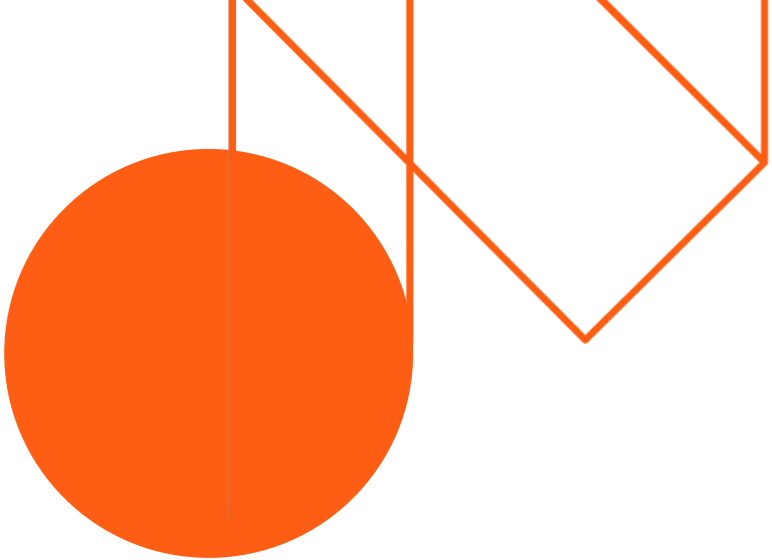
Ethics of Genomics and AI

Before We Begin

This presentation is my personal aggregation and interpretation of available resources and it prioritizes what I believe is important for you. It may not be complete, so please use this along with other references you find.

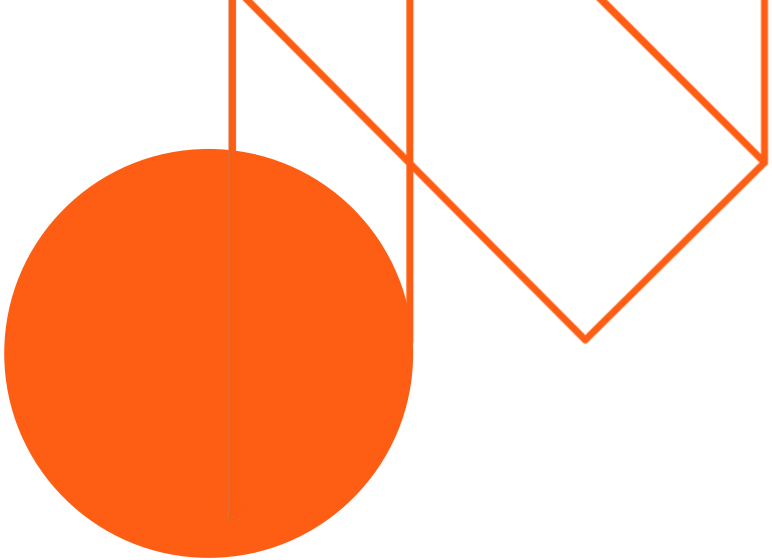
The intersection of Genomics and AI is still novel and not many publications exists exploring the ethics.

Subjects covered



- Ethics in Machine Learning
  - Types of Bias
    - Sampling bias
    - Exclusion bias
    - Prejudice bias
    - Measurement bias
    - Bias through Interaction
    - Emergent Bias
  - Liability, Trust, and Malicious use of ML
    - Liability
    - AI Snake Oil
    - Trust
    - Explainability
    - When not to build and Frameworks to help you
  - Additional Resources

An analysis of Ethics in AI Genomics

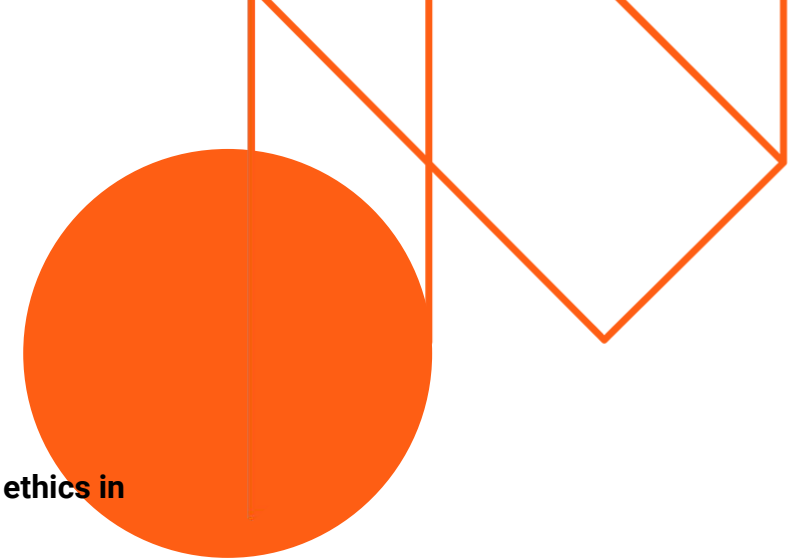


- Ethics in Genomics Research
  - Privacy
  - Mandatory Genetic Databases
  - Working Open
  - Interoperability
  - Liability
  - Recontacting
  - Regulatory
  - Malicious Use

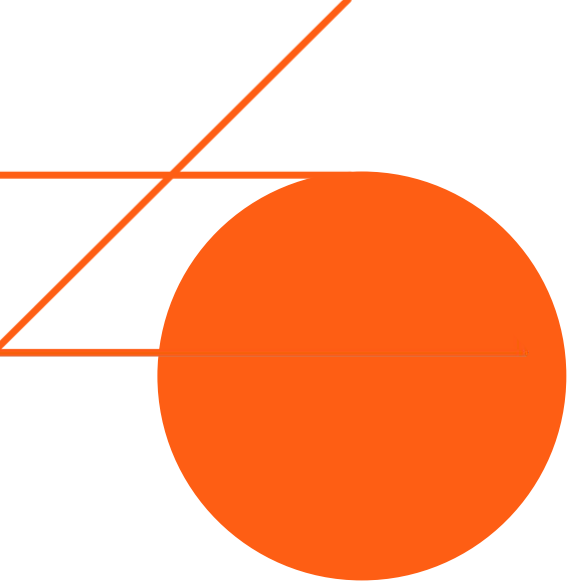
Priming Questions

- **Who has done an ethics course before?**
- **Who has done an ethics course in genomics?**
- **Who has done an ethics course in AI?**

The addition of this lecture makes us special



The majority of Data Science related courses in the US do not include ethics in their data science courses (Martin, 2015)

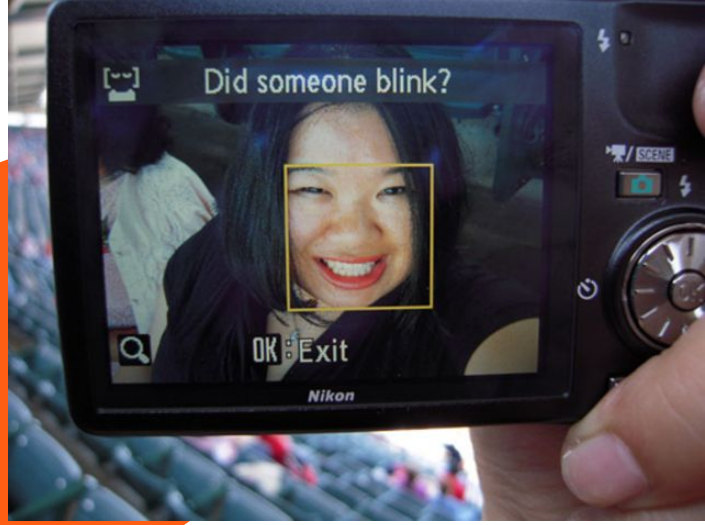


ML Bias

Sampling Bias

Collecting Data that doesn't properly represent the environment it's going to be used in.

