Big Data, Health Care, and International Human Rights Norms

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Abstract

In the era of “big data,” researchers manage high-volume, high-variety, and high velocity data sets, which are increasingly available to the general public. This paper explores the human rights implications of data-driven health care, focusing on the rights of persons who either live with disabilities or may be perceived as having an elevated risk of developing a disability in the future. Access to high-quality data at reasonable cost can help governments to fulfill the right to health, which is well established in international human rights law. The data revolution has also empowered individuals to take greater control over their own health and to monitor their governments’ compliance with human rights treaties, including the Convention on the Rights of Persons with Disabilities (CRPD). Yet big data can also inadvertently promote discrimination and violations of privacy. In theory, governments should ensure confidentiality and respect for the privacy of individuals’ health data. In practice, it is difficult to prevent data miners from using re-identification techniques to link anonymized health information with non-medical open data. It is therefore important to enact antidiscrimination legislation that prohibits not only discrimination on the ground of existing, past, and imputed disabilities but also discrimination on the ground of a disability that may develop in the future. Governments may also need to take a proactive approach and require employers, insurance companies and other private actors to disclose whether they are using re-identification processes or purchasing health-related data from data brokers.

Keywords: Human Rights, Right to Health, Disability Discrimination, Data Mining

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I. Introduction – Big Data and Human Rights

The health care sector has always generated significant amounts of data, as doctors and other health care professionals are required to keep detailed records of patients’ medical history, conditions, treatments, and progress towards recovery. When medical record-keeping transitioned from hard-copy files to digitalized records, the variety and volume of patient-related data greatly expanded. In addition to clinical data from CPOE\(^1\) systems, data is produced by medical imaging, laboratory tests, and machines that monitor patients’ vital signs.\(^2\) Health-related data can also be gleaned from administrative records, including insurance and payment records. Individuals also now regularly disclose their own health-related data, through employment-based “wellness programs” or on health information sharing websites and other forms of social media. Even Twitter has become a source of data on public health.\(^3\) The tools for storing, managing, and analyzing this data have also evolved at rapid pace, creating enormous opportunities, not only for professional researchers but also for “citizen scientists”.\(^4\)

Thus, in the era of “big data,” researchers manage high-volume, high-variety, and high velocity data sets, which are increasingly available to the general public. Human rights experts and monitoring bodies recognize that “big data” can have both positive and negative effects on human rights.\(^5\) The challenge is to find ways to limit the

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\(^1\) CPOE refers to “computerized physician order entry,” the process by which patient records and doctors’ instructions are entered electronically and communicated over computer networks to medical staff, pharmacies, laboratories, insurance companies, and other users.


potential for negative effects without unduly limiting the positive effects. Although much of the attention of human rights experts thus far has focused on the right to privacy, 6 big data has implications for many other human rights, including the right to health and the right to equality. This paper focusses on the rights of two groups of people who have a strong interest in the impact of data-driven health care – those who live with disabilities now and those who may be classified by data scientists as having a higher-than-average risk of developing a disability in the future.

Part II of the article analyzes how big data can promote the right to health, which is recognized in international law and also in many national constitutions. Big data can advance medical research, improve healthcare outcomes, make health care more affordable, and empower individuals to take greater control over their own health. Big data can also assist those who research disability and health 7 and make it easier for advocates to monitor their governments’ compliance with human rights treaties. 8

Nonetheless, as demonstrated in Part III of the article, big data also poses significant threats to the rights to privacy and equality. Private actors – such as employers, financial institutions, and insurance companies – have a strong incentive to discriminate, not only against persons with existing impairments but also against persons who are deemed to be at risk of developing impairments in the future. Individuals often assume that their health-related data will be kept confidential or has been anonymized before becoming publicly accessible. In fact, data breaches are all too common. Moreover, determined data miners can use “re-identification” techniques to link anonymized health information with non-medical open data.


Recognizing these risks, Part IV of the article takes a comparative approach and considers the extent to which antidiscrimination legislation can protect individuals from discrimination arising from the misuse of health-related data. The Americans with Disabilities Act, which has served as a model for many countries’ legislation, prohibits discrimination on the ground of an existing, past, and imputed disability; but it does not expressly prohibit discrimination on the ground of a disability that may develop in the future. Legislation prohibiting genetic discrimination only partly fills that gap. A leading American expert has thus called for amending the Americans with Disabilities Act (ADA)\(^9\) to expressly prohibit discrimination on the ground of a disability that may develop in the future.\(^10\) However, even very broad antidiscrimination legislation (such as Australia’s Disability Discrimination Act and Hong Kong’s Disability Discrimination Ordinance) can be difficult to enforce.

