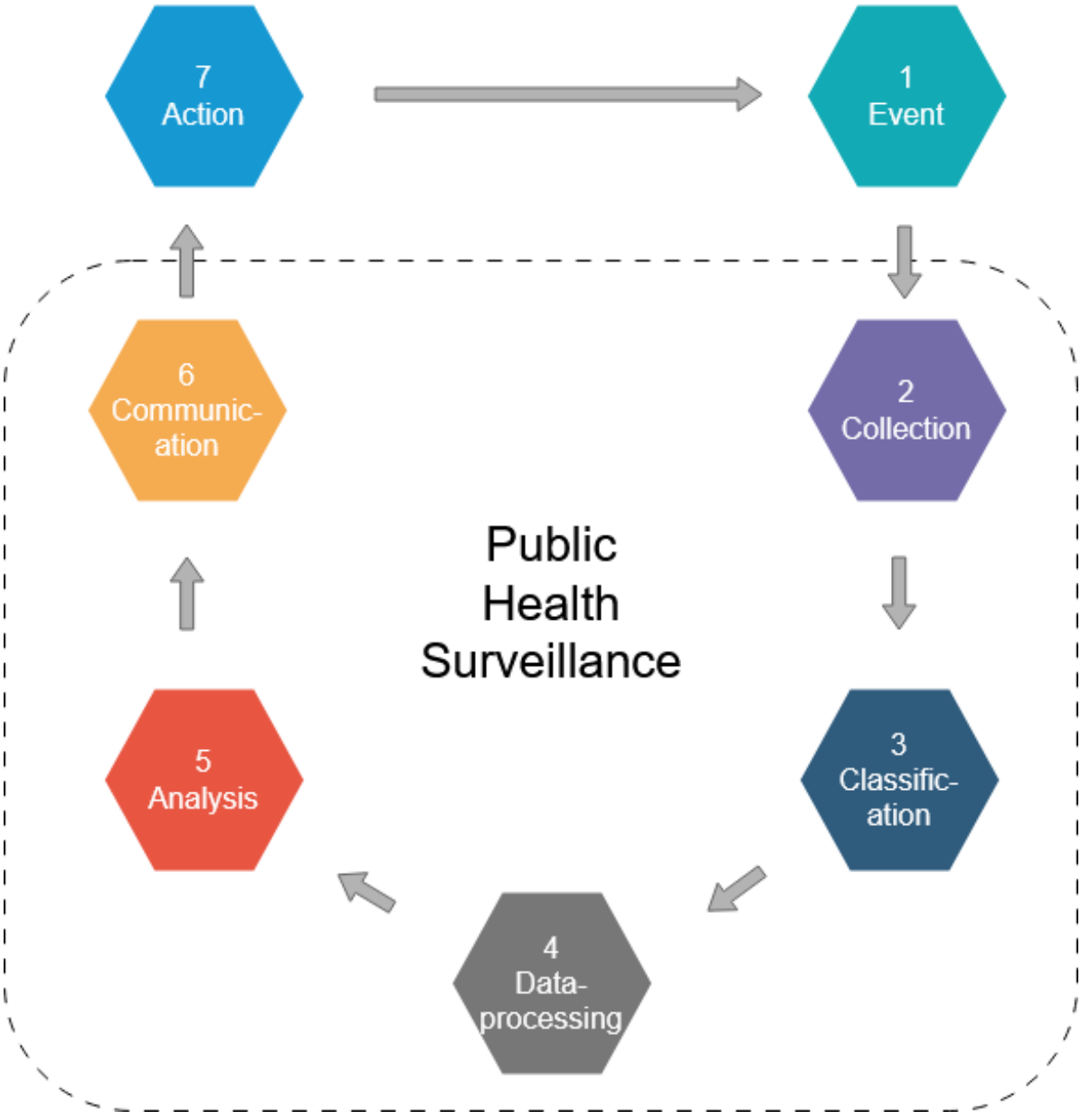


Figure 3.1: Steps of a surveillance system

3.1 Infection event

- The event that is monitored can vary
- Typical event: a case

3.2 Collection

- Events are collected by an agency

3.3 Classification

- The events are classified (see case definition)
- By classifing the events are turned into data

3.4 Data processing

- Data systems store and distribute data
- At this step data can be made as open data

3.5 Analysis

- The data is analysed by public health experts
- The data is turned into information

3.6 Communication

- The information is communicated to decision makers
- Usually done via reports
- Visualising information is important

3.7 Action

- Decision makers act upon the information

4 Types

- Surveillance systems can be categorized
- These categories are not mutually exclusive
- Some are well defined others more a convention
- The name usually comes from the event that is monitored

4.1 Case-based surveillance

- The typical surveillance system in infectious diseases
- The event is that a person that gets infected or diseased
- Sometimes its named: physician-based system or lab-based system

