DONOR SPACE

Bringing everyone together to support volunteer donors in Blood stem cell donation process

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Foreward

I would like to thank my peers, friends, and staff at Umeå Institute of Design for your inspiration, motivation, and help that you have given me throughout this thesis and my master education.

Thanks to my tutor, Niklas Andersson, for inspiring conversations, your advice, and patience. I am really grateful to my external tutors, Sara and Tara for our talks, reviews of presentation in advance and eye for potential in different phases of the project. Special thanks to Stoffel, for guiding entire Interaction Design IxD simultaneously with his PhD.

Thank you to my collaboration partner, DKMS Germany specially Sabine Hildebrand, Head of International Donor Recruitment and Jürgen Sauter, Head of Scientific Project Department for their insights, enthusiasm and hospitality. Thank you to Lars Skagerlind, Study Nurse/Transplant Coordinator the Hematological Department, Cancer Centre University Hospital of Umeå, Sweden for coming on board, and bringing me on board. Without your continuous support this project would not exist today. Thank you to all the nurses, and people who shared their experiences during the past few months.

Special thanks to Kempe Fonden and Brita-Stina Nordenstedts Donation for granting individual scholarships to this project. Without these grants this thesis would not have become what it is today, and for this I am very grateful.

Lastly, I would like to thank my family for all the encouragement, giving me optimistic outlook, supporting me in my rational and irrational decisions and enabling me move far up north.
Abstract

Every 20 minutes, somebody in the world gets to know that they have a blood-related disorder or disease. For many of them, the only hope of recovery is stem cell transplant. For the transplant, the blood stem cells are often recruited from someone unknown, a volunteer donor. However, one in ten patients does not find a donor.

Today worldwide more than 50,000 transplants are carried out annually and are increasing each year. In order to meet the continual requirement of stem cells, there is necessity for more volunteers.

The donors, a non-patient group invite themselves into medical process of blood stem cell donation. For them, the donation journey isn’t an easy process. First of all, becoming a potential match to a patient happens in rare cases. In comparison to other donation procedures, this process is quite challenging and complicated; the donor goes through a lot of tedious and time consuming steps over ambiguous time frame. They have lot of individual responsibility, involves considerable commitment and have to connect with a lot of stakeholders involved in the process performing in silos across different geographies. These stakeholders involve NGO, healthcare professionals, family members and in some cases, patients too. The project explores how we might enhance the blood stem cell donor’s experience by combining healthcare and interaction design practices. How might we assist donors throughout the donation process? What if every stakeholder involved in the process comes together to build the experience for the donors?

DONOR SPACE, a framework focuses on creating a cohesive, end-to-end experience, optimising it for all the stakeholders rather than focusing only on one aspect of the donation process. It revolves around how the young millennials can be made aware, engaged and feel acknowledged for their efforts throughout. The touch points of the service include a donor flock, a pack and a deck which impacts society behaves around blood stem cell donation.

The project is supported by user research and analysis, value proposition, user journey, stakeholder mapping, and testing recommendations in the future.
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### Background

Globally in the medical and healthcare field, due to technological advancement and higher success rate of life-saving procedures, there has been a dramatic increase in the number of blood stem cell transplants performed each year. Consequently, the demand for blood stem cells from the donors is continual. The process of acquiring these cells from donors has its obstacles. Once volunteers are willing to donate and are identified as a potential match to the patient, they go through various stages, involving a long waiting period for the donors.

The aim of the project is to apply and combine interaction design practices in the healthcare and medical world: how it would affect and shape specific experiences for the blood stem-cell donor. I would propose a digital service design that provides strategies to enhance the donation journey experience for the volunteer donors and the stakeholders involved in the process.

The thesis project explores how we might design alternative ways to enhance a donor experience through digital services.
Collaboration

I collaborated with DKMS, Germany. DKMS is a non-profit advocacy group that works to raise awareness of the need for donors for hematopoietic stem cell transplantation (HSCT), which people with blood cancers need for treatment. It also helps people sign up with national bone marrow registries. DKMS was founded in Germany in 1991 and as of 2017 had affiliates in the US, the UK, Poland, and Spain.

The two primary contact persons were Jürgen Sauter, Head of Scientific Project Department at DKMS and Sabine Hildebrand, Head of Global Donor Recruitment at DKMS.

Within my thesis collaboration, DMKS took in the perspective of the role of validating the project and its relevance at the larger scale to the society. Eventually, they are the ones who will further implement my project outcomes to improve the experience for the donors. I shared my ideas with them remotely, and we were in contact via emails after the research phase of the project and co-creation happened virtually, gave feedback on generated ideas. They actively played a role in my project after the research phase, as I got them as collaborators during the ideation phase. They gave more insights into behind the scenes and procedures concerned with administration, logistics and different public healthcare setups in different countries. They let me explore my ideas and concepts in a designerly way.

Cooperation

The project was supported by the Hematological Department, Cancer Centre, University Hospital of Umeå, Sweden. My primary contact person was Lars Skagerlind, Study Nurse/Transplant Coordinator. Including other responsibilities, one of his roles is to coordinate between donor registries globally, donors and patients and blood banks. He helped me throughout my project and got me in touch with other nurses and donors involved in the process. He arranged my visits to observe the donation process and co-created with me and other nurses during my ideation phase.

During the research, I had access to critical information such as donor names and contacts that I won’t disclose. However, this did not affect the process of creating insights/findings, and eventually the deliverables.

Personal Interest

In the past, I never had an opportunity to work on a healthcare project intensively. There is a personal motivation to explore a project in the healthcare and medical field. I wanted my project to be grounded on a human-centred approach. I observed a scope to enhance the Donor Experience in the stem cell donation process. I saw this thesis as an opportunity to explore interaction design domain in the healthcare and medical field. The primary focus has been the donors because they voluntarily invite themselves into the medical process.
**Design Approach**

Throughout the project, the human-centred approach is applied. Different stakeholders involved in the process were identified and reached out during the design research phase. The project aims: how it would affect and shape specific experiences for the stem cell donor over time.

**Vision**

The vision is to support donors in pre-donation, during the process and finally, post care to build follow-up with them. I would propose a digital service design/system intervention that provides practical and applicable design tactics and strategies to develop stem cell donor experience.

The original intent of the project is to look into organ donation. I narrowed down to stem cell donation as the donor is alive and it is a long process. During early research stages of the project, I narrowed down to volunteer donor experience. For most of the design project, there has been a lot of focus on patient group and healthcare professional stakeholders related and limited to hospital environment from an interaction design perspective. I saw a lot of room to play around and explore because non-patient groups because they voluntarily involve themselves in the medical process, and work towards enhancing experience for them which could large section of society.
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Summary

This chapter presents the research done during the project. It will describe the findings, approaches and methodology that was utilised during the research phase.

The research spanned the first five weeks of the project and was scheduled to split into the plan for each week for user studies and academic papers. In these weeks, interviews with the focused group were conducted, the 4th week involved field visits to meet the donors, observe the donation process and to map the donation journey as-is with donors and the last week was planned for synthesis.