Part V of article concludes by recommending that governments take a proactive approach to protect individuals from discrimination based upon health-related data. In addition to reviewing the scope of anti-discrimination legislation, governments may also consider enacting laws to prohibit the use of health-related data mining in any decision-making process relating to employment, education, or access to financial services. At a minimum, employers and other private actors should be required to disclose when they mine data and engage in re-identification processes.

II. Positive Effects: Promoting the Right to Health and Disability Rights Advocacy

A. Big Data and the Right to Health

The right to enjoy the “highest attainable standard” of physical and mental health was first articulated in the Constitution of the World Health Organization (WHO), which proclaimed, in 1946, that “the enjoyment of the highest attainable standard of


health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.” 11 Two years later, the Universal Declaration of Human Rights (UDHR) listed health as part of the right to an adequate standard of living. 12 Although the UDHR was a nonbinding resolution of the United Nations General Assembly, the right to health was also subsequently included in the International Covenant on Economic, Social and Cultural Rights (ICESCR), 13 a legally binding treaty that has been ratified by 165 members of the United Nations, including the Republic of Korea. 14

Although the ICESCR cannot guarantee that all citizens will enjoy good health, it obligates states parties to “recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.” 15 The treaty also sets forth specific steps that governments should take to promote health, including the “prevention, treatment and control of epidemic, endemic, occupational and other diseases” and the “creation of conditions which would assure to all medical service and medical attention in the event of sickness.” 16 The nature of states’ obligations to promote the right to health have been further developed in interpretative instruments issued by the Committee on Economic, Social and Cultural Rights. 17 In the early decades after the ICESCR came into force, jurists sometimes referred to the treaty as “promotional” or “aspirational,” implying that it is less justiciable than treaties that protect basic freedoms, such as the International Covenant on Civil and Political Rights. 18 However, the UN Committee on Economic, Social and Cultural Rights has


15 ICESCR, supra note 13, art. 12 (1).

16 ICESCR, art. 12 (2).


worked hard to counter this perception, emphasizing that the ICESCR creates legally binding obligations for states parties. The Optional Protocol to ICESCR (which came into force in 2013 and now has 22 states parties) should further strengthen the enforceability of the treaty.

More recent international human rights treaties have further developed the right to health, particularly for those citizens who have traditionally suffered discrimination when accessing health-care services. For example, the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) obligates states to take all appropriate measures to eliminate discrimination against women in the field of health care while the Convention on the Rights of the Child requires states to “strive to ensure that no child is deprived of his or her right of access” to health-care services. The CRC also lists specific healthcare services that should be provided to children.

At the regional level, the right to health has been recognized in the African Charter on Human and Peoples’ Rights (1981), the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (known as the Protocol of San Salvador, 1988), and in the European Social Charter (1961, as revised in 1996). The right to health is also referred to in the national constitutions of more than 100 nations.

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24 See also International Convention on the Elimination of All Forms of Racial Discrimination (1965), art. 5 (e); the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (1990), arts. 28, 43 (e) and 45 (c).
26 Id.
The right to health received special attention during the drafting of the Convention on the Rights of Persons with Disabilities (CRPD),\(^27\) which came into force in 2008 and now has 174 states parties.\(^28\) The CRPD provides legal authority for the global movement away from the outdated medical model of disability.\(^29\) But this does not mean that access to health care is not important to persons living with physical and mental impairments. Indeed, the drafters of the CRPD recognized that access to health care has often been denied on the basis of disability.\(^30\) The treaty thus emphasizes that persons with disabilities shall enjoy “the highest attainable standard of health without discrimination” and sets forth detailed measures that governments should take to ensure that persons with disabilities receive “the same range, quality and standard of free or affordable health care and programmes as provided to other persons.”\(^31\)

Access to high-quality data at reasonable cost can help governments meet their obligation to promote the right to health of all citizens, including those who live with impairments. Traditionally, patient-related data was collected by a doctor’s office or hospital and then retained within the boundaries of the healthcare provider, making it difficult to derive insights from the aggregation of data. In the era of big data, the information recorded by doctors and other health care providers is digitalized and shared across networks. It can then be aggregated with other patient-related data (including, for example, laboratory tests, readings from electronic devices, patients’ lifestyle information, insurance data, and medical journal articles). When properly analyzed, these large data sets have the potential to dramatically improve both the quality and the accessibility of healthcare.\(^32\) For example, insights gained from big

\(^{27}\) CPRD, supra note 8.