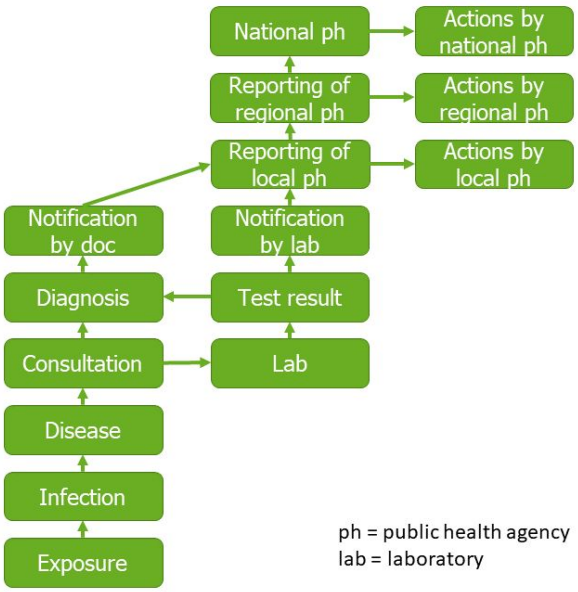


Figure 4.1: Adapted from ECDC Handbook Data quality monitoring and surveillance system evaluation

4.2 Syndromic surveillance

- Instead of a specific disease its a syndrom (a group of diseases) that is monitored
- Is more sensitive and can find unkown diseases

4.3 Event-based surveillance

- This system detects unkown events
- It can be a group of persons who talk every week what they found

4.4 Wastewater surveillance

- This system detects pathogens in wastewater

4.5 Mortality surveillance

- This events detects deaths (and sometimes the cause of deaths)

4.6 Mass-gathering surveillance

- Surveys one specific mass gathering

4.7 Actvie vs. passive surveillance

- Some systems actively look for cases
- Some systems are passive and collect secondary data

4.8 Sentinel vs. comprehensive surveillance

- Some systems focus on a fraction of the population under surveillance - a sentinel
- Other systems try to capture everything in a population

4.9 Mandatory vs. voluntary

- Reporting can be made mandatory or it can be voluntary

5 Attributes

- Surveillance systems have attributes
- The definitions vary a lot
- This book follows ECDCs Handbook
- Other notable definitions: European medicines agency
- Closely related is data quality (which is completeness and validity)

5.1 Underestimation

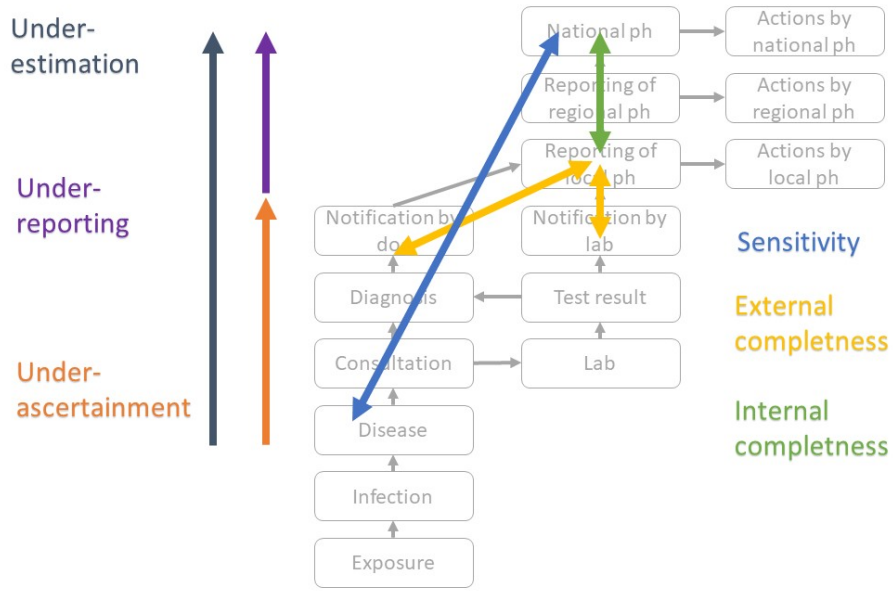


Figure 5.1: Attributes around underestimation

5.1.1 Sensitivity

- **Definition:** *Proportion of cases in a population that are reported. Underascertainment and underreporting*

- **How to measure:** Compare to gold standard, capture-recapture

5.1.2 Positive predictive value

- **Definition:** *proportion of real reported cases, divided by the total number of reported*
- **How to measure:** Case-follow up

5.1.3 Internal completeness

- **Definition:** *the number of completed data fields out of the total number of data fields*
- **How to measure:** Analyse the data

5.1.4 External completeness

- **Definition:** *whether the data reflect the true number of reported cases - 'sensitivity of reporting'* This corresponds to underreporting
- **How to measure:** Capture-recapture

5.2 Validity

5.2.1 Internal validity

- **Definition:** *extent of errors within the system - 'errors in reporting'*
- **How to measure:** Analyse the reporting system

5.2.2 External validity

- **Definition:** *whether the information recorded about the cases is correct*
- **How to measure:** Test against a gold standard

5.3 Timeliness

- **Definition:** *speed between steps in a public health surveillance system*
- **How to measure:** Analyse database

5.4 Usefulness

- **Defintion:** *contribution to the prevention and control of infectious diseases*
- **How to measure:** Survey

5.5 Representativeness

_ **Defintion:** _accuracy of describing the occurrence of a health-related event across time, place, person___ - **How to measure:** Population covered by surveillance divided by the total number

5.6 Simplicity

5.7 Flexibility

5.8 Acceptability

5.9 Balancing attributes

6 Evaluation

6.1 Indicators of a surveillance system

- Number of cases
- Incidence
- Percentage of people hospitalised

6.2 Describe a surveillance system

- Legal framework
- Objectives of a surveillance system
- Public health actions for prevention and control
- Which information does the surveillance provide to inform these actions?