The research phase broadened the initial project intent which was earlier only to focus only on volunteer donors to rather involve all the stakeholders to create a holistic donation experience.
**Intention**

The goal of research was to validate the project direction, to break or confirm initial hypothesis done to start the project. It helped to understand better the context and people involved in it – the motivations and challenges of the different stakeholders around the world were involved.

Ultimately intent was to find possible opportunity areas, and to develop guiding principles that could be used to create the concept proposal.

**Approach**

To start with, I spent time doing foundational research and simultaneously looking for the focus groups through social media, arranging interviews.

I conducted co-creation workshop and field visits. The focused group included donors who have already donated in the past, donor registries, whose intention is to recruit, retain a match donors, healthcare professionals, nurses, transplant coordinators, doctors, family members of the donors and the patients. My primary focus was the donors who have already donated in the past years.

After conducting research, I mapped out all of the collected data and analysed relationships between the stakeholders at different points in the journey. This mapping served as a basis for clustering of findings and having a systematic overview of the process.

I shared my findings and understanding back to the field, which strengthened my learnings.

Further opportunity areas were identified in the different phases of the donation process – before and after the donation – and five underlying principles were developed from research synthesis for ideation phase.

**Foundation Research**

Through literature, videos, articles, and blogs where people shared their personal donation experiences over the internet, I was able to build the foundation; get a perspective of what blood stem cell donation means and its effects on the donor. The project started off with a phase of secondary research. The academic papers studied were mainly in the area of medical volunteerism, the motivation of being organ donors, long-term medical effects of donation on sibling donors, donor follow-up, donor recruitment and their deferral rates. Books on the topics of stem cell donation, healthcare and design were read with the intention of better understanding the entire donation scenario.

The foundation research helped me to set grounds for my primary research regarding the information I was missing.

For instance, current challenges faced by NGO to assist the donors, perspective of patients or blood stem cell receiver was not available.

People who wrote the academic papers were further contacted during primary research.
Steps involved in Peripheral blood stem cell transplant for the volunteer donors
The first section of the secondary research consisted of understanding the process itself and the second phase included healthcare trends in the field of interaction design concerning the topic.

**Peripheral Blood Stem cell Transplant**

A procedure in which a patient receives healthy blood-forming cells (stem cells) to replace their stem cells that have been destroyed by disease or by the radiation or high doses of anti-cancer drugs that are given as part of the procedure. The healthy stem cells may come from blood of the patient or a donor. ("NCI Dictionary of Cancer Terms", 2018)

**Source of Blood Stemcells: Donors**

The healthy stem cells may come from the blood or bone marrow of the patient, from a donor, or from the umbilical cord blood of a newborn baby. Donating stem cells is an act of medical voluntarism, which usually involves no financial cost at the end of the donor. From preliminary research.

People were categorised into 3 categories:

1. **Voluntary Action**
2. **Sibling Match**
3. **Patient itself can be a donor in some cases**

Stem cells are recruited from various sources such as umbilical cord or sibling donor. I narrowed down to volunteer donor during the research phase because of specific factors:

1. Accessibility of the volunteer donors to reach out and talk to. I was only able to reach out to a limited number of sibling donors.
2. The motivation of sibling donors is different than a volunteer donor (which is later mentioned in the primary research phase).
3. Volunteer donors themselves enrol in the donation process. I wanted to understand their motivations and make them the focus of my project.

Still, during primary research, I reached to sibling donors to understand the similarities and differences.

**How PBSCs are obtained for transplantation?**

The stem cells used in PBSCT (Peripheral blood stem cell transplant) come from the bloodstream. A process called apheresis or leukapheresis is used to obtain PBSCs for transplantation. For 4 or 5 days before apheresis, the donor may be given a medication to increase the number of stem cells released into the bloodstream.
In apheresis, blood is removed through a large vein in the arm or a central venous catheter (a flexible tube that is placed in a large vein in the neck, chest, or groin area). Furthermore, the blood goes through a machine that removes the stem cells. The blood is then returned to the donor, and the collected cells are stored. Apheresis typically takes 4 to 6 hours. The stem cells are then frozen until they are given to the recipient. ("Blood-Forming Stem Cell Transplants", 2018)

Types of donation

A stem cell transplant can be
1. Autologous (using a patient’s stem cells that are collected and saved before treatment)
2. Allogeneic (using stem cells donated by someone who is not an identical twin)

Over the past two decades, allogeneic hematopoietic stem cell transplantation (HSCT) has become an established therapy with increasing numbers of procedures every year. Several stem cell sources, such as mobilised peripheral blood stem cells (PBSCs), bone marrow (BM), and umbilical cord blood (UCB), are suitable for HSCT in clinical practice. During the past decade, PBSCs have almost replaced BM as a stem cell source in autologous transplantations.

Donating BM or peripheral stem cells is a challenging process that requires a considerable commitment on the part of the donating individual.

The following section contains details about the process and information related to findings in literature during my secondary research phase.

Communication and Support to the Donors

Research shows that to support the potential donors there is a need to provide relevant information to the public— to all potential donors—and proper training in communication by health workers. The health worker’s professional involvement is different at various points over the time when it comes to building the relationship with the potential donor. The emotive participation plays a primary role and influences the relationship, particularly near the time of donation.

I narrowed down to allogeneic method during the research phase of the project, because of its current frequent occurrence against the other two processes.
There is a need to learn the emotive and cognitive matters in building relationships with the donors in a better way for excellent communication between those involved.

Effective communication, emotive involvement and personalised experience to each donor is crucial as each donor has different concerns about the donation. There is a need to communicate effectively at the beginning, while a person registers for the donation by the healthcare professionals. Also, communication should be expanded not only through informing about the donation process, but also emotional aspects should also be addressed throughout the donation. (Aurelio et al., 2011)

**Stem cells From Different Ethnicities**

It has been consistently observed considerable benefits of intra-population donor recruitment as it provides more chances of a been match to a patient. More of donor recruitment activities need to be carried out in specific countries and targeted at defined populations. For that, population-specific donor recruitment expenditure is required. (Schmidt, Sauter, Pingel & Ehniger, 2014)

**Personalised Care and Attention to the Donors**

There has been an emphasis on the care of each donor, that should take into consideration his or her situation and needs, including the relationship (Kisch, Boilmsjö, Lenhoff & Bengtsson, 2015)

Some donors desired more emotional support from the hospital. Emotional support provided by the hospital was ‘moderate’ or ‘very adequate’. The quality of interaction with medical staff also impacted on emotional coping. As a reflection of differing practices by health professionals, the extent of positive communication with medical staff varied across donors. Not all donors agreed that they received high-quality support. Some donors expressed a desire for more emotional support from the hospital. Others reported that they felt neglected and that they were used merely as a means of curing the patient. (Pillay et al., 2012)

Donors offered the following recommendations for improving their preparation and hospital-provided emotional support: post-donation follow-up care; provision of preparatory information about the physical and emotional burden of donation well before the actual event; help with self-injecting and information about the post-donation condition of the recipient. (Pillay et al., 2012)

**Follow-up With the Donor**

There are several limitations in the study regarding consequences of donation on the patient in the long run, not only physically but at an emotional level as well. (Kennedy et al., 2003)
In past clinical trials, observational information collected from randomised donors represents a vital resource to capture the overall incidence of adverse occurrences, including rare events. Follow-up is not only required after the donation but also during the donation (Pamphilon et al., 2009). A better understanding of all risks, including short-term and long-term, as well as of low-frequency events, is needed. Psychological consequences are poorly understood. (Pamphilon et al., 2009) It will be essential in future to ensure that all donors, including children below 16 years receive appropriate follow-up. (Pamphilon et al., 2009)

**Preparedness to Donate**

Counselling donors before HSC collection should be based on a good understanding of the different risks associated with both BM and PBSC collection. (Pamphilon et al., 2009) There is a requirement that the donor thoroughly understands the risks and complications that are related to the donation. For that, the donor needs to be educated by the healthcare professionals in a timely manner.

