IDC School of Design
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Designing a service to improve the physical and psychological wellbeing of Thalassemic patients in rural India

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Amit Kumar Ram
Roll no. 216330005
IDC School of Design, IIT Bombay

Prof. Pramod Khambete
Project Guide

Declaration

I declare that this written document represents my ideas in my own words and where others ideas or words have been included, I have adequately cited and referenced the original sources. I also declare that I have adhered to all principles of academic honesty and integrity and have not misrepresented or fabricated or falsified any idea, data, fact or source in my submission. I understand that any violation of the above will be cause for disciplinary action by the institute and can also evoke penal action from the sources which have thus not been properly cited or from whom proper permission has not been taken when needed.

Amit Kumar Ram

Amit Kumar Ram

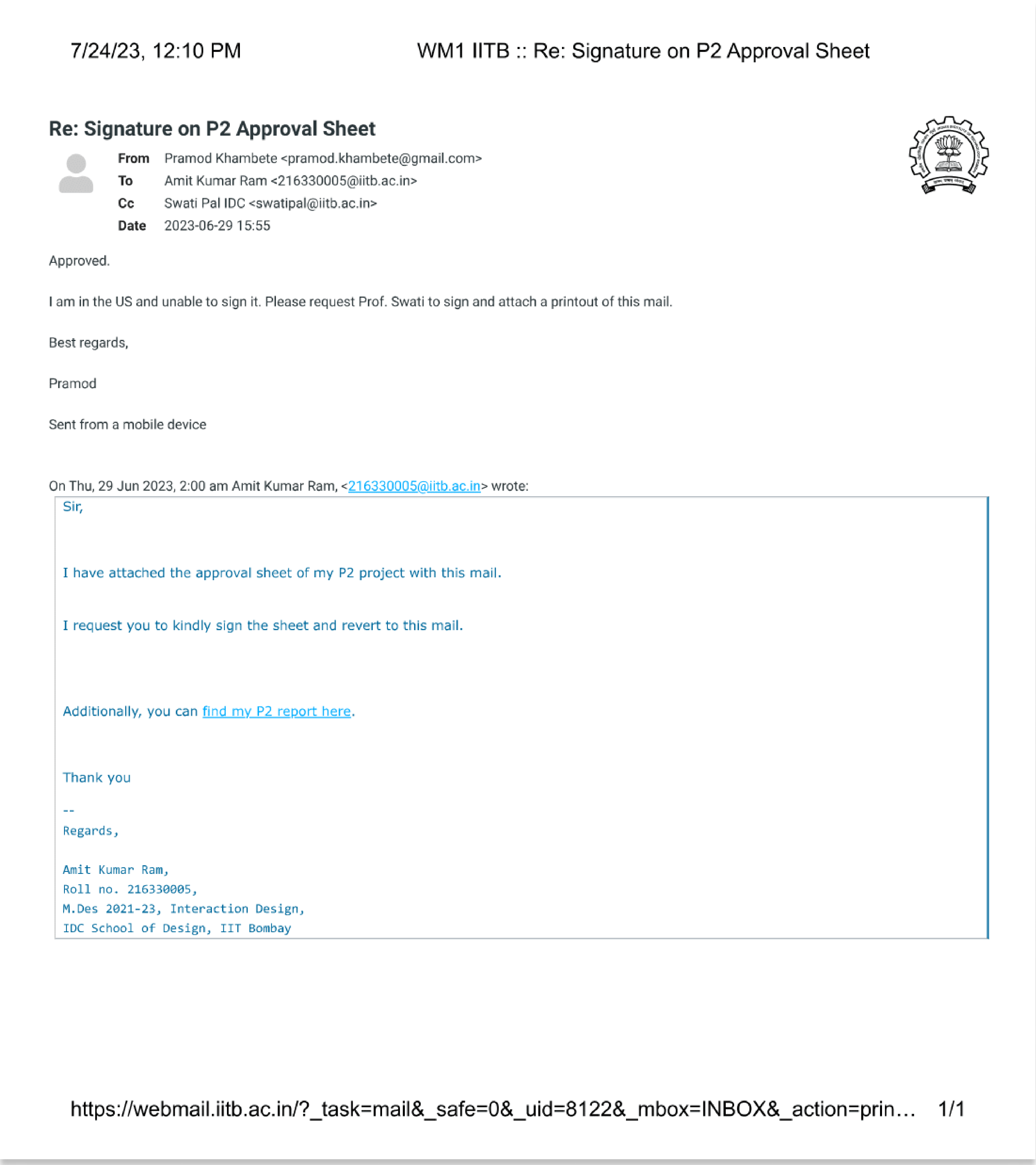
216330005
Interaction Design
IDC School of Design, IIT Bombay.
November 2022

Approval Sheet

Interaction Design Project 2 titled “**Designing a service to improve the physical and psychological wellbeing of Thalassemic patients in rural India**” by Amit Kumar Ram, (Roll Number 216330005) is approved for partial fulfilment of the requirement for the degree of ‘Masters in Design’ in Interaction Design at IDC School of Design, Indian Institute of Technology, Bombay.

Swati Pal.

Guide:
Prof. Pramod Khambete (**approval sent over mail, attached on the next page**)
Approval sheet is signed by Prof. Swati Pal, as requested by Prof. Pramod Khambete



Re: Signature on P2 Approval Sheet

From Pramod Khambete <pramod.khambete@gmail.com>
To Amit Kumar Ram <216330005@iitb.ac.in>
Cc Swati Pal IDC <swatipal@iitb.ac.in>
Date 2023-06-29 15:55

Approved.

I am in the US and unable to sign it. Please request Prof. Swati to sign and attach a printout of this mail.

Best regards,

Pramod

Sent from a mobile device

On Thu, 29 Jun 2023, 2:00 am Amit Kumar Ram, <216330005@iitb.ac.in> wrote:

> Sir,
>
> I have attached the approval sheet of my P2 project with this mail.
>
> I request you to kindly sign the sheet and revert to this mail.
>
> Additionally, you can find my P2 report here.
>
> Thank you
>
> --
> Regards,
>
> Amit Kumar Ram,
> Roll no. 216330005,
> M.Des 2021-23, Interaction Design,
> IDC School of Design, IIT Bombay

Acknowledgement

I would like to take this opportunity to express my gratitude towards Prof. Pramod Khambete, for his support, guidance and motivation, so far into the project. His uniquely thoughtful insights have helped me understand the field of design, specifically service design, better. I hope to be able to do justice to the efforts he has put into guiding me.

I am also extremely grateful to the staff of Dattaji Bhale Blood bank, especially Mr. Kedar Joshi and Dr. Manjusha Kulkarni (Head of Dr. Hedgewar Hospital) for being so warm and welcoming, and for clarifying my doubts around the subject of Thalassemia. The detailed walkthrough that they gave me - familiarised me with the functioning of Dattaji Bhale Blood Bank. I am also extremely grateful to Mr. Joshi for introducing me to several parents of Thalassemic patients. Discussions with these parents gave me an insight into their perspective and their lives.

Lastly, I am grateful to all my batchmates, especially Shivangi Negi, who, being on the same boat as I am (she is also doing a service design project for her Project 2) - is a constant source of motivation.

Contents

Glossary of Terms

HLA Type matching : Human Leukocyte Antigen matching is a process done before a donor stem cell or organ transplant to find out if tissues match between the donor and the person receiving the transplant.

BMT operation : Bone marrow transplant operation, a medical procedure that infuses healthy blood-forming stem cells into the body, replacing bone marrow that's not producing enough healthy blood cells

NAT tested blood : NAT or nucleic acid test is a technique used to detect and identify a particular species or subspecies of organisms, often a virus or bacterium that acts as a pathogen in blood, tissue, urine, etc.

SBTC card : The State Blood Transfusion Council card allows people suffering from Thalassemia to get free monthly blood (as per their requirements) in any blood bank in Maharashtra, subject to availability of blood

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Abstract

Thalassemias are one of the most common blood-related, genetic disorders globally. India has a huge no. of Thalassemic patients, around 100,000 patients with a β thalassemia syndrome [1 , 2]. Of the 10,000 to 12,000 thalassemic children born annually in India, very few are well taken care of, especially in urban regions [3]. Thalassemia patients require regular attention throughout their life. They need to be on top of all necessary medical processes and need ways to ensure their monthly transfusion happens. The majority of the parents from rural areas, and coming from a low income household are unaware about the process involved.

The objective is to help Thalassemia patients and their parents - keep track of all the medical procedures relevant to them, get accessible treatment regularly and also ensure their psychological well-being.

Initially, I talked to the Head of Dr. Hedgewar Hospital, Dr. Manjusha Kulkarni, and a staff of Dattaji Bhale Blood Bank. I talked to a thalassemic patient's parent. I also talked to Dr. Ajey Joglekar, who ran his own blood bank. Even though these conversations weren't very long, they were a good exploration that helped me gain some insights, and design directions. Even though these conversations weren't very long, they were a good exploration that helped me gain some insights, and design directions. Initial explorations made me realise that there were a lot of physical, psychological and economic burdens on Thalassemic patients and their families. Even the task of securing regular and safe blood transfusions is difficult in rural India.

Also, there is social stigma, difficulties with fitting in and in general, a lack of awareness of the best practices related to Thalassemia. Parents are also not aware of the possibility of Bone Marrow Transplant, and the medical and economic preparations required for the same. To understand these issues further I visited Dattaji Bhale Blood Bank in Aurangabad and talked to several parents of Thalassemic patients, who were at that time taking their monthly blood transfusions. I tried to understand the overall lifetime journey of a Thalassemic patient right from diagnosis, to registering for a SBTC card to taking monthly transfusions, and eventually undergoing a bone marrow transplant, if possible.

I also tried to understand the functioning of Dattaji Bhale blood bank, with respect to the service/s it provides to Thalassemic patients.

Even though the problems related to Thalassemia are well known, there is almost no design related work done in this field. Given the grave nature of this problem, it is surprising to note that the only representation of design work is through awareness brochures, and informative websites [4].
There is not much literature either, about the application of service design concepts to improve the functioning of blood banks.

It must be also understood that blood banks are not one service, but a constellation of many services [see Fig. 1], some primary and crucial - while others supporting.

Therefore, there in untapped opprtunity here to improve the experience of a blood bank's customers, by incorporating concepts of service design in the functioning of the blood bank. This work done leverages opportunities of value co-creation, efficient and useful touchpoints and holistically examines the overall service constellation

With this motivation, I started with primary research - by interviewing the staff of Dattaji Bhale blood bank and some Thalassemic patients' parents. My goal was to gain a bird's eye view of the different services that work in tandem to ensure the survival of Thalassemic patients, as well as the lifetime trajectory of Thalassemia patients and their parents.

From the larger service constellation that I had created, I picked 1-2 critical service encounters and detailed their blueprint. I have also compared the service blueprints, with and without my design interventions. I used the value equation to analyse whether my redesigned service creates any value for Thalassemis patients and their parents. I also detailed out some touchpoints within this critical service encounter.

1.Introduction

Suggested treatment for Thalassemia is stem-cell transplant, but this treatment is unaffordable (3-6 lakhs) for many middle and lower income families. One feasible option commonly suggested in literature is - prenatal diagnosis and subsequent abortion of Thalassemic foetuses, if required. Other suggested solutions involve promoting education and awareness programmes, and developing adequate facilities for genetic counselling and prenatal diagnosis in public institutions.

Even though this disease is not curable, safe blood transfusions and adequate iron chelation allows patients to have a better quality of life. Studies conducted (4) had shown improvements in mean age of thalassemia patients through these treatments. But even these treatments are very expensive for low and middle income families (the monthly blood transfusion costs Rs. 7-8k, monthly medicines cost 2-3k), and are extremely expensive for blood banks to bear. (As per a report obtained from Dattaji Bhale blood bank).

Thalassemia major patients faced other associated problems like heart, liver, endocrine and skin, glands. (As per a report obtained from Dattaji Bhale blood bank).

In addition to the physical and economic burdens, Thalassemic patients as well as their families, over time, are forced to bear a multitude of psychosocial burdens as well. They are likely to suffer from reduced self-esteem, feelings of difference, poor self-image, and anxiety over issues of pain and death.

Treatment is expensive, even though government hospitals are providing free medicines for patients (they require iron reducing medicines and vitamins mostly), people are not aware of these opportunities.

I started with some initial questions to help me understand the problem space better.

- Are patients and their parents really aware of these medications and the implications it will have if they skip these medications?
- Are they aware of the places where they can get medications for free or at a cheaper rate?
- Is keeping track of the health and necessary medications difficult for thalassemia patients?
- Is regular medicine delivery from hospitals possible?

Finding volunteers who can donate blood - is seemingly not a big issue for these larger blood banks, even though this was a challenge during the initial stages of these blood banks.

- Similarly, can a system be put in place that ensures regular, uninterrupted blood donations for thalassemia patients?
- Blood donors are very diligent when it comes to donating blood regularly. Can this quality be leveraged?

Many times patients miss their transfusion appointments and then it is a big hassle to get another appointment in the same blood bank. Getting the same treatment from a different source, in short notice, is extremely difficult for middle and low income households, as this can prove to be extremely expensive.

Fragmented nature blood transfusion services in India is another issue. There is not much coordination between different NGOs/ blood banks and thus, they are not able to refer patients to other blood banks in case they are suffering from blood shortage.

- Counselling, and ways to keep a check on a thalassemia patient's mental health - is another much needed solution. What sort of messaging should this solution contain?
- Should there be a common platform for thalassemic patients to connect with each other? Will that help? Can this platform help patients easily seek counselling or therapy?
- How to create more awareness about the issue of Thalassemia? If people learn about this issue, will they be more motivated to donate blood?

To answer all these questions, I visited Dattaji Bhale blood bank in Aurangabad, and the hospital that they are affiliated with - Dr. Hedgewar Hospital. I conducted primary research with parents of Thalassemic patients and tried to understand their journeys and pain points. I also conducted a study, where **I shadowed two parents of Thalassemic patients to try and understand their routine during the day of the transfusion**.

I chose the day of the transfusion because the patients and parents consider monthly transfusions to be the most important service encounter, failure in receiving which can lead to disastrous consequences, adversely affecting the health of the patient. It is also a frequently occuring encounter, happening once in a month. I spent the whole day with them to understand nuances of their journey, and empathise with their frustrations and pain points.

Fig. 1 Dattaji Bhale Blood Bank

Dattaji Bhale blood bank was selected because of ease of access. Pramod sir suggested that we work together with this organization because of their previous engagements with other service designers and their familiarity with service design.

The following reasons proved crucial in helping me decide on sticking with this organization -

- Initial conversations proved fruitful as the staff of Dattaji Bhale blood bank were very excited and appreciative of the work that we are doing.
- Access to documents and patients for research
- This blood bank is one of the best in the state, and maybe even the country and thus studying their workflow helped in understanding how a reliable and efficient blood bank should function
- The learnings from studying the functioning of this blood bank, and improving the service/s they provide to Thalassemic patients would result in the synthesis of a service blueprint. This blueprint can be followed by other blood banks who serve Thalassemia patients.

2.Scope

The scope I have defined for this project is as follows -

- Gaining a thorough understanding of the context. Understanding the pain points and the journey of Thalassemia patients and their parents.
- Identifying gaps in the already existing service blueprint
- Designing service blueprints that improve the experience of patients and their parents, and create value for them
- Designing touchpoints within service encounters and detailing out a few of those touchpoints - through wireframes, prototypes etc. If time permits, I plan to create experiential prototypes (videos) to help people visualise how the touhpoints I have designed can bring value to Thalassemia patients and their parents.
- Getting my work evaluated by a panel of experts, and getting feedback from them

3.Primary Research

Dattaji Bhale blood bank is a blood bank affiliated with Dr. Hedgewar Hospital in Aurangabad. It is a fairly large and optimised blood bank with a special unit in place to handle transfusions for Thalassemic patients. They conduct regular blood donation drives as well to inform and motivate people to donate blood, as well as to increase donations.

I chose qualitative analysis (user interviews) as a lot of the parents of Thalassemic children were not very literate. Through initial discussions I found that they are comfortable in conversing in Marathi, and in Hindi. Most of the parents are also comfortable in reading Hindi and Marathi. But very few are comfortable in communicating in English.

Floating survey forms or Likert scale type questionnaires - might not work best as there may be gaps in terms of how the parents understand and interpret the questions. Also **nuances may get lost** if there is no effort to qualitatively try and understand their contexts, thoughts, actions and their journey.

Fig. 2 Dr. Hedgewar Hospital

I conducted interviews with the staff of the blood bank, and parents of Thalassemia patients. Some key insights that came from it -

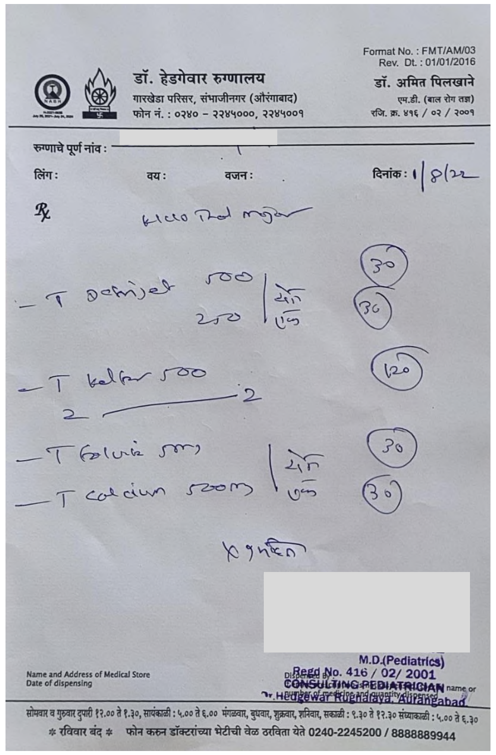
- A lot of parents are not aware that their child is Thalassemic during the time of birth, especially in rural areas.
- Through my interviews I found out that most detections happened at the age of two or three years, when the patient started showing symptoms of weakness and health complications. As one parent put it, “Hume laga tha yeh gori hai”, referencing the fact that they didn’t realise their child was Thalassemic and just thought that she was fair.
- A civil surgeon diagnoses the child, and gives specific prescriptions about how much blood they require and how much gap should there be between each transfusion.
- SBTC (State Blood Transfusion Council) Card enables patients to avail blood transfusions from any blood bank for free.
- They also check other vitals and prescribe necessary medication, such as Iron chelation tablets, Vitamins, Calcium, and Folic acid.

3.1 Pain points of patients and parents

Merely coming to terms with the fact that their child is suffering from a life threatening disease - proves to be extremely difficult for parents, and this is just the first step of a long and arduous journey. There is no counselling or awareness available either, that can mentally prepare parents for all the issues that will arise eventually, or the ways through which they can navigate some of these issues. Some pain points are -

- There are issues with regular, stable blood availability in many hospitals across the country, both civil and private.
- Many hospitals and blood banks outright refuse to treat thalassemia patients - as giving out 400-500 ml of free blood each month, per patient - is not economically feasible for these institutions.
- Most of these institutions do not have access to a reliable donor pool either, and therefore, they ask Thalassemia patients to bring their own donors, which is another hassle of its own.
- Therefore there isn’t a sustainable source of blood. Parents are left scrambling for donors and end up calling people close to them regularly for blood donations. Parents mentioned how their friends and relatives stopped picking up their calls after a while, and how asking for blood donations hampered their social connections.
- One main reason why parents chose Dattaji Bhale blood bank - was the availability of NAT (Nucleic Acid Testing) facility. Parents are very concerned about whether the blood is NAT tested. One particular parent confided that their child got Hepatitis because the transfused blood was not NAT tested.