- Population under surveillance
- Geographic coverage

- Events under surveillance
- Type of surveillance

- System's indicators?
- Notification of cases

- Format of case notification

- Format of reporting

- Hierarchy levels in reporting
- Who are the system's participants/data providers
- Who are the recipients/users of the system data

Part II

What is surveillance?

7 Information for action

On the 28th of October in 2020 German chancellor Angela Merkel and the head of the federal states stuck their heads together. They had to make tough decisions about measurements to mitigate the COVID-19 pandemic. We dont know exactly what they were talking about but we can be certain that they were making the decisions with graph in picture 1 in mind.

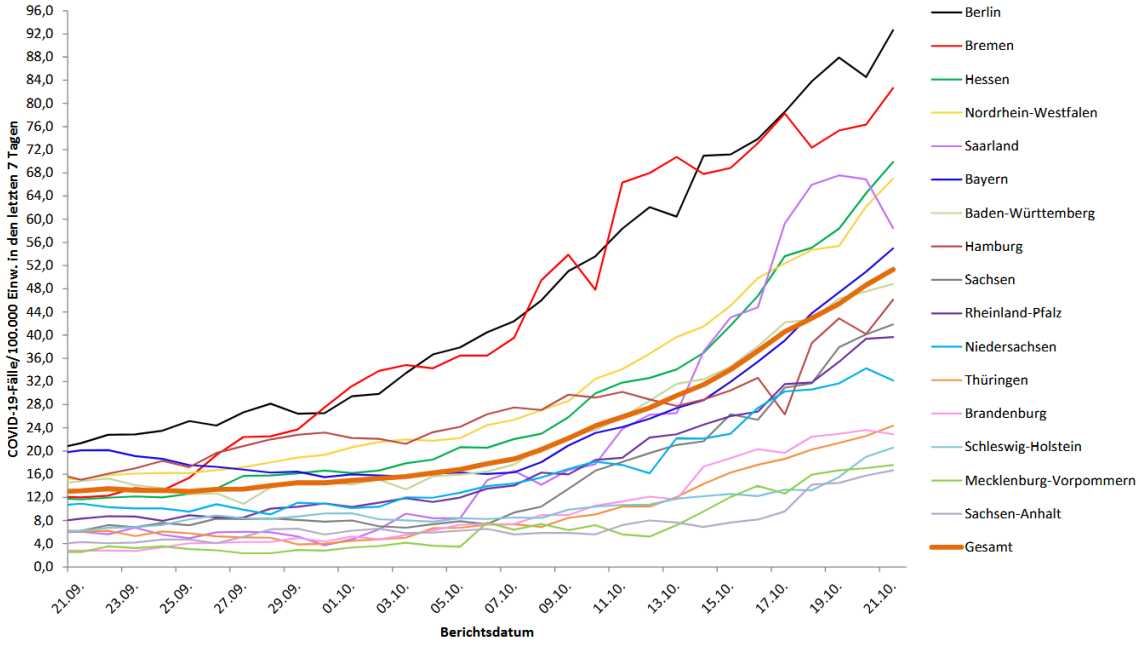


Figure 7.1: Picture taken from "Täglicher Lagebericht des RKI zur Coronavirus-Krankheit-2019 (COVID-19) 21.10.2020"

Infectious diseases are a threat to humanity: some have the ability to easily spread from one person to others persons and infecting all of mankind, some can be transmitted before the infectious persons knows that he is sick, some have no cure and a high fatality rate, some are able to spread long distances via air, water or food.

To combat infectious diseases mankind has developed numerous techniques throughout the ages. On very important tool that is a prerequisite to most count measures is infectious

disease surveillance. Knowing what happens when and how is one of the cornerstonse of every response. And infectious disease surveillance does exactly that.

8 Definition of surveillance

> Public health surveillance is the systematic ongoing collection, collation and analysis of data for public health purposes and the timely dissemination of public health information for assessment and public health response as necessary. [1]

The definition of public health surveillance is very informative. It gives us all important elements of a surveillance system.

Element	Explanation
systematic	surveillance is a planned undertaking that works with clear definitions
ongoing	surveillance is planned for a longer time (usually). This is in contrast to a scientific study
collection	Events are collected and stored in datasystems
analysis	The data is analysed and turned into information
timely	Focus on speed because this is needed for measures
dissemination	Visualisation and reporting of the information
assessment and public health response	The information guides public health responses

[1] World Health Assembly 2005 (similar definition from Langmuir AD. William Farr: Founder of modern concept of surveillance. Int J Epidemiol 1973;5:13-8)

9 Other forms of surveillance

Nearly all complex biological and technical systems have mechanisms to monitor and control the system's condition. Many social systems also regularly analyze their current state. There are various terms for these status assessments: A scientific study is one form of status assessment, as is the police surveillance of a group or the evaluation of a project in the corporate sector. Surveillance is also a form of status assessment.

9.1 Neighbourhood surveillance

Neighbourhood surveillance is the oldest form of surveillance. In its broadest sense it es people watching other people. Small Communities such as villages usually have a strong neighbourhood surveillance. Neighbors see and know everything what other neigbohrs are doing. This can be framed positively as in the saying: "it takes a village to raise a child" or negatively when people blaspheme other people.

