

Summary:

In the United States, big pharma and hospitals prey on unsuspecting patients by taking advantage of their health data. Pharma acquires health data from hospitals & 3rd parties to create valuable drugs and diagnostic tools. These data acquisitions and products are worth billions, but patients don't see a penny. When properly utilized, health data can significantly shorten drug development timelines, improve patient quality of care, and increase positive health outcomes. However, progress should not be made at the expense of patients.

We propose Health X Change, a novel platform that incentivizes patients to share their health data by providing our token as compensation, X-token (*Note: placeholder name – official token to be named in the future*). Health X Change plans to collect a unique set of health data that pharma will preferentially purchase due to its scale and ability to centralize distinct data sources. Health X Change achieves this through 3 main components: a patient-facing platform, an ERC-20 token, and a pharma-facing platform.

The first component is a consumer-facing platform, that allows patients to seamlessly request and share their health records. Records may include EHR, genomics data, fitness data, or any other health data that consumers are willing to share. These records would be anonymized to protect patient privacy. To incentivize patients to stake their data, Health X Change will introduce a second component, an ERC20 token – X-token. This token will be regularly rewarded to patients who share their data with Health X Change. The token will have a fixed supply – and will have special utility associated with ownership. The third component will be a pharma-facing R&D platform, which only verified parties will have access to. Health systems, pharma, and government entities interested in utilizing R&D and population health services would contract with Health X Change and form partnerships to create revenue streams.

By signing up, patients will gain access to a central source for all of their health data. Health X Change will set aside 5% of net profits on an annual basis and deposit these proceeds into a token fund that will back the value of X-token. X-token will also have additional utility including, but not limited to:

1. Purchasing genetic testing services
2. Stake for more X-token rewards
3. Vote on the asset allocation of the token fund
4. Vote on the governance of a community run research fund

As more partners utilize data sets and more people share their data on the platform, the price of X-token will increase. This increase in price is expected to incentivize the average, crypto naïve citizen to share data with Health X Change. This, in turn, increases the value of the network – effectively establishing a positive feedback loop. As the network scales, Health X Change aims to further its mission of bringing novel therapeutics and advancing healthcare while compensating patients for their contributions.

1. Mission

Our mission is to compensate users while enabling next generation precision medicine. We accomplish this by creating a platform that enables healthcare providers to effectively treat and diagnose patients.

1. Users – ability to extract value from their health data in the form of Health X Change tokens with strong guarantees around security and personal privacy
 - Financial rewards – token payments for minimal user effort , ability to pass assets to loved ones
 - Health Record Viewing – view your data at any time and share with your provider
 - Clinical trial matching – get matched with trials you are eligible for
 - Pharma offers – get coupons and copay cards that can reduce your drug bills

2. Pharmaceutical Companies – ability to analyze health data for a variety of use cases, including:
 - Clinical trial recruitment – recruit diverse sets of patients to trials
 - Streamline Algorithm Development and Deployment – create algorithms to predict diseases and deploy algorithms on platform
 - Perform Real World Evidence Studies – analyze care patterns and outcomes after drug prescription to make stronger, more statistically significant claims / promotional materials
 - Optimize R&D Efforts – analyze clinicogenomic data to optimize the drug discovery process

3. Healthcare Providers – ability to access novel diagnostic algorithms for patients
 - Optimize care pathways – identify patients at risk of developing diseases and intervene with more precise medicine

While multiple parties benefit from the creation of the platform - including Health X Change – our aim is to ensure benefits accrue to the patient. These benefits not only compensate for patient data, but lead to better, quicker diagnoses, more effective drugs, and increased quality of care for the average patient in the United States.

