*Campaigners in the recent Brexit debate "failed to communicate with the public, did not offer adequate or honest accounts of the alternatives, and did not provide the basic means for voters to judge the real options, the real opportunities or the real risks,” according to Onora O’Neill.*

*What sort of knowledge is required for an individual to give their informed consent? Explain the principles that apply, and how they bear on informed consent (i) to Brexit, (ii) to sex, or (iii) to a medical procedure. (You may choose one or two of these).*

Informed consent is a way of giving people protection and autonomy[[1]](#footnote-1). By providing someone with the appropriate information they need to give meaningful consent that person has an opportunity to act in his or her best interest, or at in accordance with their own preferences. In order to make this assessment a person must first know what is likely to happen if they do or do not make the, and secondly the sort of the risks involved in the choice. In order to be of any use information must be as truthful and accurate as possible as a decision based on misleading or untruthful information cannot be legitimate. However, in order to give meaningful consent a person does not necessarily need every piece of information available. A patient cannot reasonably expect to be put into a position where they can make an assessment of the risks as accurately as a professional clinician with years of specialist training and years of experience.

However, just because a patient may not be able to evaluate information in the same way as a professional does not make the process of imparting meaningful information any less valuable. This is because the person being advised may be performing a different form of assessment of the information; where the clinician’s assessment may be objective and cognitive, the patient’s assessment is likely to be more subjective and, more emotional. These two forms of judgment are not mutually exclusive but the type of information required to make the former assessment is not necessarily the same as the type required to make the latter assessment.

When giving consent, a person is agreeing to a certain action in the future which must, to some extent, involve uncertainty and speculation. In order to assess whether to consent, a person will need information that is as factually accurate as possible. Information should therefore be based, where possible, on independently verifiable statistics, facts and probability; ideally, data should therefore be based on outcomes from similar situations in the past.

Data will not always be available, however, on all aspects of a decision. Rumsfeld[[2]](#footnote-2) famously identified 3 types of knowledge, “*there are known knowns; there are things we know we know. We also know there are known unknowns; we know there are some things we do not know. But there are also unknown unknowns – the ones we don't know we don't know*”. In order to give informed consent, information on all three should be given and it should be provided in a truthful, comprehensible and balanced way.

However, a person is not bound to take into account the information they are given. A person is able to base a decision on almost anything, whether he or she considers a particular result to be morally acceptable, religiously acceptable or even the role of a dice. Because it is not possible for the person giving information to know exactly which factors will be taken into account, it is important that they do not merely provide information which they themselves would find useful. When asking a person to give consent to an option which has few “knowns” or is likely to have “unknown unknowns”, consent can only be meaningful if that person is informed about the extent to which we lack relevant knowledge. The absence of data on a particular outcome is itself a factor which must be explained. Situations where there are a lot of unknown unknowns arise frequently, such as, in medicine in experimental drug trials and in politics when unprecedented decisions must be made, like Brexit. In these situations, it is the absence of accurate, independently verifiable data, which is the most important information; the decision makers cannot give informed consent unless they are told about the limits of the information available. Even when the only accurate information is that nothing is known about the possible consequences of a decision, the decision can still be taken. A person can make a decision on a “no-matter-what-the-consequence-I-want-change” basis; however, this decision, whilst perfectly valid, cannot be said to have been properly informed.

A common way to help people evaluate and understand the risks of an event is to present them with statistics. When doctors are trying to explain risks to patients, they may resort to statistics. However, do statistics truly help most people to make cool, rational, and autonomous decisions or do such decisions remain based on uncertainty and emotions.

In simple cases statistics may provide valuable assistance. The statement: “you could die if you have this procedure” says very little about whether it is a good idea to have the procedure or not. However the statement that “there is a 0.001% chance you will die if you have this procedure, but a 100% chance that you will die without it” quickly gives the patient a clear idea of the risks involved in the decision. However statistics are very easy to manipulate and hard to compute. This puts considerable power into the hands of the person presenting the facts. If an operation is presented as working amazingly 80% of people it is likely to be perceived as more beneficial than if it is presented as causing horrible complications for 1 in 5 people. These two statistics can be simultaneously true, but one presents the positives and the other presents the negatives.

In more complex cases, however, statistics may provide little assistance. For example is a 0.0001% risk of heart failure better or worse than a 0.03% chance of kidney failure? In reality when confronted with such information, many people will turn to the doctor: “what would you do doctor in my position?”