With the widespread availability of cameras and the possibility to communicate directly this form of surveillance has gained a large momentum. The largely unsuccesfull Google glass project could have been an even larger driver of participatory surveillance. Now Surveillance becomes a tool that does not lie in the hands of a strong actor such as a state or less strong actors such as companies but in the hands of the individuals. This gives infectious disease specialists the opportunity to gather information from thos eindividuals as it is done in epidemic intelligence.

This form of surveillance is sometimes also called participatory surveillance - if you want to emphasize the empowerment of the people. One rather negative example of a participatory surveillance is vividly depicted in the book and film the circle. Sometimes this form of surveillance is called bottom-up-surveillance to emphasize the opposition to top-down-surveillance.

9.2 Rhizomatic surveillance

Rhizomatic surveillance is a term coined by Haggerty and Ericson[1]. The term comes from rhizom - the large underground network from Fungi. This form of surveillance shows similar

[1] Haggerty KD, Ericson RV. The surveillant assemblage. Br J Sociol. 2000 Dec;51(4):605-22. doi: 10.1080/00071310020015280. https://pubmed.ncbi.nlm.nih.gov/11140886/

characteristics of the rhizom: is is being not directly visible (being "underground")), it is horizontal in contrast to the top-down surveillance (like the rhizom that does not follow the typical direction of plants growing upwards to the sun)) and the surveillance is a group of different actors instead of one single responsible body. The surveillance done by the big tech companies is a form a rhizomatic surveillance. Collecting millons of datapoints that are left behind by users in the internet can give valuable inside that can be turned into profit. The cambridge analytica scandal is an example of such a surveillance system. State actors are of course also capable of doing rhizomatic survaillance as could bee seen in the documents leaked to PRISM.

9.3 Top-down-surveillance

The top-down-surveillance is the surveillance which we usually think of first when we hear the word surveillance. There is an agent usually a dominent one like the state who watches was its constituents do. This can take the form of an Panopticon, where one person can watch many different person and after which some prisons have been modeled. This form of surveillance often aims to achieve a specific behavior among those being monitored. Epidemiological surveillance belongs to this level of surveillance.

9.4 Learn more

You can read more about different types of surveillance in this article by Tieman et al. [2]

[2]Timan, Tjerk and Galič, Maša and Koops, Bert-Jaap, Surveillance Theory and Its Implications for Law (December 1, 2017) https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3098182

10 Objectives of surveillance

Objective	Description
Action for cases	guidance/quarantine/isolation
Action for the population	lockdown/school closings
Action from the medical professionals	substitute antibiotic in response to antibiotic resistance
Action from the community	mask, voluntary social distancing
Detect and alert	Serves as an early warning system for impending public health emergencies
Describe	Monitors and clarify the epidemiology of health problems
Evaluate	Documents the impact of an intervention, or track progress towards specified goals
Inform	Allows priorities to be set and to inform public health policy and strategies

10.1 Example: Objectives of EU/EEA surveillance

- Detect and monitor any multinational infectious disease outbreaks with respect to source, time, population, and place in order to provide a rationale for public health action;
- Monitor trends in infectious diseases over time and across Member States to assess the present situation, respond to rises above warning thresholds and facilitate appropriate evidence-based action;
- Contribute to the evaluation and monitoring of prevention and control programmes targeted at infectious diseases in order to provide the evidence for recommendations to strengthen and improve these programmes at the national and European level;
- Identify population groups at risk and in need of targeted prevention measures;
- Contribute to the awareness of and the assessment of the burden of infectious diseases on the population using such data as disease prevalence, complications, hospitalisation, and mortality; and
- Generate hypotheses on (new) sources, modes of transmission and groups most at risk and identify needs for research and pilot projects

10.2 Action for cases

Many public health interventions focus around the identification of cases and their surroundings. This action is usually taken by a local public health agency. For this objective a surveillance systems needs to directly identify cases together with the possibility to contact the case.

Typical interventions taken are: - guidance: The local public gives the case or his contact persons guidance on what to do and how to behave - mandate: The local public health official could order a case or a contact person to do something. This could be quarantine for example - information: the local public health agency informs everybody who needs to know about this public health event

10.3 Action for the population

Some public health interventions focus a specific group of people. These interventions are sometimes described as non-pharmaceutical-interventions - although this sometimes also compromises case based interventions. This kind of intervention is often done via a regulation by a federal state or a national body. But it can also be taken by a local public health agency, especially if the public health problem is local. This action requires usually only trends and not necessariliy case based information.

Typical interventions are: - Boiling water before drinking - Requiring to wear masks - Closing schools - Giving advice

10.4 Action taken from medical professionals

Some findings of surveillance systems lead to a change in practice of medical professionals. A medical professional society could change the guidelines according to findings. This intervention is initiated by the medical people and not necessarily by the public health agencies

Typical interventions are: - change in calculated antibitotic therapy (so before information about resistance of the specific pathogen is available) according to a higher resistancy in an area - change in immunization strategies

10.5 Action taken from the community

The information from surveillance systems can lead to people changing their behaviour. This compromises many different interventions, that are taken by the people themselves (if it is

initatied by an agency it would be a group-based intervention). These interventions can be ineffective or even counterproductive.

Typical interventions are: - Wearing masks - Washing handy frequently - Not using public transport - Avoiding specific groups

10.6 Detect and alert

Surveillance systems serve to detect impeding public health problems and then to alert the ones who need to be alerted. Systems that are build to do this are called early-warning system. The systems can be very broad in nature and usually rely on detecting a trend.

