



EDNA

Property * Privacy * Access

EDNA Whitepaper

25 November 2018

greg.simpson@edna.life

The Problems

EDNA seeks to solve three primary problems related to human DNA.

1) Property: In ever-increasing numbers, people are handing over their personal DNA to corporations and businesses in exchange for trivial (and even made-up) bits of information about themselves. In most cases, the terms of service used as a default create a contract which turns over genetic property and monetization rights as a part of the bargain. These agreements are highly one-sided and result in massive profits for the organizations that acquire the rights to profit from the information. Were these organizations only able to re-sell the genetic data only once, they would operate at a significant loss. Instead, the current market sustains as many as 200 sales of the same persons' data to multiple research projects around the globe. The average fee for this data is \$350, making the financial downside to the consumer as much as an estimated \$70,000.

2) Privacy: While that "trade" is bad enough, worse is the wide broadcast of their genetic identity to hundreds of centralized repositories. The data is shipped and stored intact, and so is susceptible to hacker attack and/or governmental demands. Forensic science, (which matches DNA samples) need not even have a persons' data to find them. A recent study showed that half of Americans of European descent could be traced to second or third cousins from anonymous DNA samples using open access databases. While most would not object strongly to using genetic data to solve violent crimes, it does illustrate that the data is clearly not secured. Current US law prohibits insurance companies and employers from discriminating based on genetics, however there is a massive profit motive to be able to do exactly that, laws can be changed, and lobbyists do exist.

3) Access: Access to genetic information is a two-pronged problem. One prong for the individual, and one for the science at large. The first prong deals with the information available in DNA that is allowed by (chiefly US) regulators to be given to an individual in direct to consumer reporting. This information comes largely in two flavors: solid science and “bunk”.

Solid (published, reviewed and most importantly replicated) science demonstrates that we have working knowledge of 1.5% of the human DNA and its primary effects on the body. Inside this 1.5% roughly 49,000 genetic variants are known pathogenic variations, meaning they cause or can cause disease. Of these 49,000 potential problems, the US FDA allows DTC reporting on exactly 10 of them. Realize this is not regulation of a pill, a shot or some other treatment; it is regulation of Information. EDNA maintains this is a massive over-reach of the agency's purpose unless one could believe the argument that suppression of potentially life-saving information is less harmful than preventing a person from knowing about it. Corporations and governments are not subject to the same restrictions.

The second prong relating to access for the science at large (though billions are to be directly and personally effected) is economic. People that are Americans and of European descent are the people most likely to experience “personalized medicine” in the near future. Personalized Medicine in this context means medical treatments which are designed to account for a persons unique genetic makeup. This is a very powerful new direction in medicine. Tens of thousands die each year from adverse drug reactions, side effects and treatments they should not have received, and would not of received if their genetic data had been available and been studied. Other humans (not of that class and lineage) are so far underrepresented in genetic science and understanding as to be near-nonexistent in the research. Inhabitants of third-world countries lack the disposable income to bother learning what percentage neanderthal they are, and so will be even further left behind. EDNA would make valuable contribution to understanding genetic inefficiencies and lack of information in these group.

EDNA is the Solution to all the above... and more

The EDNA entity is currently being organized as a Decentralized Autonomous Community (DAC) wherein members will hold ownership of the organization and elect custodians to manage day to day operations as required. 14 pro tem appointed custodians are currently serving to help direct ongoing development. These functions as well, will ultimately be managed by the edna-dac smart contract. (of which an early version and design is currently posted on our GitHub).

This contract empowers the EDNA user with the ability to monetize their own DNA by offering access to their genetic data on a purely individual opt-in basis to research proposals submitted to the contract by organizations/ researchers seeking access. Research proposals will be vetted by the DAC as to funding sources, purposes of research, negotiated result profit-sharing and other criteria as appropriate. Researchers in most cases will be required to post a bond to the contract warranting security and ultimate destruction of the data offered, as well as agreement to abide by both the EOS and EDNA constitutions. Full disclosure of the vetting results will be made to EDNA Community Members before they may elect to opt-in. The DAC contract as written is highly configurable regarding disbursements of earned funds between members, investors and others providing services to the DAC, and is expected to be worked out and refined over time by the likewise built-in custodial and referendum processes.

