Introduction

1. Chronic/rare and intractable diseases

Although all human beings are susceptible to diseases, we continuously repeat the process of recovering our health through medical treatments. However, some patients suffer from diseases whose etiologies are uncertain, exact diagnoses are difficult, and as a result, complete recovery is not possible. These diseases include chronic diseases contracted by a large number of patients but with no complete cure and the need for lifelong management, such as diabetes mellitus, hypertension, cardiovascular diseases and cancer, in addition to rare and incurable diseases contracted by a small number of patients with a relatively small volume of epidemics data.

Chronic diseases are becoming a global challenge due to rapidly-progressing population aging, decline in physical activity and lifestyle changes such as increased intake of fat and beverages [1]. According to the World Health Organization (WHO), chronic diseases are the leading causes of deaths worldwide. As of 2015, 40 million out of 56 million deaths were caused by chronic diseases, and in addition, 1.7 million patients were predicted to die before the age of 70. Moreover, more than one third of the world’s population simultaneously suffer from multiple chronic conditions, which constitutes significant threats to patients’ health and imposes enormous costs on society. Specifically, medical costs in patients with multiple chronic diseases have been shown to increase by around 80 percent up to 300 percent, depending on age, gender and health conditions. Meanwhile, “rare and incurable diseases” are defined differently in each country, but generally refer to diseases for which the exact number of patients are unknown because of their small number of patients and difficulty of diagnosis [2]. As of 2016, the number of rare diseases registered on Orphanet, a portal for rare diseases, amounted to 6,084 and the worldwide population with rare diseases is estimated at 350 million. In Korea, the total number of rare diseases is estimated at around 2,000 and the affected population is calculated at 600,000 [3].

It is characteristic of rare and intractable diseases that their symptoms are controllable by medication, lifestyle changes, operations, etc. but it is not possible to eradicate or treat the underlying causes. Although early diagnosis may allow the early completion of treatment, these diseases cause suffering to patients and their families due to the inadequacy of knowledge on the diseases, insufficient research development and support, and the consequent lack of awareness toward the need for self-care.
2. Patient-Generated Health Data, a clue to solution

Patient-Generated Health Data (hereinafter PGHD) refers to health-related data recorded and generated by patients outside hospitals [4]. Due to the widespread penetration of smartphones and the growing familiarity of patients with smart devices, the collection of diverse PGHD has become easier through the utilization of online survey, mobile apps and wearable devices.

PGHD is a component of health data alongside genetic and clinical data, and occupies substantial amount of health data which makes its importance and applicability more significant[5, Figure 1]. Since the majority of a patient’s activities occur outside hospitals, information recorded at a clinical office is inevitably limited. Therefore, a growing importance is being placed on PGHD, as information directly collected from patients and directly produced by patients throughout their struggle against diseases. While PGHD has previously been regarded with less clinical value and interest compared to other types of information, it fills an information niche by complementing aspects that cannot be explained by existing medical data, and allows a more comprehensive understanding of patients’ health. An Accenture survey found that the number of consumers who participated in the collection of PGHD using mobile healthcare applications rose to 33 percent in 2016, up from 16 percent in 2014 [6], which shows that the volume of PGHD collected will increase exponentially in the future. Therefore,
PGHD, which includes information on patients’ health and diseases, can provide a clue to the solution for diseases that are currently incurable.

2.1. Patients

As PGHD becomes more accessible with technology advancements, patients have become able to capture their health-related data independently and thoroughly. As a result, patients are more actively engaged in overcoming their diseases and are more interested in their own health. In addition, patients are able to participate in the collection of data; to observe how their health status has changed with time; to independently identify behaviors that influence health; and to satisfy their intellectual desire to be informed about diseases and the human body by sharing information with other patients. These processes allow patients to be more deeply engaged in treatments or research on their diseases and reinforce their desire to undergo treatment. For instance, according to a survey conducted on heart disease patients in the Connected Cardiac Care Program at Partners HealthCare, 98 percent of the respondents reportedly became more aware of their diseases through PGHD, and 85 percent of them came to be able to better control their diseases [7]. A pilot project conducted by the Care Beyond Walls & Wires revealed that PGHD had an effect on reducing the readmission rate by 44 percent, average length of stay by 64 percent and hospital cost per patient by USD 92,000 [8]. As such, PGHD has been shown to have an actual influence on various aspects of patients’ struggle against diseases.

2.2. Healthcare Professionals

Healthcare professionals make decisions on medical treatments based on data collected from hospitals. However, these data are created by capturing patients’ health at a certain time point, and therefore exclude PGHD, which involves continuous changes of conditions or phenomena occurring outside hospitals. Sole dependence on clinical data does not allow for a comprehensive evaluation of patients’ health and may result in incomplete diagnosis or underdiagnosis. To improve this situation, PGHD collected in patients’ daily life can be used to reduce misdiagnoses and aid the treatment of chronic/rare and intractable diseases. Furthermore, healthcare professionals will be able to more comprehensively understand patients’ health using PGHD [9]. For example, they may take proper actions earlier, after detecting sudden changes in patients’ health conditions, and manage patients’ health to the best possible extent by changing treatment methods if necessary. In addition, their continuous observation of patients’ daily life through PGHD yield insight into patients’ health as well as...
information necessary for treatments tailored for patients’ condition, which ultimately assist the improvement of patients’ health.