10.7 Describe

Surveillance systems collect data that can also be used for public health research. Scientists can use the data to analyse specific public health problems. The system can give information about the nature of a pathogen and epidemiological characteristics of a public health problem. One example would be the change of variants that follow the introduction of a new vaccine.

10.8 Evaluation

Public health interventions should be benefical for the population. The intervention can measure output, outcome and impact. Measuring the impact can be considered the most important part because it shows the benefits. This impact measurement can be done in with a surveillance system.

10.9 Inform

Governments need to decide about their priorities and the distribution of resources. These decisions can be taken upon the information from surveillance systems.

11 Laws and recommendations for surveillance

Surveillance is firmly anchored in national and international legal systems. The International Health Regulations—one of the few nearly globally applicable frameworks—include articles that require surveillance from states. These articles aim to prevent cross-border threats from infectious diseases. During the COVID-19 pandemic, the value of such international collaboration became evident. There are currently efforts to supplement the International Health Regulations with an International Treaty on Pandemic Prevention.

Surveillance is also a component of the "Essential Public Health Operations." The goal of this fundamental component is to provide information and insights for health needs assessments, health impact assessments, and the planning of health services.

Part III

Steps of surveillance

12 Step 1: Infection Event

The infection-related events monitored in a surveillance system can be diverse. The term objects of a surveillance is sometimes used insted of event. The choice of the specific event has a decisive impact on the entire system. What event is monitored depends on the aim of the surveillance system. It is useful to be precise about the event that wants to be monitored. This helps in the communication and in the quality assessment.

Surveillance systems are often named after the event that is monitored: Emergency room surveillance is one such example. Also the categorization of surveillance systems depends on the event being analyzed: For example, a system classified as "syndromic surveillance" is based on the monitoring of syndromes.

A classic event that is monitored is the occurrence of an infectious disease in a person. However, there are many variations and other infection events that may be relevant:

- an available ICU bed
- the colonization of a person by a pathogen
- a physician's ICD-10 classification of a patient
- the discovery of a newspaper article about a disease outbreak
- the subjective assessment of a public health department employee that something poses a threat to the population.

One important but sometimes difficult distinction is differing between infection and disease. A lab confirmation usually shows an infection, which means that we know, that a person has a infection but is not necessarily sick, whereas a confirmation by a physician usually means that a person is sick.

13 Step 2: Collection

Infection events are collected and collated. How exactly this collection takes place depends on the type of surveillance system. This may happen, for example, through a report from a doctor. An event can also be recorded through a commissioned laboratory examination, such as a PCR test in wastewater. Other recordings are made by health authorities, which investigate further cases after an initial report. There is also the use of other data sources not primarily collected for surveillance, such as illness reports to health insurance companies or death certificates from doctors. This step also often leads to the naming of a surveillance system: a physician-based system as opposed to a laboratory-based system, or secondary data surveillance.

14 Step 3: Classification

Classification means categorizing the recorded events. Sometimes the word “collation” is used for this step. A person or software decides based on a definition how the event is included as a data point. Often, classification involves agreeing on what exactly counts as an event and what does not. This classification is often done using a so-called case definition. Classification is important because recorded events can be erroneous and should not be counted. Or there may not be enough information to decide whether a real event has occurred. Without classification, the events form an unclear collection with questionable significance. Classification is often a hidden part of the surveillance system or built into the system in a way that it is not recognized as such. For example, the application of case definitions in the reporting system is built into the reporting software. Even in seemingly trivial classifications, important definitions must be agreed upon: Does the death of a tourist with a foreign passport count as a death in the context of mortality surveillance?

15 Step 4: Data Processing

Data processing is seldom mentioned in classical surveillance literature, but it is a step that significantly improves surveillance systems. Many people at all levels are involved in data processing within surveillance systems. In the past, data was transmitted monthly by mail in surveillance systems, whereas today, data flow mostly occurs through interfaces between software programs and databases. The way data is transmitted affects data quality and, consequently, the evaluation of the data. Data processing also includes the application of scripts that prepare the data for subsequent evaluation. An example is automated outbreak detection. Here, data is analyzed using an algorithm or machine learning to determine whether there is a high probability of an outbreak. The resulting dataset can be made available as open data, a publication format that has increased significantly in recent times.

16 Step 5: Analysis

The analysis step consists of analyzing the data and subsequently drawing conclusions (assessment). In other words in the analysis steps the available data is transformed into information. In some cases, the analysis is straightforward; for example, when a case of Ebola is reported in a returning traveler, it is clear that this is an important event that necessitates action. In other cases, analysis is highly complex and requires a lot of experience and exchange between the evaluators: Is a relative increase in a variant of SARS-CoV-2 a reason for action? This analysis step converts data into information, following the first two parts of the "data–information–knowledge–wisdom" pyramid[1]. assessment is a subjective process and context-dependent. Knowledge of the limitations is particularly important for assessment. An increase in cases may seem like a clear event on paper but could be caused by intensified recording, making it less relevant and even a sign of relief, for example, if a comprehensive diagnostic of all hospital staff finds fewer cases than expected. The publication as open data means that the assessment is not only carried out by designated individuals but is open to everyone, enabling independent verification of this step in surveillance but also posing the risk of misinterpretation.