- Many parents said that they were not aware of necessary medication, for close to 2 years after diagnosis



Format No. : FMT/AM/03
Rev. Dt. : 01/01/2016

डॉ. हेडगेवार रुग्णालय
गारखेडा परिसर, संभाजीनगर (औरंगाबाद)
फोन नं. : ०२४० – २२४५०००, २२४५००१

डॉ. अमित पिलखाने
एम.डी. (बाल रोग तज्ञ)
रजि. क्र. ४१६ / ०२ / २००१

रुग्णाचे पूर्ण नांव : [redacted]
लिंग : वय : वजन : दिनांक : 1/8/22

Rx [illegible]

– T [illegible] 500 | [illegible] — (30)
250 | [illegible] — (30)

– T [illegible] 500 — (120)
2 ——— 2

– T [illegible] 5mg | [illegible] — (30)
– T calcium 500mg | [illegible] — (30)

[illegible]

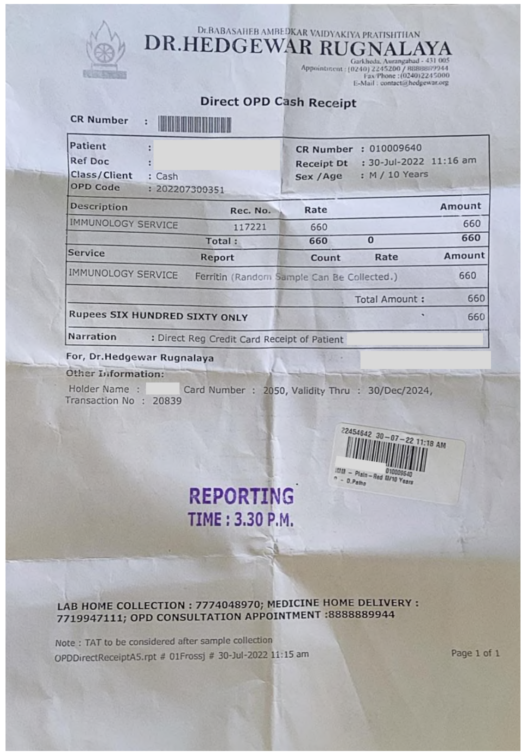
[redacted]

M.D.(Pediatrics)
Regd No. 416 / 02/ 2001
CONSULTING PEDIATRICIAN
Dr.Hedgewar Rugnalaya, Aurangabad

Name and Address of Medical Store
Date of dispensing
Dispensed By ... name or number of medicine and quantity dispensed

सोमवार व गुरुवार दुपारी १२.०० ते १.३०, सायंकाळी : ५.०० ते ६.०० मंगळवार, बुधवार, शुक्रवार, शनिवार, सकाळी : ९.३० ते १२.३० संध्याकाळी : ५.०० ते ६.३०
✻ रविवार बंद ✻ फोन करून डॉक्टरांच्या भेटीची वेळ ठरविता येते 0240-2245200 / 8888889944

Fig. 3 Medicine Prescription for Thalassemia patient



Dr.BABASAHEB AMBEDKAR VAIDYAKIYA PRATISHTHAN
DR.HEDGEWAR RUGNALAYA
Garkheda, Aurangabad - 431 005
Appointment : (0240) 2245200 / 8888889944
Fax/Phone : (0240)2245000
E-Mail : contact@hedgewar.org

Direct OPD Cash Receipt

CR Number :

Patient : [redacted]
Ref Doc :
Class/Client : Cash
OPD Code : 202207300351
CR Number : 010009640
Receipt Dt : 30-Jul-2022 11:16 am
Sex /Age : M / 10 Years

Description	Rec. No.	Rate		Amount
IMMUNOLOGY SERVICE	117221	660		660
	Total :	660	0	660

Service	Report	Count	Rate	Amount
IMMUNOLOGY SERVICE	Ferritin (Random Sample Can Be Collected.)			660
			Total Amount :	660

Rupees SIX HUNDRED SIXTY ONLY 660
Narration : Direct Reg Credit Card Receipt of Patient [redacted]

For, Dr.Hedgewar Rugnalaya [redacted]

Other Information:
Holder Name : [redacted] Card Number : 2050, Validity Thru : 30/Dec/2024,
Transaction No : 20839

22454642 30-07-22 11:18 AM
010009640
– Plain – Red M/10 Years
– D.Patho

REPORTING
TIME : 3.30 P.M.

LAB HOME COLLECTION : 7774048970; MEDICINE HOME DELIVERY : 7719947111; OPD CONSULTATION APPOINTMENT :8888889944

Note : TAT to be considered after sample collection
OPDDirectReceiptA5.rpt # 01Frossj # 30-Jul-2022 11:15 am
Page 1 of 1

Fig. 4 Immunology Service cash receipt of Thalassemia patient

- Parents don't want their children to play sports that require physical exertion, and this proves to be difficult for kids to come to terms with. Parents also expressed that they realize their kids want to play sports, but letting them play or exert themselves was a risk that leaves a potential for injuries, which can be life threatening.
- There was a general lack of awareness about diet, which most parents were not aware of. Diets rich in iron can have severe negative effects on Thalassemic patients.
- Parents did not know that there is a Bone Marrow Transplant (BMT) process - and what are the requirements for that. The transfused blood must be of a certain quality in order to qualify patients for BMT. This also depends on the filtration equipment used, as well as the donors. This process also demands extensive financial planning, since the process costs close to 15-30 lakhs

Even though it's heartbreaking to learn about the hardships that Thalassemia patients and their parents undergo, it is at the same time motivating to realize that these pain points also provide opportunities for design intervention.

3.2 Key Insights

Community value co-creation : Most parents learn about Thalassemia, and the different do's and don'ts from other parents of Thalassemic children, or from the employees of their local blood bank or the doctors that they visit. Most importantly, there is knowledge sharing about critical pieces of information, like 'pharmacies where parents can find Thalassemia medication', 'centres for stem cell preservation', 'hospitals that perform bone marrow transplantation', 'financial aids for bone marrow transplantation' etc. Whatsapp groups are the most commonly used touchpoint for sharing information like this.

Role of parents as touchpoints : The role of parents is extremely critical in their ward's journey through Thalassemia. Parents are often the touchpoints for - procuring medicines, or for transporting their children to the blood bank for transfusions etc.
Parents are also co-customers of the service that is a "blood bank". They receive blood bags every month for their children's transfusion and they are involved throughout the patient's journey.
Infact, parents are directly involved in most of the service encounters (getting medicines, getting blood test reports from the hopital), and are somewhat indirectly involved in other service encounters (waiting while their children receive blood transfusions).

Dilligence in donors and patients : Patients are very dilligent when it comes to taking medicines on time, parents procure medicines around 7-10 days before the current batch ends, and donors do not miss their donation appointments unless there is an emergency.

Relationship between the blood bank and its beneficiaries : There is a lot of trust, reverance and respect for Dattaji Bhale blood bank within its beneficiaries. Parents of Thalassemic patients reach out to the staff of Dattaji Bhale blood bank for any queries, right from what diet they should follow, to where they can get bone marrow transplant operation done.

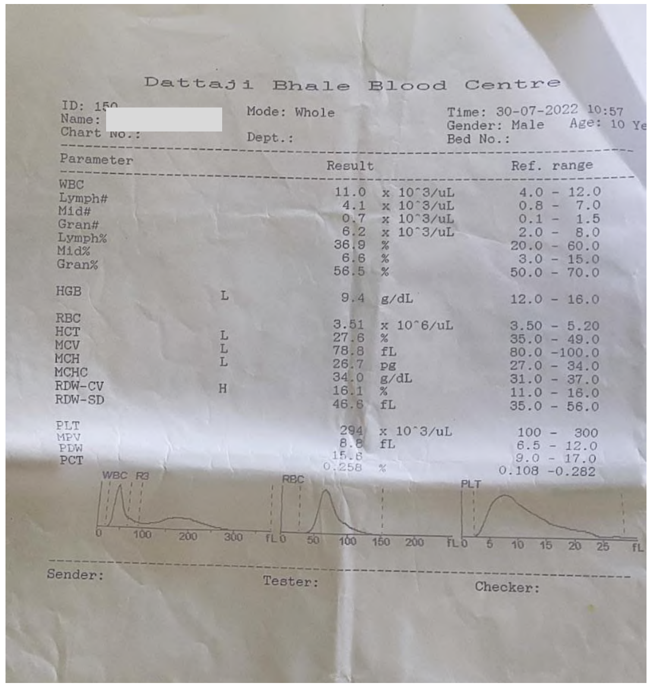
These are practices that evolved organically over time, within the context of this space. There are potential gaps within these practices, even though the existence of these practices itself is commendable.

3.3 What happens on the day of transfusion

However, the day begins early in the morning - with patients and parents waking up early, taking necessary medicines, having breakfast and then traveling long distances usually to reach the blood bank.

The day of transfusion begins early. Usually there is a tentative period within which patients must get their transfusion done, otherwise their health will worsen.

- Parents come to the blood bank on the day of transfusion, other routine remains same
- In the context that I am studying, often parents come from far off places to this particular blood bank
- They make an entry in a register, the information is entered in the blood bank website
- Parents and patients go to the hospital and get their blood tests done
- As per the test reports, doctors recommend the quantity of blood that a patient requires



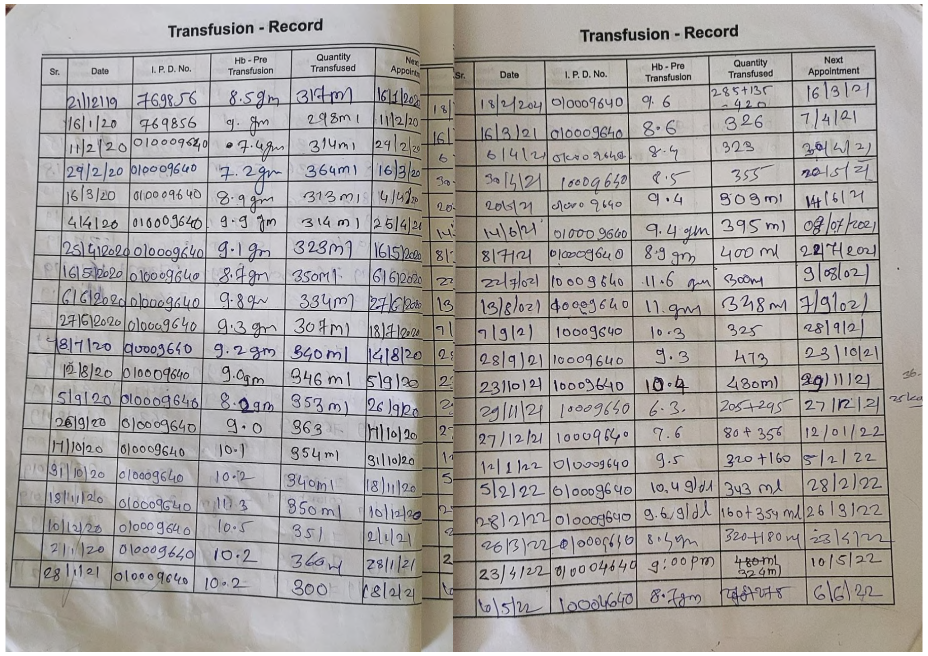
Dattaji Bhale Blood Centre

ID: 150
Name: [redacted]
Chart No.:
Mode: Whole
Dept.:
Time: 30-07-2022 10:57
Gender: Male Age: 10 Ye
Bed No.:

Parameter		Result		Ref. range
WBC		11.0	x 10^3/uL	4.0 - 12.0
Lymph#		4.1	x 10^3/uL	0.8 - 7.0
Mid#		0.7	x 10^3/uL	0.1 - 1.5
Gran#		6.2	x 10^3/uL	2.0 - 8.0
Lymph%		36.9	%	20.0 - 60.0
Mid%		6.6	%	3.0 - 15.0
Gran%		56.5	%	50.0 - 70.0
HGB	L	9.4	g/dL	12.0 - 16.0
RBC		3.51	x 10^6/uL	3.50 - 5.20
HCT	L	27.6	%	35.0 - 49.0
MCV	L	78.8	fL	80.0 -100.0
MCH	L	26.7	pg	27.0 - 34.0
MCHC		34.0	g/dL	31.0 - 37.0
RDW-CV	H	16.1	%	11.0 - 16.0
RDW-SD		46.6	fL	35.0 - 56.0
PLT		294	x 10^3/uL	100 - 300
MPV		8.8	fL	6.5 - 12.0
PDW		15.6		9.0 - 17.0
PCT		0.258	%	0.108 -0.282

Sender: Tester: Checker:

Fig. 5 Blood test report of a Thalassemia patient showing the count of different blood components



Transfusion - Record

Sr.	Date	I. P. D. No.	Hb - Pre Transfusion	Quantity Transfused	Next Appointment
	21/12/19	769856	8.5gm	317ml	16/1/2020
	16/1/20	769856	9. gm	298ml	11/2/20
	11/2/20	010009640	7.4gm	314ml	24/2/20
	29/2/20	010009640	7.2gm	364ml	16/3/20
	16/3/20	010009640	8.9gm	313ml	4/4/20
	4/4/20	010009640	9.9 gm	314 ml	25/4/20
	25/4/2020	010009640	9.1 gm	323ml	16/5/2020
	16/5/2020	010009640	8.7gm	350ml	6/6/2020
	6/6/2020	010009640	9.8gm	334ml	27/6/2020
	27/6/2020	010009640	9.3gm	307ml	18/7/2020
	18/7/20	010009640	9.2gm	340ml	14/8/20
	12/8/20	010009640	9.0gm	346ml	5/9/20
	5/9/20	010009640	8.2gm	353ml	26/9/20
	26/9/20	010009640	9.0	363	17/10/20
	17/10/20	010009640	10.1	354ml	31/10/20
	31/10/20	010009640	10.2	340ml	18/11/20
	18/11/20	010009640	11.3	350ml	10/12/20
	10/12/20	010009640	10.5	351	2/1/21
	2/1/20	010009640	10.2	360ml	28/1/21
	28/1/21	010009640	10.2	300	18/2/21

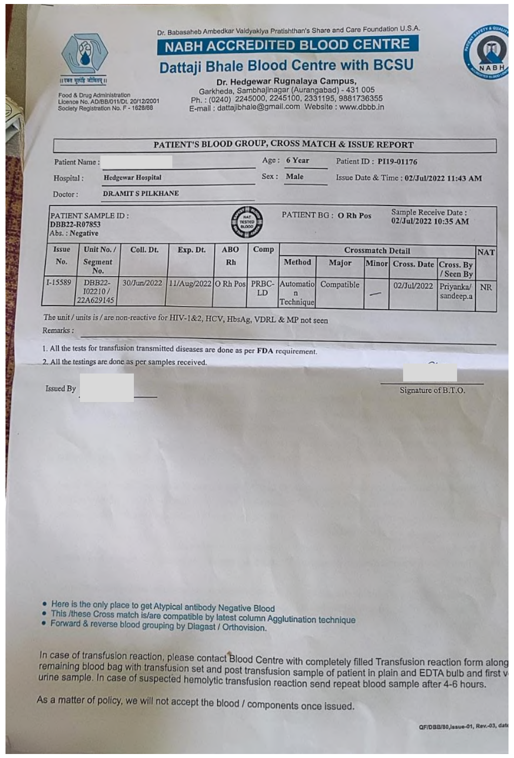
Transfusion - Record

Sr.	Date	I. P. D. No.	Hb - Pre Transfusion	Quantity Transfused	Next Appointment
	18/2/2021	010009640	9.6	285+135 =420	16/3/21
	16/3/21	010009640	8.6	326	7/4/21
	6/4/21	010009640	8.4	323	30/4/21
	30/4/21	10009640	8.5	355	20/5/21
	20/5/21	010009640	9.4	309ml	14/6/21
	14/6/21	010009640	9.4 gm	395 ml	08/07/2021
	8/7/21	010009640	8.9 gm	400 ml	22/7/2021
	22/7/021	10009640	11.6 gm	300ml	9/08/021
	13/8/021	10009640	11.gm	348ml	7/9/021
	7/9/21	10009640	10.3	325	28/9/21
	28/9/21	10009640	9.3	473	23/10/21
	23/10/21	10009640	10.4	430ml	29/11/21
	29/11/21	10009650	6.3.	205+295	27/12/21
	27/12/21	10009640	7.6	80+356	12/01/22
	12/1/22	010009640	9.5	320+160	5/2/22
	5/2/22	010009640	10.4 g/dl	343 ml	28/2/22
	28/2/22	010009640	9.6 g/dl	160+354 ml	26/3/22
	26/3/22	010009640	8.5gm	320+180ml	23/4/22
	23/4/22	010004640	9:00pm	~~480ml~~ 324ml	10/5/22
	6/5/22	10004640	8.7gm	[illegible]	6/6/22

36.
25kg

Fig.6 Blood transfusion record of a Thalassemia patient

Fig. 7 Thalassemia patients receiving their blood transfusion treatment in Dr. Hedgewar hospital



Dr. Babasaheb Ambedkar Vaidyakiya Pratishthan's Share and Care Foundation U.S.A.

NABH ACCREDITED BLOOD CENTRE

Dattaji Bhale Blood Centre with BCSU

Dr. Hedgewar Rugnalaya Campus,
Garkheda, Sambhajinagar (Aurangabad) - 431 005
Ph. : (0240) 2245000, 2245100, 2331195, 9881736355
E-mail : dattajibhale@gmail.com Website : www.dbbb.in

Food & Drug Administration
Licence No. AD/BB/011/DL 20/12/2001
Society Registration No. F - 1628/88

PATIENT'S BLOOD GROUP, CROSS MATCH & ISSUE REPORT

Patient Name : [redacted]
Age : **6 Year**
Patient ID : **PI19-01176**
Hospital : **Hedgewar Hospital**
Sex : **Male**
Issue Date & Time : **02/Jul/2022 11:43 AM**
Doctor : **DR.AMIT S PILKHANE**

PATIENT SAMPLE ID :
DBB22-R07853
Abs. : **Negative**
PATIENT BG : **O Rh Pos**
Sample Receive Date :
02/Jul/2022 10:35 AM

Issue No.	Unit No. / Segment No.	Coll. Dt.	Exp. Dt.	ABO Rh	Comp	Crossmatch Detail					NAT
						Method	Major	Minor	Cross. Date	Cross. By / Seen By	
I-15589	DBB22-I02210 / 22A629145	30/Jun/2022	11/Aug/2022	O Rh Pos	PRBC-LD	Automation Technique	Compatible	–	02/Jul/2022	Priyanka/ sandeep.a	NR

The unit / units is / are non-reactive for HIV-1&2, HCV, HbsAg, VDRL & MP not seen

Remarks :

1. All the tests for transfusion transmitted diseases are done as per **FDA** requirement.
2. All the testings are done as per samples received.

Issued By [redacted]

[redacted]
Signature of B.T.O.

- Here is the only place to get Atypical antibody Negative Blood
- This /these Cross match is/are compatible by latest column Agglutination technique
- Forward & reverse blood grouping by Diagast / Orthovision.

In case of transfusion reaction, please contact Blood Centre with completely filled Transfusion reaction form along remaining blood bag with transfusion set and post transfusion sample of patient in plain and EDTA bulb and first v urine sample. In case of suspected hemolytic transfusion reaction send repeat blood sample after 4-6 hours.

As a matter of policy, we will not accept the blood / components once issued.

QF/DBB/80,Issue-01, Rev.-03, dat

Fig. 8 Blood issue report of a patient
Fig. 9 Thalassemia patients receiving their blood transfusion treatment in Dr. Hedgewar hospital

- This information is then given to the blood bank by the parents and accordingly, blood bag/s is given to the parents
- Parents collect the blood bag, the bank keeps the bag ready (patients need hemoglobin or RBC)
- Parents then have to carry the blood bag with them, manually, to the hospital and then; sometimes they have to wait to get a cabin
- It is obvious that **a lot of back and forth happens during this process**, and parents need to run to and fro between the blood bank and the hospital
- Transfusion begins after this, and goes on for 3-4 hours. The transfusion process takes the entire day, right from coming to the bank, issuing blood to getting transfusion in the hospital
- Patients were bored and had to put with pain in their arms and hands

3.4 What are the long term goals of patients and parents?

Thalassemia patients need to receive regular blood transfusions, and take necessary medicines. However, there are ways through which patients be treated completely, and one such way is through a BMT operation. Essentially, healthy blood-forming stem cells from a donor are infused into a Thalassemia patient's body during this procedure. Therefore, the first step is finding a willing donor, then checking if their stem cells match the patient's through a process called HLA type matching and then going ahead with the procedure.

The key pain points with undergoing this procedure are -

- Finding a donor with compatible stem cells
- Finding a medical facility that does HLA type matching, or stem cell preservation
- Gathering funds for BMT operation
- Finding a reliable hospital that does BMT operations

3.5 Interview with a blood donor

I also conducted an interview with a blood donor, who donated blood through a donation camp organised in their college. This interview also led to multiple interesting insights, such as -

- All information, as well as reach of this camp was done through social media, mainly instagram. Instagram posts and stories from the event's page informed people about the event's details, and using social media for a blood donation drive mainly aimed at younger people seemed to work. The attendance of this camp was pretty high apparently, with both students and parents attending.
- The interviewee wasn't completely sure whether their blood was going to a Thalassemic patient or not, but they believed that had they been informed about Thalassemic patients beforehand, they would have been even more motivated to donate her blood
- Lots of people were anxious about donating blood
- Most of this anxiety was caused by not knowing what exactly this process involved
- Motivation from friends - was the major driving force behind donors going and donating blood

Even though my project's focus is not on donors, I felt I needed this complementary information in order to gain a holistic understanding of this space.