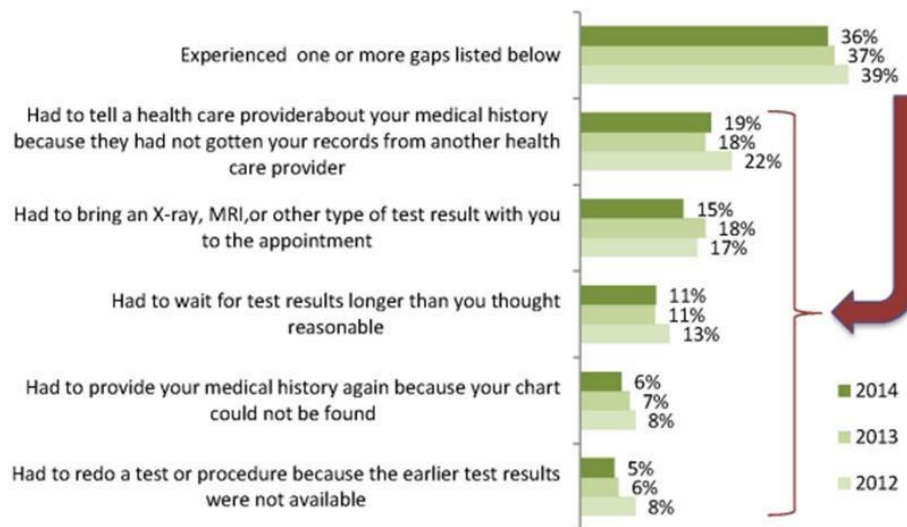
2. Background

2.1 – Evolution of Electronic Health Information in the U.S.

Though much progress has been made, health data remains underutilized in the United States. Prior to 2008, healthcare data in the United States was primarily recorded on paper forms, and in many parts of the world, still is. As part of the American Recovery and Reinvestment act of 2009, the HITECH Act was signed into law “to promote the adoption and meaningful use of health information technology while addressing privacy and security associated with electronic transmissions of health records”¹. This act required the adoption of electronic health records (EHRs). Non-compliant hospitals would face fines and penalties if not using approved EHR systems. This bill also legislatively codified the Office of the National Coordinator for Health Information Technology (ONC), which is a federal entity charged with coordinating nationwide Health IT efforts. The HITECH Act drove EHR adoption from ~10% in 2008 to >96% by 2018.² By 2014, though hospitals were rapidly adopting EHRs, many did not allow for patients to easily access their health records. These information blocks caused inefficiencies, and in some cases, major issues when patients transition their care from one provider or hospital to another.³

Among individuals who visited a health care provider within the past year, over one-third experienced at least one gap in information exchange in 2014.

Figure 9: Among individuals who visited a health care provider within the last year, proportion of individuals who experienced one or more gaps in health information among their providers or between themselves and their providers when seeking care for a medical problem, 2012-2014.



NOTE: No significant differences between estimates in 2013 and 2014.
SOURCE: 2012-2014 Consumer Survey of Attitudes Toward the Privacy and Security Aspects of Electronic Health Records and Health Information Exchange

Figure 1: 2012-2014 consumer survey research accessed from the healthIT.gov website³

In December 2016, with the intent to “accelerate medical product development and bring new innovations and advances to patients who need them faster and more efficiently,” the 21st Century Cures Act (Cures Act) was signed into law.⁴ This large bill had different areas of focus, including reducing regulatory processes for novel drugs, and enabling real world evidence (RWE)

studies. However, Title IV of the Cures Act was specifically designed to advance interoperability, increase EHR accessibility, and reduce occurrences of information blocking by healthcare providers and insurers.⁵ In essence, this was to enable patients to more easily access their own health data.

“The core goal of the health IT portion of the Cures Act is to provide patients with control of their health care and their medical record through smartphones and modern software apps. While considerations of privacy are very important, these choices should be made by the patient, not taken away by a doctor, hospital, or health IT developer under the narrative of “protecting patient privacy.”

