Data sharing: An Ethical Perspective

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Data sharing

Beyond safety and privacy:
we need to talk about **fairness**

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Data sharing

Today I'm talking ***only*** about data sharing in the context of medical research

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What is sharing?

- Sharing as putting in common

- Sharing as not excluding from access

~~FOR USE BY WHITE PERSONS~~

~~THESE PUBLIC PREMISES AND THE AMENITIES THEREOF HAVE BEEN RESERVED FOR THE EXCLUSIVE USE OF WHITE PERSONS.~~

~~By Order Provincial Secretary~~

~~VIR GEBRUIK DEUR BLANKES~~

~~HIERDIE OPENBARE PERSEEL EN DIE GERIEWE DAARVAN IS VIR DIE UITSLUITLIKE GEBRUIK VAN BLANKES AANGEWYS.~~

~~Op Las Provinsiale Sekretaris~~

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Two sides of sharing

- Active sharing:
  Sharing as allowing to use - not excluding
- Authorised sharing:
  Sharing as being allowed to use -
  not be excluded

What sharing is not

- Sharing is not giving away
- Sharing is not dispossessing

The logic and ethics of sharing

- Generosity and benevolence
- **Reciprocity** - treating others as your equal, as having the same claim over something, and expecting to be treated as an equal
- **Trust** - believing that the good shared will not be spoiled or seized or used at the expenses of someone else
- (for non-rivalrous goods) **Transitivity** - expecting that those who have been granted access, will not exclude others

Why data sharing in medical research?

Innovation for better health and better lives - Patients centrality

But what does this imply?

- Innovation - Developing new and effective products
- Access - Making safe and effective products available
- A working infrastructure –
  A functioning, equitable and
  sustainable healthcare system

All Local Teams Are

Journal American

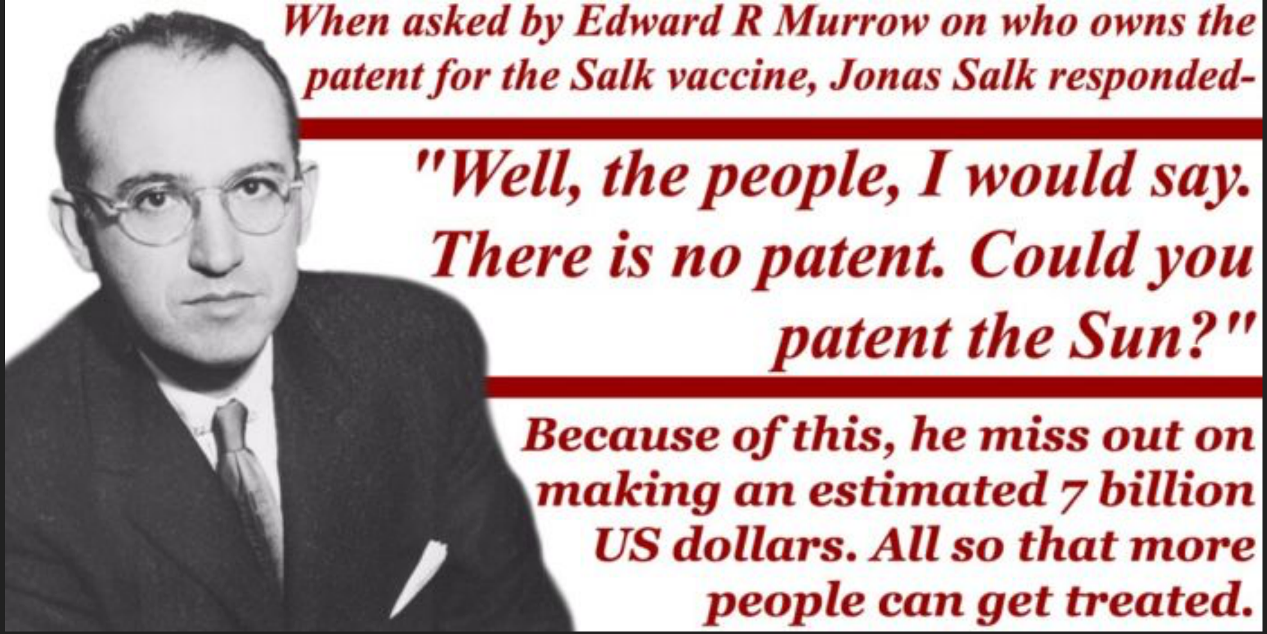
7 WALL ST SPECIAL

SALK'S VACCINE WORKS!

