

A RIGHT TO KNOW – BUT UNLIKE A RIGHT TO KNOWHOW (INFORMATION)

Adv. Veena Nair,
Research Scholar,
MATS University, Raipur, India

Abstract: Right to giving an informed consent' is a Civil Right that deserves a distinct legal status, given the recent splurge in technological innovations and technological advancements in many fields. This Right is not complementary to the Right against Self-incrimination. Rather it is a self-defined Right having, “‘**desire**’, **to know about the consequences of permissibility and accessibility**”, ingrained in its essence. It is not the same as the Right to information since here, the ‘Seeker’ must inform the ‘Sought’ about the consequences of the former’s undertakings beforehand while soliciting permissibility/ accessibility (as the case may be) to the information held by the seeker. It is different from the Right to Life & liberty since its inception is based on the cognitive faculty of assessing for oneself the worth and value of the information wanted by the seeker, in order to permit/give or refuse to give access to that information. This is all the more necessary as the seeker may exploit or gain advantage and the sought may not know of it. The right against Self-incrimination has a negative connotation due to its preventive nature, but the right to an informed consent stems from the rationale of ‘cognizant undertaking’ or ‘cognizant permissiveness’. The nature of cognizance is a positive approach to any given circumstance since it creates awareness about the worth of the information held by the sought ensuring the complete picture of its usage/manipulation by the seeker. The Indian Constitution permits assessment and evaluation of circumstances to determine the scope of any given right, but if informed consent is made a legal right, defining thus far and no further, the burden of proof on the victim of infringement is considerably reduced.

IndexTerms - Civil Right, Cognizant, Right to Information, Seeker, Legal Right, Burden of proof, Victim, Informed Consent

I. INTRODUCTION

A ‘civil right’¹ is defined as a class of nonpolitical rights of a person that is inherent in their existence as human beings. Chapter III of the Indian Constitution² enumerates certain rights which are termed ‘fundamental’ and guaranteed to persons or citizens (as the case may be). It clearly states that no law can be framed by the parliament or any legislature of the states, that takes away or abridges these rights and any such law in existence or so framed shall become void to the extent that it contravenes or is inconsistent with these guaranteed rights. Upon violation of a Civil Right, a Civil Wrong³ is said to have caused. As opposed to an ‘offense’/ ‘Crime’ a ‘Wrong’ takes place when there is an infringement of personal rights during interactions between individuals or groups of people or between individuals themselves. The correlative of every right is ‘duty’ which is in the nature of a mandatory action; from which stems an accountability to the holder of the right⁴. A liability arises upon breach of that duty and upon the infringement of the correlative right⁵. In case of a Civil Right, the violation of the right essentially gives rise to an action in law provided the corresponding duty is particularly enumerated. This is because a Civil Right is conferred by statute or by common law and is developed according to the trends prevailing in the society at any point in time. Therefore, in order to realize any claim due to violation of a Civil Right, one has to define the ‘right of the holder’ as well as ‘the corresponding duty’ that has not been performed: or in other words, the accountability factors on the part of the party against the right holder. The civil rights so enumerated by the laws are granted to curtail unequal treatment, to check discrimination based on certain specified characteristics’ and to guarantee fairness to individuals in their dealings with one another and the Governments and /or Governmental or private Authorities⁶. In today’s technology dominated era and with digitalization in progress it is essential to

¹ Civil_and_political_rights, available at https://en.wikipedia.org/wiki/Civil_and_political_rights

² The Constitution of India, 1950, Art. 12 to Art. 35 available at [http://lawmin.nic.in/olwing/coi/coi-english/Const.Pock%20Pg.Rom8Fsss\(6\).pdf](http://lawmin.nic.in/olwing/coi/coi-english/Const.Pock%20Pg.Rom8Fsss(6).pdf) – PART III

³ "Difference between Crime and Civil Wrong." DifferenceBetween.Com. January 12, 2015. Available at <http://www.differencebetween.com/difference-between-crime-and-vs-civil-wrong/> >

⁴ R W M DIAS, JURISPRUDENCE, 230-31, (5th ed., 2013).

