# Citizen Science:

Public participation in scientific research is being encouraged and normalized in increasing numbers. The phrase "citizen science" has come to refer to a broad range of initiatives that include the general people in science. Citizen science is a global phenomenon, as millions of volunteers are collecting, analyzing, and sharing data that contribute to scientific knowledge. Recognizing its potential, the U.S. 2013 Open Government National Action Plan encouraged Federal agencies to harness American ingenuity toward helping address a broad range of scientific and societal challenges, specifically invoking crowdsourcing and citizen science. The October 2015 Plan reinforced this charge, calling on agencies to increase public participation through both means. Thus, citizen science opportunities are actively being sought across a wide range of Federal programs. Citizens can become involved with scientific research in three distinct ways; consultation, collaboration, and control[1]. Initially, consultation entails asking for the opinions of the public through surveys, for example, and could be a valid step toward their full participation, albeit it does not guarantee that the public's worries and suggestions would be considered. Second, cooperation involves the redistribution of power between people and academics through discussion and dialogue; as a result, it entails reaching an agreement on a full partnership and sharing planning and decision-making duties. In a study, control refers to the citizens having the majority of seats at the table or total management authority. In citizen science, members of the public are considered citizen co-researchers who bring different and complementary forms of knowledge, expertise, and skills. Thus, using the lens of epistemic (in)justice, new ethical issues emerge related to collaboration, co-ownership, and democratic decision-making.[1] The important ethical challenges in citizen research, such as those involving data quality and integrity, data sharing consent and intellectual property, conflict of interest, and exploitation, are supplemented by these new ethical issues. And the key ethical aspect regarding this that is being focused on is the case of consent and its static nature here.

# Consent:

Citizen science and its approach to consent leave us with a large space for improvement as it violates various Conditions for consent under the General Data Protection Regulation(GDPR) 2018. These violations come in the of, multiple data sharing, reusing data, and mainly ‘purpose limitation’[2]. Purpose limitation can be explained as collecting data with the consent of the people for one specific research and utilizing the same data for other studies without intimating the participants about this shift. This is recognized as static consent where the participants are oblivious to the usage of the data that they provided for a different use case. This raises severe ethical concerns as the matter of consent to data cannot be taken lightly with the rise in cases of misuse of data to obtain biased and misleading results through targeted studies. This is where dynamic consent comes to play. Dynamic consent and its multilevel consent make sure that the participants stay informed at all times when it comes to the usage and results obtained for the data that they have provided.

# Working of Dynamic consent:

A Dynamic Consent platform can be set up to provide most of the information about a research project online in a user-friendly and standardized way across research sites. This will act as an active interface between the research scientists and the participants.  For instance, researchers may use the platform to give participants regular updates about the research or ask participants to upload new health data throughout the duration of the research project. Research participants may use the platform to set up their preferences regarding access to their health data by third parties or how often they would like to be contacted by the researchers.

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Figure . Dynamic Consent’s contribution to phases of research. From Dynamic Consent: a potential solution to some of the, 25 January 2017, <https://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-016-0162-9/figures/1>

Dynamic Consent enables researchers to provide participants with regular updates about early findings, follow-up studies, key outcomes, presentations, and publications, or invite them to information meetings or follow-up consultations. Application of the such a model will lead to greater development when it comes to the field of biomedical research with genetic data. Another major plus point that dynamic consent hails is participant retention which is an antagonist to purpose limitations discussed earlier A recent survey conducted among participants in the CHRIS study shows that ongoing communication motivates research participants to continue with the research.

# Ethical considerations:

* **Transparency** in any business model ensures Data privacy while maintaining to and fro communication between researchers and participants from time to time. This gives better research and a better research experience for both parties.
* **Digital interface** establishes better communication and prevents any, out-of-consent activities that might occur. This interface can be through text messages, websites, or web applications, and hence easy to access the terms at any instant.
* **Data encryption** embraces new homomorphic encryption techniques, which allow information to be processed in its encrypted state while permitting the processing results to remain encrypted, also called ‘wrapped information’, which ensures Data security.
* **Data ownership** can be held with the participants who can have the choice to opt in or out at any point in time, hence giving a dynamic choice to every individual.
* **Legal standards** of Data ethics would be in perfect compliance with Dynamic consent while maintaining the highest standards in data privacy protection and risk assessment, going further than the current standard required by many international legal requirements and privacy impact assessments[1].

# Special features of Dynamic consent

* Research requirements can be effectively communicated with the participants and participants can also choose between various research activities. The dynamic consent interface allows general research results to be returned to participants according to their preferences[1].
* Data management infrastructure is quite flexible, which even allows from participants’ end to allow access less or more data or even destroy complete data in case of withdrawals.
* Streamlines recruitment as the interface is an interactive functionality that provides an easy mechanism for individuals to be identified, approached, and recruited for new studies, to participate in online surveys, or to canvas opinions on a range of concerns.
* Scientific literacy is improved across various communities as the information about the research is open to the participants.

# Challenges:

Same as any framework Dynamic consent also comes with some challenges. Implementing Dynamic consent requires a cultural change for both researchers and participants. It requires the development of new policies, terms, and styles of work. Various teams to monitor and deploy the technological platforms need to be deployed, which would take an investment of resources like time, effort, expertise, and money.

# Ethical evaluation:

* Dynamic consent complies with **Kantian ethics** as it would be a principle that applies to all people and involves the choice that every individual can have.
* The implementation of Dynamic consent does yield better results in terms of research and Data ethics and hence **Act Utilitarian ethics** are satisfied here.
* **Rule Utilitarian ethics** require the act to be in the best of intentions and rules that everyone can comply with, which are most accurately met by our framework.
* The transparency and communication between both parties at all times is the characteristic that makes Dynamic consent unique. As both parties are in agreement with the terms **Social contract theory** is satisfied here.
* **Virtue ethics** are also satisfied as transparency and trust imply utmost morals and wisdom.

# RUDY:

Rare UK Diseases Study (RUDY) is a five-year prospective cohort study on an internet-based platform that aims to improve research processes and address many of the challenges of carrying out rare musculoskeletal disease research[2], funded by a partnership between the NIHR Rare Diseases Translational Research Collaboration and the Oxford NIHR Musculoskeletal Biomedical Research Unit, University of Oxford. Its dynamic consent framework consists of online registration, initial verbal consent, and online capture of patient-reported outcome measures and events within a dynamic consent framework.

Diagram

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<https://ojrd.biomedcentral.com/articles/10.1186/s13023-016-0528-6/figures/1>

The implementation of Dynamic consent here prompted further sub-studies in which the participants were interested. RUDY was also on social media which increased its audience and prospective participants, hence aiding biomedical research. Six weekly Skype calls, ongoing access to a secure website, and discussions about the latest research were some actions taken by RUDY to engage participants. The strengths of RUDY include low burden for the clinical team, low research administration costs with high participant recruitment, and ease of data collection and access[2].

# Conclusion:

Data ethics has been a broad subject even before digital data has come into the world. New technologies have always brought us opportunities along with some challenges and there are cases where these technologies are used to do more harm than good. Dynamic consent is an example where technology has been used to preserve Data ethics. Having accurate consent prompts more research activity by maintaining ethical standards.

# References:

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