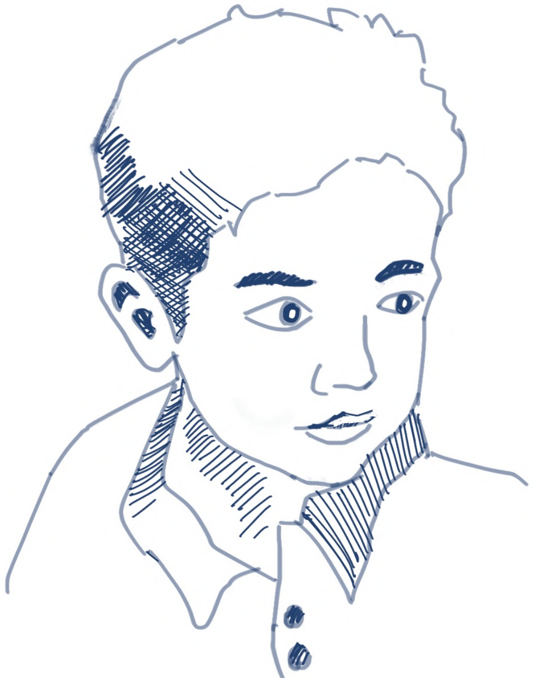
4.Personas & Patient lifetime trajectory

Based on the learnings from my research, I tried to create a lifetime trajectory map of a Thalassemia patient. The lifetime, in our context starts from the detection of Thalassemia in children (usually happens when they are 2-3 months old) and continues till they undergo a BMT operation.

However, it is imperative to note that the **key decisions throughout this journey is taken by the parents of Thalassemic patients, and not by the patients themselves**.

The lifetime trajectory can be be broken down into a several key journeys, starting from detection of Thalassemia in patients to them getting a BMT operation eventually.

4.1 Personas



Akhil

9 yr old Thalassemia Major patient

Brief description

- 9 year old boy
- Was diagnosed with Thalassemia Major 9 years back, at the age of 3 months
- **Lives in a small town, 20 kms away from Aurangabad**
- Gets his regular blood transfusions at an established blood bank in Aurangabad
- Is now slowly **coming to terms with his condition** and is very much **aware of the necessary medications**

- He is **very punctual in terms of his medical activities**, like taking his medicines on time etc.
- Even though **he dislikes taking transfusions - he patiently goes through the process** every month

Skills & Interests

- **Loves sitting in front of his computer for hours**, **playing games or watching YouTube** videos
- Also likes to draw in his free time
- He likes studying English in school
- He **wants to play outdoor sports but his condition limits him from doing so**

Persona Main Goals and Motivations

- **Wants to live a normal life, like other kids in his school**
- Wants to be completely independent of all the different medical procedures related to Thalassemia
- Until that happens, wants the transfusion process to be as convenient and painless as possible
- **Wants to live a successful and long life**
- Wants to be able to play sports and games, just like other kids
- Doesn't want to cause trouble to his parents

Personality

- Is very motivated about living a healthy and medication free life
- Is very motivated about being independent and strong
- Courageous, even if the transfusion process hurts, he braves it like a champ
- Is curious to learn about new things and direct his energy towards things that he can do without exerting himself

Tech savviness

- Akhil knows how to search the internet and has basic knowledge about how to operate computers

- Is very proficient with handling phone apps

Needs

- Needs **a way to overcome his medical condition**, and get fully cured so that he can live his life without aby limitations, or life-threatening risks
- Needs **hassle-free, convenient and painless blood transfusions** every month
- Needs good quality, **NAT tested blood** so that he can lead a healthy life
- Needs regular, quality transfusions so that he can become **eligible for Bone Marrow Transplant**
- Akhil needs **counseling and therapy** to help him cope with the gravity of his medical condition

Pains

- **Finds the regular transfusion sessions very boring and painstaking**
- Does not like the limitations that are placed upon how he can live his life, due to his condition
- Hates the weakness and the illnesses caused due to his compromised immune system
- Thalassemia causes lots of other accompanying health effects, which Akhil has a difficult time dealing with
- Usually struggles with the comprehending and dealing with the gravity of his medical condition

Atul

32 yr old father of a Thalassemia Major patient (Akhil)

Brief description

- 32 year old
- works as a clerk in a small government office
- Only child was diagnosed with Thalassemia Major 9 years back, at the age of 3 months
- **Lives in a small town, 20 kms away from Aurangabad**
- Travels to Aurangabad to for transfusions
- **Was not aware of the necessary medications to begin with, but is now aware**
- Is extremely devoted to his son,
- Is determined to help Akhil lead a healthy and normal life
- Wants to save money for his son's BMT, but is not sure how exactly he can do that.

Skills & Interests

- **Likes to read about Thalassemia from whatever sources he and his son can find**
- Is educated till 12th std. and can read and write in Marathi and Hindi
- Can read and write in English at an intermediary level

Persona Main Goals and Motivations

- **Wants Akhil to live a normal life, like other kids in his school**
- Wants to raise money for his son's BMT treatment - Until that happens, wants the transfusion process to be as convenient and painless as possible
- **Wants Akhil to live a successful and long life**
- Wants regular, NAT tested, blood for Akhil's transfusions
- **Motivated to pass on his learnings with other parents/ patients**

Personality

- Is very motivated about supporting Akhil
- Is very **punctual and responsible when it comes to his son's medical care**
- Courageous and a go-getter
- Is curious to learn about new things
- Very motivated to learning about Thalassemia, as much as he can

Tech savviness

- **Knows how to operate Whatsapp**
- Knows how to type on Google docs
- Is not very proficient with handling computers and is not very good at using the Internet

Needs

- Needs **a way for Akhil to overcome his medical condition**
- Needs **hassle-free, convenient and painless blood transfusions** for Akhil every month
- Needs good quality, **NAT tested blood** so that Akhil can lead a healthy life and be ready for his BMT operation
- Needs **funding and financial support**
- Needs a way to get **Akhil's necessary medicines whenever required**
- Needs **a way to easily access new information and findings about Thalassemia**
- Akhil needs **counseling and therapy** to help him cope with the gravity of his medical condition

Pains

- **Finds the regular transfusion sessions very boring**
- Is not adept at using the internet for researching about Thalassemia
- Most literature is difficult to understand
- Initially, **finding donors, medicines and safe, quality blood for Akhil**
- **Gathering funds for Akhil's operation**
- Keeping all of Akhil's medical needs satisfied
- Keeping Akhil mentally motivated and cheerful

4.2 Lifetime Trajectory

Thalassemia is chronic in nature. Patients and parents have to deal with it over a timeline that usually spans decades. And throughout this “lifetime”, they interact with many services - one of it being the blood bank.

Therefore, it was **essential to understand this long term trajectory before narrowing down on any one or two service encounters**.

Stage 1 : Detection of Thalassemia

- This stage involves “finding out the cause of the patient’s weakness”
- Akhil’s parents take him to a civil hospital, where the doctor prescribes some blood tests
- Based on the results of the blood test, Akhil is diagnosed with Thalassemia
- This first stage is mentally taxing for the parents, as they are not fully aware of such a grave illness
- Parents feel lost, frustrated and sad
- Patients are very young to understand anything that is going on

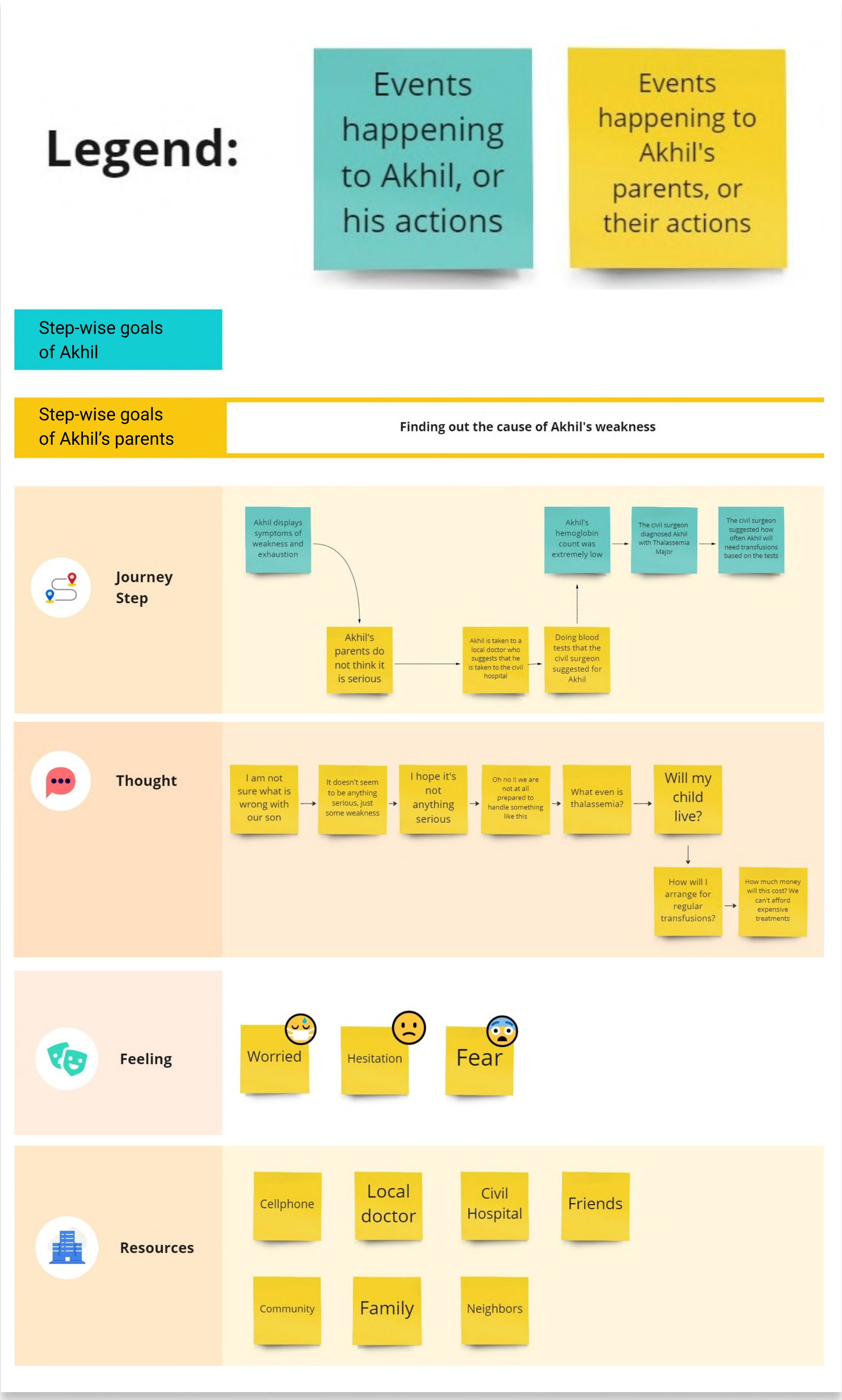


Fig. 10 This figure shows the legend and the first stage of the lifetime trajectory

Stage 2 : Getting an SBTC card

This stage is very crucial as parents must get an SBTC card for their children.

This card allows patients to get the required quantity of blood from any blood bank in Maharashtra free of cost.

However, there are monetary reasons why many blood banks refuse to give blood to Thalassemia patients, which is understandable as giving out 300 - 500 ml of free blood on a monthly basis for one patient - is not very sustainable for blood banks in the long run.

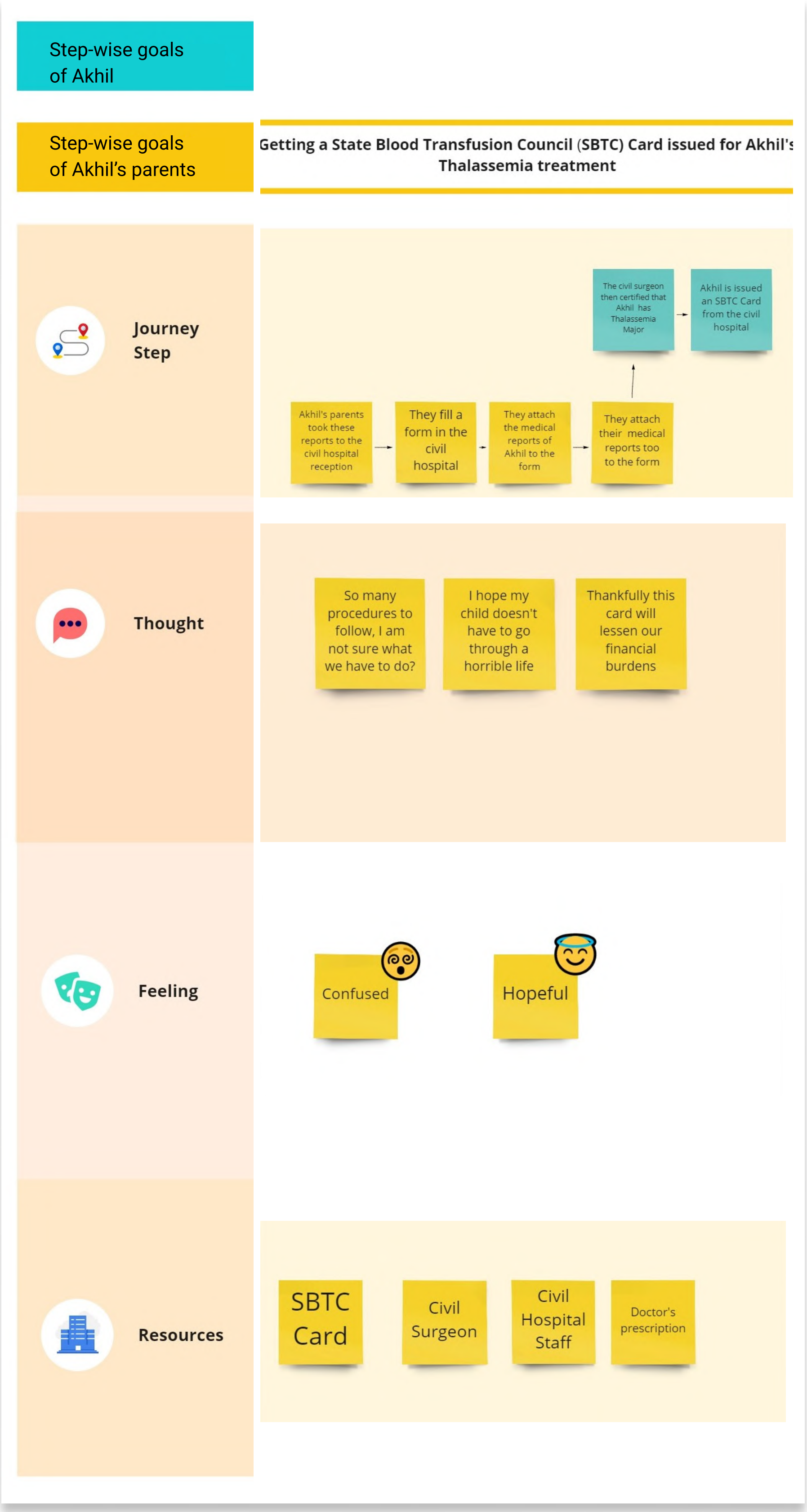


Fig. 11 This figure shows the second stage of the lifetime trajectory

Stage 3 : Starting regular blood transfusions for Akhil

This stage is extremely uncertain and anxiety causing for parents, as they have not yet found a reliable source of blood that can provide NAT tested blood, as per Akhil’s requirements at a monthly level, and without fail.

This stage involves the following.

- Akhil's parents plan to get their blood transfusions from the civil hospital
- They follow the prescription written by their doctor
- During the period when the transfusion is due, they go to the civil hospital
- They are told that blood is not available and they are asked to come back some other time
- The hospital does not give a fixed date on which blood will be available
- Akhil's parents go to another blood bank nearby hoping to receive a blood transfusion
- Owing to Akhil's rare blood type, the blood bank says that blood unavailable
- The blood bank asks them to find a donor for Akhil
- Akhil's parents try contacting several hospitals and blood banks but to no avail
- This fills the parents with a lot of panic and anxiety, as they scramble to find people in their immediate circle who can donate blood to Akhil

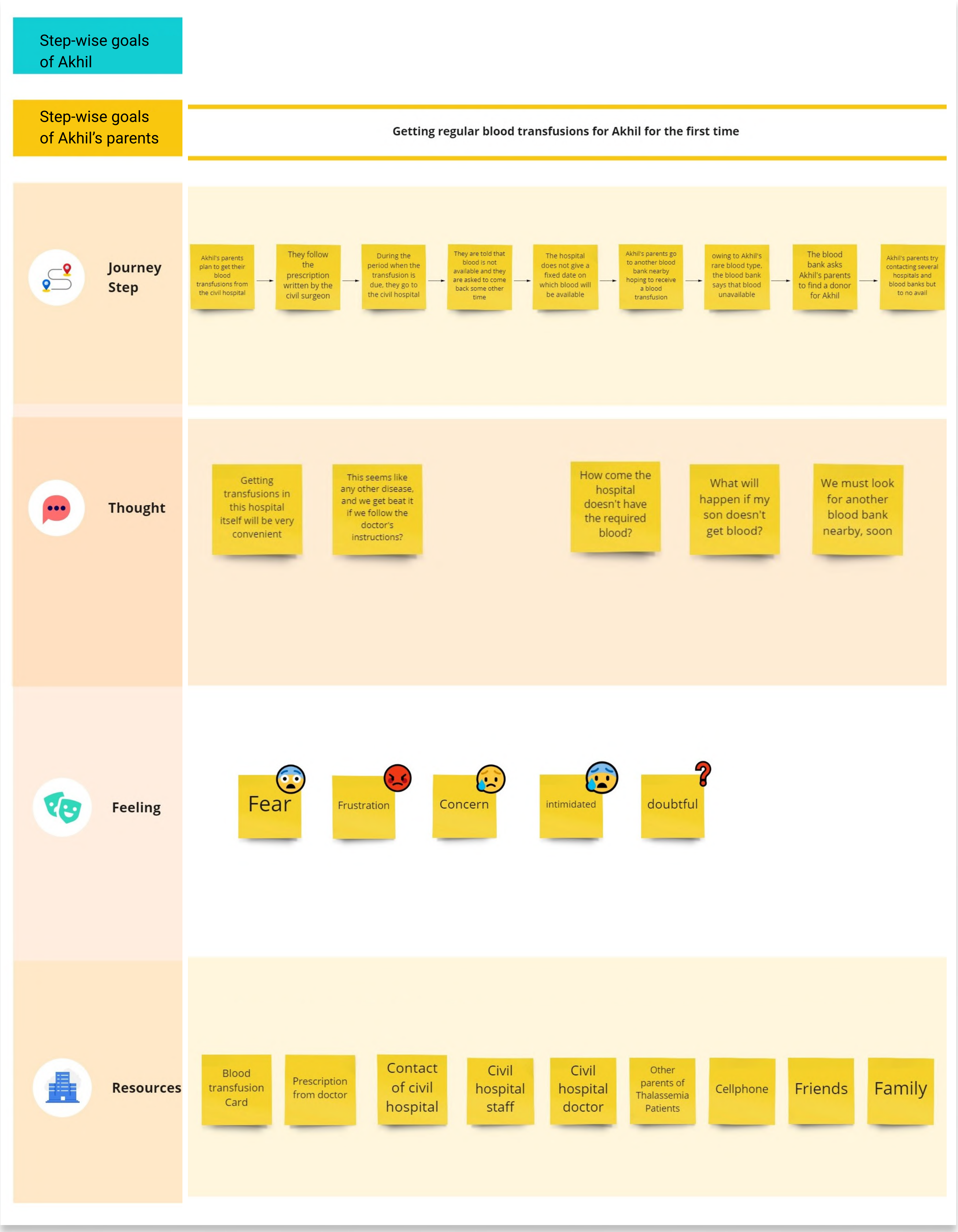


Fig. 12 This figure shows the third stage of the lifetime trajectory

Stage 4 : Finding donors for Akhil

In a panicked state, Atul calls up his acquaintances, friends and family hoping to find someone who can help them out.