- If AI system were to judge a beauty contest and were training by white people...Well guess who would win.
  - http://beauty.ai/
- Did HP make their Laptops racist?



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Exclusion Bias

- **If you remove some features from your dataset with the intention of cleaning the data**
- **Titanic Survival prediction:**
  - **If you wanted to predicted who survived and who died, you may exclude passenger ID as a feature. However, those with smaller ID's were actually closer to lifeboats as it was used as the method to select their rooms.**

Methods to reduce Exclusion Bias

- **Investigate before discarding**
- **Ask a colleague**
- **Tools exists to calculate Feature Importance (scikit-learn)**

Link: http://bit.ly/mlbiasD3

Prejudice Bias

- **When stereotypes are introduced into your dataset. For example, you want to detect if someone is at work. If you train the model on data that and you feed the data thousands of pictures where men are coding and females are cooking, your system will obviously be biased.**

- **Ignore statistical relationships between gender/race/country and task**
- **Ensure there is an even amount of representation in your data**

Link: http://bit.ly/mlbiasD3

Reducing Stereotype Bias (Barbosa & Chen, 2019)

Problem:

- Large amounts of data being manually labelled through services like mechanical Turks.
- There are concerns that this may lead to two effects data bias IRT Stereotypes and unfair payment
- For example cultural differences can impact algorithmic accuracy.
- Time the tasks is available limits the candidate pool available to do the task

Proposed Solution

- Control for demographic information of the workers
- Ensure that the payment for the tasks is as close as possible t minimum wage of the worker in their country and not below

https://dl.acm.org/doi/abs/10.1145/3290605.3300773

Reducing Stereotype Bias (Barbosa, Chen, 2019)

Results

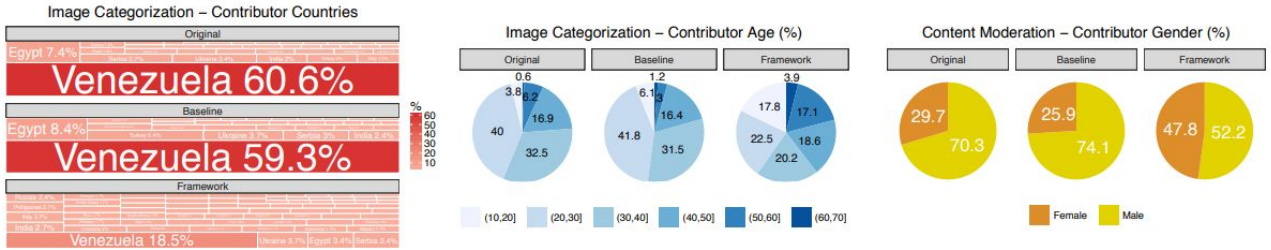

Figure 3: Left: Percentage of contributors from each country in the three conditions for the image categorization task. Middle: Percentage of contributors from each age group in the image categorization task. Right: Percentage of contributors from each gender in the three conditions for the content moderation task. Demographics in baseline and original tasks were biased by demographics of online active users of the platform.

- **Small increase in accuracy of the contributors based on history of doing similar task**

https://dl.acm.org/doi/abs/10.1145/3290605.3300773

Measurement Bias

- **When there is a problem with the tool being used to observe or measure something**
  - **For example, using two different types of cameras for object detection when collecting data and when deploying your model**

- **Methods to correct include using multiple measuring devices or have someone with experience who can compare the outputs**

Link: http://bit.ly/mlbiasD3

Bias through interaction

Tay - The Microsoft twitter bot which became sexist and anti-semitic due to biased Data

- **Users can message it and it learns over time how to interact with you**

District 3

Emergent Biases

Social Media -Echo Chamber.

If you look at content on your facebook and you like things that are of a specific nature, the algorithms learns that you like certain types of information and will provide new content similar to the stuff you liked before

Article published in PNAS

- Looked at 376 Million English Speakers on Facebook
    - Examined how they interact with English speaking news sources in terms of:
        - Consumption
        - Articles they shared liked , and commented on
- Authors found that FB users only interact with a small number of news outlets and limited their activity to a limited set of pages.
- FB's Algorithm learnt this and created selective exposure to content.
- Though social media critics have been making this claim for a while, this adds quantifiable evidence that it's happening

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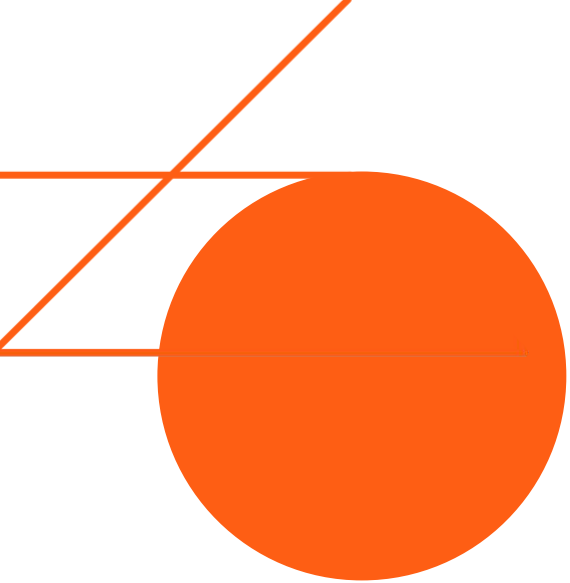

Liability, Trust, and Malicious use of ML

Liability

MedCityNews

Fitbit profits fall ahead of pending Google merger

Make-A-Wish partners help grant more wishes every year

Startup bringing gig-economy approach to nurse staffing raises $45M

What will private equity investment in healthcare look like in 2020?

Another company took an old drug and jacked up the price. Now, biotech CEOs are throwing shade

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Healthcare startups: Apply now to participate in the 2020 INVEST Pitch Perfect startup competition

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Healthcare must overcome AI's 'Black Box' problem

For artificial intelligence to gain wider interest from clinicians, the way the algorithms arrive at their conclusions needs to be understandable.

By STEPHANIE BAUM

Post a comment / Jan 9, 2019 at 1:02 PM

Liability

Determining liability if a AI system fails is something which we still don’t have a clear answer for.

For example: If a self Driving vehicle hits a pedestrian. Who is liable to cover the medical bills?

- Is it the insurance company?
- Car Manufacturer?
- Creator of self driving system?

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▲ Apple engineer killed in Tesla crash had previously complained about autopilot (kqed.org)

604 points by jelliclesfarm 9 days ago | flag | hide | past | web | favorite | 885 comments | share with hootlet

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reply

▲ jm4 9 days ago [-]

That's the part I don't get either. The only thing I can come up with is he wasn't paying attention to the drive up to that point and didn't notice he was in a problem area.

