



ADAM MICKIEWICZ UNIVERSITY, POZNAŃ

Access and Use of Smart Hospitals Data for Research Purposes

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DARIAH Annual Event 2019: Humanities Data



Plan

Selected problems of accessing data for scientific purposes

- 1.Data market
 - 2.Data as fuel for science
 - 3.Who has access to data?
 - 4.Right to property
 - 5.Right to property as a human right
 - 6.Right to enjoy the benefits of scientific progress
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Data market

The data industry as a whole is comprised of approximately 255,000 data companies in 2016 in the EU.

It is expected to increase to 359,050 by 2020.

The estimated annual growth rate is 8.9%

<https://ec.europa.eu/digital-single-market/en/news/final-results-european-data-market-study-measuring-size-and-trends-eu-data-economy>



Data market

The value of the EU data economy was more than EUR 285 billion in 2015, representing over **1.94%** of the EU GDP.

In 2020 the value of EU data market is expected to rise to EUR 739 billion - **4%** of the overall EU GDP

In comparison - the aggregate value of agriculture, forestry, and fishing constituted **1.52%** of the EU GDP in 2017.

<https://data.worldbank.org/indicator/NV.AGR.TOTL.ZS?locations=XC>

<https://ec.europa.eu/digital-single-market/en/policies/building-european-data-economy>



Data as fuel for science

1. D.Su, J, Zhou, M. S. Kelley, T.L. Michuad, M. Siahpush, J. Kim, F. Wilson, J.P. Stimpson, J.A.Pagánde, **Does telemedicine improve treatment outcomes for diabetes? A meta-analysis of results from 55 randomized controlled trials**, Diabetes Research and Clinical Practice 2016, Nr 116, p. 136-148.
 2. S.Yanga, M. Santillanab, S. C. Koua, **Accurate estimation of influenza epidemics using Google search data via ARGO**, Proceedings of the National Academy of Sciences. 47/ 2015 p.14473-14478.
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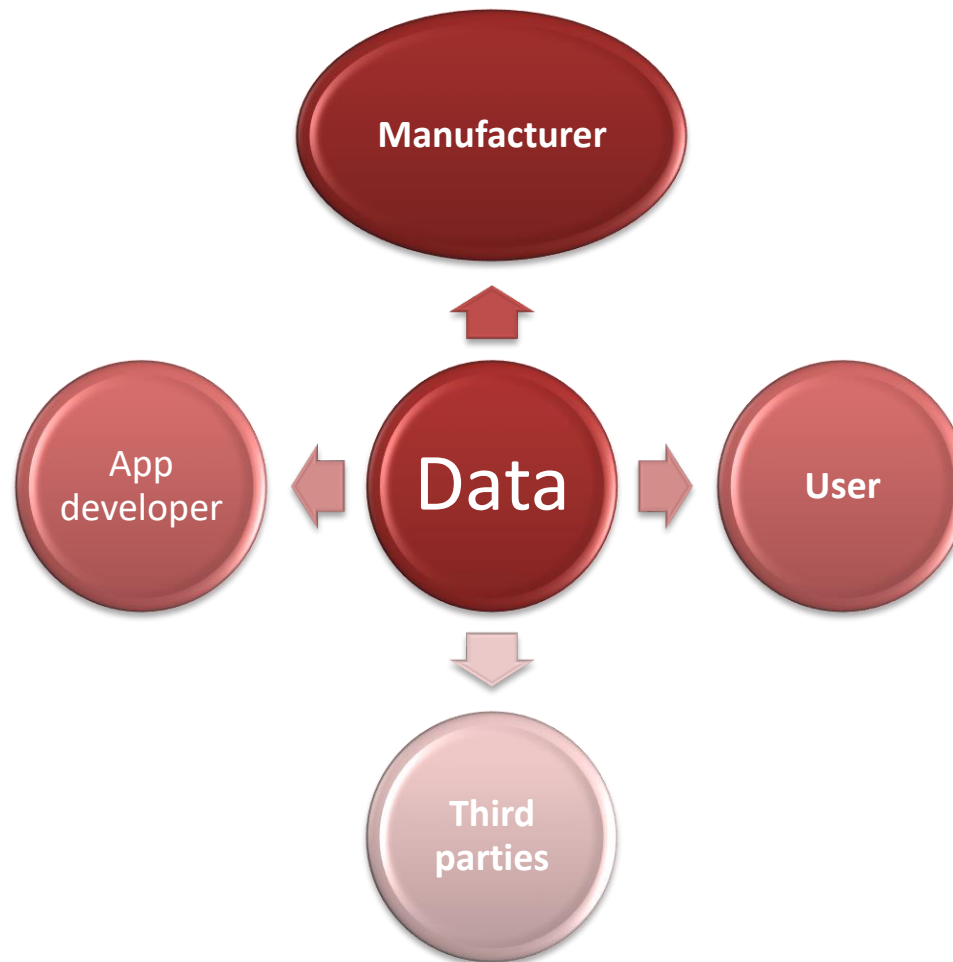