- Akhil's parents call up relatives and friends for help
- They finally find a friend who can donate blood to Akhil
- Akhil's parents take their friend to the blood bank and get the transfusion done
- Every time they need to get blood transfusion for Akhil, they need to find a donor
- Eventually the parents' friends and relatives stop picking up their calls

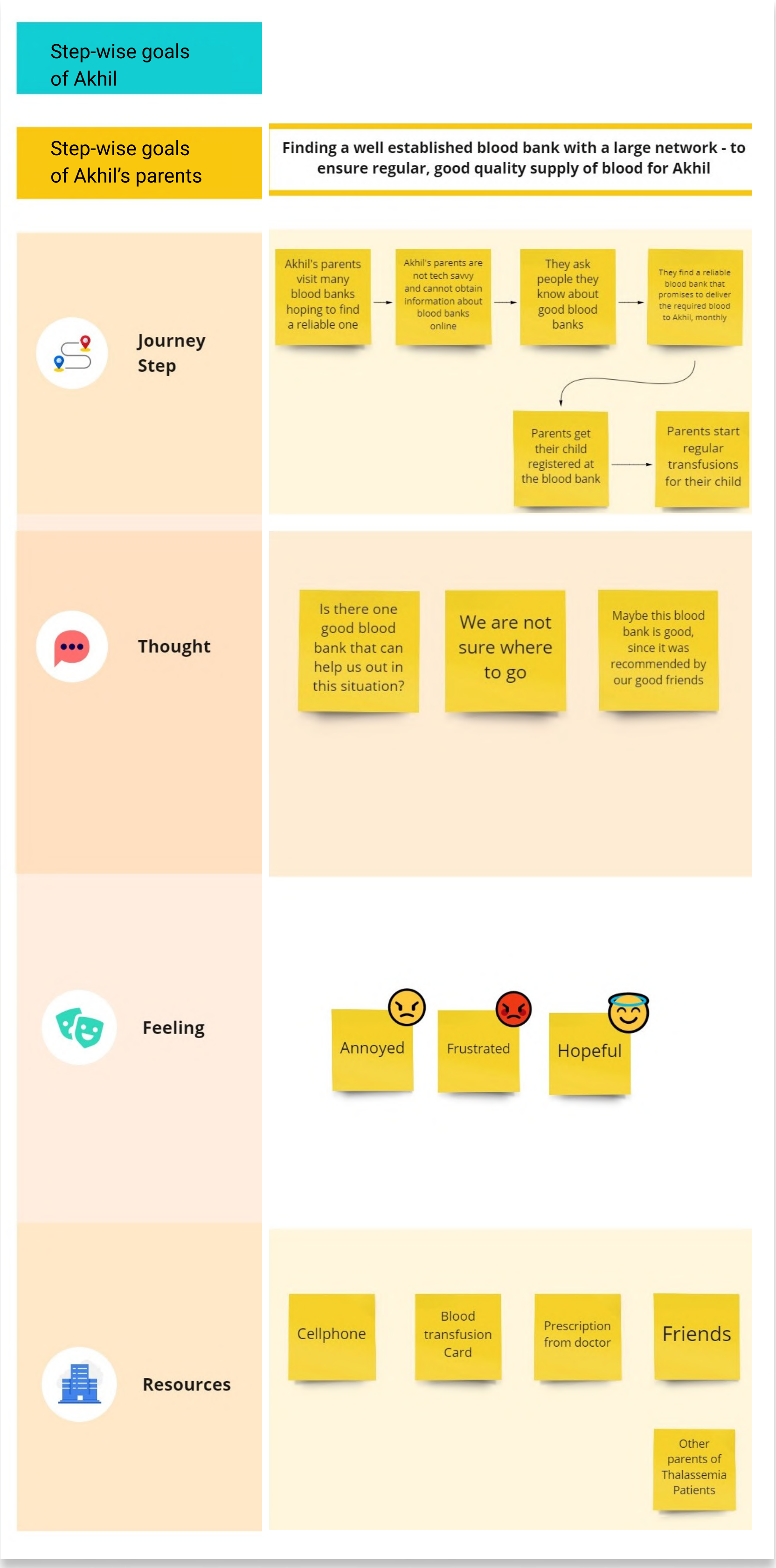
Fig. 13 This figure shows the fourth stage of the lifetime trajectory

Stage 5 : Finding a reliable blood bank

- Akhil's parents visit many blood banks hoping to find a reliable one
- Akhil's parents are not tech savvy and cannot obtain information about blood banks online
- They ask people they know about good blood banks
- They find a reliable blood bank that promises to deliver the required blood to Akhil, monthly
- Parents get their child registered at the blood bank
- Parents start regular transfusions for their child

The initial frustration and enxiety of this stage turns into hopefulness when parents find a reliable blood bank.

They find contacts of other blood banks mostly through other parents of Thalassemic patients.



Step-wise goals of Akhil	
Step-wise goals of Akhil's parents	**Finding a well established blood bank with a large network - to ensure regular, good quality supply of blood for Akhil**
Journey Step	Akhil's parents visit many blood banks hoping to find a reliable one → Akhil's parents are not tech savvy and cannot obtain information about blood banks online → They ask people they know about good blood banks → They find a reliable blood bank that promises to deliver the required blood to Akhil, monthly → Parents get their child registered at the blood bank → Parents start regular transfusions for their child
Thought	Is there one good blood bank that can help us out in this situation? We are not sure where to go Maybe this blood bank is good, since it was recommended by our good friends
Feeling	Annoyed Frustrated Hopeful
Resources	Cellphone Blood transfusion Card Prescription from doctor Friends Other parents of Thalassemia Patients

Fig. 14 This figure shows the fifth stage of the lifetime trajectory

Stage 6 : Habituating with the condition

The journey that Akhil takes during this stage is as follows.

- Akhil is slowly become aware of his health condition although he doesn't realize it fully
- Akhil wants to play outdoors like other students in his class
- Akhil does not like sitting for hours in the hospital taking blood transfusions
- Akhil receives some counseling to help him come to terms with his condition

Journey of Akhil's parents -

- Parents were not aware that a patient's diet must be maintained
- Become aware about necessary medications (like iron chelation tablets, calcium and vitamin medicines) and other treatments for Thalassemia
- Atul generally goes and gets the medicines while Akhil's transfusion is going on
- Parents find out through other parents - the importance of NAT testing, because blood that is not NAT tested can contain undetected pathogens

This stage involves a lot of learning, and understanding more about Thalassemia, mostly through other patients' parents, and the staff of the blood bank.

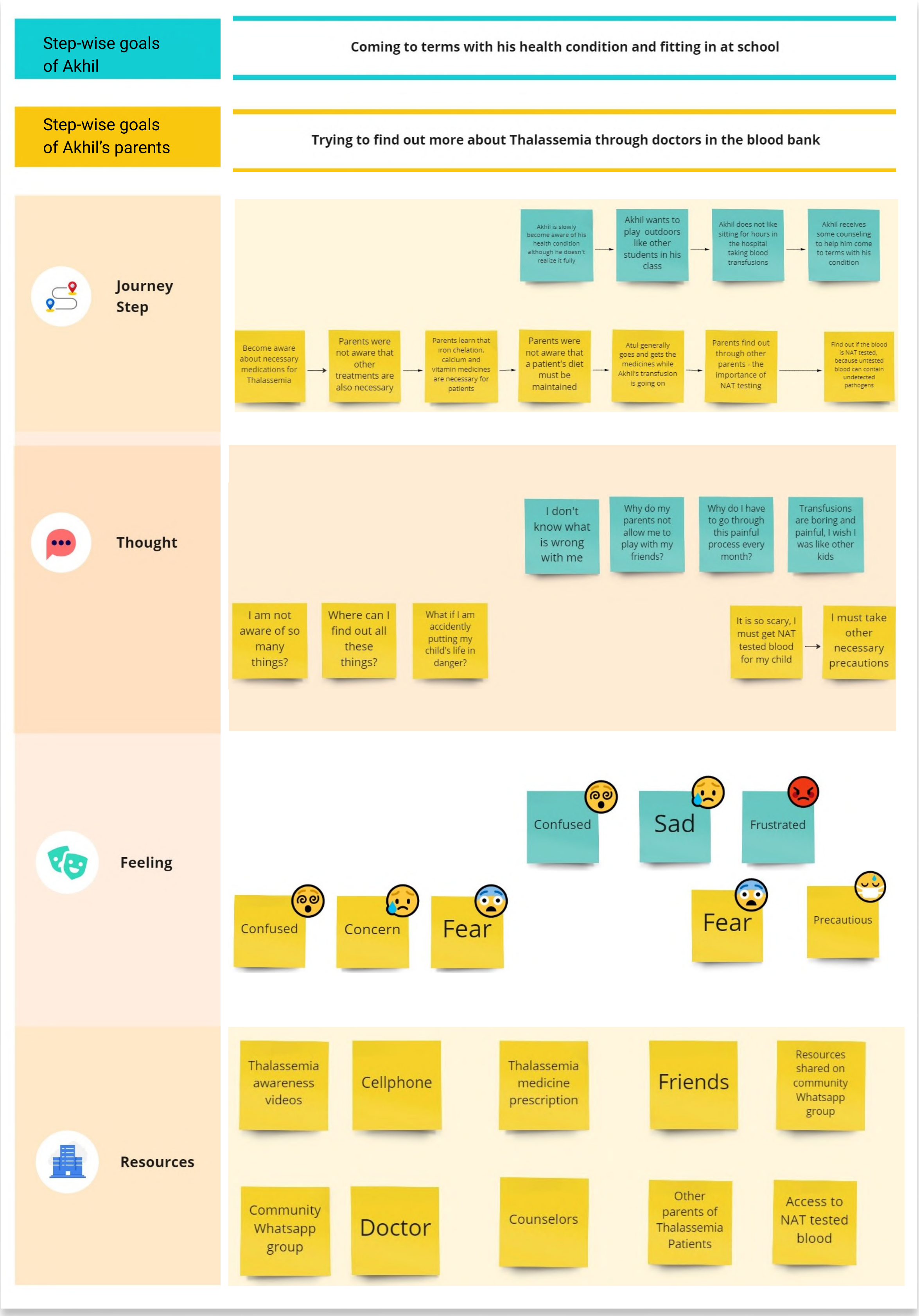


Fig. 15 This figure shows the sixth stage of the lifetime trajectory

Stage 7 : Getting used to the new normal

This stage represents how patients and parents are mentally coping with Thalassemia

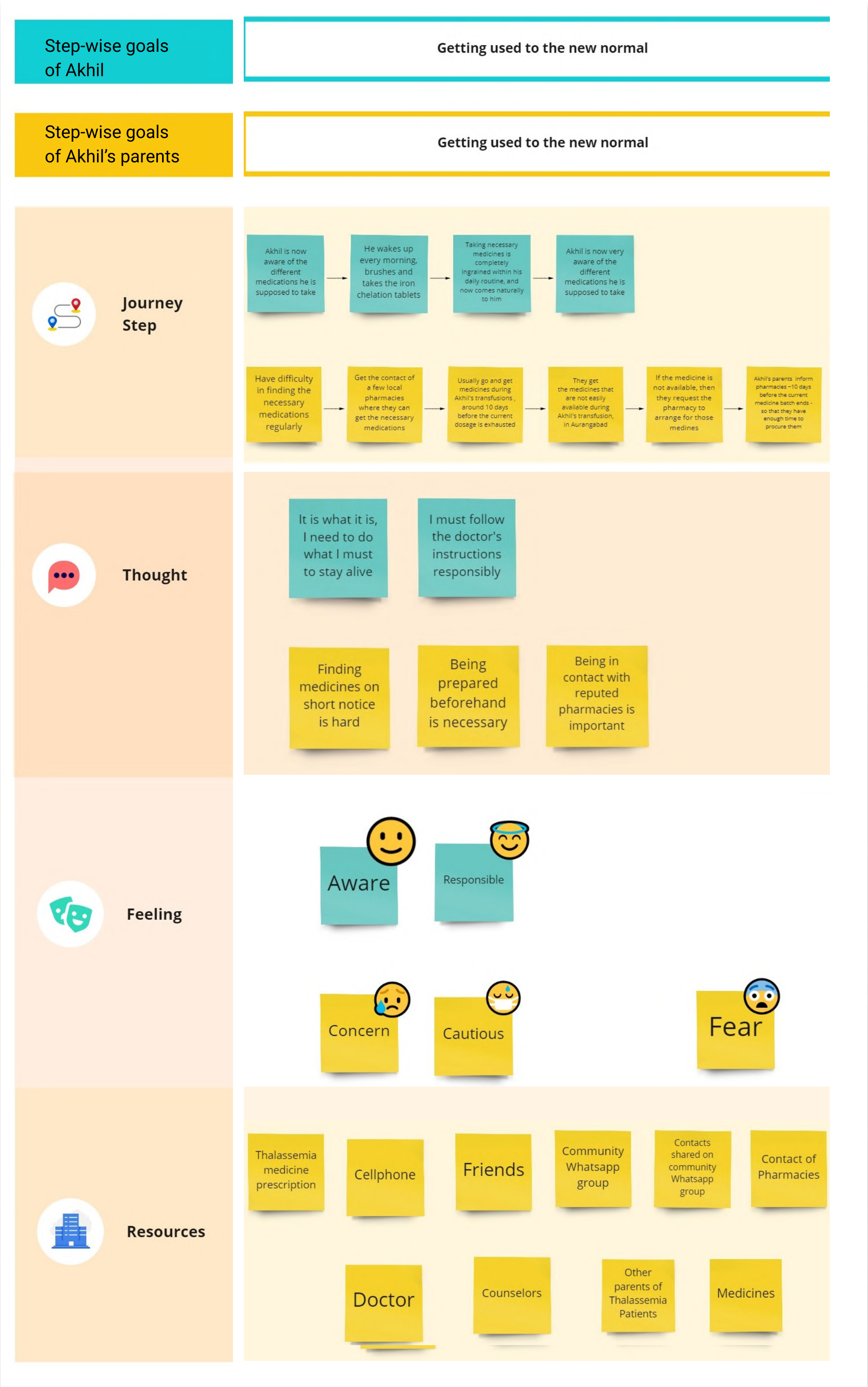


Fig. 16 This figure shows the seventh stage of the lifetime trajectory

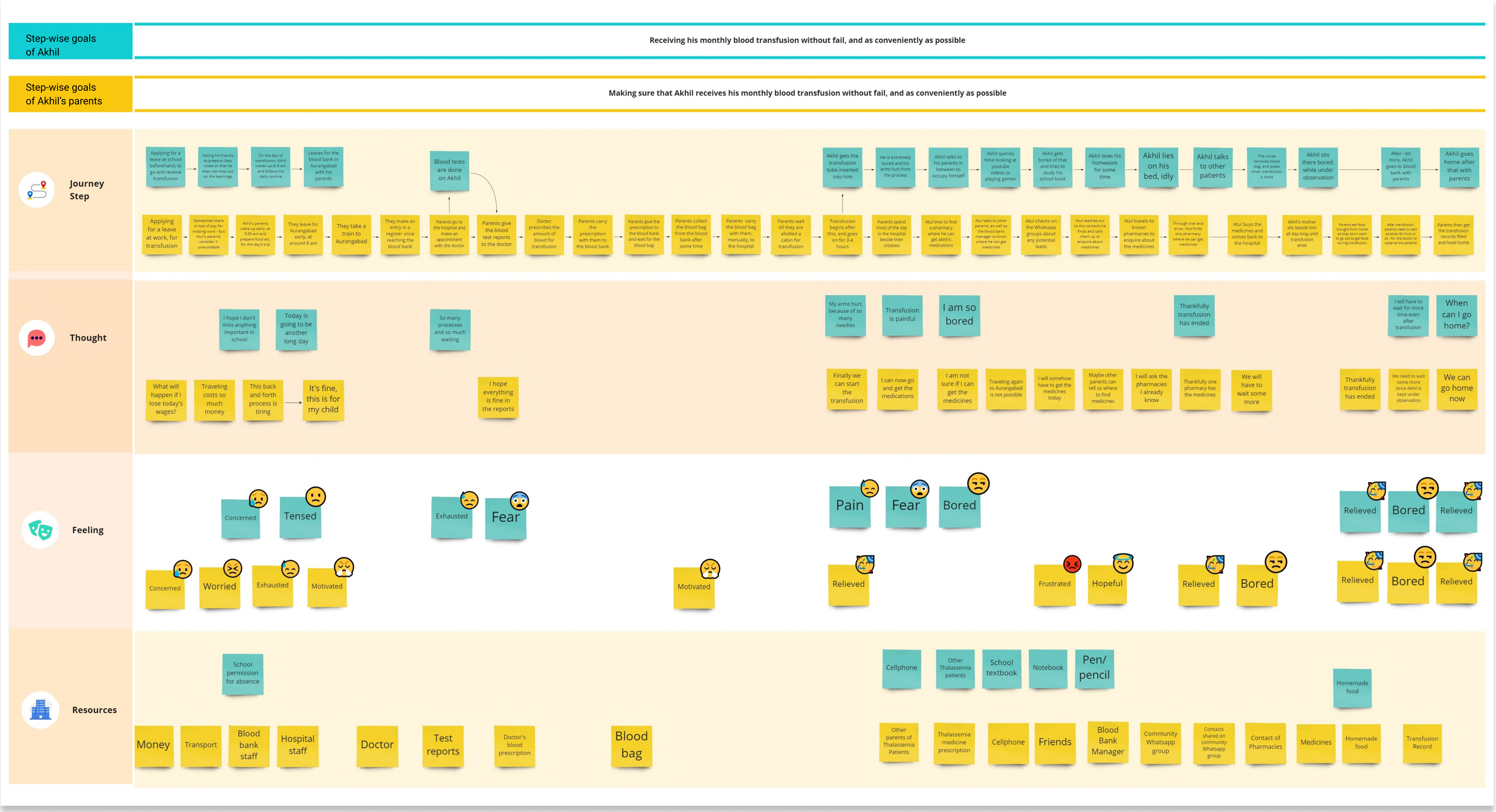


Fig. 17 This figure shows the eighth stage of the lifetime trajectory

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Stage 8 : Getting regular blood transfusions

This stage is the **most critical as per the patients and their parents**. Missing blood transfusions can have detrimental impact on a patient's health.

Thus it becomes important to consider service failures and appropriate recovery methods for this stage.

This stage entails the following on Akhil's part -

- Applying for a leave at school beforehand, if the transfusion day falls on a weekday
- Asking his friends to prepare notes etc. so that he does not miss what was taught in class
- On the day of the transfusion, Akhil wakes up at 6 am and carries on with his daily routine of brushing, taking pills etc.
- Gets ready to leave for the blood bank in Aurangabad
- Akhil gets the transfusion tube inserted into him
- He is extremely bored and his arms hurt from the process
- Akhil talks to his parents in between to occupy himself

This is how Atul's day goes -

- Applying for a leave at work beforehand, for transfusion
- They make an entry in a register in the blood bank
- Atul goes to the hospital and makes an appointment with the doctor
- Atul give the blood test reports to the doctor, and get the precription from him
- Atul carry the prescription with them to the blood bank
- Giving the prescription to the blood bank and waiting for the blood bag
- Collecting the blood bag from the blood bank
- Carrying the blood bag with them, manually, to the hospital
- Then they wait till they are allotted a cabin for transfusion
- Transfusion begins after this, and goes on for 3-4 hours
- Atul tries to find a pharmacy where he can get Akhil's medications
- Atul talks to other parents, as well as the blood bank manager to know where he can get medicines
- Atul checks on the Whatsapp groups about any leads
- Atul reaches out to the contacts he finds and calls them up to enquire about medicines
- Atul travels to known pharmacies to enquire about the medicines
- Through trial and error, Atul finds one pharmacy where he can get medicines
- Atul buys the medicines and comes back to the hospital
- Then he sits beside Akhil all day long until transfusion ends
- After transfusion, parents need to wait another 60 mins or so - for the doctor to observe the patients
- They then get the transfusion records filled and head home

Fig. 18 This figure shows the ninth stage of the lifetime trajectory

Stage 9 : Getting the BMT Operation done

On Atul’s part, this stage involves gathering the necessary funds for the treatment. He must also find a reliable center for HLA Type matching. Atul must find reliable hospitals where he can get Akhil’s bone marrow transplant done.

They are currently planning to do the HLA Type matching with Atul’s elder brother.

5.Scenario

Akhil is going to get his monthly transfusion today.
He wakes up at 6 am in the morning and brushes and takes his iron chelation tablets like always. Akhils packs his school textbooks and then leaves with his parents to the blood bank. They must travel 12 kms to get there. After all the necessary processes are done, Akhil must now receive his blood transfusion. “Another long, boring and painful day” - he thinks to himself, as he prepares himself mentally for transfusion.

Atul also wants to go and get the necessary medicines for Akhil during this particular visit, as traveling to Aurangabad again and again is not at all feasible for their family, in terms of costs as well as time.

Atul talks to his pharmacy contacts but it seems that the medicines are not available. In a frenzy, he starts calling up other parents of Thalassemic children to find out if any pharmacy in Aurangabad has the necessary medicines.