Foundational research helped in building my scientific and theoretical knowledge about the topic. It also set the ground for my primary research concerning which type of donation process to focus on, what aspects of the donation phase to consider while conducting interviews.

**Primary Research**

Based on the knowledge I gained through secondary research I assembled a list of people and NGO, I would like to get in touch with for primary research. I identified the different stakeholders that are a part of the BSC donation process. This helped me to clarify what kind of people I would investigate for my research.

I spent time in looking for the user groups and arranging interviews with through social media.
In total, I was able to talk to 32 different stakeholders. Taking human-centred design approach in the project, the focus was
Eight volunteer donors who have donated in the past, three registered donors, two sibling donors, four nurses, one doctor, one
transplant coordinator, four patients, seven professionals working in 4 different NGOs (working towards donor recruitment), two
family members, two stem cell experts plus some young millennials who were not aware of the donation process. I tried to engage
people from various backgrounds and demographic groups to bring diversity in my research. It included visits to the University
Hospital of Umeå, Sweden. Further, DKMS was contacted to get detailed information.

The interviews were conducted differently — individually, in groups, and in a workshop format. Some were done remotely, via
Skype as well as over the phone and some in person. I was not able to separate the different research phases according to the
stakeholders as planned in the beginning. I decided to go with the flexible approach of mixing up interview types and adapting the
questions while learning more about the topic because of availability of interviewees from different countries.

I prepared semi-structured questionnaires for it, which covered aspects of their donation experience, current challenges and future
expectations with the donation process. While talking to NGOs in India and Germany included group participants. It gave me
collective responses and attitudes towards donor recruitment and assistance.

SEE APPENDIX (PG 115)
I got an opportunity to observe the apheresis process, the donation process, where I shadowed the donor and the nurses. During the donation, I got chance to have conversations with the donor, opportunities before and after the donation were identified.

I organised inperson meeting, a workshop was conducted remotely through Skype, which didn't help me to understand subtle nuances faced by the donor. During the session, I used the method of Journey-Mapping where I mapped donation steps. The emotional journey was immediately visualised on the board through post-it notes and paper drawings. The Journey mapping turned out to be ideal for me, as I was able to cover each donation step in greater depth and breadth. It made it convenient for me understanding donation as a journey at one place.
Interviews, field activities, Journey Mapping creation conducted throughout the research phase were synthesised and summarised to understand the point of view of all stakeholders.

During the meetings, I could see the clash of interests and terms of responsibility among them. To maintain the privacy of the donors and others names and details are not disclosed in the report.

Below is the insights summary from the participatory observations and interviews conducted:
NGO as Facilitator

**ENGAGEMENT**

“Hard of connect and track the registered Donor after certain years as some change their location, address, sometimes names as well”

**COMMUNICATION**

“We explained verbally over phone, lot of times things get lost”

“People don’t believe us when we contact them, they think it’s a spam in first go”

**RELATIONSHIP**

“Having one point of contact makes things easier for the donor.”

Healthcare Professionals as Caretaker

**ENGAGEMENT**

“Most of the registered donors belonged to the medical world, such as nurses, doctors, there is a need to spread awareness about it.”

**COMMUNICATION**

“They understand it, but don’t really understand it.”

**RELATIONSHIP**

“They feel abandoned after the donation, no way to repay then. They undermine their efforts, thinking about the patient.”

Family Member as Protector

**COMMUNICATION**

“I didn’t rely much of the information given by my son (volunteer Donor), wanted to talk to professionals.”

**AFTER DONATION**

“Now, I know fortunate I was. I feel the pain of people who are having trouble finding donors.”

Donor as a Giver

**ENGAGEMENT**

“I was unprepared for the severity or duration of pain after donation.”

**COMMUNICATION**

“I wish now nurse would have bit more clear in explaining few things and in translations, else they were quite helpful.”

**RELATIONSHIP**

“I harboured self-blame thinking if the recipient had complications or died.”
### Donor Mindsets Towards Donation

Represents various attitudes and mindsets of donors during different steps of the donation.

<table>
<thead>
<tr>
<th>Donor Mindset</th>
<th>Attitudes/States</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Optimistic</strong></td>
<td>Confident, Easy-going, Responsible</td>
</tr>
<tr>
<td><strong>Despondent</strong></td>
<td>Distress, Concerned, Worry</td>
</tr>
<tr>
<td><strong>Conformist</strong></td>
<td>Seeker, Search, Perspectives</td>
</tr>
<tr>
<td><strong>Skeptic</strong></td>
<td>Doubts, Uncertainty, Questions</td>
</tr>
</tbody>
</table>

#### Optimistic

"I would lose nothing and be able to save a life."

#### Despondent

"I was often anxious and worried about treatment failure. What if the receiver dies?"

#### Conformist

When I was told that I am a match to the patient, I was looking for stories for others to learn from their journey.

#### Skeptic

"Don't know what happened to my samples after I gave it."

### Donor Motivation to Donate

<table>
<thead>
<tr>
<th>Motivation Type</th>
<th>States/Qualities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Building Positive Identity</strong></td>
<td>Sense of Achievement + Pride, Meaningful Life</td>
</tr>
<tr>
<td><strong>Social Obligation</strong></td>
<td>Encouraged by the Family</td>
</tr>
<tr>
<td><strong>Saving Life</strong></td>
<td>Natural Instinct, Altruistic</td>
</tr>
<tr>
<td><strong>Others</strong></td>
<td>Religious Conviction</td>
</tr>
</tbody>
</table>

### Case Studies

- **Optimistic Donor**
  - Confident, Easy-going, Responsible
  - "I would lose nothing and be able to save a life."

- **Despondent Donor**
  - Distress, Concerned, Worry
  - "I was often anxious and worried about treatment failure. What if the receiver dies?"

- **Conformist Donor**
  - Seeker, Search, Perspectives
  - When I was told that I am a match to the patient, I was looking for stories for others to learn from their journey.

