Ethics, Epidemiology, and Environmental Surveillance

MetaSUB Annual Meeting | Miami Beach, Nov. 21, 2022

Kenneth W. Goodman, PhD, FACMI, FACE University of Miami Institute for Bioethics and Health Policy kgoodman@med.miami.edu

Surveillance / Sousveillance

- 14th-15th Centuries: Black Death three "guardians" of the Venetian Republic inspect ships and isolate some for quaranta days.
- 16th Century: London Bills of Mortality
- 17th Century: Plague data to the Parish Clerks' Company; analysis of Bills of Mortality by John Graunt

Bulletin of the World Health Organization 1994;72(2):285-304

T				The Table of CASE								UALTIES. 59/1660 1629/1630 1631 1632/1633 1634 163							100	16391633164716511655 163616331648165216561655 16381638165216561659 163716551649165316571649 163716551649165316571649 163716551649165316571649 163716551649165316571649									
T. T.	The Years of our Lord	647 1	648	649'1	6501	651	100.00		123	1222	6561	657 1	658	6591	1660 1	6291	630 1	631	1632	1633 1	634 10								
2		335	329	327 889	351	389	381		433		419	463 869 1	467	421	544	499 579		410	445	500	600 0	121.00		93 200 75 281	512220	1452	2680 2	2771 15	559
6	Find Fever 1	260 :	884	751	970 1	038	212	282 1	86	689	275	999 1	000	3032	148	9561	36	115	1108	953 I 24	279 16	22 23	60 44	18 023	13005	4903	4363 4	010 23	784
3	firx and Suddenly	00	74	64 1	74	7	2				1		.30				S				27	T		541 14	1	9	1	10	15
9	ed data	43	1 2	. 5	1	3	4	3	2	77	3	25	5 4	37	8 2	13	2	10 5	13	6 4 278	4 3			16 7	u	12	19	17	65
6	Flax, Scouring and Flux	155	176	208	289	833	762	200 3	7	168	368	362	233	346	251	449	438	352	348	278	3 3	46 3		25 . 19	24			19 1	25
4	and and Fifula	1 26	29	31	19	31	2	36	37	73	31	3 24	35	63	52	20	14	23	28	27	30	24	30 8	15 112	105	157	150 I		13
148 6	ir, Sore-mouth and Thruth	66	28	54	8 42	68	51		72	44	81	200			68	0	4	4	1		1	5		5 79	190	244	161 1		89
14	Beed	161	106	114		206	213	158 1	192	177 3	021	1621	10.000	8081	1020	colar	25 20	2012	2031-	120 23	15 211	3 18	30 37	7 8453	4678	1910 -	788 45	19 321	
10	ikand Wind	103	71	85	82	76	102	80 1	101	85 1	20	113	175	116	167	48	57		55		54 3	7	50 10	7 8453 87 4 207 7 8266	341 00	359	497 2 140	47 13	89 98
			2002		882	350 2	410 22	86 28	368 2	606 31	842	75730	5102	982	34141	827 1	10 17	13 1	797 1	754 19	55 208	0 24	77 515	8 1734	89999	20563	377 13	97 444 74 90	
	and Proceedings and	684	491	530	493	509	653 6	000 0	23	702 10	27	807 1	641	742	031	52	87	10	0	0	0	0	0 0	5 10	10	0	0	17	28
111/6_B	giele Stone one and Tympany		2 434						200 1 200			631			872			121			50 32		1 12	8 1734	1538 2	23212	982 130 215 13	2 95	
	owned ceffive drinking	47	40	30	27	49	50	53	30	43	49	63	60	57	48	43		29	34		10	1 20			2	76		2	2
Ex	ecuted	8	17	29	43	2.4	12	19	21	19	22	20	18	7	18	19	13	12	18		1	3	13	52 52 57 24	97	1 8	s		1
All	nted ina Bath ling-Sicknefs m and fmall Pox	3	400	2	184	525	279	39 8	1 812 1	294 8	3	835	409	4	5 354	3 72 18	10 40	7 58	531		54 2	P3	271 70	11840		27553	301 278	105	
01	und dead in the Streets	6	6 29	9 15	18	7	9 20	14	4 20	3	4 23	25	53	2 51	6 31	18	33	20	6 12	13		14	22 5	3 48	80 9	81	2	3 3	22
Ti	ighted iut	4	4	1 12		37	-	2 5	6	18	1	8	13	14	92	1 2	5	3	4	4	5	7	8 1	4 24	35	25		1 8	34
Gr	ief	12	5 13	16	27	17	14	11	17 9	10 14	7 13 16	10	12	13	36	18	20	22	11	4	17	5		7 10	48	47	7- 3	3-1 2	2.2
and the second	inged, and made-away themfelves ad-Ach	1000	10	13	14		2	6	671	5	3	4	5	35	26	47	59	35	43	35		4	63 18	4 197		1000		50 9	51 98
av	uodice w-film	57.	35	39	49	41 3 80	43		2	2	41	3	1	105	96	10	16	13 73	8	10 50	10	10000	30 28	7 35 2 315 6 10	02 260	5		28 16	
te	npollume ch	75	61	65	59		105		58				134	0.91	47		55		46	10 49			50 20	2 201		:07	194 1	18 10	
10	illed by feveral Accidents ing's Evil	27	57	39	94 19	47	45	57 26	26	52	43 24	52 23	47 28	55 28	54	54	25	47	38	35		2	2 9	7 150	94 13	9+ 21	21	2	37 67
	ethargy epvolee	3	+	2	4	4	4	3	10	9	4	12 1 1	2	-8	4 2	2			87	\$2	77	2	39 39	2 350	1 213	269	191 1	52 7.4	C6 21
	iver-grown, Spleen and Rickets unatick	53	46	56	59	51100	72	67 50	65	52	50 76	18 11	5:50	14 50	15	94	12	99	5	4	2	2	5 2	8 13	47	39 34	22	05 1	58 32
	feagrom featles	12	92	3	33	33	62	-	14 52 2	-11	53	15	80	6	74	42	2	24	80	21	33		12 6	01 3	133	155 4 13	255	01	57
1	fother furdered	2 13	2		5	4 28	3	3	3	58	30	5 44	3750	70 46	20		10	3	77	8	6	s		46	111	13		86 5	29
	verlaid and flarved at Nurfe	25	22	19	28 20	23	29	30 29	30	22	53 23 6	20	22	17	43 21 14	4 17	23	13 17 274	25	14			17 155	10401	87	90 61	33 1		23
	lague lague in the Guts	3597	611		15 1	23	16 110	6 32	16	9 87	315	440	16	253	402	26			36	21	1	1	11	2 00	61	142	8+4 2	53 5	191
	leurifie oifoned	30	20		20 7	1	19	17	23	10	9	17			200		24	26	38	2 24	25 24		2 1	4 6 701	10	00	00	00	14
	urples and Spotted Fever Joinfie and Sore-throat	145	47	43	65 17	54		75	89 9	56	52 13 458	30	120	21	14	32	58 8	58	7	- 10 C - 10 C -	04	5	22 (55	54	71	45	34 3	47
	ickets fother, riling of the Lights	150	224			260		229	372 178	100	212		476	210	249	44	72	99	98	60	84	19 72 1 10	50 04 13	21 30	777	585	809 3	69 27	01
8	upture cal'd head	16		7 7	6	7	16	7	15	11	20	19	18	1005	123	2	6	4	5	5	1			33 34	1	1	2		05
	curvy mothered and Rifled	32		21	21	29	43	41	44	103	71	82	82		1.43	5	24	9		15	1	11 23	~	24 91 Sg	2	1 Section		2	20
20	ores, 11lcers, broken and bruife hot (Limb	d 15	1	7 17	16	20	32	25	32	23	34	40	47	61	20	23		20	48	15	19	22	29		29		6 L.S. 6.	07	27
li i	pleen hingles	12	17	7	hin	-	1	13	13	sixes	6	2	5	1000	7	600 M	100		No. No.	I				14	19	- 1	1	1 29	2 51
S	tarved	1		4 8	7	1	2	1	1	3	1	3	6		14	2.1%				- 5		33		14 18	1		1		1
S	tirch tone and Strangury	4	5 4	2 25	28	50	41	44	38	49	57	72	6	15.2	2	1213	39	58	50	58 3	49	1	45 1	1	4	Sec.	and an	131	937
5	ciatica topping of the Stomach	2	9 3	19 3 37 13	6 12	5	67	66 178	107	94 128	145	129	27		6 214 2 192		157	149	86	104	114	132		145 72	1 613	671	644 .	0.000	669 094
5	Surfet Swine-Pox	21	4	4	3	10.0	9 905	1	4	2			103	1	2 1001	8 440	506	335	1 6	3 432		\$39 1	207 1	23 1 751 263 68 6	2 250	3436	39151	819 14	57 236
	Teeth and Worms Titlick	70	62 5	97 54 47	1"	10	1005	.,.				1.00			1	1	12	1.	470 4 34 7 40	23	31	27 34 6		95 5	3		123	15	242
	Thruth Vomiting		1	6	3	75	4 6	3	14	- 7	27	57		9	8 1	0	1 4	2	1 1	1 2 19	51	27	3	95 5 7 1 105 7	6 17 14 42	1 124		12	136 830
	Worms Wen	1	47 1	07 1	1		2 2 2	53	2	1			1	2	1	I			1	2 58		78	FELD	221 2	4	2 4	4	63	15
	Suddenty	1	1	1	1	1		1		1	199	1	1	t	1	10	31 55			-1 -		this T		page s			1 13	419 22	9.51
© PA				THE					1200		1			1	-			-					-turle d	1.9. 1	- T.		a started	A COLUMN	-2.

