

Is True Informed Consent Achievable?

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Imagine you have just found out that a loved one, such as a parent, sibling, or close friend, suffers from a rare and deadly genetic disorder. There are currently no successful mainstream treatments for this disorder. However, the doctor mentions a highly experimental treatment that would involve removing bone marrow from a healthy donor once a month for a full year and could potentially cause permanent damage to them. It turns out that you are a match. How would you make your decision regarding treatment? Most individuals would suggest leaving it to the doctor's discretion, but because it is your body, it is ultimately your choice. You attempt to do further research on the internet but end up confused and frustrated. How will you ultimately decide as to whether you should give informed consent for the procedure?

Informed consent is the ability to make a conscious decision based on having access to all relevant information in an environment free of bias or pressure (Shah et al. 2020). Arguably, true informed consent is impossible as there is no way to provide an individual with every anticipated outcome for a decision. According to the Canadian Medical Protective Association (CMPA), the responsibility to obtain informed consent lies with the doctor who will be performing the procedure or treatment (Evans 2016). Scientists and medical professionals need to provide as much information as necessary for the patients in question. This information should include all the risks and benefits of a procedure. If autonomy is taken away through incomplete knowledge or misinformation, informed consent collapses and the medical community has failed the patient.

The concept of informed consent originated long ago. Alcmaeon of Croton, circa 500 B.C., was one of the first natural philosophers to perform dissections and vivisections (live dissections) of animals for the sole purpose of figuring out how the human body works (Magner 2002). Later, Hippocrates and Galen built on this previously established knowledge. Specifically, Galen believed that disease was caused by an imbalance of four humors: black bile, yellow bile, phlegm, and blood (Steluack & Stalkas 1991). This belief led him to introduce treatments like bloodletting, which involves cutting an individual to drain any diseased substances from their body (Fitzharris 2012). Although Hippocrates and other scientists at that time made significant discoveries, they failed to inform their patients of the potential risks of these medical treatments for fear that this knowledge would make patients uneasy (Murray 1990). Although a valid

point—patients should be comfortable around their doctor—they should also be free to decide if the benefits outweigh the risks.

Many Greek philosophers were physicians and performed medical procedures to treat illness but, arguably, one of the most influential was Hippocrates. In about 400 B.C., Hippocrates became well-known for his contributions to medicine and for developing the Hippocratic oath for medical practitioners (McPherson 2015). This built the knowledge framework needed to highlight the importance of recognizing the patient as a person rather than just a disease which would provoke change leading to the use of consent before procedures. The Hippocratic Oath was later introduced to western society in the 1700s (McPherson 2015). There isn't one universal version of the oath used now, but each one directly involves patients in their own medical care by acknowledging that treatment is meant to serve and help them; they also emphasize that a patient's privacy should be respected (Tyson 2001). Honesty is one of the most important things to cultivate a good relationship between a doctor and their patient, which will lead to trust and an environment in which informed consent can be fostered (Miles 2009). Having a set of standardized guidelines helps guide medical professionals to the appropriate treatment and helps patients maintain their autonomy.

Informed consent was instituted as a direct result of situations or events where autonomy was violated. The Doctors' Trial, in 1947, was a trial conducted against Nazi physicians which held them responsible for performing appalling human experimentations during World War II (Ethics of Human Experimentation 1964). This trial resulted in the Nuremberg Code's formation authored by two American doctors: Dr. Leo Alexander and Dr. Andrew Ivy; the document is an ethical guideline for experimentation on humans (Shuster 1997). Later, in 1957, in the court case of *Salgo versus Leland Stanford Junior University Board of Trustees*, the judge ruled that the doctor had the duty to inform the patient of any potential negative consequences of the procedure, and the term "informed consent" was born (Beauchamp 2011). Prior to this case, patients were expected to rely solely on the word of their physician. The results of the trial shifted the focus towards the implementation of informed consent, giving patients the freedom of choice (Shah et al. 2020), something that required an increased amount of accessible information.

Before the internet's introduction to the public domain in 1993 (History.com 2020), reliable knowledge was obtained from physical literature. Today, the internet and smartphones make public access to mountains of information easier than ever. Many sources are available, but, unfortunately, they are unreliable without being overt. Most information online is from biased, non-peer-reviewed sources, and the general population has generally not been taught

how to critically assess mainstream media (Takahashi 2016). Furthermore, with the use of algorithms and cookies by social media sites (Jetten & Sharon 2016; Krstić & Čigojja Piper 2020), users are not exposed to a random sampling of opinions. Instead, their recommended advertisements and sites serve to reinforce existing opinions rather than challenging them with opposing ones. When people do not know how to question a source's validity or understand differing opinions, they may believe almost anything.