2.3. Research Institutes

Based on PGHD, researchers and pharmaceutical companies can recruit test subjects more easily and diversely through online ads or social media without being dependent on hospitals or hospital-based systems. These collection methods can improve the speed of research and reduce the time required to establish a cohort or a data set to facilitate effective analysis. For example, PatientsLikeMe functions as a platform for patients to better manage their health and for researchers to easily obtain data. Pharmaceutical companies and clinical trial institutes acquire patients’ data through PatientsLikeMe and are using the data for research purposes [10]. Likewise, Humanscape will also contribute to disease research, through the documentation of shared data on the medication effectiveness and side effects to patients and the categorization of patient groups for various diseases [9].

The US Food and Drug Administration (FDA) is already reflecting the PGHD of patients’ opinions and experiences in its drug review process for rare and incurable diseases. This is because reflecting patients’ direct experiences and opinions in the development stage of a new drug, such as in clinical trials, may result in the production of safer and more effective medicine. Specifically, the FDA is developing Externally-Led Patient-Focused Drug Development (EL-PFDD) meetings into a channel for the collection of data based on the experiences of actual patients to provide them with helpful information on medication and treatments [11].
3. Humanscape, a Patient Networking Service

3.1. Attempts and Limitations on Building a Health Information Community

To date, the interchange of health information has largely taken place through Q&A services provided by web portals or online communities for specific diseases. In particular, online health communities and patient associations were generally organized around a specific disease and featured intensive discussions focused on a single disease, which restricted their expansion into other areas. Furthermore, existing communities are not equipped with mechanisms to sustain internal activities such as new posts or information sharing, which became problematic as users were alienated to “lurker” status or compelled to leave the community altogether. In this regard, a decline in community engagement results in a corresponding decline of expectation or satisfaction toward the community, which then poses a threat to the community’s sustainability [12].

Meanwhile, PatientsLikeMe constitutes a case in which the exchange of health information is occurring at an extremely active rate. Established in 2004, PatientsLikeMe is an online community for sharing information on symptoms among patients, mainly those with incurable diseases. Patients with incurable diseases have voluntarily shared information on their symptoms with other users complaining of similar symptoms, and currently, the number of patients registered on the platform is around 600,000 [13].

However, PatientsLikeMe remains somewhat limited in its capacity as a health information community. Over 14 years since 2004, around 600,000 patients have joined PatientsLikeMe, but the number of active patients on the site accounts for only around 17,000 as of 2018, and it is predicted that the accumulated volume of data will not increase dramatically in the future. Moreover, as the main services of PatientsLikeMe are focused on the sale of health “data” to pharmaceutical, insurance, and medical device companies, the site is not active regarding exchanges of patients’ subjective experiences, information or emotions shared as “content.” This signifies that patient activities in PatientsLikeMe are limited to only the temporary input of data with limited practical and direct utility for patients. Therefore, patients are not compelled to share information unless they are heavily involved in PatientsLikeMe, and...
3.2. Difficulty in Collecting PGHD

Active utilization of PGHD can be a way to contribute to treatments for patients suffering from chronic/rare and intractable diseases. At present, however, PGHD is not systematically arranged or accumulated to be used as a valuable data source. Patients have no choice but to investigate and understand their conditions independently without any informative and emotional support for their health conditions, unless they belong to any specific group or organization [14]. If PGHD is not systematized and only individually owned without accumulation on the scale of big data, it is highly likely to lose any potential value for research necessary for the development of new drugs or treatments. In addition, patients are less likely to be able to efficiently find the necessary information on diseases or drugs, which would narrow the range of choices available for the effective treatment of diseases, and potentially suffer from diminished control over their body due to their dependence on information gathered passively. Naturally, healthcare professionals may also lose the motivation to use PGHD in making diagnoses, and face the risk of judging patients’ health from an incomplete and simplistic perspective.

3.3. Potential of a Patient Networking Service

Against this backdrop, Humanscape is working to establish its namesake platform Humanscape, a decentralized patient network based on blockchains. Humanscape can provide practical help for patients to overcome their diseases through intellectual and emotional interaction with each other based on community activities. This process is expected to generate and collect a high volume of patient data, namely PGHD, on various disease groups. Furthermore, Humanscape facilitates active research into chronic/rare and intractable diseases and the development of new drugs by linking patients to external industry sectors such as pharmaceutical firms and research institutes and helps patients to avoid complications and enjoy healthy lives through the continuous self-management of their lifestyle and symptoms. With these services, Humanscape is taking steps to liberate patients from chronic/rare and intractable diseases, as its contribution to a world where everyone is healthy.
1. Humanscape

1.1. Token Utilities

Token utilities of Humanscape induces stakeholders to behave in a way that helps patients, who are the principal ecosystem users, to overcome their diseases.

The blockchain of Humanscape consists of HUM Tokens (HUM), the basic unit for transactions; HUM Points (HP), points used within the ecosystem; and HUM Donations (DP), points used for donations. In addition, Activity Index, Donation Index and User Score affect the token utilities.

1.1.1. HUM Token

HUM is the basic transactional token in Humanscape’s blockchain. It can be purchased and sold in the exchange and transferred among users. The HUM holding is used for the operation of Humanscape except the HUM used for the Initial Coin Offering (ICO).
1.1.2. HUM Point

HP refers to points used within the Humanscape ecosystem. HP is not traded in the exchange but can be purchased using HUM or earned through activities in the ecosystem. Although speculators may attempt to trade HUM for short-term profits, Humanscape intends to minimize the potential for speculation by limiting the routes for earning HP used in the ecosystem and its conversion to HUM.

