



Ethics & Translational Research:

New Challenges in Genetics, Public Policy and Health Information Technology

**UM Miller School of Medicine
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Overview

- History of EBM
- Decisions under uncertainty
- Ethics and technology: Health information, genetics, clinical machines

EBM History/Origins

Thomas Beddoes (1760-1808)

“Why should not reports be transmitted at fixed periods from all the hospitals and medical charities in the kingdom to a central board?”

Beddoes, cont.

What would be the effect of register offices, not exactly for receiving votive tablets, like certain ancient temples, but in which attestations, both of the good and of the evil, that appears to be done by practitioners of medicine, should be deposited?

To lose a single fact may be to lose many lives. Yet ten thousand, perhaps, are lost for one that is preserved; and all for want of a system among our theatres of disease, combined with the establishment of a national bank of medical wealth, where each individual practitioner may deposit his grains of knowledge, and draw out, in return, the stock, accumulated by all his brethren.

Pierre Charles Alexandre Louis (1787-1872)

“As to different methods of treatment, it is possible for us to assure ourselves of the superiority of one or other ... by enquiring if the greater number of individuals have been cured by one means than another...

Duh.

Louis, cont.

“Here it is necessary to count. And it is, in great part at least, because hitherto this method has not at all, or rarely been employed, that the science of therapeutics is so uncertain.”

Archie Cochrane (1909-1988)

“It is surely a great criticism of our profession that we have not organised a critical summary, by specialty or subspecialty, adapted periodically, of all relevant randomized controlled trials.”

DISEASES and CASUALTIES.

<p>AGED 1456 Bed-riden 5 In all } 1456 Ague 6 Fever 2902 } 2908 Apoplexy 74 Sudden-ly 74 } 148 Asthma _____ 1 Bleeding 6 Bloody Flux } 18 6 Flux 6 _____ } Bursten 1 Rupture 28 } 29 Cancer 56 Canker 11 } 101 Thrush 34 _____ } Childbed _____ 225 Chrisomes 44 Infants 29 } 73 Colick 91 Wind 1 _____ } 92 Consumption 2678 Tif- } 2962 sick 284 _____ } Convulsion _____ 5532 Cough 3 Chincough 2 } 6 Hooping Cough 1 _____ } Cut of the Stone 1 } 40 Stone 39 _____ } Diabetes _____ 4 Distracted 1 Lunatick 28 } 29 Dropsy 708 Tympany 15 } 723 Evil _____ 55 Flox and Small Pox 1095 } 1099 Measles 4 _____ } French Pox _____ 57</p>	<p>Gangrene 15 Fistula 19 } 42 Mortification 8 _____ } Gout 16 Cramp 1 } 19 Sciatica 2 _____ } Grief _____ 5 Griping in the Guts _____ 1136 Headmouldshot _____ 6 Jaundies _____ 86 Imposthume _____ 53 Lethargy _____ 4 Livergrown _____ 8 Looseness _____ 2 Megrims _____ 3 Pain in the Side _____ 1 Palsy _____ 18 Pleurisy _____ 37 Quinsy _____ 7 Rheumatism _____ 10 Rickets _____ 455 Rising of the Lights _____ 98 St Anthony's Fire _____ 1 Scald Head _____ 2 Scurvy _____ 8 Sores and Ulcers _____ 60 Spleen _____ 2 Spotted Fever 68 Pur- } 77 ples 9 _____ } Stoppage in the Stomach 375</p>	<p>Strangury _____ 9 Surfeit _____ 55 Teeth _____ 1261 Vomiting _____ 21 Water in the Head _____ 3 Worms _____ 41</p> <p style="text-align: center;">CASUALTIES.</p> <p>Abortive 101 Stillborn } 628 527 _____ } Bruised _____ 2 Burnt _____ 8 Died by Misfortune (so } 1 reported) _____ } Drowned _____ 81 Excessive Drinking _____ 1 Executed _____ 15 Found dead in the Streets, &c. 22 Frighted _____ 1 Hang'd and made away } 40 themselves _____ } Kill'd by several Accidents 69 Murdered _____ 12 Overlaid _____ 83 Poisoned _____ 1 Wounded _____ 1</p>
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<p>CHRISTENED { Males — 8102 Females 7514 In all 15616</p>		<p>BURIED { Males — 10270 Females 10201 In all — 20471 } Pl. 0</p>
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Increased in the Burials this Year 1028

Decisions under Uncertainty

- All evidence as probabilistic
- Fallacies as uncertainty reducers
- Disputes over evidentiary hierarchies



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FRIEDR. BAYER & CO.
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Data Mining

- Knowledge-based (AI) vs. statistical
- As pattern recognition, not hypothesis-based
- Applications

Genetics/Genomics

- Highly probabilistic
- Clinical applications vs. epidemiology
- Unexpected findings
- Returning study results to patients

Electronic Health Records

- Accuracy, redundancy
- “Secondary use”
- Data de- and re-identifying
- Unintended consequences
- Meaningful use, ACOs, etc.

Policy

- What to study? (Whose bench? Which bedside?)
- Budget competition
- ARRA and HIPAA



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