⁵ R W M DIAS, JURISPRUDENCE, 23-24, (5th ed., 2013).

⁶ Prabhat S. "Difference Between Civil Rights and Civil Liberties." DifferenceBetween.net. March 2, 2011, available at Difference Between Civil Rights and Civil Liberties | Difference Between <http://www.differencebetween.net/miscellaneous/politics/difference-between-civil-rights-and-civil-liberties/#ixzz4wKuOfPnm>

know what an individual is signing up for. Only then can one determine the course to take upon infringement of any right whether it is an inalienable right or a conferred right. And in order to be better informed it is not sufficient to gather information by oneself. This is so because sometimes the technical aspects of a study/process/technological application may be so complicated that even a person acquainted with the field may not be capable of assessing the infringement upon the right of another that may be caused by the technological application. Sometimes the extent of infringement may be difficult to gauge due to lack of sufficient materials or evidence in the field of study and the infringement maybe even necessary to collect materials in order to assess the infringement upon the rights of another. This is especially true of the advanced technologies in today's era since technology always requires technology itself as its basis to develop further upgraded technologies. It is in order to bridge the gap between the efforts made for furthering technology's progression and the contribution of an unsuspecting and ill-informed individual towards it that there should be a legal right, that protects the interests of the innocent contributor and enables him for compensation in the event of a violation of any of his/her civil rights. Since India does not have a separate Right to Privacy, it is essential that in order to respect a person's autonomy⁷, the right to giving an informed consent is defined and granted a distinct legal status as a legal right albeit with minimum restrictions imposed upon it.

II. FUNDAMENTAL RIGHT OR FUNDAMENTAL FREEDOM

The fundamental rights as guaranteed by the Indian Constitution are justiciable which means that an aggrieved person can seek the Supreme Court or High Courts in India to invoke the writ jurisdictions. The Indian Constitution also guarantees the individual, protection against self-incrimination vide Art.20 (3)⁸. Now, consider a scenario where a person 'Z' has illegally accessed a database containing the DNA profile of an individual 'X' and uses the DNA profile of 'X' as a control/standard reference for some research purpose. Here, the first part is an offence for which 'Z' may be prosecuted against but the second act of 'Z' namely using the DNA profile of 'X' will involve the violation of the right to privacy of 'X' and will constitute an intrusion upon the autonomy of 'X' as a result of which though his person is not violated his sense of his 'self' is definitely violated. It is intrusions of such nature that are being sought to be addressed by this paper. If the Constitution doesn't allow 'Z' to incriminate himself following a crime then why should the Constitution disallow 'X' from preventing others from incriminating him in this context or at the least prevent him from claiming compensation for violation of his self-autonomy. The intrusion into the life of the individual 'X' is through, the violation of, his right to, determine who should have access to his personal or private information, which right requires to be spelled out and defined for the sake of the 'self-worth' of 'X', and perhaps for his sense of identity too. The concept of Civil Rights envisages protection of individual's right which includes his constitutional right. But technological developments have put so much information into the public domain that free consent or free will are insufficient to guard them against exploitation or misuse by any individual or authority or institution, regardless of the purity of their purpose. Therefore, defining the 'Civil Right' of 'giving an informed consent', can save the 'Sought', against any 'Seeker' of information, at any point in time even if the transgression had occurred at a date far back in time. Despite being a Civil Right and the 'Seeker' being the wrongdoer the Constitutional right under Art.20(3) can be invoked by the 'Sought' in a positive manner to prevent further revelation of information held by the 'Sought' against the 'Seeker'.