Atul relies on the community to help him out but it is uncertain if he will find any pharmacy that sells the required medicines today.

6.Redefining the Scope

Which service are we designing?

It must be clarified and realised that **Dattaji Bhale blood bank is not just one service but a constellation of interconnected services.** It provides the following micro-services -

- Blood collection and storage service
- Blood testing service
- Blood issuing service
- Blood transfusion service
- Counseling service, and
- Information dissemination and awareness building service

Therefore it becomes important to narrow down the services that I shall focus on in this project. I will be **primarily focusing on the blood transfusion service, as well as the awareness building services**. Why these ?

Who are we designing for?

Like I have already mentioned above, most decisions are made by the parents of Thalassemic patients. It is the parents who are involved in carrying out most of the required activities. Parents procure medicines, take their children to hospitals and in general, stay on top of necessary medical procedures. Therefore, its imperative that our design intervention not only aims at improving patients' wellbeing, but also their parents.

Why Service Design?

Service design helps establish interaction between humans through channels, products and in varying contexts. We can look at service design and draw connections by interpreting Shove's practice theory: (Zomerdijk et al., 2010; Lusch et al., 2007; Shove et al., 2012)

- **Holistic approach to design :** Service designers zoom out and analyze an ecosystem, various stakeholders, value flows and the context as they design. In social practices, it is not just the artefacts, but an interconnected complex network of people, systems and behaviours that drive interaction. Especially in the given context. As my guide had told me already, "**Remember that a child is growing up**".

- And thus, with this coming of age, a multitude of social, psychological, emotional and physical changes in patients. At the same time, the parents also must deal with gradual changes around them, as well as the changes that their children undergo.

- **Strengthen the channels of value co-creation :** Co-creates value : Service providers and service beneficiaries attain value by interacting and working together to realize the value of the service. Social practice looks at how collectives co-create value by performing the practice as a result of shared knowledge and understanding of the practice. **A Whatsapp group, set up by some proactive parents and members of the blood bank is the primary platform for community knowledge.** How can we establish other channels of community knowledge-sharing, that will complement the already existing channels.

- **Conceptualising the overall service, rather than one particular touchpoint**

- **Temporal Nature, value builds cumulatively**

7.Follow-up questions

After the first visit, there were a few questions I still had in my mind and I visited Dattaji Bhale blood bank in Aurangabad again to understand some of these questions better.

- **How do personas change over time?** Thalassemia is a lifelong disorder and this presents a unique challenge, the context, knowledge level and environment of Thalassemic patients and their parents change over time. Thus it also implies that these personas will change over time as well.

- Which service encounter do parents and patients consider most important? Discussions with parents and patients revealed that **receiving monthly transfusions is the most critical service encounter**. As per (Building Service Relationships : It's All About Promises; Mary Jo Bitner, Arizona State University), certain service encounters are more critical and can make or break a customer's overall experience. Thus **it becomes imperative that any potential service failures during this particular encounter are anticipated, and service recovery is planned.**

- How does this particular service encounter end? After what process do patients go home? The ending of the customer journey makes the most impact and thus it felt necessary to understand this particular aspect.

- What sort of habits/ interests do most patients have? Can they be nudged towards art or alternative ways of engagement/ learning? How do they generally spend their time during the transfusion? What extent of physical activity is possible during transfusion? Can children read, write or draw while their transfusion is happening?

- **What makes the beneficiaries (patients and parents) choose this particular blood bank** over others? Have they ever considered availing the services of another blood bank? Would they ever consider? Again, these decisions are made by the parents of Thalassemic parents, and not by the patients themselves. Parents are the key decision makers throughout this entire journey, and through my user interviews I have learnt that the key

- Service relationships rely on the concept of value co-creation. Rather than being passive recipients of a service's benefits, customers decide how value should be created for them and are in a way, co-architecting the value that they can derive from a service. Long term value co-creation results in the formation of service relationships, which benefit the service provider as well as its customers. The benefits of maintaining service relationships from the perspective of the service provider is well known. However, in this regard, the benefits mostly lie with the patients and their parents, since the blood bank provides them with NAT tested, good quality blood, reliably and as per the patient's requirement every month.

- Therefore it become imperative to ask “What exactly do the patients/ parents do to maintain this service relationship?”

- Value co-creation between customers and service providers happens through unique, personalized interactions between them - wherein customers are enabled to create their own unique personalized experience within the experience environment (CO-CREATION EXPERIENCES : THE NEXT PRACTICE IN VALUE CREATION; C. K. PRAHALAD AND VENKAT RAMASWAMY). Therefore, what opportunities can be found in this context to allow for the patients and their parents to have their own unique experiences?

- Is there a unique relationship between the service providers and the patients, or their parents and if yes, how can this relationship be leveraged to better the patients’, or their parents’ experience? How has this service relationship evolved? What aspects will change over time? And what aspects remain constant? Eg. knowledge level of the people involved may change, but social surroundings may not change

- What can the blood bank do proactively so that parents discover them easily?

Service blueprint during discovery, walk-in, Whatsapp message etc. - what are the touchpoints that can be leveraged
How do most parents discover the blood bank?
How do we help best utilize the 3-4 hours parents spend during transfusion for Volunteering, awareness etc.
Pain and boredom - how do we tackle these issues for the patients

How do parents feel about carrying the blood bags?
Can there be some packaging etc that the patients can carry back
Is there such a community between the students?
Are parents in a common platform, or have a community
Eg. like a Whatsapp group
Could there be WA group with the Blood Bank staff and the parents?
How long after registration can patients regularly receive blood donation from a blood bank?
Is every patient accepted? When is the confirmation sent?
Do patients receive any sort of guarantee that they will get blood?
Do donors know who is the thalassemia patient is who they are donating blood ?
Opportunity for Endowment effect?
Are there confidentiality related concerns?
Can personal relationships be built without revealing identity?
Do donors get anything in return other than personal satisfaction?

8.Design Directions

The broad goals that I am tryin to achieve are as follows -

- Selecting one or two service encounters which allow for a possibility of feasible design interventions
- Coming up with concrete design ideations related to potentials areas such as - Designing awareness programs; leveraging the initial service encounters related to diagnosis and detection for the same
- Engaging patients and parents while transfusion is happening. How do we help best utilize the 3-4 hours parents spend during transfusion for Volunteering, awareness etc.? Pain and boredom - how do we tackle these issues for the patients
- Conceptualizing a platform where parents can find access to donors, and information about pharmacies, as well as reliable medical facilities
- Validating the learnings and ideations with stakeholders
- Implementing feasible solutions through the help of Dattaji Bhale blood bank and Dr. Hedgewar hospital

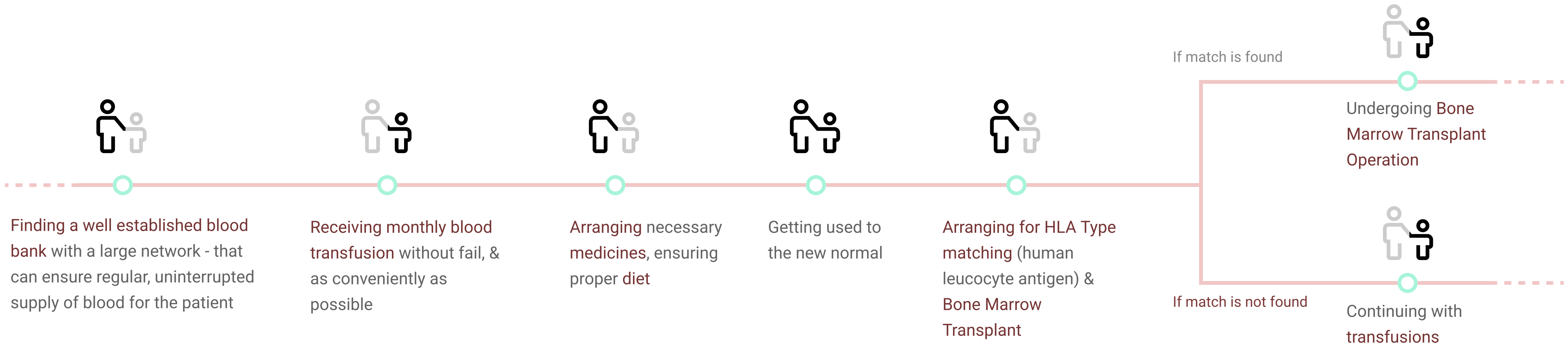
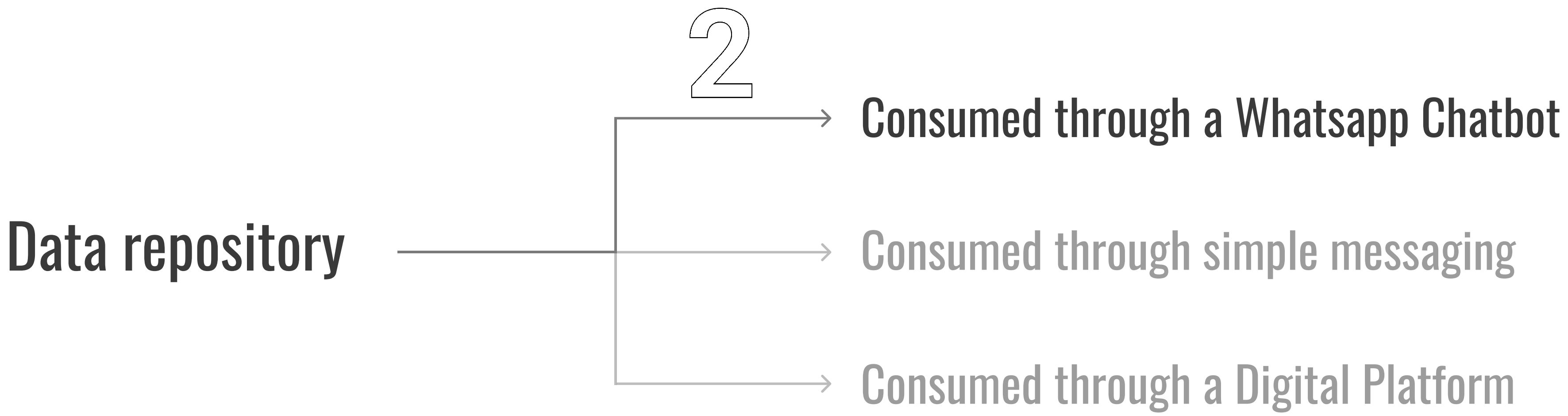


Fig. 19 This figure shows customer journey after finding a reliable blood bank, and whether the parent or the patient is involved in a particular encounter

8.1 Discoverability of Resources/ Treatment Facilities

- Parents use their phones mostly for WhatsApp, tech literacy is not enough for using Google, Youtube etc.
- WhatsApp is already being used for Information dissemination
- Can be consumed on the go
- Repository must be updated in real time by aware parents, pharmacists, blood bank managers, doctors and other hospital staff



2

Data repository

Consumed through a Whatsapp Chatbot

Consumed through simple messaging

Consumed through a Digital Platform

Fig. 20 This figure shows which touchpoint I will be focusing on creating

Touchpoint : Whatsapp Chatbot

- Cuts across multiple service encounters
- Parents have a hard time finding pharmacies that have Thalassemia medicines in stock
- Parents don’t know which medical facilities do HLA Type Matching, or hospitals are good for BMT Operations
- Finding a blood bank is easy, finding a good blood bank that can regularly and reliably satisfy a patient’s blood transfusion requirements is hard
- Current touchpoints : Clinicians, blood bank manager & other parents through Whatsapp groups or word of mouth
- The flow of communication, the messaging used in the chat
- The mechanism - how will data flow in and be disseminated
- When exactly will human moderators come into picture? For voice based texting etc.
- Blueprint of this particular service encounter

Information Architecture of Whatsapp Chatbot

1. Input → 2. Upload or Access Info → 3. Broad Topics

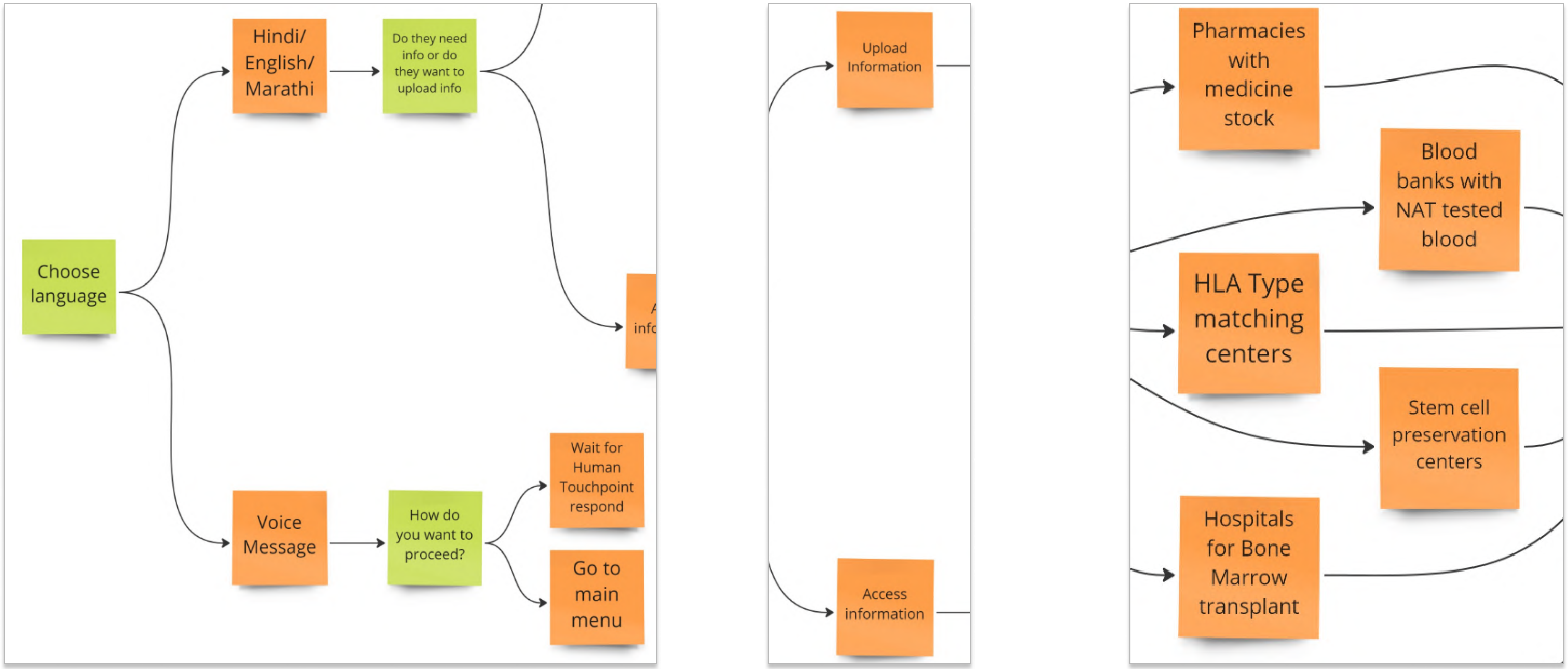
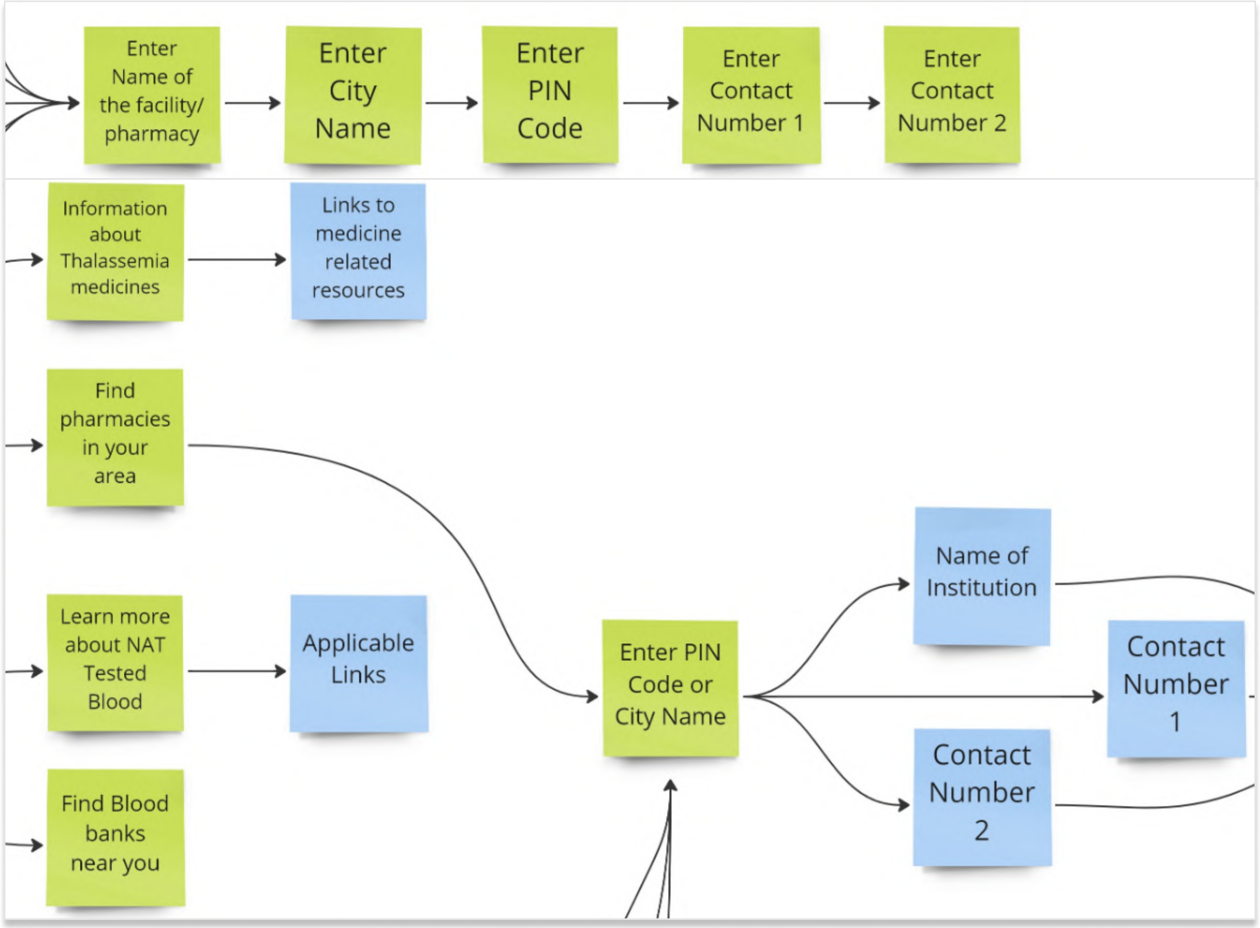