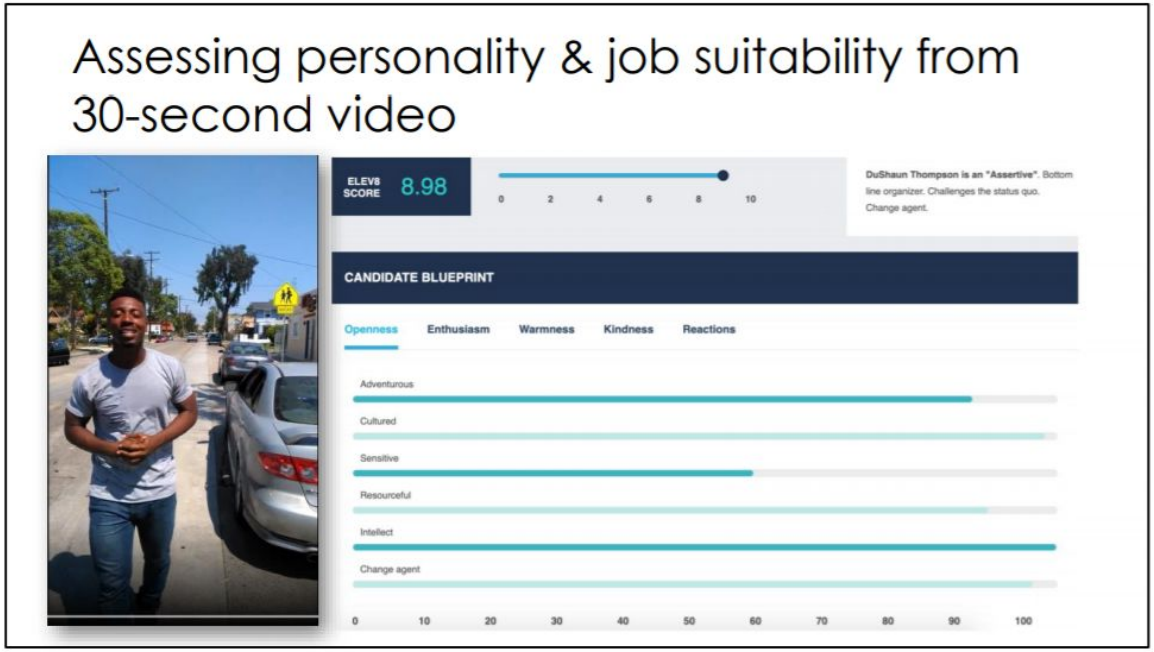
I have a Tesla and there are definitely problem areas. You learn them fairly quickly when you are taking the same route all the time and you're trained to either turn off autopilot or at least be alert when going through those areas. Or maybe you test it out with your hands on the wheel ready to take over to see if they fixed the bug.

There were a couple spots on my normal driving routes where the car would inexplicably swerve. It happened one time in each spot and that was enough. Both those spots have been fixed since, but there's no way I'd be on my phone not paying attention driving through there. I'm still cautious. There are two more spots where the car will brake to 45 mph on the highway and then speed back up after a few hundred feet. I am always on high alert around there and usually won't even use autopilot in those areas.

reply

▲ microtherion 8 days ago [-]

AI Snake Oil



"Common sense tells you this isn't possible, and AI experts would agree. This product is essentially an elaborate random number generator"

-Arvind Narayanan Associate Professor at Princeton

https://arxiv.org/pdf/1906.09208.pdf

http://bit.ly/snakeoilAI

Why is there AI Snake Oil?

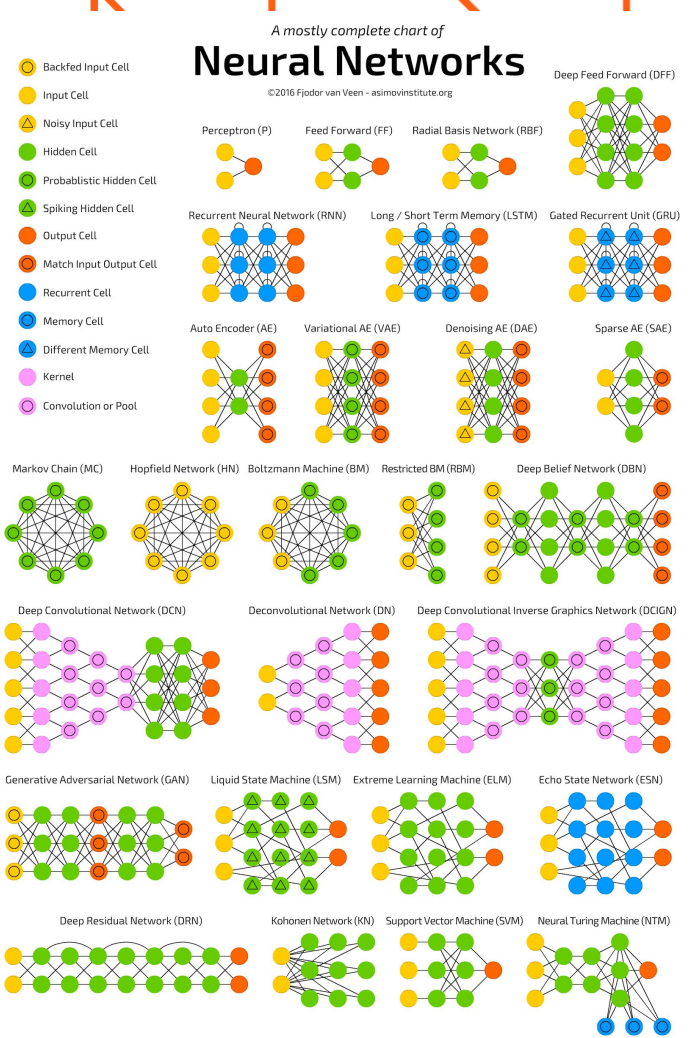
Public understanding of what's currently viable is not well understood. It would require for the to understand:

- **The current achievable benchmarks for that task and the evaluation metric used (eg. Google recently announced their conversational agent is able achieve a score 79% SSA versus humans who are at 86%)**

- **Limitations of available computational power**

Why is there AI Snake Oil?

- **Understanding of different ML models and what each one is good at**
  - **Variations of Neural Networks (2017) (http://bit.ly/neuralnettypes)**



Problems in Explainability and Trust

- **Explainability (providing insight into model behavior) when it comes to Machine Learning is done poorly due to the fact that it's usually structure for Engineers to communicate with each other to help debug the model**
- **Generally not developing methods to communicate the models to the end users**
- **Methods of improving explainability to end users described in section below**

https://dl.acm.org/doi/abs/10.1145/3351095.3375624

Conflicting Reports in Trust of AI in Medical use

TECHNOLOGY

AI Can Outperform Doctors. So Why Don't Patients Trust It?