- **Skeptic Donor**
  - Doubts, Uncertainty, Questions
  - "Don’t know what happened to my samples after I gave it.”
Striving to be a Quality Donor

Unresolved Guilt

Post Donation

Medical Dismissiveness

Feeling Neglected

Disappointment Over Recipient Death

Pervasive Pain

Valuing Recipient Gains

Exceeded Expectations

Mental Preparedness

Looked Online

Burden of Responsibility

Paper work + Commitment + Managing between work
Research Synthesis

The collected data from various stakeholders inquiry was condensed into personal interviewee profiles. Each profile contained relevant information about the interviewee and notes as well as quotes specific to that person. This visual overview helped me to identify common patterns, and highlight interesting findings.

I anticipated the challenges from the donor perspective at the beginning of my project, but the aspect of all the stakeholders became apparent patterns emerged only during the research, mapping donation.

Insights were analysed as opportunity risk, the probability of losing the donor here when resources are irreversibly committed.
Preparation

Verification Typing
Sample Matching
Pre Screening
Mobilization (GCSF injection for 5 days)
Peripheral Blood Cell Donation
Recovery

Support

Fear of medical procedures
Medical Volunteerism
Seeking Sources to learn about the process
Family Discouragement
Reassurance
Risk was minimal before proceeding

Concerns

Disappointment By themselves
Management by Donors
Stressful
Change in Procedure
Preparedness for symptoms
Particular Concerns
Unknown side effects
Opportunity Risks

Probability of loss of a potential donor arising when resources are irreversibly committed.

- Mental Preparedness
  - Valuing Recipient Gains
  - Exceeded Expectations

- Minimize Pain Related Distress
  - Pervasive Pain
  - Disappointment Over Recipient Death

- Acknowledgment

- Striving to be a Quality Donor
  - Assurance
  - Burden of Responsibility

- Respect
  - Unresolved Guilt
  - Feeling Neglected Acknowledged

- Post Donation
  - Follow Ups
  - Medical dismissiveness
  - Simplify

- Valuing Recipient Gains
  - Gains Exceeded Expectations

- Disappointment Over Recipient Death
  - Pervasive Pain

- Mental Preparedness
  - Opportunity Risks

- Striving to be a Quality Donor
  - Assurance
  - Burden of Responsibility

- Respect
  - Unresolved Guilt
  - Feeling Neglected Acknowledged

- Post Donation
  - Follow Ups
  - Medical dismissiveness
  - Simplify
One thing strongly came from primary research, people registered in the donor registries were mostly working in healthcare and medical field or somehow related to the area, that's how they learnt about the process. Others were through donor drives and campaigns. At the same time, there was the concern regarding the rising demand of stem cells for different ethnicities and social backgrounds. External stakeholders reflected about not being aware of the process at all, mostly had the misconception of being the painful process.

Opportunity identified was to How to create more in-depth community engagement within different social backgrounds and ethnicities?

Segmented Process
Various stakeholders involved in the process trapped in silos, separated by department, geography, and were using different tools to communicate with the donors and among themselves. It was very evident having one point to contact for the donor build the trust and comfort in the donor.

How might we create a system where the donor is in the centre while others come together to improve the experience for the donor? How might we assist the donors and others involved in the entire Process?

Communication
When a match to a patient, Most of the information is given to the donors by various stakeholders through phone and essential decisions and people don’t believe when registries contact them, they think it’s spam in the first go

Donor understood it but indeed didn’t understand the complexity involved it. Even the full information was given to them, for their assurance and security they looked for stories and experiences of other donors and personally contacted them to learn about the process more.

There were specific points in the donation, where they expressed that it was hard for to recall things told by Ngo or healthcare professional over telephonic conversations. How can donor be navigated throughout the process?

Donor Acknowledgement
Donor expressed concerns about not been acknowledged at their workplace after the donation. Also, in a lot of cases donor undermined their efforts thinking about what patient was feeling.

One of them, felt abandoned after the donation, thank you mail didn’t, she was expecting much more. Opportunity identified was to How the donor can be acknowledged at each step of the donation?
System Mapping

Grouping and labelling different stakeholders into different labels as per their roles.

<table>
<thead>
<tr>
<th>Giver</th>
<th>Facilitator</th>
<th>Caretaker</th>
<th>Receiver</th>
<th>Protector</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donor</td>
<td>NGO</td>
<td>Healthcare professionals</td>
<td>Patient</td>
<td>Former donors</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Former patients</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Family members</td>
</tr>
</tbody>
</table>

Research 1 55
Current Scenario

Current segmented system, The stakeholders trapped in silos, separated by department, geography, and their use of different tools.

Initiative

To bring everyone together to support the volunteer donors in the donation journey

How might we bring everyone together to support donors involved in the SCD process
Before entering the first ideation phase, I wanted to be able to communicate my research findings as clear as possible. It was necessary to me since parts of the ideation would be carried out with people unfamiliar with the donation process.

The underlying principles of the found patterns would help me in having a set of parameters to design for, similar to success matrix of the project.

**Design Principles**

- **Curiosity in the process**
  - Addressing time gaps in various donation stages by building continuous interest in the process

- **Surfacing the Content**
  - Bringing behind the process activities to the donors to build trust

- **Instant Accessibility**
  - Accessing information at any point by anyone involved in the process

- **Narratives as a hook**
  - Engaging the donors through stories throughout the process
Concept Development

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75 Branding
77 Refinement
The concept development is based on the findings, design principles, and the updated research questions. There were several iterations of participatory ideating (ideation workshops, remote ideation, co-creation sessions). Between these ideation-rounds, concepts were updated and refined.

During the ideation phase, to effectively create and engage people the donor journey was categorised into onboarding, engaging in the process and offboarding.

I mapped the resulting concepts in low-fidelity prototypes into a service-framework. The donor journey was developed further into animation style and shared with the stakeholders. I had a chance to perform follow-up conversations to evaluate the prototypes and capture people’s expectations from them.

Based on these feedbacks a concept was selected to explore and refined further and eventually presented as the design proposal.
I conducted an ideation workshop with peers from Design school. During that session, specific **how might** were generated, and various ideas related giving incentives to the donor came out. Thoughts and ideas were **scribbled** and **collected** on post-its.

**Ideation**

**With Peers**

During the ideation phase, Rather than only focusing on one phase of the donation, I had to take a set back and broadly **categorise** the **donation phases**, where I crafted an initial service blueprint, and an idea of digital touch points was on focus as well. After that, to **break the journeys I was constantly zooming** into one phase simultaneously connecting it with entire donor journey.

**Own ideation**

Mapping ideas to support **stakeholders in the donation Journey**
Building Incentive system where donor feel rewarded at every point with connected service to feel acknowledged.

Donor care Kit to assist during the Process.

Building Relationship between Donor-Nurse-Patient. An object is given to donor and patient in the beginning. With every interaction, build it the object. It turns out to reward for the donor in the end as memory.

Initial Ideas

Shortlisted: Holistic Experience

On Boarding

In the Process

Off Boarding

On Boarding

In the Process

Off Boarding

Donor care Kit to assist during the Process.

Building Relationship between Donor-Nurse-Patient. An object is given to donor and patient in the beginning. With every interaction, build it the object. It turns out to reward for the donor in the end as memory.
I shared the donor journey service blueprint and various directions with the healthcare professionals, who made specific ideas concrete and particular ideas fade away because of emerging ethical issues during that session.

