Bo

An intelligent network agent to promote physical activity in children with Congenital Heart Defects

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Appendix

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Appendix B

CHD complexity table

Table 1. Severity level of CHD based on adult patients from Warnes et al. (2001)

Low severity congenital heart defect	Moderate severity congenital heart defect	Great complexity congenital heart defect
Native disease Isolated congenital aortic valve disease Isolated congenital mitral valve disease (e.g., except parachute valve, cleft leaflet) Isolated patent foramen ovale or small atrial septal defect Isolated small ventricular septal defect (no associated lesions) Mild pulmonic stenosis **Repaired conditions** Previously ligated or occluded ductus arteriosus Repaired secundum or sinus venosus atrial septal defect without residua Repaired ventricular septal defect without residua	Aorto-left ventricular fistulae Anomalous pulmonary venous drainage, partial or total Atrioventricular canal defects (partial or complete) Coarctation of the aorta Ebstein's anomaly Infundibular right ventricular outflow obstruction of significance Ostium primum atrial septal defect Patent ductus arteriosus (not closed) Pulmonary valve regurgitation (moderate to severe) Pulmonic valve stenosis (moderate to severe) Sinus of Valsalva fistula/aneurysm Sinus venosus atrial septal defect Subvalvar or supravalvar aortic stenosis (except HOCM) Tetralogy of Fallot Ventricular septal defect with: * Absent valve or valves * Aortic regurgitation Coarctation of the aorta * Mitral disease * Right ventricular outflow tract obstruction * Straddling tricuspid/mitral valve * Subaortic stenosis	Conduits, valved or nonvalved Cyanotic congenital heart (all forms) Double-outlet ventricle Eisenmenger syndrome Fontan procedure Mitral atresia Single ventricle (also called double inlet or outlet, common or primitive) Pulmonary atresia (all forms) Pulmonary vascular obstructive diseases Transposition of the great arteries Tricuspid atresia Truncus arteriosus/hemitruncus Other abnormalities of atrioventricular or ventriculoarterial connection not included above (i.e., crisscross heart, isomerism, heterotaxy syndromes, ventricular inversion)

Appendix C

De-identification protocol

De-identification protocol

Name and surname

The names of family members, doctors and nurses will be substituted for the most common names enlisted in the 5 different countries.

Sources for names and last name:

UK
https://www.britishbabynames.com/blog/top-1000-names-in-england-and-wales-2017.html
http://www.locatemyname.com/topsurnames.php?country=uk
https://www.independent.co.uk/news/uk/home-news/baby-names-top-100-most-popular-boys-and-girls-names-10459074.html

US
https://www.thoughtco.com/most-common-us-surnames-1422656
http://www.babynamewizard.com/the-top-1000-baby-names-of-2016-united-states-of-america
https://www.rong-chang.com/namesdict/100_last_names.htm

The Netherlands:
https://www.behindthename.com/top/lists/netherlands/2011
http://www.locatemyname.com/topsurnames.php?country=netherlands

Australia
https://www.practicalparenting.com.au/most-popular-baby-name-of-2018-and-the-top-200-baby-names-of-year

Canada
http://www.studentsoftheworld.info/penpals/stats.php3?Pays=CAN

Hospital names

Names for hospitals will be deleted from the text. They will be searched with the “search” function from Microsoft Word and then be removed.

Association names

Names of institutions will be replaced with double letters of the alphabet starting with ZZ. For example:

Sick Kids: ZZ
Tiny Tickers: YY

They will be search throughout the text with the “search and replace” function from Microsoft Word.

Dates

If the date is mentioned as:

dd/mm/yyyy
mm/dd/yyyy

Only the month and year will be left in the text. Numbers will be be searched with the “search” function from Microsoft Word and then be adapted as previously mentioned.

Weight

Explicit numbers of weight will be removed. Numbers will be be searched with the “search” function from Microsoft Word and then be removed.

Pictures

The face of all the persons in a picture will be blurred using Adobe Photoshop.

Location

Names of specific places or regions will be removed from the text using the following list from the 5 different countries.

US
https://simple.wikipedia.org/wiki/List_of_U.S._states
https://simplemaps.com/data/us-cities

Canada
https://www.canada.ca/en/immigration-refugees-citizenship/services/new-immigrants/prepare-life-canada/provinces-territories.html
https://simplemaps.com/data/world-cities

The Netherlands
https://en.wikipedia.org/wiki/Category:Cities_in_the_Netherlands

Australia
https://simplemaps.com/data/world-cities

UK
https://simplemaps.com/data/world-cities

Appendix D

Pros and cons computational tools table

Tool	Definition	Pros	Cons	Source
Keyword extraction	Extracting the most important words and expressions in a text. It helps summarize the content of a text and recognize the main topics which are being discussed. Recognize what is relevant	Automated keyword extraction allows you to analyze as much data as you want. Keyword extraction acts based on rules and predefined parameters. Real-time analysis	Depending on your parameter you can loose important information that the algorithm didn't find important	https://monkeylearn.com/keyword-extraction/
Topic analysis	Automatically extract meaning from texts by identifying recurrent themes or topics.	Have the data indexed	Tag data in order to train Have clear feature (list of words) for each category (manual). Convert features to vectors in case of ML approach. Topic detection needs around 250 examples per tag (topic) for good accuracy levels.	https://monkeylearn.com/topic-analysis/
Word cloud/ word count/word frequency	Listing the words and phrases that most commonly appear within a text.	Easy to do Lots of websites that can help with the task	Consider documents as a mere 'bag of words', leaving aside crucial aspects related to the meaning, structure, grammar, and sequence of words. Synonyms, for example, can't be detected by this keyword extraction method, dismissing very valuable information.	https://monkeylearn.com/keyword-extraction/
Sentiment analysis	Identify subjective information in texts. It can be a judgment, an opinion or an emotional state. Polarity detection, that is, understanding if a text about a given subject is positive, neutral, or negative.	Scalability Real-time analysis Consistent criteria: Humans don't observe clear criteria for evaluating the sentiment of a piece of text. It can be done with a ML classifier model	Rule-based approaches: system is very naïve since it doesn't take into account how words are combined in a sequence. If more precision needed, it becomes complex very quickly ML needs to transform the text into a numerical representation Sentiment analysis classifiers might not be as precise as other types of classifiers. Sentiment analysis needs at least 500 examples per tag (sentiment) to produce good results.	https://monkeylearn.com/sentiment-analysis/
Concordance	Identify the context and instances of words or a set of words.	Identify context in a broader sense Look at how words are used in different contexts.	It is a part of a bigger process	https://monkeylearn.com/text-analysis/
Named-entity analysis	Locate and classify named entity mentions in unstructured text into pre-defined categories such as the person names, organizations, locations, medical codes, time expressions, quantities, monetary values, percentages, etc. Identifying and classifying key elements from text into pre-defined categories.	Identify entities transform unstructured data to data that is structured provide a useful view of unknown data See a structured representation of all of the the names of people, companies, brands, cities or countries, even phone numbers in a corpus that could serve as a point of departure for further analysis and investigation.	Loose the relationship between words. Each term is isolated You need extra processes to see connections	"https://en.wikipedia.org/wiki/Named-entity_recognition https://www.expertsystem.com/entity-extraction-work/"

Named-entity possibilities

Entity extraction based on semantic technologies can disambiguate meaning and understand context, therefore enabling a number of useful downstream operations valuable for a variety of functions for business and security/intelligence. These include:

Entity relation extraction: Reveals direct relationships, connections or events shared among different entities as well as complex relationships through inferred, indirect connections.

Linking: Establishes links between knowledge banks; for example, it could identify all of the places mentioned in a corpus and link to the corresponding location on a map, or cross-reference entities with other information sources.

Fact extraction: Extracts all of the data associated with an entity to respond to question answering or queries from a corpus (in contrast to a query that would just return a list of documents containing the "answers").

https://www.expertsystem.com/entity-extraction-work/

Appendix E

Stories management Excel file

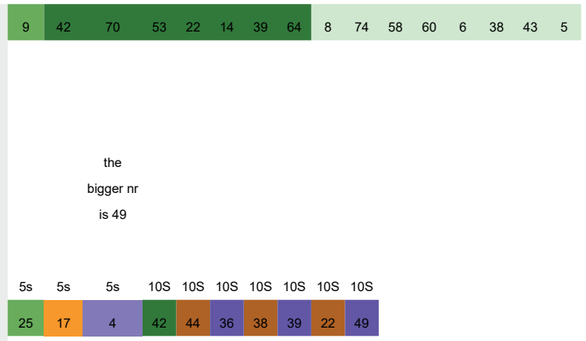
Proportionate Stratified Random Sampling

Country	Website name	Website URL	Number of stories	Sampling fraction (2/10 -> 1/5)	Representative (w/decimals)	Representative (integer)
				2		
				10		
Australia	heartkids	https://www.heartkids.org.au/how-we-help/meet-the-people-we-help	4			
	heartcentreforchildren	http://www.heartcentreforchildren.com.au/patient-stories.html?start=0	16			
	hearts-of-hope	http://www.hearts-of-hope.org/awareness/family-link/	20			
		TOTAL AUSTRALIA	40		8,00	8
Canada	cbc	https://www.cbc.ca/news/canada/new-brunswick/a-complicated-heart-facing-my-baby-s-mortality-before-his-life-began-1.4531379	0	1		
	cchaforlife	https://www.cchaforlife.org/sandra-clarke-writes-about-her-daughter-emily	0	1		
	cardiackids	https://www.cardiackids.ca/meet-the-cardiac-kids.shtml	5			
	cardiackids	https://cardiackids.wordpress.com	19			
	babycenter	https://community.babycenter.com/groups/a5055/babies_and_children_with_heart_problems	0			
		TOTAL CANADA	24		4,80	5
UK	cardiomyopathy	https://www.cardiomyopathy.org/family-carers/cardiomyopathy-in-children	2			
	chfed	http://www.chfed.org.uk/category/your-stories/	34			
	lagans	https://lagans.org.uk/family-stories/#1515671202765-c22001d4-5a7d	0	8		
	heartlog	https://heartlog.tumblr.com/archive	15			
	heartchild	https://heartchild.info/web/features/jakes-story/	5			
	tinytickers	https://www.tinytickers.org/category/your-stories/	78			
	lhm	https://www.lhm.org.uk/family-stories/family-stories-children-stories/	15			
		TOTAL UK	149		29,80	30
New Zeland	heartkids	https://heartkids.org.nz/heartkids-stories	0			
		TOTAL NEW ZELAND	0		0	0
The Neherlands	hartekind	https://www.hartekind.nl/verhalen	45			
	hartedroom	http://www.hartedroom.nl/cardiomyopathie/verhalen.241.lynkx	33			

Random story numbers

R#1	R#2	R#3	R#4	R#5	R#6	R#7	R#8	R#9	R#10	R#11	R#12	R#13	R#14	R#15	R#16	R#17	R#18	R#19	R#20	R#21	R#22	R#23	R#24	R#25	R#26	R#27	R#28	R#29	R#30	R#31
5s	5s	5s	**10S**	5s	5s	**10S**	**10S**																							
16	1	15	36	10	40	12	32																							
5s	5s	5s	10S	10S																										
13	22	8	3	25																										
5s	5s	5s	10S	10S	10S	10S	10S	10S	10S	10S	10S	10S	10S	**8S**	**9S**	**8S**	**9S**	**8S**	**9S**	**8S**	**9S**	**8S**	**9S**	**8S**	**9S**	**8S**	**9S**	**8S**	**9S**	**9S**
65	11	55	76	96	63	138	115	133	136	91	101	112	24	82	72	139	12	33	125	56	52	142	122	99	26	53	5	107	21	38
0																														
		bigger nr																												
		is70																												
5s	10S	10S	10S	10S	10S	10S	10S	**8S**	**8S**	**8S**	**8S**	**8S**	**8S**	**8S**	**8S**															

		TOTAL THE NETHERLANDS	78	15,60	16
USA	cdc	https://www.cdc.gov/ncbddd/birthdefects/stories/hlhs.html	3		
	littlehearts	https://www.littlehearts.org/featured-stories	2		
	childrensheartfoundation	https://www.childrensheartfoundation.org/blogs/	9		
	conqueringchd	https://www.conqueringchd.org/nicholas-basken/	0		
			37		
		TOTAL USA	14	2,80	3
		TOTAL STORIES	305		61



Criteria for decimals

.4 goes to the number on the left

.5 goes to the number on the right

Criteria for randomization

Tool: google random number generator

Assistant assignation

Name	Qty stories
Frans	23
Regina	23
Hosana	24
Total stories	70

Appendix F

Table of 61 codes from manual analysis

#	CODE	COUNT	SUB-CODE	COUNT
1	“Having a son with CHD changed us”	17	Describing change	12
			Describing journey	2
			Describing feel -	1
			Describing feel +	1
			Describing feel N	1
2	“Hoping for the best but planning for the worst”	7	Describing dilemma	4
			Describing situation	1
			Physician’s influence	1
			Physician’s influence +	1
3	“Re-playing what happened”	24	Deepness of recap	4
			Describing recap	9
			Describing recap -	3
			Moment of recap	4
			Physician’s influence	1
			Physician’s influence -	2
			Physician’s influence +	1
4	“Tending to think he is cured”	11	Disabilities not exposed	7
			Lifetime condition	2
			Moment of realise	2
5	“whatever we need to do”	19	Being strong for others	6
			Describing requirement	2
			Describing willingness	5
			Give opportunity	4
			Implications for family	2
6	Admitted into the hospital	32	Admission time	3
			Change of location	6
			Describing feel -	5
			Medical procedure scheduled	2
			Reasons for being admitted	8
			Reasons for transference	8
7	Baby thriving after treatment	19	Child being able to	6
			Child health level	10
			Future opportunities	1
			Steps to improve health	2
8	Before discovery of CHD	67		
9	Being a normal baby	12	Child being normal	3
			Child preferences	2
			Disabilities not exposed	2
			Overcoming challenges	2
			Parent-child relationship	1
			Perception of normal	2
10	Being afraid of the future	12	Death	5
			Uncertainty	7
11	Being proud of your kids	20	Activeness level	3
			Feelings towards child +	6
			Journey influence	7
			Reason for proudness	4
12	Being unprepared	13	Anticipation not possible	5
			Consequences	3
			Perception of situation	5
13	Body-machine connections	37	Describing apparence	12
			Describing feel -	10
			Describing feel +	4
			Giving explanations	2
			Unit of measure -	4
			Unit of measure +	6
14	Challenges after hospitalization	22	Describing feel -	7
			Describing situation at home	2
			Physical complication	11
			Physical condition degenerating	2
15	Cherishing the moment	11	Describing feel +	3
			Seeing improvement	3
			Time value	5
16	Child battling for its life	10	Battle time	2
			Describing challenge	6
			Describing feel +	1
			Describing feel N	1

17	Child being discharged	54	Activities after	7
			Bringing home extra -	3
			Bringing home extra +	5
			Child health level	2
			Complications	6
			Describing feel -	1
			Describing feel +	4
			Procedures for discharge	5
			Release timing	8
			Release timing +	10
			Transition to normal	3
18	Child coping with CHD	20	Attitude towards CHD	4
			Child being normal	2
			Child connecting with others	2
			Child connecting with others -	2
			Child connecting with others +	1
			Child's attitude	3
			Child's perception	3
			Humor	3
19	Child having ups & downs	18	Complications	8
			Describing feel -	2
			Describing feel N	2
			Describing situation	6
20	Child's physical activity	23	Achievements	4
			Child's attitude	3
			Describing activities	5
			Future opportunities	2
			Limitations	9
21	Connecting with other CHD families	26	Describing feel +	6
			Describing feel N	3
			Describing interaction	6
			Future contact	2
			Support network	9
22	Dealing with set-backs	10	Describing feel -	4
			Recovery set-back	6

23	Doctor Fearing your child might not live	10	Communication	7
			Describing feel -	1
			Describing feel N	2
24	Early detection	14	Consequences +	2
			Describing feel -	1
			Describing feel +	4
			Describing feel N	1
			Moment of detection	2
			Moment of detection -	4
25	Emergency happening	37	Baby crashing	6
			Call early in the morning	2
			Complications	7
			Describing feel -	1
			Describing feel N	1
			Emergency	1
			Physical condition degenerating	1
			Physician's influence	1
			Physician's influence -	1
			Rushing	12
			Symptoms	4
26	Facing reality	28	Describing challenge	6
			Describing feel -	8
			Describing feel +	2
			Describing realisation moment	9
			Level of intensity	4
27	Family life changed	22	Describing feel -	3
			Describing journey -	3
			Future plans -	5
			Limitations	1
			Location	3
			Medication	1
			School	1
			Siblings	2
			Work	3

28	Feelings after hospitalization	44	Child health level	1
			Child's attitude	1
			Describing feel -	5
			Describing feel +	12
			Feelings towards child +	11
			Journey influence	3
			Seeing improvement	3
			Thoughts about the future	3
			Time value	5
29	Feelings towards medical staff	59	Admiration	12
			Angry	1
			Annoyance	1
			Being grateful	24
			Complaints towards treatment	2
			Expressing worries	4
			Reassurance from medical staff	13
			Stressing importance	2
30	Finding something is wrong	118	Describing feel -	15
			Detecting symptoms	11
			Diagnosis	49
			Examination	18
			Instinct	6
			Not being able to process info	9
			Speculations	10
31	Follow-up checking and treatment	55	Attending meetings	6
			Complications	2
			Diagnosis	7
			Examination	11
			Expressing worries	3
			Frequency of follow-up	8
			Future medical steps	1
			Future operation	2
			Medication	4
			Physical condition degenerating	3
			Pregnancy	4
			Reassurance from medical staff	1
			Recovery	3
32	Getting information	14	Being prepared	3
			Describing feel -	3
			Other's stories	3
			Physician's influence +	1
			Wanting to know everything	4
33	Giving birth	32	Child being taken away	6
			Complications	4
			Describing feel -	1
			Describing feel +	4
			Disabilities not exposed	5
			Giving birth	15
34	Having a new chance	9	Describing feel +	5
			Procedures	1
			Seeing improvement	3
35	Interaction with medical staff	60	Caring for the child	8
			Complaints towards treatment	7
			Giving explanations	21
			Giving the discharge	1
			Procedures	12
			Reassurance from medical staff	11
36	Looking forward to the future	18	Describing feel -	1
			Describing feel +	4
			Feelings towards child +	2
			Future opportunities	6
			Journey influence	1
			Thoughts about the future	4
37	Medical decisions	38	Chances of survival	10
			Describing dilemma	3
			Describing feel -	4
			Describing feel +	1
			Describing medical options	5
			Future operation	6
			Give opportunity	6
			Medication	1
			Nothing matters if baby is ok	3
			Reassurance from medical staff	2
			Wanting life to be easier for child	2

38	Not going home	8	Describing feel -	2
			Future operation	3
			Hospital being home	3
39	Not knowing diagnosis	27	Child being taken away	2
			Describing feel -	5
			Detecting symptoms	4
			Physician's influence -	2
			Speculations	11
			Wanting Dr's reassurance	3
40	Parents showing relief	21	Describing journey	9
			Feelings towards improvement	5
			Outcomes of being relaxed	3
			Seeing improvement	4
41	Parents Worrying	37	Child health level	2
			Death	4
			Describing feel -	8
			Extreme worries	3
			Reassurance from medical staff	2
			Recovery	5
			Regrets	2
			Survival uncertainty	1
			Uncertainty	10
42	Patient's development	43	Achievements	9
			Child being able to	6
			Child health level	8
			Child's attitude	1
			Describing activities	2
			Limitations	12
			Seeing improvement	5
43	Physical contact	23	Being with the child	2
			Holding the child -	5
			Holding the child +	10
			Talking to the child	1
			To caress the child	5
44	Procedures	58	Catheterization	5
			Complications	6
			Describing activities	2
			Describing feel -	3
			Describing feel +	2
			Describing journey	4
			Describing medical options	5
			Eating problems	2
			Future medical steps	5
			Giving explanations	4
			Medical requirements	1
			Medication	5
			Own interpretation	1
			Physician's influence	1
			Physician's influence -	1
			Physician's influence +	1
			Procedure done	3
			Procedure time	2
			Time passing	1
			Transferred	2
			Transplant	2
45	Protect child	11	Describing protection	4
			Expressing the need to	3
			Unable to	4
46	Realise seriousness	40	Describing challenge	8
			Describing dilemma	1
			Describing feel -	27
			Describing journey	4
47	Realise strength of child	28	Achievements	4
			Describing feel +	2
			Feelings towards child +	8
			Journey influence	9
			Realise strength of child	4
			Seeing improvement	1

48	**Recovery**	72	**Closely monitored**	2
			Complications	10
			Constantly waiting	2
			Describing feel -	4
			Describing feel +	6
			Describing feel N	1
			Disabilities not exposed	1
			Eating problems	4
			Future medical steps	1
			Future medical steps -	2
			Gaining strength	3
			Medication	1
			Seeing improvement	13
			Smooth recovery	10
			Surgery outcome	2
			Symptoms going away	8
			Thoughts about the future +	2
49	**Religion procedures**	11	**Blessing before surgery**	3
			Praying	8
50	**Saying goodbye to undergo medical procedure**	10	**Describing feel -**	4
			Saying goodbye	2
			Survival uncertainty	4
51	**Seeing baby**	19	**Being with the child**	1
			Brief period of time	6
			Describing feel -	4
			Describing feel +	5
			Relieve	5
			Talking to the child	1
52	**Support from family and friends**	32	**Describing feel +**	7
			Describing feel N	1
			Describing interaction	9
			Support network	15
53	**Supporting child**	11	**Being with the child**	4
			Everyday things	2
			Giving positive attitude	4
			Recognise achievements	1
54	**Surgery**	76	**Complications**	5
			Describing feel -	8
			Describing feel +	3
			Describing journey	5
			Future medical steps	2
			Future medical steps -	1
			Future medical steps +	1
			Giving explanations	4
			Medical requirements	3
			Postponed	2
			Surgery outcome	5
			Surgery outcome +	8
			Survival uncertainty	1
			Timing of surgery	28
55	**Symptoms**	91	**Complications**	4
			Eating problems	10
			Getting cold	2
			HR problems	4
			Instinct	9
			Irritable	4
			Losing breath	11
			No energy	8
			Pain	2
			Physical condition degenerating	23
			Seizures	2
			Skin color	11
			Timing	1
56	**Taking news from staff**	42	**Death**	1
			Describing feel -	2
			Describing feel +	3
			Future operation	4
			Giving explanations	10
			Not being able to process info	11
			Not being able to process info -	7
			Not believing	3
			Reassurance from medical staff	2
			Uncertainty	1

57	**Telling each other everything will be allright**	6	**Describing feel +**	3
			Describing journey	3
58	**Time perception**	21	**“Felt like forever”**	12
			Slow days	4
			Time passing	3
			Very fast	2
59	**Understanding diagnosis**	44	**Describing feel -**	1
			Describing feel +	1
			Detecting symptoms	4
			Future medical steps	1
			Future operation	6
			Giving explanations	5
			Lifetime condition	5
			Other’s stories	4
			Own interpretation	16
			Reassurance from medical staff	1
60	**Waiting**	29	**Constantly waiting**	5
			Describing feel -	7
			Gaining strength	1
			Medical interaction	6
			Physical condition degenerating	7
			Procedures	1
			Reassurance from medical staff	2
61	**Waiting for surgery date**	20	**Constantly waiting**	2
			Describing feel -	5
			Describing journey	1
			Expressing worries	1
			Future plans -	3
			Gaining strength	4
			Medical interaction	2
			Physical condition degenerating	2

Appendix G

Definition of different classification algorithms

Logistic Regression Algorithm

“A logistic regression algorithm is a machine learning regression algorithm which measures the ways in which a set of data conforms to two particular variables. The algorithm dictates the variables, the relationship, and the ways in which the variables interact. The most common form of a logistic regression algorithm is a binomial algorithm. This form of the algorithm has two particular outputs which can result from the function. The algorithm places the data set into one of these areas and then maps changes in the data set over time. This map represents a curve that displays the relationships inherent in the data set. There are also more complicated forms of logistic regression that display multiple variables.