EDNA also is seeking to fund expansion of the existing prototype sequencing lab developed by the organizations founder and grow it as a non-profit entity capable of serving the EDNA community. EDNA (the DAC) will operate as a for-profit organization, and will as it is able to acquire the proprietary software developed by the founder used to protect the privacy of the

DNA owner while still leaving the data “in the clear” rendering the data highly available for multiple value-added software programs to be written in the future, while at the same time protecting the DNA owners property and privacy rights up to and beyond even attempted forensic matching or reverse engineering of the genomes stored. The odds of reconstructing a single individuals DNA from the data In the clear are 3 million to the 4800th power to one. No proof is possible that that data was correctly reconstructed unless all 4,800 genomes in a “load group” were already sequenced and known to whoever was attempting the reconstruction. A forensic match is theoretical under the same but slightly less difficult math; the unauthorized access attempt would need to exactly reassemble 200 to the 4800th power pieces, but again, no proof is possible without all 4,800 individuals sequenced, known and identified as the proper targets. Even a forensic match would only reveal that the person existed in the system, and nothing more. The system offers an extremely high likelihood of being an unsolvable problem without the users private key used to access their personal index required for DNA reassembly.

So far, the EDNA approach to property, monetization and privacy solutions have been outlined. Access (the third issue) please recall, is a two-pronged problem.

The first; personal access to an individuals information and relevant available knowledge will not be directly addressed nor solved by EDNA since the current structure of EDNA is subject to US regulations, and we are wholly uninterested in violating existing laws. However, One only need a cursory look at the open source code design of EDNA to realize the DNA data can be reconstructed by the holder of the private key. This could occur in any wallet, website or software tool capable of accepting that key, designed and built by anyone and hosted anywhere or everywhere. That coupled with the fact that the known science of the currently identified 49,000 pathogenic genetic variants mentioned above are publicly available and replicated in multiple databases shows that the access problem is solvable by anyone with a mind to solve it. We believe a solution is only a matter of time.

The second prong of the access problem, as stated, is one of economics. We believe this is best solved by the application of a free market. In addition to the features outlined above, the EDNA DAC contract is being coded to house an EDNA “DNA exchange”. Investors may submit funds to the exchange seeking to subsidize individuals seeking to get their DNA sequenced and monetized in the EDNA contract. Investors and the market will decide rates of return, and investors will be offered participation in investment pools spreading their risk over multiple “bid takers”. The contract will manage the return of funding to the investors plus profits as the owners monetizes the data. There is a massive shortage of research-ready DNA belonging to financially disadvantaged groups available in the market making health conditions like addiction challenging to effectively study, not to mention some diseases that are known only to effect certain genetic traits found most frequently in restricted human populations.

The access problem goes beyond the two explanation given above, and sadly carries with it a further blow to humanity. Currently a complete human genome costs the organizations producing them between around \$700 and \$900 US depending on which technologies are used. A great number of more specific tests have been developed that cost much less to run, but they do not read the entire 3-billion base pair of molecules as in a complete or “full” genome and are of limited resale value to research.

Current marketing efforts have allowed companies doing complete genome work to offer substantially less expensive (below cost) tests knowing most consumers will not read the terms of service and end up opting-in, thereby allowing those companies to make many hundred times over the investment they used to subsidize their own consumers by reselling the consumers' data. The EDNA model allows investors to provide those subsidies, earn substantial returns and still leave the monetization potential largely intact for the end consumer. Further this model allows EDNA to offer competitive pricing in the market.

It is difficult to imagine EDNA struggling much with marketing once our customers get on chain and begin cashing in proceeds from their personal data. There is a substantial volume of data circulating in social media concerning we humans and our genetics. The topic is current, comparative (could be called “trendy”) and certainly is a topic of conversation when people gather. Who we are and what our genes say about us generates a lot of human curiosity and interest.

It’s easy to imagine the outcome when a group of party-goers are comparing genetic report results, discussing who is how much neanderthal and what percentage Italian heritage, or mentioning they had a wine personally selected for them based on “scientific analysis” of their genetic code or are totally thrilled with their new puppy whose breed was highly indicated as a perfect match for their personal genetics. Talking on and on about how their new face-cream was hand crafted in a laboratory specifically for them based on their DNA alone.

It’s easy to imagine the EDNA consumer causing the abrupt end to the conversation with one sentence. “Well, my DNA test didn’t tell me any of that, and I didn’t get any wonder-creams, but my test did pay me tens of thousands of dollars for helping advance genetic science.” “Maybe I even helped saved lives, and I did learn I have the potential to develop a unique genetic heart problem so I’ve stopped running marathons for now and consulted my doctor.”

Incidentally (or not) all the above example tests are on the market today along with hundreds of others of a similar nature, the market in “specialty DNA tests” is exploding. Even though the FDA chooses to regulate free access to the health information that really could (and should) make a difference to us. Companies that sell complete and utter scientific nonsense are allowed to do so under the simple disclaimer of entertainment.