Furthermore, when providing information to patients, to what extent should the doctor prioritise the patient’s right to information over the doctor’s primary job of caring for the patient, advising the patient, and relieving the patient of unnecessary worry. In the court case[[3]](#footnote-3) Montgomery v Lanarkshire Health Board, Mrs Montgomery was going to have a large baby and was worried about the risk of delivery. Her doctor explained the most important risks. During birth, complications because of the baby’s size resulted in the baby being born with permanent disability, the risks of which had not been explained. There had been a 0.2% risk of this event occurring and, if it did happen, the risk of it resulting in disability was only 0.1%. Therefore the probability of the child becoming disabled in the way it did was 0.0002% (0.2/100 x 0.1/100 x100). The Judge found that this risk should have been explained. However, the risk of an average person accidently drowning in a bath is 0.0001%[[4]](#footnote-4) . Does this mean that every patient who takes a bath in hospital must be advised of the risks of drowning? If not, why not? Clearly everyone needs knowledge to give their consent but how far can doctors reasonably be expected to go? The answer must depend on the circumstances.

When unprecedented decisions are being made there is likely to be limited knowledge of the relevant risks and limited statistical data to help make the decision. In the Brexit referendum the electorate could not give informed consent for two reasons: firstly, there was almost no “hard”, verifiable, data on the consequences of voting to leave the EU and secondly the vote was in the abstract with no defined terms of exit. Many opinions were put forward as to whether the country would be more or less stable and/or have a stronger or weaker economy outside the EU, but there was limited verifiable data. What, however, was inexcusable about the conduct of the politicians in the Brexit referendum debate, was the level of misinformation that was provided. The electorate were given statistics, information and promises that suggested politicians knew more than they could possibly know about the pros and cons of exit. Proof of this can be seen in Boris Johnson’s claim[[5]](#footnote-5) that Brexit would mean leaving the EU law-making system whilst still remaining in the free market with no tariffs. He also claimed that Brexit would mean immigration could be “controlled, thereby neutralising the extremists.” Other leave campaigners insisted the £350 million given to the EU every week could be given to the NHS instead; besides the fact that this number is a gross overestimation[[6]](#footnote-6) of the amount the UK gives to the EU, these false claims mislead the public and exploiting public feeling, like public support for the NHS. On top of the fact these claims misinformed the public, they also meant the “known unknowns” were concealed and there was inadequate recognition of the existence of unknown unknowns.

It is impossible to know whether the Brexit referendum would have been decided differently had politicians only been permitted to provide independently verifiable data and statistics as to risks and probable outcomes. However despite many people’s belief that they were providing informed consent to Brexit, in fact, they lacked the necessary information to exercise any meaningful judgment on the key risks.

Here politics has a lot to learn from medicine. Informed consent in medicine only became a matter of law after the Nuremberg trials[[7]](#footnote-7). Following the horrific actions of physicians in Nazi Germany the Nuremberg codes attempted to empower patients to control their own treatment, ending the idea that a patient should unquestioningly trust their doctor. For medicine, laws[[8]](#footnote-8) introduced since the Nuremberg codes now seek to ensure that patients are informed before giving consent. However these laws do not apply to politics in the same way. There is no law that demands politicians tell the truth or prevents them from manipulating public emotions. If politicians were held to the same laws on informed consent as doctors, and if they were forced to give voters information on risks and uncertainties and show that their facts were independently verifiable, then people might be provided with the information they need to give something approaching informed consent in relation to political decisions. This might also help restore some of the confidence in politicians which has been lost.

As the system currently stands, it is only after giving consent that people find out whether they placed their trust in the right place. Due to the fact that there is no way to hold politicians to account there is no real incentive to ensure the public is given the truth. An election every five years is a very blunt tool to hold the body politic to account, and whilst individual politicians may be changed the body of politics cannot be changed so.

In conclusion, before they can give informed consent, people need information which is truthful, easy to understand and balanced. It must also inform people of the risks and benefits so they can weigh up the pros and cons and it must include the “unknowns” as well as the detail of the “knowns” Finally the information provided must not only take into account their own approach to making the decision but also the fact that the person making the decisions may be basing the decision on more than just hard data. The information provider should, therefore, provide people with the type of information that might be relevant to a moral, religious or political objection.

(1979 words)

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