\(^{31}\) CPRD, supra note 8, art. 25.

data can be used to make better predictions regarding the trajectory of a disease and how a particular patient is likely to respond to a particular treatment.33 The data revolution also has accelerated the development of precision medicine, which seeks to tailor diagnosis, treatment and prevention of disease to individual variability in genes, environment, and lifestyle.”34

Mining vast quantities of health-related data can also enhance research, surveillance, and prevention of infectious diseases, facilitating the early detection of global public health threats.35 For example, the website “healthmap.org” and the mobile application “Outbreaks Near Me” deliver real-time intelligence on a broad range of emerging infectious diseases, which can be accessed by health departments, governments, and the general public. HealthMap brings together “disparate data sources, including online news aggregators, eyewitness reports, expert-curated discussions and validated official reports, to achieve a unified and comprehensive view of the current global state of infectious diseases and their effect on human and animal health.”36 Through an automated process, the online system continually monitors, organizes, integrates, filters, updates and disseminates information in nine languages.

The data revolution has also empowered individuals to take greater control over their own health and to actively participate in research.37 Individuals increasingly participate in online health communities, where they share their experiences and exchange information regarding symptoms, treatments, and side effects.38 As a result,

36 See the “About” section of the HealthMap website, (accessed Aug. 1, 2017), http://www.healthmap.org/site/about.
37 See, e.g. Sabatello and Appelbaum, supra note 35, at 20.
physicians are now regularly questioned by assertive and well-informed patients, who can access a wide range of data on medical conditions and possible treatments. Some individuals even use publicly accessible data to become “citizen scientists” and research treatments for rare conditions, which might otherwise receive little attention. Participatory health initiatives are also important to professional researchers because crowdsourcing can be such a rich source of data.\footnote{Melanie Swan, \textit{Crowdsourced Health Research Studies: An Important Emerging Complement to Clinical Trials in the Public Health Research Ecosystem}, 14(2) JOURNAL OF MEDICAL INTERNET RESEARCH (2012), (accessed Aug. 24, 2017), http://www.jmir.org/2012/2/e46/.

It is important to note that the health benefits of “big data” are not confined to economically and technologically advanced nations. Indeed, the efficiency gains can be even more transformative for developing nations. For example, Dr. Joel Selanikio has vividly described how the “big data revolution” has dramatically improved the ability of health care workers to collect and analyze vaccination data from rural areas; they use smart phones in place of stacks of obsolete paper records and the data can be aggregated and analyzed in a fraction of the time that was previously required.\footnote{Joel Selanikio, \textit{The Surprising Seeds of a Big Data Revolution in Healthcare} (recorded Feb. 2013), (accessed Aug. 1, 2017), https://www.ted.com/talks/joel_selanikio_the_surprising_seeds_of_a_big_data_revolution_in_healthcare.}

This is just one example of the capacity of “big data” to promote the right to health in developing countries. Advanced technology can also be used by international aid agencies to hasten and strengthen their responses to natural disasters, pandemics, and other crises.

Moreover, as analyzed below, it is not only the right to health that can be facilitated by the data revolution. Big data also can be used to promote the civil, social and economic rights of persons with disabilities.

\section*{B. Disability Rights and Advocacy in the Era of Big Data}

The CRPD embraces the social and human rights models of disability and thus recognizes that social and physical barriers are often more “disabling” than individual impairments.\footnote{Chinmoy Nath, Jina Huh, Abhishek Kalyan Adupa, and Siddhartha R Jonnalagadda, \textit{Website Sharing in Online Health Communities: A Descriptive Analysis}, 18(1) JOURNAL OF MEDICAL INTERNET RESEARCH (Jan. 2016), (accessed Aug. 10, 2017), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4730108/.