Logistic regression is different from linear regression in that it represents a curve with a changing slope. Linear regression is more fixed and unchanging. It is more focused on drawing a line that fits the means of a data set than drawing a curve which reflects the relationship between variables. This process of logistic regression is not only applicable to an existing data set. It may also be used to predict future behavior.”

Wingate, J., (2018). Logistic Regression Algorithm. Retrieved from <https://www.engineeringbigdata.com/logistic-regression-algorithm/>

Random Forest Algorithm

“A random forest is a classifier consisting of a collection of tree-structured
classifiers {h(x, k), k = 1,...} where the {k } are independent identically distributed
random vectors and each tree casts a unit vote for the most popular class at input x..”

Breiman, L. Machine Learning (2001) 45: 5. https://doi.org/10.1023/A:1010933404324

Random Forest Algorithm

“Artificial neural networks are nonlinear mapping structures based on the function of the human brain.”

Lek, S., & Park, Y. S. (2008). Artificial Neural Networks. In Encyclopedia of Ecology, Five-Volume Set (pp. 237–245). Elsevier Inc. https://doi.org/10.1016/B978-008045405-4.00173-7

Appendix H

Moment cards

284 - 93.1%

Finding something is wrong

"The words the cardiologist spoke at the time are engraved in my memory: "Your son has a serious heart defect ..."."

"I will never forget hearing my husband ask the doctor "Why is he purple? Why isn't he breathing?" immediately after Zachary was born."

Parents hear for the first time that their baby has a Congenital Heart Defect (CHD).

This moment can happen during pregnancy (most cases are detected before birth), at the moment of giving birth or during the first weeks of life of the baby.

241 - 79%

Recovery

"After my daughter's third heart operation I broke down in tears because it was the first time I had ever seen her lips, fingers and cheeks pink, they were always blue before."

After successful procedures, patients start getting better, which means hope and a new chance for their babies. It is visible to parents that their baby is getting better by looking symptoms going away; some of them describe this as "seeing a miracle".

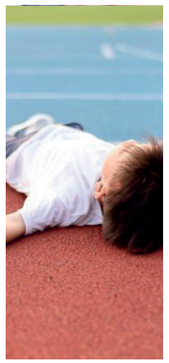
271 - 88.9%

Symptoms

"As the week went on, Sophie started to become increasingly breathless, tired and started vomiting."

"Joseph started school but still struggled with minimal exertion."

Babies with CHD start to show symptoms like being cold, not eating well, or don't breathe properly. With time they start deteriorating and making the symptoms more evident to the parents.

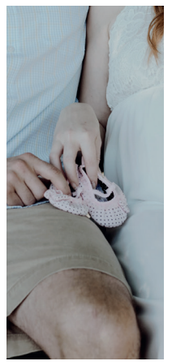


230 - 75.4%

Before discovery of CHD

"We didn't know anything about heart problems and like most people, when we went for our 20-week scan for our second born son, we were just looking forward to having his gender confirmed."

Parents are expressing thoughts, feelings of excitement, and ideas before they know that their baby has a Congenital Heart Defect. Usually, they share the expectations of the medical appointment.



232 - 76.1%

Surgery

"At six days old, the doctors and surgeons finally felt he was ready to have open-heart surgery."

"The surgery was an anxious 3 hours, at the conclusion of which Dr Jack came out to confirm that the procedure had been textbook which was a great relief."

For parents, surgery starts when physicians take their child to the OR. After this, parents enter a state of worry, in which feelings of shock and anxiety are related to being afraid of losing their child.

200 - 65.6%

Feelings towards medical staff

"Along the way, we have been fortunate to meet some of the most amazing and compassionate doctors and heart teams who have dedicated so much time and effort to helping Mia get well."

Parents have a strong feeling of gitatude towards all the heart team composed of nurses, doctors, and social workers who have been with them during the whole process.

241 - 79%

Child being discharged

"On December we were allowed to take Emma home! We went home with a bag full of medicines, doctor appointments and advice, we were so happy! We never thought we would experience this again!"

Parents cherish the moment of being at home. They feel happy and grateful for it. They become relaxed because they can enjoy their baby and share quality time with their family. Nonetheless, parents have some challenges like taking care of feeding tubes, giving medicines and look for signs of deterioration.

198 - 64.9%

Admitted into the hospital

"We were rushed to a specialised hospital in the early hours of the morning, we followed behind in a rapid response ambulance not knowing if our son would survive the journey."

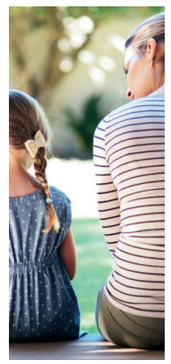
Some newborns with a CHD arrive home without being diagnosed. These babies start to show symptoms, and therefore, parents try to contact GP and midwives, but their concerns sometimes are not being heard. When the child's health gets worse, then it produces an emergency that results in an unexpected admission to the hospital.

194 - 63.6%

Feelings after hospitalization

"I sometimes find myself sitting and staring at him, processing a true miracle right before my eyes."

Even if parents remember the experience as painful, stressful and sad memory, these negative experiences help them to see the value in the little moments in life with their child.



192 - 63.0%

Follow-up checking and treatment

"Of course we are always very tense when we have to go to the hospital for another check-up, but luckily he is doing very well so far."

"We had regular check-ups and pottered along nicely until the time came that he began to struggle more and more."

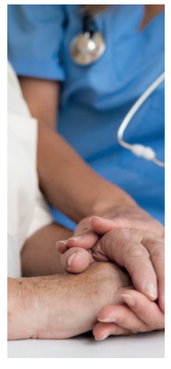
Through the child's development, there are follow-up appointments that sometimes makes parents feel scared. If required, parents will have to follow more medical procedures with their children. They are aware that this condition is for life, and that their child will never be out of risk.

188 - 61.6%

Interaction with medical staff

"A cardiac nurse took me aside and said: Don't worry. You'll soon be walking Freya around the supermarket on a trolley and she'll be a spoilt little princess."

From the moment of diagnostic to the follow-up appointments, the heart team composed of nurses, doctors, and social workers always tries to re-comfort the parents and make their best in explaining medical options.



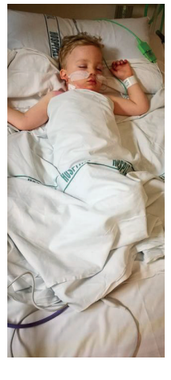
178 - 58.4%

Procedures

"We stopped keeping track of how many ECHOs, EKGs, and lung perfusion scans she's undergone a long time ago."

"She will need several more catheterizations, as well as additional heart surgeries as she gets older."

During a surgery recovery or later in life, most of the children will have to undergo other medical procedures (invasive and noninvasive) to be sure that their heart is in good condition.



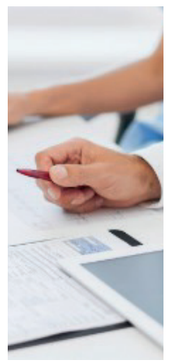
177 - 50.6%

Understanding diagnosis

"Henry's heart has been described as similar to "Swiss cheese" due to the number of holes in it."

"Heart defects will always be there in some way."

After being in a state of shock, parents begin to understand the CHD with the help of the explanations provided by the medical staff, sometimes previous knowledge and with their interpretations of what the doctors said.

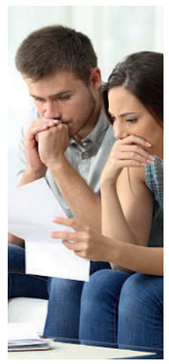


169 - 48.3%

Parents Worrying

"How does something like that even happen? Could it be fixed? Would our baby live a 'normal' life?"

Since the moments of the diagnosis, parents start showing their concerns about their child's health. This state appears to be more in-depth when their child undergoes a new medical procedure or updates in child's health is provided.

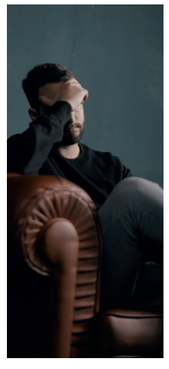


169 - 48.3%

Realise seriousness

"Quite honestly we felt like our world had crumbled, I can only describe it as abject despair."

Understanding the CHD results in parents realising the seriousness, which means that there is no cure, and makes them think about the future and uncertainty that this health condition brings. There are mixed feelings, such as being in shock and having the sense that their world turned upside-down.



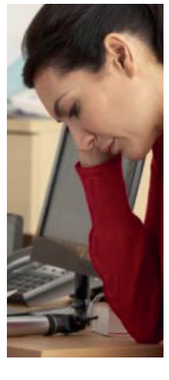
166 - 47.4%

Taking news from staff

"As cliché as it sounds, I could see that she was speaking but couldn't hear what she was saying."

"If I'm honest, I didn't really understand what the operation would do, I only understood that either Logan had the operation or we could take him home to die."

There are 3 phases of hearing unexpected news from medical staff. First, parents **try to listen** to the explanation from the physician. However, they **don't understand** what is happening, they can't believe it, and therefore **enter a state of shock** with feelings of guilt because they think they might cause this.



159 - 45.4%

Patient's development

"Because of their amazing care and knowledge, we are able to see our son meet all his milestones and give him all of our love."

"He enjoys school and is performing well in all of his subjects."

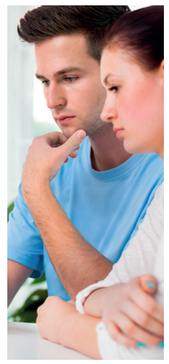
Parents can see how their child is developing in different aspects. This development is usually measured by seeing the baby gaining strength day by day, reaching development milestones, and seeing the child being able to do activities according to his age.

130 - 37.1%

Medical decisions

"We were given two options: to take our baby home so that she could die peacefully in her sleep, or let her have an operation which had a 60 percent chance of survival."

The physician explains possible treatment and provides information about the chances of surviving, which increases the hope of parents. Later the doctor asks them to make a decision, and parents try to balance the chances of surviving with what they know about the future, and even if they feel afraid about the future, they decide to trust the treatment and give the baby a chance.



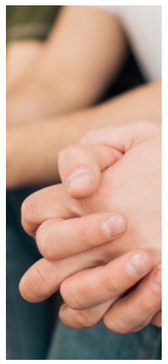
92 - 26.3%

Time perception

"The operation took nearly 7 hours. The longest 7 hours of my life."

"They closed the ward and tried to resuscitate him and make him stable for what seemed hours."

Parents have to wait many hours for the open-heart surgery to finish. Their level of stress and anxiety makes their perception of time distorted, making them feel like it is taking longer.

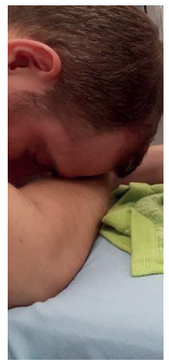


75 - 21.4%

Seeing baby

"We were told that they were happy with how the surgery went but in that moment it didn't offer much relief from the pain of seeing him in this way."

Parents describe their first encounter with the baby as being in shock and pain after seeing their baby with a lot of connection to his/her body.

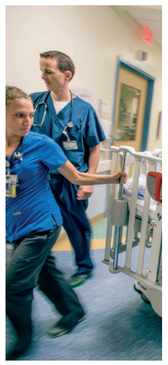


156 - 44.6%

Emergency happening

"They decided to do blood tests and an echogram but again they were struggling to get any blood, at this point he collapsed and stopped breathing. The crash team were called and he was taken away from me."

A very stressful moment in which the health of the child is severe, and all the medical staff is trying to save the child's life. This moment usually is expressed to happen during birth or recovery.



118 - 33.7%

Body-machine connections

"Seeing him after his surgery was tough as there were wires coming out of every part of his body, something we had been told to prepare for since I was 24 weeks pregnant."

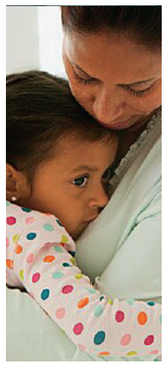
After processing the shock of all the tubes, parents start looking at machine connections as a measure of progress, in which fewer tubes means more physical contact and progress, and more connection becomes a setback.

91 - 26.0%

Physical contact

"An amazing and supportive team at Hospital let us have a few special moments of skin-to-skin cuddles before they whisked him away."

After surgery, parents want to protect their child. They try to support him by trying to have some physical contact such as touching their arm or leg, or when possible, have a cuddle. They also try to interact with the baby by talking to him. During this period, there is a great need for physical contact; when it is allowed, it increases their happiness exponentially.



66 - 18.9%

Connecting with other CHD families

"Most of all they understand what we are going through and are always at the end of the phone."

During the hospital stay, or by attending foundation events, CHD families meet. They express that connecting makes them feel understood. Another way in which they express a connection with other families is by sharing these stories, so others can feel more hope, and see that their child can live a happy life.

156 - 44.6%

Giving birth

"When we saw him raised up above the curtain, he was kicking and screaming and bright pink! The most beautiful baby."

Another way in which parents know if their child has a CHD is seeing their baby very ill or in pain when he/she is born. When the baby is born, they are being told that surgery needs to take place soon, and therefore they will not be able to go home as expected.

100 - 28.6%

Waiting

"Finally, he was taken and the agonising wait started."

"Because, like us, you never know when this "deterioration" will start."

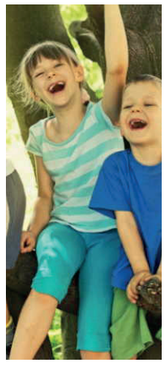
Parents describe waiting as "difficult" and "agonising". When they know surgery is finished, it makes them feel scared, but at the same time, they feel relief that surgery went well. They can't see the baby right away, and in the meantime, the medical staff tries to prepare them for what they will see.

85 - 24.3%

Baby thriving after treatment

"This operation was extremely successful and we are all delighted with the results – Ollie is even able to enjoy sport again."

When the baby has a smooth recovery, a new measure of health appears when the time of recovery starts getting short. Shorter recovery time is associated with making parents remember the physical strength of their children. In the end, the patient can go home and makes parents happy about finally leaving the hospital.



65 - 18.6%

Facing reality

"It was a very long journey on the train, surrounded by people focused on their 'normal' routines, whilst we felt like a massive bomb had been dropped on us."

"It all became very real, very fast."

Days after having the diagnosis, parents are still thinking about all the things that are about to come. When the moment of open-heart surgery arrives, they realise that everything is happening fast and RIGHT NOW.

149 - 42.6%

Support from family and friends

"Whether by choice, or by design – fathers, grandparents, siblings, neighbours and more all contribute to the daily conditions of having a heart kid."

During stressful moments, parents express that family, friends, and neighbours are often offering help by taking care of their other children, providing food, or trying to be there for them.

98 - 28.0%

"Re-playing what happened"

"My memories of the events that followed are a bit patchy but they still make me feel sick to this day."

Replaying what happened is described as a two-way path. First parents describe that they went through a trauma when remembering their experience at the hospital. They feel afraid of having to go through that experience again. On the other hand, this reflection makes them exponentially appreciate life.

81 - 23.1%

Realise strength of child

"I have discovered strength where I didn't think there was any, I have discovered courage, and I have seen firsthand what bravery looks like on the face of a child."

After the shock of seeing him intubated, parents think that "nothing matters if the baby is ok". All the machines connected help parents realise the strength he/she has in spite of being so young and that their baby is a fighter.

62 - 17.7%

Not knowing diagnosis

"This was the first time we had ever been there and it was a scary and daunting experience – not knowing what was wrong with our baby."

Sometimes, parents don't know the condition of the baby until he/she is born. During this moment, the baby presents visible symptoms which generate a scary and unexpected feeling in parents. Doctors here try to their best to find a diagnosis. Meanwhile, parents are expecting reassurance from the doctors to know that their child is ok.

55 - 15.7%

Waiting for surgery date

"Surgeons wait until you are sick enough to require the surgery but not sick enough that you won't survive the surgery."

"From the moment that you are on the waiting list for the operation, you will no longer be doing anything else."

Waiting for surgery is described by parents as being difficult. Either while being a baby or during childhood, the health deterioration that the child experiences is a painful process to see for parents

44 - 12.6%

Looking forward to the future

"She is now looking forward to a beautiful adventurous future and ready to take on any challenges life gives her along the way, with her dad always by her side."

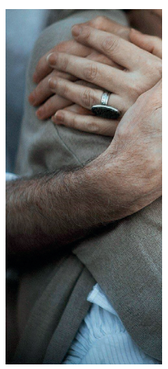
As a result of having positive outcomes from medical procedures, parents start being positive about all the possibilities they will have when their baby is discharged from the hospital.

50 - 14.3%

"Whatever we need to do"

"None of us would choose this place; none of us want our children to suffer one more day, and given a chance I can guarantee that were we given a choice each of us would lay down our life if it would mean a cure for our kids."

After deciding to give their baby an opportunity, parents start preparing for the arrival and adopt an attitude of "whatever we need to do" to help the child.



39 - 11.1%

"Having a son with CHD changed us"

"Learning your child has a complex heart defect changes everything about you, everything about your life."

Having been through open-heart surgery, parents describe this moment as an enriching experience that made them grow and learn different things personally and as a family.

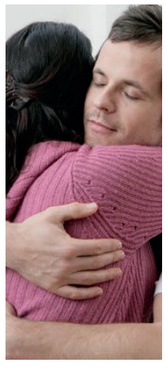
48 - 13.7%

Parents showing relief

"It was at this point we felt we could name him."

"But for now it is going well and we have the feeling that the rollercoaster has stopped for a while."

After having good health outcomes from surgery or other invasive medical procedures, parents start to feel more relief. This high levels of worry compared to the more positive feelings, makes them feel like a "rollercoaster".

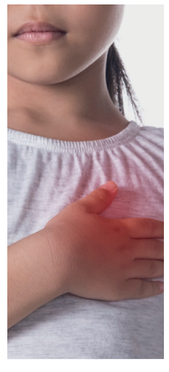


39 - 11.1%

Child having ups & downs

"We were home only one week when she developed pneumonia that sent us back to the hospital for another month."

During recovery, or after being discharged, the child is always propense to suffer decay in health. Sometimes everything goes as expected, but other times, the health deteriorates, and the family needs to come back to the hospital.



46 - 13.1%

Child's physical activity

"Now 4 years later Isa is doing pretty well, she has ups and downs but she is also doing very well (she even achieved her swimming diploma A)."

Seeing their child full of life, and being able to practice all the activities he likes, such as swimming, soccer, running, among others, makes the parents very happy.

36 - 10.3%

Family life changed

"I sent an email to my boss at 4am in the morning to let them know I wouldn't be in for a while."

"With the potential of surgery years apart your life as a family can be put on hold."

All the time that parents need to be at the hospital has an impact on the life of other members of the family, such as older siblings; parents need to find a place for them. Moreover, having to skip work alter their financial stability, and planning for the future becomes very complex as there is too much uncertainty.

34 - 9.7%

Child coping with CHD

"It is also difficult when you can't keep up with your peers and are always the one struggling or making yourself feel poorly by trying so hard to do what the other boys are doing."

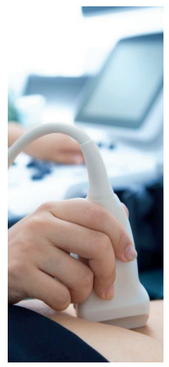
When children are older, they start to become aware of their health capabilities compared to their peers, and with which activities they feel more comfortable.