For example, the idea of a kiosk disposing the swab kit, really made one of the nurse excited. I asked questions connected to the donor journey with touch points I was showing. I created donor care packs from pre-, during and post-donation, and we discussed what could go in there and at what of the donation journey could be introduced to the donor.

During discussions, the direction of arranging the concept into three broad stages: onboarding, in the process and off-boarding, became more concrete and viable.

To assemble my thoughts, I made a demo animated video of a donor journey (fig) and sent it across online to the donors as a probe, and the specific question was framed and asked them to fill in their opinions. But I received only replies from two donors. I figured out the survey was not the best way to get feedback from stakeholders. Answers I received included that it would be nice to have a swab kit through the kiosk, but I was looking for more responses in more depth. For instance, what is helpful and strong about the concept? Alternatively, I met one of the donors in person and shared my concept, and in turn got more constructive feedback. For example, he mentioned it would be better to take home the swab kit disposed from the kiosk rather than doing it in public space.
As a next step, the developed ideas and concepts were clustered depending on similarities. By doing this, the number of idea-groups was introduced during the donation journey.

To detail my ideas further, I organised an ideation workshop with nine students from Umeå Institute of Design (fig). The intention was to develop features for the digital touchpoints at various stages of the donation.
I shared that animation video with DKMS at the same time. We had a call setup to discuss further and refine the ideas. It also helped me checking facts and made me more conscious of the fact that the healthcare system in each country varies. They gave feedback on the proposals and made me narrow down the target group, too. They helped me ground certain things, but the feedback session also expanded on some ideas and gave suggestions on how I could add to them, for example, to adapt to specific user groups such as young millennials. It was great to hear what merely seemed exciting from their perspective; details such as a receipt bag in the donor care pack.

During prototyping, I parallelly designed for the donors various stages of the donation simultaneously: onboarding, offboarding and engaging them in the process. To explain prototyping phase, I categorised it into different identified touch points. These touch points in the service were picked because of its novelty factor, highlights existing concrete artefacts in the service and to the existing service.

To bring coherency in the entire process, I named the donor-focused service as donor space. The kiosk as donor flock (metaphor to gather), the collaborative platform as donor deck (metaphor to a platform) and the kit as donor pack.
Based on the research insights and design principles, branding the entire donor journey played a crucial role in the project. The objective of branding here is to motivate people to value the voluntary donation process more than they would do otherwise. It bought cohesiveness to all touchpoints involved in the service.

I conducted a workshop, where I prepared five mood boards focusing on the visual style. Different illustrations were shown to the workshop participants and were asked what the figures are communicating to them. Finally, I took a path of creating the visual language which was empathic to the donors, user-friendly, inviting and blended with playfulness but at the same time communicated the message to the young millennials.
# Concept Evaluation

The touch points donor flock and pack were evaluated with the two healthcare professionals, DKMS, two donor and ten students at Design schools. In total, I conducted 5 follow-up conversation with different stakeholders. I was not able to evaluate the donor deck in too much depth due to time constraint.

## Service Blueprint

I started detailing out the service blueprint simultaneously and developing the narrowed touch points by filling it with facts and more concrete information.

## Early draft of service blueprint snippet

<table>
<thead>
<tr>
<th>Concept Evaluation with Nurses</th>
<th>Concept Refinement</th>
</tr>
</thead>
</table>

### Concept Development I 77

#### Stages

<table>
<thead>
<tr>
<th>Stages</th>
<th>Time in the service</th>
<th>Potential Match</th>
<th>Suitable Match</th>
</tr>
</thead>
</table>

#### Donor Steps

<table>
<thead>
<tr>
<th>Time</th>
<th>Donation spike</th>
<th>1 week</th>
<th>2 week</th>
</tr>
</thead>
</table>

#### Channels/Medium

<table>
<thead>
<tr>
<th>Word of mouth</th>
<th>Swab kiosk in public space</th>
<th>Online registration</th>
<th>Quarterly email</th>
</tr>
</thead>
</table>

#### Physical Evidence

<table>
<thead>
<tr>
<th>Swab sample</th>
<th>Physical kiosk</th>
<th>Receiving the swab sample</th>
<th>-</th>
</tr>
</thead>
</table>

#### Digital Evidence

<table>
<thead>
<tr>
<th>Receiving the swab sample</th>
<th>Physical kiosk</th>
<th>Receiving the swab sample</th>
<th>-</th>
</tr>
</thead>
</table>

#### Donor Early Action

<table>
<thead>
<tr>
<th>Read the details</th>
<th>Motivation effort to walk to the kiosk</th>
<th>To come across the webpage</th>
<th>-</th>
</tr>
</thead>
</table>

#### Donor Action

<table>
<thead>
<tr>
<th>Sign up for it</th>
<th>D1. read about the process</th>
<th>D2. check the eligibility</th>
<th>D3. fill it online</th>
</tr>
</thead>
</table>

#### Donor Expectations/ Need

<table>
<thead>
<tr>
<th>Why am I doing this, benefit of signing up</th>
<th>Easily accessibility</th>
<th>A. might stumble upon it accidentally, B. Visit after interacting with kiosk</th>
<th>Get reminded</th>
</tr>
</thead>
</table>

#### Emotional Journey

<table>
<thead>
<tr>
<th>Trust the referring person</th>
<th>Feel connected and personalized</th>
<th>Memory, recall, Feel connected</th>
<th>Nostalgia, trusting the system</th>
</tr>
</thead>
</table>

#### Backstage

<table>
<thead>
<tr>
<th>Have sample in the donor kit so the person can pass on</th>
<th>Web page maintenance</th>
<th>Donor is identified as a match to the patient</th>
<th>Streamlining the experiences from the donor's point of view</th>
</tr>
</thead>
</table>

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*Concept Development I 77*
Since I was focusing on the digital touch points, the form of the artefacts was explored to the minimum because of time constraint. To develop wireframes for onboarding of the donors, Card sorting method (fig) was used to build the features for the onboarding. User flows were created and wireframes were shared with students at the school. I went back to circles. Landing screens as “are you a donor” / “become a donor” were not inviting for people to walk to the kiosk. One of the test participants mentioned “I know even what stem cells are? Why would she even donate them?” Those comments helped me refining the wireframes. I reflected on my design principles to build the interface, for instance creating narratives as a hook. Ultimately, I decided to tell the story from a perspective of the blood stem cells.

**Donor Deck**

To begin with, I explored the idea of a digital portal personalised for the suitable donors, where they can keep track of the whole donation journey, access their health record, understand the next steps and connect with other stakeholders involved in the process such as donors who have already donated in the past. I collected stories from the donors to create the experience.
Donor Pack

To make the pack, I made lo-fi prototypes to share it with the donor, healthcare professional, and DKMS. Everyone’s feedback helped me in building it. One of the donors said he would like an organiser as he always loses his papers. After getting all the elements together, I explored the form and opening experience of the pack. A lot of paper exploration was done to get the sizing correct. Points such as fitting into the mailbox, portability and size of the injection box became a guide to the measurements.

