LifeBlocs - Bone Marrow, Blood, and Organ Donation

Section 1: Summary

Use Case Summary			
Use Case ID:	HLC-005	**Use Case Type:**	Vertical
Submission Date:	January 3, 2019	**Is Use Case supporting SDGs**	Yes
Use Case Title:	LifeBlocs	**Domain:**	Healthcare
Status of Case	PoC	**Sub-Domain**	Bone marrow, blood, and organ donation
Contact information of person submitting/ managing the use-case	*Full Name:* Cathy Chen *E-mail address:* cathy.chen@lifeblocs.com *Social media:* N/A	*Job Title:* Co-Founder & CMO & Head of Government Relations *Telephone number:* +1 805 304 5849 *Web site:* www.lifeblocs.com	
Proposing Organization	LifeBlocs		
Short Description	LifeBlocs endeavors to reinvent the donation value chain for bone marrow, blood, and organs globally by utilizing the blockchain technology. In doing so, it aims to reduce the number of lives lost as a result of inefficiencies in the donation and matching processes. Moreover, LifeBlocs strives to increase the number of donations amongst the population. Our first use case and current primary focus is bone marrow data storage and matching.		
Long description	LifeBlocs is a start-up that aims to increase blood, bone marrow, and organ donations, and optimize the matching process between donors and receivers. Powered by the Ethereum blockchain, LifeBlocs hopes to optimize supply chain efficiency by equipping each actor in the donation supply chain with a data storage and matching process, from donors and donor organizations to hospitals and patients. It hopes to give patients their much-needed access to healthcare essentials by offering a secure data storage and higher rate of match compatibility, thereby enabling timely availability of life-saving material. In executing its mission, LifeBlocs aims to save human lives by providing the following solutions: 1. An easy-to-integrate, decentralized data storage and matching platform that enables greater access for patients, and fosters collaboration between organizations and nations; 2. An incentive system that rewards blood and bone marrow donors through a non-monetary incentive, and through which donors can visualize the impact of their donation;		

	3. Spreading awareness and increasing the participation of donors worldwide. Finally, through the implementation of LifeBlocs' system in multiple smart cities and the learnings gathered in this process, it also plans to provide its system in countries where existing donor systems do not exist.
SDG in Focus (when applicable)	SDG 3, indicator 3.8. LifeBlocs aligns with SDG 3, indicator 3.8, in that it seeks to achieve universal access to a quality essential healthcare services and access to safe, effective, quality and affordable essential bone marrow, blood, and organs for all.

Value Transfer:	LifeBlocs will not generate a token or an asset for transactions on the blockchain.	**Number of Users:**	N/A

| **Types of Users:**	Donors, Donor organizations, Hospitals
Stakeholders	Individual donors, donor organizations, hospitals, patients.
Data:	***What data are expected to be stored in distributed ledger in terms of types, record structure, privacy, etc.*** - The method of storage can be adjusted to comply with specific countries' privacy and health data storage laws. Outlined below is a general description of the default structure. PII (Personally Identifiable Information) - PII will be stored separately on a conventional, secure database. Medical Data - Medical Data, specifically HLA (Human-Leukocyte Antigen) types, will be stored on IPFS (Inter-Planetary File System). Links to PII and Medical Data - The links that provide access to the two sub-sets of data will be stored on the blockchain. Given increased computing power and storage capacity prove to be quite expensive on the blockchain, we aim to utilize blockchain as the technology for the facilitation of storage and matching of health data. ***How DLT solution would interact with external data and other systems.*** - The DLT solution interacts with bone marrow registries, IPFS (Inter-Planetary File System), and a conventional, secure database. The DLT stores the separate links to the PII and the Medical data and facilitates cross-border matching.
Identification:	When bone marrow registries register new donors, PII and HLA lab results are stored. Bone marrow registries only have access to the PII of individuals that they have registered themselves.
Predicted Outcomes:	Donors: Individual donors will be able to visualize their individual impact as the LifeBlocs system provides a transparent and up-to-date overview of where

their donation has been located along the supply chain. Moreover, those who are not donors yet will be encouraged to donate through the non-monetary incentive system.

Donor organizations:
Organizations that manage donations along the supply chain will become visible and traceable. Furthermore, the data storage and matching process will become more secure.