Data as fuel for science

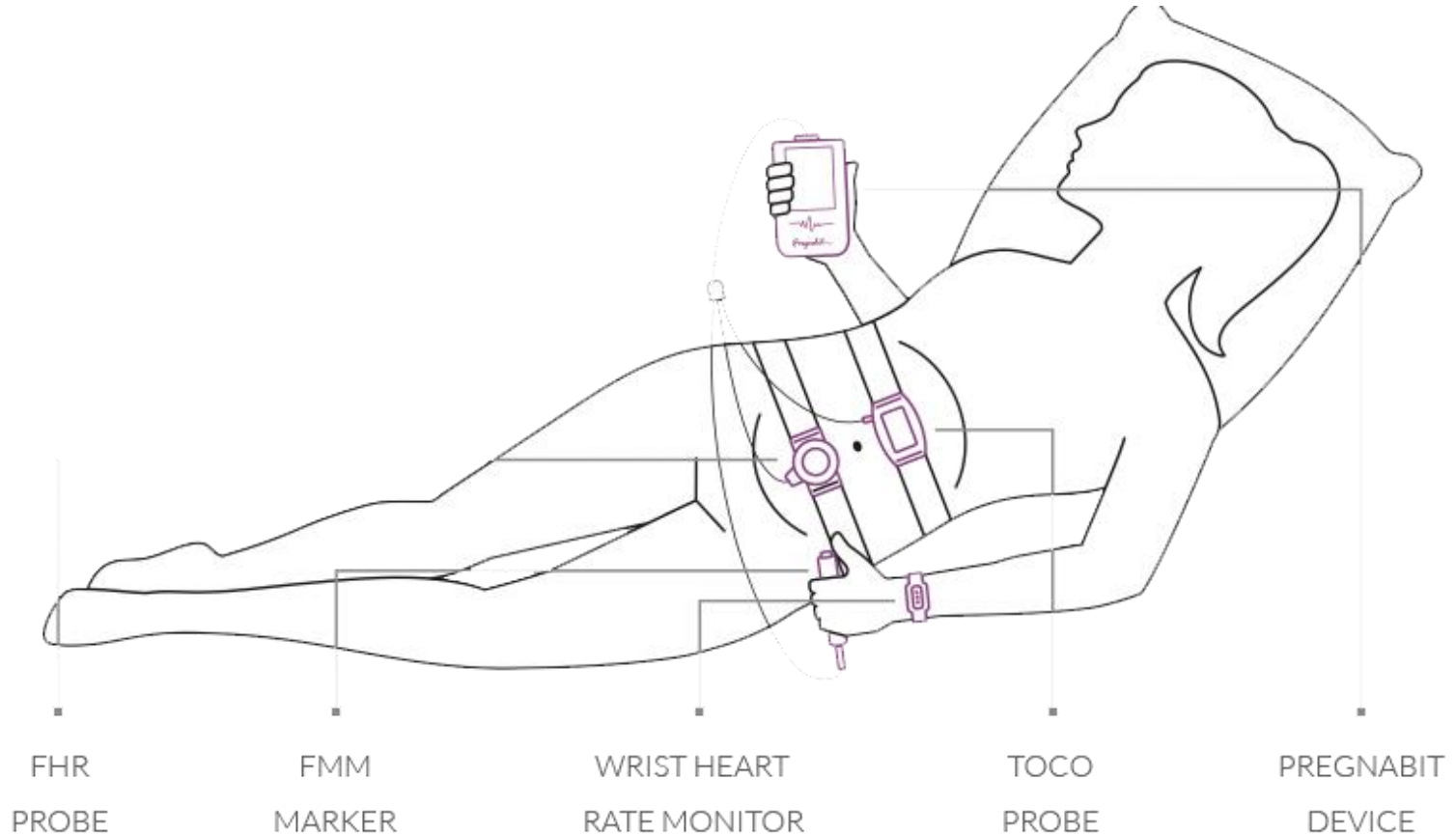
Data analysis by IBM in 330 hospitals has helped to prevent 29,000 deaths and reduce healthcare spending by almost \$ 7 billion.