- Office of the National Coordinator for Health Information Technology⁵

Many electronic health information API companies have been formed recently as a result of the Cures Act, such as SEQSTER, Pluto Health, REDOX, Particle Health, and 1UpHealth. These companies are laying the technical foundations for developers and patients to easily access health records and insurance related health data with patient consent. The ONC has also set a timeline to prohibit Health IT developers from restricting communications, standardize data formats, and mandate EHI export capabilities by 2023.⁶

The Office of the National Coordinator for Health Information Technology **New Applicability Dates included in ONC Interim Final Rule**

Information Blocking and the ONC Health IT Certification Program:
Extension of Compliance Dates and Timeframes in Response to the COVID-19 Public Health Emergency Interim Final Rule

Certification



EHI = Electronic Health Information USCDI = United States Core Data for Interoperability

Figure 2: From the ONC's guidance in response to the COVID-19 pandemic, accessed from healthIT.gov⁶

Health IT regulations have shaped the landscape and usability of health data over the last 15 years. As of 2023, the market is primed to meaningfully use health data. The next section of this whitepaper focuses on current and future utility of health data to pharmaceutical companies and healthcare providers.

2.2 – Value of Health Information

Longitudinal health data, which is health data tracked over time, is immensely valuable to pharmaceutical companies, healthcare providers, and even the US government. To understand the value of health data, we must first understand what is contained in an electronic health record (EHR), the most comprehensive store of patient health data.

*“An Electronic Health Record (EHR) is an electronic version of a patient’s medical history, that is maintained by the provider over time, and may include all of the key administrative clinical data relevant to that person’s care under a particular provider, including demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory data and radiology reports. The EHR automates access to information and has the potential to streamline the clinician's workflow. The EHR also has the ability to support other care-related activities directly or indirectly through various interfaces, including **evidence-based decision support, quality management, and outcomes reporting.**”*

*EHRs are the next step in the continued progress of healthcare that can strengthen the relationship between patients and clinicians. The data, and the timeliness and availability of it, will **enable providers to make better decisions and provide better care.**”*

- Center for Medicare and Medicaid Services (CMS.gov)⁷

The description above from CMS describes the current state, but the bolded sections refer to future utility of EHRs. Fundamentally, providers can use data on how a patient was treated to study patient outcomes based on different types of treatment. With robust health data, doctors and care providers can optimize their treatment decisions, and ultimately provide better care for patients.

By treating patients using data driven insights, hospitals can potentially profit in two different ways. In a value-based revenue arrangement, a hospital is incentivized to provide the most optimal care at the lowest price. Health data can be used to enable this optimization. In a fee for service arrangement, hospitals are compensated for their services rendered to patients, while maintaining high quality of care. In this case, hospitals are incentivized to identify eligible patients for procedures. Regardless of hospital revenue arrangements, hospitals are constantly looking to enable better quality of care to attract patient populations and improve their reputation and competitiveness in the provider market. Healthcare data enables providers to build tools that can identify patients and predict disease states and health events before they occur.

Providers, who could potentially use health data, do not normally aggregate data sets (usually they just use data that they have collected). However, pharmaceutical companies regularly purchase anonymized healthcare records for a variety of purposes. These use cases include:

1. Disease/Event Prediction Algorithm Development
2. Accelerated Drug Development
3. Real World Evidence (RWE) and Clinical Trial Recruitment

The first use case is currently being pursued by various pharma companies. Due to competition between pharma brands, brand teams see a need to move up the funnel and capture patients at the time of diagnosis. The easiest way to do this is to provide software to assist in making accurate diagnoses. These types of algorithms already have use cases today. However, in the future, when drugs are more targeted, diagnosis will be even more important as it will be the rate limiting step in drug prescription.

In this future state, algorithmic diagnosis of patients will be crucial to identifying patients for treatments, especially specialty targeted treatments. Two potential examples of earlier identification include targeted cancer therapies like Keytruda (PD-1 Inhibitor) and Tagrisso (EGFR Inhibitor). High levels of PDL-1 for Keytruda or mutations in the gene EGFR for Tagrisso may indicate appropriate usage for these specialized drugs. However, both therapies are not first line (i.e. they are considered after chemotherapy). As targeted therapies mature and better diagnostic indications are created, these types of solutions will eventually progress to first line treatments, assuming the patient is positive for certain biomarkers (biological measurements), risk factors etc. As a result, using algorithms to identify patients for drugs boosts appropriate use of therapies, which boosts topline growth for branded therapeutics. Pharma can also use clinicogenomic data sets to discover novel biomarkers for existing therapies.