24 - 6.9%

Early detection

"Had Phoebe's heart defects been diagnosed during one of my many pregnancy scans, things would have been so different."

Parents feel grateful for knowing beforehand the CHD. This situation gives them more time to prepare the arrival of their baby. On the other hand, if they don't know the diagnosis beforehand, they complain about not being able to prepare.



30 - 8.6%

Being a normal baby

"Now my son is like every other one year old, but with a very important scar on his chest."

"I now need to learn to see him as a normal, robust little boy and not the frail baby of before."

After a while, parents start seeing their baby as a healthy child. The absence of visible symptoms and the childhood milestones achieved cause this change in perception.

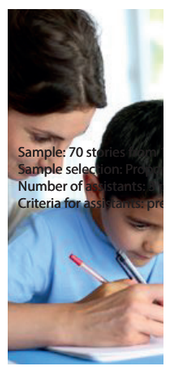
21 - 6.0%

"Tending to think he is cured"

"It has taken a while for teachers to realise that his condition affects him in so many ways."

"To look at her, you wouldn't know she had such a severe heart condition."

The lack of visibility of symptoms and milestones reached, makes external people (teachers) feel admiration for the child's journey, and even forget that the child has a CHD. However, the reality is that he will never be cured.



29 - 8.3%

Cherishing the moment

"We celebrated every small victory and enjoyed every minute with Anna."

"I love to see him smile and hearing him laughing just makes my life complete."

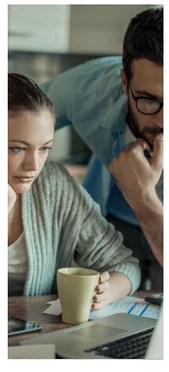
After had passed difficult times, parents feel very grateful towards life and seeing their child being "full of life". This vitality makes them positive about the future.

18 - 5.1%

Getting information

"Getting the right information early can make all the difference, as a parent, often it's the only power you have left."

After parents know the diagnosis, they start looking for more information on the internet, foundations and sometimes by asking for a second opinion.



27 - 7.7%

Challenges after hospitalization

"But taking one home with a CHD and being told to "look out for signs they're struggling...shortness of breath, blueness, sudden death..." Well, it was totally overwhelming."

When being discharged from the hospital, parents sometimes need to take care of different things such as feeding tubes, various medications, or always having to look for symptoms. This situation generates a fear of not being able to take care of your child.

18 - 5.1%

Protect child

"I wanted to make her feel that she was not alone, no matter how hard it was for me to see her so sick."

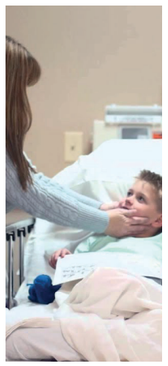
After seeing their tiny baby surrounded by all the machines and tubes, parents feel a great necessity of protecting their child. Unfortunately, most of the time they can't and this makes them feel helpless.

18 - 5.1%

Saying goodbye to undergo medical procedure

"When we arrived there we had to say goodbye to Luuk! This was extremely difficult for us because you do not know whether he will survive it or not (he had already deteriorated considerably in a short time)."

Some parents will have the chance to say goodbye before surgery, but others will not. After this moment, parents enter a state of worry, in which feelings of shock and anxiety are related to facing the possibility of losing their child.



15 - 4.3%

Being unprepared

"I'm afraid to say it is not something any parent can prepare for."

"Nothing in the world can prepare you for seeing your child after heart surgery – it's an image I will never get out of my head."

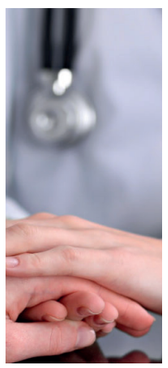
During the journey, there is a constant feeling of not being able to handle the situation. Parents describe that they don't believe something or someone could have prepared them for the journey they have been through.

16 - 4.6%

Doctor Fearing your child might not live

"The doctors couldn't tell us if our girl would survive this."

There are some critical cases in which even the doctor is not confident about the chances of survival of the child. This reality increases the level of worry in parents exponentially.

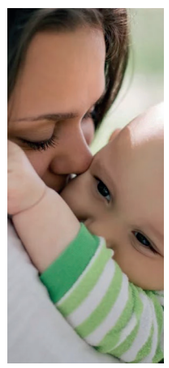


15 - 4.3%

Having a new chance

"He DID!!! I was so scared though I remember saying to my mum I thought Dylan would die."

After the baby beat the first open-heart surgery, parents felt a huge excitement of him being alive.



15 - 4.3%

Being afraid of the future

"He really has a complex heart defect and there will come a time when he will be worse."

Parents have in the back of their minds, always the future surgeries that the child needs to undergo. There are feelings of anxiety since they are seeing their child deteriorating over the years until the doctors say that it is time for the new surgery. Thinking about surgery, causes them to be terrified of the future, and feel awful when thinking about the next operations.

15 - 4.3%

Religion procedures

"There were a few times when we prayed that he would see the light of a new day."

While waiting for surgery date or surgery outcome, some parents try to find comfort in praying or getting their baby baptised before the medical procedure.

15 - 4.3%

Being proud of your kids

"I want you to know that I love you, I am the proudest mother in the world of what you have been through and what you have endured."

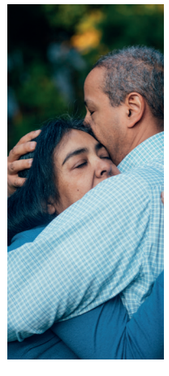
When parents look back at all the moments, the child has been through, and the achievements he has accomplished, they feel very proud.

15 - 4.3%

Telling each other everything will be allright

"We told him that he had to stay strong and that it would all be fine."

When a difficult time comes, parents try to make the other feel better by talking or showing support between each other.



14 - 4.0%

Supporting child

"To help me focus on this I have created a "Pride Journal" for each of my 6 kids."

"She loves being different and I'm so glad we, as her family have been able to give her such a positive attitude."

While children get older, parents always try to support them to have a life as "normal" as possible, considering their limitations. They show support by encouraging the child, or just by remembering their achievements.

6 - 1.7%

"hoping for the best but planning for the worst"

"We tried to balance being positive but realistic at the same time."

When parents begin to face reality, they enter a state of mind in which they "hope for the best but plan for the worst". Inside of this dilemma, they try to balance not getting too excited about their baby and giving each other hope.

11 - 3.1%

Dealing with set-backs

"When Louis came out he started having fits for two days, so they scanned his brain and to our horror he had a bleed on the brain, which affected the right side of his body."

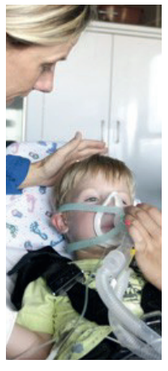
In some cases after surgery, the child does not react to the treatment as expected, and parents have to deal with setbacks, which compromise the health of the baby.

8 - 2.3%

Child battling for its life

"We were asked to leave while the SCBU doctors examined her further, at this point Evelyn stopped breathing and had to be resuscitated."

When the child's health complications are life-threatening, they can undergo extreme medical procedures to save the baby's life. This situation generates an intense feeling of fear and helplessness due to parents being present when the situation occurs.

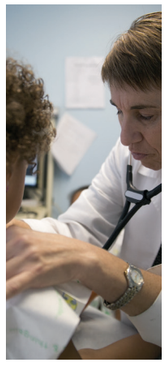


7 - 2.0%

Not going home

"Harvey was scanned multiple times and we were informed that he couldn't leave hospital until he had undergone surgery, but they were unsure when this would be."

When the baby presents symptoms, but doctors don't know the exact diagnosis, children who were before home, can't go back until physicians recognise the health problem.



Appendix I

Timeline Version 2

1. Finding something is wrong
2. Admitted into the hospital
3. Being born
Feelings
Before discovery of CHD 230 - 75.4%
Finding something is wrong 284 - 93.1%
Process info
Taking news from staff 154 - 50.5%
How?
Understanding diagnosis 155 - 50.8%
Realise seriousness 155 - 50.8%
Parents have to take
Medical decisions 120 - 39.3%
How?
Getting information 16 - 5.2%
Decision made
"Whatever we need to do" 49 - 16.1%
While
Symptoms 271 - 88.9%
Therefore
Admitted into the hospital 198 - 64.9%
Not knowing diagnosis 58 - 19.0%
Not going home 7 - 2.3%
Sometimes
Giving birth 140 - 45.9%
"Hoping for the best but planning for the worst" 4 - 1.3%
Emergency happening 144 - 47.2%
4. Surgery
5. Recovery
Support from family and friends 131 - 43.0%
Family life changed 34 - 11.1%
Facing reality 60 - 19.7%
Waiting for surgery date 50 - 16.4%
Sometimes
Religion procedures 14 - 4.6%
Saying goodbye to undergo medical procedure 16 - 5.2%
Telling each other everything will be allright 13 - 4.3%
Surgery 232 - 76.1%
Waiting 94 - 30.8%
Connecting with other CHD families 61 - 20.0%
Time perception 88 - 28.9%
Sometimes
Parents showing relief 46 - 15.1%
Parents worrying 157 - 51.5%
Makes them
Seeing baby 71 - 23.3%
Makes
Protect child 17 - 5.6%
Physical contact 85 - 27.9%
With
Body-machine connections 109 - 35.7%
Being unprepared 14 - 4.6%
Realise strength of child 72 - 23.6%
Recovery 241 - 79.0%

5. Recovery
6. Being discharged
7. Follow-up appointments
Feelings
Having a new chance 15 - 4.9%
Dealing with set-backs 9 - 3.0%
Causes more
Sometimes
Doctor fearing your child might not live 16 - 5.2%
Child battling for its life 155 - 50.8%
Interaction with medical staff 188 - 61.6%
Procedures 178 - 58.4%
Finally!
Baby thriving after treatment 80 - 26.2%
Causes
Child being discharged 241 - 79.0%
Comes with
Feelings after hospitalization 194 - 63.6%
Challenges after hospitalization 23 - 7.5%
Makes
"Re-playing what happened" 92 - 30.2%
Have
Possitive
Feelings towards medical staff 200 - 65.6%
Due to
Early detection 23 - 7.5%
Follow-up checking and treatment 192 - 63.0%
When
Child having ups & downs 36 - 11.8%
8. Patient's development
Now
Makes
"Having a son with CHD changed us" 37 - 12.1%
Patient's development 144 - 47.2%
Makes
Being proud of your kids 12 - 3.9%
Child coping with CHD 32 - 10.5%
Parents
Supporting child 14 - 4.6%
Cherishing the moment 27 - 8.9%
To
Being a normal baby 27 - 8.9%
Sometimes
"Tending to think she is cured" 19 - 6.2%
Makes
Looking forward to the future 43 - 14.1%
Being afraid of the future 14 - 4.6%
Child's physical activity 39 - 12.8%
Makes

Appendix J

Interview structure

Generative interviews

Research goal
Understand how does parental overprotection and anxiety manifest during the patient's participation in physical activity.

Research question (s)
Which aspects of physical activity prompt anxiety in parents and the patient?
Which aspects of physical activity trigger overprotective behaviours towards the patient?

Method
Semi-structured interview
Generative tools

- **Scope -** (Fields of experience around the focus that provide links and perspectives)

General understanding of the life of families with a CHD patient

- Daily activities
- Free time activities
- Social behaviour
- Perception

- How does the family live?
- How does the family spend their free time?
- How do parents behave towards their child?
- How does the child perceive the world?
- How does the child perceive himself?
- How do parents perceive their child?

- **Focus -** (Fully understand)

The role of a patient's physical activity in overprotection and anxiety in parents.

Focus sensitizing
The meaning of being physically active for family members.

Focus session (interview)
Overprotective and anxious behaviours related to physical activity participation.

(see the interaction between child and parent during the interview when they talk about PA)

Assumptions

Negative

1. See **health deterioration over time** & find it scary ("terrifying")
   - Waiting for next surgery means health condition deteriorating

2. **Uncertainty about the future**
   - "Hoping for the best, but planning for the worst"

3. When/how start they **replaying what happened**
   - Comparing past experiences

Positive

1. When do they realise the **strength of the child**?
   - "He is a fighter"
   - When they see child with lots of tubes?
   - Admiration towards child's journey

2. Child full of life = **patient's development**
   - Being able to
   - Milestones
   - Gaining strength

Schedule

Activity	Description	Time (minutes)	Material
Intro project	Present each other, goal of the interview, structure and time of the interview	5	Name tags schedule printed
Consent form and voice recorder	Show consent form, sign it and start voice recording	5	Consent form Dutch/ English Charged phone to record voice
Activity 1 Active day timeline	Observe, reflect and describe CURRENT physical activity experience	**5**	Timeline canvas and images for timeline markers in case they want to write somethin
Activity 2 Circle map of worry	Select and reflect PREVIOUS experience Share experience and discuss (access underlying needs and values)	**15**	Circle canvas (2 per interview) and extra images
Activity 3 What makes you feel safer?	Exploring aspirations for future experience	**10**	Post its, markers for writing
Saying goodbye	Ask if they will like to hear more about the outcome of the project. If yes fill the form	5	Form for family emails
	Total time	**45**	

Interview guide

1st activity

INSTRUCTIONS
Think of your **weekly routine** for a few minutes. Look at these **pictures** if you need a bit of **inspiration** to remember.

Now, the next step is together to **place these images** to represent a **day** you think NAME OF THE CHILD is **very activ**
It can be a weekday or a weekend day.

2nd activity

INSTRUCTIONS
The next activity will be **individual**.

Child
From the activities in your timeline, are there **activities in which you feel worried about your heart**?
Take new images and paste them in the circles. The smaller circle means that you feel super worried, the middle circl
more or less worried and the bigger circle that you feel less worried.

Parents
From the activities in your timeline, are there activities in which you feel worried about your child's heart?
Take new images (same as the timeline) and paste them in the circles. The smaller circle means that you feel super worried, the middle circle more or less worried and the bigger circle that you feel less worried.

Now, let's **see each other's circles**.

QUESTIONS

1. What will you say is the **difference** between the activities in the **smaller circle and the bigger circle**?
2. When your child is doing these activities, **what is worrying you**?
   - When would you say that your **worry begins**?
3. Do you **see or feel symptoms** like being tired, feeling you lose your breath, while you are doing these activities or after you do them?
   - Do you see or feel that these symptoms have been being **better or worse over time**?
4. **What** will you say that is the **cause** of your worry?
   - Do you think that **future medical procedures** could influence your worry about these activities?
   - Do you feel that your **past experiences** could influence your worry about these activities?
5. Are there moments in which you **recognise** that your **child is strong** to keep doing the activities?
   - Perhaps when he or she achieves a **milestone**?
   - Or, when later he is able to **do something on his own**?
   - Or maybe just when you **see him better**?

3rd activity

INSTRUCTIONS

Now that we thought more about how you feel, how do you think that you **both could feel safer** while NAME OF THE CHILD is doing the activities?

We will write your ideas on a post-it and past them near the pictures of the activities.

QUESTIONS

1. Do you think there is **something or someone** that helps you to feel **less worried**?

Interview gids

1e activiteit

INSTRUCTIES
Denk een paar minuten aan je **wekelijkse routine**. Bekijk deze **foto's** als je **inspiratie** nodig hebt.

Nu is de volgende stap om deze afbeeldingen te plaatsen om een dag weer te geven waarvan u denkt dat NAAM VAN HET KIND zeer actief is. Het kan een weekdag of een weekenddag zijn.

2e activiteit

INSTRUCTIES
De volgende activiteit zal **individueel** zijn.

Kind
Zijn er vanuit de activiteiten in uw tijdlijn activiteiten waarbij u zich zorgen maakt over uw hart?
Maak nieuwe afbeeldingen en plak ze in de cirkels. De kleinere cirkel betekent dat je je super bezorgd voelt, de middelste cirkel min of meer bezorgd en de grotere cirkel dat je je minder bezorgd voelt.

Ouders
Zijn er vanuit de activiteiten in uw tijdlijn activiteiten waarbij u zich zorgen maakt over het **hart van uw kind?**
Maak nieuwe afbeeldingen (hetzelfde als de tijdlijn) en plak ze in de cirkels. De kleinere cirkel betekent dat je je super bezorgd voelt, de middelste cirkel min of meer bezorgd en de grotere cirkel dat je je minder bezorgd voelt.

Laten we nu elkaars cirkels bekijken.

VRAGEN

1. Wat is het **verschil** tussen de activiteiten in de **kleinere** cirkel en de **grotere** cirkel?
2. **Waar** maakt u **zich zorgen** over, wanneer uw kind deze activiteiten doet?
   - Wanneer zou u zeggen dat uw **zorgen beginnen**?
3. **Ziet** of **voelt** u **symptomen** zoals moe zijn, het gevoel dat u uw buiten adem raakt, terwijl u **deze activiteiten doe** of nadat u ze hebt gedaan?
   - Zie of voel je dat deze symptomen in de loop van de tijd **beter of slechter zijn geworden**?
4. **Wat** is volgens u de **oorzaak** van uw zorgen?
   - Denkt u dat **toekomstige medische procedures** uw zorgen over deze activiteiten kunnen beïnvloeden?
   - Heeft u het gevoel dat uw **ervaringen uit het verleden de zorgen** over deze activiteiten kunnen beïnvloeden?
5. Zijn er momenten waarop u inziet dat je kind **sterk is om de activiteiten te blijven doen**?
   - Bijvoorbeeld wanneer hij of zij een **mijlpaal bereikt**?
   - Of, wanneer hij later in staat is om **iets alleen te doen**?
   - Of misschien als je **hem beter ziet**?

3e activiteit

INSTRUCTIES

Nu we hebben nagedacht over hoe jullie je voelen, hoe denken jullie dat je **beiden veiliger kunnen voelen** terwijl NAAM VAN HET KIND de activiteiten doet?

We zullen uw ideeën op een post-it schrijven en ze bij de foto's van de activiteiten plakken.

VRAGEN

1. Denken jullie dat er **iets** of **iemand** is die er bij kan **helpen om de zorgen te verminderen**?

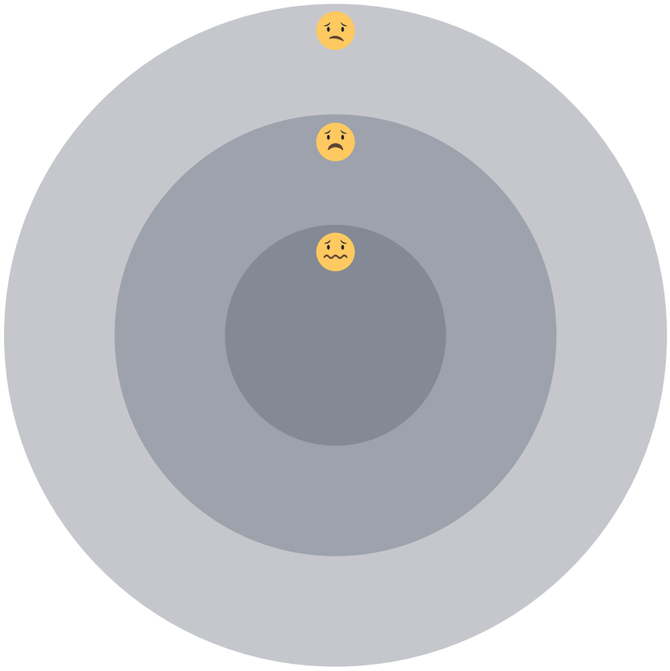
Appendix K

Material for interviews

Hoe ziet een actieve dag in je leven eruit?
Dit kan een doordeweekse dag zijn of een dag in het weekend.

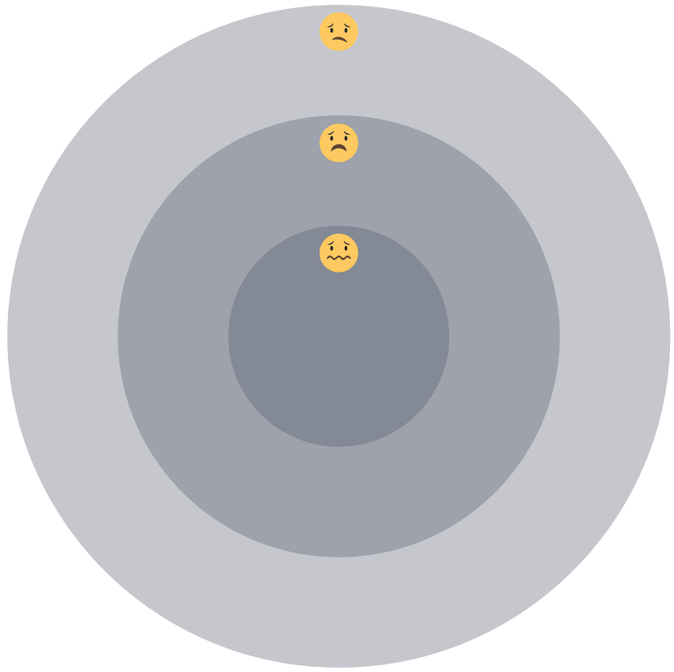
Zijn er activiteiten waarbij u zich zorgen maakt over uw hart?

Een beetje bezorgd Bezorgd Super bezorgd!



Zijn er activiteiten waarbij u zich zorgen maakt over het hart van uw kind?

Een beetje bezorgd Bezorgd Super bezorgd!



Appendix L

Statement cards for analysis phase

Mother and son don’t agree on transportation method to school.

1; I bring him to school with the car, because it is a bit far
1; no with the bike
1; yeah sometimes with the bike, not often

Child expressing being worried while biking because he could fall on his belly (where the scar is).

1; (to son): so you are very worried when you bike?
1; yeah, when I fall then
1; o when you fall
1; then I fell on my belly
1; and then you worry?
1; yeah sometimes

Asking for doctor’s approval when she considers the situation is harder for the child.