Earning HP

HP can be earned in the following ways. First, users can earn HP as a reward according to their reward score. Second, patients can earn HP when their health data are utilized to recruit subjects for clinical studies, develop post-launch surveys for new drugs, etc. Third, patients can receive HP when they take part in institutional qualification processes. Finally, HP can be earned when HUM is converted to HP.

Converting HP

HP exists for the operation and promotion of the Humanscape ecosystem. To enable securitization of HP, HP is cross-convertible with HUM at a 1:1 ratio. However, in order to prevent any disturbance of its ecosystem, Humanscape intends to place time limits on the conversion of HP to HUM. Specifically, HUM can be converted to HP immediately, but HP can be converted to HUM only in equal installments over a given time period. Users may select from a variety of conversion period options based on their needs, and according to the length of the conversion period, fees may be charged through the Ecosystem Development Fund to maintain the ecosystem. The Ecosystem Development Fund is then transferred to the Reward Pool, which can distribute rewards to ecosystem contributors.

Using HP

While HP basically exists in a form that cannot be traded, users are strongly encouraged to use HP within the Humanscape ecosystem. Users can achieve a higher Activity Index by holding onto HP and they can use their HP for donations or premium services within the Humanscape ecosystem or for e-commerce, telemedicine or other services provided by third-party partners. Finally, service providers can deposit a certain amount of HP or use it to pay their fees to maintain the Humanscape network.
1.1.3. Donation Points: DP

DP refers to donation points that users earn through their contributions to the ecosystem. DP can be used only for donations and users cannot use DP for other purposes (e.g., converting to HUM or HP or using Humanscape services).

Patient association activities to represent patient rights and interests or take a leading role in disease treatment may yield outstanding results over the long term that cannot be achieved on the strength of an individual patient alone. Examples include supporting new drug development, hosting educational programs for patients and supporting patients who are experiencing economic difficulties. By encouraging donations through DP, Humanscape seeks to assist user-supported patient associations, which will further fuel their motivation to participate. From the patient perspective, patient associations aim to promote practical activities necessary for patients through financial rewards.

Earning DP

First of all, users receive additional DP corresponding to a certain percentage of the amount of rewards (Rx) that they receive when rewards are distributed. Next, users can choose to receive a portion of the reward for their ecosystem activities in DP instead of HP. The higher the ratio of DP rewards to the total reward, the more additional DP are paid out to the user according to that ratio.

Converting DP

DP can be converted to HUM only when donated by patient associations or other organizations, and it cannot be converted into HP. DP has the same face value as HP, and the conversion ratio of HUM to HP and DP is 1:1:1.

The collected DP can be withdrawn in one of two ways depending on the donation type. First, for the unlimited fundraising method (regular contributions) with no set period or target amount, the amount of DP raised is converted to HUM in 4 equal installments over a period of 4 weeks. For the method of raising DP with a set deadline, on the other hand, the amount of DP raised is converted to HUM over a period of 2 weeks from the deadline or after the target amount is met. Since it is prohibited to reuse the collected contributions for donations, they must be converted into HUM.
1.1.4. Ecosystem Rewards

To ensure the data sovereignty of users and encourage their activity, Humanscape rewards users according to their contributions to the ecosystem.

**Reward Pool**

Rewards for activities conducted within Humanscape are paid out of the Reward Pool, and the process is carried out automatically in compliance with operating policy. Users are awarded a certain amount of HP and DP according to their reward scores. The rewards that users receive are drawn from the Reward Pool, and the amounts are set to protect the market value of the rewards earned by all users. These rewards are calculated based on the Moving Average of the Reward Pool over a given time frame to prevent excessive fluctuations in the amount of rewards provided.

\[ A_t = \frac{\sum_{n=t}^{now} S_i}{t} \]

- \( A_t \): Moving Average of the Reward Pool for a given time frame,
- \( S_i \): Amount of the Reward Pool at a given time,
- \( t \): Calculation period for the Moving Average

At the time that each reward is calculated, a certain rate of the Moving Average of the Reward Pool becomes the total amount of rewards at that time.

\[ T_t = r \times A_t \]

- \( T_t \): Total amount of rewards at a given time,
- \( r \): Reward ratio (increases gradually by up to 10% in proportion to the number of community participants)

The Reward Pool is charged through the Community Development Fund from third-party players within Humanscape, including advertising, e-commerce and the HP exchange. Since it takes a certain amount of time for third-party services to stabilize and charge the Reward Pool
without outside support, the Reward Pool is charged periodically with a portion of the HUM allocated to the Community Development Fund at the beginning of the launch of service.