III. WHY GIVE THE 'RIGHT' A LEGAL STATUS

In order to seek any legal remedy one has to know what constitutes the right for which there has to be a clear definition of the right. This is also essential because only upon defining a right can we define what would be the wrongs that can be committed against that Right as well as what remedies can be suggested. So, if, a Right is in the nature of something that is to be **derived** from the fundamental right of the person like the Right to Life and Liberty, at the same time the infringement of which constitutes the infringement of, right in a property or a property in a right, then, such a right should be defined, as well as given a legal status. One such Right that has re-emerged in the present digital era is the right to giving an Informed Consent. I say re-emerged because, though the origin of this right date back to the times since when the physician-patient relationship began and has undergone numerous changes till today, its **scope** has only enlarged due to the advent of Cyber technologies and Genetic Engineering technologies. Both these technologies have brought to fore the key concept of, Right to privacy, which unfortunately has not been granted Constitutional status albeit the Constitution Bench of the Hon'ble Supreme Court of India recognizing it as a fundamental right. The Right to giving an informed consent assumes greater significance in today's era because the pervasiveness of technologies within our lives do not ensure the protection of any data or information whether such data or information has been collected from substances inherent within us or whether such data obtained, is related to us. If we consider information contained in databases from different sources⁹, which information may have been given voluntarily by us, for any particular project or purpose, **we do not have recourse to any remedy in case such data or information is exchanged or used illegally or used for**

⁷The justification behind normative and instrumental reasons for rights as explained in, James Griffin, 'First Steps in an Account of Human Rights', European Journal of Philosophy, 9 (2001) 306-327.

⁸ The Constitution of India, 1950, Art.20(3)

⁹ Sources such as websites, medical databases, insurance databases, company surveys etc which collect personal information from people generally and store it for any specified purpose.

profit without any benefit sharing. This is even truer regarding the data that will be contained within DNA databases once they will come into existence. In the case of DNA databases, it is not only the individual but also the individual's twin that can be identified. Supposing, the twin turns out to be a criminal whereas the individual is an innocent citizen, who did not know the existence of such a twin, unwittingly, this newly generated information would have led to a case of tortious liability on the part of the authority of the 'State' for causing the citizen mental trauma and disrupting his/her innocent existence. Unfortunately, the State does not recognize such a right of the citizen or a liability within itself. In the event, the right of giving an informed consent is defined the innocent citizen can choose to save himself from the trauma or seek compensation or damages from the 'State'. This is so because the 'State' will have to inform the innocent citizen about the 'knowledge' they have come into, with the help of the know-how already within their means¹⁰ even if it is only to save the innocent citizen from future mental trauma as also because it is an obligation on the part of the 'State' to inform the innocent citizen of the transgression committed by it upon the right to privacy of the innocent citizen.

In addition, in the event of the family of the innocent citizen coming under such mental pressure, due to being blackmailed on the basis of that information illegally acquired by another, a defined right of giving informed consent, will enable the innocent to create a vested right in favour of his/her family regarding the manner in which they can be saved from persecution. This is because the original information finds its source in the innocent citizen and the related twin, who are both an essential part of the human resource of the 'State'. Therefore, the 'State' has the obligation to reveal to the innocent citizen the manner in which the information acquired from within the innocent citizens and stored in the DNA databases is used; in the event, it is used for a purpose other than the one specified by the 'State'. In effect, the family of the innocent citizen can claim compensation individually under their respective rights of privacy as well within this vested right. This will also serve as a protection for the notions of bodily autonomy, integrity, and privacy from transgressions by the 'State'. This is an illustration of the concepts of having a property in a right and a right in property – bodily right as well as intellectual right.

The definition of civil right guarantees, an individual, protection against violation, by providing remedies, but here, since the offense of intruding into the right of privacy of an individual remains undefined; he has no remedy available to seek from any source. Therefore, any violation of privacy has to be considered only after it is read into and derived from the Right to Life and Liberty, (Art.21 of Indian Constitution). From the above illustration it is clear that as such there is no violation of the private life of 'X' but what remains is the threat to his privacy or more importantly the breach of his inviolability, which is the basis of the differentiation between a human and an animal.

Therefore, in case the right to giving an informed consent is developed as species of the right to privacy with reasonable restrictions like the fundamental freedoms, it will reduce the burden of proof on the victim to prove the extent of violation or damage. Since the right to privacy is already being read into the right to life and liberty this new right can be granted the status of an independent statutory legal right with reasonable restrictions and in the event of an unforeseen violation of the right, the victim may be allowed to seek remedy via writs and /or compensation. And since such a violation is in the nature of a civil 'wrong' the victim can also seek for punishing the intruder.