[1]Rowley, J. (2007). The wisdom hierarchy: representations of the DIKW hierarchy. Journal of Information Science, 33(2), 163-180. https://doi.org/10.1177/0165551506070706

17 Step 6: Communication

Communication is the dissemination of the obtained information in words, writing, and images. Communication consists of traditional elements such as press releases and press conferences or the preparation of reports. Communication now also includes social media and fact-checking. The presentation of data and information in dashboards also counts as communication. Last but not least, the graphical representation of information related to time, place, and person is part of this surveillance step. The communication of epidemiological information was a major focus towards the end of the pandemic and is an area with strong development potential. Almost worldwide, a significant portion of the population rejected the measures to combat the COVID-19 pandemic, thereby influencing the course of the pandemic.

18 Step 7: Public Health Measures

Measures are not strictly speaking a step of surveillance, but they are the goal towards which surveillance is directed. Public health measures are all deliberate efforts by commissioned actors aimed at preventing the further spread and generally minimizing the harm caused by infectious diseases. Measures are often legally defined, for example, in the Infection Protection Act. Measures can be divided into case-based measures and population-based measures. Case-based measures include, for example, informing an affected person about transmission routes or measures such as quarantine. Population-based measures are those that affect many people, for example, the population of a federal state.

Part IV

Types of surveillance

19 Case based surveillance

A case based surveillance system focuses on identifying instances of diseases. They are very typical around the world. Its usually physicians that need to notify the occurence of a disease (physician-based surveillance) or a laboratory (lab-based surveillance).

A typical example is a system that requeires a physician to fill out a form when she or he finds a person that has a disease. The form is then send to a local public health agency where the event is collected and classified. The data is entered into a software and then analysed by public health experts

19.1 A typical scope of a case based surveillance system

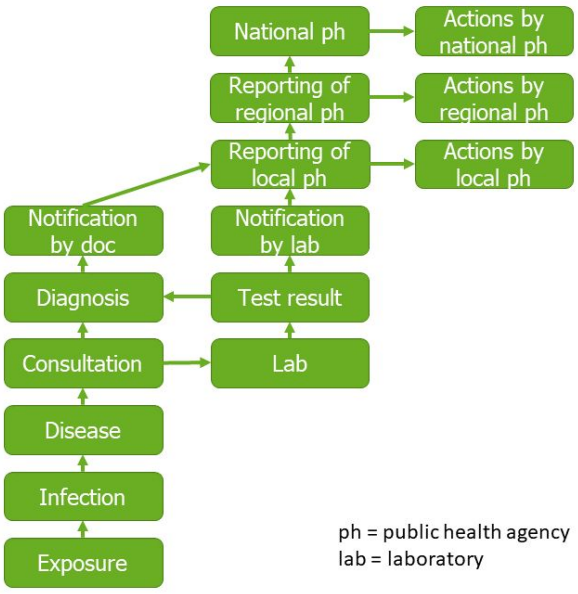


Figure 19.1: Scope of a case based surveillance system. Adapted from ECDC Handbook Data quality monitoring and surveillance system evaluation

19.2 Example of a case based surveillance system

The German infectious disease reporting system is governed by the Infection Protection Act (IfSG). It is the backbone of epidemiological surveillance in Germany. It has developed historically and has its roots in the Imperial Epidemic Act of 1900. This act hat for example the following regulation: *"Any case of illness and any death from leprosy, cholera (Asian), typhus, yellow fever, plague (Oriental bubonic plague), smallpox [...] must be reported immediately to the competent police authority."* The current reporting system was established in 2000 with the creation of the Infection Protection Act. The reporting system is legally regulated in Sections 6 to 11 of the Act, which have been amended multiple times, usually in response to acute events such as the HUS epidemic in 2011.

The events (Step 1) monitored are typically the occurrence of infectious diseases. However, the reporting system encompasses various reporting obligations and multiple reporting channels. It can therefore be viewed as a collection of related but essentially different surveillance systems. A significant component of the reporting system is the obligation for physicians, pathologists, and other professionals to report. The event captured in this context is the suspicion of a disease, the diagnosis of the disease, or the death from a diseases. The infectious diseases are laid out in the text of the law and consists out of severe diseases that can be medically diagnosed, such as measles, polio, or HUS. Another relevant component is the obligation for laboratories to report. The monitored event is a laboratory finding indicative of an acute infection. This laboratory reporting obligation applies to a wide range of infectious diseases. In addition to the physician and laboratory reporting obligations, there are other components, such as non-nominal reporting obligations for the laboratory detection of certain pathogens like HIV, which follow a separate reporting pathway.

The capture of physician and laboratory reports (Step 2) is usually carried out through the reporting process and investigations by the health authorities. For many years, the method of reporting was not standardized and was typically done via fax. In the last decade, the German Electronic Reporting and Information System (DEMIS) has been developed, primarily digitizing the reporting process from the reporter to the health authority. This method of reporting is now legally required for many reporting channels under the Infection Protection Act. The way health authorities conduct investigations is not prescribed, although there are, of course, restrictions due to privacy rights. A common investigation involves a phone call from the health authority and an infection control interview with the affected individuals. The reporting system is thus a hybrid system of passive and active surveillance. It is passive because the monitored events do not exist solely because of the reporting system. For instance, in most cases, a laboratory test is performed for clinical reasons, not for epidemiological reasons. It is active because health authorities actively investigate and contact the affected individuals. Investigation is a central part of the job profile for public health inspectors.