Hospitals:
Hospitals will benefit from increased success rates of match compatibility, and face lower administrative costs as a result of the system.

Patients:
Personal and health data will be stored securely on the system, and patients will have timely availability of life-saving material.

Overview of the Business Problem or Opportunity

- Technological advancements are lacking in the current tissue and organ donation systems, and lives are lost as a result of inefficiencies in the value chain. As of today, major issues prevent universal access to essential blood, bone marrow, and organs for patients. For example, issues include individuals that are not incentivized to donate, donation registries that are not integrated seamlessly, and large, centralized players in the donor value chain that prevent transparency and traceability.

Why Distributed Ledger Technology?

- DLT will seamlessly integrate data siloes across countries without centralizing and harbouring all data in one centralized location. This is essential as many bone marrow registries would be hesitant to share and centralize all of their data into one location. Each of the features listed above (immutability, security, verifiability, transparency) are valuable for our use case of blockchain. For example, having a verifiable source of truth for tracking blood transfusions can be invaluable in countries such as India where, in the past 10 years, 20,000 cases of HIV transmission from blood transfusions have occurred.

Section 2: Current process

Current Solutions

- World Marrow Donor Association currently utilizes a centralized server for matching internationally. DKMS has set up offices in multiple different countries. Neither of these organizations/systems have decentralized/distributed databases. Although, both strive to develop as large of a database as possible.

- Aside from the issue of having siloed data, the administrative processes for registering donors is quite inefficient. Many organizations still use manual paper registration without immediate electronic data or consent storage.

Existing Flow (as-is)		
Step	**User Actions**	**System Actions**
1.	Donor elects to sign up as donor (fills out paperwork manually) and provides DNA sample	
2.	Donor recruiter swabs cheek and sends sample via envelope mail with barcode	
3.	Donor organization lab scans barcode to confirm receipt	System logs receipt
4.	Lab conducts tests and inputs data	System stores lab results
5.	Hospital send DNA sample of patient	
5.1	Repeat Step #4 for patient	System stores lab results
6.	Match patient data against donor database, if no match, manually contact international databases	System matches patient data against database
7.	If there is a match, does the potential donor agree to further testing?	
8.	If so, donor provides blood and doctor runs additional tests	
9.	If additional tests prove positive, donor is eligible to donate	

Process scheme (as-is)

Bone marrow testing/matching flow
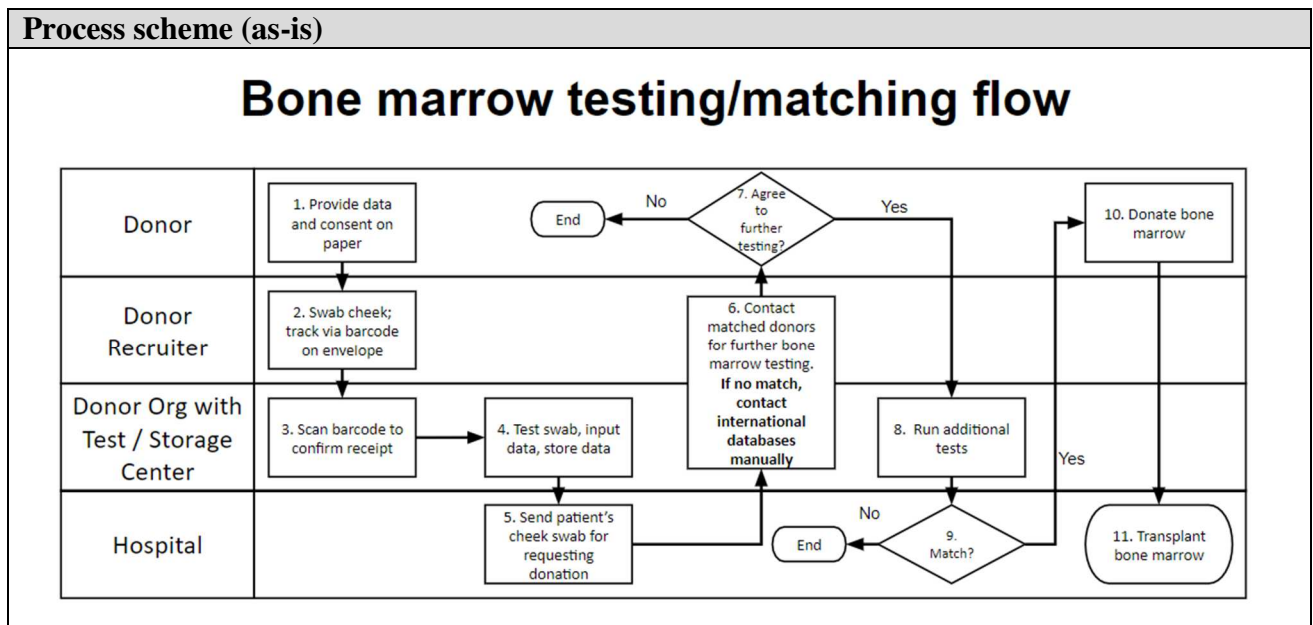
Data and information (as-is)		
Data	**Type**	**Description**
1	*PII Data*	Personally Identifiable Information such as name, email, phone number, address, ethnicity, country, etc.