IV. RIGHT TO INFORMATION OF THE 'VICTIM' FROM THE 'WRONGDOER'

The question about the ownership rights and privileges is left unanswered when companies/individuals/Governments utilize the DNA¹¹ of members of the public without their knowledge and gain profits. For example, in the patent "'Unique T-lymphocyte' line and products derived therefrom", the inventors used the spleen of a patient Mr. John Moore who suffered from hairy cell leukemia and came for treatment to Dr. David Golde at UCLA¹². As part of the treatment, his spleen was removed and Dr. Golde developed a cell line with enriched T-lymphocytes that produced large amounts of lymphocytes useful for cancer or AIDS treatment. Without Mr. Moore's initial knowledge or consent, but requiring his repeated visits to the hospital, Dr. Golde and the University of California applied for a patent on the cell line derived from Mr. Moore's spleen which was granted in 1984. Mr. Moore subsequently sued Dr. Golde and the University in the Supreme Court. Both the Appeals Court and the Supreme Court recognized the novelty of Mr. Moore's claim on the issue of conversion¹³ (unauthorized use of his body part), but refused to entertain it, but **recognized his right to be informed** of what the physician was doing involving his health and well being. It's an irony that a person is not given any benefit of the substance which he himself had produced, and at the same time, others are commercially exploiting the same substance.

From the above case, it becomes clear that a 'Sought' has the right to know and be informed by the 'Seeker' about

1. What the Sought is being subjected to whether it is a process/study/condition/technological application
2. What the sought is being used for

¹⁰The 'knowhow' or information contained within the DNA database of the innocent citizen along with the DNA profile of the criminal, both of which are known to the 'State'.

¹¹ DNA-De-oxyriboNucleicAcid–Nuclear genetic material–details available at <https://en.wikipedia.org/wiki/DNA>

¹²Moore_v._Regents_of_the_University_of_California available at https://en.wikipedia.org/wiki/Moore_v._Regents_of_the_University_of_California, (Last visited on August 10 2017)

¹³Conversion_(law) available at- [https://en.wikipedia.org/wiki/Conversion_\(law\)](https://en.wikipedia.org/wiki/Conversion_(law)) (Last visited on August 5 2017)

3. What the 'Seeker' seeks to do with the information obtained from the physical body of the 'Sought'
4. In what manner the 'Seeker' wishes to utilize the information obtained from the 'Sought'
5. And what would the consequences of such
 - 1.1. study/process/technological application be,
 - 1.2. the utilization of the 'Sought' as a subject
 - 1.3. Using the information obtained from the 'Seeker'
 - 1.4. The manner in which or conditions under which the information obtained from the 'Sought' will be used.
6. What would be the probable benefits arising out of such process/study/condition/technological application and whether such benefits shall be shared or are capable of being shared with the 'Sought' or the heirs of the 'Sought'.

This is exactly the meaning and essence of the term 'informed consent'. Presenting the exact facts of the events or programs that would be undertaken or uncovered by the 'Sought' in order to attain a particular aim or purpose which have to be delineated before the 'Sought' so that the 'Sought' is endowed with the ability to decide whether to grant or refuse permission or access to the 'Seeker' to the information within the 'Sought'. This is in the nature of a mandatory duty of the 'Seeker'. Thus, the 'Seeker' is prevented from accessing such information without the permission of the "Sought". This in turn vests with the 'Sought' the rights to proceed against the 'Seeker' in the event of a perceived violation of his right to consent or dissent or maybe seek compensation for not disclosing the complete picture or even not sharing the benefits of the completed program, at a later stage or at the stage of discovery.