Official Count

Polio Vaccine Reported 80 to 90% Effective

All Local Teams Are Rained Out

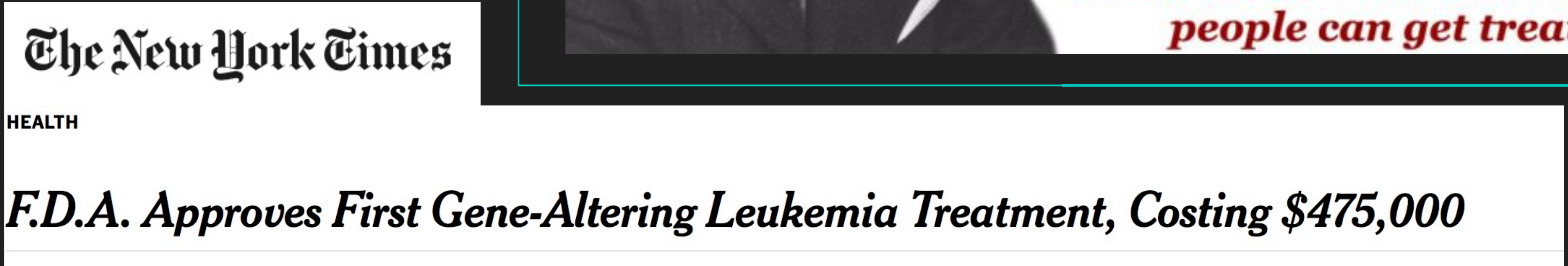


When asked by Edward R Murrow on who owns the patent for the Salk vaccine, Jonas Salk responded-

"Well, the people, I would say. There is no patent. Could you patent the Sun?"

Because of this, he miss out on making an estimated 7 billion US dollars. All so that more people can get treated.

Medical progress



The New York Times

HEALTH

F.D.A. Approves First Gene-Altering Leukemia Treatment, Costing $475,000

By **DENISE GRADY** AUG. 30, 2017

Months After Approval, Breakthrough Cancer Drug Given to Just Five Patients

By **Michelle Cortez**, **Caroline Chen**, and **Natasha Rausch**

14 December 2017, 10:00 GMT *Updated on* 14 December 2017, 14:47 GMT

Medical innovation

Innovation for better health: How to get there?

Innovation needs to be:

- Safe and effective
- Profitable
- Accessible and sustainable

“a strong sentiment has developed that pharmaceutical companies should share benefits with the communities and families who have made their financial success possible”

(Chadwick, R. and Berg, K., 2001. Solidarity and equity: new ethical frameworks for genetic databases. *Nature Reviews Genetics*, 2/4, pp 318-321, p. 320).