The second use case is probably the most lucrative in the long term, though it is unclear the extent to which pharma companies have effectively utilized their data sets. A patient's health record captures health events (outcomes) as well as biomarkers (measurements of health). By investigating the correlation between specific outcomes and biomarkers, pharma companies can accelerate their drug development efforts by targeting biochemical pathways or genes that are more likely to affect a given disease. With advances in genomic editing (ie. CRISPR/Cas9), genomic data sets tied to real world health outcomes and disease states become even more valuable, as these data sets can be mined for CRISPR targets.

Chart 3: Drug Discovery and Development: A Long, Risky Road

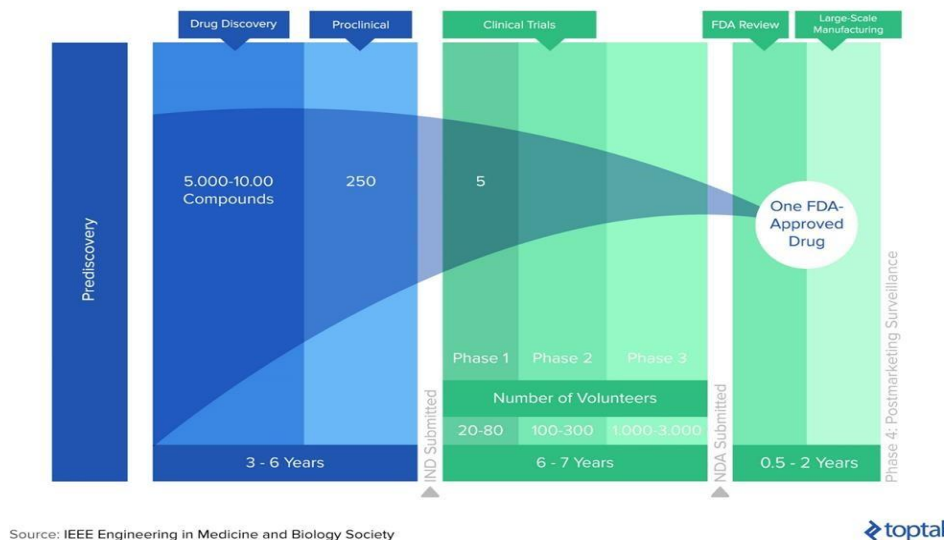


Figure 3: Drug discovery development timeline image accessed from a toptal insight article⁸ - originally created at IEEE Pules at EMBS⁹

This type of targeted drug development rapidly accelerates timelines to commercialize new therapies. Instead of filtering from a list of 10,000 compounds in early drug discovery, a pharma company can identify high priority targets and tailor their development by creating a hyper targeted approach. In traditional medicines, this means reducing the amount of initial compounds, but for the next generation of therapies (like CRISPR), this data will enable a new kind of drug development that centers around genetic signatures.

The final use case is around recruiting and conducting real world evidence (RWE) studies. These are studies that determine the effects of treatments in the real world by measuring actual outcomes of patients outside of a trial environment. Pharma companies can use this data to put together evidence packages to either expand their labels, or as promotional material to make a stronger clinical case for their treatments. This is an example of how data can be used after a drug is launched, but pharma can also use these datasets to identify patients eligible for clinical trials.

These are all traditional uses of healthcare data. However, in theory data from insurers (claims data) can also be used for unique commercial purposes. This is not done today at scale, but will likely be the future of direct-to-consumer (DTC) pharma advertising. For example, claims data could be used to anonymously serve offers and marketing communications to patients of interest. For example, a patient with a heart failure diagnosis could be messaged offers for clinical trials studying novel heart failure drugs. Similarly, a pharma company would see high value in advertising relevant heart failure drugs to patients with known heart failure.

The value that pharma sees in health data today has driven business activity in the health information space. The next section explores the business of health information, and how it currently takes advantage of a system that takes power away from patients, the true owners of data.