Scientifically Proven!!
(for entertainment purposes only)

This is the wide-open gate there to let in the muddy-boots of ethically-marginal commerce free to stomp all over scientific truth while burying the average Joe in a mountain of “fun for you” entertainment, and piled there to distract from the important even the vital while corporations and governments quietly gobble up what matters.

We crypto-fans are not exempt. One look at the top uses of even the most brilliant of blockchains shows the popularity of entertainment, notably games and gambling in our micro-crypto-society. EDNA has been and continues to be a project hard-pressed to even place a scratch on the face of the entertaining and life-distracting giants.

We do know this with certainly though... Wealth is every bit as powerful as an attention grabbing tool as is quick entertainment. When EDNA consumers and investors begin to talk about their returns and benefits, the perception that EDNA is “some DNA thing, but that’s already mainstream” will change and the heads will turn.

Bonus Solution

Just recently we have realized EDNA is sitting smack-dab in the center of a potential identity solution for lost and compromised EOS accounts. The answer is quite simple but requires three conditions:

1) The EDNA DAC member/customer will need to use their EOS Main-net account to generate their EDNA keys used to secure their DNA, thereby linking the EOS account with their genetic data.

2) The member/customer will need to submit to the lab a saliva sample for processing and storage in the EDNA system, this serves as the identity they wish to store.

3) The EDNA private key used to secure the DNA data can not be lost (as it only known to the DNA owner), though if it were compromised, that would not preclude EDNA from genetically verifying a claim to the account that created the EDNA original account.

To recover their compromised account or lost EOS private key. Users would submit a second saliva sample and the private key to the original EDNA account. This would allow EDNA to extract from the system the original DNA used to create the EDNA account created by the EOS Account in question. A match could be verified to the new saliva sample and proper ownership (at least of the sample) verified.

One important note to mention this type of matching is significantly less expensive than the full genome sequencing discussed in all other aspects of EDNA. This type “identity or forensic” matching only requires the processing of about 200 base-pairs of molecules in known locations as opposed to full genomes made up of 3-billion pairs. The validity of the match is one in billions and currently sufficient proof of identity in many countries to send humans to death-row.

EDNA could easily offer such a service at very low cost for those seeking only forensic identity storage & retrieval.

EDNA Need for the Blockchain

We wish to be clear, blockchain is not a requirement for either extracting or storing or retrieving DNA.

IPFS storage, data fragmentation, (privacy coin-like) tumbling and cryptography-based keys for reconstruction of more than cover the EDNA use case for the DNA data itself, and none of these require a blockchain.

EDNA requires use of the blockchain as a source of truth for contractual agreements and monetary accountability plus DAC operation, management and voting transparency and nothing more. Just as any business that wishes to operate in the proposed transparent and decentralized world of tomorrow, EDNA embraces these tools as a better way to organize human endeavors. Blockchain and along with our model offer the potential to scale on a global stage and does not act as a central authority but gives people control of their DNA.

EDNA Need for a Token

EDNA could have adopted the EOS Main-net token as a mechanism to track financial activities within EDNA. However, if the need to distribute DAC profits is ultimately decided by membership to be allocated via token holdings, the EOS-Based token would have presented obstacles to fair allocation of those profits, specifically as it regards founders, early contributors and any venture capital funding used to jump-start EDNA. Conversely, we believe having a token in place and airdropped with reserves has allowed EDNA some degree of

recognition within the EOS ecosystem and in the future will allow EDNA to equitably and easily manage its financial aspects and create incentives for its members

Team, Accomplishments & Road Map

EDNA is organized as a DAC, and as such many persons holding tokens or working for tokens have contributed and continue to contribute to the EDNA effort. These persons have not always been the same people; many come and go as their particular skills are needed for a particular phase of the project. Rather than list and detail these people and events here in this paper, we invite the reader to explore the Project Menu posted and regularly updated on the EDNA website (<https://edna.life>) here you will find the current core team members, history of what has been achieved and current future plans for the project as it evolves.

In Closing

Some readers seeking highly intricate technical diagrams and explanations may find this paper lacking in detail, others might object to a lack of complete financial statements, written DAC policy or other documentation. Others may feel it lack step-by-step layouts of certain project activities and intended actions. We acknowledge this paper is not a one size fits all rather it was written to as concisely as possible convey the intention, purpose and need for EDNA and where we see the future DAC, while also addressing a few of questions people looking at this project would likely to be asking. For the rest of the story we invite you to add our FAQ's to your reading list, and/or to bring your questions directly to us. Our telegram group (https://t.me/edna_life) is usually quite active, and should you join us there, you can expect prompt direct answers to your questions.

Lastly, We thank you for supporting EDNA!