by Chiara Longoni and Carey K. Morewedge

October 30, 2019

Summary Save Share 0 Comment Print $8.95 Buy Copies

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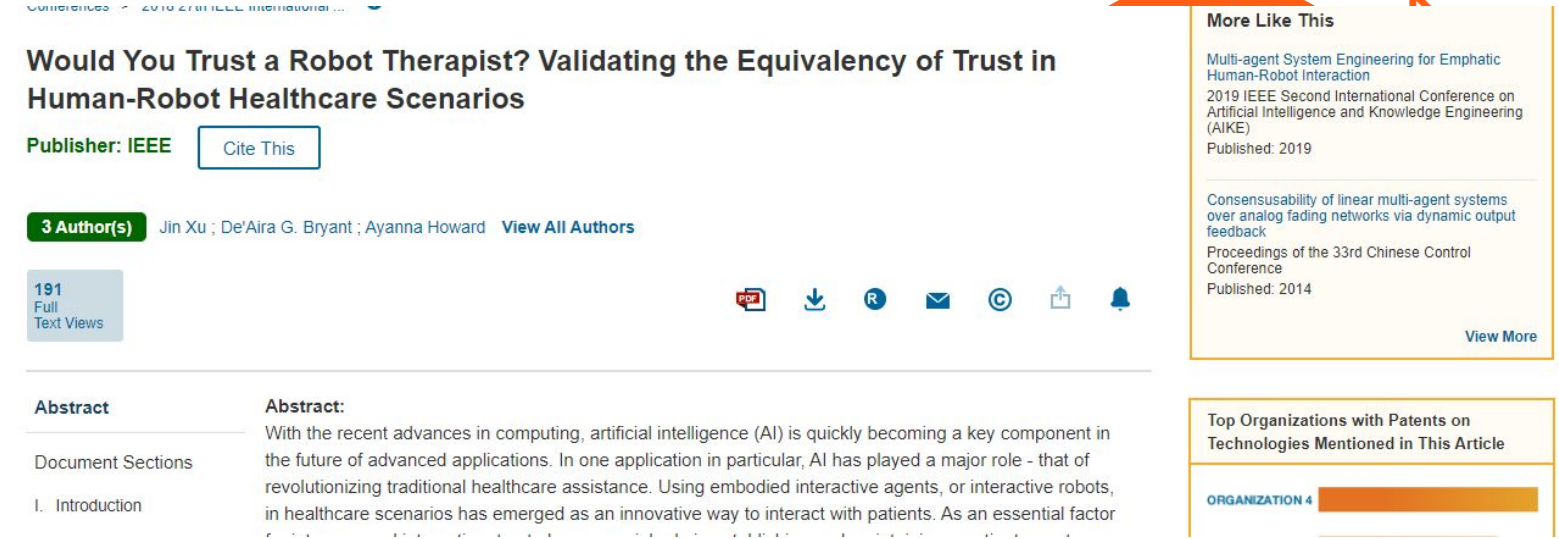
Trust of robotic/AI Intervention in healthcare



Would You Trust a Robot Therapist? Validating the Equivalency of Trust in Human-Robot Healthcare Scenarios

Publisher: IEEE | Cite This

3 Author(s) Jin Xu ; De'Aira G. Bryant ; Ayanna Howard View All Authors

191 Full Text Views

Abstract

Document Sections

I. Introduction

Abstract:
With the recent advances in computing, artificial intelligence (AI) is quickly becoming a key component in the future of advanced applications. In one application in particular, AI has played a major role - that of revolutionizing traditional healthcare assistance. Using embodied interactive agents, or interactive robots, in healthcare scenarios has emerged as an innovative way to interact with patients. As an essential factor

More Like This

Multi-agent System Engineering for Emphatic Human-Robot Interaction
2019 IEEE Second International Conference on Artificial Intelligence and Knowledge Engineering (AIKE)
Published: 2019

Consensusability of linear multi-agent systems over analog fading networks via dynamic output feedback
Proceedings of the 33rd Chinese Control Conference
Published: 2014

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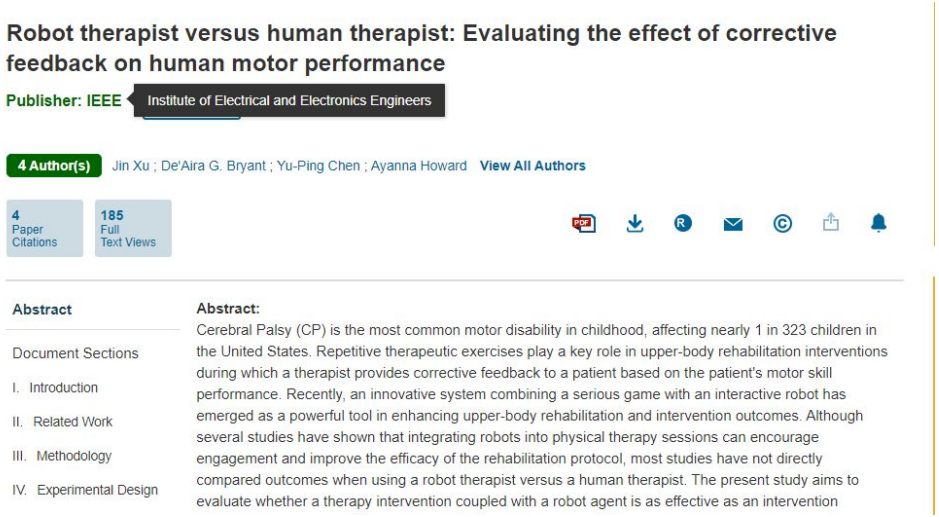
Top Organizations with Patents on Technologies Mentioned in This Article

ORGANIZATION 4

https://ieeexplore.ieee.org/document/8525782

Therapy Interventions with robotic agent is just as trusted versus one with a human agent.

Trust of robotic/AI Intervention in healthcare



Robot therapist versus human therapist: Evaluating the effect of corrective feedback on human motor performance

Publisher: IEEE — Institute of Electrical and Electronics Engineers

4 Author(s) Jin Xu ; De'Aira G. Bryant ; Yu-Ping Chen ; Ayanna Howard View All Authors

4 Paper Citations | 185 Full Text Views

Abstract

Document Sections

I. Introduction

II. Related Work

III. Methodology

IV. Experimental Design

Abstract:
Cerebral Palsy (CP) is the most common motor disability in childhood, affecting nearly 1 in 323 children in the United States. Repetitive therapeutic exercises play a key role in upper-body rehabilitation interventions during which a therapist provides corrective feedback to a patient based on the patient's motor skill performance. Recently, an innovative system combining a serious game with an interactive robot has emerged as a powerful tool in enhancing upper-body rehabilitation and intervention outcomes. Although several studies have shown that integrating robots into physical therapy sessions can encourage engagement and improve the efficacy of the rehabilitation protocol, most studies have not directly compared outcomes when using a robot therapist versus a human therapist. The present study aims to evaluate whether a therapy intervention coupled with a robot agent is as effective as an intervention

https://ieeexplore.ieee.org/document/8333308

Those in Robot therapy group improved faster but the effect of corrective feedback lasted longer in the therapy group.

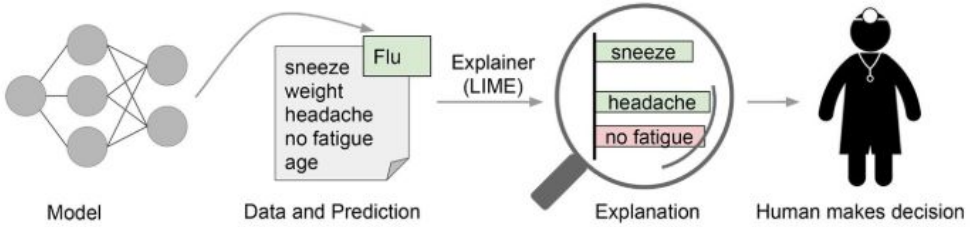
Reducing Black Box and Improving Trust: LIME

Local Interpretable Model-agnostic Explanations (LIME)

If thousands of features contribute to a decision, it is not reasonable for someone to be able to understand how a system came to its results.