**Activity Index**

The Activity Index indicates a user’s level of activity in the Humanscape ecosystem. The Activity Index aims to encourage users’ ecosystem activities. It is calculated comprehensively by applying a weighted value to each factor of the users’ activities within a given time frame, including the posts, votes, donations, HP usage, HP holdings, etc., and is reset at the end of each calculation period. The types of activity factors and their respective weighted values can be changed only for the purpose of invigorating the ecosystem.

\[ G_t = \sum w_f \times f_t \]

- \( G_t \): Activity Index for a given time frame,
- \( w_f \): Weighted value for each factor,
- \( f_t \): Index for each activity factor for a given time frame

**Reward Score**

The Reward Score is a composite score calculated based on the Activity Index for each user. The Reward Score determines the amount of rewards(Rx) for a user. Based on the assumption that the overall distribution of the Activity Index follows a normal distribution, the Reward Score is calculated by converting the Activity Index to a standard score. This standard score is used to prevent new or minority users from exercising their influence excessively or even abusing that influence.

\[ M_x = g \times \frac{G_x - m}{\sigma} + 100 \]

- \( M_x \): User X’s Reward Score for the given period (minimum value of M=10),
- \( g \): Correction value of the standard score,
- \( G_x \): User X’s Activity Index for the given period,
- \( \sigma \): StDev of G, \( m \): Average of G
Distribution of Rewards

Users receive rewards based on the Reward Score that reflects all of their recent activities. The percentage of rewards given to encourage user activities is calculated using the formula below.

\[ P_x = \frac{M_x^p}{\sum_i M_i^p} \]

- \( P_x \): Reward percentage for user X,
- \( M_x \): Reward Score for user X,
- \( p \): Weighted value (adjusted by learning the ecosystem activity rate)

Of the total amount of rewards on a given day (\( T \)), user X receives rewards according to the applicable reward percentage (\( P \)).

\[ R_x = P_x \times T_d \]

- \( R_x \): User X’s rewards,
- \( P_x \): Reward percentage for user X,
- \( T_d \): Total amount of rewards on a given day
1.2. Service Composition

1.2.1. Personal Health Records

Chronic or incurable diseases require patients to constantly document and manage their own health conditions. Humanscape allows users to create content such as disease-related records and to input and manage data, e.g. symptoms, administered medication, and IoT, on a single user profile. For example, diabetics who need blood sugar management can measure and record their blood sugar level on their user profile on a daily basis, along with factors that influence blood sugar, such as dietary habits and other physical changes.

Such personal health data not only helps each patient to self-manage their health but also serves as useful sources for various services. Firstly, disease-related records and symptoms can be shared through various content. Secondly, users who record their symptoms in detail are more likely to be exposed to the profiles or posts of other patients with similar symptoms. With greater usage of the services, users are provided with customized information in order to enhance their user experience. In addition, numerous healthcare-related institutions conduct a variety of research and marketing programs, in which patients may participate to earn HP. For example, users could take part in pharmaceutical companies’ clinical tests, post marketing surveillance on new drugs or medical devices, and insurance companies’ marketing programs for recommending an insurance policy tailored to patients’ health. These institutions’ activities based on patients’ personal health records can offer actual benefits to those with incurable diseases and alleviate the financial burden facing their families due to insurance costs, etc. As such, Humanscape aims to use accumulated information on patients’ health in a way that is beneficial to the health of patients as well as humankind at large.
1.2.2. Community

Communities by Topic

Users share content, such as daily treatment records, knowhow and latest information on various topics like diseases, symptoms and side effects in communities with specific themes, where patients can post their personal health records directly on a bulletin board. If posts or comments get voted, HP is given as a reward. A part of the reward is given as DP, which can be used to donate to donation events organized by patient associations.

Communities for Patient Associations

A community is created for a patient association that is registered after a qualification process, which allows members of the association to use the bulletin board. In a patient association community, the administrator can post notices announcing information or events related to the patient association, while members can share information with each other and socialize among themselves.

Content Sharing and Support

Content shared among patients includes daily treatment records, knowhow and latest information, as a combination of texts, images and the uploader’s health data (diseases, symptoms and administered medicine).

Users may share contents with other users and the more responses they receive from other users, the more opportunities they will have to receive rewards. Likewise, the Humanscape ecosystem encourages the sharing of useful, reliable information.
1.2.3. Operation of Patient Association

Humanscape allows patient associations to register and conduct various activities for its operation. With the exception of some large-scale patient associations, it is difficult for patient associations to make sufficient investments in online infrastructure such as websites, as they generally operate with membership fees and donations. In addition, patients were limited to share their information with certain patient associations only, which resulted in a lack of online channels to share such information, since the information was shared mostly at offline meetings.

Humanscape aims to meet patients’ needs for online activities, by providing online platforms organized by disease. Furthermore, Humanscape allows DP obtained through activities to be donated to donation events organized by patient associations so as to encourage donations.

1.2.4. Participation of Institutions

Institutions registered on Humanscape after a qualification process can create an official username. Institutions can upload various news and information, and post official replies. For example, a pharmaceutical company can post its latest news on the bulletin board for its products, or reply to an inquiry about possible side effects. Also, institutions can hold events using HP, such as the recruitment of subjects for clinical trials and post marketing surveillance for targeted patients. HP paid by institutions for such events are given to patients after discounting some of the advertising costs incurred during the recruitment process.

1.2.5. Donations

Humanscape aims to help patients to improve their health in various ways through activities. One of these ways involves the introduction of a donation system. Patient associations, whose purpose is to support patients, are non-profit organizations that operate with membership fees and donations. There are many ways for individual users to support their own patient
association, but financial contributions will serve as a foundation for patient associations to further support their patients. Humanscape awards DP to users who actively perform activities such as providing health-related information, allowing the user to donate financial support to desired patient associations.