1; Yeah I do not worry, only with swimming sometimes he has to **swim a whole track below wate**
ıd I also just asked the doctor if that is a problem. […]

Mother informing the sports organization about the child’s health condition.

1; […] But yeah you know, **I do inform the sport organization that he has it** be he does not show
ymptoms to make me worry currently. But when we will see symptoms, I will directly blow the whist

When she notice symptoms, she will act on them.

1; […] But yeah you know, I do inform the sport organization that he has it be he does not show
ymptoms to make me worry currently. **But when we will see symptoms, I will directly blow the**
histle

f there is a place where she is not present, she will inforn the person in charge about the child’s health condition.

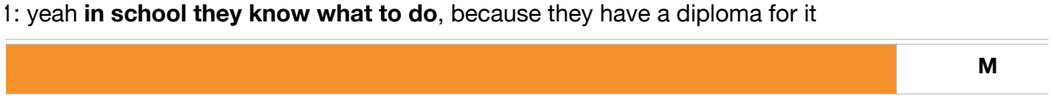
1; yeah **when he goes somewhere where I am not**. So when they see he does not come up, they
ill act directly

he wants to make sure others know what to do when sh is not around.

1; or when he comes up and his lips are totally blue they have to do something. On school as well,
ere they know it too. So **I want to make sure that where I am not available the people know**
hat they have to do

He knows the others know what they have to do in case something goes wrong.

1: yeah **in school they know what to do**, because they have a diploma for it



Mother stressing the importance to child about others knowing his health condition.

1 (to son); yes true, but **it is always important to know you have it**

Every tim she comes to the hospital she feels anxiety.

1; **every time I come here I have some anxiety**, you hope it is the same. […]

Surgery it is a hustle for her, but you should wait for it and don’t worry beforehand.

1; […] Because **the doctor said a surgery is possible and then I think, o dear what a hustle. Bu**
ah, you just wait for it, I do not worry on beforehand

She will not act unless she sees symptoms going on.

1; […] And playing outside makes you tired, all the impressions. That he is also sensitive to, to all e impressions. **As long as I do not see blue lips**

Mother doesn’t like surgery because afterwards there are a lot of complications.

1; when a surgery is needed, **that is not nice**
1; no I don’t think so
1; when it must happen it must, **but there are lot of complications**

Giving information to others, so they know what the child has and can act on it.

1; **give information**, like I said, make sure the **sport organization knows** that my child deals with aking aortic valve, because that’s what he has.
nm
nd the symptoms see you blue lips > **call 112 and say what the problem is**

When the child is outside, she wants to know where he is She would do it even if he weren't sick.

1; And with biking, when he goes **biking** by himself, **we often have contact**. Also with **playing utside**, **I want to now where he is**, I follow him.
ut **I would also do that when he would not have the problem**

Mother and child don’t feel worried about any activity regarding their heart.

o she made a picture of it. Place it in that place in the circle to indicate how much you worry abou or how careful you are with yourself
2; **haha totally not**
2; **no totally not**

Mother told the swimming teacher to look if her child presented symptoms and if yes, get her out of the water.

2; […] And from the start I had told every time she went to a higher level **I had told the teacher: sh as a heart disease,** she does not really have problems with it, **but when she goes blanc, gets rec rcles around her eyes or goes below the water, then you have to get here out**

She wants others to watch her child.

2; so next week I went with her and told them very specifically that this is not what **I want and tha ey have to watch her.**

She was always pushed her child to do the normal activities a child does.

2; no I was always the one who said, you just go to kindergarten, you just go to swimming class, u just do sports, you go biking, you go outside, **come on just do it**

The child goes to roller coasters even if it is not ecommended to do, and mother and child are OK with it

2; I still have to try things out, like going in a rollercoaster
2; yeah **she also goes in rollercoasters, which they actually advise against.** But she just goes i and does not have any problems

When the child stopped with medicine, the parents thought they would find eventually what she could and couldn't do.

2; […] but since November 2006 she is already **medicine-free, so we thought, well we will find ut what she can do and not. And when it goes fine it goes fine.**

The child misused her health condition to skip school.

2; And there was a period **she misused it, when she was at school she told the teacher 'my elly hurts so much, can I go home'** and then she came home, so then I went to school again and ld them: 'Hm, **there is nothing wrong with her**'

The doctor said the child would not live more than 6/7 years, and when the child was seven, they had a big celebration.

2; yeah super good, **my little miracle**. Yeah, Dr ten Arco was then her cardiologist and **he said sh ould not be older than 6/7 years** because her heart would not be able to handle the growth but eah she is now 14. So, **when she became 7 we had a huge birthday party**

You only feel something when you are in a lot of pressure (knowing your child might not live).

2; **well you only feel something when you dive to the bottom of the swimming pool right?**

The child goes straight through difficult moments instead of walking around them.

2; […] **People do not do that, they try to walk around it with a lot of difficulty. I just go through**

Mother thinks the child is not worried, and she needs to remember him.

3; no he is not a bit worry, not a bit more worried and not over worried
oh he is never worried?
3; **I am often the person who tells you** it

The child sometimes worries a bit about breaking a leg, but the mother says that never about the heart.

so for you everything is in the white place
3; well **sometimes I worry a bit**
3; yeah when you jump from a roof you think about 'will I break my leg or not' but **you do not thinl bout your heart and if you can do it, my heart cannot do this. You do not think about it, you ju o**

Mother wants her child to rest after school before going outside to do more activities.

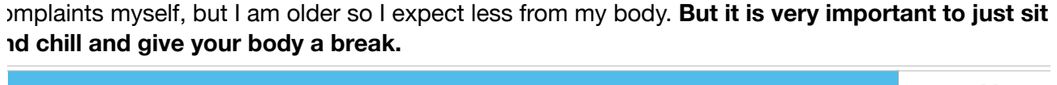
3; **he does not understand the rule of going home after school, rest a bit and then go outside** e goes by bike to school and they do a lot of activities on school […]

Because he does a lot, in the evening he is very tired because he oversteps his health boundaries.

3; […] But it is difficult for him to follow this rule **but in the evening you see he is very tired. Then e overstepped his boundaries**

It is very important to rest and give your body a break.

3; it are the moments in between, **taking your rest then is very important**. I also have some mplaints myself, but I am older so I expect less from my body. **But it is very important to just sit nd chill and give your body a break.**



The child likes adrenaline but not energy-intensive activities.

3; […] Then I get a phone call from somebody who says 'hey, your son is in a tree and he can not me down anymore' or I have to get him from the roof. **Yeah he really is an adrenaline junk. ut not very energy-intensive things**

He likes being independent.

3; **I like doing things by myself**, I like being in myself

M

Mother needs to help her child to learn to take breaks and come back again when the child feels frustrated.

3; […] Then he has a tendency to hit his feet on the desk and all, but when I say five minutes, he nows I mean go five minutes away from what you are doing, come to rest, and try again. **So you do ot give up, but you just take a break, that is the only thing I have to help him with**, the rest he oes all by himself

M

Mother wants to know when the heart rate of the child is not OK and the location of the child.

3; yeah I think it would help for children with heart problems to have a wrist band that is connected my phone, so **when his heart rate is abnormal a notification to my phone will be send with ey, I am on this location and my hear rate is not okay'**

M

An APP that is linked to the parent's phone, because children don't know what to do in case of an emergency.

3; yeah who doesn't anymore nowadays, everybody has a smartphone, so just an app that is linke ith the **wrist band and a notification to the parents**
directly
3; yeah directly, **because children do not know what to do**, and I have been in the ambulance any times myself

M

She thinks (and experienced herself) that children ignore the symptoms.

3; […] But yeah I was lying in the ambulance very often because I went on and did not listen to my ody. I thought 'o a little bit short of breath, that's not a big problem' but the first signs are your brea nd that kind of stuff. Tingling in your hands and all, but **children just ignore it. Children think reall fferent about it.**

Mother needs to be looking for the first symptoms when the child is playing a sport.

3; yeah you go from 0 to 100 in one time and then **I sometimes had to yell to the coach get him ut.** Because then I see he starts breathing heavily, gets tired, looks confused around. Then I say ge m out, **these are the first symptoms**

M

Mother doesn't see the problem of being able to locate the child with a bracelet.

3; but you are a really silly person if you hack a heart
that's true
3; **what is so interesting about it. Like I will hack a child to see what his heart rate is or then they can see it is a problem**

M

Training the child is very important.

3; true, he also has a epi-pen, so then he can give himself a shot of adrenaline before the nbulance is there. **I think training the child is very important**

M

It is difficult as a parent who doesn't have a heart defect to know when to react regarding the symptoms without affecting childhood.

3; and parents, **parents who don't have heart problems themselves cannot imagine how it els** for the child and when they have to react. I am alert because I have it myself, felt the symptom yself and I am older now and learned from it and I think a parent who does not have heart problem mself, **for them it is way more difficult to know when to react. Because you do not want to ke away the childhood of the child.**

M

There is a dilemma between protect the child and let him be a child.

3; **so you have two sides, protect him and let him be child.** And if you then think 'hey I think he as some problems now' that is more difficult, because he can also just be tired

Because parents don't understand how it feels, it is important to give them knowledge about the symptoms.

3; yeah, do you understand, because you don't know how it feels yourself, you don't know what
ur body does. **So guiding the parents is important**
good one, and guiding as in knowledge
3; yeah **knowledge about the symptoms.** When your child starts speaking strange, or not strange
is more unclear, that is a symptom.

BOTH

Guide the child towards self-recognition of the symptoms

3; and **training the child itself,** you are diagnosed but the child is not trained, **how do I recognize**
gns from my body
3; **how can I see it goes wrong**

M

Children don't listen to their symptoms because they want to be able to do what other healthy children do.

3; **you can guide children but they won't listen.** When you bike with a group of children, there is
one who would say 'hey I cannot do this, please hold up a bit. Children go on
you want to be part of the rest
3; **you want to do what others do**

M

Parents think they see symptoms, but they are not sure if it is related to the heart condition or not.

4; A little and we have like in summer we did a hike in the mountains. And there you see that **he is**
uch slower than his brothers. He has three brothers. And that's not a problem. But then you with
m **you start asking, okay, is this just a child? Is this just this condition? Or is this related to hi**
eart?

M

Parents don't know if something is a symptom that the condition is getting worse or if it is not a symptom.

4; And **is it a sign that is going back or is it a normal?**

A child doesn't feel different from other children because he has been with this condition since birth.

4; No, I don't think for him. It's a problem.Yes. His **experiences from very young. And for him. It'**
natural way of how he is yes. When someone asked to do a contest. Go ahead. I just walk here.
eah, he doesn't feel the pressure to do so. So, that's nice.

M

Children look for activities in which they feel comfortable with their physical capabilities.

4; Like one year. Last year, he played soccer at a soccer club. And then he loves to go in the goal.
then he can afford the running. **So in a natural way he looks his way to.**

M

When children overpass their physical limits, they are confronted with their health condition and decide to stop

4; […] But he never did so much running. but its okay, He is smiling and laughing and, and then a
eek after, **he didn't want to go**. And I really, I couldn't get a grip on why he didn't want to go and a
e end, like a lot of questions. And we we noticed that he **he had also noticed his physical**
apacity. And he didn't run that much before. So he was confronted with it really.

M

If a teacher says something to the group instead of pointing out one student, the child with CHD recalls better the advice.

4; […] So to who, had to do you have to listen here, and he had to the teacher. Yeah, of course. But some
mething else, **you have to listen to your body. If your body says it's okay, then you've got to stop.** And
at was **for my child really a good**, a good. How do you say it? **remembering**?

M

The child is aware that if he feels tired, it is okay to take a rest.

4; Something to hold on? Yes, yes. So **now if he's tired**, or in a mountains, or in swimming, **he ca**
y, Okay, I have to listen to my body. I'm going to take a rest. So he understands that it's okay t
ten to your body and feel it and to do something with it. Yeah.

Mother feels happy that her son was not pointed out in front of the sports group because of his health condition.

4; Yeah. It was **really nice**.
e didn't pointed him out.

M

Mother believes that his son is not experiencing other symptoms besides feeling tired.

4; No, I don't think so. **I think that's the only symptom. He experiences**. Yeah.
eah.

M

When her child is doing sports and the difficulty increases the mother doubts if her son will make it, and that makes her worry.

4; Because when something goes wrong, in the swimming pool, it can be dramatic. -laughing- And
ey like, **they always start to swim with the clothes on and that is really heavy. And I think oh...**
he going to make it? -laughing-

4; Yeah, **I was a a bit worried towards, a bit worried**, I think. And they had half an hour. **They ha**
run as many rounds as they could. Oh, and **he really went for it**. Get some running? I'm runnin
. Ok. Ok. Ok. **can you do it? can you do it? This is okay. Then, then. Yeah, really? It's Yeah. It'**
orried consciousness. It's a little bit like that.

M

When the difficulty is more serious, the mother starts thinking that her son will have more problems than others

4; So, that's it. And maybe it's just a mother feeling? I don't know. But, yeah. Yeah. And at him, **I**
ways have when it's heavy. He might have more problems than others. He doesn't that he
esn't have per definition, but **I am. Yeah. Just a little bit more sharp over it or worried, or**
nscious.

M

With new sports activities, the teachers need to know the health condition so they can respect when the child says he needs to rest.

4; They know, yeah. At every sport or club, they know, just in case that **they also understand wha**

You never know when something can happen, so the mother prefers to tell everyone for prevention.

4; So that is not to mention really active. But still, they also know. **It's just yeah. You never know**
.]

M

Mother tries to respect his independence, and she sees that he is proud of being able to do things on his own.

4; […] Okay, **it's getting bigger. I should let them go.** And then... sometimes he starts getting a
ocery little one. all by himself. And **he's really proud and that he can do that by himself.**

M

Mother thinks that her child gets worried about only specific cases but not in daily life activities.

4; […] So it's just like the this the **once in a while cases he get worried. Not on daily live**, we do
el a limitation. No.

M

Something that can tell parents if the heart is in good or bad state.

4; Huuuuh, ah... Actually, you want to put **something on his heart which says** Okay, goes good.
es? Like **like a green light or red light**?
r where you **get a signal when it's going down** or something?

M

Something that can help the child to indicates how he feels regarding his heart.

4; […] But **how can he indicate what he feels so that we can see if it's normal or not?** Does he
el tired? Does he have pain in his heart? Or does he have pain in his legs or **something that helps**
m to better indicate what he feels?

Mother wants to be able to interpret what the child expresses.

4; Because then **we can translate or interpreter** interprets?
Yeah.
4; **The consequences**.

M

Since it is hard for children to say what they feel, she wants to enable the child to express, so she can identify the cause of the symptoms in her child.

4; Yeah, yeah. listening to your body. Okay, that's fine. And we know it's something with the body.
ut then again, it's the legs. Is it a condition? is it is heart, is it?
Yeah, it is. When you were saying in the mountains
4; yeah, **it's very hard for a child to tell what he feels.** What's going on?

M

She wants to be able to identify more symptoms so that she can take the correct actions.

4; Yeah, because when he tells about is it his legs or **is it his condition he is tired**, **okay**, we know
e can, **we can just continue and let him rest**. And it's okay. **But when he really feels like**
essure on his heart or something, that is another thing, then you think, okay, we should
aybe have a control as a doctor sooner or make a goal? […]

M

She worries about not being able to identify more symptoms on time.

4; […] Yeah. **I know. He won't collapse just in a moment. So that's we don't worry about that.**
ut yeah, when it goes down? You want to have sign when it goes? Yeah.

She doesn't know when the health condition will decrease, and if her son will be aware, so she is always searching for symptoms.

4; The health can be increased or the condition or but the working of the donor valve, **the conditio**
ill go down. And we don't know at what time or how soon. […]
.] **And yeah maybe he can tell but I don't know**, you live in like a kind of a radical. Okay, is this is
omething like indicating that we're going down? Or is it just still the normal condition, which might b
wer than other children? Which is ok. But so you **You're always searching** for? Is it the normal
ing? Is the child thing just a person thing? Or is it related to his heart?

M

She knows that maybe they will not notice the symptoms but she is always conscious that something her child's health could decrease.

4; […] we actually never experienced that parents saw it sooner than what we see here in the
searchers and that in the ECHO, the ECG, And so **probably we won't even notice**. We come here
nd they say, Okay, let's go back a little. So we have to increase the frequency of controls, and then
e deal is so bad. We have to get a new operation. But so properly, it won't change anything. **But**
ill, it's for your mindset is it's your you're always conscious about it.

C

Child attributes her tiredness to the size of the bike.

5; with biking I easily get tired at school, **because I have a small bike** so a need a lot of power to
forward

BOTH

The child is not aware of her mother's level of worries about sports.

5; that I worry about sometimes
5; very worried?
5; well not very, but sometimes,
5; because you put it at very worried

Mother talked with the doctor to corroborate that doing sports was OK after her child's surgery.

5; oh yeah we talked about it
you just talked about it with the doctor that it is okay?
5; yes
.]
5; she just had a surgery, so that is where the wound is from

C

The child trusts the doctor's recommendations.

5; yeah but **the doctor said it does not matter; I can do what I want.** I can sport, do stuff, play utside

M

Seeing the child happy makes the mother let her do more activities.

5; of course, you will stay worried. But **when I see how good things go and how happy she is, I t her go**

M

With sports, the mother will see if everything is OK.

5; but sometimes **with soccer I will watch to see if everything is alright,** to look if she is blue or.

BOTH

he child was afraid of symptoms while swimming and th mother preferred to wait till she was stronger.

5; yeah but healthy children have that as well so yeah. But when she was 5 and she started vimming I thought **maybe we just wait a while. So she gets a bit stronger**
5; yeah, because **I was afraid, I did not like it and my lips were really purple/blue**
5; yes, so then we started at seven and she got diploma A and B and no she will go for C

She wants to have all the titles because her classmates have them.

5; […] I want ABC, because **I am the only one of my classmates who does not have all the plomas already**

M

Because they told the mother that difficult times were coming, she didn't know if her child would be healthy, bu now the child does what she wants.

5; yeah, in the beginning we were quite anxious, **they told us it would be a difficult time**, it would e hard for us… so I thought, **will it be a normal child?** But, tss, I think she does everything quite ormal. **She does what she wants to do**

M

The mother worries less because she knows more, but before she didn't know what to expect.

5; and now **I worry less, I know more**, I did not know what the future would give me

BOTH

Mother is aware that during sports, they are fair with her daughter.

and then you get the change to ask to be the changing person?
5; no, **the teacher asks who has not been the change yet**
5; yes everyone gets the opportunity to change, **they are fair**

M

The mother thought the sports was intensive and asked the doctor's opinion. For now, she is OK but still a bit worried.

5; when I heard it from the doctor, I wondered myself if we should go on with **soccer because it is uite intensive. But the doctor said, no worries**
5; he said I could do what I want
5; **of course, you still worry a bit** and you are always there with the training, just like other parents

'he child thinks is nice the doctor gave the 'GO' to socce because now she can do what she wants.

[…] But I already hear that when the doctor says, no worries, that already helps
5; yes, because then you know **'I can do what I want'**
yes, that is nice for you
5; **yeah then I directly know I can go on**. Because next week I have my first match

M

Mother looks after her child while doing sports and tells the trainer to slow down when she thinks is necessary or just watch her.

5; I watch her, **I look at her**, I feel it
5; with soccer she sees when I am tired, or with swimming, because I move a lot with swimming
5; yes and then **I give a signal to the teacher**, I tell them please give here the a break when she is ed
.]
5; yeah because she just had surgery, before she did not ask. But because she just had surgery **I sk the teacher to watch her.**

C

Children are not aware of pain until they finish the sport.

5; no, because **while doing it the wound does not hurt, but afterwards it does**

M

The mother instinct can help to know when things are no OK with your child.

5; I think you have to look at your child as a mother, that is the best. **My mother-instinct helped e a lot.** The doctors also learned a lot from me, they say you know here the best

C

The child is aware that she can ask others to be allowed to slow down when she feels tired or not well.

5; and **I know that I have to take it easy** no, **because I get tired more easily**. With soccer as wel with sports at school I tell the teacher when I have pain, muscle pain for example, because at uesdays we also have sports and then I tell the teacher I have muscle pain and **will take it easy or**

Mother is not worried about heart, more about falling and scratches.

6; mwa, not really
t of grazing/**scratches** and bit of **falling**

C

The child feels worried when the sport demands him to persist.

5; yes, **I have a long track** and the first part goes easy and the second part as well, but **the third art, then I am already tired**. But it is better when you can pump it up at the end to make some peed. So **the last part I really have to keep up/persist**

M

Mother doesn't want to see if her son falls off the bike; she prefers others to tell her.

6; yeah, you can fall very hard with it. So **I stand with my back to the track and if I hear a child lling I ask someone else who just fell.** But for is heart, yeah...

C

The child feels when his heart is asking him to stop.

5; often I feel it in my legs, but yeah that is logical. Often I think I will just go on for a while, ometimes **I then feel my heart beat in my throat and then I stop for a while.** Then I know that hen I go on I will not make it

M

f you inform others about your child's condition, then you are not treating your child as a healthy child.

did you inform the trainers about his heart problems?
6; oh I don't know anymore? **Most of the time I do that**, but I cannot remember. **We try to give m a normal life and upbringing.**
so you do not constantly inform the people around you
6; no

Because of what she previously knew, she called the hospital to verify medical recommendations.

6; so when his teeth had to be pulled **I called the hospital to ask what to protocol is now**, but
ey said that it was out of date. But **for that kind of stuff I do place a phone call to ask**

The child knows that if you feel tired, you should take it easy.

But imagine that you would be very tired very often, what would your solution be?
3; **take it easy** and … when you play outside you are very busy so playing less outside I think. […]

Calling the hospital is the best way to get medical information.