If recent history is any proof, misinformation seems to plague society. Following the publication of Wakefield et al.'s 1998 paper which associated the measles, mumps, and rubella (MMR) vaccine with autism, there was a decrease in the number of MMR vaccines administered due to the newfound major public distrust of vaccines (Qian et al. 2020). After the discovery that the paper was fraudulent, the journal published a formal retraction of the article in 2010 (The Lancet 2010); however, the falsified paper has had lasting effects on the public's hesitation of vaccine usage (Rao & Andrade 2011). This minor article, although only accessible for a relatively short period of time, caused many people to believe that they should not have their children vaccinated. Consequently, measles outbreaks documented in 2006 and 2008 in the United Kingdom, and pockets of measles in the United States and Canada, can be attributed to the decreased MMR vaccination rate following the article's publication (Eggertson, 2010).

Similarly, just as quickly as people incorrectly associated the MMR vaccine with autism, the COVID-19 vaccine became associated with Big Brother. Generally, Big Brother, used in George Orwell's novel *1984*, refers to a typically well-funded, elite entity which will go to any lengths to surveil and control the public (Merriam-Webster n.d.). Approximately twenty percent of Americans (66 million people) believed that micro-chips, supposedly funded by the multi-billionaire Bill Gates, would be injected into their bodies under the guise of a COVID-19 vaccine (Swikar 2021). Because of this outlandish idea, people were ultimately hesitant about getting the vaccine so that they could avoid Big Brother. There are no microchips in the COVID-19 vaccines, and never have been (Ontario 2021) but the idea rapidly spiraled out of control. This incorrect theory likely started due to gross misinformation starting from a small number of conspiracy theorists who quoted Bill Gates out of context and did not follow up with any significant critical analysis (Goodman & Carmichael 2020). The inability to evaluate information by understanding its origin can cause individuals to reach erroneous conclusions and make impulsive decisions regarding their health and safety. However, if a reputable source is discovered, it is possible that the content will be misunderstood due to its overly complicated language.

Although the internet has massively assisted the circulation of information today, the frequently-used scientific jargon found in medical or scientific papers and reports — which are restricted to exclusive, but reputable, databases — makes comprehension overly difficult. Jargon is a term used to describe the unnecessarily formal and complex language used for published works in a specialty (Merriam-Webster n.d.). Scientific jargon can be complicated to read, let alone fully understand. Even professionals who have worked in a particular field for an extended period may experience challenges in gaining a complete understanding of a paper's main point. The formality of scientific writing decreases the opportunity, and willingness, for people to acquire new knowledge. The challenging format and language of scientific papers discourages readers and tends to belittle their intelligence. Writing using overly complicated language also gives the impression that reputable information should only be accessible to an “elite” group of people, for example, those with formal post-secondary education. In some cases, the only way to access peer-reviewed sources is through a formal institution, such as a university library or professional database.

The fees and subscriptions required to access these resources further complicates people's ability to do independent research. Large publishing companies often own most of these papers (Corbett 2009). When such a small group of people control the most reputable information, it presents an issue called gatekeeping. Gatekeeping is when access to something is carefully controlled (HarperCollins Publishers Ltd. n.d.), whether it be a physical item or non-physical item, like information. Large corporations have the power to limit the number of free, peer-reviewed sources and can remove them from being accessed by most of society. Consequently, people without access will exclusively obtain their facts from free websites prone to biased misinformation like Facebook, blogs, or news posts.

There are so many obstacles for citizens between the desire to acquire knowledge and being knowledgeable and capable of informed consent. With increased access to copious amounts of information, consent for experimental or medical procedures has become more complicated than ever, even though it is a cornerstone of the medical practice. However, for true informed consent, patients must have access to all relevant details to make an informed decision, understand said information, and make their decision free of external bias or influence (Kalina 2020; Faden et al. 1986). They must first know the risks and benefits before consenting. Reputable sources, or medical reports, require more effort than normal to achieve complete comprehension; in this way, people are being denied information they could use to further inform their decisions. When people cannot access coherent and comprehensible documentation on subjects concerning their well-being, valid informed consent is not possible.

So how can one be expected to make an informed decision regarding their own body when they are not receiving all the essential facts? Although scientific articles generally provide abstracts for free, they are still often composed using scientific language. As an alternative, a one-page summary of the article in common language and with helpful visual aids should be provided. This summary should provide the main points of the paper in simple-to-understand language and in a format that makes it easy to apply the knowledge for other uses. Then, if the reader needs more information, they can decide if it's necessary, and worthwhile, for them to purchase access to the larger article.

Due to the multitude of barriers preventing the public from gathering information through their own means, or from health professionals, patients are being excluded from making decisions about their health. When opportunities for growth and inquisitive thinking are not provided or cultivated, informed consent will remain just an unattainable goal. The basis of informed consent includes access to all information, presented without external influence or pressures; however, with many false or biased sources readily available through the internet, there is no perfect situation in which true consent can occur. So, even though informed consent is not actually possible, there should still be simple, reliable, and easily accessible documentation and information so that everyone has an equal chance at attempting to make a truly informed decision.

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