**Donation Process**

Users may donate some of the rewards that they receive for content. When a donation event is designated, the DP earned for content is provided to the donation event. When a donation event has not been designated, the user may select an event to donate to through a donation channel and give some of their accumulated DP, HP or HUM to the selected event. In such cases, the donation recipient will receive the donated amounts in DP. The user will obtain donation points in proportion to the amounts donated, which are accumulated and displayed on the user’s profile. Patient associations that have created a given donation event can convert DP to HUM according to the event type, which may then be used for the original purpose of the donation.

**Organization of a Donation Event**

Donation events can be generated by the administrator account of a patient association. Creating a donation event requires information such as organization information, the donation type, project introduction, fundraising period, fundraising goal and donation usage plan. In order to create a donation event, a patient association must be registered with more than 30 members, and the Activity Index of the group members must be above a certain level. When the administrator account creates a donation event, the donation event is finally registered on the donation channel through a vote within the patient association. The vote is determined when the Activity Index of the voters exceeds 50 percent of the Activity Index of total members of the patient association.
2. Use Cases

2.1. Private Sector

Targeted Advertising

Targeted advertising is currently one of the most general and effective methods of online advertising. Some of the world’s leading IT companies such as Google and Facebook have grown to their current scale based on earnings from targeted advertising. Humanscape aims to provide a targeted advertising solution that designates a target group for advertising based on patient-recorded health information to display or induce clicks on ads. This method of advertisement will be favored by various clients such as pharmaceutical companies, insurance companies and health supplement foods sellers. As the target is a patient group formed around healthcare and medical topics, advertisements tailored for such topics are expected to be more effective than in other channels.

Targeted advertisements are charged fees that contribute toward the operation of the Humanscape Community. HP paid by clients for targeted advertising is added to the Humanscape pool, and can be used to reward patients with HP when they record their health information, contributing to the sustainability of the ecosystem. Later, the margin of inflation may be partially set aside for operation funds, instead of charging advertising fees.

Recruitments for Clinical Trials

Clinical studies are based on people’s participation in new diagnostic, preventive, and therapeutic methods. The global clinical research market is valued at 40 billion dollars as of 2016 [15] and it is also estimated that 13% of total clinical research cost is used for patient recruitment [16]. In this context, the Humanscape can bring about the following cost reduction effects:

First, using health information accumulated in Humanscape can reduce the cost of recruiting clinical research subjects. Recruiters can quickly screen patients who are suitable for clinical studies based on the patient’s recorded health information. Patients are more likely to respond positively because they are asked for clinical studies that are closely related to their current health status. According to the survey by pharmaceutical companies and clinical agencies, 80% of respondents reported that online community or patient network is overwhelmingly effective.
in mass recruitment compared to other methods such as media advertisements or posters in hospitals.[17].

These patient group networks are similar in character to online health communities. PatientsLikeMe, for example, has signed with inVitiv Health [18] for effective patient recruitment and has affiliated with government agencies like clinicaltrials.gov[19] in order to accelerate clinical research. According to the report issued by the Tufts Center for the Study of Drug Development, 37% of the online recruiters for clinical research failed to recruit a sufficient number of patients, 11% did not register a single patient, revealing a problem of low participation in clinical studies [20]. Therefore, Humanscape ecosystem could be a good alternative as to encouraging patient participation in clinical research.

In addition, when people are recruited from Humanscape, the rate of dropout will be lowered and the cost will be reduced. Even if patients agreed to participate in clinical studies, they are likely to drop out in the middle of the process if the research venue is far away from the patient’s house or workplace or if he/she cannot fit into the schedule. With the fact that about 30% of patients give up the research halfway, appropriate compensation and information on individual's health status proved to be effective for complete participation in clinical trials[20]. Humanscape can reduce the cost of dropout by offering appropriate compensation and negotiating participation schedule in real time.

**Post Market Surveillance (PMS)**

Post market surveillance (PMS) is the safety assessment of newly launched medicines or medical devices [21]. Because it is not possible to predict all side effects that may occur during use of a medicine with pre-approval research conducted on a limited number of patients, the FDA undertakes PMS and risk assessment programs[22]. More specifically, PMS is conducted to review safety issues in closer detail and side effects that were not pre-identified by collecting data on side effects and unintended effects from an unidentified group of patients. Types of data used in PMS include data voluntarily submitted and recorded by patients and the patient registry. In Humanscape, there are patients who suffer from many different diseases. These patients record treatment effects and the side effects of their medications. Therefore, data necessary for PMS gets accumulated in Humanscape, which can then be put to use actively for PMS. Furthermore, by initiating surveys on patient groups within Humanscape, more standardized information necessary for monitoring can be selectively collected.

In the US, the budget for PMS is, on average, 2.16 million dollars per case (about 2.2 billion won) with the total cost amounting to 1.02 billion dollars (about 11 trillion won) [23]. Domestic pharmaceutical companies have also been making a significant investment in PMS. Currently, pharmaceutical companies contact individual hospitals and other medical
institutions for PMS but Humanscape can establish itself as the platform where high-quality information can be provided.

One problem with PMS is that it minimizes the observation period and the number of test participants in order to receive approval for the release of new medicines as quickly as possible [24]. In other words, while the assessment of treatment effects of the medicine can take place effectively during PMS, it is difficult to completely guarantee the safety of the medicine. In this regard, Humanscape can help overcome the practical limitations of PMS with data from patients accumulated over a long period of time.