Fig. 21 How information will flow to and from the Whatsapp chat

Information Architecture of Whatsapp Chatbot

4. Necessary Information to Upload or to Access → 5. Feedback



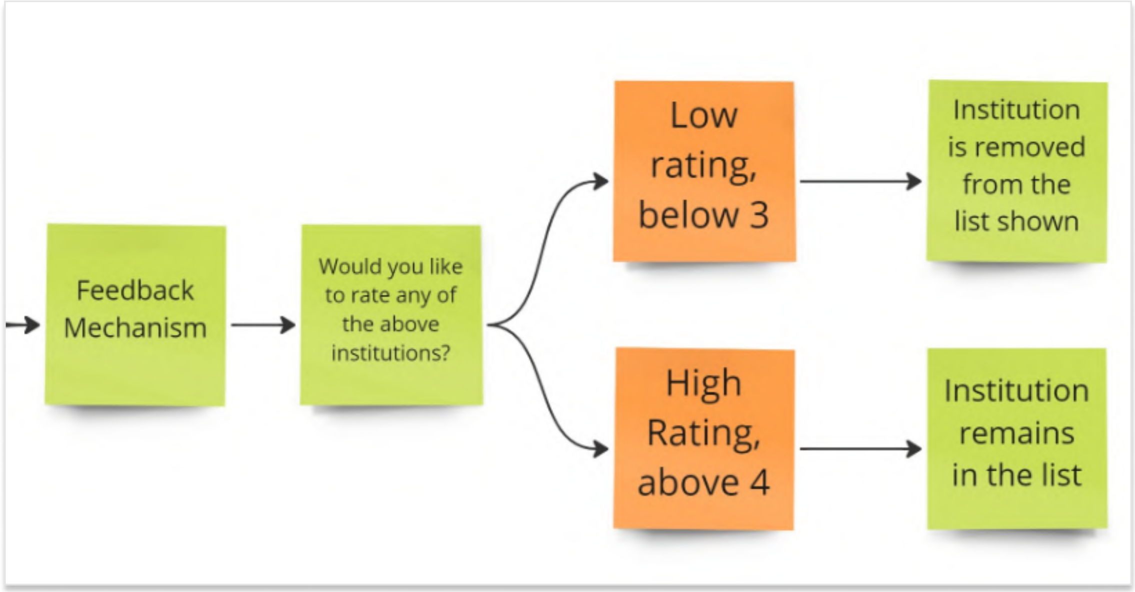
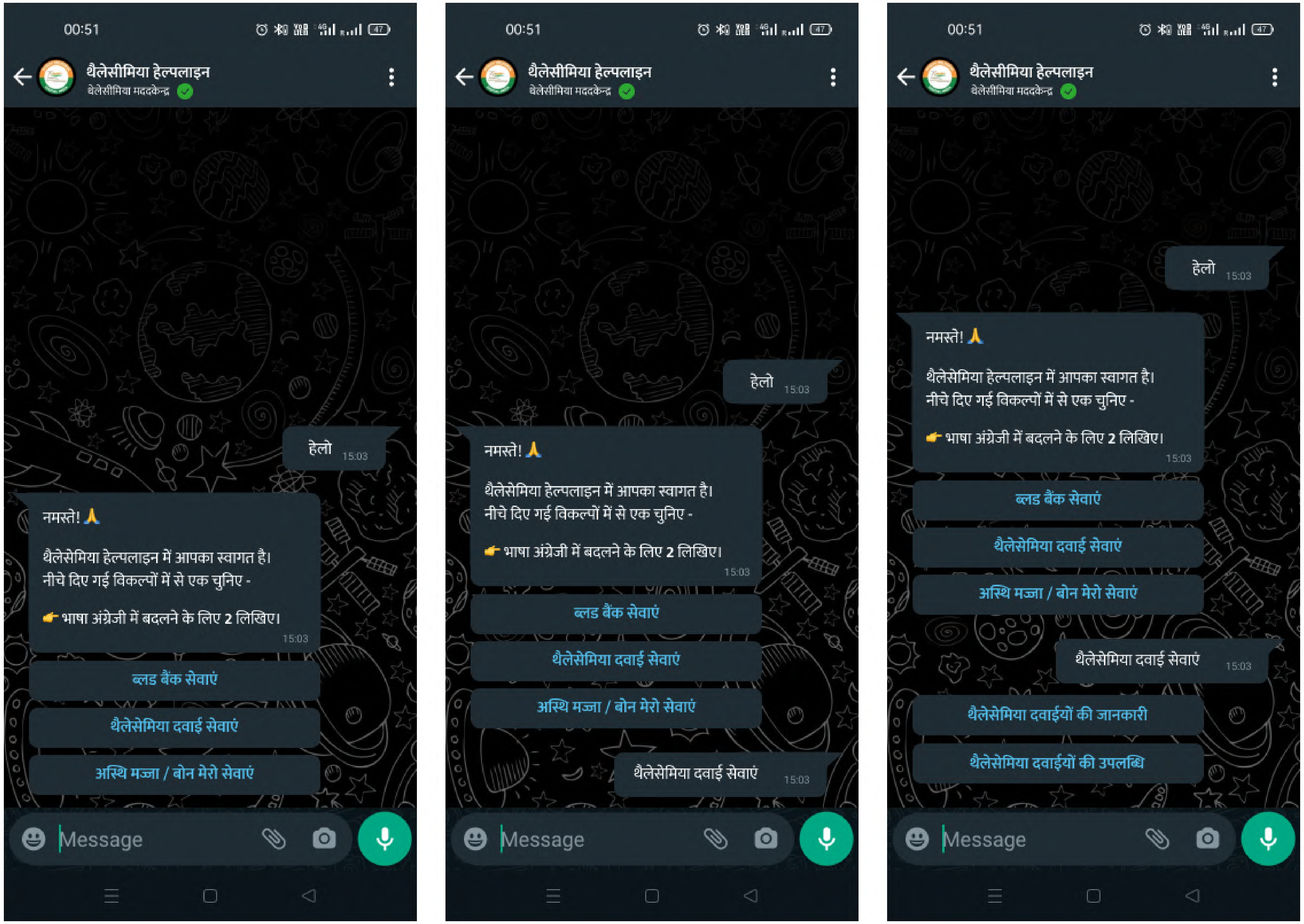


Fig. 22 How information will flow to and from the Whatsapp chat

Screens of Whatsapp Chatbot



हेलो 15:03

नमस्ते! 🙏

थैलेसेमिया हेल्पलाइन में आपका स्वागत है।
नीचे दिए गई विकल्पों में से एक चुनिए -

👉 भाषा अंग्रेजी में बदलने के लिए **2** लिखिए।
15:03

ब्लड बैंक सेवाएं

थैलेसेमिया दवाई सेवाएं

अस्थि मज्जा / बोन मेरो सेवाएं

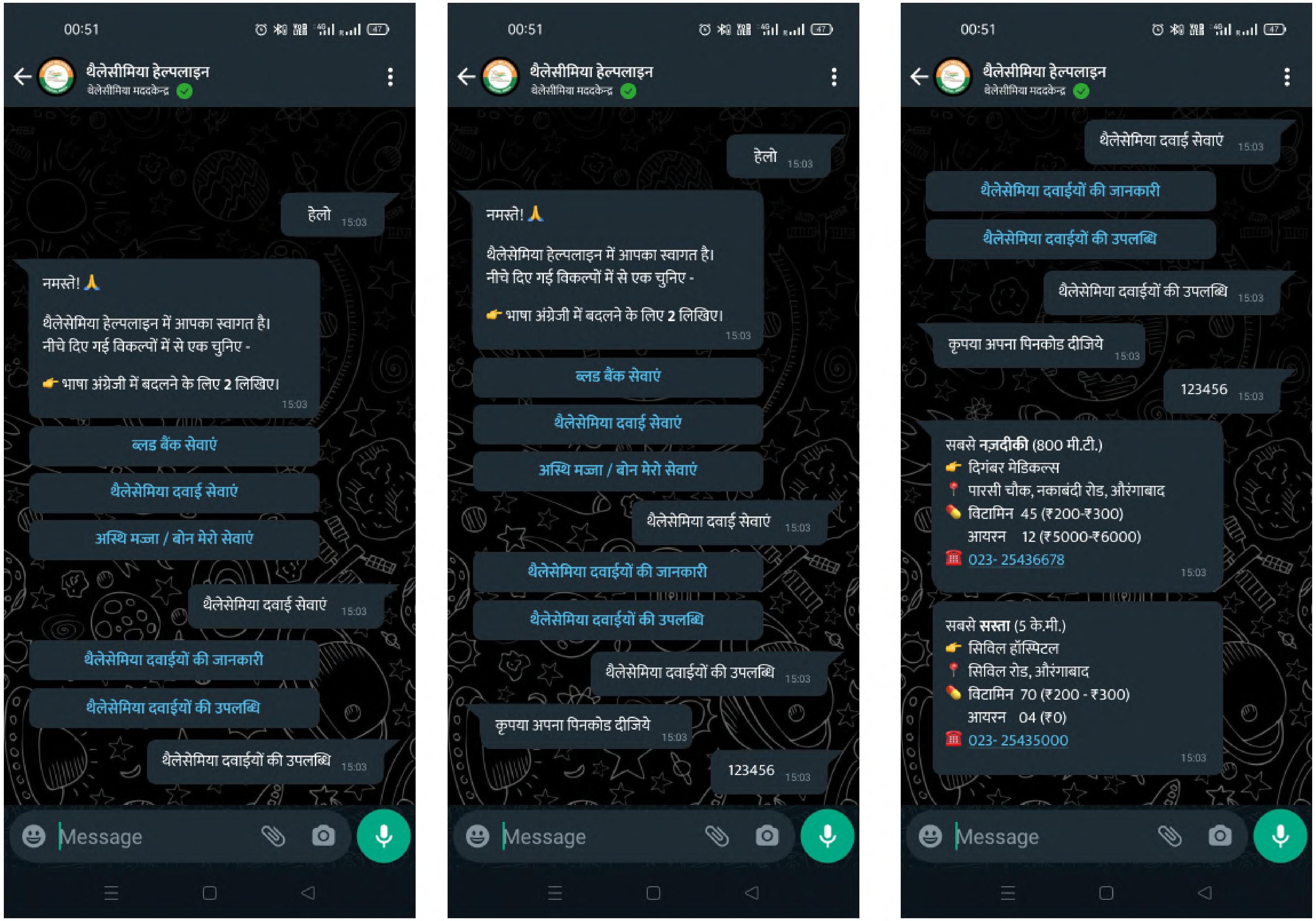
थैलेसेमिया दवाई सेवाएं 15:03

थैलेसेमिया दवाईयों की जानकारी

थैलेसेमिया दवाईयों की उपलब्धि

Fig. 23 How conversation will begin on the chatbot once someone sends “Hi” or “Hello”

Screens of Whatsapp Chatbot



हेलो 15:03

नमस्ते! 🙏

थैलेसेमिया हेल्पलाइन में आपका स्वागत है।
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👉 भाषा अंग्रेजी में बदलने के लिए **2** लिखिए। 15:03

थैलेसेमिया दवाई सेवाएं 15:03

थैलेसेमिया दवाईयों की उपलब्धि 15:03

हेलो 15:03

नमस्ते! 🙏

थैलेसेमिया हेल्पलाइन में आपका स्वागत है।
नीचे दिए गई विकल्पों में से एक चुनिए -

👉 भाषा अंग्रेजी में बदलने के लिए **2** लिखिए। 15:03

थैलेसेमिया दवाई सेवाएं 15:03

थैलेसेमिया दवाईयों की उपलब्धि 15:03

कृपया अपना पिनकोड दीजिये 15:03

123456 15:03

थैलेसेमिया दवाई सेवाएं 15:03

थैलेसेमिया दवाईयों की उपलब्धि 15:03

कृपया अपना पिनकोड दीजिये 15:03

123456 15:03

सबसे **नज़दीकी** (800 मी.टी.)
👉 दिगंबर मेडिकल्स
📍 पारसी चौक, नकाबंदी रोड, औरंगाबाद
💊 विटामिन 45 (₹200-₹300)
आयरन 12 (₹5000-₹6000)
☎ 023- 25436678
15:03

सबसे **सस्ता** (5 के.मी.)
👉 सिविल हॉस्पिटल
📍 सिविल रोड, औरंगाबाद
💊 विटामिन 70 (₹200 - ₹300)
आयरन 04 (₹0)
☎ 023- 25435000
15:03

Fig. 24 User asks for Thalassemia related information - they are looking for medicines, shares their pin code and receives all details like

Fig. 22 Service encounter on the day of transfusion

8.2 Pain, anxiety and stress during transfusion

- Receiving transfusions is the most important service encounter
- Essentially a life-long process
- Painful, boring, stress-inducing and anxiety inducing
- Current coping mechanisms : Studying school books, using phone for texting/ Youtube/ Facebook, Sleeping

Finding a well established blood bank with a large network - that can ensure regular, uninterrupted supply of blood for the patient

Receiving monthly blood transfusion without fail, & as conveniently as possible

Arranging necessary medicines, ensuring proper diet

Getting used to the new normal

Arranging for HLA Type matching (human leucocyte antigen) & Bone Marrow Transplant

If match is found

Undergoing Bone Marrow Transplant Operation

If match is not found

Continuing with transfusions

Touchpoint : Interactive magazine for Children (6-11 years)

Why?

- Stories, puzzles and art related activities reduce anxiety, and stress
- Guidelines for creating the magazine - so that it can be created sustainably
- Constructing the magazine in a way that children are successfully engrossed in it for the duration of the transfusion, which is typically 3-4 hours
- Can distract children from physical pain during transfusion
- Artworks drawn on the magazine by patients be used as thank you notes, greetings cards, progress reports - to share with donors to improve donor motivation

What will I design?

- Guidelines which consist of - Open Source archive of stories (in English, Hindi and Marathi) and Puzzles; design guidelines such as color scheme, size and layout, fonts; as well as directions on the structure of the magazine - what should each page contain
- Can be serialised so that children have something to look forward to for the next visit
- Mapping a child’s mental state during different stages of the transfusion process - to make the magazine contextual
- Can be carried back and made into a collection
- How hands-on art and storytelling can be incorporated to make the magazine interactive
- Making the magazine cost-effective and contextual to differentiate it from other magazines in the market

Story taken from an open source archive - StoryWeaver.org (Link)

PRATHAM BOOKS

वाचन पातळी २

दहांची शक्ती

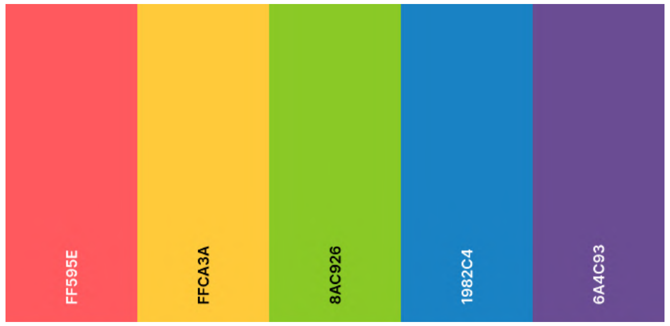
Author: Anita Roy
Illustrator: Joanna Mendes
Translator: Ashlesha Mahajan

Lorem ipsum dolor sit amet, consectetur adipiscing elit.

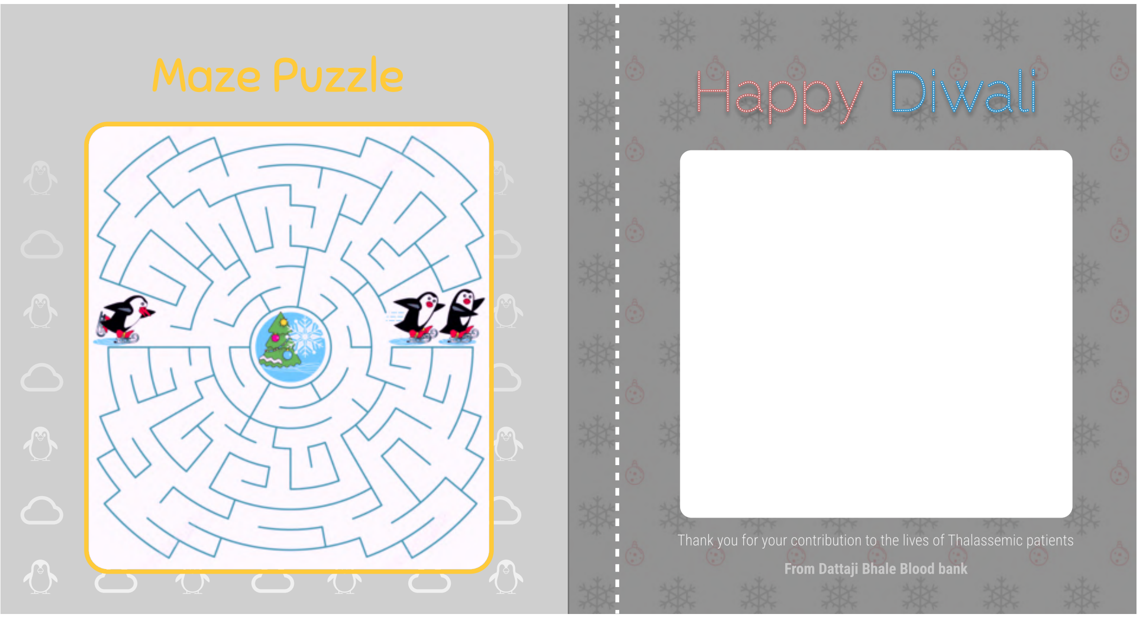
Lorem ipsum dolor sit amet, consectetur adipiscing elit.

10

देवदूत नाचत आहेत
एका सुईच्या टोकावर.