Persons with disabilities are rights holders who have been regularly
denied the right to equal education in mainstream schools, the right to work in the
mainstream economy, and the right to participate in public affairs. They may not
even be permitted to live independently in the community or to move about freely as
members of society. Indeed, many legal systems continue to deny persons with
disabilities the right to legal capacity, compelling them to live under “guardianship”
throughout their adult lives.42

One of the core principles of the CRPD is accessibility, which is essential in order
for persons with disabilities to exercise their rights. Article 9 of the treaty thus
obligates states parties to “take appropriate measures to ensure to persons with
disabilities access, on an equal basis with others, to the physical environment, to
transportation, to information and communication, including information and
communication technologies and systems, and to other facilities and services open or
provided to the public, both in urban and in rural areas.”43 The U.N. Committee on
the Rights of Persons with Disabilities, which monitors compliance with the treaty,
has observed that governments often fail to adequately monitor the extent to which
their communities are truly accessible.44 Fortunately, in the era of big data, it is
becoming much easier for private citizens to monitor and promote accessibility. For
example, online tools are being developed to collect and publicize the location of
schools, workplaces, and public buildings that are accessible. One such tool is
“Project Sidewalk,” developed at the University of Maryland’s Human-Computer
Interaction Lab (HCIL). It links big data, machine learning, computer vision and
geographic information systems to map and visualize the accessibility of Washington
D.C. for persons with disabilities.45 Similarly, AXS Map was developed by a
filmmaker based in New York City, who uses a motorized scooter to move about the

41 See, e.g. Kanter, supra note 29, at 291; and Petersen supra note 29, at 825-826.
42 For analysis of the position of the U.N. Committee on the Rights of Persons with Disabilities on
this issue and responses of governments, see Carole J. Petersen, Promoting the Rights of Older Persons:
Addressing Adult Guardianship and Substituted Decision-Making in Health Care, 10(1) ASIA PACIFIC
JOURNAL OF HEALTH LAW & ETHICS 41-70 (2016).
43 CRPD, supra note 8, art. 9.
44 Committee on the Rights of Persons with Disabilities, General Comment 2 – Article 9, Accessibility,
CRPD/C/GC/2 (May 22, 2014), para. 10.
45 Aysha Khan, How Project Sidewalk is making DC more accessible, TECHNICALLY D.C., (accessed
city. He developed a crowdsourcing tool, which is powered by Google Maps and available on the web or as an application for mobile phones. AXS Map allows users to find, rate, and review restaurants, public buildings, and other locations based on their accessibility for persons who live with a wide range of impairments, including hearing, vision, and mobility impairments. By widely publishing this information, AXS Map empowers persons with disabilities. It also gives governments, public authorities, and private businesses an incentive to make their facilities more accessible, so as to obtain a positive review.

Equally important, these crowdsourcing tools help to build awareness regarding barriers and political support for disability rights. For example, AXS Map invites able-bodied persons as well as persons with disabilities to contribute reviews and it provides training videos to teach able-bodied users to review the accessibility of buildings. AXS Map also helps to organize coordinated reviewing efforts, known as “mapathons.” A mapathon can include parties for the volunteers and prizes for those who input the largest number of reviews. Promoting and monitoring accessibility thus becomes a community project rather than simply an obligation of the government.

Access to data is also important for the international monitoring process. When a government ratifies the CRPD it assumes an obligation to submit an “initial report” within two years of ratification to the U.N. Committee on the Rights of Persons with Disabilities and then to submit “periodic reports” every four years or when

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48 For additional examples of how “big data” can promote the rights of persons with disabilities, see Gabriel Pestre, Big Data and Disability, Part 1 (Mar. 1, 2016), DATA-POP ALLIANCE, (accessed Aug. 13, 2017), http://datapopalliance.org/big-data-and-disability-part-1/ (Data-Pop Alliance describes itself as “a global coalition on Big Data and development created by the Harvard Humanitarian Initiative, MIT Media Lab, and Overseas Development Institute that brings together researchers, experts, practitioners, and activists to promote a people-centered Big Data revolution through collaborative research, capacity building, and community engagement.”).


51 CRPD, supra note 8, art. 34(2)-(3) (providing that the Committee shall consist of twelve experts in the field, with high moral standing and recognized competence and experience, and shall serve in their personal capacities).
requested to do so by the Committee.\textsuperscript{52} These reports should describe the legislative and policy steps that a government has taken to comply with the CRPD, as well as any barriers to implementation. The government report is the start of a review process, which leads to a public dialogue between members of the Committee and the government delegation. Prior to the dialogue, the Committee will also receive reports from nongovernmental organizations (which are known as “NGO reports,” “alternative reports” or “shadow reports”). Following the interactive dialogue (which is now regularly webcast over the internet), the Committee drafts “Concluding Observations,” which identify concerns and make recommendations on how a government can better comply with the CRPD. The Concluding Observations are public documents and thus can provide additional support for activists when they lobby for law and policy reforms at the domestic level.