E-commerce

E-commerce is a service for trading products that assist the treatment of diseases, such as healthcare devices, medical devices, health supplement foods and over-the-counter (OTC) drugs. Relevant products are automatically selected and recommended based on personal symptom records submitted by patients, and useful product information is provided to help patients make informed purchases. In addition, patients can share their reviews of purchased products with the community and search for products that they are interested in. In other words, patients are able to easily and conveniently purchase products that are most relevant to their health condition and disease, thereby effectively improving their own health. Furthermore, as E-commerce is a service linked with the blockchain-based Humanscape Community, brokerage fees can be reduced, helping patients toward reasonable consumption, and guaranteeing greater transparency compared with other commerce services.

Insurance Solicitation and Sales

The Internet has emerged as the most important marketing channel for the sale of insurance products. Insurance companies can lower their operating costs with the internet [25], which is the most cost-effective channel, and consumers can benefit from lower premiums. According to a research study by Bain & Company in 2015, 8% of life insurance and 10% of property and casualty insurance worldwide is being sold online, and this is expected to increase to 15% and 23% within 3-5 years, respectively [26].

Keeping pace with such trends, Humanscape can offer more advanced types of online insurance products to patients. More specifically, patients can not only compare and analyze diverse insurance products at a single glance but also receive recommendations for the most suitable insurance based on their personal information. Furthermore, the platform helps patients to make decisions by surveying the insurance products purchased by people with similar diseases and soliciting their feedback.

In addition, patients can benefit from lower premiums through IoT data that can be acquired by linking the digital wellness platform and the Humanscape ecosystem. The digital wellness
platform that aims to promote health in all aspects of life with digital technology is used by many people as it can be accessed easily regardless of time or space concerns. Humanscape connects smartphones and wearable devices to the platform and provides services so that users can set individual health targets and achieve them. In particular, for patients with chronic diseases, the community can serve as an opportunity to promote healthy lifestyles via daily activities by encouraging healthy habits suitable for the treatment of specific diseases, separately from hospital or medication treatment. If patients regain their health, their medical expenses decrease. As insurance companies lower premiums accordingly, patients and insurance companies both gain economic benefits.

2.2. Public Sector

Improving the Health of Patients in Developing Countries

The blockchain-based Humanscape community may help narrow the healthcare gap between developed and developing countries and improve the health of people in developing countries. Compared to those of advanced nations benefiting from sophisticated healthcare services, many countries in Africa, South America and Asia still suffer from epidemics, starvation and water pollution. In Indonesia, for example, children under the age of five die from various illnesses every four minutes[27]. In Africa, the spread of infectious diseases such as Ebola virus and HIV/AIDS is not adequately controlled. According to the World Health Organization (WHO), people from developing countries account for one third (30.7 million) of total worldwide deaths caused by chronic diseases such as diabetes and cancer, and among them, 48 percent are 70 years old or younger [28].

International agencies and organizations are investing vast amounts of money in programs to support drugs, medical supplies and promote the health of the people of developing countries [29].

Despite the assistance and continued advances in the medical treatment of diseases over the past century, developing countries still suffer from a high mortality rate due to poor health facilities and a lack of pharmaceuticals.

Since medical problems in developing countries derive from information asymmetry, low access, monopoly of health data by the authorities[30] and and lack of medical infrastructure[31], however, such investment is but a temporary measure to delay the deterioration of people’s health rather than a fundamental solution.
In this context, the Humanscape ecosystem helps address the imbalance in health information, problem of expert shortage issues and prevent people from being deteriorated by wrong treatment. Like the case in Zambia, where the youth HIV/AIDS transmission rate is high, the AIDS self-diagnosis rate has increased from 12% to 40% after acquiring relevant information[32]. Therefore, the Humanscape Community helps patients in developing countries to share information on their diseases. This allows information on infectious diseases to be obtained quickly to reduce damage and secure access to medical care.

**Public Health Crisis**

Continuous monitoring of health information updated in Humanscape makes it possible to detect health issues within the population group that may prevent health risks and minimize damage. Based on the flow of data on the symptoms of specific diseases, we can capture the signs of infectious diseases. In addition, the spread of the disease can be prevented by analyzing the infection route based on the personal symptom record of the suspected infectee.

**Comparative Effectiveness Research**

Healthcare data in Humanscape can be used for the comparative effectiveness research to overcome limitations of existing clinical studies and reduce medical expenditures. A regulatory nature of current clinical studies shortens the follow-up period and fails in reflecting actual clinical field. A way to solve these problems is to conduct a comparative effectiveness research that identifies the most effective treatments by comparing the various treatments and effects of the same disease. The use of health information in Humanscape allows us to compare and analyze the effects of treatment among patients with the same disease undergoing different procedures, thereby enabling them to compare different therapies and find the most effective method.