| Data and information (as-is)		
Data	**Type**	**Description**
2	*Medical Data*	Human Leukocyte Antigen genotypes
3	*Other Medical Data*	Not currently designed into the bone marrow use case, but for the blood and organs use cases, additional medical data will be necessary such as height, weight, age, sex, sexual orientation/history, recently traveled countries, etc

Participants and their roles (as-is)		
Actor	**Type/Role**	**Description**
1	*Donor*	Individual that is willing to donate bone marrow or peripheral blood stem cells (PBSC) to save a patient's life
2	*Donor recruiter*	Organizations that focus on increasing the number of donors by running bone marrow drives and facilitates the spread of education and knowledge
3	*Donor organization / test center / storage center*	Organizations that consolidate donors' information to build a database of potential donors
4	*Hospital*	Provides cheek swab of patient in need of bone marrow transplant

Other Notes
-   *N/A*

Section 3: Expected process

Expected Flow (to-be)		
Step	**User Actions**	**System Actions**
1.	Donor elects to sign up as donor (provides necessary information electronically) and provides DNA sample	
2.	Donor recruiter swabs cheek and sends sample via envelope mail with QR code	System logs sending of cheek swab with a PII link generated stored on secure database
3.	Donor organization lab scans QR code to confirm receipt	System logs receipt
4.	Lab conducts tests and inputs data	System stores lab results to Inter-Planetary File System (IPFS)

Expected Flow (to-be)		
Step	**User Actions**	**System Actions**
5.	Hospital scans QR code and sends DNA sample of patient	System logs sending of cheek swab with a PII link generated stored on secure database
5.1	Repeat Step #4 for patient	System stores lab results to Inter-Planetary File System (IPFS)
6.	Match patient data against global donor database	System matches patient data globally
7.	If there is a match, does the potential donor agree to further testing?	
8.	If so, donor provides blood and doctor runs additional tests	
9.	If additional tests prove positive, donor is eligible to donate	

Process scheme (to-be)