2.3– The Business of Health Information

Patients own their health data. However, in every instance where health data is being sold from one business to another, patients are not compensated. The most public example of this activity is seen in 23AndMe and GlaxoSmithKline’s partnership. This deal essentially was to leverage genetic and phenotypic data collected by 23AndMe to develop therapies. 23AndMe customers opted into this agreement, however these patients did not receive any compensation. On the contrary, all of these customers paid ~\$100 per genetic test. As part of this partnership, GSK invested \$300 million into 23AndMe and paid another \$50 million in cash to extend their R&D partnership until 2023.¹⁰ Patients consented to donating their data for research, but when 23andMe commercialized this data, patients were not rewarded.

23AndMe is the clearest public example, however numerous companies acquire and sell anonymized patient health data without paying patients. In most cases, patients are not even aware their data is being sold. Large hospital systems anonymize their patient data and try to sell it to pharma. Genetic testing companies like Caris and Tempus Labs all try to take advantage of the data they generate, with business models centered around the data they generate from patients. A good example of this type of activity by an established player is Roche’s acquisition of their (now) subsidiaries, Flatiron Health and Foundation Medicine. Flatiron Health was a specialty electronic health record company focusing on oncology. Foundation Medicine is a genetic testing company, best known for providing genomic tests for cancer patients. Using the data from the two acquired companies, Roche plans to build a database that links clinical and genomic data.

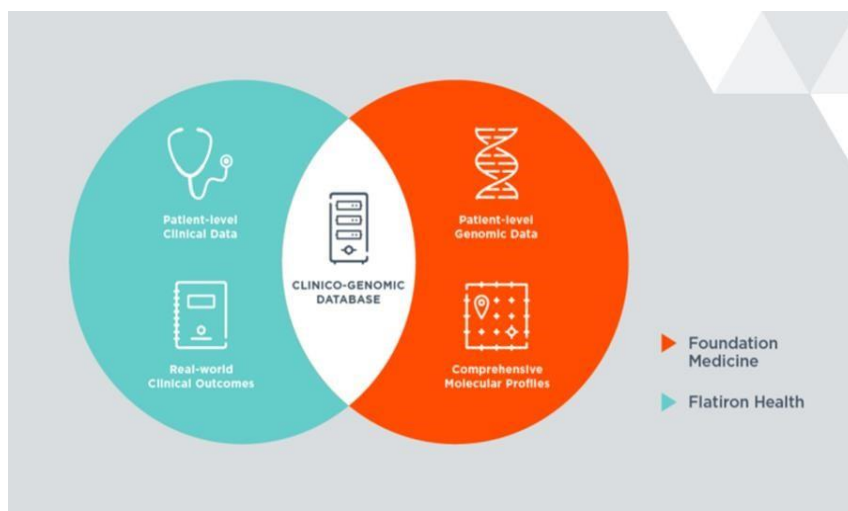


Figure 4: Graphic of Roche’s two subsidiaries creating a clinico-genomic database. Accessed from Roche Website¹¹

*“We believe that genomic information gleaned from comprehensive genomic profiling (CGP) can help inform treatment options for patients today, while also accelerating our understanding of tumor biology and real-world outcomes to optimize effective treatment options for the patients of tomorrow. **The next frontier of discovery and impact will be reached by integrating genomic data with clinical outcomes**, so we can understand which therapies work – or don’t work – for which patients, and how advanced biomarkers can help us predict that as early as possible.”*

-Gaurav Singal, Roche’s Chief Data Officer¹¹

There is clear value of health information, and numerous companies have mobilized to extract value from this data. However, there haven’t been good examples of this type of activity where the patient gets fairly compensated for usage of their own data. Fundamentally, this only occurs because patients are either unaware or unable to leverage a portion of the value created from their own data. In the next section of this whitepaper, we propose a novel system that uses token economics to fairly compensate patients for their data. On top of compensating patients, this system would build the most comprehensive clinico-genomic database in the world, effectively accelerating medical research to fundamentally shift the way care is provided.

