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- HeLa Cell line
Background info
- Publication of the
Genome Sequence
- Decision: Form a
Committee.
- OLE
 - Question 1
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Publication of the HeLa Genome Sequence

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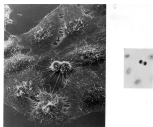


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Background to the Case

- “Immortal” human cervical cancer cells.
- The cells were harvested from Henrietta Lacks without her consent (which was legal at the time) in 1951.
- Has had a major impact in scientific research; it is the most used cell line.
- Commercially successful.
- Has impacted the lives of the Lacks family.

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(a) HeLa Cells



(b) Henrietta Lacks



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- In March 2013 Lars Steinmetz and his team published the genome sequence of a strain of the HeLa cell line.
Paper title: "The Genomic and Transcriptomic Landscape of a HeLa Cell Line" Genes, Genomes, Genetics.
- No one involved in the publication took the interests of the Lacks family into account prior to publishing.



Decision: Form a Committee.

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- A six-person committee was formed to control access to the genome sequence.
- The committee consists of two members of the family, as well as members of the scientific, medical and bioethics communities.
- All data from studies of the genome are to be stored in a single database.



Question 1

Will there be any ethical problems or conflicts in the context, in the organisation or in the group where your decision will be applied or your solution will be used?

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- Weighing the rights of an individual against the interests of various groups in society.
- Changes in Science, Ethics, Laws.
- The greater good

Example: Publication of the genome sequence may adversely affect members of the Lacks family (for example: health insurance, employability).



Question 2

Will your decision or solution cause any ethical problems or conflicts?

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- Responsibility transferred from single researcher/publisher to committee.
 - Committee decides on behalf of the whole family, scientific community and society.
 - Decisions taken on individual basis, without guidelines.
 - Problems within the committee; veto rights, voting power, member numbers, asymmetric information.
 - Voluntary, not law.



Question 3

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Are there any alternatives to your solution?

- Open access to the sequence.
- Forbid publication of the genome sequence.
- A compromise based on, for example, written guidelines for access to the genome sequence.



Question 4

What groups, individuals, organisations, etc, will in any way be affected by or have a stake in the development, use, application or mere existence of your decision and solution? (Including society at large and the environment.)

- The Lacks family
- Researchers
- Publishers
- Corporations
- Patients

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Question 5

What values, interests, duties, standpoints and attitudes are involved in the use of your solution and of the possible alternatives?

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- Scientific advances.
 - More effective medical treatments.
 - Public access to information
 - Economic interests of corporations.
 - The protection of privacy.
 - Ownership of your own genetic information.



Question 6

What effects will your solution (and the alternatives) have on each of these values, etc? Will these solutions fit certain values and conflict with others? What values and how?

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- The chosen solution
 - Compromise between the privacy of the Lacks family on the one hand and the promotion of scientific advances on the other.
- Open access
 - Winner: Scientific advances, public access to information.
 - Loser: The protection of privacy, rights of ownership to the personal genome.
- Secrecy
 - Winner: The protection of privacy.
 - Loser: Scientific advances, public access to information.
- Set of rules
 - Varies, depending on rules.



Question 7

What will you do to make sure that the use of the solution will be optimal with regards to ethical aspects? For instance, adapt the design of the product, user training, organizational changes, inform stakeholders, etc? How exactly are you going to succeed with this?

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- Continuity of the committee.
- Revision of decisions.
- Ability to adapt the rules of the committee to changing circumstances.
- Keeping the members of the committee well-informed.
- Judicial relevance of committee.
- Not an efficient long-term solution.