The classification (Step 3) within the reporting system is performed by the health authority, assisted by the respective reporting software. After entering the collected data, the software indicates whether the event matches the defined criteria. These definitions are twofold: first,

there is a definition for events that must be reported to the state authority and the RKI ("reporting definition"), and second, there is a definition for cases officially counted in the RKI statistics ("reference definition"). Establishing these definitions is crucial for ensuring comparability and identifying increases or decreases in the number of cases. At the start of the COVID-19 pandemic, the Chinese government changed the case definition of COVID-19, leading to an artificial spike in the statistics. Case definitions can be sensitive, aiming to capture as many cases as possible, or specific, aiming to include only a small number of false-positive cases. Case definitions exist not only for a surveillance system but are also often established separately for outbreaks. Additionally, case definitions are not necessarily the standard for implementing measures. For example, in a suspected case of hemorrhagic fever, action does not need to wait until a case definition is met.

Data management (Step 4) takes place after classification. The reporting system has significantly benefited from more professional data management. Before the introduction of electronic reporting software, data was transmitted laboriously and prone to errors via mail or fax. With increasing digitization and the reduction of media disruptions, data management has become increasingly precise and faster. The most well-known reporting software, SurvNet, from the Robert Koch Institute (RKI), sets the standards for transmission from the health authority to the state authority and from there to the RKI. Data management is carried out in databases operated by the RKI. This process includes quality assurance and data preparation for the subsequent evaluation step. The preparation also involves automated signal detection, identifying and appropriately displaying potential outbreaks.

The analysis of the reporting system's data occurs at all three levels: local, state, and national. This is similar to the interventions taken. Usually the local agency takes case based measurements, whereas the state and the nation take population-based measurements

20 Syndromic Surveillance

Syndromic surveillance refers to surveillance systems where the relevant event is not a diagnosed disease but rather cases from a group of illnesses. For example, in syndromic surveillance, instead of tracking cases of SARS-CoV-2 infection, cases of acute respiratory illness are recorded. This approach makes the surveillance system more sensitive, capturing a broader spectrum of diseases. When a signal suggests a relevant event, such as an outbreak, further investigation can be conducted to identify the exact pathogen.

21 Event-Based Surveillance

Event-based surveillance, better known by its English name, is somewhat different from the usual concept of surveillance because the events being monitored are not known in advance. Through a defined system, relevant events are actively sought. An example of such surveillance is an expert commission that regularly meets to collect potentially relevant events. These events could be news reports or rumors heard by the experts. The collected events are then evaluated, and the critical information is passed on.

22 Wastewater

Wastewatersurveillance is a system that measures indicators of diseases in wastewater. Pathogens can be excreted via stool, urine or washed into the drain during shower. These pathogens can be detected at a wastewatertrement plant.

23 Mortality surveillance

Mortality surveillance asses the number of deaths. One example would be the collection of deaths certificates by physicians. They are legally required to fill out a form after a person dies. These forms are collected by specific agencies and the number of deaths or the reasons for death can be analysed by public health experts.

24 Mass-Gathering Surveillance

Mass-gathering surveillance refers to surveillance systems set up for the duration of a special event. Typically, different components from other surveillance systems are employed. For instance, a separate surveillance system might be implemented during a European Football Championship.

25 Active vs passive

Case based surveiallance systems can be divided whether they are active or passive. Many surveillancesystems have elements of both.

25.1 Active surveillance system

An active surveillance system involves a group of individuals who actively collect information for the surveillance system.

An example of an active surveillance system would if the staff of an agency goes door-to-door to gather information.

25.2 Passive surveillance system

A passive surveillance system uses data collected for other purpose. Passive surveillance can be seen as secondary data analysis.

An example for a passive surveillance system could be a system that extracts data from a hospital database.

26 Sentinal vs comprehensive

Sentinel surveillance is a system that does not monitor all individuals about whom conclusions are to be drawn but rather only a defined portion. The term "Sentinel," means "watchman,". A sentinel system saves resources and generally allows for more detailed information to be collected. The level of detail is often crucial for assessing epidemiological questions, such as evaluating the severity of a disease. For example, a few medical practices might be selected to collect detailed information on respiratory illnesses, including vaccination status, disease severity, and information on individuals without respiratory illnesses as a comparison group. These practices' data can then be extrapolated to represent all medical practices. The alternative—examining all practices directly—is much more labor-intensive and risks lowering data quality because some information may be provided reluctantly.