Accurate and detailed data on the situation of persons with disabilities in each state party is essential to the integrity of this international reporting process. The drafters of the CRPD recognized this and also knew that individuals living with disabilities are often hidden from public view and thus excluded from traditional government reports on social and economic development. In order to address this deficiency in data, the CRPD obligates governments “to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect” to the CRPD.\textsuperscript{53} The treaty further provides that the information collected “shall be disaggregated, as appropriate. . . and address the barriers faced by persons with disabilities in exercising their rights.”\textsuperscript{54} Governments are also responsible for “the dissemination of these statistics” and must “ensure their accessibility to persons with disabilities and others”.\textsuperscript{55}

Despite these express obligations in the treaty, governments often fail to collect sufficient data that is specific to the situation of persons with disabilities. For example, in 2013, during its review of Australia, the U.N. Committee on the Rights of Persons with Disabilities expressed regret regarding the “low level of disaggregated

\textsuperscript{52} CRPD, art. 35.
\textsuperscript{53} CRPD, art. 31(1).
\textsuperscript{54} CRPD, art. 31(2).
\textsuperscript{55} CRPD, art. 31(3).
data collected on persons with disabilities and reported publicly.”56 Similarly, in 2014, the Committee called upon the South Korean government to systematize the collection, analysis and dissemination of disaggregated data relating to persons with disabilities and to ensure that these statistics are freely accessible.57 The Committee made similar comments following its reviews of Thailand58 and the People’s Republic of China.59 These governments are not alone – the lack of disability-specific data has been a common concern when the Committee has reviewed states parties to the CRPD. Indeed, the importance of disaggregated data was identified as a particularly pressing issue during the Tenth Session of the Conference of States Parties of the CRPD, which concluded in June 2017.60

There is no doubt that the data collection and analytical tools that are becoming available in the era of “big data” will make it easier for governments (and also independent researchers and disability rights activists) to produce disaggregated data. However, governments have a simultaneous obligation to prevent the misuse of this data. For example, the CRPD provides that the process of collecting and maintaining data shall “comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities” and also “with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.”61 The U.N. High Commissioner on Human Rights has also emphasized the duty of governments to protect the confidentiality of individuals’ personal data.62 Yet, as

59 Committee on the Rights of Persons with Disabilities, Concluding Observations in relation to the initial report of China, U.N. Doc. CRPD/C/CHN/CO/1 (2012), at paras 47-48 (noting that data is particularly scarce in China due to laws that define “state secrets” in very broad language and other restrictions on access to information).
61 CRPD, supra note 8, art. 31.
demonstrated in the next section of the article, it will be challenging for governments to prevent disclosure and misuse of data related to health.

III. Health-Related Data as a Tool of Discrimination?

Data related to disability and health is particularly sensitive and its disclosure may expose individuals to discrimination. The right to equality is a core principle of the CRPD and states parties are thus obligated to prohibit discrimination against persons with disabilities.\(^6^3\) Unfortunately, it is extremely difficult to prevent data miners from using “re-identification” techniques to link anonymized health information with non-medical open data. Not surprisingly, there is a strong market for this type of data. For example, financial institutions, retailers, and service providers can use data to “categorize” their customers, with the goal of offering different prices or discounts to different categories of customers. Thus, certain groups may receive offers for “gold level” credit cards while others receive offers for subprime credit cards with higher interest rates and fewer benefits. If a financial service company does this on the basis of race or gender or an existing disability then it is acting unlawfully in many jurisdictions. However, differential treatment on the basis of predictions about future health is less likely to be considered unlawful. Moreover, it is difficult to detect and regulate differential treatment because unregulated “aggregate scoring models” assess credit risks, not based on the credit characteristics of individual consumers, but on the aggregate credit characteristics of groups of consumers.\(^6^4\)

Employment is another field where discrimination is likely to arise as a result of health-related data. Employers have always tried to seek out “healthy” employees and in some jurisdictions they can do so by requiring applicants for jobs to submit to pre-employment physicals or to provide personal health records.\(^6^5\) Of course, many

\(^{63}\) CRPD, \textit{supra} note 8, art. 5.