You may not be able to do global faithful but local faithful is possible. In other words, you should be able to understand how a machine learning system makes a decision for one particular instance

Designed to be model agnostic



LIME attempts to play the role of the 'explainer', explaining predictions for each data sample. Source

https://christophm.github.io/interpretable-ml-book/lime.html

https://arxiv.org/pdf/1602.04938.pdf

Improving Trust

Source: https://pair.withgoogle.com/chapter/explainability-trust/

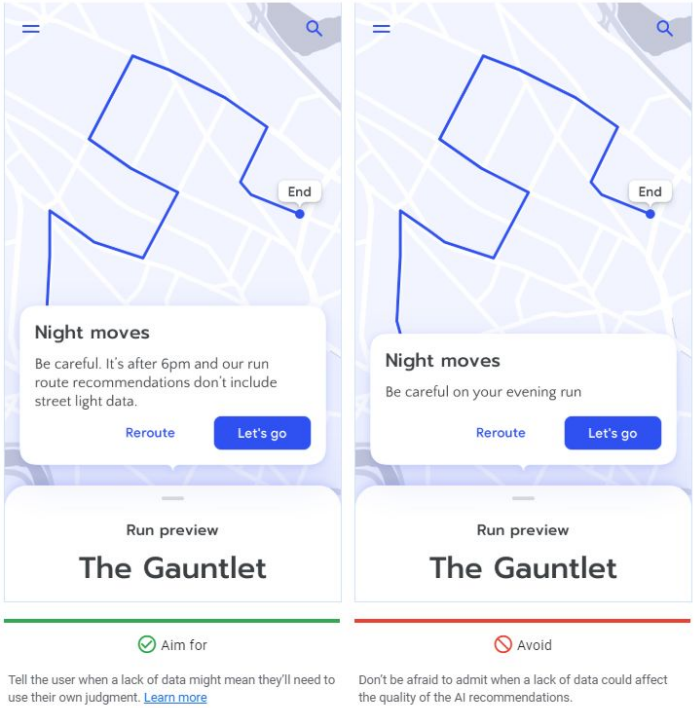
Plenty of examples where people are suspicious of algorithmic solutions or being over trusting of AI system assuming it can do something which it can't

Improving Trust: Articulate Data Sources

Explain where the data is coming from when being used in the ML model . You should explain:

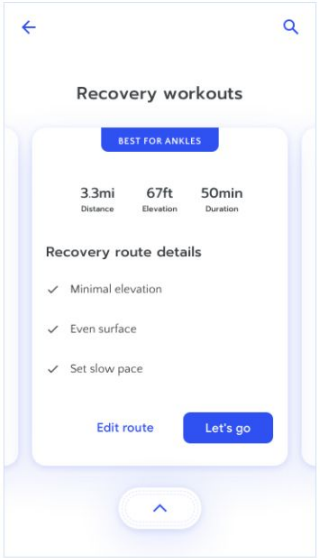
- **What data is being collect and what is the purpose in collecting that data**
- **Explain if their data is being used for personalize for one user or aggregated with other users**
- **Inform if they can remove or reset their data**

Improving Trust: Inform user if there is a Lack of Data for an informed decision



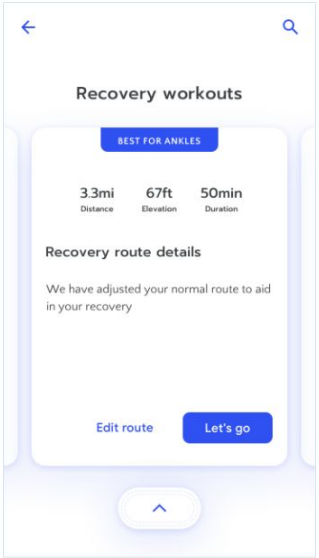
Provide Explanations in High Stake Scenarios

the local airport as their destination, let them know that traffic data only refreshes every hour.



Aim for

Give the user details about why a prediction was made in a high stakes scenario. Here, the user is exercising after an injury and needs confidence in the app's recommendation.
Learn more



Avoid

Don't say "what" without saying "why" in a high stakes scenario.

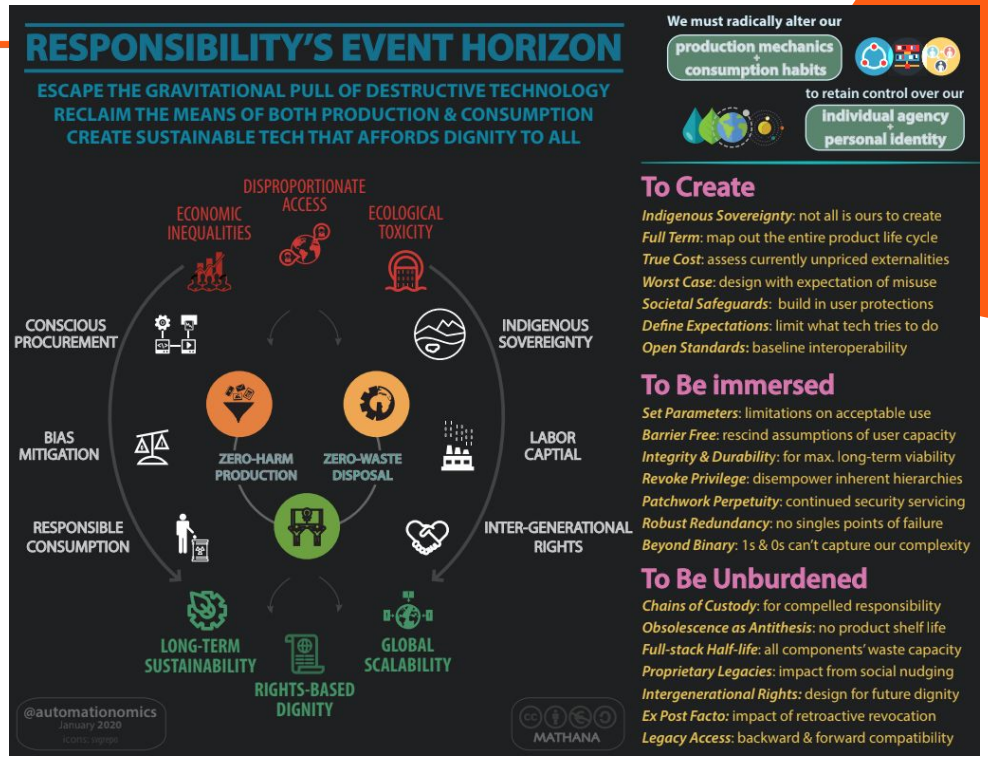
Ethics Questions to ask (Saltz et al,2019)

Table 2. Ethical Questions About Machine Learning

Challenge	Theme	Questions
Oversight related challenges	Accountability & Responsibility	1. Which laws and regulations might be applicable to this project?
		2. How is ethical accountability being achieved?
Data Related Challenges	Data Privacy and Anonymity	3. How might the legal rights of organizations and individuals be impinged by our use of the data?
		4. How might an individuals' privacy and anonymity be impinged via aggregation and linking of the data?
	Data Availability and Validity	5. How do you know the data is ethically available for its intended use?
		6. How do you know the data valid for its intended use?
Model Related Challenges	Model and Modeler Bias	7. How have you identified and minimized any bias in the data or the model?
		8. How was any potential modeler bias identified, and then if apprioriate, mitigated?
	Model Transparency & Interpretation	9. How transparent does the model need to be and how is that transparency achieved?
		10. What are likely misinterpretations of the results and what can be done to prevent those misinterpretations?

