Infectious disease surveillance

Learn how infectious diseases are monitored

Jakob Schumacher

Table of contents

About the book

> ⚠ Warning
>
> This book is work in progress and currently not in an acceptable state. Please return to this book to check for updates.
> jakobschumacher.github.com/infectious-disaese-surveillance

This book is about infectious disease surveillance. It explains what surveillance ist, how it is related with other similiar concepts, what the stages of a surveillance systems are 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.

Learning objectives

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

Who writes this book

The contents of the book come mainly 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. The book does not represent the opinion of the insitutions that the author is affiliated. It does also not represent the opinion of the ECDC. Training section.

Read more about the background in the About section

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.

Helpful ressources

- ECDC Handbook: Data quality monitoring and surveillance system evaluation

Preface

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.

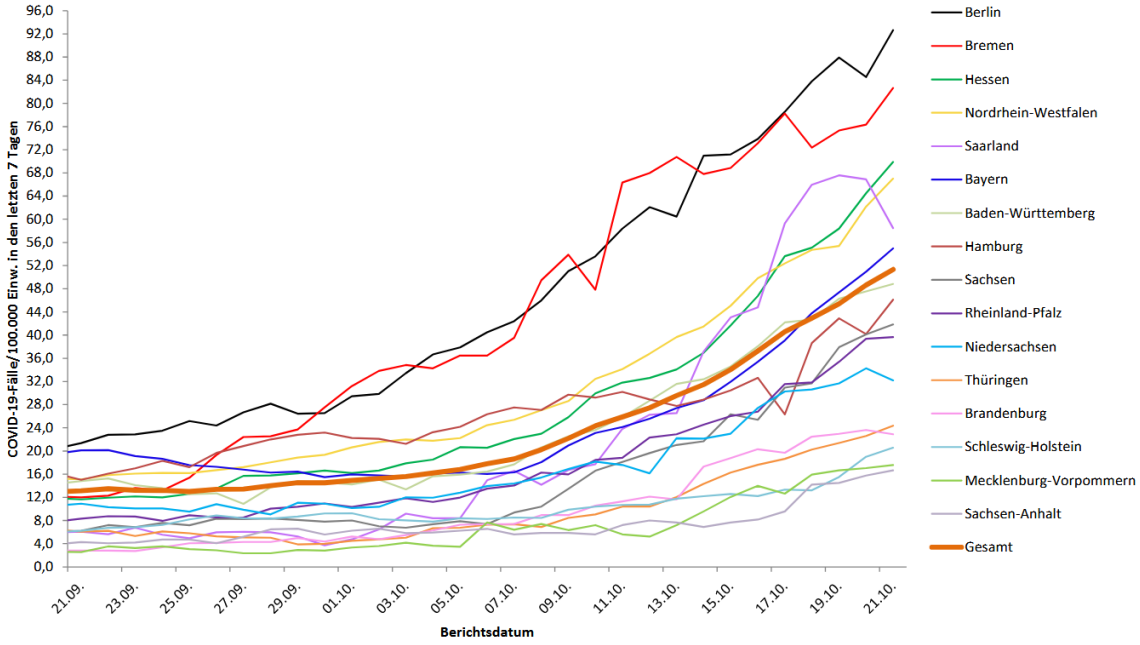

Figure 1: Picture taken from "Täglicher Lagebericht des RKI zur Coronavirus-Krankheit-2019 (COVID-19) 21.10.2020"

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.

Presentations

Generel presentations about infectious disease surveillance

Einführung

Target	Description
Presentation	The link to the presentation
Content	This presentation gives an introduction to surveillance system. How it is defined, how it falls in the domain of general surveillance, what its objectives are
Time	90 Minutes
Language	German
Intended audience	Ärztinnen und Ärzte in Weiterbildung zum Facharzt für öffentliches Gesundheitswesen.
Learning objectives	(1) Surveillance ist wichtiger denn je (2) “Daten für Taten” (3) Schritte der Surveillance (4) Surveillance muss durchdefiniert werden

Introduction to surveillance systems

Target	Description
Presentation	The link to the presentation
Content	This presentation gives an introduction to surveillance system. How it is defined, how it falls in the domain of general surveillance, what its objectives are