\(^{65}\) For example, pre-employment physicals are still common in Hong Kong, a jurisdiction that has a
jurisdictions now prohibit such practices during the application process. For example, in the United States employers generally cannot conduct medical examinations or seek medical information from job applicants. However, after an offer of employment is made, employers can request far more information and many employees sign forms authorizing their employer to obtain personal health records. In some cases, an employee may voluntarily disclose an impairment, perhaps because she needs a reasonable accommodation (such as special equipment) to perform her job.

Moreover, in the era of big data, employers and other actors have many alternative means of obtaining health-related data. Indeed, employers may prefer to use alternative means, especially if they can obtain health-related information without an individual’s knowledge. For example, employers “can and do scour Facebook, Twitter, and other social medial platforms in which workers reveal abundant details about themselves.” Employers may also choose to retain “data brokers.” These are companies that collect personal information from a variety of public and private sources and then create personal profiles of individuals, which they can market to interested parties. Although the data provided by data brokers is generally de-identified, it can sometimes be “re-identified” by skilled experts. Data miners accomplish this by matching anonymous health information to publicly accessible data, such as newspaper reports of accidents and voter registration records.

In the United States, many employers also now offer their employees “wellness programs,” in which employees may record significant health-related data, often by wearing “Fitbits” that collect data automatically. In theory the vendors of these programs should only provide this data to the employer in aggregated form; however, many commentators have expressed concerns that employers are obtaining

66 42 U.S.C. s 112112 (d).
67 Hoffman, supra note 10 at 780.
68 Id. at 781.
69 Id. at 782.
70 Id. at 783-4.
individualized information through wellness programs.\textsuperscript{72} One of the stated (and laudable) goals of these programs is to improve the health and wellbeing of employees. It is, however, no secret that an additional incentive for offering such programs is the desire to reduce absenteeism and productivity losses due to ill health. In the United States, employers are also interested in reducing the cost of employer-provided health insurance. If a wellness program does, indeed, make employees healthier then that is one way of accomplishing these goals. But an additional way to accomplish the employer’s goals is to find a reason to terminate employees who fail to comply with the wellness program and/or inadvertently reveal health-related data that makes them look “risky” to the employer.\textsuperscript{73}

Individuals also may be exposing themselves to discrimination when they voluntarily contribute health-related data to online health communities. Interestingly, these websites do regularly warn potential members of the risk of identification. For example, the “Privacy Policy” on the “PatientsLikeMe” website categorizes information as “restricted data” and “shared data” but makes it clear that only a few types of information are considered “restricted” (e.g. the user’s name, which is collected and verified as part of his/her registration, his/her password, address, and date of birth). Most of the information that a user submits will fall within the “shared data” category, including: condition or disease (e.g. diagnosis date, first symptom, and family history); treatment information (treatment start dates, stop dates, dosages, side effects, and treatment evaluations); symptom information (e.g. severity and duration of symptoms); laboratory results; and genetic information (e.g. information on individual genes and/or entire genetic scans). The PatientsLikeMe website also warns users they may inadvertently expose themselves to identification, noting that:

Members should expect that every piece of information they submit (even if it is not currently displayed), except for Restricted Data, may be shared with the community, other patients, and Partners. Members

\textsuperscript{72} Hoffman, \textit{supra} note 10 at 781-782.

are encouraged to share health information but should consider that the more information that is entered, the more likely it is that a Member could be located or identified.74

PatientsLikeMe also expressly warns potential members of the consequences of identification, noting that employers, insurance companies, or others may discriminate based on health information.”75 Despite these warnings, a huge percentage of the public is participating in these online health communities and other forms of social media that encourage the sharing of health-related data.

Given this level of risk, governments need to consider whether their existing anti-discrimination legislation is sufficient to deter and remedy discrimination arising from misuse of health-related data. That issue is addressed in the next section of the article.

IV. The Scope of Anti-Discrimination Legislation and Barriers to Enforcement

Persons living with disabilities have always experienced significant discrimination, both in access to education and in the employment market. Thus, a major goal of the CRPD is to encourage governments to enact laws prohibiting disability discrimination in these important fields. However, the typical anti-discrimination law probably will not protect persons from discrimination arising from the misuse of health-related data.