6; then **I just call the hospital/his doctor here or the GP, I do not like to look up things myself**,
try out stuff

The mother doesn't like the information in the internet.

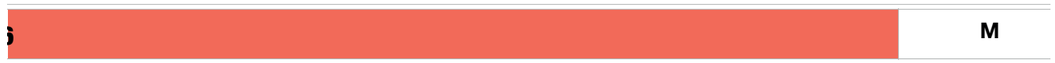
just a call
6; yes, they know a lot more about it here
not on Internet
6; no, **you see the most terrible things** then

The hospital supports the mother to raise her child normally.

sometimes people have a lot more worries
6; yeah **I always got a good backup here**, about the fact that **I wanted to raise him normally**

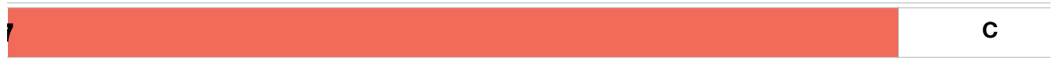
Mother is aware that her level of worries and her child's level is not the same.

7; I am curious how you fill in the paper, **I think I fill it in differently than you**



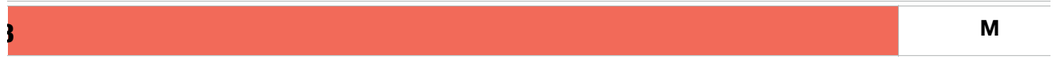
Mother knows that her child is not worried about her heart condition.

7; (to son) **you are never worried right, I knew it**
7 -laughs innocent-
7; did you seriously not put anything in the circle
7; no, I have to start
.]
7; yes you will leave it like this, right? **I know you, you do not worry**



The child is aware that she doesn't pay attention to her heart.

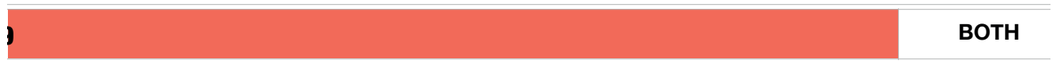
you do not pay attention to it
7; no



Mother felt more worried/anxious closer to the surgery date.

7; **when you would have asked it two weeks ago it would have been differently**, but I fill it in
ow I feel now

7; with physical activities. But she did not used to have complaints with physical activities before
urgery, so that is something I have got anxious about.



The child felt a bit strange about going outside to play after having surgery.

7; But you thought it was a bit exciting, the first time when you were allowed to play outside again.
ou were a bit anxious but you did go. That you were allowed to do everything again, you thought
as exciting right.
7; no

Mother knows she is not very aware of her condition, but she tries to look after her.

7; well she is only allowed to do sports again since this week, last Wednesday she has been playin nnis for the first time since a week. **She does not think about it, but I watch here through the indow.**

01 BOTH

The mother seems very anxious about the surgery still.

that's a short time ago. Did you have many surgeries?
7; one
7; yeah one big one actually
and did you have to be in the hospital for long
7; a week
7; 12 days actually

02 M

The mother worries about the different levels of physical condition. From doing nothing to start doing sports again

7; yes, from not able to do anything, a surgery is of course quite an attack on your body, **she had ero condition. That is why I am a bit worried**, not a lot, so that is why it is in the outer ring

03 C

The child is not worried about her heart condition.

[…] (to child) And you do not have any worries at all
7; no

04 M

Since the mother knew about the diagnosis, she started to look for symptoms and see things differently.

7; yes **since the diagnosis** I did, **you wonder** how it will develop, but she did not have any mptoms. The doctor assumed she was often tired but that was not the case. But when you have e diagnosis, **you look at it with a different view**. **You look for symptoms** kind of. **You get spicious**. The same with sports. **In the past I would not have thought about it, but now...**

The mother thinks the worries will go away with time.

do you think your worries will go away in a few weeks?
7; yes I do think so

06 M

Mother doesn't like to come to the hospital, but when her child's health gets better, the worries will disappear.

7; no the surgery was successful, but there was only some fluid around her heart and that was a bi oublesome but now it is less. **We did not want to go back all these weeks but yeah**

7; yes. When the fluid is totally gone, then we are really finished and then **these worries will sappear**. They check her very well every time

07 M

She feels calm when she sees how carefully they monitor her child and how much time they spent on her child.

so the people here give you peace
7; yes absolutely, **they watch her so closely and do not quickly send her home**

08 M

Having direct contact with the hospital gives the mother relief.

aha, and imagine she is playing outside or doing tennis and you have worries, can you then direct ll to here or...?
7; yes directly, I am sure of that, you get a card. And **they always say you are closely connected the hospital and I feel it that way**.

09 BOTH

The child will say to her mom when she does not feel OK and mother will act on it, but she also will start having thoughts about the health condition of her child.

7; uhm, **I would go to mom**
7; and **then I would call**
so you would go to mom and...
7; yes because her complaints started with a stinging pain so **when she would come to me my oughts would start rolling again**

Appendix M

Co-creation procedure

Goal of session

1. Get Inspired from the data already collected and pre-processed
2. Ideate potential parental supporting system that reduces anxiety and overprotective
behavior

Time to be inspired from data (Group) (15 mins)

Goal
· To understand what is going on the timeline & cards
Task
· Skim through the timeline and cards
· Put attention towards interesting parts that may **help to create potential parental supporting system** that reduces anxiety and overprotective behaviour

1st Ideation (individual work- 10 mins)

Goal
· Individually, ideate potential supporting systems direction based on understanding from
the timeline

Task
· Ask questions to ideate the supporting systems, such as
· What, which information should be shared?
· To whom, from whom should the data be collected /shared /notified ?
· When should the data be shared?
· How should the information be collected or presented?
· Draw your system ideas or information flow on your board given
· Try to involve as many stakeholders as possible
· Using smart device is requirement.

2nd Ideation (group) 35 mins

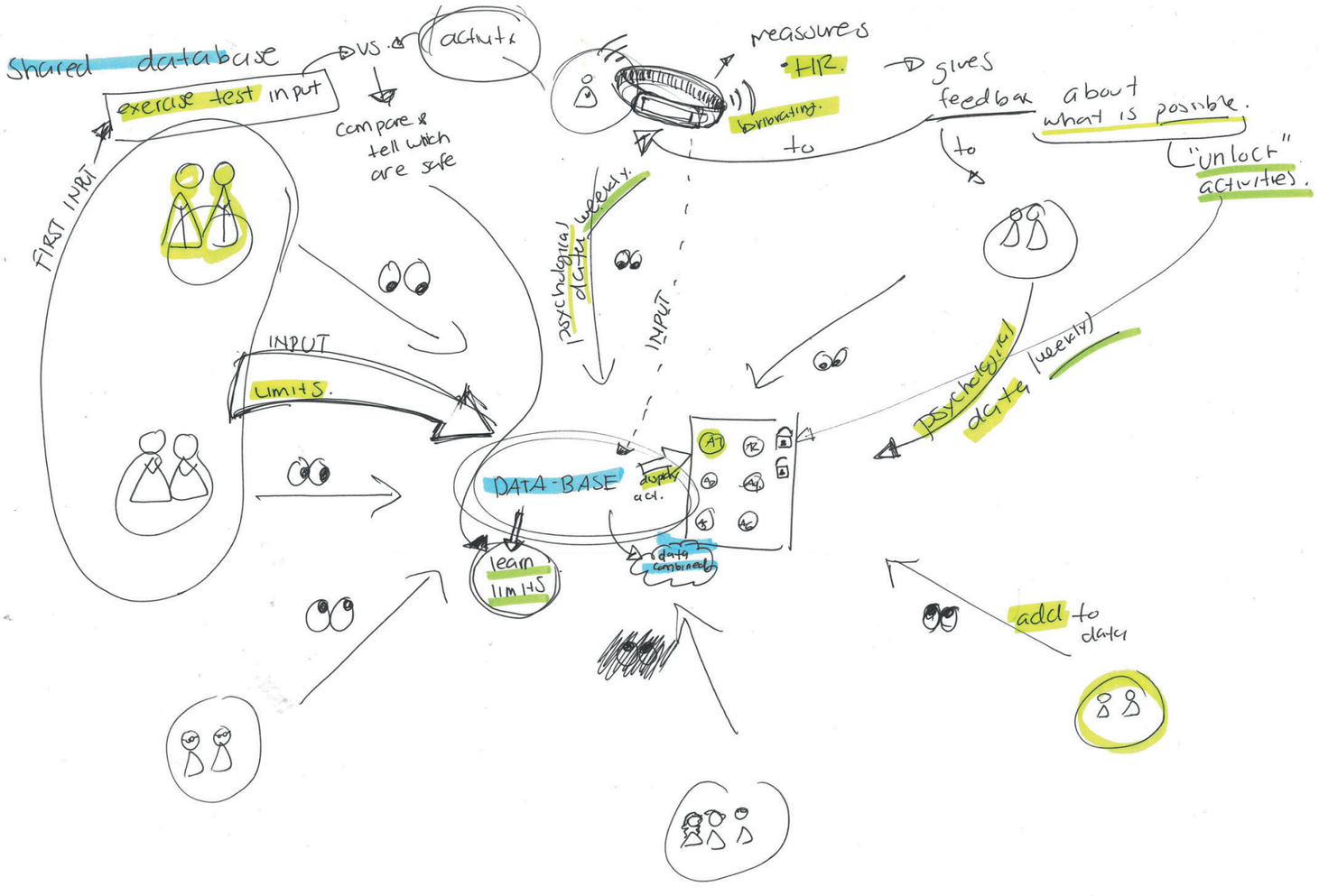
Goal
· Ideate potential supporting systems direction in a more completed picture
· Include all the dimensions of physical activity
· Include all stakeholders
Task
· Based on your individual idea, quickly ideate the full system of parental supporting
system, as a group
· Quantity >>>> Quality

3rd ideation (Final Idea) 10 mins

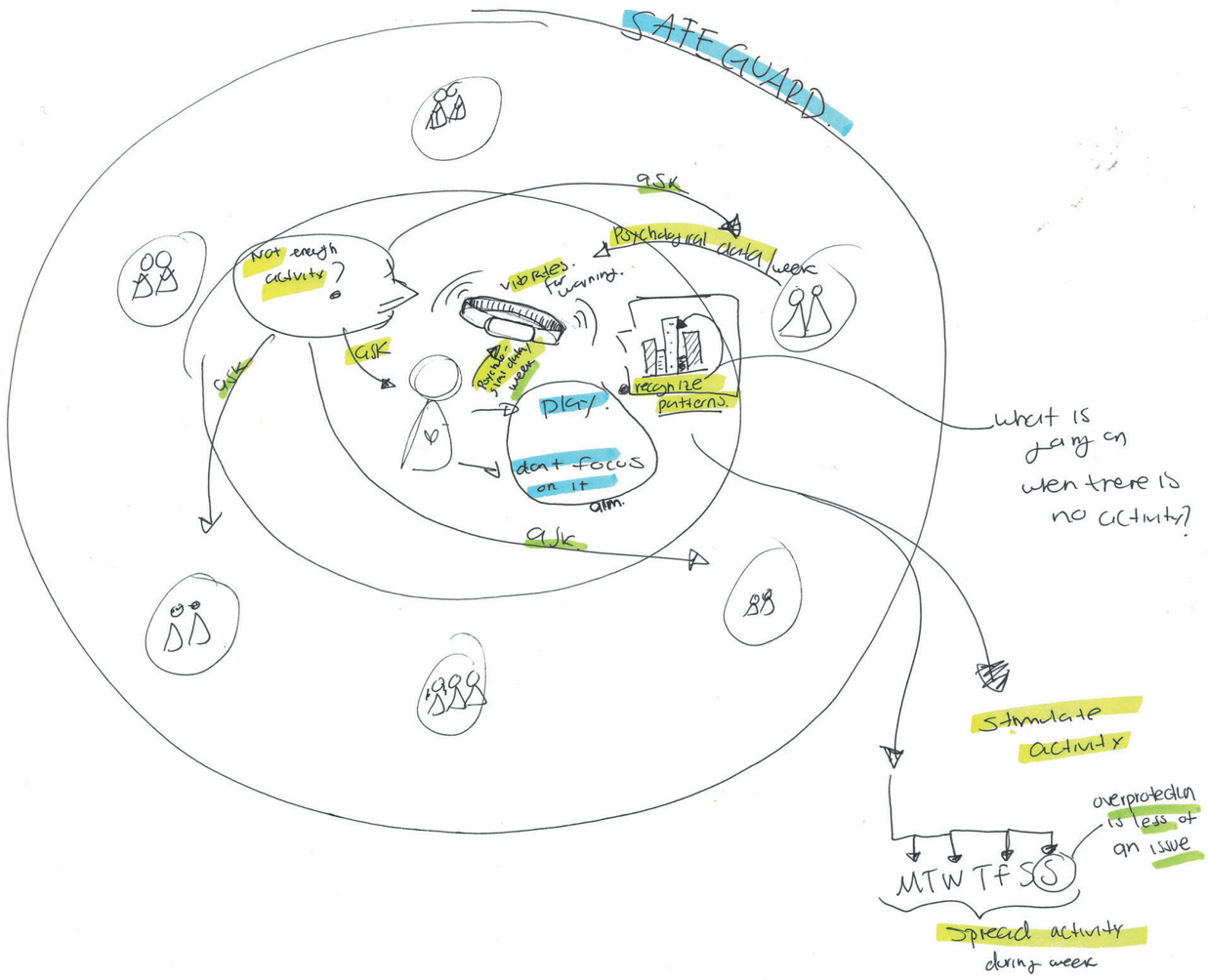
Goal
· Generate/draw the best idea in a more complete picture
Task
· Based on group ideas, draw final and best idea in a completed system form