Target	Description
Time	15 Minutes
Language	English
Intended audience	Young professionals, Fellows of the European programme for intervention epidemiology
Learning objectives	(1) Know the important parts of the definition (2) Understand the domain surveillance (3) Know the objectives

Stages of surveillance systems

Target	Description
Presentation	The link to the presentation
Content	This presentation gives an overview of the stages of an surveillance system.
Time	10 Minutes
Language	English
Intended audience	Young professionals, Fellows of the European programme for intervention epidemiology
Learning objectives	(1) Understand that the definition of surveillance includes most stages (2) The stages are: Events, Collection, Classification, Data management, Analysis, Communication, Action

Types of surveillance systems

Target	Description
Presentation	The link to the presentation
Content	This presentation gives an overview of the types of surveillance system e.g. case based, syndromic, event based, wastewater, active vs passive
Time	20 Minutes
Language	English

Target	Description
Intended audience	Young professionals, Fellows of the European programme for intervention epidemiology
Learning objectives	(1) Understand that different overlapping types of surveillance system exist (2) Know what case based surveillance is (3) Know what syndromic surveillance is (4) Know what event based surveillance is

Attributes of surveillance systems

Target	Description
Presentation	The link to the presentation
Content	This presentation covers the attributes of a surveillance system. It covers underestimation, validty, timeliness and other attributes
Time	20 Minutes
Language	English
Intended audience	Young professionals, Fellows of the European programme for intervention epidemiology
Learning objectives	(1) Be able to describe characteristics of a surveillance system (2) Understand underestimation (3) Understand validity (4) Understand timeliness (5) Know that there are many attributes often with unclear defintions

Evaluation of surveillance systems

Target	Description
Presentation	The link to the presentation
Content	This presentation gives an overview of how to evaluate a surveillance system.
Time	10 Minutes
Language	English

Target	Description
Intended audience	Young professionals, Fellows of the European programme for intervention epidemiology
Learning objectives	(1) Learn the steps of an evaluation (2) need to adapt the evaluation to the trigger and the attributes (3) Surveillance is a team effort

Part I

Introduction

1 Definition of surveillance

Surveillance is information for action!

The motto of public health surveillance ist information for action. This is also the shortest definition of surveillance but does not capture all elements. A history of the definitions can be found in the Article The Past, Present, and Future of Public Health Surveillance by Bernard Choi. The most influential definition is from Alexander Langumir that set out the path for the future definitions.

1.1 Definition of Public health surveillance by WHO

> Public health surveillance is an *ongoing*, *systematic collection*, *analysis* and *interpretation* of health-related data essential to the planning, *implementation*, and evaluation of public health practice. [1]

1.2 Important parts of the definition

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

Table 1.1: Elements of the public health surveillance definition

Element	Explanation
ongoing	surveillance is planned for a longer time (usually). This is in contrast to a scientific study or a survey
systematic	surveillance is a planned undertaking that works with clear definitions
collection	Events are collected and stored in datasystems

[1] World Health Organisation 2005 - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3820481/table/tab5/

Element	Explanation
analysis	Indicators are calculated and the data is parsed according to time, place and person
interpretation	Assessment of the indicators and sense making
implementation of public health practice	The information guides public health responses

1.3 Infectious disease surveillance

The infectious disease surveillance is that part of public health surveillance that is concerned with the surveillance of infectious diseases.

2 Other forms of surveillance

What is the larger picture 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.

2.1 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.

2.2 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 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.

2.3 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.

2.4 Learn more

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

[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/

[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

3 International regulations

How is surveillance regulated internationally

3.1 International health regulations

Surveillance is firmly anchored in national and international legal systems. The International Health Regulations (IHR) is a legally binding regulation for 196 countries. The IHR includes articles that require surveillance from the countries. The aim is to prevent cross-border threats from infectious diseases.

During the COVID-19 pandemic, the value of such international collaboration became evident. New amendments of the IHR were adopted on the first of June 2024. It will come into place in 2025/2026.