For example, the Americans with Disabilities Act (ADA)76 prohibits discrimination on the ground of an existing, past, or presumed disability; but it does not expressly prohibit discrimination arising from an assessment (accurate or otherwise) that a person is at risk of developing some future impairment. Because the ADA has served as a model for other countries,77 numerous anti-discrimination statutes use similar

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75 Id.
76 Americans with Disabilities Act, 42 U.S.C. ss. 12101-12213 (2012). The the term “disability” is defined at s. 12102.
language. For example, the Republic of Korea’s Act on the Prohibition of Discrimination Against Disabled Persons states (at Article 6) that “[n]o person may discriminate against anyone based on his/her disability, previous disability, or presumed disability.” Of course in some circumstances, it will be possible to argue that an employer “presumed” a disability when deciding to treat an individual less favorably on the grounds of health data. But that would not be the case if an employer honestly believes that an employee or job applicant is quite healthy now but has decided (correctly or incorrectly) that she is at a higher-than-average risk of developing a disability at some point in the future.

In the United States, the legislative gap in the ADA has been partly filled by state laws and by the enactment of the Genetic Information Nondiscrimination Act (GINA). Title II of GINA prohibits the use of genetic information in employment decisions; it also restricts employers and other “covered entities” (including employment agencies, labor organizations, and joint labor-management training and apprenticeship programs) from requesting, requiring or purchasing genetic information. The law also limits the disclosure of genetic information. However, this does not prohibit employers from making an adverse employment decision because of other factors that employers deem to be predictors of future health. For example, an American employer could lawfully decline to hire a person because the employer believes that the person’s eating habits, biomarkers, travel habits, stress levels, exposure to toxins, or a “myriad of other hazards” will render the individual likely to develop a future disability.

Sharon Hoffman, a leading expert on big data and discrimination in the United

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79 Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233; see also Lara Cartwright-Smith, Elizabeth Gray, and Jane Hyatt Thorpe, Health Information Ownership: Legal Theories and Policy Implications, 19 V. AND. J. ENT. & TECH. L. 207 (2016) (analyzing a range of state and federal laws that may help to protect against privacy violations and misuse of health-related data).
80 Id. It should be noted that the scope of GINA is not as wide as the ADA (although insurance companies are also covered by Title I of GINA). For additional information on the law, see the US Equal Employment Opportunities Commission, Genetic Information Discrimination, (accessed Aug. 20, 2017), https://www.eeoc.gov/laws/types/genetic.cfm.
81 Hoffman, supra note 10 at 786.
States, has recommended that the ADA be amended to expressly prohibit discrimination on the ground that a person is at risk of developing a physical or mental impairment in the future.\textsuperscript{82} If her proposed amendment were adopted, a potential plaintiff would not be required to prove that an employer believed that the plaintiff would definitely develop an impairment; rather, the plaintiff would only need to prove that the employer was “worried about a non-transitory physical or mental impairment” and acted upon that worry.\textsuperscript{83}

This would bring the ADA closer to Australian federal law, which already prohibits discrimination on the ground of a disability that presently exists, previously existed, may exist in the future, or is imputed to a person.\textsuperscript{84} This clause in the Australian Disability Discrimination Act can also be relied upon in cases of discrimination on the ground of an imputed future disability. For example, gay men who experienced discrimination because of an assumption that they were at risk of developing HIV/AIDS at some point in the future have obtained remedies after filing complaints with the Australian Human Rights Commission, the federal agency charged with investigating and attempting to conciliate complaints of unlawful discrimination.\textsuperscript{85}

Hong Kong provides another example of a jurisdiction that already expressly prohibits discrimination on the ground of a disability that may develop in the future. It also provides an interesting case study on the extent to which an employer may, nonetheless, try to exclude applicants on the basis of assumptions regarding future health. Hong Kong’s Disability Discrimination Ordinance (DDO) was enacted in 1995 and is largely based upon Australian law.\textsuperscript{86} Although the law was officially proposed by the Hong Kong government, it did so rather reluctantly (as means of defeating a more progressive competing bill introduced by an individual legislator). As a result,

\textsuperscript{82} Id. at 786.

\textsuperscript{83} Id. at 787.


the Hong Kong government was somewhat unprepared to implement its own legislation when the law came into force. This became clear when the Hong Kong Equal Opportunities Commission (Hong Kong EOC) began receiving complaints from individuals who had applied, unsuccessfully, for government jobs.