V. RIGHT TO KNOW DISTINGUISHED FROM RIGHT TO KNOWHOW

Whereas under the statutory right to information¹⁴, the 'Seeker' seeks information from an authority specially constituted for the purpose, here in this context, the 'Sought' replaces the authority. The statute enumerates the procedure by which and the authorities from whom the seeker can gain the information required by him and even provides for penalties for authorities in the event of not providing the information unless the information belongs to a specified, classified, category, supplying of which information is prohibited by the statute. But, in this context the 'Sought' is not a statutory body rather the 'Sought' is an entity which has the obligation to reveal to the 'Seeker' the nature of the task and the benefits therefrom, in which task the information obtained from the 'Seeker' will be put to use so that the 'Seeker' may impart the information and permit its use by the by the 'Sought'. There is no information that can be withheld by the 'Sought' from the 'Seeker' under any classification or at the discretion of the 'Sought'. As this would be a ground for breach of the Right of the 'Seeker' "to know" in detail in entirety about the task of the 'Sought' such that the 'Seeker' may be capable of granting the 'informed consent' to the use of the information held by the 'Seeker' and maybe even benefit out of it.

VI. RIGHT OF INFORMED CONSENT A COROLLARY TO OWNERSHIP RIGHTS?

In another context, in the event of, any Government/State/Authority, acquiring any patent rights to any DNA sequence and using the information contained within any genome stored in any Governmental Database, can the concept of 'eminent domain' be evoked to seek just compensation for the property in genetic material of an individual? Though this is an imaginative argument if it cannot be considered then what other measure would be available to the public against the Government for infringement of their constitutional right to property - even if it is property in one's own self. After all the genetic material is a tangible mass from within the cells of the human body, but the information contained in the genes constitutes an intangible property. When the contents of such an intangible property are reduced into nucleotide sequences and stored into databases the nature of the property is converted into 'incorporeal tangible property' capable of identifying the individual from whom it has been derived. The people of a nation constitute the manpower of a nation and the most important property of the nation. All the laws framed are for the benefit and well being and complete development of the individuals of the nation. Therefore, how can the property that comes from within individuals be considered the property of the nation without it being considered their own property first? For this to happen, the concept of property will have to be redefined to include the mass of genetic material.¹⁵ A case in illustration is provided below:

In, **Hecht v. Superior Court**¹⁶, the Californian court did find property interests in biological material produced by the person and stored outside the body of the owner. The petitioner's boyfriend had killed himself but saved his sperm for artificial insemination in her, as specified in his contract with the sperm bank and his will. His adult children requested that the sperm be destroyed, but the decedent's girlfriend sought review after the lower court held in favor of the adult children. The appellate court concluded that at the time of his death, the decedent had a property interest in his sperm because he had decision-making authority regarding them. Thus; we can see another aspect of the right to informed consent being exercised here that of exercising the right of self-autonomy by will: thereby preventing others from deciding what a person seeks to do with his bodily property in the event he/she dies after making a will regarding it.

¹⁴ RTI Act of 2005 available at-<http://righttoinformation.gov.in/rti-act.pdf>,

¹⁵ ROBERT P MERGES,102-03,(2011)

¹⁶Hecht v. Superior Court available at- <http://law.justia.com/cases/california/court-of-appeal/4th/16/836.html>

With the completion of the Human Genome Project¹⁷ and the entry of the human genome sequence into the public domain the seriousness of the above issue is only enhanced. This is because the human genome that has been sequenced belongs to the entire humanity and benefits deriving out of its uses also should belong to the entire humanity. How could a research community or company claim the ownership of a sequenced genome of an individual especially if it has been obtained from an individual who has not given his informed consent to make available his/her genome for sequencing? Even upon giving an informed consent the owner of the genome would still be the human who donated the genome for sequencing since the genome belongs exclusively to the giver since barring his/ her identical twin there is nobody who can possess that sequence of nucleotides specifically, i.e. his/her DNA sequence is unique to him/her. So the ownership of patented DNA sequences will have to be limited to some extent. This brings us to another idea that of whether the 'Seeker' may be limited in utilizing the information obtained from the 'Sought' on the basis of limited ownership rights or licensing rights?