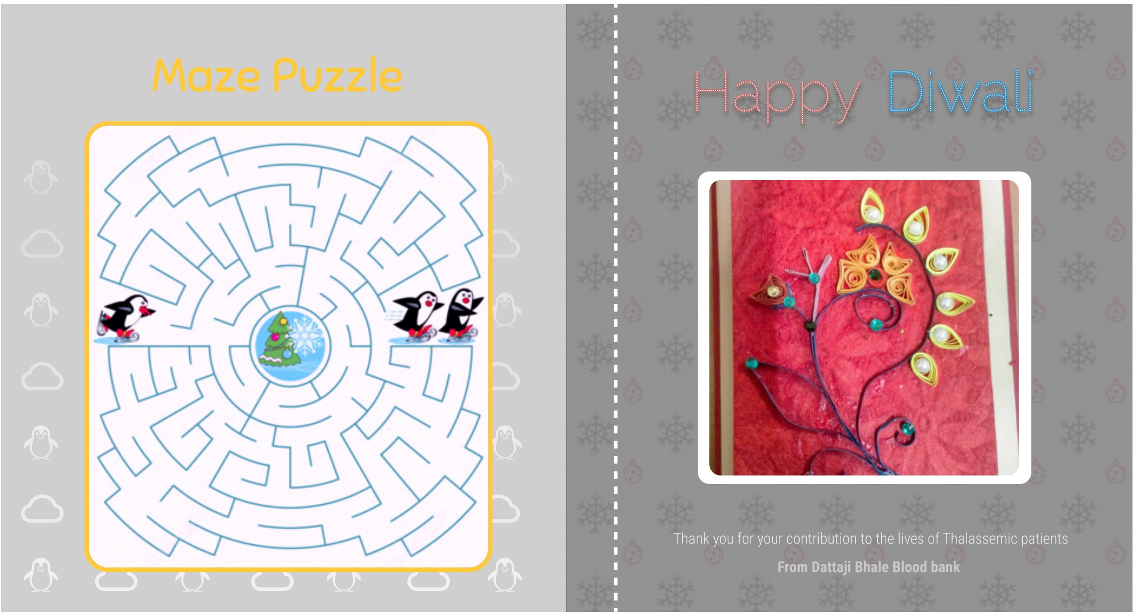


Puzzle taken from a free online puzzle repository



Thank you for your contribution to the lives of Thalassemic patients

From Dattaji Bhale Blood bank



Thank you for your contribution to the lives of Thalassemic patients

From Dattaji Bhale Blood bank

Fig. 23 Initial Ideations for the interactive magazine

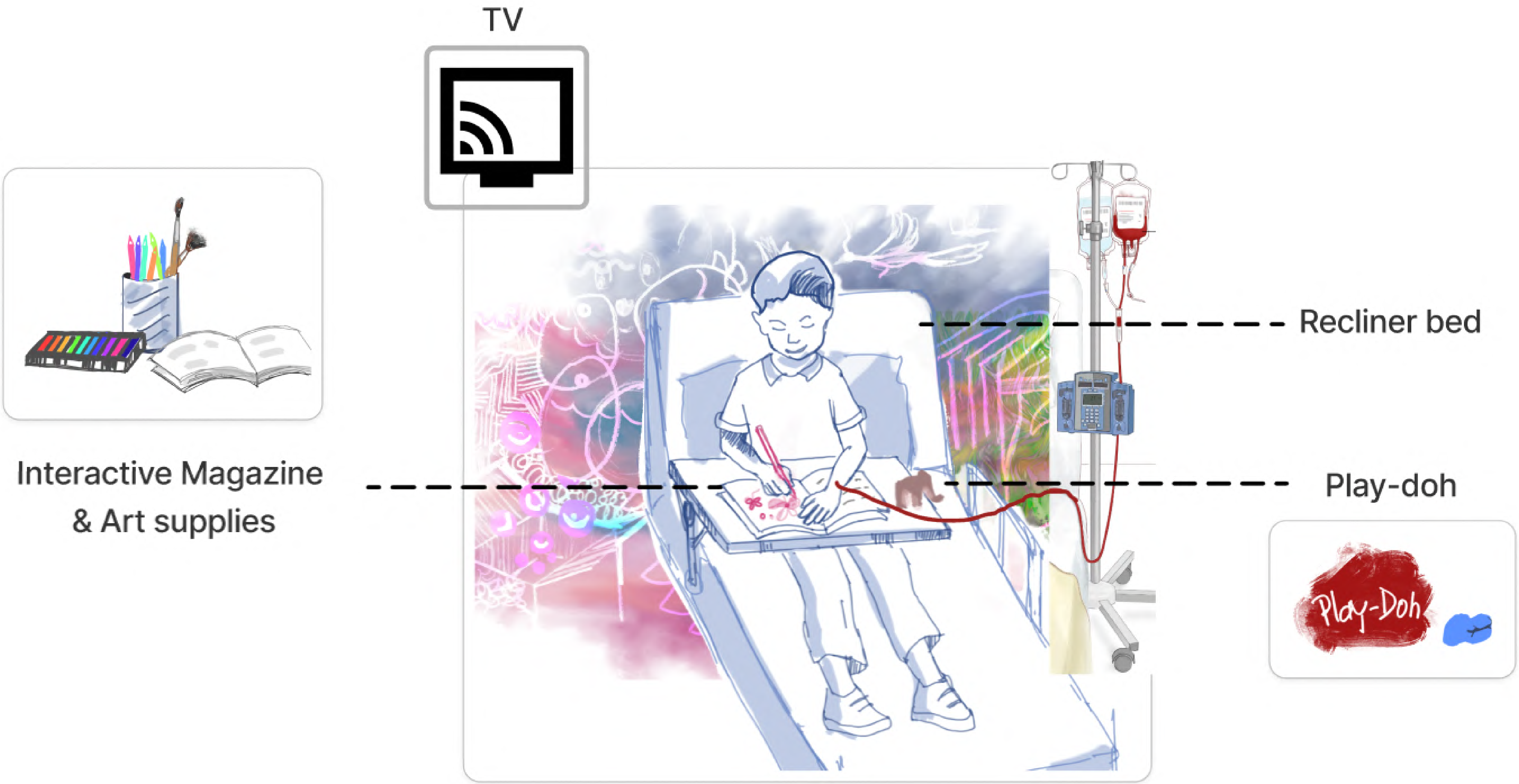
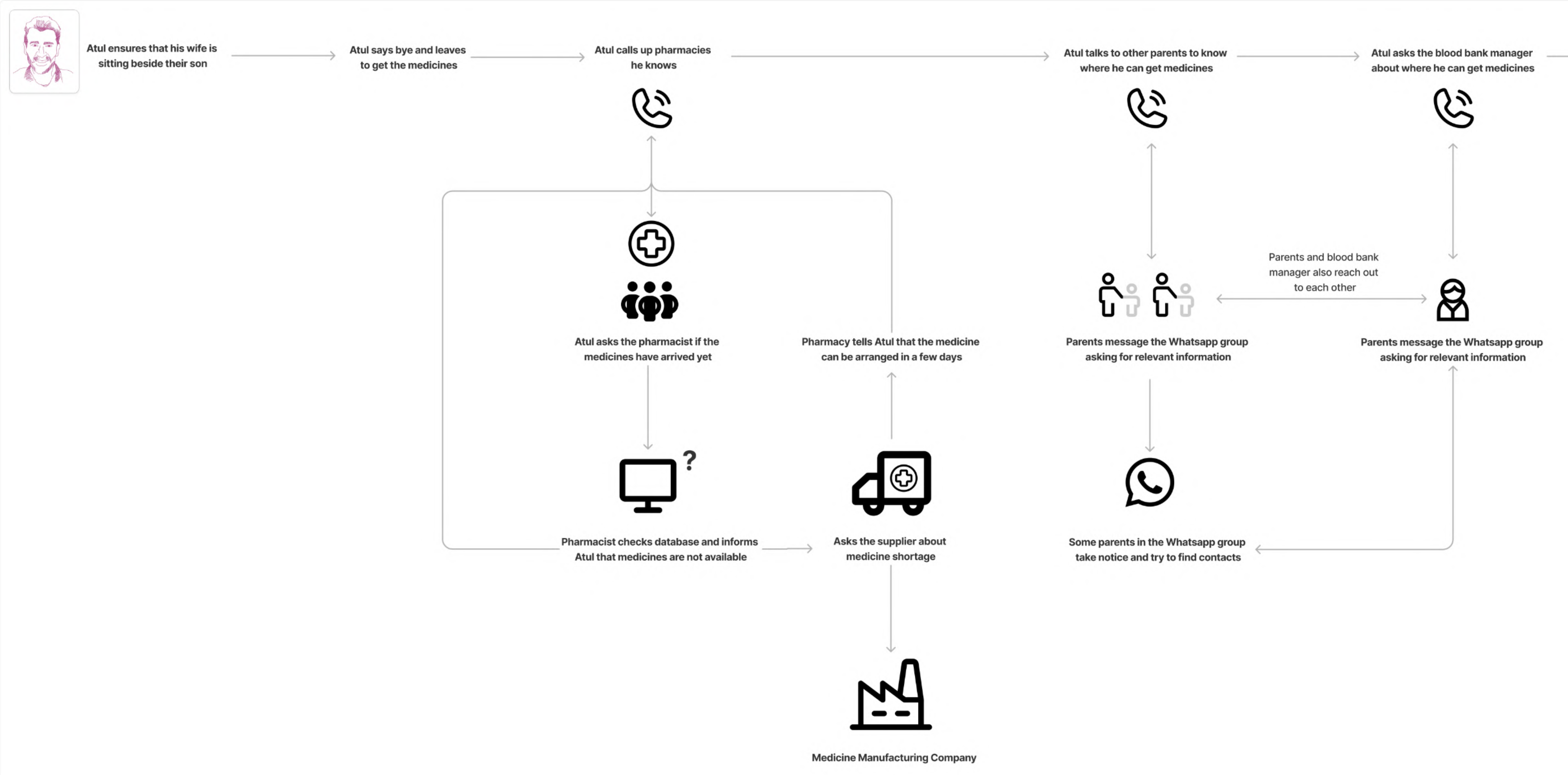


Fig. 24 Designing a service-scape to distract children from pain, boredom and dullness while taking transfusions

9.Service Blueprints (link to all blueprints)

The first Goal is to get Akhil's medicines. This is how it used to happen earlier, without the service interventions.



Atul ensures that his wife is sitting beside their son

Atul says bye and leaves to get the medicines

Atul calls up pharmacies he knows

Atul talks to other parents to know where he can get medicines

Atul asks the blood bank manager about where he can get medicines

Atul asks the pharmacist if the medicines have arrived yet

Pharmacy tells Atul that the medicine can be arranged in a few days

Parents message the Whatsapp group asking for relevant information

Parents and blood bank manager also reach out to each other

Parents message the Whatsapp group asking for relevant information

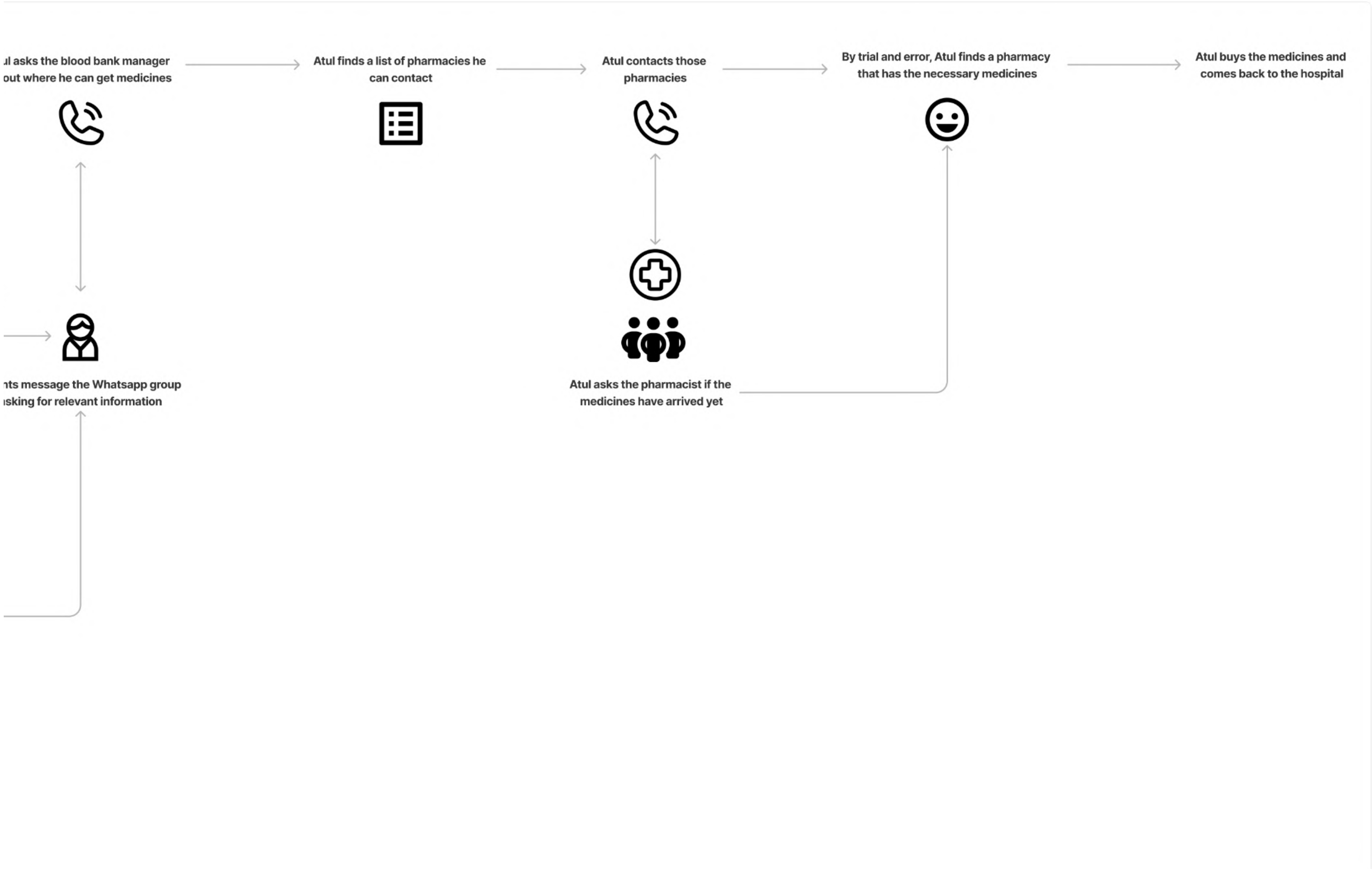
Pharmacist checks database and informs Atul that medicines are not available

Asks the supplier about medicine shortage

Some parents in the Whatsapp group take notice and try to find contacts

Medicine Manufacturing Company

The first Goal is to get Akhil's medicines. The service blueprint without interventions is continued on this page -



l asks the blood bank manager out where he can get medicines

Atul finds a list of pharmacies he can contact

Atul contacts those pharmacies

By trial and error, Atul finds a pharmacy that has the necessary medicines

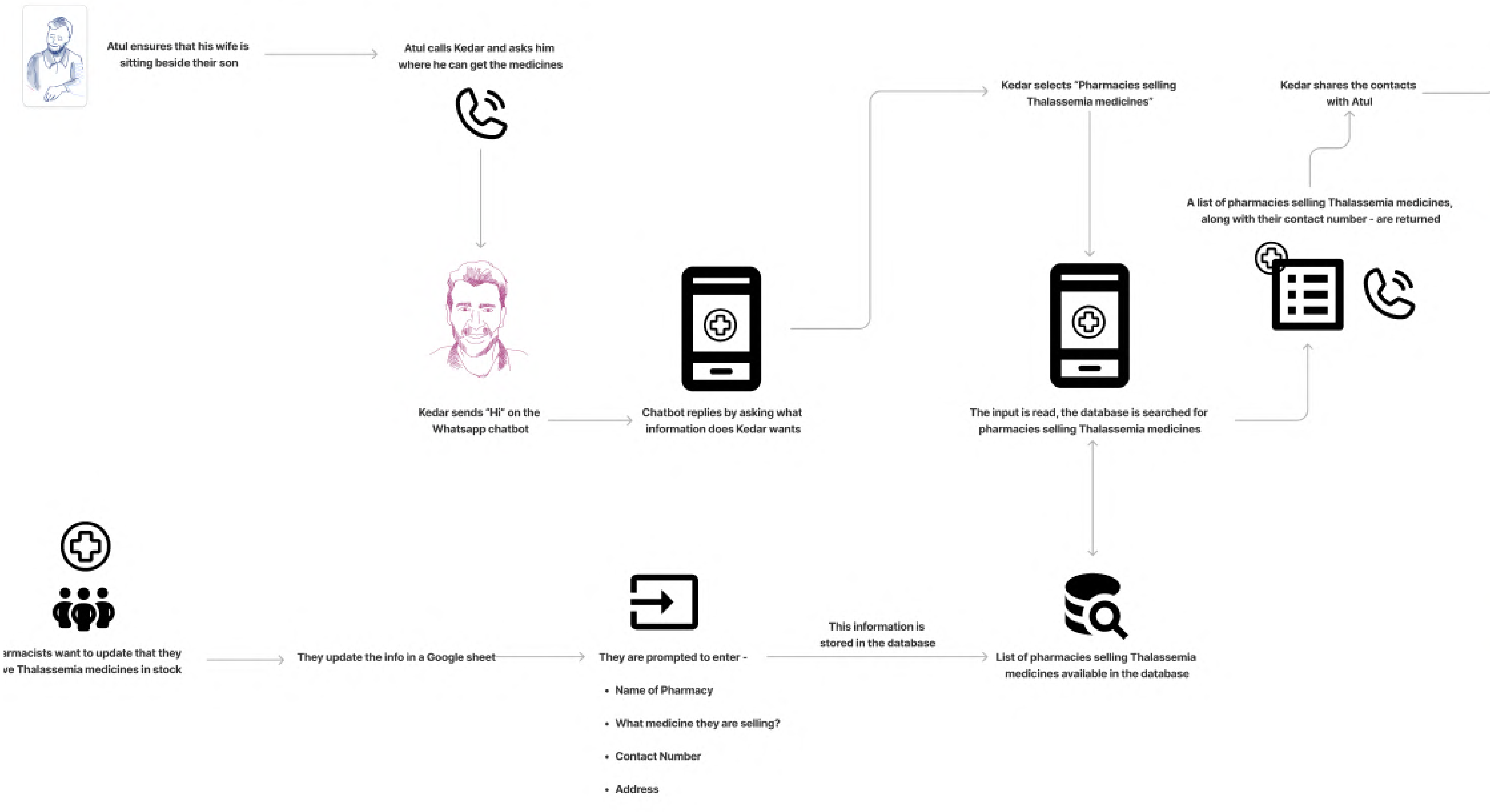
Atul buys the medicines and comes back to the hospital

nts message the Whatsapp group sking for relevant information

Atul asks the pharmacist if the medicines have arrived yet

The same blueprint with relevant touchpoints and interventions introduced -

Goal of Encounter : to get Akhil's medicines (with interventions)



Atul ensures that his wife is sitting beside their son

Atul calls Kedar and asks him where he can get the medicines

Kedar sends "Hi" on the Whatsapp chatbot

Chatbot replies by asking what information does Kedar wants

Kedar selects "Pharmacies selling Thalassemia medicines"

The input is read, the database is searched for pharmacies selling Thalassemia medicines

A list of pharmacies selling Thalassemia medicines, along with their contact number - are returned

Kedar shares the contacts with Atul

armacists want to update that they ve Thalassemia medicines in stock

They update the info in a Google sheet

They are prompted to enter -

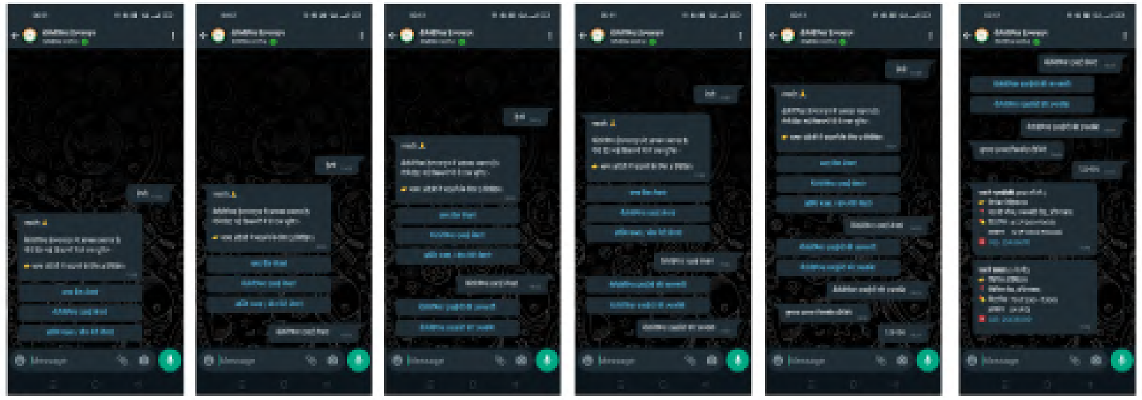
- Name of Pharmacy
- What medicine they are selling?
- Contact Number
- Address

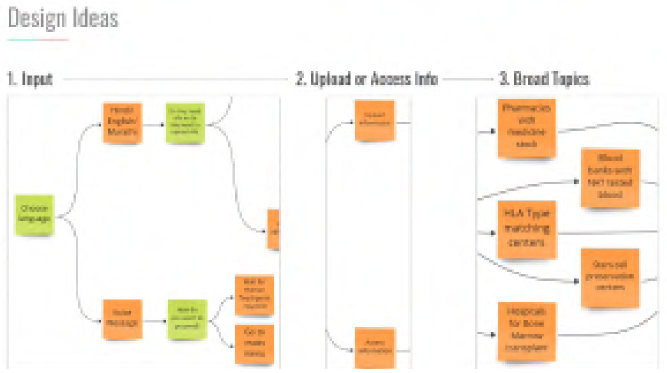
This information is stored in the database

List of pharmacies selling Thalassemia medicines available in the database

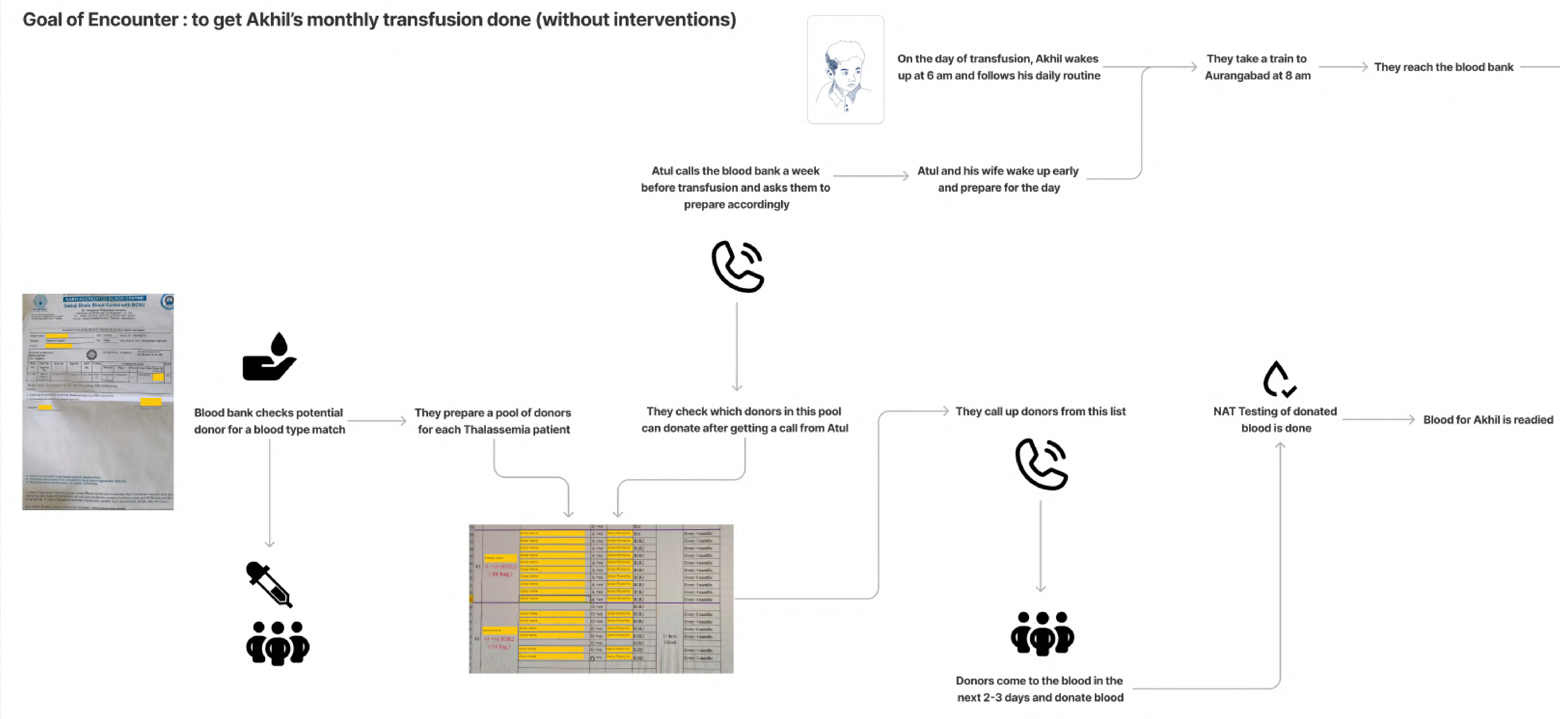
The same blueprint with relevant touchpoints and interventions introduced (contd.)-

Atul calls the pharmacies whose contacts he got → Atul decides to go to the civil hospital since it sells medicines free of cost → Atul gets the medicines → Atul thanks Kedar for his help → Kedar comes back to the hospital





The second Goal is to get Akhil's monthly blood transfusion. This is how it used to happen earlier, without the service interventions.