3. Health X Change – A Novel Platform to Monetize Health Data

3.1 - Design

Health X Change aims to incentivize patients to share health data by designing a tokenomic system that is rewarding to all participants in the ecosystem - but most rewarding to users who share data. Just by signing up, users can view their data to share with providers free of charge. Health X Change will host the data allowing for quicker access to data, which helps both the user and future pharma partners. This decision was made since previous iterations of this idea (ie. Nebula Genomics, EncrypGen) focused more on decentralization and yielded a product that required more individual permissions for pharma to create a dataset. This system sacrifices true decentralization in order to build a better product for pharma. We believe that this will increase likelihood of high value deals, therefore increasing outcomes for our users.

This sort of centralization causes issues in other industries, where a company with enough power can make decisions that negatively affect their users (ie. tech companies collecting and selling data without compensating users). However, due to the nature of HIPAA and other information security laws pertaining to health data, a consumer can revoke data access at any time, and the penalty for a company retaining personal health data without a patients' express written consent can be up to \$50,000 per violation (also read as \$50,000 per record). This creates a situation where Health X Change users have leverage over Health X Change, even in the absence of any corporate governance measures.

Essentially, there is nothing stopping Health X Change users from revoking data access and leaving the platform. Users would only lose the value that Health X Change provides to them. In this scenario, the greatest loss would be to Health X Change, since the value of the platform is directly tied to the amount of data being shared at a given time. As such, the X-token tokenomics system is meant to reward data owners and incentivize long term data sharing with Health X Change. On top of the tokenomics system, Health X Change's business model relies on the cooperation of its users. Although centralization does give Health X Change a certain level of power, the community ultimately decides Health X Change's fate.

3.2 – X-Token Tokenomics

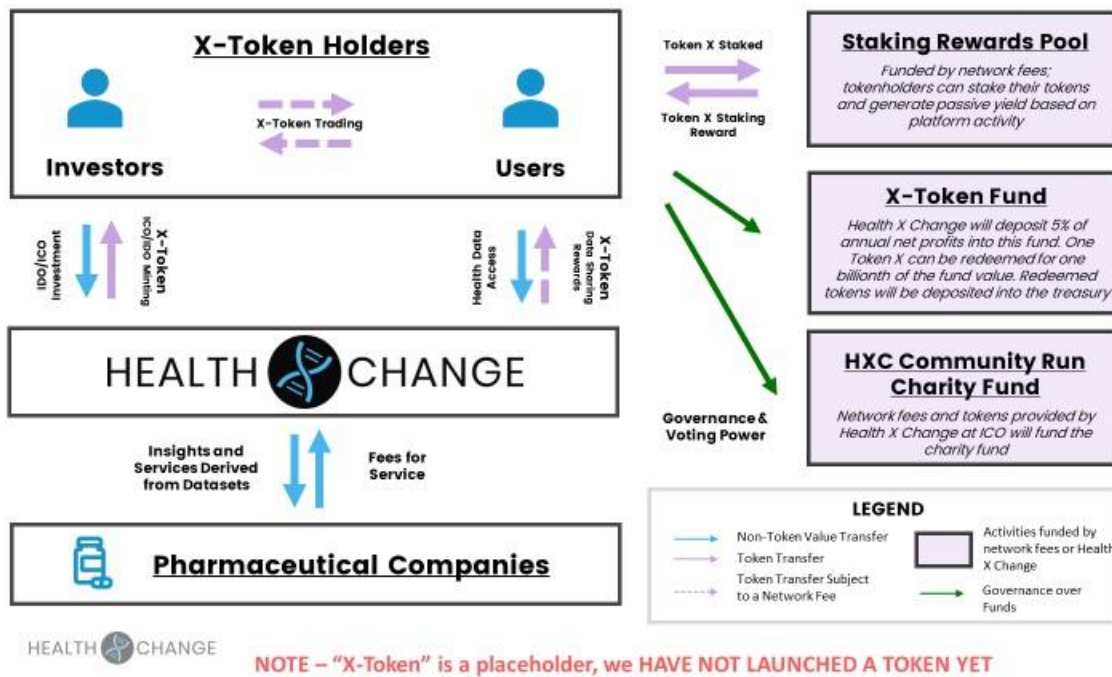


Figure 5: The different parties and transactions occurring according to the draft tokenomic designs described below.

