



# Ethics, Epidemiology, and Environmental Surveillance

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# Surveillance / Sousveillance

- 14<sup>th</sup>-15<sup>th</sup> Centuries: Black Death – three “guardians” of the Venetian Republic inspect ships and isolate some for *quaranta days*.
- 16<sup>th</sup> Century: London Bills of Mortality
- 17<sup>th</sup> Century: Plague data to the Parish Clerks’ Company; analysis of Bills of Mortality by John Graunt



The Table of CASUALTIES.

Table with columns for years (1647-1659) and rows for various ailments like 'The Years of our Lord', 'Live and Still-born', 'Fever', 'Plex and Suddenly', etc. Each cell contains numerical counts for that year and ailment.

Place this Table at page 114.

Natural and Political OBSERVATIONS

Mentioned in a following INDEX, and made upon the Bills of Mortality.

BY Capt. JOHN GRAUNT, Fellow of the Royal Society.

With reference to the Government, Religion, Trade, Growth, Air, Diseases, and the several Changes of the said CITY.

— Non, me ut miretur Turba, laboro, Contentus paucis Lecloribus. —

The Fifth Edition, much Enlarged.

LONDON, Printed by John Martyn, Printer to the Royal Society, at the Sign of the Bell in St. Paul's Church-yard, MDCLXXVI.



**Bloody flux:** blood in the stools, see dysentery.

**Bursten:** hernia or rupture.

**Chrisoms** - Infant who died before or shortly after baptism

**Falling Sickness** - Epilepsy

**French Pox** - Venereal disease

**Headmouldshot:** this is when the sutures of the skull, generally the coronal, ride: that is, have their edges shot over

**Horseshoehead** - Inflammation of the brain

**Imposthume:** a collection of purulent matter in a bag or cyst.

**Kings evil:** scrofula, a tubercular infection of the throat lymph glands. The name originated in the time of Edward the

**Livergrown:** having a great liver. (Possibly as a result of high alcohol consumption!)

**Loosness** - Dysentery

**Overlaid** - Infants suffocated when their mother or nurse rolls over on them in bed

**Planet Struck** - Paralytic, confounded

**Purples:** spots of a livid colour, which break out in malignant fevers.

**Quinsy:** an acute inflammation of the soft palate around the tonsils, often leading to an abscess. Synonyms: suppura

**Rising of the Lights:** croup - any obstructive condition of the larynx or trachea (windpipe), characterised by a hoars

**Stone** - Gall-stones

**Stranguary:** restricted urine flow. A difficulty of urine attended with pain. This could have included bladder stones. Se

**Thrush:** a disease in which there are white spots and ulcers in the mouth, and on the tongue, caused by a parasitic t

**Tissick** - Consumption

**Tympany:** A kind of obstructed flatulence that swells the body like a drum.





# John Snow Cholera / London 1854



**Table 1: Development of surveillance in the last 100 years**

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1888: Mandatory reporting of eleven communicable diseases and death certificates, in Italy

1893: Publication of international list of causes of death by the International Statistical Institute (founded in London in 1885)

1911: Use of surveillance data from National Health Insurance, in the United Kingdom

1935: First National Health Survey, in the USA

1943: First registry, the Danish Cancer Registry  
First Sickness Survey, in the United Kingdom

1965: Establishment of an Epidemiological Surveillance Unit in the Division of Communicable Diseases at WHO headquarters, Geneva

1966: First publication of Communicable Disease Surveillance Reports by WHO

1967: Development of General Practitioners' Sentinel Systems, in the United Kingdom and the Netherlands

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# Wastewater Surveillance

## II. POLIOMYELITIC VIRUS IN URBAN SEWAGE\*

By JOHN R. PAUL, M.D., JAMES D. TRASK, M.D., AND SVEN GARD, M.D.

*(From the Departments of Medicine and Pediatrics, Yale University School of Medicine, New Haven)*

(Received for publication, March 21, 1940)

In the preceding paper (1) attention has been called to the fact that poliomyelitic virus can be readily isolated from the stools of some patients with this disease. Our own experiments, and those of many others, now testify to the ease with which this can be accomplished; not only with paralytic cases but also with the more common abortive types; and not only during active stages of the disease but also during convalescence. Obviously, therefore, when an epidemic of poliomyelitis occurs within a city there must be ample opportunity for the virus to enter the local sewage system. And, considering the frequency of mild and unrecognized forms of poliomyelitis, and the length of time which such cases may be potentially infectious, it seems possible that the concentration of virus in urban sewage may become appreciable. Prior to 1939, however, poliomyelitic virus had never been actually demonstrated in sewage, although it is questionable how vigorously it had been looked for; at least there are no published records of such attempts.<sup>1</sup>

*J Exp Med.* 1940 May 31;71(6):765-77.  
doi: 10.1084/jem.71.6.765.



# Foundations

Population health science has always been

- Information-intensive
- Able to presume the consent of its beneficiaries
- Utilitarian





# Privacy and Science

- Privacy and confidentiality were never seriously considered to be hard barriers to sharing and analysis
- Biomedical research has long relied on the work of trusted entities to collect health information; thus
- Security, de-identification, anonymization, pseudonymization



# Is Big Data Special?

- With adequate governance, Big Data should not foster new concerns as regards risks to people who are the sources of data.
- More urgent concerns are of decisions made based on bad data, inferior programming or inappropriate uses and users.



# That is ...

Ethical concerns should focus on

- Decision support – given variable data and database quality, uncertainty, software of variable quality, etc.
- Appropriate uses
- Appropriate users ... and by extension,
- DEI



# This is not to say...

- ... concerns about privacy, confidentiality, stigma, etc. are not worthy of attention.
- It is to say that Big Data itself, all other things being equal, raises no new privacy challenges.



# Privacy

- Is not – has never been – an absolute right
- Must therefore be balanced against other rights (including a “right to benefit from science”\*)
- Is often mistakenly invoked by individuals

\* <http://www.ohchr.org/EN/Issues/CulturalRights/Pages/benefitfromscientificprogress.aspx>



# Information Free-Riders

- Emphasize privacy over public health
- Risk little if anything
- Benefit from others' contributions of information



# ↑ Health ≠ ↓ Privacy

- Smart laws and policies; nimble governance at professional and social levels
- Recognition of duties to collectives, and that such duties do not violate individual rights
- Trust and trustworthiness



# Surveillance

- Is essential for identifying emerging disease, disease in the population, future disease
- Surveillance reduces morbidity, mortality
- Failure to perform surveillance would be blameworthy – as would failure to attend to and manage bias





# Consent

- Required for most research, clinical care
- Would undermine public health if required
- Hence tacit, latent, implied consent



# Trust

- Most people in most civil societies trust public health scientists
- Distrust has been increased by surveillance for marketing, politics, etc.
- Distrust has been actively fostered by ideologues and zealots
- Failure to communicate transparently to affected communities can erode trust



# Now what?

- Just when we need robust surveillance, trust is at a nadir
- Opportunity to improve public health literacy and education, e.g., RADx-Rad
- Rethink incidental findings and return of results
- Outreach, communication, transparency, DEI



# Sousveillance



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