Goal of Encounter : to get Akhil's monthly transfusion done (without interventions)

Blood bank checks potential donor for a blood type match

They prepare a pool of donors for each Thalassemia patient

Atul calls the blood bank a week before transfusion and asks them to prepare accordingly

They check which donors in this pool can donate after getting a call from Atul

Atul and his wife wake up early and prepare for the day

On the day of transfusion, Akhil wakes up at 6 am and follows his daily routine

They take a train to Aurangabad at 8 am

They reach the blood bank

They call up donors from this list

Donors come to the blood in the next 2-3 days and donate blood

NAT Testing of donated blood is done

Blood for Akhil is readied

The second Goal is to get Akhil's monthly blood transfusion. This is how it used to happen earlier, without the service interventions (contd.).

They make an entry in a register once reaching the blood bank

Blood tests are done on Akhil and doctor prescribes the quantity of blood

Atul gives the prescription to the blood bank and waits for the blood bag

Blood bag for Akhil is prepared based on the prescription

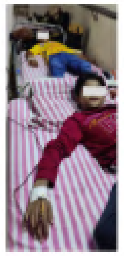
Atul collects the blood bag and brings it to the hospital

Akhil & his mother wait till they are allotted a cabin for transfusion

Cabin is arranged for Thalassemia patients receiving transfusion today

Nurse inserts transfusion tube into Akhil

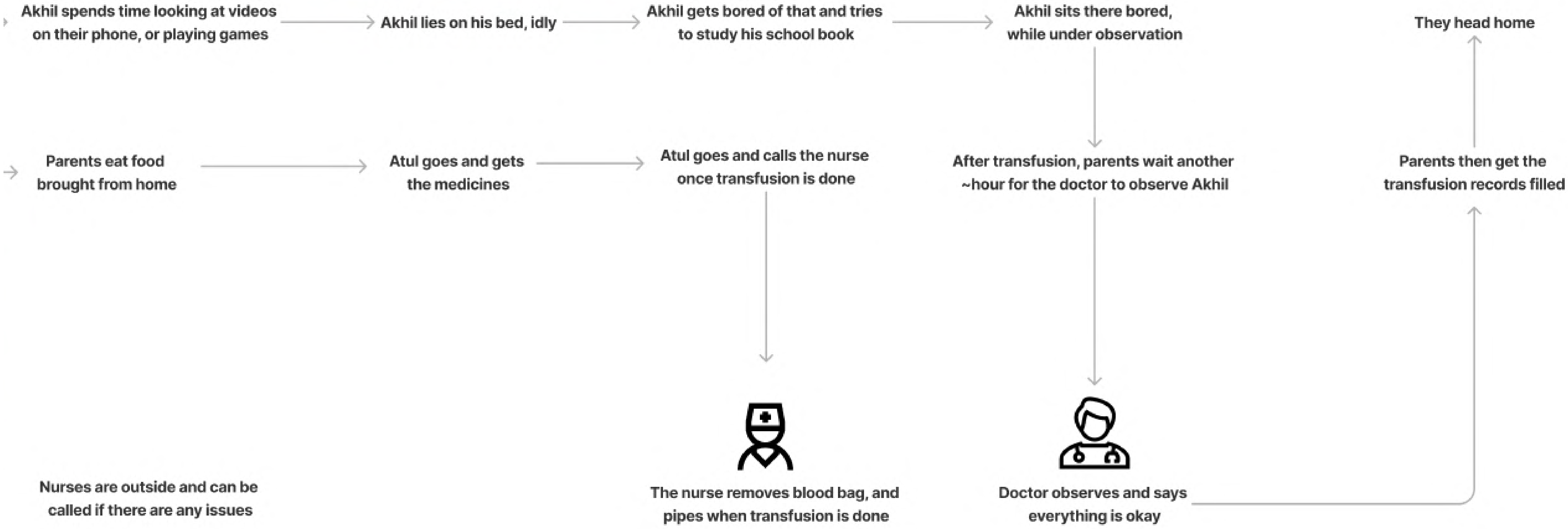
Transfusion begins and goes on for the next 3-4 hours



He is extremely bored and his arms hurt from the process

Parents spend most of the day in the hospital beside their children

The second Goal is to get Akhil’s monthly blood transfusion. This is how it used to happen earlier, without the service interventions (contd.).



Akhil spends time looking at videos on their phone, or playing games

Akhil lies on his bed, idly

Akhil gets bored of that and tries to study his school book

Akhil sits there bored, while under observation

They head home

Parents eat food brought from home

Atul goes and gets the medicines

Atul goes and calls the nurse once transfusion is done

After transfusion, parents wait another ~hour for the doctor to observe Akhil

Parents then get the transfusion records filled

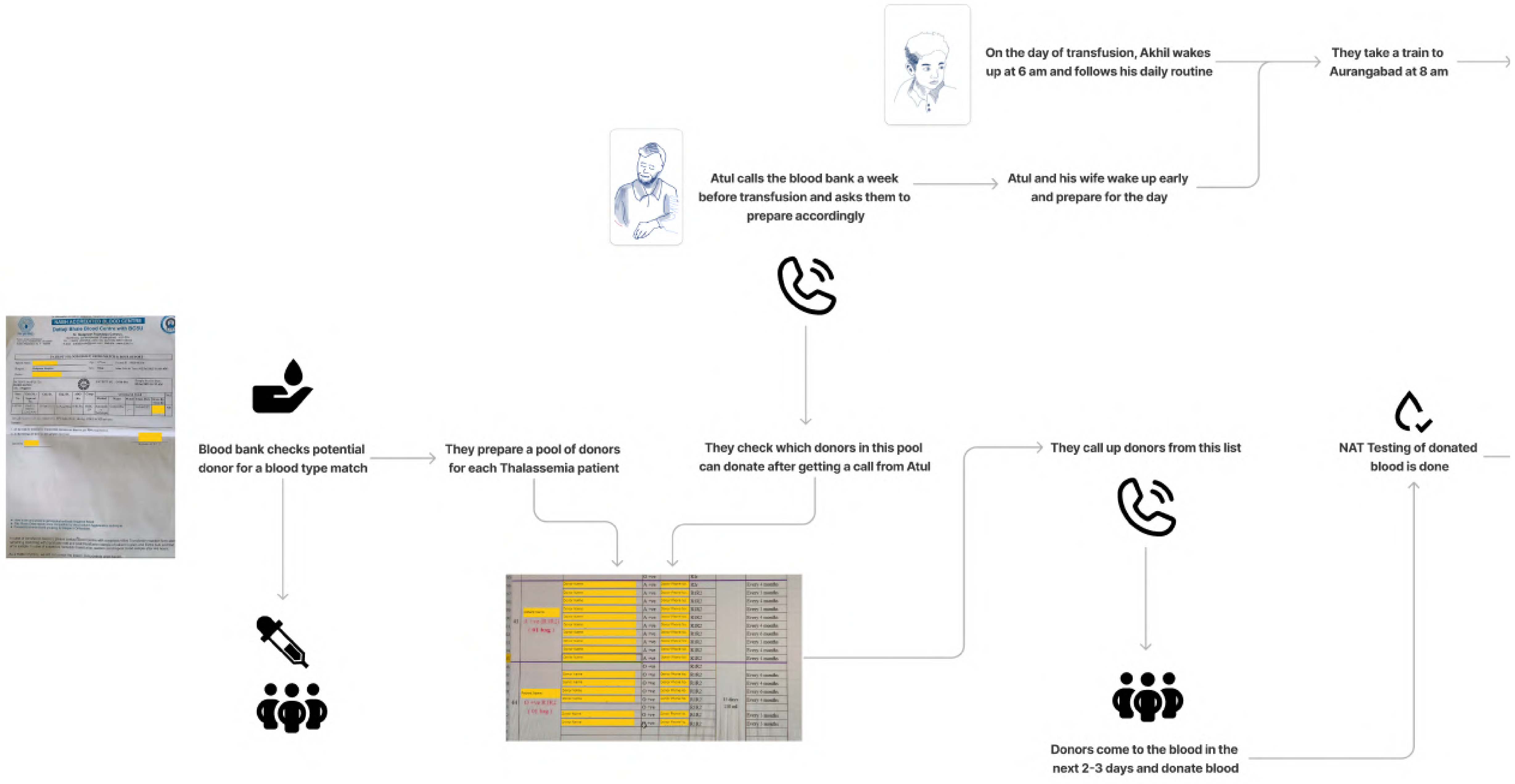
Nurses are outside and can be called if there are any issues

The nurse removes blood bag, and pipes when transfusion is done

Doctor observes and says everything is okay

The second Goal is to get Akhil’s monthly blood transfusion. The **new service blueprint - with relevant touchpoints and interventioned introduced** is below -

Goal of Encounter : to get Akhil’s monthly transfusion done (with interventions)



Atul calls the blood bank a week before transfusion and asks them to prepare accordingly

Atul and his wife wake up early and prepare for the day

On the day of transfusion, Akhil wakes up at 6 am and follows his daily routine

They take a train to Aurangabad at 8 am

Blood bank checks potential donor for a blood type match

They prepare a pool of donors for each Thalassemia patient

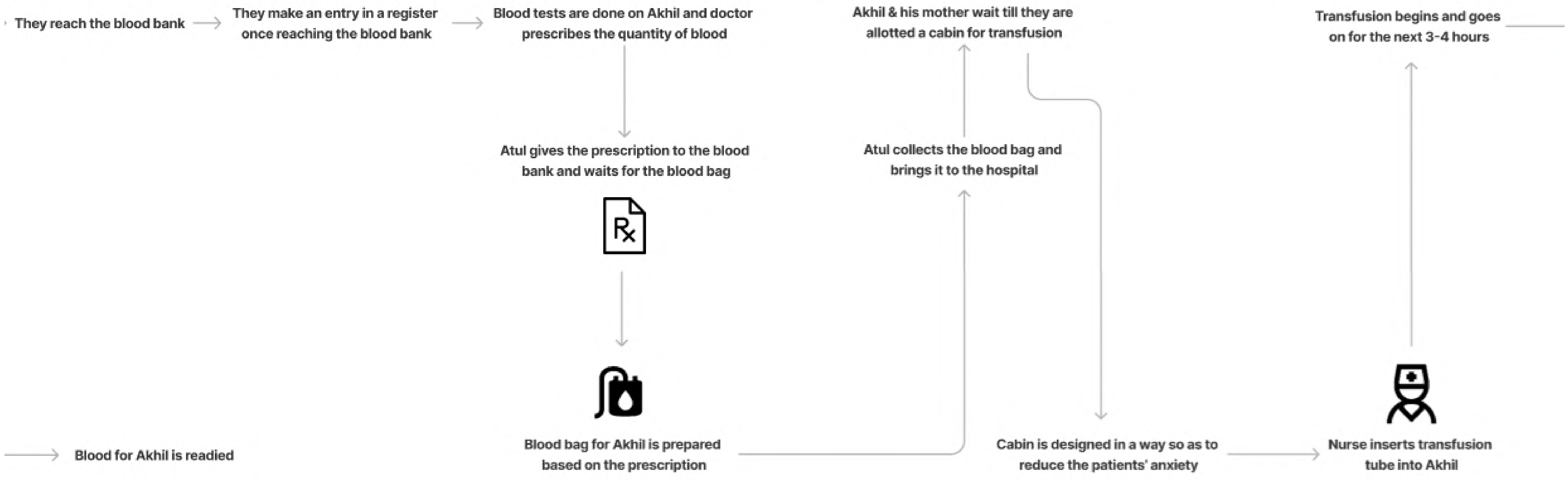
They check which donors in this pool can donate after getting a call from Atul

They call up donors from this list

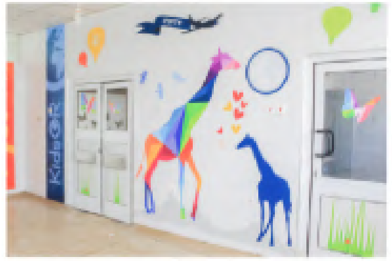
Donors come to the blood in the next 2-3 days and donate blood

NAT Testing of donated blood is done

The second Goal is to get Akhil's monthly blood transfusion.
The **new service blueprint - with relevant touchpoints and**

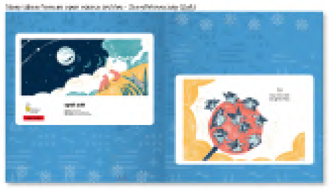


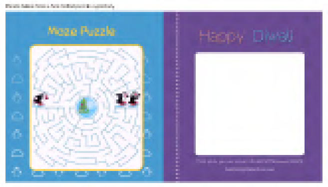
There are art supplies and playdoh to nudge the patients towards creation



Fluoroscopy room at Boston Children's Hospital : Imaginative décor, lighting and knowledgeable staff help ease anxiety and make for an enjoyable patient and family experience.

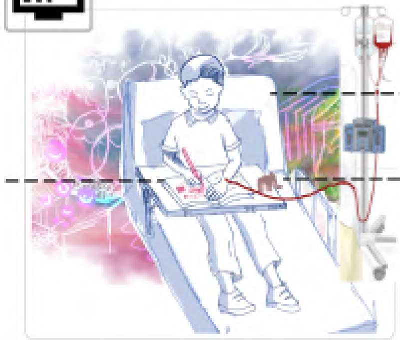
The second Goal is to get Akhil's monthly blood transfusion. The **new service blueprint - with relevant touchpoints and interventioned introduced** is below (contd.) -

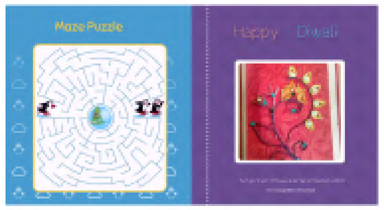




Interactive Magazine
& Art supplies

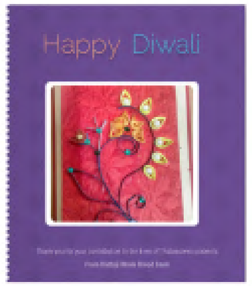
TV





Transcribing begins and goes on for the next 3-4 hours → Akhil is given an interactive magazine to distract him from the pain → Akhil lies on his recliner bed, drawing on the magazine → Akhil can choose from multiple touchpoints to ease his pain & boredom → Akhil finishes a Diwali drawing on the magazine page → Akhil is busy playing v different touchpoints a

Meanwhile parents are called one by one for counsling → Parents eat food brought from home → Atul goes and gets medicines for Akhil



Nurse inserts transfusion tube into Akhil

A counselor is arranged on the day of transfusion for a couple of hours

Magazine has perforations to tear apart this page

A person from the blood bank comes and collects this drawing

Doctor comes and visits the other patients to c check if everything is

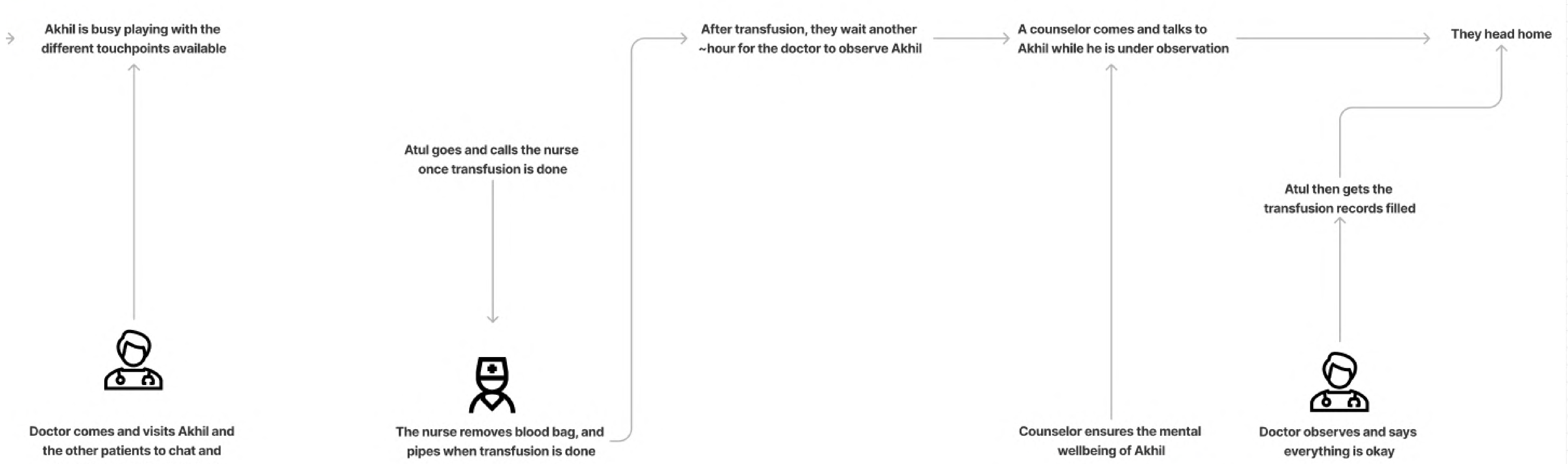
A list of counselors from the hospital is prepared

Counselors take turns counseling parents of Thalassemic patients

Donors who donate to Thalassemia patients are sent this greeting card as a token of gratitude

Other donors may also be given this card to motivate them to donate blood more frequently

The second Goal is to get Akhil's monthly blood transfusion. The **new service blueprint - with relevant touchpoints and interventioned introduced** is below (contd.) -



Akhil is busy playing with the different touchpoints available

Doctor comes and visits Akhil and the other patients to chat and check if everything is alright

Atul goes and calls the nurse once transfusion is done

The nurse removes blood bag, and pipes when transfusion is done

After transfusion, they wait another ~hour for the doctor to observe Akhil

A counselor comes and talks to Akhil while he is under observation

Counselor ensures the mental wellbeing of Akhil

Doctor observes and says everything is okay

Atul then gets the transfusion records filled

They head home

10.Evaluation

- Review by Expert panel
- **User Interviews - How did the experience change?**
- **Value Equation :** Did the intervention affect the elements in the value equation?

$$\text{Value} = \frac{\text{Benefits (Functional + Emotional + Social ....)}}{\text{Costs (Monetary + Time + Efforts + Psychic ....)}}$$

- Developmental Evaluation
- Feedback ratings of users

11.Learnings and Reflections

Working on a service design project to improve blood bank services for thalassemia patients has been a truly enlightening experience. The nature of this project, dealing with a complicated and rich service ecosystem, has provided me with valuable learnings and insights:

1. Complexity of the Service Ecosystem: Thalassemia patients require continuous and lifelong medical support, involving various stakeholders such as hospitals, blood banks, healthcare professionals, and support organizations. Understanding and mapping this intricate ecosystem is crucial to identify pain points and opportunities for improvement.

2. Evolving Personas: Thalassemic kids grow and change over time, which directly impacts their requirements and preferences. This highlights the importance of a dynamic approach to persona development, ensuring that the service design addresses the needs of patients at different stages of their lives.

3. Importance of Empathy: Working on this project has reinforced the significance of empathy in service design. Understanding the emotions, challenges, and daily struggles faced by thalassemia patients and their families has been essential in developing meaningful solutions.

4. Conceptual vs. Real-World Impact: One of the regrets I encountered was the limitation of proposing solutions at a conceptual level. While my ideas held promise, the challenge of implementing them in the real world with existing infrastructures and regulations was significant. It taught me the importance of involving stakeholders from the beginning and considering real-world feasibility from the outset.

5. Long-term Commitment: Improving blood bank services for thalassemia patients requires a long-term commitment from all involved parties. Changes in the healthcare sector often take time and require sustained effort to bring about meaningful transformations.

6. Data-Driven Design: Access to reliable data is vital for making informed decisions. I learned that leveraging data from various sources, including patient experiences, medical records, and service usage, is crucial in shaping effective interventions.

7. Learning from Failures: While some proposed solutions may not have been feasible or immediately actionable, every failure served as a valuable learning opportunity. It taught me to adapt, iterate, and refine my approaches continuously.

12.References

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