The language was personalised with help od sessions with design students and native english speaker at the school, for instance, “CGSF injections” changed to “your injections”. One of the students pointed out CGSF sounds super scary. “Steps completed so far” was changed to “done”. The intention was to simplify medical language and terminology as much as possible, reduce the text to increase the legibility and still communicate the message.
Hi! Thank you for registering as Stemcell Donor 2 months back

You are match to a patient

I am Anna, I will get in touch with you soon and will assist you in the donation process.
The DONOR SPACE, a service framework focuses on creating a cohesive, end-to-end experience, optimising it for all the stakeholders rather than focusing only on one aspect of the donation process. It revolves around how the young millennials can be made aware, engaged and feel acknowledged for their efforts throughout.

The service represented is through three key touch points. Firstly, DONOR FLOCK creates awareness and deeper community engagement around the topic. These information kiosks are strategically placed in public spaces where people can grab a swab kit to register themselves. It supports in making donor registration more convenient and frequent, helping in cutting administration cost.

Later, once a donor is a potential match to a patient, DONOR DECK; a collaborative platform assists them in navigating the entire process, eliminating ambiguity. It streamlines tasks for everyone, reducing burden of travel and overseas cost for people involved, also providing a support system for their emotional well-being. The deck connects them to healthcare professionals, NGO, and pool of donors around the world, currently which happens through phone calls.

When a potential donor becomes exact match to the patient, DONOR PACK is delivered with CSGF injections making them feel special and appreciated.

Visual language is taken into account to make process inviting for the donors. To communicate the concept, a fictional youtube influencer takes viewers through his donation journey in the video.
The DONOR SPACE proposes a service blueprint which maps how volunteer donor experience the donation process would in the future.

It is split into three key swim lanes: service interactions and its steps, touch points, and expectations and needs of the donors in a chronological order. It visualizes the relationships between different service components — people, props (physical & digital), and processes.

The blueprint is instrumental because it maps complex scenarios spanning before, during, and after the donation. Blueprint depict the donor experiences that are omnichannel, involve multiple touchpoints, or require a crossfunctional effort between multiple stakeholders.

<table>
<thead>
<tr>
<th>Experience Stages</th>
<th>On-boarding</th>
<th>Service Interactions</th>
<th>Touch Points</th>
<th>Donor Expectations/Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opt In</td>
<td>Learn about the donation</td>
<td>Web page</td>
<td>Curious about the process</td>
<td>Aware about the commitment</td>
</tr>
<tr>
<td></td>
<td>Check eligibility Register</td>
<td>Kiosk</td>
<td>Informed about behind the scenes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Submit the Tissue Sample</td>
<td>Sample</td>
<td>Feel connected with the process</td>
<td>Trust</td>
</tr>
<tr>
<td></td>
<td>Reminder</td>
<td>Personal Details</td>
<td>1:1 Interaction</td>
<td>Via Phone</td>
</tr>
<tr>
<td></td>
<td>Notification</td>
<td></td>
<td>Been a match</td>
<td></td>
</tr>
</tbody>
</table>
### Engaged in the process

<table>
<thead>
<tr>
<th>Suitable Match</th>
<th>Definite Match</th>
<th>Off-boarding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continuous Support</td>
<td>Schedule Sessions</td>
<td>Comfort building At home</td>
</tr>
<tr>
<td>Check ins</td>
<td>Preparation</td>
<td>Donate</td>
</tr>
<tr>
<td>Updates</td>
<td>Follow up</td>
<td>Recovery</td>
</tr>
</tbody>
</table>

### Notification
- Virtual stories Meetings
- Perform Medical tasks
- Check ins
- Preparation
- Updates

### 1 Interaction Phone
- 1:1 Interaction phone
- Collaborative platform
- Own Journey
- Stories of others
- 24*7 assistance
- Health dashboard
- Access the results

### Personalized experience
- Streamlined

### Mentally prepared

### Simplify

### Acknowledged for the efforts
- Receiver (patient)
- Donor
- Non government organization (NGO)
- Healthcare professionals
- Family members
- Ex- Patient (Receiver)
- Ex- Donors

### Step Guidance
- Pre - knowledge about meetings

### Guide for the next steps

### After donation Result
- Thank you Feedback
- Healthcare professional
- Schedule follow up if required
- Recovery support via kit
- Incentive card

### Final Goodbye
- Recommend to others
- Remove from the registry

### Continuous Support

### Schedule Sessions

### Comfort building At home

### Donate

### Recovery

### Ending the Relationship
Donor Flock would create deeper community engagement from various backgrounds, help in building future donors. It would make donor registration more frequent and convenient, cutting down the administration cost for us.

- DKMS, Germany (NGO)

**On-boarding Experience**

The flock is placed strategically in public spaces where young millennials are reachable and match to the cause, such as university campus, gym or pharmaceutical stores.

They learn about the donation through the kiosk. It becomes instrumental in strengthening engagement in the society and secondly millennials have possibility to enrol themselves as donor. The flock disposes of the swab kit, which is currently used a way to register as a donor. The person can decide and read more about if the person interested in the contribution.

Through interface, people could learn basics about the stem cell donation and check their eligibility.

SEE APPENDIX (PG 125)
Engaging In the Process

Once a donor is a match to a patient, he/she gets access to a personalized online collaborative dashboard DONOR DECK where they get access to all the information to the donation at one point. It’s accessible by family members, healthcare professionals, and NGOs – the pool of donors. It brings all the varied stakeholders working across silos across geographies, departments together on one platform. The deck offers features such stories from former donors, Virtual doctor visit, 1:1 interaction with the doctor and nurses to build comfort among the donors with the process.

SEE APPENDIX (PG 125)
Engaging In the Process

When a potential donor is an exact match to the patient, with the injections they get a donor care kit, where they gain a complete overview of the process. The visual style of the pack is designed to engage and create curiosity among them. It contains different sections:

1. Steps completed so far.
2. Injections, instruction manual how to take doses, side effects of the prescriptions
3. To-Do on the day of apheresis, what to tell your family about the donation
4. Steps to be taken after the contribution, swab kit to pass it on to another donor
5. Donation Organiser.

“ I was only expecting to get C-GSF injections to prepare myself for apheresis, but I recieve this handy box pack with all clear instructions. It gives me complete overview of entire journey through empathic drawings, makes me eager about the next steps.”

- A Potential donor
Segment 1
It shows steps completed by the donor so far in their donation journey. As a reward, gift card is included in the pocket.

Segment 2
It depicts injection side effects in pictorial manner. It contains injection box and self guide injection manual in the pocket.

Segment 3
It contains family guide and things a donor could possibly consider on the day of apheresis.

Segment 4
It indicates reminder of things a donor should consider once the donation process is complete. It contains a swab kit to pass to the family members/friends.

Segment 5
The organiser sections helps the donor to manage paper work related to the donation. It includes: checklist, receipt bag for reimbursement etc.
UX Branding

Color Palette

Circular Std Book  Circular Std Black

Visual Language

Warm, Empathic, Inviting

Brand Tone

Trust, Approachable, Personalised
Please Ask Us
Assistance At Any Point
Not Scary

Micro Copying

You Can Visit The Nurse
Visit Nurse

Community Feeling, Multi Ethnicity
Icons
Narrative

To communicate the concept, I created a fictitious narrative of the volunteer donor, a youtube influencer who has experienced the donor space service. He shares his experience of the blood stem cell donation, where he takes his viewers throughout his donation journey.