https://dl.acm.org/doi/abs/10.1145/3341164

When not to build (ACM FAccT)



Additional Resources

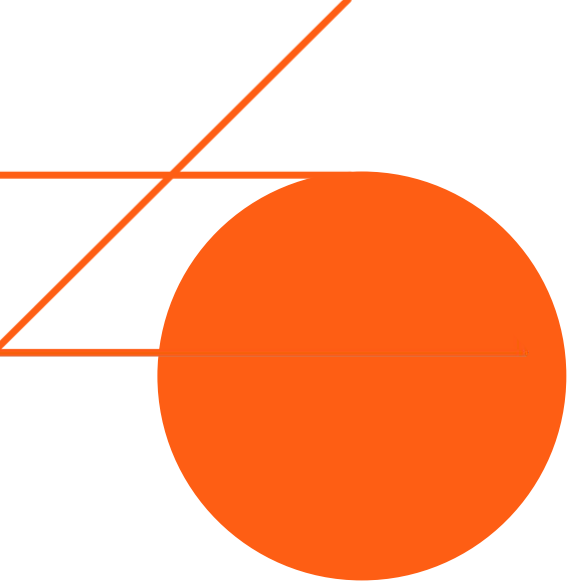
Videos are not up yet, but you can view talks related on the following workshop on the FAccT website Youtube channel https://when-not-to-build.github.io

FairML: Python Library to determine the impact of each input in predictive models: https://github.com/adebayoj/fairml

LIME Python Package (https://github.com/marcotcr/lime**)**

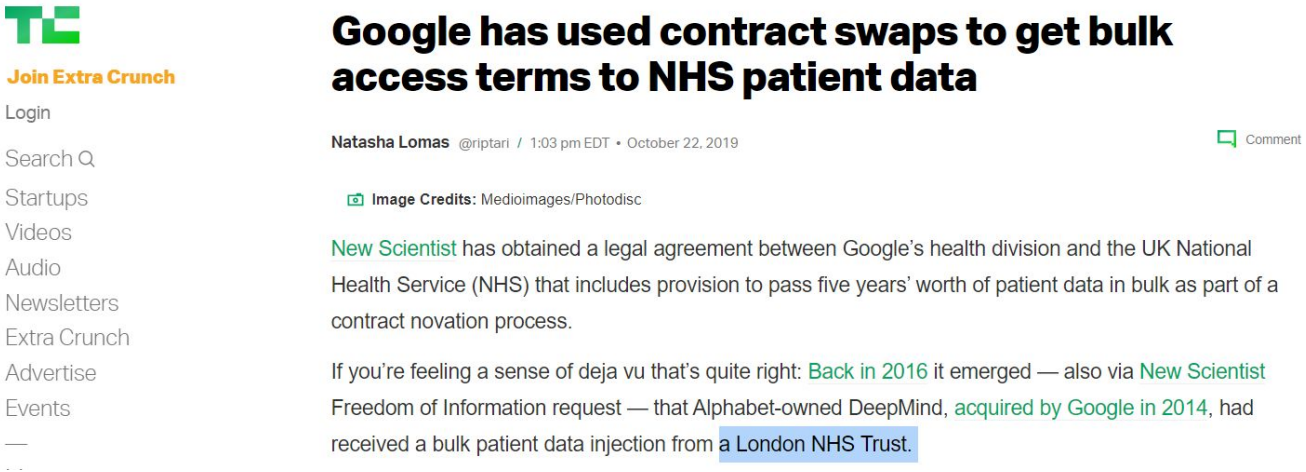
AI Fairness 360 from IBM: https://aif360.mybluemix.net/

What if Tool from Google: https://pair-code.github.io/what-if-tool/



Ethics within Genomics

Privacy



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Google has used contract swaps to get bulk access terms to NHS patient data

Natasha Lomas @riptari / 1:03 pm EDT • October 22, 2019

Comment

Image Credits: Medioimages/Photodisc

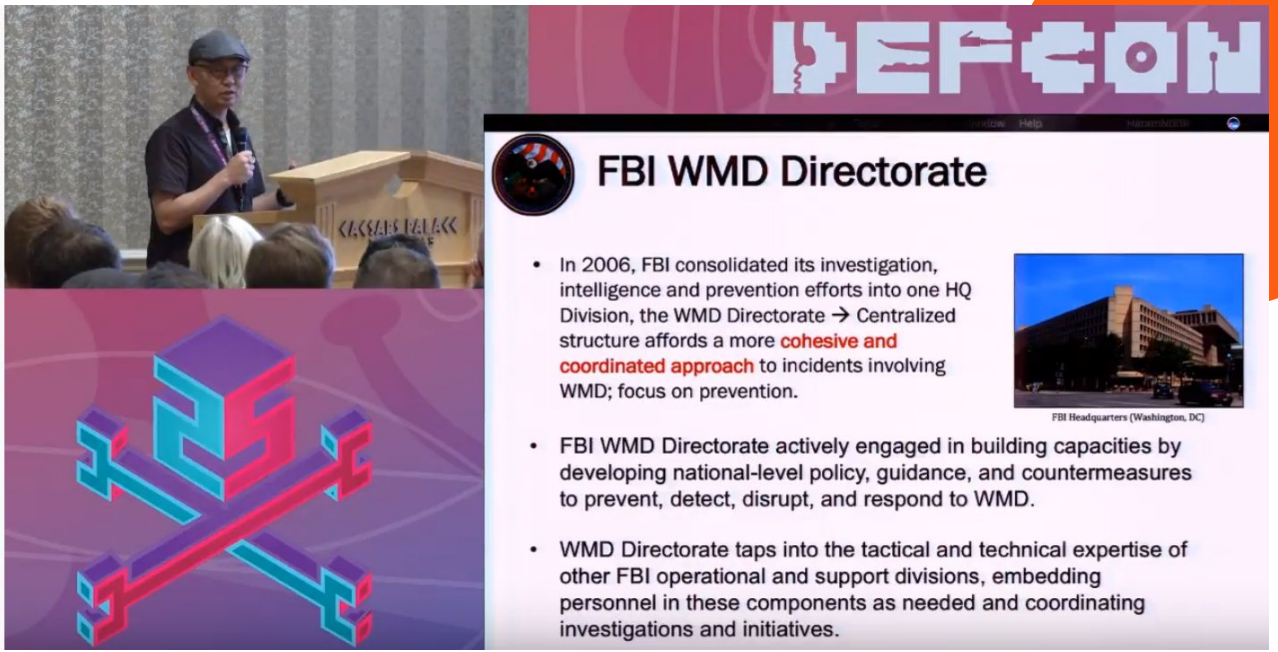
New Scientist has obtained a legal agreement between Google's health division and the UK National Health Service (NHS) that includes provision to pass five years' worth of patient data in bulk as part of a contract novation process.

If you're feeling a sense of deja vu that's quite right: Back in 2016 it emerged — also via New Scientist Freedom of Information request — that Alphabet-owned DeepMind, acquired by Google in 2014, had received a bulk patient data injection from a London NHS Trust.