When the Hong Kong EOC investigated the complaints against the Hong Kong government it discovered that various branches of the government’s “disciplined services” (e.g., the police, fire services, immigration, customs and excise, and correctional services departments) had a policy of refusing to hire any applicant who had a relative with a history of mental illness. This policy was applied in a sweeping manner: applicants were required to give detailed health information regarding their parents and siblings and if one of them suffered from mental illness the civil service’s Medical Examination Board would declare the applicant “unfit” for employment. The Board routinely made this determination without conducting any individual assessment of an applicant’s own mental health or ability to perform the inherent requirements of the job in question. Because the government refused to change its policy, the Hong Kong EOC ultimately had to litigate.87 In court, the government argued that “safety” was a genuine occupational requirement of the jobs in question and that a family history of mental illness would prevent any applicant from fulfilling that requirement. The court rejected this argument because it found that the government’s assumptions – that the applicants were at a significant risk of developing mental illness – were unfounded and that there was no reason to conclude that they could not perform the jobs safely.88 In one sense, the case set an important precedent and the policy has now been reformed. However, it is also sobering to think that government officials had been rejecting job applicants – for many years – on the basis of pure speculation about applicants’ future health. Moreover, even when the Hong Kong EOC advised the government that its hiring policy violated the law, the government was willing to spend public money to defend the policy in court.

Given that the Hong Kong government was unwilling to comply with its own Disability Discrimination Ordinance, it is not surprising that employers in Hong

88 Id.; for further analysis of the case, see also Carole J. Petersen, The Right to Equality in the Public Sector: An Assessment of Post-Colonial Hong Kong, 32 HONG KONG L.J. 103 (2002).
Kong’s private sector also continue to require pre-employment medical examinations. Indeed, they know that they can discriminate on the ground of a current or future disability with very little fear of liability. This is partly because the enforcement model relies upon individual complaints and job applicants often have difficulties detecting and proving disability discrimination. Moreover, Hong Kong lawyers are not permitted to work for contingency fees. This means that the vast majority of victims of disability discrimination cannot afford to retain a lawyer in Hong Kong. Instead, they rely upon the free investigation and conciliation services offered by the Hong Kong EOC. If conciliation fails (which is common), the Hong Kong EOC has the power to offer assistance to litigate; but it does so very infrequently. Without the threat of litigation, employers and other respondents have little incentive to offer a significant remedy during the conciliation meetings.

Of course, every legal system has to develop its own enforcement model for antidiscrimination laws – some countries rely upon conciliation, some use informal tribunals, and some put more emphasis on formal litigation. But regardless of the model that is developed, employers, insurance companies, and others who may gain access to health-related data need to know that there is some effective mechanism for enforcing the relevant antidiscrimination laws. A strong enforcement model is required to counter the temptation to acquire and misuse sensitive health-related data.

90 Carole J. Petersen, Janice Fong and Gabrielle Rush, Enforcing Equal Opportunities: Investigation and Conciliation of Discrimination Complaints in Hong Kong, Centre for Comparative and Public Law 2003 (reporting findings from study of more than 400 complaint files and interviews with participants in conciliation meetings).
V. Conclusions

There is no doubt that data-driven health care is here to stay, and it will have many positive effects on human rights. In addition to promoting all citizens’ right to the highest attainable standard of health, big data will also expand opportunities for persons with disabilities to participate in society and enforce their rights under the CRPD. But health data is also far less private as a result of the data revolution and even “anonymous” aggregated data may become a tool for discrimination in certain hands. While governments should do their utmost to protect the confidentiality of our health-related data, we should assume that those measures will be fallible.

It is therefore important for governments to review their antidiscrimination statutes and amend them, if necessary, to ensure that all forms of disability discrimination are prohibited, including discrimination based upon a perception that a person is at risk of developing a disability in the future. Moreover, given that antidiscrimination laws are notoriously difficult to enforce,92 governments may need to take a more proactive approach to prohibit data mining and re-identification in certain contexts. Laws could also be enacted to expressly prohibit reliance on health-related data in decision-making processes related to employment, education, and access to financial services. At a minimum, employers, insurance companies, and other private actors should be required to disclose whether they are using re-identification processes or purchasing health-related data from data brokers. This may help communities to make informed decisions on whether more restrictions are necessary to protect the confidentiality of health-related data and to prohibit health-related discrimination.

Received: September 22, 2017
Revised: November 4, 2017
Accepted: November 21, 2017