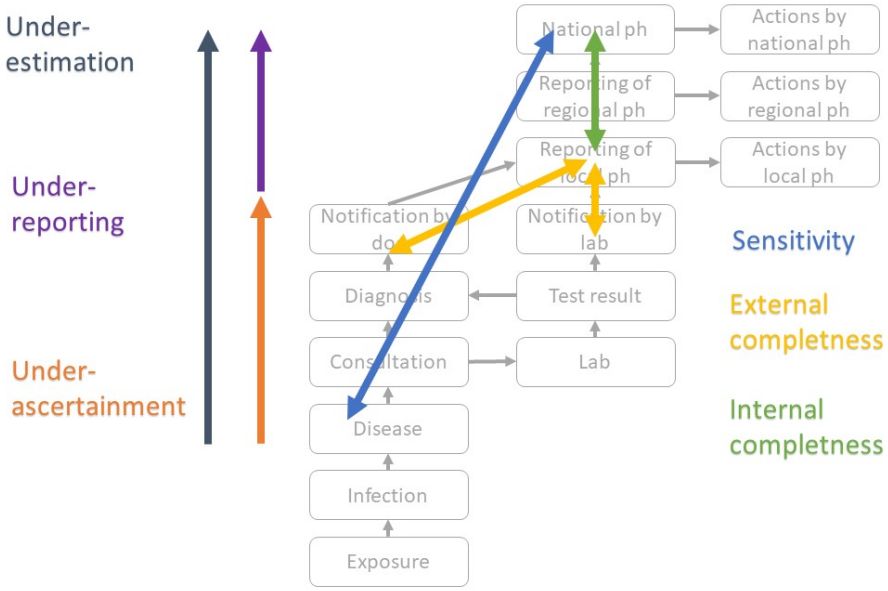
Part V

Attributes of surveillance

27 Sensitivity

27.1 Underestimation

Underestimation = unerascertainment + underreporting



27.2 Sensitivity

What proportion of the true number of cases are counted

27.2.1 How to measure

- Compare to gold standard

27.2.2 How to improve

- Improve the detection
- Change case definition

27.2.3 Example

- Imagine a case based system
- People that don't go do a physician wont get reported

27.3 External completeness

What proportion of the true number of diagnosed cases are counted ('sensitivity of reporting')

27.3.1 How to measure

- Capture-recapture

27.3.2 How to improve

- Make notification obligatory
- Give incentives
- Do a sentinel system

27.3.3 Example

- Lets assume a mortality surveillance system
- Doctors are required to fill out death certificates
- These death certificates are collected at a national level
- External completness means: of all deaths that are recognized by doctors how many get reported

27.4 Internal completeness

- How complete is the information in our database

27.4.1 How to measure

- Expected value of completeness vs actual value of completeness

27.4.2 How to improve

- Improve the technical quality
- Teach

27.4.3 Example

- Lets assume a mortality surveillance system
- We have ten records of deaths
- One of the records misses the age
- Three of them miss the probable cause of death

28 Validity

28.1 External validity

To what extent does the value in the surveillance system correspond to reality Closely realted to accuracy: how close do we come to reality

28.1.1 How to measure

- Difficult to measure
- Causal realation

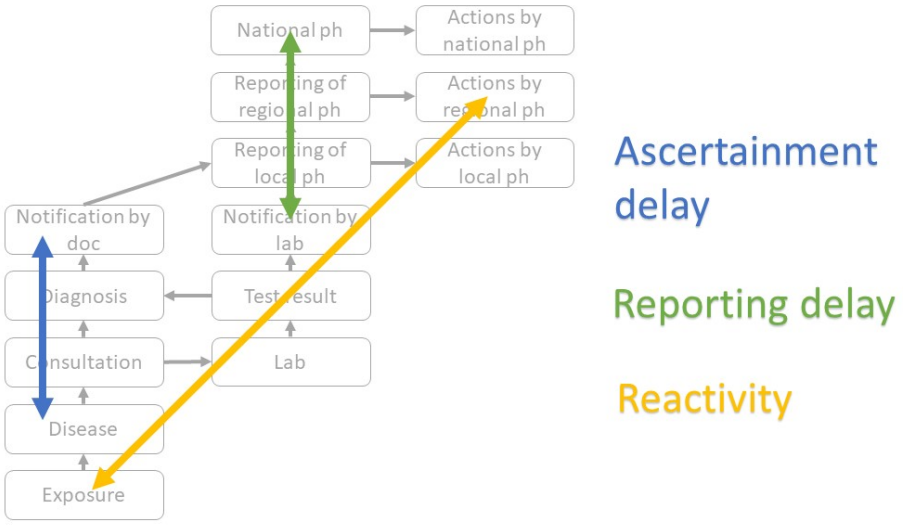
28.1.2 Examples

- If we want to record deaths by heatstroke
- Some physicians missclassify diseases

28.2 Internal validtiy

- The amount of coding errors

29 Timeliness



To what extent does the value in the surveillance system correspond to reality Closely realted to accuracy: how close do we come to reality

29.0.1 How to measure

- Difficult to measure
- Causal realation

29.0.2 Examples

- If we want to record deaths by heatstroke
- Some physicians missclassify diseases

29.1 Internal validtiy

- The amount of coding errors

30 Usefulness

31 Representativeness

32 Simplicity

The simplicity of a public health surveillance system refers to both its structure and ease of operation. Surveillance systems should be as simple as possible while still meeting their objectives [5].

33 Flexibility

33.1 Flexibility

A flexible public health surveillance system can adapt to changing information needs or operating conditions with little additional time, personnel, or allocated funds. Flexible systems can accommodate, for example, new health- related events, changes in case definitions or technology, and variations in funding or reporting sources. In addition, systems that use standard data formats (e.g. in electronic data interchange) can be easily integrated with other systems and thus might be considered flexible [5].

34 Simplicity

The simplicity of a public health surveillance system refers to both its structure and ease of operation. Surveillance systems should be as simple as possible while still meeting their objectives [5].

35 Other attributes

35.1 Stability

Ability of the system to accommodate changes with little additional time, persons or allocated funds New event to follow-up New case definition New data about an event New sources of information

35.2 Reliability

Refers to the ability to collect, manage, and provide data properly without failure

35.3 Adequacy

Refers to the ability of the surveillance system to address its objectives