Appendix N

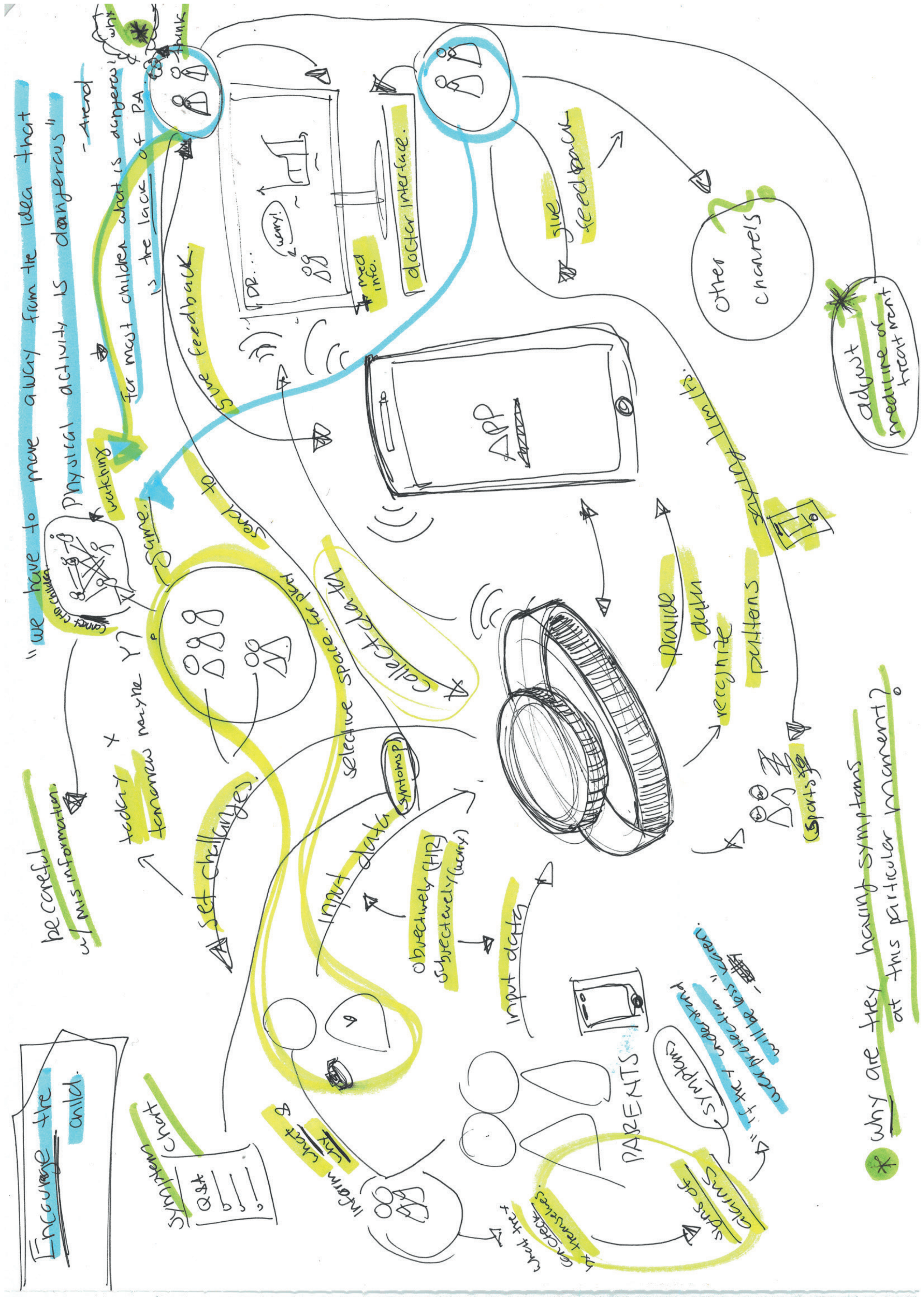
Drawings of audio Co-creation session

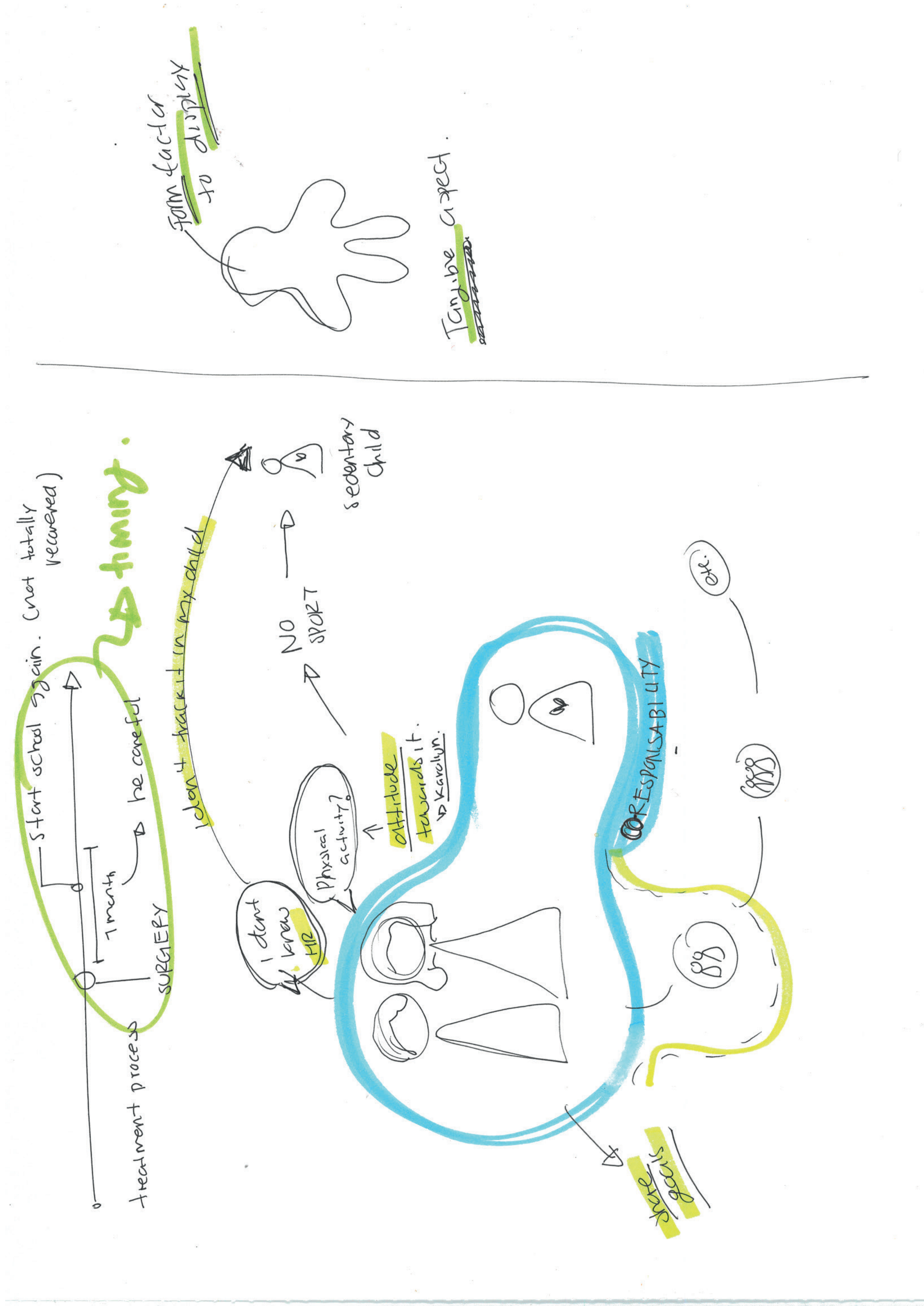


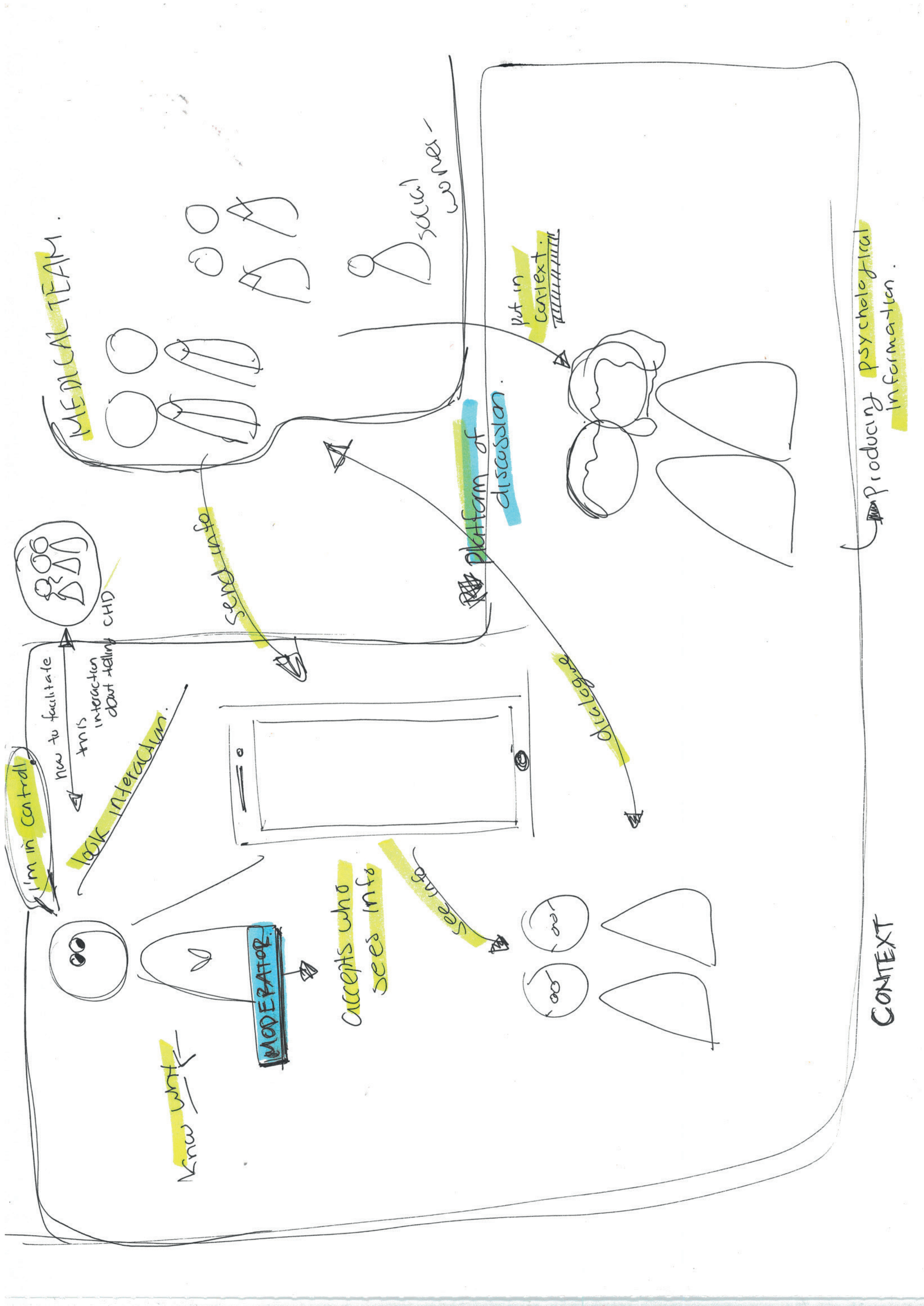
limit child

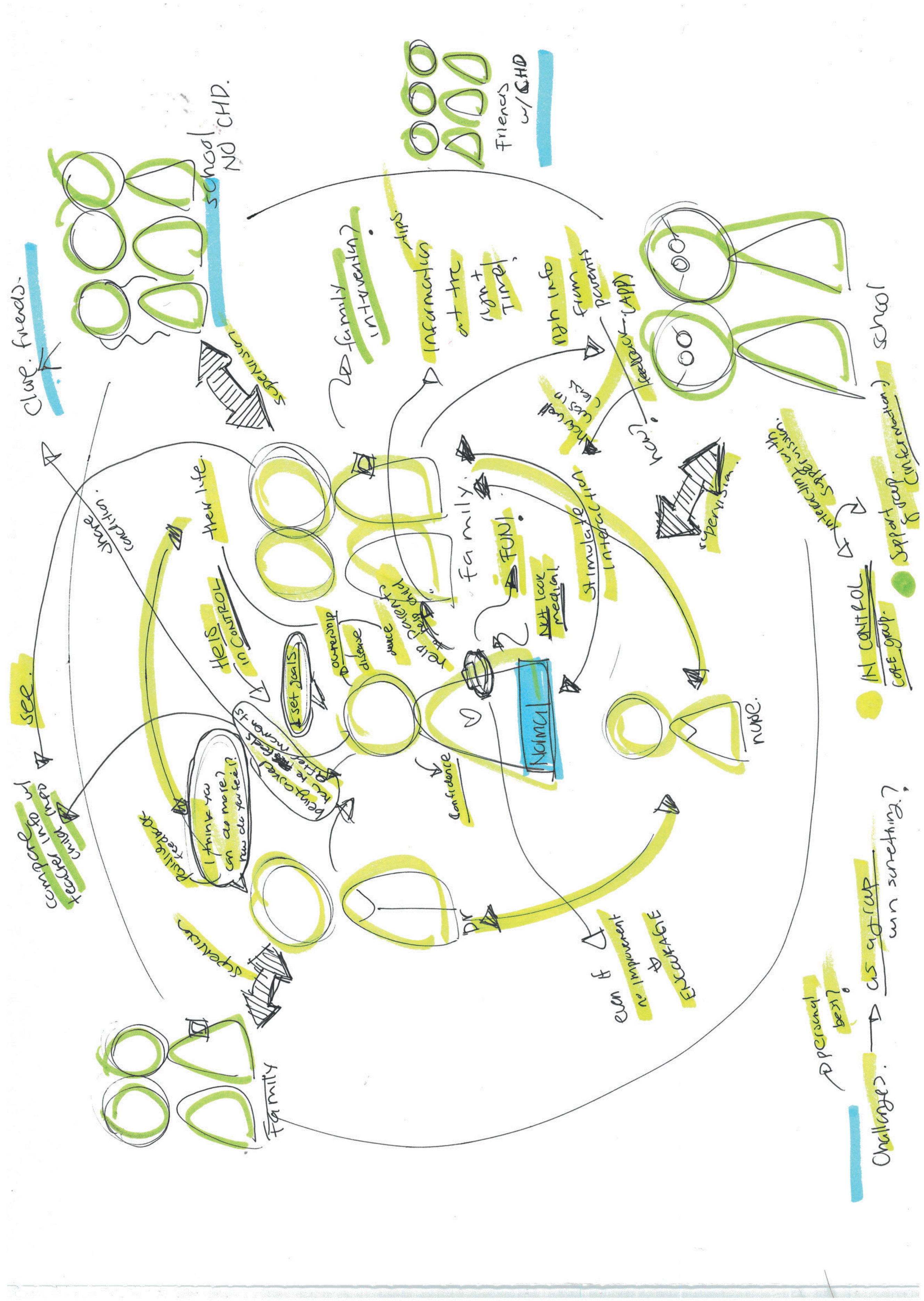


limit the child


"we have to move away from the idea that Physical activity is dangerous" - Arend
for most children what is dangerous is the lack of PA
be careful w/ this information
today x tomorrow maybe Y?
set challenge
give feedback
doctor interface
give feedback
other channels
adjust medicine of treatment
APP
provide data
recognize patterns
input data
Input data
PARENTS
Encourage the child
symptom chat
Why are they having symptoms at this particular moment?


form factor to display
Tangible aspect
treatment process
SURGERY
start school again. (not totally recovered)
be careful
Identify & track it in my child
NO SPORT
sedentary child
Physical activity?
attitude towards it
I dont know HR
RESPONSABILITY
share goals

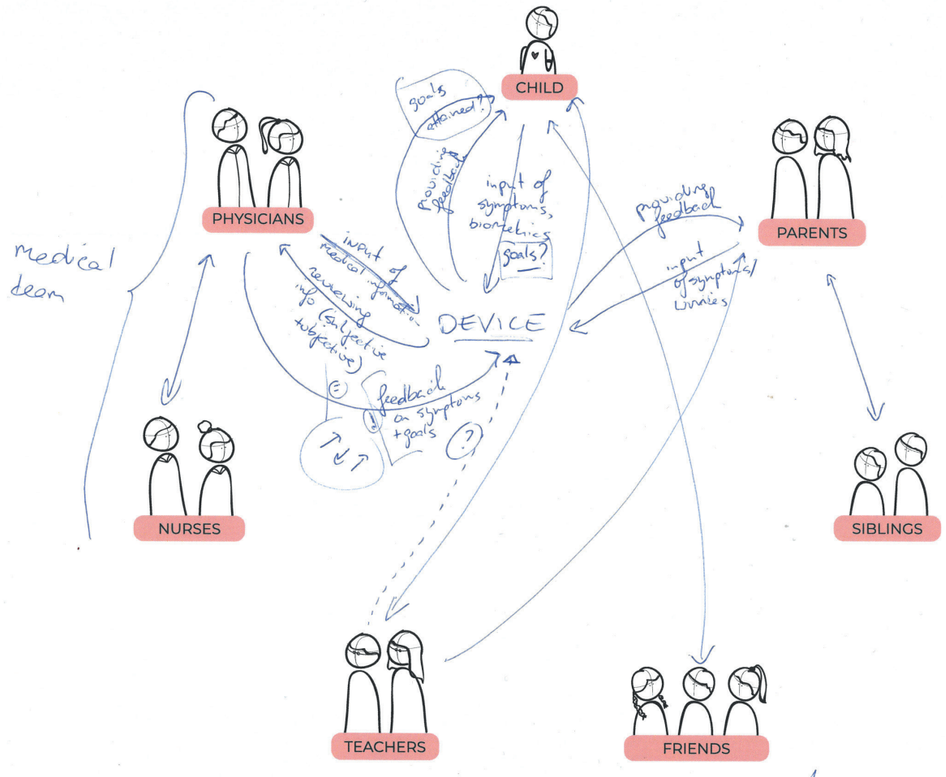

MEDICAL TEAM.
MODERATOR.
send info
platform of discussion.
dialogue
put in context.
Producing psychological information.
CONTEXT


Family
school
NO CHD.
Friends w/ CHD
IN CONTROL
support group (information)
nurse.
challenges?
ENCOURAGE
FUN!

Appendix O

Drawings co-creation Participants

Producer name .....[redacted].....



Six dimension of physical activity

1. **Mobility**: moving from place to place, moving the body in space.
2. **Object manipulation:** control of equipment needed for the activity.
3. **Cognitive function:** memory, understanding, relationships.
4. **Behavior and social skills:** appropriate behavior, interaction with others.
5. **Communication and perception:** information to/from environment/others.
6. **Fitness:** emotional and physiological.

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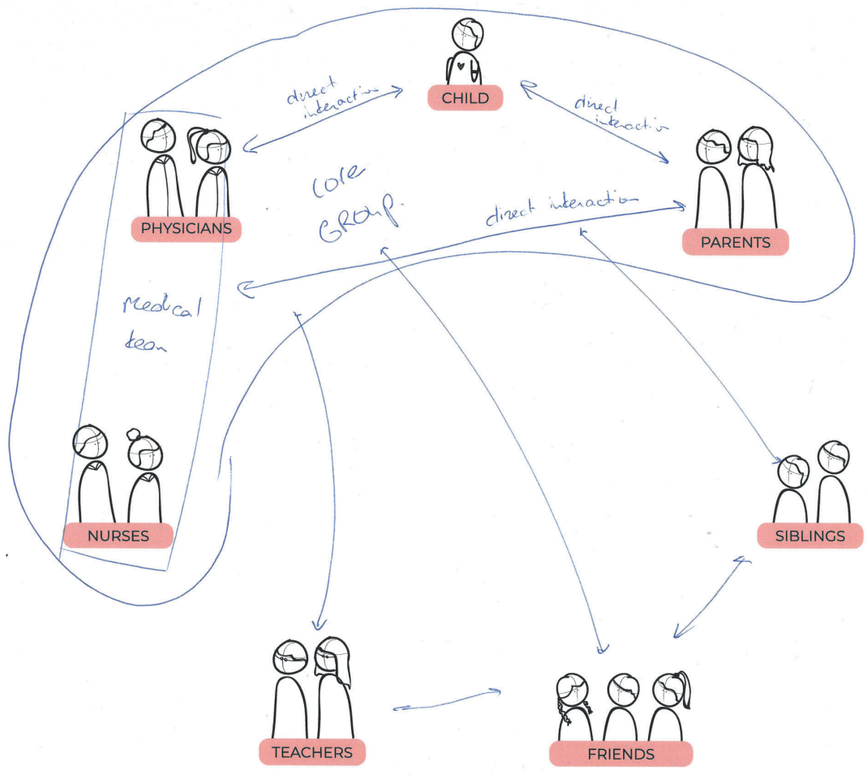

Six dimension of physical activity

1. **Mobility**: moving from place to place, moving the body in space.
2. **Object manipulation:** control of equipment needed for the activity.
3. **Cognitive function:** memory, understanding, relationships.
4. **Behavior and social skills:** appropriate behavior, interaction with others.
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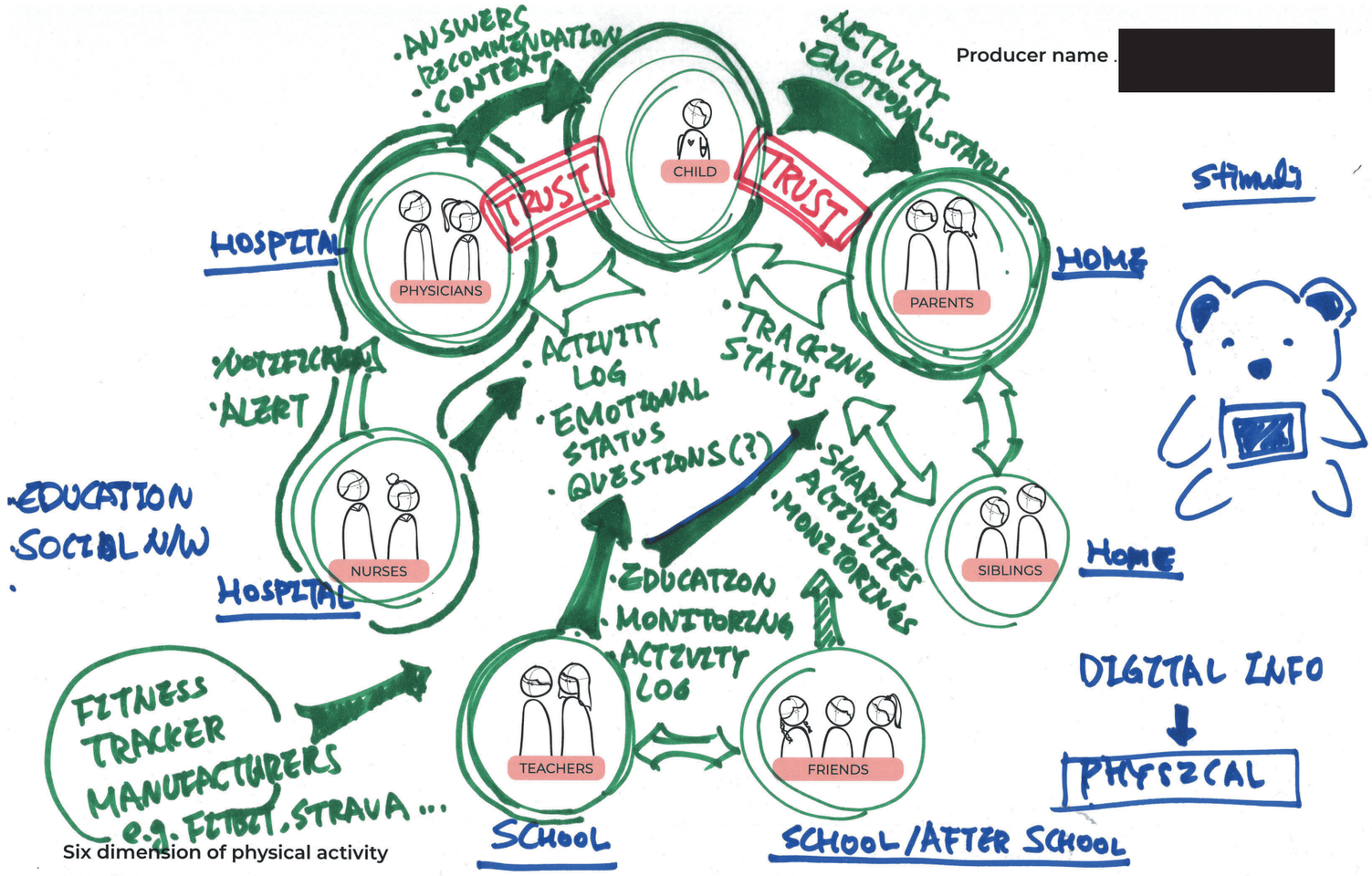

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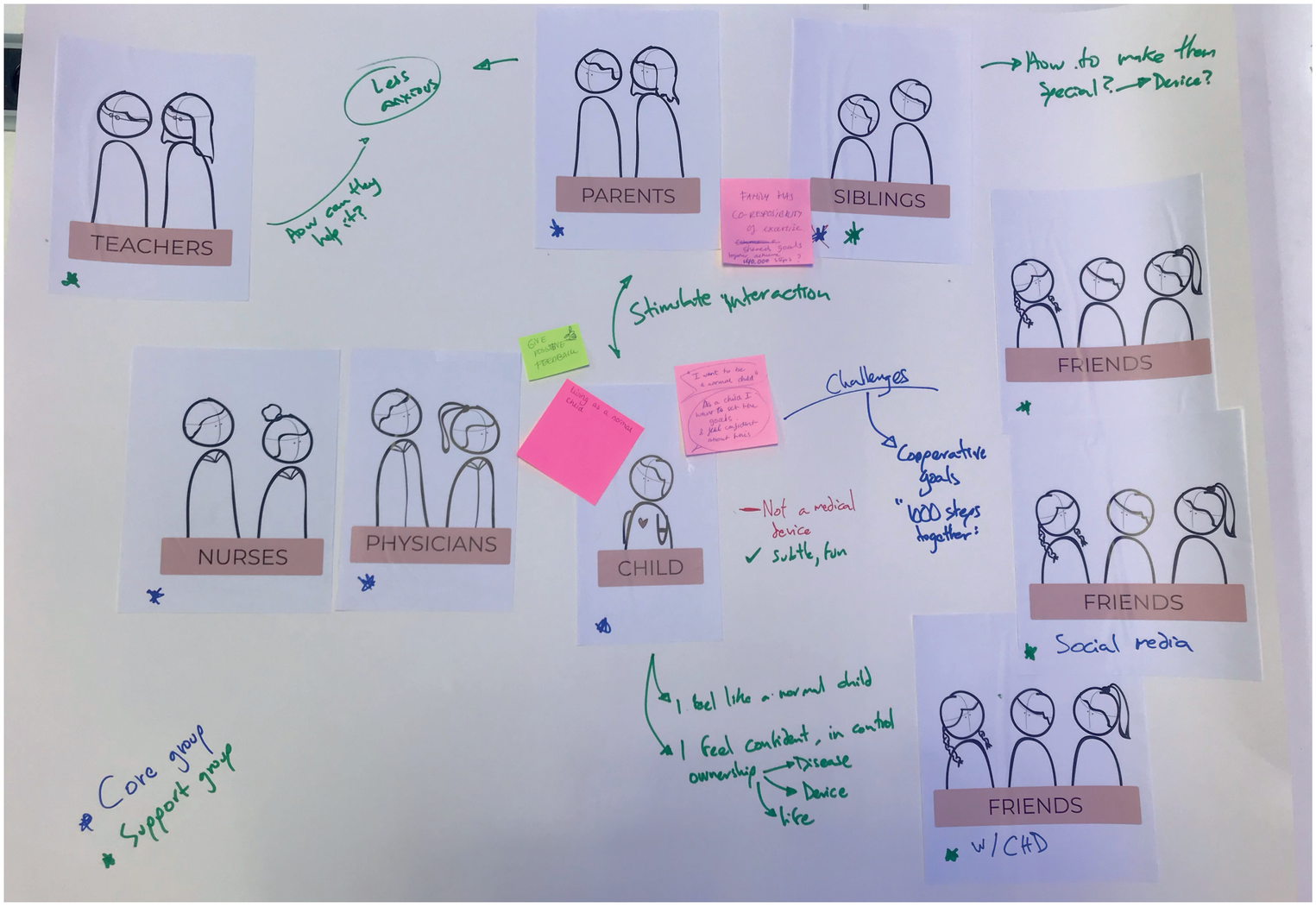