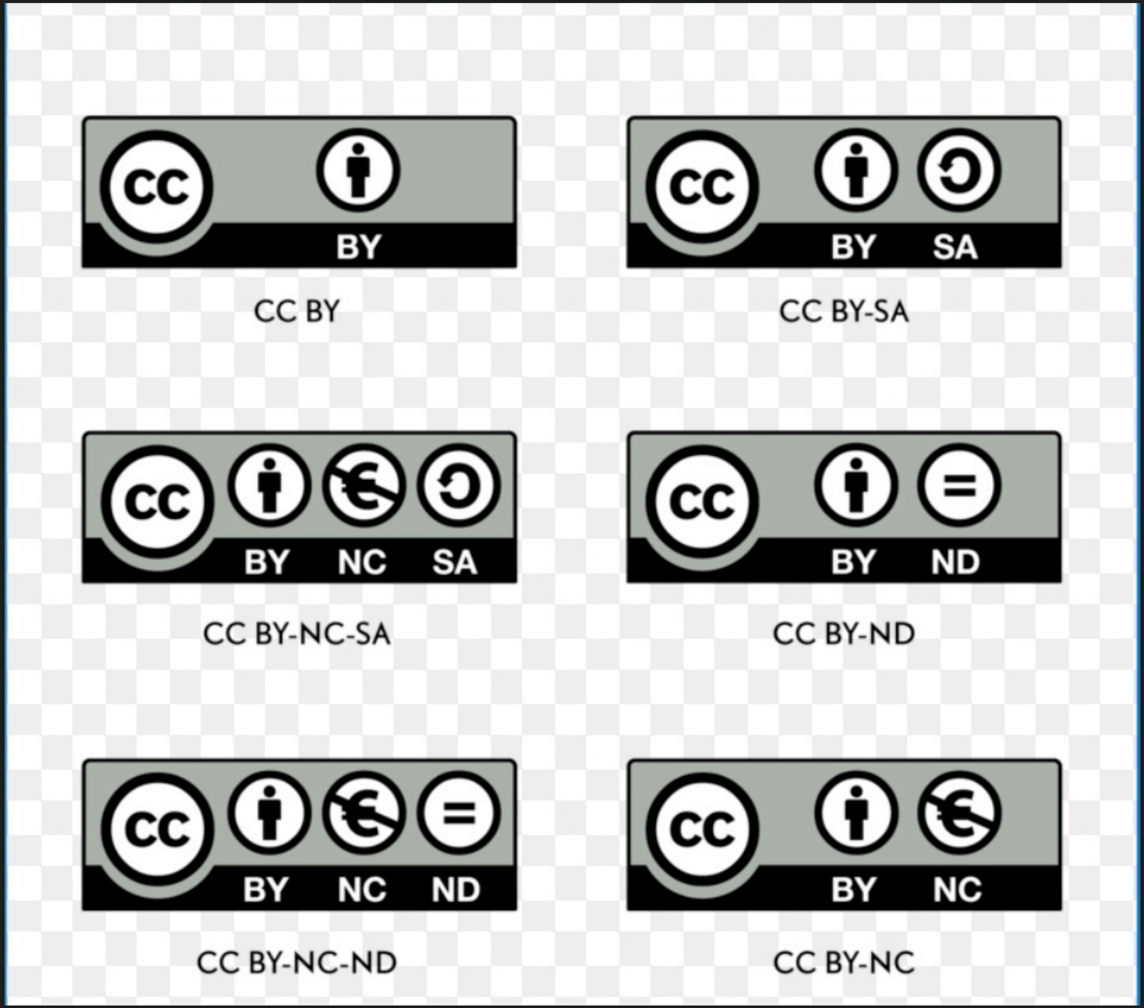
A good example of sharing

Creative commons licenses, for instance:

Attribution-NonCommercial-ShareAlike

This license lets others remix, tweak, and build upon your work non-commercially, as long as they credit you and license their new creations under the identical terms.

Types of Creative Commons licenses



Yes, but…

The problem of adding value and providing incentives

- Data sources 🎁
- Data extractors **$**/🎁
- Data refiners **$**
- Data-based products developers **$$$**

Profit without profiteering

Remember that we said that innovation needs to be profitable

- Profit through patents
- From sharing to excluding

“The truth is that those who participate as subjects and who provide vital genetic research material are the key components of the genetic research machine and are crucial to its continued success. Whether they are represented by individuals or by communities, they are currently undervalued, under-respected and undermined”

(Laurie, G., 2002. *Genetic privacy: a challenge to medico-legal norms*. Cambridge University Press, Cambridge, p. 302).

“There is an economy around this data,’’ said Sharon Terry … “Why shouldn’t the consumer be part of it?”

(Quoted in: Daley B., and Cranley, E. ‘Biorights’ rise: Donors demand control of their samples, *Boston Globe*, October 10, 2016.

Inversion and tragic irony

Can we prevent sharing and non-excluding to be turned on their head and become the sources for exclusionary and exploitative practices?

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YES
WE
CAN

Whose ownership? Which benefits?

Individual ownership is a bad idea: individual data have very limited value and it would undermine the integrity and value of data sets.

Community ownership is a much more promising option:

- either local communities,
- or patients communities.

Monetary rewards are the wrong incentive: they undermine altruism and solidarity.