+

Natural and Political **OBSERVATIONS** Mentioned in a following INDEX, and made upon the Bills of Mortality. BY Gapt. JOHN GRAUNT, Fellow of the Royal Society. With reference to the Government, Religion, Trade, Growth, Air, Difeases, and the feveral Changes of the faid CITY, Non, me ut miretur Turba, laboro, Contentus paucis Le El oribus. The Fifth Edition, much Enlarged. lls be LONDON, Printed by John Martyn, Printer to the Royal Society, at the Sign of the Bell in St. PanPs Church-yard. MDCLXXVI. ef (BN)

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 hoarse Stone - Gall-stones

Stranguary: restricted urine flow. A difficulty of urine attended with pain. This could have included bladder stones. See **Thrush**: a disease in which there are white spots and ulcers in the mouth, and on the tongue, caused by a parasitic **Tissick** - Consumption

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

Rictor Norton, Early Eighteenth-Century Newspaper Reports: A Sourcebook, "Bills of Mortality", 19 December 2001 / http://www.edstephan.org/Graunt/diseases.html



John Snow Cholera / London 1854

Table 1: Development of surveillance in the last 100 years

- 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

Bulletin of the World Health Organization 1994;72(2):285-304

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.¹

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 $\neq \downarrow$ 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



This work was supported by a National Institutes of Health grant, U01DA053941.