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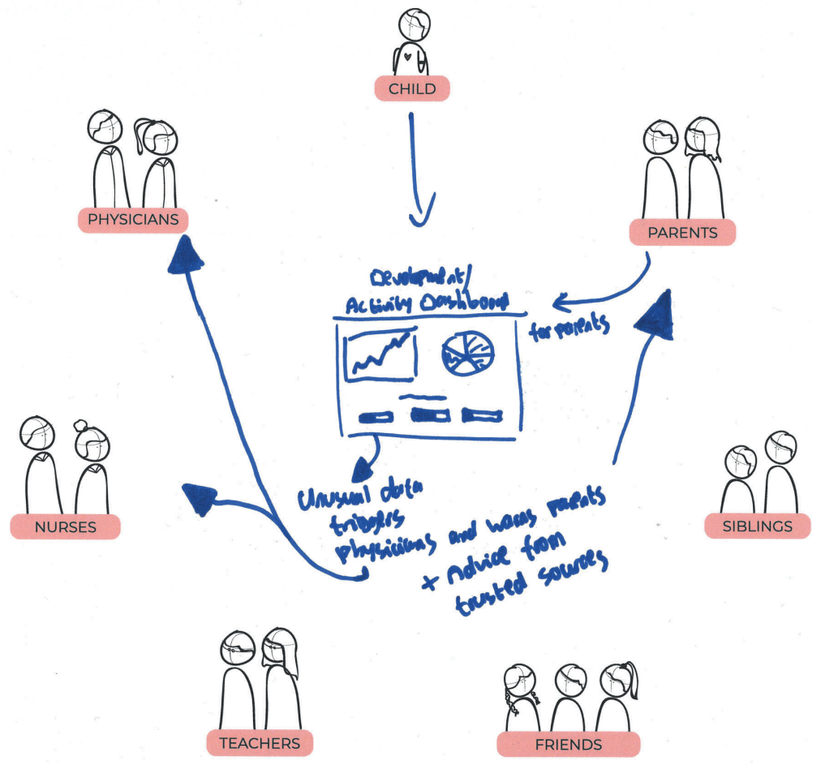

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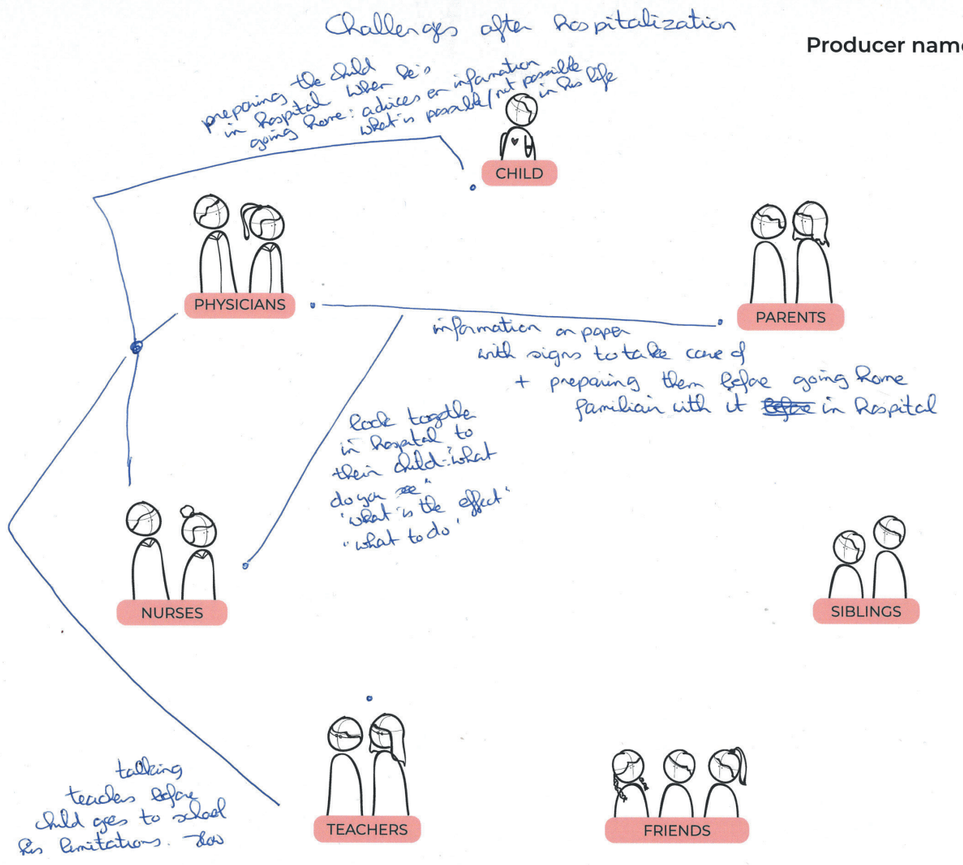

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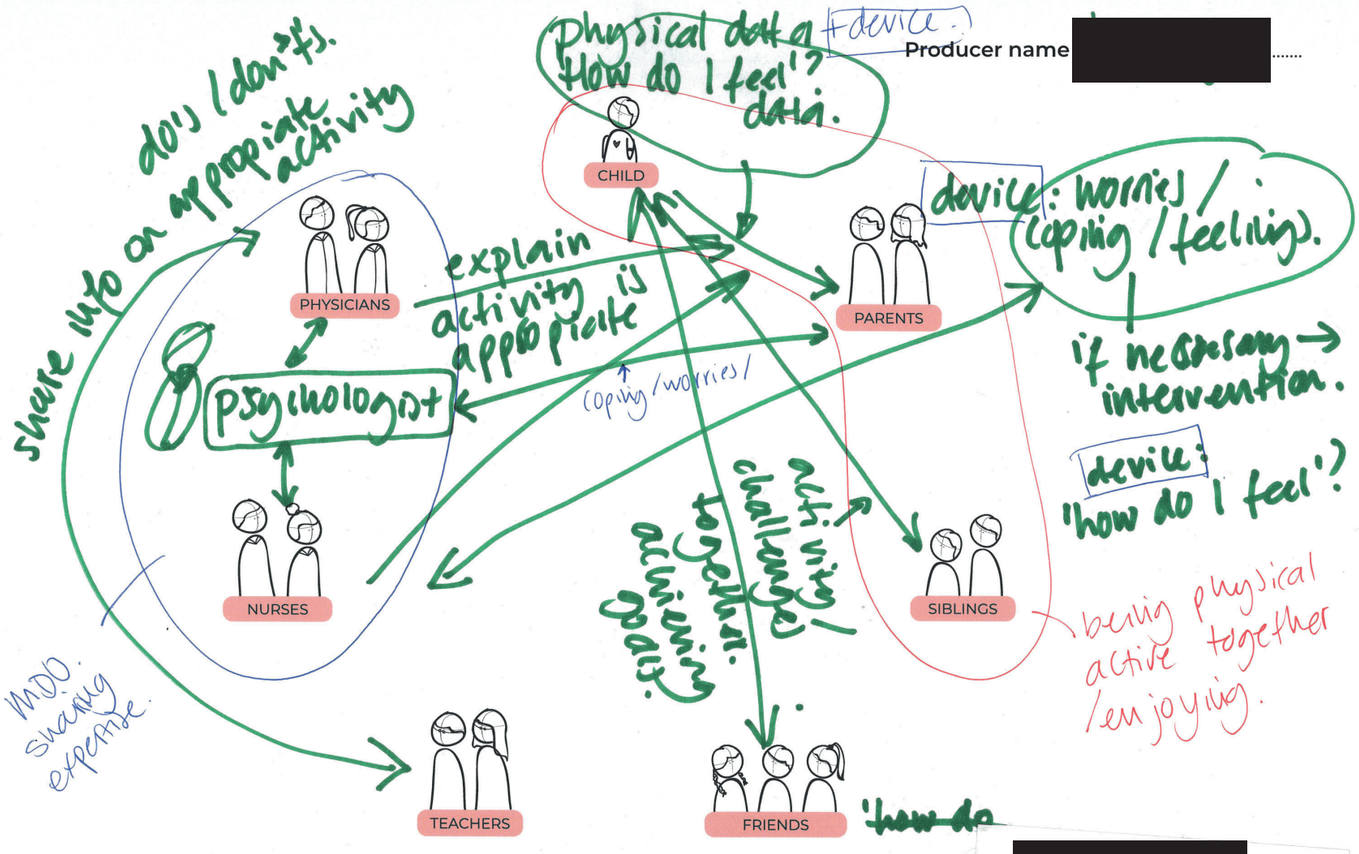

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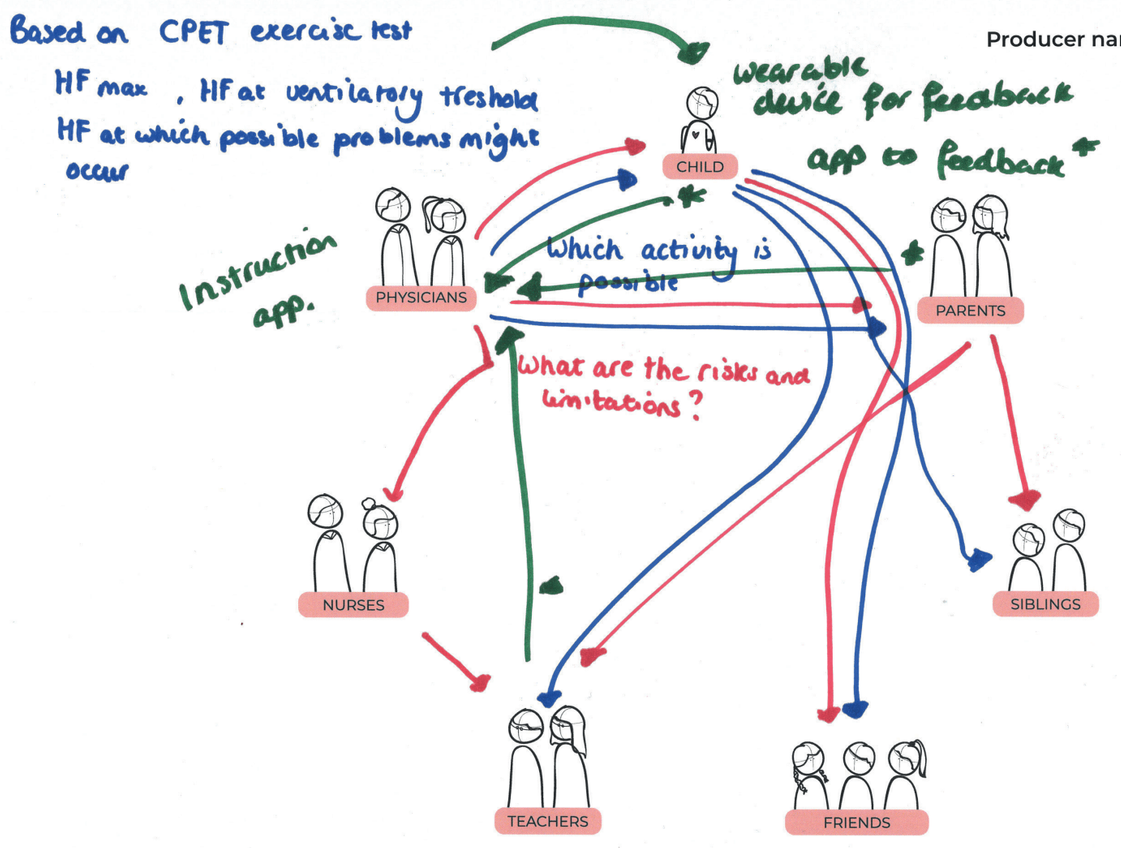

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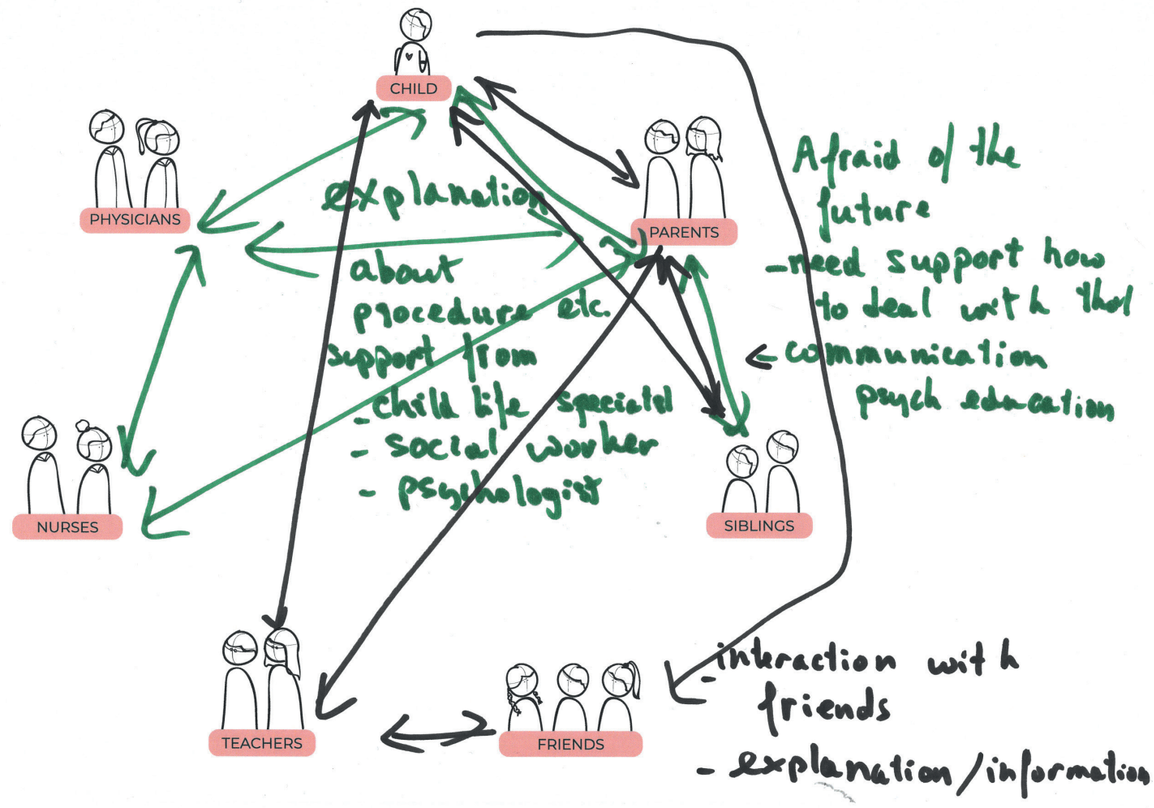

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Around a shared visual database

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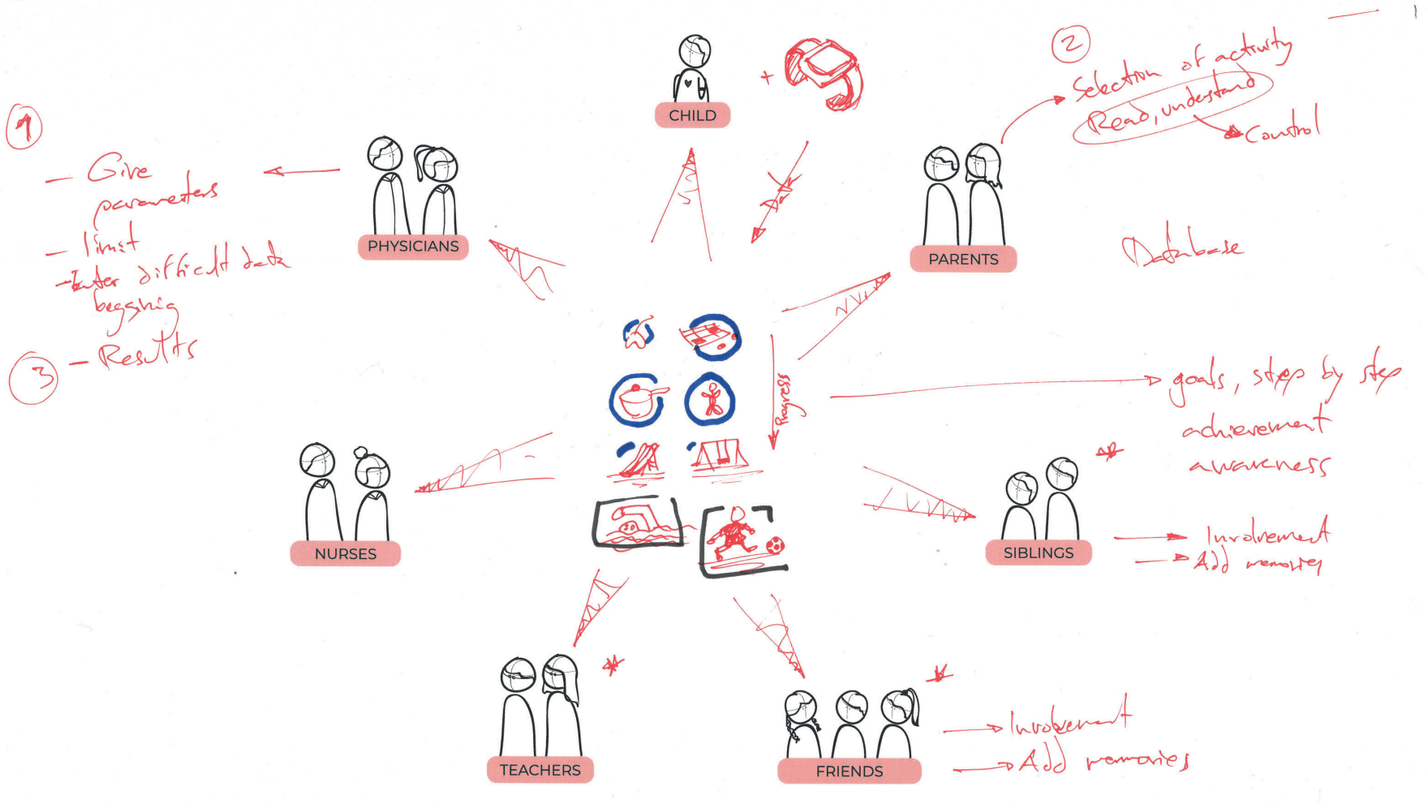

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Appendix P

Problem cards

Underlying problem #1

Lack of psychological data from family members

Times mentioned: 10

Underlying problem #2

Inexistent hierarchy in information management

Times mentioned: 9

Underlying problem #3

Misunderstanding of physical activity safety limits

Times mentioned: 9

Underlying problem #4

Child doesn't have ownership of health condition

Times mentioned: 5

Underlying problem #5

Lack of HR measurement outside hospital context

Times mentioned: 5

Underlying problem #6

Disappointment for reaching physical activity limits

Times mentioned: 4

Underlying problem #7

Not remembering symptoms

Times mentioned: 4

Underlying problem #8

Child be perceived as 'abnormal' by others

Times mentioned: 2

Underlying problem #9

Lack of commitment to physical activity as a group

Times mentioned: 2

Underlying problem #10

Lack of contextualized physical activity data

Times mentioned: 2

Underlying problem #11

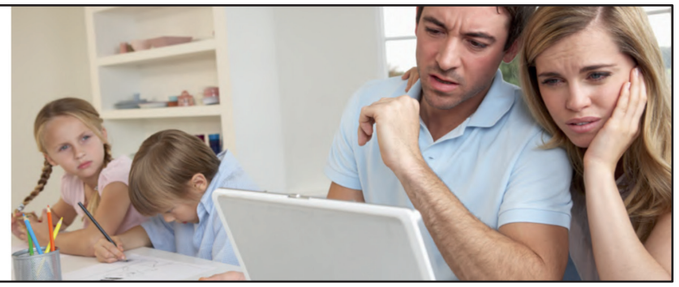
Miscommunication between core stakeholders (parents-child-doctor)

Times mentioned: 2

Underlying problem #12

Mistrust of physical activity data

Times mentioned: 2



Underlying problem #13

Physical activity not being a fun activity for CHD children

Times mentioned: 2

Underlying problem #14

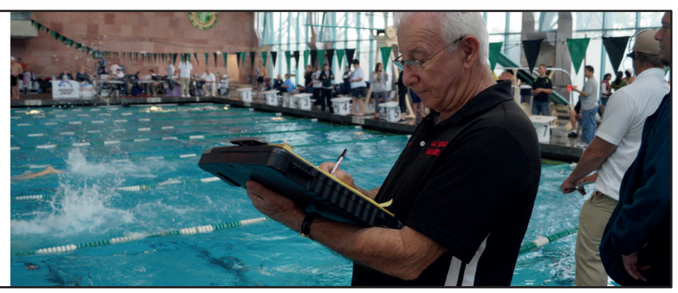
Lack of connection between CHD children

Times mentioned: 1

Underlying problem #15

Lack of sports development data

Times mentioned: 1



Underlying problem #16

Lack of knowledge on child's preferences

Times mentioned: 1

Underlying problem #17

Lack of physical activity

Times mentioned: 1

Underlying problem #18

Overprotection as an impediment for physical activity

Times mentioned: 1

Appendix Q

Concept cards

Concept 1	'THE OBSERVER CLOUD' Sharing data between stakeholders
Description:	*The aim is to know what is possible for the child and make the limits more clear for him and the family. Everyone can add info to the platform and see the status.*
Problem:	*It is difficult to notice the physical activity limit in a daily life setting. Besides, gathering and sharing information about the child's health between all stakeholders is challenging.*

Features	Topic
Psychological data (child)	Entering data
Psychological data (parents)	Entering data
Physicians set the physical activity limits (with exercise tests)	Dr sets limits
Give feedback to child without having to look	Subtle feedback
Make restrictions easy-related to daily life	Show data (all)
Provide feedback to the parents (what is possible)	Tell why & what
Measure HR	Collecting data
All the stakeholders can provide data points	Entering data

Concept 2	'THE LIFESAVER' Creating a safeguard for children
Description:	*Other stakeholders should create a safe space for the child to play without worrying much about the limits he has.*
Problem:	*The child has to be aware of his limitations and assume the responsibility to take care of the limits settle by the medical team.*

Features	Topic
Psychological data (child)	Entering data
Psychological data (parents)	Entering data
Recognize patterns of activity	Patterns
Ask stakeholders why there is no much activity	Entering data
Stimulate activity	Stimulate PA
Spread activity during week (when overprotection is less)	Stimulate PA
Give feedback to child without having to look	Subtle feedback

Concept 3	'THE COACH' Encouraging positive aspects of physical activity
Description:	*The child should be encouraged to pursue an active life instead of always showing what he can't do. The family members can express their physical activity concerns; the doctor thinks of WHY are symptoms happening and adjust medicine or treatment.*
Problem:	*Constantly exposing all the limitation makes others think that physical activity is dangerous.*