The revelation that vast numbers of NHS patients records (around 1.6 million in that case) had quietly been passed to a **Google** -owned company led to a lengthy regulatory investigation and, finally in 2017, a finding that the Royal Free NHS Trust had breached UK law when it passed patient data to DeepMind for the development of an alerts app called Streams.

https://techcrunch.com/2019/10/22/google-has-used-contract-swaps-to-get-bulk-access-terms-to-nhs-patient-data/

Edward You (FBI)



https://www.youtube.com/watch?v=qDEJMc9JiJ0

Privacy Concerns

Privacy

JUNE 10,2019

Grassley, Rubio Call on HHS IG to Examine CMS Payments to Chinese-linked Companies

WASHINGTON – U.S. Senate Finance Committee Chairman Chuck Grassley (R-Iowa) and Sen. Marco Rubio (R-Fla.) sent a letter today to Department of Health and Human Services (HHS) Acting Inspector General (IG) Joanne M. Chiedi requesting oversight on potential payments made to U.S. entities with partnerships to companies with ties to the Chinese government.

"According to a February 2019 report released by the U.S. Department of Health and Human Services Office of the Inspector General (OIG), the Federal Bureau of Investigation (FBI) has identified national security risks related to sharing genomic data, and recognizes China as a country as a primary source of those risks," **the senators wrote**.

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02/18/20 Ernst Endorses Grassley-Wyden Bipartisan Prescription Drug Bill

02/14/20 ICYMI: Grassley Expects Prescription Drug Bill to Pass by May 20

Some weird approaches to return control of patient data

Augmented-Genomics: Protecting Privacy for Clinical Genomics with Inferential Interfaces

https://dl.acm.org/doi/abs/10.1145/3180308.3180326

may have some negative effect on the patient.

Figure 1: A list of mutated genes is presented to the caregiver using augmented reality glasses.

E. Toch et al.

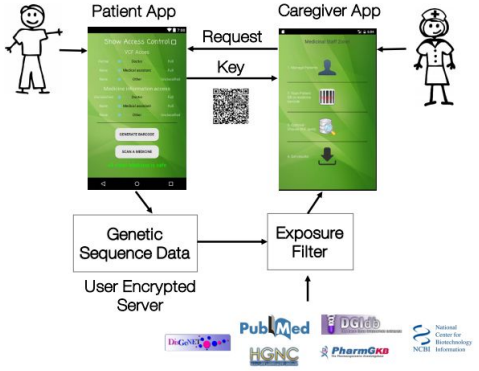

Figure 2: A depiction of the architecture and information flow of Augmented-Genomics

Compulsory Genetic Databases

https://science.sciencemag.org/content/363/6430/938.2

Risks of compulsory genetic databases

In their Policy Forum "Is it time for a universal genetic forensic database?" (23 November 2018, p. 898), J. W. Hazel *et al.* propose a nationwide forensic database for DNA information [Combined DNA Index System (CODIS) markers] from all citizens. Although the authors recognize that there have been similar attempts to create such a database in the past, they avoid mentioning that those efforts were met with widespread disapproval.

In 2007, when a UK court of appeal judge

constitutional court invalidated the law on these grounds (*4*).

Hazel *et al.* propose such a database as a way to correct issues that they recognize already exist in the current system of DNA databases, including discrimination, questionable search practices, mismanagement, and misuses of genetic information. However, creating compulsory genetic databases will not make the system more humane for minority groups or improve strained relationships with government agencies. Better regulation

Compulsory Genetic Databases

more effective strategy.

The proposed database would be expensive (*5*) and intrusive for everyone, and it would increase the risk of abusive usage of genetic information. Such an endeavor is also likely to exacerbate the existing climate of mistrust (*6*) and negatively affect public perception of genetics. The analogy with public health newborn screening programs as a justification is particularly tendentious and unhelpful. These programs are developed to detect severe genetic disorders (such as phenylketonuria) in asymptomatic newborns in order to treat them early, which is in their best interest.

Working Openly

Use of patents in genomics has introduced major roadblock

- **slower,**
- **less efficient,**
- **Reduces access:**
- **Introduces High cost:** a course of treatment against melanoma using Bristol-Myers Squibb's drug Opdivo cost USD$120,000 in 2015, m. In 2005, the US government, through state-funded programs, spent USD$210 billion on prescription drugs. If a generic version was created it would have only costs the government USD$50 billion.
- Patent thicket: company (or a researcher) must navigate its way through the "web" of patents in order to commercialize new technology

https://mjlh.mcgill.ca/issues/volume-13-issue-1-131-2019/could-open-be-the-yellow-brick-road-to-innovation-in-genomics-in-north-america/

Working Open helping to foster R&D in developing countries

Genomics for All: International Open Science Genomics Projects and Capacity Building in the Developing World

(Hetu et al, 2019)

https://www.frontiersin.org/articles/10.3389/fgene.2019.00095/full

Projects like: HapMap, Malaria Genomic Epidemiology Network "play an importan role in genomics capacity building in developing countries, but play a more limited role with regard to the potential redistribution of the benefits of research to the populations of these countries"

		Africa Initiative	Epidemio
Indicator no. 1: The data collected in the framework of the project include data collected from populations in developing countries	Seventy-eight percent (78%) of the data were collected from populations in developing countries.	One hundred percent (100%) of the data were collected from populations in developing countries.	One hundr the data w population countries.
Indicator no. 2: Part of the project concerns a disease significantly affecting the health of populations in developing countries	The data are relevant for research on diseases affecting the population of developing countries.	The data are relevant for research on diseases affecting the population of developing countries.	The data a research c the popula countries.
Indicator no. 3: Researchers in developing countries are involved in the project	Twenty-eight percent (28%) of the research centers involved were located in developing countries.	The majority of the research centers involved were located in developing countries.	Fifty-one p research c located in
Indicator no. 4: Researchers in developing countries have access to the data collected in the context of the project	Data are placed in the public domain and are accessible to all.	Data are accessible to all after the expiration of temporary measures favoring the researchers who collected the data.	Data are a the expirat measures researcher data.
Indicator no. 5: The data collected in the context of the project are used by researchers in developing countries	Twenty-seven percent (27%) of the 2,057 published studies using data from the project involved researchers from developing countries.	One hundred percent (100%) of the three published studies using data from the project involved researchers from developing countries.	Eighty-nine nine publis data from researcher countries.
Indicator no. 6: The project contributes to the development of research infrastructures in developing countries	No specific program addressing the development of research infrastructures.	The project contributed to the establishment of genomics research centers and a bioinformatics network.	Impact on research ir developing clearly iden
Indicator no. 7: Decision-making positions are assigned to researchers and managers in developing countries	None of the project's decision-making positions were attributed to researchers from developing countries.	Forty-four percent (44%) of the project's decision-making positions were attributed to researchers from developing countries.	Sixty-three project's d positions researcher countries.
Indicator no. 8: The project includes training opportunities accessible and relevant to researchers/students in developing countries	No specific training program accessible to researchers/students in developing countries.	All of the research sub-projects must involve a training component and training workshops are frequently organized.	The projec scholarshi workshops organized.
Indicator no. 9: The project's intellectual property management policies are favorable to developing countries	Discoveries resulting from research using the project's data may be patented. No policy favoring the redistribution of benefits from patented discoveries to populations of developing countries.	Discoveries resulting from research using the project's data may be patented. No policy favoring the redistribution of benefits from patented discoveries to populations of developing countries.	Discoverie research u may not b protection transfer of developing Benefits fr discoveries to populati countries.