Bone marrow testing/matching flow
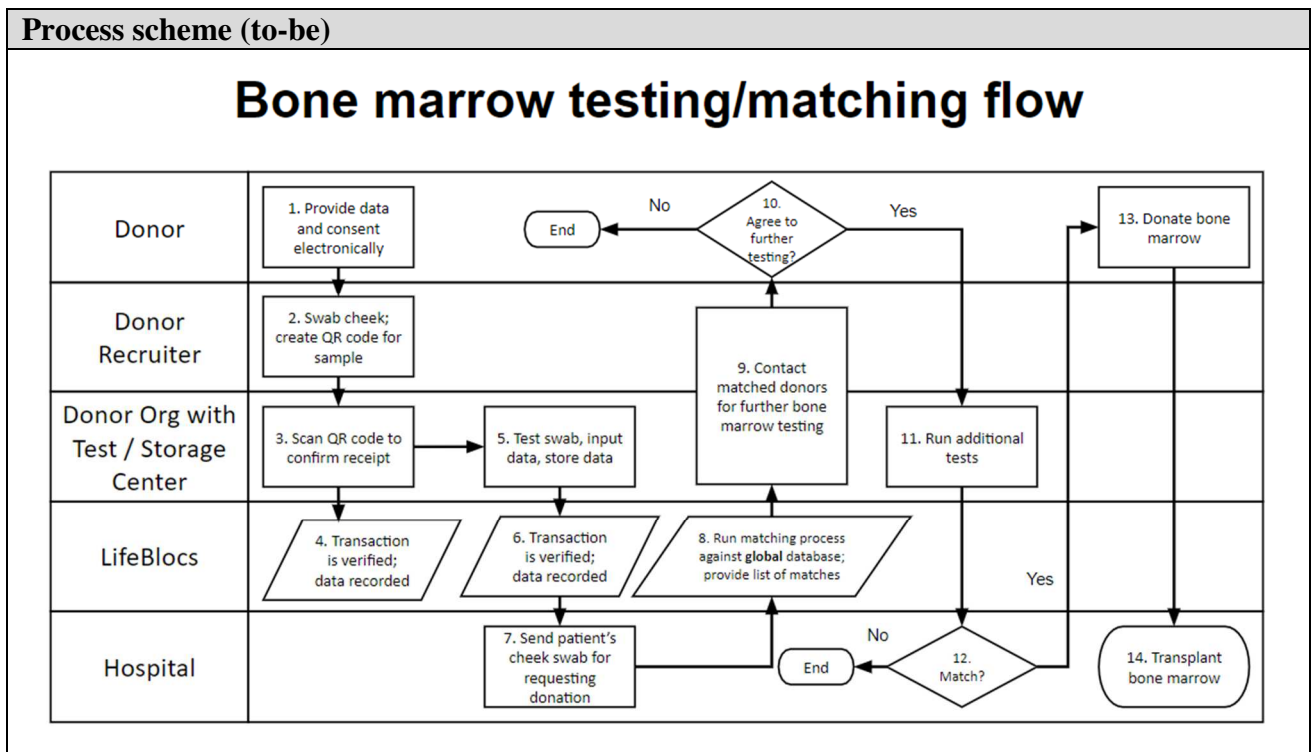
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4	*Hospital*	Provides cheek swab of patient in need of bone marrow transplant
5	*LifeBlocs*	Provides participant #3 with a system that allows a more seamless solution for searching for bone marrow matches globally

Data and information		
Data	**Type**	**Description**
1	*PII Data*	Personally Identifiable Information such as name, email, phone number, address, ethnicity, country, etc.
2	*Medical Data*	Human Leukocyte Antigen genotypes
3	*Other Medical Data*	Not currently designed into the bone marrow use case, but for the blood and organs use cases, additional medical data will be necessary such as height, weight, age, sex, sexual orientation/history, recently traveled countries, etc
4	*Links to Data*	The current infrastructure is built in a way that the blockchain stores the 2 separate links 1. To the PII data and 2. To the medical data.

Security and privacy
- N/A

Main Success Scenario + expected time line
- Global adoption with every major bone marrow registry as a member. Best practices and learnings will be applied to create bone marrow registries in countries where registries do not yet exist. We plan to have our pilot implementation completed by end of 2019. Each year, we'd like to have additional implementations in different countries with all countries onboarded by 2030. During this time, we also plan to expand our solution to the blood and organ use cases.

Conditions (pre- or post-)
- N/A

Performance needs

- For the bone marrow use case, frequency or load is not of primary concern as bone marrow matching is with a relatively much smaller volume than many other DLT use cases. The current standards should suffice.

Legal considerations

1. USA: HIPAA
    a. PII and Health data will be stored separately on authorized/certified databases.
2. EU: GDPR
    a. We will build in a mechanism for breaking the links that provide access to the PII and health data. By destroying the hash, the data becomes inaccessible and unreadable.
3. Korea: Health Data Privacy Consent
    a. Korean law requires disclosure of what legal entities will have access to / ownership of the data collected. Our current approach to address this is to either 1. Build onto a permissioned/private blockchain or 2. Conduct private transactions on public blockchains.

Risks

Legal risks

- Cross border PII and health data privacy

Business risks

- Limited number of potential revenue channels to sustain the business. Potential to sustain the business through charitable donations

Technical risks

- As with any other DLT use case, advancements in quantum computing poses a risk in the security of the technology

Special Requirements

- N/A

External References and Miscellaneous

- A detailed document with descriptions can be provided upon request.

Other Notes

- We assume all stakeholders in the value chain prioritize increasing the number of lives saved through a more efficient, globally integrated process