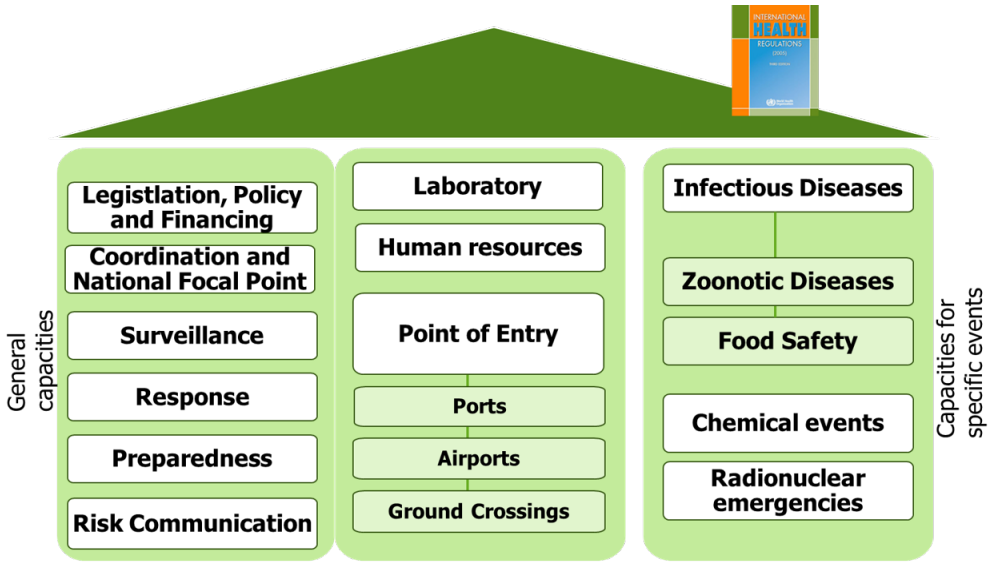

Figure 3.1: Contents of the IHR. Graph by ÖGD-Kontaktstelle RKI

3.1.1 Important contents of the IHR

- The IHR defines a Public Health Emergency of International Concern (PHEIC). It is defined as an extraordinary event which is determined to constitute a public health risk to other states and potentially requires a coordinated international response
- A PHEIC is declared by the Director General of WHO
- Notification accoring to Article 6 Annex 2: Sate Parties to notify WHO withing 24 hours about events within their terriory wich can consitute a PHEIC
- Article 8: State Parties can seek consultation from WHO
- Article 10: WHO can request State Parties to verify an event and offer to collaborate on this event. States are obliged to give information within 24h
- Annex 2: Decision tool for deciding if an event should be notified. It consists of a flowchart with 4 questions. There are helpful ressources to learn how to use the annex 2
- The IHR Monitoring and Evaluation Framework provides an overview of approaches to review implementation of country core public health capacities under the IHR (2005)
- The Monitoring and evaluation framework describes mandatory and voluntary approaches
  - IHR State Party Self-Assessment annual report (mandatory)
  - simulation exercises (voluntary)
  - after action reviews (voluntary)
  - joint external evaluation (voluntary)

3.1.2 History of PHEICS

- 2009: H1N1 Pandemic
- 2014: Resourgence of Polio
- 2014: Ebola Westafrica
- 2016: Zika
- 2019: KIVU Ebola
- 2020: SARS-CoV-2
- 2022: Clade II Mpox
- 2024: Clade I Mpox

3.2 EU Regulation 2022/2371

- The EU has its own regulation on infectious diseases
- Regulation on serious cross-border threats to health
- Content:
  - Establishing a health security committee

  - reference laboratory networks
  - surveillance
  - network for substances of human origin

- Mandatory events to notify in the Early warning and response system (EWRS)
  - unusual or unexpected, may cause significant morbidity or mortality in humans, may grow rapidly in scale,
  - may exceed national response capacity;
  - may affect more than one Member State; and
  - may require a coordinated response at Union level
  - Anything they notified to WHO via Annex 2

3.3 Essential public health operations

Surveillance is also a component of the Essential Public Health Operations. The essential public health regulations are a tool of WHO Europe and defines central tasks for public health institutes. The goal of this surveillance component is to provide information and insights for health needs assessments, health impact assessments, and the planning of health services.

Part II

Stages