IBM: Data Driven Healthcare Organizations Use Big Data Analytics for Big Gains; 2013,
<https://www.ibmbigdatahub.com/whitepaper/data-driven-healthcare-organizations-use-big-data-analytics-big-gains>

Who has access to data?



Who has access to data?



<http://www.pregnabit.com/en/technology/#urzadzenie-pregnabit>

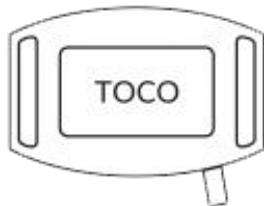
Disclaimer: This is a simplified example of how medical IoT can work and collect data but it is not a reflection of Pregnabit device works.

Who has access to data?

WRIST HEART RATE MONITOR



FHR PROBE



TOCO PROBE



FETAL MOVEMENT MARKER



<http://www.pregnabit.com/en/technology/#urzadzenie-pregnabit>

Disclaimer: This is a simplified example of how medical IoT can work and collect data but it is not a reflection of Pregnabit device works.

Who has access to data?

CPAP – Continuous Positive Airway Pressure



<https://commons.wikimedia.org/w/index.php?curid=26427457>

Who has access to data?



<https://jalopnik.com/why-autonomous-cars-could-be-the-change-disabled-people-1688864804>



Who has access to data?



Manufacturer – aggregate database, AI's predictions, consumer profile

App developer – database containing raw information

Third parties (medical staff) – limited access to database and AI's predictions

User – access to some data



Lack of access for independent researchers



Right to property

Material interests of data owner are protected in national and international law:

1. copyrights,
 2. trade secrets,
 3. patent law,
 4. database protection.
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Right to property as a human right

Right to property is one of the human rights.

1. Universal Declaration of Human Rights (art. 17)
 2. International Covenant on Economic, Social and Cultural Rights (art. 15)
 3. Convention for the Protection of Human Rights and Fundamental Freedoms
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Right to property as a human right

The States Parties to the present Covenant recognize the right of everyone:

to **benefit from the protection of the moral and material interests** resulting from any **scientific, literary or artistic** production of which he is the author

art. 15. 1 (c) ICESCR



Right to enjoy the benefits of scientific progress

The States Parties to the present Covenant recognize the right of everyone:
to **enjoy the benefits of scientific progress** and its applications.

art. 15. 1 (b) ICESCR



Right to enjoy the benefits of scientific progress

1. Academic freedom
2. Use of the achievements of scientific progress and its applications
3. Protection against the abuse of science and the destructive effects of applications of scientific progress.



Right to enjoy the benefits of scientific progress

Academic freedom, the freedom of teachers and students to teach, study, and pursue knowledge and research without **unreasonable interference or restriction** from law, institutional regulations, or public pressure.



Right to enjoy the benefits of scientific progress

The use of the achievements of scientific progress and its applications by society should take place in two ways:

1. sharing the benefits of scientific progress in society (sharing of benefits)
 2. public participation in scientific progress (participation).
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Right to enjoy the benefits of scientific progress

"Sharing the benefits" of scientific progress should be understood as **solidarity** between social partners - citizens, business and public authorities - in increasing access to scientific knowledge and applications of scientific progress.



Right to enjoy the benefits of scientific progress

"Participation" means providing the public with the **opportunity to participate** in scientific development, including by informing about conducted research, and their results.



Right to enjoy the benefits of scientific progress

States Parties are ultimately accountable for the implementation of the ICESCR.

The specific obligations of states include respect, protect and fulfill human rights.



Right to enjoy the benefits of scientific progress

International Covenant on Economic, Social and Cultural Rights (art. 2)

Each State Party to the present Covenant undertakes to take steps (...) with a view to **achieving progressively** the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures.



Right to enjoy the benefits of scientific progress

Non-state parties are **socially responsible**
(social licence to operate)



Thank you!

Questions? Contact me: greser@amu.edu.pl

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