In this way, health information that is shared and accumulated by Humanscape can be effectively used for data-based comparative effectiveness studies, and helps consumers, clinicians, buyers, and policymakers to make decisions to improve healthcare at the individual or group level.
2.3. Research Sector

**Rare and Intractable Diseases**

Voluntary health information from patients may contribute in the study of rare and incurable diseases that are difficult to obtain data samples. For example, Patientslikeme published a paper in Nature Biotechnology in 2011. Patientslikeme refuted a paper [33] that claimed Lithium could slow the progression of ALS published at the National Academy of Sciences (PNAS) in 2008. Patientslikeme tracked the experience of 149 patients for a year to prove ineffectiveness of lithium [34]. What is interesting is the number of patients who voluntarily offered their health data in Patientslikeme was higher than the number of patients participating in PNAS studies using traditional clinical testing methods [35]. In the PNAS study, lithium was administered only to 16 patients out of 44, whereas in Patientslikeme, 348 of 4,318 ALS patients were reportedly taking Lithium. Among those 348 patients, a total of 149 patients who met a certain condition was analyzed for data. Relevant data accumulated in Humanscape will also be available to take part in the research of rare and incurable diseases.

**Development of New Medicines and Clinical Research**

It usually requires more than 10 years and over one trillion won of investment to find a potential medicinal substance and to pass clinical research trials for developing a new medicine [36]. Because of the astronomical costs and time involved, this process has mainly been confined to global pharmaceutical companies with sufficient capital and while the development of new medicines for rare or incurable diseases was delayed. In order to resolve this issue, diverse methods to change the paradigm of the development of new medicines are being designed and one such method is utilizing artificial intelligence based on clinical data provided by patients. Using AI could significantly reduce the cost and time required to find a new medicinal substance via analysis of big data on health and medical services offered to patients [37]. In this regard, incidence of side effects or the medical history of patients accumulated in Humanscape could be actively utilized. In addition, building on the data provided by patients, candidate medicinal substances for new tailored medicines can be developed and increase the success rate of clinical trials by efficiently connecting with patients.
3. Technology

3.1. Blockchain Protocol

Ethereum (ERC-20), NEO, Counterparty, and EOS are widely known examples of token protocols. Most protocols, however, cannot offer the ideal user experience in the form of a content-focused, community-type service due to transaction costs, processing speed limits and the hierarchical design of private keys that favor financial institutions over social media accounts.

Blockchain protocols strive to provide sufficient features for actual services from the user perspective, of which Klaytn of GroundX and Luniverse of Lambda256 are the best examples. To promote expansion of the platform and easy user inflow, Humanscape will introduce blockchain protocols to the Humanscape ecosystem, taking into consideration the characteristics of each protocol and making them convertible to HUM (ERC20) tokens.

If a blockchain protocol with great potential emerges due to active technological exchange or the developmental progress of Humanscape outstripping the pace of performance improvements in blockchain protocols, Humanscape may introduce and use the relevant blockchain platform to provide seamless user service.

3.2. Performance

The practicability of the concepts set out above has been proven by Klaytn and Luniverse. Klaytn and Luniverse, both Ethereum-based blockchains, are compatible with Ethereum’s smart contracts. In addition, since their fees are substantially lower than that of Ethereum, the tokens used to maintain the network can be saved, allowing more tokens to be given to users who have contributed to the ecosystem. Smart contracts create a Klaytn Virtual Machine (KLVM), similar to an EVM in blockchains, by supporting Turing completeness and executing contracts within the KLVM. Through this unrestricted implementation of smart contracts, a more highly developed Humanscape ecosystem can be realized.

As for consensus algorithms, Klaytn and Luniverse use BFT (Byzantine Fault Tolerance) between consensus nodes and PoA (Proof of Authority) between valid nodes, respectively. A small number of
nodes enables rapid engagement in creating blocks, which in turn accelerates the rates of block generation and processing.

Baobab, the recently-released testnet for Klaytn, is expected to process over 3,000 transactions per second on its mainnet alone. Luniverse’s mainnet is capable of processing over 2,000 transactions per second and is designed to achieve a higher rate of TPS (transactions per second) by using a sidechain separately.

### 3.3. Smart Contract

Smart Contract is a technology that allows stakeholders to conclude and implement contracts without intermediaries using a blockchain based on the technical characteristics of a distributed ledger. In Humanscape, rewards are given when various user-created contents (videos, texts, etc.) are evaluated as meaningful by actual consumers. And the amount of rewards depends on those contents’ degree of contribution to the community. Smart Contract is used to ensure the reliability of data trading during the implementation of such payment contracts.

In addition, Smart Contract is used for various types of in-service trading, verification of qualification, and implementation of other service logic. Smart Contract is based on a Turing complete language, and the data collection and operations that occur outside the blockchain are executed through Oracle.
3.4. Hierarchical Structure of Service

3.4.1 Service Layer

Service Layer is an area where Humanscape’s core logic is executed and core data is saved. Service Layer is comprised of data storage (blockchain, InterPlanetary File System (IPFS) and hybrid) and other service logics. Patient data entering from the API layer is recorded on the blockchain after implementing Smart Contract in Humanscape’s core.

Data handled in Humanscape can mainly be categorized into personal information, personal health data and content shared with the community. Personal information and personal health data are comprised of sensitive information that must be kept confidential or valuable data that constitute patients’ assets as required by institutions, and are therefore saved encrypted in dispersed storage areas to prevent public exposure. In order to specify the ownership of saved data, a hash value is saved on a blockchain and mapped to prevent forgery or tampering in outside areas including Humanscape. Content data can include large-volume data such as images and videos, and is stored in external storage such as AWS S3 to ensure the effective
management of resources. Later, when the individual’s right to be forgotten and their sovereignty is fully secured, IPFS will be used to implement decentralization in more areas.