The outcome of the project can readily be tested and implemented for the donors to improve their experience. A lot of the aspects are also applicable to a sibling donor. At the same time, learnings can be made in medical volunteerism field. The scope of giving personalised experience to a donor might require more administration.

I look forward to opportunities to present and share the work, and the chances for development of thought that might follow. It would be interesting to evaluate further what the very core of the concept is and what would be needed as a bare minimum to turn it into reality.
Suggestions

This section includes future suggestions for other disciplines to take inspiration from to improve and enhance the focus experience in healthcare design and public health system. The below recommendations come from my learnings and observations made during the 20 weeks thesis project.

These learnings can be applied to healthcare system across departments and disciplines. It can potentially to improvement of the experience for patients, non-patients and people involved in healthcare.

Employing Visual language

In the medical world, the examples of visual branding encountered during the project gave impression of being impersonal and mechanical to the non-patient groups. Their role is to guide and give instructions to the user. These elements, such as illustrations and colour palettes, are used in instruction manuals, information pamphlets and digital platforms.

It could be utilised more powerfully to empathise with them. There is a massive design opportunity: the visual language could be more empathic, user-friendly and welcoming. It would help in building trust and would reduce a lot of anxiety among users. Not only the user but also family, friends can reduce a lot of stress among them.

One of the references is the donor pack, the outcome of my project where illustrations are inviting and create an empathic relationship with the donors in the case.

Labelling Stakeholders in Healthcare System

I would like to challenge the use of the terminology ‘donor’. The word donor has connotations of being technical, action based, taking and limiting in the society. Whereas as the word ‘giver’ has more generous implication. During research synthesis phase, I introduced new way of labelling and categorising various stakeholders involved in the process.
Altering the labels would make medical volunteerism process more acceptable in the society at the larger scale. For instance, action word donate can be rethought to word /we donate/ to we give. Eg. I am donating my cells to I am giving my cells.

I suggest to develop generous Considerate labels for the various stakeholders involved in the healthcare system in other processes too. It would make not only this process but other processes would connect the healthcare system more user-centred and friendly.

Due to the time constraint, The point of a donor as a giver was not emphasised because of the time frame and I was myself trying to understand the entire process.

The notion of difference in donor and giver in different languages is not studied here.

**Simplifying Medical Language**

While prototyping the touch points, during user testing sessions the donor bought difficulty in understanding medical/technical terms as they don’t have any medical background. The complicated sounding words made the process scary and hid a simple meaning. In the project outcome, technical explanations are written is simplified to communicate enough with donors and others.

**Interactive Storytelling in the Medical World**

Describing medical processes can be daunting task, lot of nuances can be undermined by the non-patient group when informed by healthcare professionals. Explanations can be made more engaging by unfolding complex procedures into engaging ways where relevant groups can relate to it. For e.g. Currently in the project storytelling can be found in introducing new information about the stem cell to the user. Further it should exploited in higher depth to throughout the medical journey.

**Physical to Emotional Wellbeing**

Currently, clinical medical records focuses and give emphasis to physical well being for health record purposes. Physical symptoms are well documented at every step of the donation at the same time emotional and psychological health parameters should be established as crucial as physical symptoms should be. The factor of emotional and mental wellbeing should be equally given attention too while assisting the donors. Dialogue should be extended beyond how are feeling today. This can further help to understand mental models of the focus group, Donors for the future groups.

The patient verbally tells them and its goes unrecorded. undermined. One of the suggestion would be to make anyone involved and document their wellbeing on daily/weekly basis which provides the source of and explores the ways.
Considering the Blood Stem cell transplant (HSCT, allogeneic hematopoietic stem cell transplantation) happens worldwide, different countries have their own rules and regulations around the donation. Every NGO and health care system in a country has own strategies in assisting the donors, and connecting donor and the patient during and after the donation.

I had unparalleled access to all the stakeholders involved in the project. I had the perspective of the nurses and transplant coordinator from Umeå University Hospital, Sweden, DKMS from Germany, donors from the United States, United Kingdom, India, Germany, Sweden, Finland, Poland, and the Netherlands. Different countries have different setups concerning donor recruitment, management and coordination. Healthcare system of one country does not bound my project. It is a much higher level where any of the healthcare systems could adopt the outcome of the project.

I decided not touch on the aspect of the relationship between the donor and receiver because of ethical issues of how and when donor-patient can contact each other after the donation.
References


I reached out to four organisations; one in the UK, one in Sweden, one in India, one in Germany. They provided me information via mail, on various aspects of the donors such as making people aware of the process and their recruitment process. Further on, one Skype call was set with the NGO Deshbandhu in India, and DKMS in Germany. DKMS decided to collaborate when I also shared my intention and initial ideas. Their primary concern was deferral rates of the donors after the registration and getting donors from various ethnicities. From their point of view, it becomes hard to connect and track the registered donors after the specified number of years as some change their location, address, sometimes names as well. When recruiting donors, they try to reach out young millennials between age group of 18-30 because of biological factors, their physical fitness and ability to regenerate cells quickly.

"Current challenges including Multi Ethnicity stem cells donors, but also donors from various social Backgrounds"

"We explained verbally over phone, lot of times things get lost" Regarding communication.

"Hard of connect and track the registered Donor" in terms of donor engagement.

On building relationships “Having one point of contact makes things easier for the donor “Current challenges including Multi Ethnicity stem cells donors, but also donors from various social Backgrounds”

Interviews Summary

// Non-government organisations (NGO)

I reached out to four organisations; one in the UK, one in Sweden, one in India, one in Germany. They provided me information via mail, on various aspects of the donors such as making people aware of the process and their recruitment process. Further on, one Skype call was set with the NGO Deshbandhu in India, and DKMS in Germany. DKMS decided to collaborate when I also shared my intention and initial ideas. Their primary concern was deferral rates of the donors after the registration and getting donors from various ethnicities. From their point of view, it becomes hard to connect and track the registered donors after the specified number of years as some change their location, address, sometimes names as well. When recruiting donors, they try to reach out young millennials between age group of 18-30 because of biological factors, their physical fitness and ability to regenerate cells quickly.

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"Hard of connect and track the registered Donor" in terms of donor engagement.

On building relationships “Having one point of contact makes things easier for the donor “Current challenges including Multi Ethnicity stem cells donors, but also donors from various social Backgrounds”

// Transplant coordinator at Hematology department Umea University Hospital, Sweden

The key role of the coordinator was of donor selection, assessment and management across the globe. They expressed concern regarding getting stem cells from various social backgrounds and ethnicity as migration is rising. “We are ones who are in direct contact with the donor and NGO. We are the bridge between them.”