VII. COGNIZANT PERMISSIVENESS OR ACCESSIBILITY.

No matter where it is derived from the right to giving an informed consent emanates from the distinction from other species, bestowed on the human race, due to a higher degree of evolvement namely- intellectual cognizance. Cognizance is that trait in a human that enables him/her to be aware and take note of the pros and cons of any given situation before analyzing it thoroughly according to one's understanding and circumstances and reach a conclusion which may culminate in some decision making thenceforth. When an owner of any information or property decides to part with his ownership rights the owner mentally undertakes an intellectual exercise to assess the worth of the impending deal and the benefits that would accrue to the owner. So when the commodity for trading, takes on the form of information stored in databases or genetic encryption or is placed exclusively within the power of a single individual, community or nation, it is logical to presume that the exercise must involve informed consent on both sides. Perhaps in the event, the consent is to be extracted from a minor then his/her rights, his/her age, level of intellectual maturity and/or guardian's authority and right to informed consent have to be taken into account. But if it is a minor then most appropriately it would be better to wait until the minor attains the age of majority and chooses to exercise the right of informed consent, unless, the informed consent is for the purpose which will have to be proved to be beneficial for the minor and/or is absolutely essential for his/her survival. Likewise, the right to giving an informed consent for medical concerns or research purposes or as mandatory Governmental schemes for identification of individuals or creation of DNA databases etc must be essentially distinguished based on the nature of the information that would be shared and accordingly remedies have to be discerned by way of compensation or punishment. In today's scenario distinguishing between genetic information and health information has become essential since issues of genetic privacy differ from issues of health of an individual. Whereas the health information of an individual reveals only the medical condition of that individual the genetic information provides the traits, medical conditions, mutations, behavioral patterns or any inheritable characteristic feature that runs in the family of that individual. Thus, the genetic profile of an individual can affect the rights of giving of informed consent of the immediate family members who may be carrying the same gene pool!

Now supposing the information contained within the database belonged to the category of genetic information and it has been shared for research purposes to be conducted on a large scale. The greatest violation of privacy and autonomy of the individual has already occurred since the information 'seeker' has not informed the 'sought' about the scope, purpose and expected result of the research or to what extent has the 'sought' contributed to it. It is not as if the 'Sought' has surrendered his/her right of privacy for the sake of research so that he/she should be refrained from knowing the purposes and methods for which the information derived from him/her is being used. Even more importantly, the individual cannot revoke the information already in the database and refuse to contribute to the research. Then where is the remedy for the 'Sought' for the infringement of the right to decide how to disseminate information held by or within the 'Sought'; which is DNA information in this instance? Besides, since there is no information regarding the research and no right, under which he/she or his/her family can seek for a remedy the 'Sought' may be prevented from benefit sharing in case the research turns out to be commercially viable and profitable. In another scenario if this information is used for discriminating against a particular group of people (say in the name of genetic superiority) or conducted with a purpose (such as classifying Indians on the basis of their caste), that may reveal itself to be against public policy at a later stage then what is the recourse for the numerous uninformed and perhaps involuntary participants against this act of State of transgressing the limits of individual liberty and discrimination of sections of its own populace?

VIII. CONCLUSION:

The Indian Constitution permits assessment or evaluation of any given circumstance for determining the scope of any right. Though the constitution of India recognizes enforceable fundamental rights which include his/her inherent right to life and freedom, it is far away from the demands of the present digital world. The Indian Constitution may not be able to provide for all the rights and remedies required in the ever-expanding digital world, it is not only essential but also a necessity to frame a law

¹⁷NHGRI Policy Regarding Intellectual Property of Human Genomic Sequence-available at <https://www.genome.gov/10000926/intellectual-property-of-human-genomic-sequence/Introduction>

creating a positive right of giving informed consent, to the 'Sought', for the benefit of the 'Sought' as well as mankind in future. Thus, if the right to giving an informed consent is defined according to the issues, as raised in this paper, thus far and no further, it will reduce considerably the burden of proof on a victim of infringement of the 'Right to Know', which is essentially unlike the 'Right to Know how'.