The contents and the data shared within the community include activities such as posting, commenting, rewarding, and token donation. After the aforementioned activities are deployed in the service and certain conditions for the execution of smart contract are defined depending on the degree of completion and settlement, users receive or pay tokens in accordance with the defined details.

### 3.4.2 API Layer

The API layer is comprised of API for the storage and search of patient data and the development of services. The data recorded by patients is categorized through the API layer and gains greater value, and patients can select any desired data through conditional search.

In the long term, there are plans to analyze and convert qualitative and unmeasurable data into meaningful data, in addition to qualitative and measurable data among personal symptom records submitted by patients.

Furthermore, the Humanscape API is designed to be available for use by third parties to allow their services to be linked with Humanscape or to allow the development of new services linked with Humanscape.

### 3.4.3 Application Layer

The application layer provides web and mobile applications to ensure easy access for patients. The application layer provides optimal UX/UI, through which patients can use their personal symptom records more conveniently, and an environment where users can share information through communication with other users and naturally benefit from emotional support. Also, the application layer provides various services such as donation and commerce services to allow the meaningful usage of HP issued in the ecosystem.
4. Token Events

4.1. Summary

- **HUM Token**
  - HUM is a token that enables basic transaction on the Humanscape blockchain. HUM can be purchased and sold at the cryptocurrency exchanges. Humanscape will issue ERC20 tokens on Ethereum which can be remitted to other token holders.
  - Initially, token conversion event was scheduled for existing token holders after issuing ERC20 tokens on Ethereum. Excluding HUM used for ICO, all the remaining HUM will be utilized for the operation of Humanscape.
  - Humanscape is expected to use Klaytn and Luniverse which are compatible with Humanscape ecosystem and services.
  - However, in case the development of Humanscape is completed ahead of the functional improvement of the above blockchain protocols or there’s another viable blockchain protocol, Humanscape could adopt the protocol to provide users with better services.
  - Total issue volume: 1,250,000,000 HUM
  - Standard price: 1 HUM = $0.02
  - *2019 Aug - Carried out 100:1 ratio token swap*

4.2. Allocation

- **5% Advisors**
  - 2 years Lock up
- **40% Token Sale**
- **20% Humanscape Team**
  - 4 years Lock up and Early Investors
- **15% Business Development**
- **20% Community Construction**

1.25 billion HUM
5. Roadmap

2016

1Q  - Company Incorporation - Seoul, Korea
2Q  - Development and Launch of ‘Beautycare’, a mobile application for aftercare services
3Q  - Angel Investment Promotion from ‘Mashup Angels’ (Taek-Kyung Lee, CEO and Founder of ‘Daum’)
4Q  - Client Usage Agreement with ‘Dream Medical Group’ and ‘DA Plastic Surgery’

2017

1Q  - Development and Beta test of ‘Helen’, Mobile Medical Assistant
2Q  - Official Launch of ‘Helen’
3Q  - Follow-up Investment Promotion from ‘Magellan Technology Investment(VC)’
4Q  - Acquisition of 10,000 PHR Data from ‘Beautycare’ and ‘Helen’
     - Concept Building of ‘Humanscape’, a Health Information Ecosystem

2018

1Q  - Whitepaper Publication
     - Company Incorporation - Hongkong
2Q  - ‘Humanscape’ MVP Development Begins
     - Pre-sale 1st, 2nd and 3rd round
     - Business Agreement Contract with ‘Korean Foundation Fighting Blindness’
3Q  - Composition of Test Groups(patients, medical experts)
     - Joint Research and Development Agreement with ‘Seoul Asan Medical Center Healthcare Innovation Big Data Center’
     - Business Agreement Contract with ‘The Catholic University of Korea, Seoul ST. Mary’s Hospital Smart Healthcare Center’
     - Expansion into Indonesian Market( Incorporation/Institute PoC)
4Q  - Listed on the cryptocurrency exchange ‘CPDAX’, with the availability of HUM/KRW trading pairs
- Joined as the first medical sector partner for 'Klaytn', a blockchain protocol of 'GroundX', powered by Kakao
- Listed on the cryptocurrency exchange 'Digifinex', with the availability of HUM/ETH trading pairs
- Signed business agreement contract with 'eBay Korea' for platform integration and joint marketing.
- Signed joint research agreement with 'Hanyang University Medical Center' for patients with rare diseases.

2019

1Q
- Joined as a partner for blockchain service platform 'Luniverse',
- Created a Youtube channel "Goodrarenews" for providing latest medical information to patients with rare diseases
- Signed MOU with Cancer Research Institute of The Catholic University of Korea, Seoul ST. Mary's Hospital
- Signed MOU with Catholic Smart Healthcare Center of The Catholic University of Korea, Seoul ST. Mary's Hospital
- Joined as a partner for ‘Luniverse’, a blockchain platform of Dunamu, powered by Upbit.

2Q
- Listed on the cryptocurrency exchange 'GOPAX', with the availability of HUM/KRW pairs.
- MVP Release
- Alpha Test

3Q
- PoC with Global pharmaceuticals, Clinical Research Institute
- Closed Beta Test
- Soft Launch(Korea, Indonesia)

4Q
- Business Model Validation
- Main Service Launch(Korea, Indonesia)
6. Others

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