Ethics of Open

Can Healthcare Overcome Its Past Pitfalls to Leverage Genomic Data?

"Eventually people realized they needed either a single EHR, or interoperability between their EHRs. With genomic data, we've started to run into that issue again."

A specialist could order a genetic test for a patient, but the results of that test may get stuck in the specialist's EHR, leading to data silos and a lack of information exchange, Diamond explained.

Overcoming these obstacles, and avoiding past data mistakes, will require institutions to adopt system-wide standards and strategies.

"Genetic data should be part of a comprehensive and enterprise-wide solution," Diamond said. "Stakeholders should develop genetic data standards as quickly as possible, and incorporate those standards into the EHR. Adopting technologies like FHIR will also be extremely important."

FHIR, or the **Fast Healthcare Interoperability Resources**, is the most efficient way to

https://healthitanalytics.com/news/can-healthcare-overcome-its-past-pitfalls-to-leverage-genomic-data

Interoperability issues

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5891224/

(Ronquillo et al, 2017)

Genome Organization Gene Nomenclature Committee

Standards did not match SNOMED CT codes

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Assessing the readiness of precision medicine interoperability: an exploratory study of the National Institutes of Health Genetic Testing Registry

Jay G. Ronquillo, Chunhua Weng, and William T. Lester

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There were a total of 25,472 genetic tests from 240 laboratories testing for approximately 3,632 distinct genes. Most tests focused on diagnosis, mutation confirmation and/or the risk assessment of germline mutations that could be passed to offspring. Genes were successfully mapped to all HGNC identifiers, but less than half of tests were mapped to SNOMED CT codes, highlighting significant gaps when linking genetic tests to standardised clinical codes that explain the medical motivations behind test ordering.

Liability

(Marchant, 2013)

https://www.nature.com/articles/gim2013142

3 Cases Highlighted

A woman from Connecticut sued her physician for failing to warn that her extensive family history of breast cancer suggested a genetic risk of ovarian cancer. The Connecticut Supreme Court recently upheld a $4 million jury verdict to her after she went on to develop ovarian cancer.1

Liability

3 Cases Highlighted

“A couple from Oregon successfully sued their physicians and hospital for negligence in performing and interpreting prenatal genetic testing for Down syndrome. The jury awarded the parents $3 million in damages after the child was born with Down syndrome.”

Liability

3 Cases Highlighted

“A woman from California sued her health-care providers for prescribing carbamazepine without first recommending genetic testing as recommended by the label approved by the Food and Drug Administration for patients of Asian ancestry. The woman, who is of Asian descent, developed Stevens–Johnson syndrome after being prescribed the drug. Her case is currently in arbitration.”

Physicians are the primary target for malpractice lawsuits due to biotech companies adopting practices to shift liability

Indicators of increased legal issues

(Marchant, 2013)

History shoes that new medical technologies spur increases in medical malpractice litigation. This is due to the fact that the more a doctor is capable of doing, the more something can go wrong.

“For example, before the advent of renal dialysis, most patients with renal failure died with few lawsuits filed; “

Indicators of increased legal issues

There are disagreements about the use of genetic testing in a clinical context. Some believe it's ready to be used now, and other think we should be more cautious

This can create a separation of doctors who use it and those who don't. This means that both sides can be argued a credible expert can be found to defend both sides.

Recontacting patients

Genetic Counsellors. The final statement includes twelve position statements that were endorsed or supported by the following organizations: Genetic Alliance, European Society of Human Genetics, Canadian Association of Genetic Counsellors, American Association of Anthropological Genetics, Executive Committee of the American Association of Physical Anthropologists, Canadian College of Medical Genetics, Human Genetics Society of Australasia, and National Society of Genetic Counselors.

https://www.cell.com/ajhg/fulltext/S0002-9297(19)30070-9

https://osf.io/preprints/lawarxiv/mtzfu/

Recontacting patients

Given these considerations, the ASHG offers the following recommendations:

1. The ASHG *strongly recommends* attempting to recontact participants to offer updated results if the reinterpretation is related to the phenotype under study or is reasonably expected to affect a research participant's *medical management*.

2. If the reinterpretation is *not expected* to affect management, recontact is advised, rather than strongly recommended, for correction of the classification of a variant previously reported to the participant and whose pathogenicity classification has changed from or to pathogenic or likely pathogenic.

The strength of ASHG's recommendations to recontact diminishes when the evidence for medical benefit is less definitive. Clinical criteria for "affecting medical management" are defined elsewhere by the ACMG and could serve as a resource for researchers; they include[4, 76]

- serious conditions
- highly penetrant variant
- effective intervention available (screening or treatment)
- risk/benefit profile of intervention is favorable
- strong knowledge base about condition overall

https://www.cell.com/ajhg/fulltext/S0002-9297(19)30070-9

https://osf.io/preprints/lawarxiv/mtzfu/

Laws and Regulations

THE GENETIC NON-DISCRIMINATION ACT: AN OVERVIEW

Because the Learn section of TalkRights features content produced by CCLA volunteers and interviews with experts in their own words, opinions expressed here do not necessarily represent the CCLA's own policies or positions. For official publications, key reports, position papers, legal documentation, and up-to-date news about the CCLA's work ***check out the In Focus section of our website.***

The **Genetic Non-Discrimination Act** (GNDA), or Bill S-201, passed into law on May 4th 2017. The bill, along with amendments in the **Canadian Labour Code** and the **Canadian Human Rights Act**, prohibits companies and employers from requiring genetic testing or the results of genetic tests. It also prevents companies from denying services based the results of genetic tests.

Laws and Regulations

Direct-to-consumer genetic testing

- The *Personal Information Protection and Electronic Documents Act* which applies federally to organizations that collect, use, or disclose personal information in the course of commercial activities;
- The *Personal Information Protection Act* which applies to private sector organizations in Alberta;
- The *Personal Information Protection Act* which applies to private sector organizations in British Columbia; and,
- *An Act Respecting the Protection of Personal Information in the Private Sector*which applies to private sector organizations in Quebec.

https://www.priv.gc.ca/en/privacy-topics/health-genetic-and-other-body-information/02_05_d_69_gen/

Malicious Use

Josiah Zayner
October 22, 2018

This is awesome, how did I not hear about his before? Luis Ceze, who gave a talk a Biohack the Planet, recently published a paper talking about framing someone for a crime by uploading fake profiles to GEDMatch or other public DNA databases that investigators have started to use! lol #Biohacking

Computer Security Risks of Distant Relative Matching in Consumer Genetic Databases
https://arxiv.org/abs/1810.02895

GEDmatch is an online service to compare autosomal DNA data files from different testing companies.

https://arxiv.org/pdf/1810.02895.pdf

Further Readings

- Awesome Artificial Intelligence Guidelines
- Critical ML Reading List
- Henry T Greely
  - Once interviewed him once for a webinar around Neuroethics. Go and listen if you are interested
- Digital Health Technologies Committee by Health Canada

- Proposed Regulatory Framework for Modifications to Artificial Intelligence/Machine Learning (AI/ML)-Based Software as a Medical Device (SaMD)

- Regulatory challenges of AI products A pre-market perspective

- Return of individual genomic research results: are laws and policies keeping step?