Becoming partners in the decision process over development and marketing strategies of data-derived products is a much more empowering solution:

- stirring R&D towards users need and
- participating in marketing and pricing decisions.

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The way forward

A central role for patients groups?

- Collecting data
- Curating data
- Controlling the derivatives (data-based products)

“In 2001, PXE International, a patient group that represents the interests of individuals afflicted with pseudoxanthoma elasticum (PXE),... successfully negotiated for a share in the patent rights obtained by researchers who identified and filed a patent application for the gene associated with the disorder. These rights include royalties from any diagnostic test or marketable product resulting from the discovery of the gene, as well as the authority to control licensing of such genetic tests. PXE International negotiated for these rights in exchange for its contributions to the research effort, which included help in identifying and soliciting participation on the part of affected families, setting up a tissue repository, and raising money to support scientific investigation. … PXE International negotiated directly with the scientists to whom they gave research support and materials in exchange for these rights”

(Gitter, D. M. (2004). Ownership of Human Tissue: A Proposal for Federal Recognition of Human Research Participants' Property Rights in Their Biological Material. *Wash.&Lee L. Rev.*, *61*, 257-345, pp. 262-3).

PXE international

Meet Sharon Terry, a former college chaplain and stay-at-home mom who took the medical research world by storm when her two young children were diagnosed with a rare disease known as pseudoxanthoma elasticum (PXE). In this knockout talk, Terry explains how she and her husband became citizen scientists, working midnight shifts at the lab to find the gene behind PXE and establishing mandates that require researchers to share biological samples and work together.

https://www.ted.com/talks/sharon_terry_science_didn_t_understand_my_kids_rare_disease_until_i_decided_to_study_it

My take home message

- If you want to benefit patients take an active role in data extraction and valorisation
- Respect the sources
- Be the data extractor
- Be the first data curators (refiner) and retain ownership
- Become co-owners of patents

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Acknowledgements

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Thank you for your attention!

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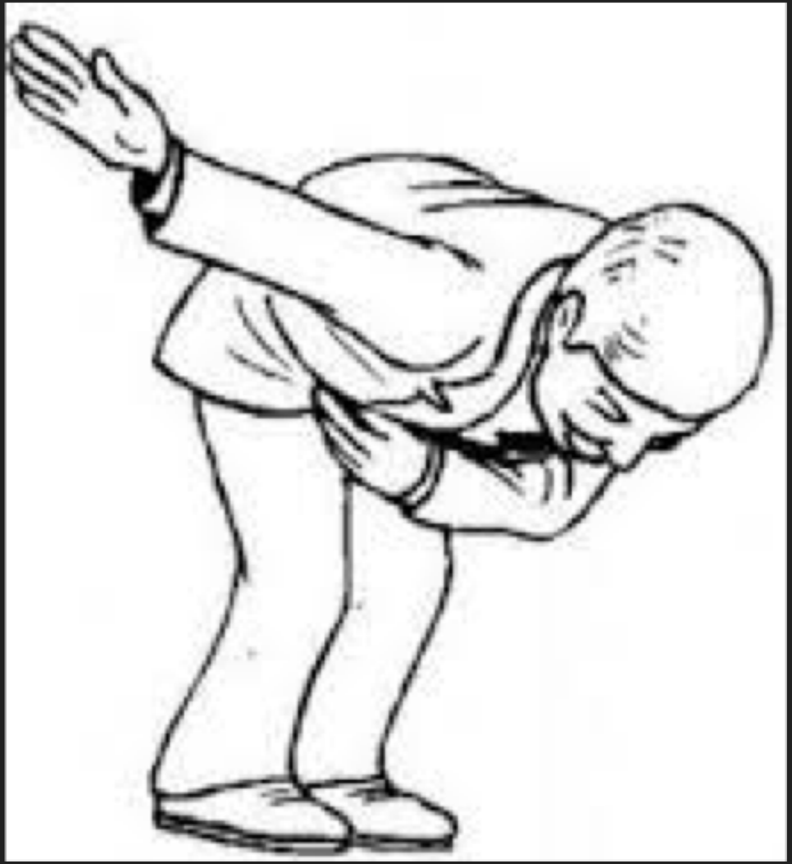

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