As more people were migrating, it became crucial to have donors from various ethnicities, and they saw language also as a barrier in communicating with the donors. On their relationship with the donor, “Donors are unique for us, they are like a special guest” “I give my number to keep in touch and organise things with them. At the moment, we are communicating verbally and via calls over phone which lot of time creates lot of confusion among donors. In my experience, Donor are quite motivated when they come for the donation that they are contributing for good cause. They usually tell us things about how they felt, physical pains etc on the day of the donation.” For coordinator, overseas logistics of blood stem cells seemed like a burden. He mentioned “most of the registered donors belonged to the medical world, such as nurses, doctors, thus there is a need to spread awareness about it.”
Nurses with various job roles within the donation process, one was from a blood bank taking care of the apheresis process. They were experts on the apheresis procedure, and taking care of the donor on the day of donation. Other nurse roles handled the logistics during and after the donor contribution. Two of the nurses univocally mentioned “our role is to take care of the donor on the day of the donation, we are not aware of before and after the donation. We have rarely come across any extreme cases.” “They understand it, but don’t really understand it.”

One of the nurses mentioned “They come here for the clinical date when to get the donation done with someone from Hematology department, then nurse from other side check the veins of the patient, if it’s okay to perform the donation from those veins.” One of the Nurse from Skåne University Hospital mentioned “They Feel abandoned after the donation, no way to repay them. They undermine their efforts, thinking about the patient.”

Family members of the donors showed mixed reactions around their loved ones donating. Some were concerned about the well being of their relative whereas others were fine and proud of it when they learnt the intentions of the donor, their family member. “I didn’t rely much of the information given by my son, wanted to talk to professionals”

Sibling donor (SD) No matter what they were willing to give their stem-cells, their focus was to save the life of their sibling. For instance, one SD mentioned that at any cost, she was ready to donate because it was her brother was the patient. Key statements were “I didn’t care about how tedious the process was, it was only the last chance to save my brother’s life.” I decided not to include them further in my project as their motivations were different. However, some of the aspects of the final deliverables can be implemented from them also in the future. Whereas, some of the insights trickled to other donors as well such as The donor mentioned “It was hard with the paperwork and appointments, I had around dozens of visit for the donation, which was difficult between the work. I wish now, nurse would have bit more clear in explaining few things and in translations, else they were quite helpful. Here I had no any other option for me to only donate.”

Patient (stem cell receiver) I conducted two Skype interviews remotely, of which one was with a recovered leukaemia patient who received an anonymous donation match from a volunteer on time. They became active supporters of the donation once they recovered from their illness. They were grateful to donors for their volunteer support. At the same time, he quoted “I was not at all aware of the donation until the doctor informed my family and my only chance to save my life. The pain I went through is nothing close to donation.”
One of the patients was still recovering, so she was not comfortable talking to me in person. I sent her questions over mail regarding her outlook towards been match to an anonymous patient. Exchange of emails confirmed what I was aware of after talking to other patients. They were more grateful towards other people and their life in general too.

I was unable to find cases where the patient did not receive the match to the anonymous donor on time. Patient stated “Now, I know fortunate I was. I feel the pain of people who are having trouble finding donors.”

// Young millennials Outside the medical world, a lot of students I met and casually talked about the topic, were hardly aware of the BSC donation; particularly about the fact that they could contribute to saving someone’s life. Most of them were curious to know in the first place, what exactly blood stem cells are.

// Volunteer Donors from their motivations, mental preparedness, their pain points in the donation process, were taken as central to develop the project further. The insights were collected and categorised under various headings:

Feeling neglected
“I didn’t do anything after my donation, and no one acknowledged me for my efforts at the workplace”, one of the donors expressed. They were looking for appreciation from family and at work. Some felt Medical dismissiveness, were overwhelmed by medical language and needed better information and impact of the donation on their health. “Don’t know what happened to my samples after I gave it.”

The motivation of being a donor
For many of them, the decision to donate felt “natural” and was viewed as a “special” opportunity to show kindness and help another person. “I would lose nothing and be able to save a life.” said one of the donors. Some viewed it as an act of building a positive identity in the society, sense of achievement and creating a meaningful life. On the other side, one said it was a social obligation, she was encouraged by her family, and some did it because of religious conviction.
Mental Preparedness

Despite being willing to donate, a few donors needed reassurance that their risk was minimal before proceeding with donation. Although donors wanted to give, their enthusiasm was somewhat quelled by fear of medical procedures, for example the needles used during the donation procedures created anxiety among people. “I was unprepared for the severity or duration of pain after donation. When I was told that I am a match to the patient, I was looking for stories for others to learn from their journey” mentioned a donor. The pain is inextricably linked to the donor’s mental preparation and expectations of donation.

Burden of Responsibility

Some showed concerns regarding striving to be a quality donor, “I stopped smoking for 2-3 months, starting from about one week before I started injecting myself.” Others expressed unresolved guilt. They assumed they were the only hope for their recipient’s survival and held themselves accountable for adverse outcomes. Few of them were often anxious after donating, worried about possible treatment failure. “I harboured self-blame if the recipient had complications or died” “When I was informed that I am match to a cancer patient, to decide whether to donate or not-I was looking for stories of others.”

System Mapping Explorations

Different Models were explored to explore the relationship between volunteer donors and other stakeholders before narrowing down to proposal.
How might we create a holistic experience for stem cell donors to support them?

How might we develop effective strategies to minimize donor distress to enhance coping mechanism?
I organised an ideation workshop was organised with nine students from design school. The intention was to develop features for the digital touchpoints at various stages of the donation.

**Workshop Material**

Structure of this workshop. As a facilitator, I explained the donation process to give an overview of the donation process.

First was Warm-up exercise and then students were divided into a group of 2 and given different responsibilities in the donation process and handed over scaled models of various digital devices to brainstorm onto.
**Donor Flock (UI)**

- **What story does your blood stem cells have to tell?**
  - Learn how you can save someone’s life.

- **Your blood stem cells live in bone marrow of your body**

- **It renews itself**

- **It can be given to cure many diseases**
  - When transferred to a patient's body.

- **Giving your blood stem cells involves**
  - Your time
  - Hospital visit

- **This is how donation process looks like**

- **Check your eligibility to donate**
  - Age
  - Weight
  - Health

- **Congratulations! You can donate**
  - Grab a swab kit to know further
  - Send it back to us via post and register yourself.

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**Donor Deck (UI)**

- **Welcome**
  - This is a personal experience to exist during our donor registration phase.

- **Ask us anything**
  - In line with your donation, you are available to help you in your donation process.

- **Your donor buddies**
  - Anonymous donors who have donated to the patient above their volunteer and have been for the patient.

- **You should know**
  - More care was shown and taken during this critical period.
  - For help, always keep your buddy.
  - To alleviate a sort doubt.
  - Click on the tab you wish to read about.

Screen showcasing the feature of reaching out to the stakeholders virtually.

Deck with donor buddies feature where a donor can read stories of other donors.
Donor Pack

Donor Pack from inside

Donor Pack from inside 2

Donor Care Pack Details

Segment 2 Injection Pack

Segment 5 Organizer Bags

Segment 2 Self Injection Guide

Segment 3 Family Donation Guide