By creating a tokenomics system that is rewarding to users, we hope that the community will avidly support and contribute to the growth of Health X Change. The success of Health X Change will grow and return more value to the community, effectively establishing a positive feedback cycle where value is created for all parties involved. To achieve this, Health X Change will create a token, X-token. This token will be an ERC-20 token with an initial supply of 250,000,000 tokens, and will have an upper limit of 1,000,000,000 tokens. However, the only way that new tokens are minted is when a patient shares data and is compensated with X-token. Health X Change will never print more tokens to raise funds (this amount is already accounted for in the initial supply). The total tokens a user can earn is based on the amount and number of unique data types shared (i.e. someone sharing their records and genome will earn more tokens than someone sharing just health records).

Health X Change will deposit 5% of net profits generated into a token fund. This fund will effectively back the X-token. Each X-token can be redeemed to the Health X Change ecosystem development fund (at any time) for one billionth of the fund’s cash amount. This effectively aligns users and Health X Change to grow revenues while providing value added services. Token holders will be able to participate in two key governance initiatives. The first is managing the charity fund, including management of assets and distribution of grants / charitable contributions. The second is the management of the token fund – which will allow the

community to decide asset allocation of the community fund (we plan to hold cash in an insured bank account until we hit enough scale to decentralize fund governance).

Health X Change will have an initial supply of 250,000,000 coins. The breakdown of the initial distribution is as follows:

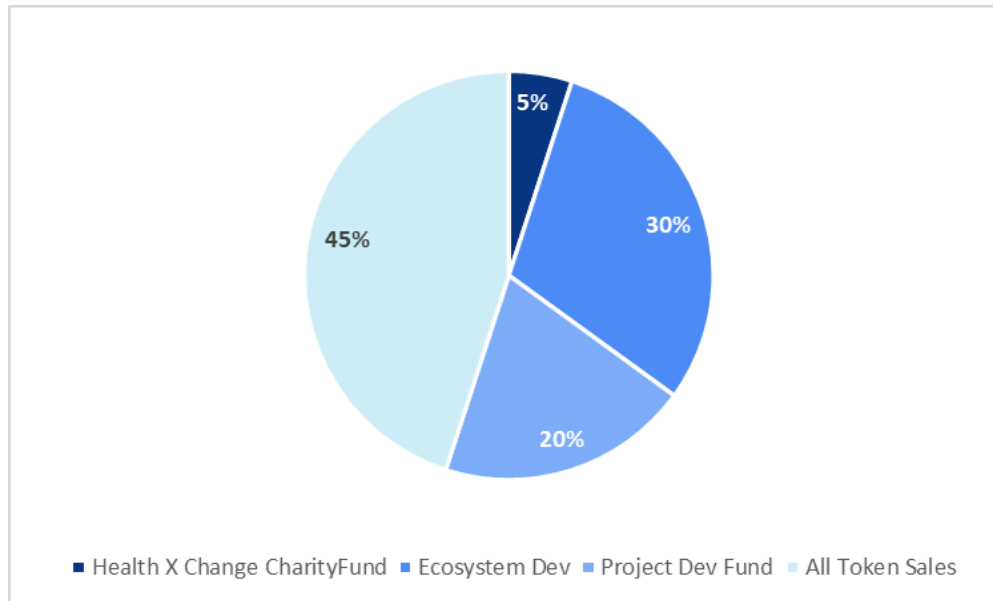


Figure 6: Current distribution percentages planned for the initial launch – responsible for 25% of the coin cap (250M out of 1B cap).

- The Health X Change charity fund is a X-token holder managed community fund. It is a fund where every few months, holders can propose and vote on health related charity ideas (5% of initial tokens, 12.5 M tokens).
- Ecosystem development refers to tokens given away to incentivize data sharing. They can be given to existing members, used to incentivize new signups, or given to ecosystem partners (30% of initial tokens, 75 M tokens). During launch, Health X Change plans to distribute 15M tokens to the first users who join the platform.
- The Project Development Fund refers to tokens set aside for early team members of Health X Change (20% of initial tokens, 50M tokens).
- The plurality of initial supply will be in a Health X Change treasury in order to finance operations of Health X Change (45% initial of tokens, 112.5 M tokens). During initial launch, Health X Change plans to sell 62.5 M tokens to finance operations, ~¼ of which will be used to fund the liquidity pool. Health X Change will retain the remaining 50M tokens to sell at a later date to raise funds as necessary, unsold tokens may be deposited into the ecosystem development fund.

After initial launch, X-tokens are minted and distributed to users who share health data. The amount of tokens depends on the types and quantity of data shared. All users will need to share their health record data before sharing any other data types, but users who have additional optional data types will receive more tokens per year. The payout scheme is listed below:

Required/Optional	Data Type	X-tokens per year on launch <i>(will decrease as more users join)</i>
Required	Total Health Records	5
Optional	Genotype (ie. 23 and Me)	20
Optional	DNA Exome	50
Optional	DNA WGS	100
Optional	DNA Tumor WGS	100
Optional	DNA Tumor Exome	100
Optional	Whole Microbiome	50
Optional	RNA Tumor Whole Transcriptome	15
Optional	Personal Fitness Data	5
Optional	Clinically Certified Device	15

Figure 7: Current X-token payout scheme for various health data types. May be adjusted in the future.

These tokens will be distributed to users who share health data every 2 months (however note that the numbers above are annualized numbers). We estimate that on average, users will earn ~30 tokens per year. At a user count of 1M users, this would add in 30M tokens into supply per year – around 12% increase in supply per year).

In order to incentivize holding, X-token will also have the option to be staked for 6 months. During this time, staked tokens will get a portion of X-token staking rewards. This rewards pool will be funded by a X-token transfer fee of 0.02% that will be charged upon wallet transfers of X-token. On top of this, 10% of these data payouts to individuals sharing data will be charged as a network fee, which will help fund staking rewards. The rewards pool will be distributed as follows:

Description of Activities	% of Staking Rewards Pool Allocated
Rewards distributed to X-token Stakers	80%
Ecosystem Development Fund	10%
Health X Change Charity Fund	10%

Figure 8: Usage of staking rewards pool, funded by transfer and data sharing fees.

For example, if the X-token has a trading volume of 1.5B tokens per year and has 1M active users earning an average of 30 tokens per year, the staking rewards pool for that year would be 3,300,000 tokens. This rewards pool would be utilized according to the table above. People locking their X-tokens up to stake would receive 80% of the staking pool during the period.

Health X Change cannot accomplish its mission without users taking an active role in volunteering their data. To incentivize this behavior Health X Change will provide its users with

the ability to purchase genetic tests using X-token. This would allow the patient to be proactive in taking charge of and planning for their long term health rather than be reactive to future problems. At the same time, this new genetic data would help Health X Change grow, reward its users, and accomplish its mission. This creates a positive feedback loop where all parties benefit.

Once 400M tokens are minted – the token generation rates for data generators will be halved. Halvings will occur every 100M tokens from 400M to 700M tokens, and every 25M tokens from 700M to 950M tokens. At this point, halving will occur at every 1M mark. This will effectively limit the total circulating token amount to less than 1B tokens. In order to incentivize future behavior and expand to other geographies, Health X Change may create another novel token after 800M X-tokens are minted – and commit additional portions of revenue to this new token.

4. Conclusion

We hope Health X Change will push healthcare forward and compensate users who contributed to this advancement. The CURES act and FHIR standards have made health records and claims data more interoperable, creating an environment where health data can easily be shared. Innovators in the blockchain space have used these foundations to build similar platforms. We differentiate ourselves through our platform that empowers and fairly compensates users while also servicing the needs of pharma.

Our tokenomics is ultimately designed to reward early adopters, increase the price of the token over time, and provide utility and compensation to the user. As the market value of X-token appreciates, more users will join the platform - allowing Health X Change to grow, accomplish its mission, and further give back to the foundation of users it's built on.

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