Features	Topic
Objective data (HR child, symptoms)	Collecting data
Objective data (symptoms by parents)	Entering data
Subjective data (worry child)	Entering data
Subjective data (worry parents)	Entering data
Collect physical activity data	Collecting data
Show collected data (+ symptoms) on the app and doctor interface	Show data (Dr)
Combine collected data with medical information (hospital)	Show data (Dr)
Recognize patterns of activity	Patterns
Physicians set the physical activity limits	Dr sets limits
Hospital informs to family and sport teachers limits (APP)	Show data (all)
Set challenges (games) to improve physical activity (step challenges)	Stimulate PA
Connect with other CHD children	Dialogue
Encourage based on what he did yesterday and what he is capable	Stimulate PA
Hospital supervises interaction with CHD children (misinformation)	Supervision
Tell WHY and WHAT to child	Tell why & what
Tell parents WHAT they can check by themselves (signs of alarm)	Tell why & what

Concept 4	'THE PHYSICAL ACTIVITY TEAM' Increasing co-responsability of PA
Description:	*Working on increasing physical activity is a goal that should be set for all the family, not just one person.*
Problem:	*If the family doesn't have a very active lifestyle, the child will hardly be encouraged to pursue an active lifestyle as well.*

Features	Topic
Track attitude towards physical activity	Entering data
Measure what influences physical activity in a good way and bad way	Stimulate PA
Increase trust in medical info collected (HR)	Show data (all)
Share the same goals of physical activity among family	Stimulate PA
Close family is the main PA loop, but other stakeholders can be involved	Empowerment

Concept 5	**'THE COACH CLIPBOARD' A platform to facilitate discussions.**
Description:	*The child moderates discussion between different stakeholders and Drs place the discussion in the right context to avoid shared misinformation and increase of anxiety.*
Problem:	*Different stakeholders interacting without the correct supervision could increase misinformation and negative perception of physical activity.*

Features	**Topic**
Child is in control of the discussion (moderator)	Empowerment
Child accepts who can see the information	Empowerment
Child looks at the adult's interactions	Empowerment
Medical team provides information	Dr sets limits
Sports teacher can see in APP	Show data (all)
Generate a dialogue between the persons in charge of the child	Dialogue
Medical team sets the context of worries	Supervision
The platform gathers psychological information about participants	Entering data
Child knows why they are discussing topics	Tell why & what

Concept 6	**'TEAM CAPTAIN' The child as captain of the stakeholder's team**
Description:	*The child sets what he wants to achieve, and other stakeholders contribute to making it happen by providing information at the right time and stimulating interaction between stakeholders.*
Problem:	*The child doesn't have any power concerning the CHD, and due to his physical activity limitations, others can notice that he is not a healthy child.*

Features	**Topic**
Child has the ownership of life, disease, device	Empowerment
Core group (family and dr + nurse) in control	Empowerment
Support group (friends, school) receiving information	Show data (all)
Two groups interact with supervision	Supervision
Child sets goals (he is in control)	Empowerment
Device should help parents to help child	Stimulate PA
There should be fun activities	Stimulate PA
Device should not look medical	Appearance
Stimulate interaction between child and parents	Dialogue
Provide information at the right time (tips)	Show data (all)
School receives RIGHT info from parents	Supervision
School can add how well the child did in sports class (APP)	Entering data
Challenges (personal best?) as a group (not competition w/friends)	Stimulate PA
Increase confidence of the child	Empowerment
DR gives positive feedback	Stimulate PA
Even if there is no improvement always encourage physical activity	Stimulate PA
Parents can see triangulation of information	Show data (all)
Ask child how he feels at key moments (after physical activity?)	Entering data

Appendix R

Exercise test

Appendix 4 - The cardiopulmonary exercise test

The cardiopulmonary exercise test is commonly used to asses the exercise capacity of children with a congenital heart defect. This test can be used to asses two different conditions that are frequent while doing exercise; these are maximal endurance resistance and sub-maximal resistance. The first one is employed to calculate the safe limits for the child when he does training, and the second aims to evaluate what happens in the body while the child is exercising at 50% of his capacity for 30 minutes. This last modality resembles how usually humans practice sports, and it is an essential part of the assessment because it provides a better overview for the doctor of what may happen outside of the hospital if the child practice sports.

In the following table are mentioned multiple variables that are relevant for the assessment of physical activity and that the CPET provides to physicians.

Reference measurements in healthy children

There are various studies such as Gulmans et al., (1997), Harkel et al., (2011) or Longmuir et al., (2013) that aim to provide data measurements related to physical activity in healthy children. These studies serve as a reference when performing comparisons with data from tests with CHD patients, and additionally, the results help physicians to evaluate levels of exercise capacity and physical activity.

Table 1. Variables typically measured during a CPET from Longmuir et al., (2013

Vairables	Description
$\dot{V}o_2$ max	The highest amount of oxygen that the body can consume during maximal exercise. The achievement of Vo2 max is recognized when there is no increase in heart rate or oxygen consumption although the exercise workload is increased or when the ratio of Vco2:Vo2 exceeds 1.1. Vo2max may be reported in liters per minute for exercise modes that are independent of body weight (eg, stationary cycling) or in liters per minute per kilogram of body weight for exercise modalities that require the participant to support their own body weight (eg, treadmill walking/jogging).
$\dot{V}o_2$ peak	The highest amount of oxygen consumed during a maximal exercise test to the limit of voluntary effort. This is the most common variable used to report aerobic exercise capacity. Vo2 peak is the outcome of an exercise test that is terminated because the participant is unable or unwilling to continue. Vo2 peak may or may not be equal to Vo2 max, depending on whether the maximal oxygen transport capacity of the body is achieved before or after the limit of voluntary effort. Vo2 peak may be reported in liters per minute for exercise modes that are independent of body weight (eg, stationary cycling) or in liters per minute per kilogram of body weight for exercise modalities that require the participant to support their own body weight (eg, treadmill walking/jogging).
Ventilatory anaerobic threshold	The point at which Vco2 and VE begin to increase out of proportion to Vo2. This is a measure of submaximal work rate that is sensitive to the effects of exercise training. It has the advantage of not being affected by patient motivation and does not require a maximal effort.
Ventilatory efficiency	The ratio and/or slope of VE/Vco2, otherwise known as ventilatory equivalent of CO2 . This is a physiologically important variable that is decreased (ie, the slope is greater) in patients with heart failure, cyanosis, and pulmonary disease. A higher value indicates that more breathing effort must be used to eliminate the same amount of CO2.

Table 1. Variables typically measured during a CPET from Longmuir et al., (2013

Vairables	Description
Work rate	A surrogate measure of muscle power and exercise capacity. Typically measured in watts for exercise performed on a cycle or arm ergometer.
Treadmill time	This is a surrogate measure of exercise capacity when a treadmill protocol is used. Means and standard deviations of treadmill times for various age groups have been published.
Heart rate profile	This is composed of resting heart rate, peak heart rate, heart rate reserve (peak rate minus resting rate), and heart rate recovery. Resting heart rate and heart rate recovery in particular can be improved with improved fitness.
Blood pressure	Arm blood pressure responses to exercise are measured during a test and can reveal hypertension not otherwise discovered with resting values alone.
Pulmonary function	Standard pulmonary function tests using spirometry can be performed to reveal obstructive, restrictive, or mixed pulmonary disease at baseline or as a result of exercise.
Oxygen saturation	Reliable oxygen saturation monitoring can be helpful in patients with resting desaturation and those at risk for desaturation during exercise (eg, those with fenestrated Fontan circuits).

Table 2 provides a classification of exercise training intensity that can be compared with results of CHD patients who performed the cardiopulmonary exercise test.

Table 3 is employed to verify if children who performed the test reached their maximal endurance capacity. It is decided in gender, and based on the height of the patient the last two columns show the load range in the CPET and the expected HR while doing maximal capacity.

What to look for during a CPET?

During the different test seen in the observation phase, it could be recognized that the physician was searching for tendencies related to each congenital heart defect. Moreover, the different defect conditions were often classified as diseases related to blood pressure diseases, rhythm diseases, and low oxygen levels in the blood. Therefore, when a patient with a specific CHD performed the CPET, cardiologist usually gave special attention to risk factors associated with the CHD of the child. Some relevant risk factor during a cardiopulmonary exercise test according to Longmuir et al. (2013) are abnormal hemodynamic responses to exercise (blood pressure), abnormal heart rate profile (heart rhythm), arrhythmias (heart rhythm), Myocardial ischemia (heart rhythm), and reduced ventilatory efficiency (oxygen levels). Furthermore, in 2010 Rhodes et al., conducted a study in paediatric patients with CHD, his findings showed several impairments related to the heart defects, and he listed them concerning the difference in oxygen levels, heart rate, blood pressure, and ventilatory anaerobic threshold.

Table 2. Classification of exercise training intensity related to endurance exercise from Takken et al., (2013)

Intensity	% $\dot{V}O_{2max}$	% HR_{res}	% HR_{max}	Type
Very light	<20	<29	<54	Active recovery training
Light	20–39	29	54	Rehabilitative training
Moderate	40–59	47	66	Endurance training
Heavy	60–84	65	77	High-intensity endurance training
Very heavy	>85	>87	>91	Interval training

Table 3. Maximum HR compared to load increase in CPET from van Deutekom (2019)

Height	Female		Male	
cm	Watt	Max. HR	Watt	Max. HR
120	45	190	55	185
125	60	195	70	190
130	70	195	85	195
135	85	195	100	195
140	95	195	115	200
145	105	195	125	195
150	120	190	140	190
155	130	190	155	190
160	145	185	165	185
165	155	185	180	185
170	170	180	195	185
175	180	175	210	180
180	190	175	225	180
185	200	170	235	175
190	210	170	250	170

Appendix S

Design vision

*"Create a **supportive exploratory environment** during the child's physical activity participat*
where parents contribute to the child's self-discovery of safe boundaries by providing a rea
time connection between physicians and family members."

Overall meaning of the P-S-S (Design goal)
To provide a supportive real-time channel between the child, parents and physicians, that offer
relief towards perceived worries during physical activity participation, and where each of the
members contributes to creating an understandable relationship between the child and his he
condition.

Reason of existence
When the child performs physical activities, and there is an increase in intensity, his parents sta
to feel worried about until what extent their child can participate safely. Family members are n
able to identify the healthy signs of participating in physical activity versus the symptoms that
Congenital Heart Defect could cause during exercise participation. Therefore, sometimes parer
ask the child to stop before he reaches a CHD symptoms zone indicated by physicians, where t
child can explore his physical activity limitations. If the child is not able to explore his boundarie
he will never be able to identify them and act on them by his own in the future.

Identity of the P-S-S
The P-S-S should be perceived as a trustworthy channel between the physicians and the family
Where the members can express their concerns without feeling judged, and all of the adults
involved build a supportive atmosphere for the child to explore his boundaries.

Which concerns are to be fulfilled?

Child
Misperception of symptoms
Misunderstanding of physical activity limits
Child be perceived as abnormal by peers
Lack of ownership of the health condition

Parent
Anxiety when child performs physical activity
Misperception of symptoms (doubt about the nature)
Misunderstanding of physical activity limits

Physicians
Lack of psychological data (concerns & feelings) from family members
Incorrect timing to analyse symptoms
Inexistent hierarchy in information management
Lack of biological measurements (HR) outside the hospital environment

What is my opinion about the future possibilities and behaviour the P-S-S- should realize with people?

Child
Uncover symptom learning area (safe threshold)
Help the child to listen to his body (symptoms)
Support the child to recognize symptoms

Make the child feel confident when body needs to rest in front of others
Develop a sense of independence

Parent
Provide a sense of relief when child is doing physical activity
Enable the parent to support their child to enter the safe threshold
Change the way symptom-concerns are perceived on the spot

Physicians
Enable biological and psychological data from child on the spot
Enable psychological data from parents on the spot

Meaning of the design: Why the use and experience of the P-S-S is appropriate within the context for the stakeholders
Children with Congenital Heart Defects need to learn how to recognize their safety limits wher
doing physical activity since CHD are a lifetime condition. Therefore, children should feel
confident at identifying symptoms in front of their peers, so they can take a break (act on them
when their body needs it.

Moreover, if their parents don't let them experience their safety barriers, children will never be
able to know how their symptoms feel. Hence, parents should allow children to discover their
boundaries in a safe environment that provides them with trust so that they can support childı
without feeling anxious.

What is the role to the company for that future?

To be able to create a safe and trustworthy environment for family members, physicians will ne
to take an active role in it since they have the necessary knowledge to provide trust in physical
activity participation.

Metaphor

The exploration of the environment will be
"As if parents were encouraging the child to keep playing with a piñata."

During this activity, children who play piñata need to discover where the piñata is with their ey
closed and a stick of wood in their hands. The persons surrounding the child (including parents
are guiding the child to find the piñata and encouraging him to find it. Everyone is having fun
while the activity takes place, and children at the beginning are nervous about what others wil
say if you fail. However, later they face the moment and enjoy looking for the piñata.



Metaphor elements translated to inspiration
- Creation of a safe environment for exploration (adults prepare the place and gather the circle
- Surrounded by people who supports, guides and encourages (friends and family singing)
- The need to discovering where the target is (piñata)
- When the target is 100% identified there is a big surprise (candies)

- There is an object that helps the user to localize the target (wood stick)
- You have a specific time for finding the target (song)
- Adults let the child explore from behind (parents looking from behind)
- The child is having fun and willing to participate (child's attitude towards activity)
- The child is in control, and the parents don't feel the need to interfere

Intended PSS-user-relationship in a specific (future) context
What relationship do people have with the P-S-S?
The overall PSS-user relationship should flourish the feeling of support between the physicians and the child and parents while the child is doing physical activity.

Child
Be perceived as a fun activity that the child wants to play with.

Parents
Be perceived by the parents as a trustworthy source of information.
Give the caregivers a supportive role.

People-P-S-S interactions

How a P-S-S is used?
Use of digital screens and sensory (tactile and visual) feedback in a physical activity context.

How it otherwise interferes with the context?
The perception of the P-S-S should be minimal to people who is not involved in the creation of the safe environment to minimize the feeling of abnormality.

What will it accomplish for a person?
Child
Comprehension of own physical activity limits.

Parents
Relief of perceived worry related to the child’s physical activity limits.

Product qualities

Qualitative characteristics *(Non physical properties as perceived by a person)*
- Building trust between physical activity context (child), parents and doctor
- Offering relief to parents and the child
- Creating an understandable relationship between the child and CHD condition.
- Providing confidence when body asks for a break

Appendix T

Discussion topics - Excel file

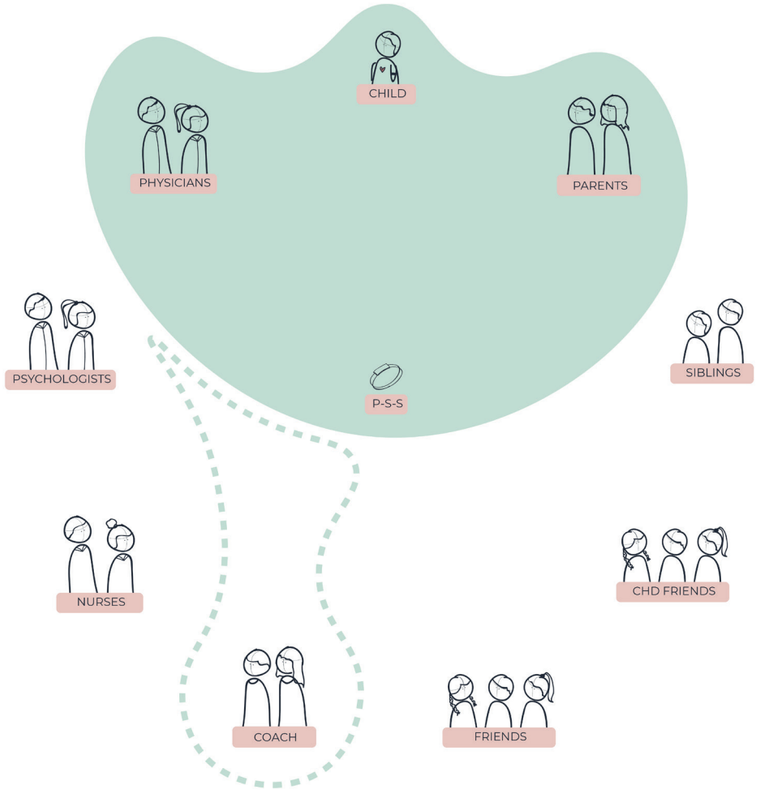
Discussion topics for V2 of system (circle on paper ‘chains of connection’)

Source	Idea features = 59	Discussion topics	Discussion topics (V2)
	DR gives positive feedback	Achievements	1 Real-time worry line
	Even if there is no improvement always encourage physical activity	Achievements	2 Feelings management
	There should be fun activities	Children challenges to increase PA	3 Family challenges to increase PA
	Challenges (personal best?) as a group (not competition w/friends)	Children challenges to increase PA	4 Children challenges to increase PA
	All the stakeholders can provide data points	Combination of data	5 Entering symptoms
	Combine collected data with medical information (hospital)	Combination of data	6 Understanding heart defect
	School receives RIGHT info from parents	Combination of data	7 Personal new goals
	School can add how well the child did in sports class (APP)	Combination of data	8 Limits
	Connect with other CHD children	Connect CHD children	9 Not enough PA
	Hospital supervises interaction with CHD children (misinformation)	Connect CHD children	10 Training
	Child is in control of the discussion (moderator)	Empower the child	11 Combination of data
	Child accepts who can see the information	Empower the child	12 Connect CHD children
	Child looks at the adult’s interactions	Empower the child	13 Achievements
	Generate a dialogue between the persons in charge of the child	Empower the child	14 Emergency line — Came up from Arend’s feedback
	Device should not look medical	Empower the child	
	Objective data (HR child, symptoms)	Entering symptoms	
	Objective data (symptoms by parents)	Entering symptoms	
	Stimulate activity	Family challenges to increase PA	
	Spread activity during week (when overprotection is less)	Family challenges to increase PA	
	Set challenges (games) to improve physical activity (step challenges)	Family challenges to increase PA	
	Share the same goals of physical activity among family	Family challenges to increase PA	
	Stimulate interaction between child and parents	Family challenges to increase PA	
	Psychological data (child)	Feelings management	
	Psychological data (parents)	Feelings management	
	Track attitude towards physical activity	Feelings management	
	The platform gathers psychological information about participants	Feelings management	
	Ask child how he feels at key moments (after physical activity?)	Feelings management	
	Physicians set the physical activity limits (with exercise tests)	Limits	
	Physicians set the physical activity limits	Limits	
	Hospital informs to family and sport teachers limits (APP)	Limits	
	Ask stakeholders why there is no much activity	Not enough PA	
	Encourage based on what he did yesterday and what he is capable	Not enough PA	
	Measure what influences physical activity in a good way and bad way	Not enough PA	
	Child has the ownership of life, disease, device	Personal new goals	
	Child sets goals (he is in control)	Personal new goals	
		Children challenges to increase PA	
		Children challenges to increase PA	
		Children challenges to increase PA	
		Children challenges to increase PA	

Increase confidence of the child	**Personal new goals**
Subjective data (worry child)	**Real-time worry line**
Subjective data (worry parents)	**Real-time worry line**
Show collected data (+ symptoms) on the app and doctor interface	**Real-time worry line**
Increase trust in medical info collected (HR)	**Real-time worry line**
Medical team sets the context of worries	**Real-time worry line**
Provide information at the right time (tips)	**Real-time worry line**
Close family is the main PA loop, but other stakeholders can be involved	**Structure**
Core group (family and dr + nurse) in control	**Structure**
Support group (friends, school) receiving information	**Structure**
Two groups interact with supervision	**Structure**
Parents can see triangulation of information	**Structure**
Give feedback to child without having to look	**Training**
Measure HR	**Training**
Recognize patterns of activity	**Training**
Collect physical activity data	**Training**
Sports teacher can see in APP	**Training**
Provide feedback to the parents (what is possible)	**Understanding heart defect**
Tell WHY and WHAT to child	**Understanding heart defect**
Tell parents WHAT they can check by themselves (signs of alarm)	**Understanding heart defect**
Medical team provides information	**Understanding heart defect**
Child knows why they are discussing topics	**Understanding heart defect**
Device should help parents to help child	**Understanding heart defect**
Make restrictions easy-related to daily life	**X (interferes with encouraging PA)**

Appendix U

Version 2 PSS individual images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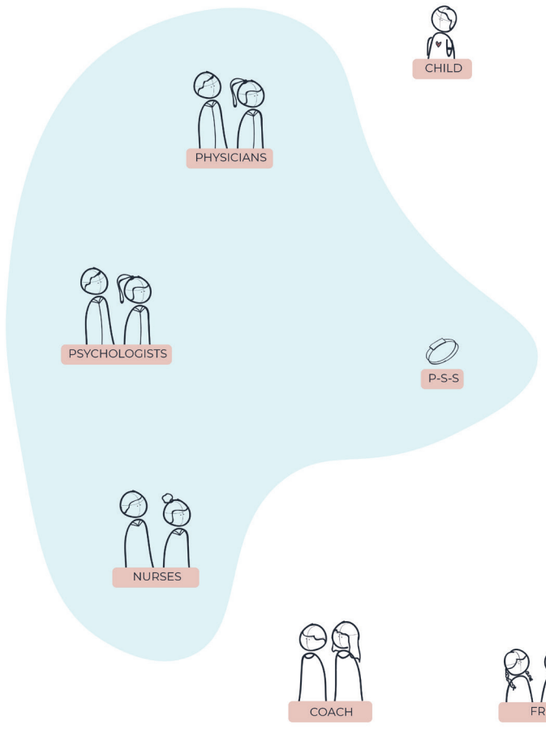
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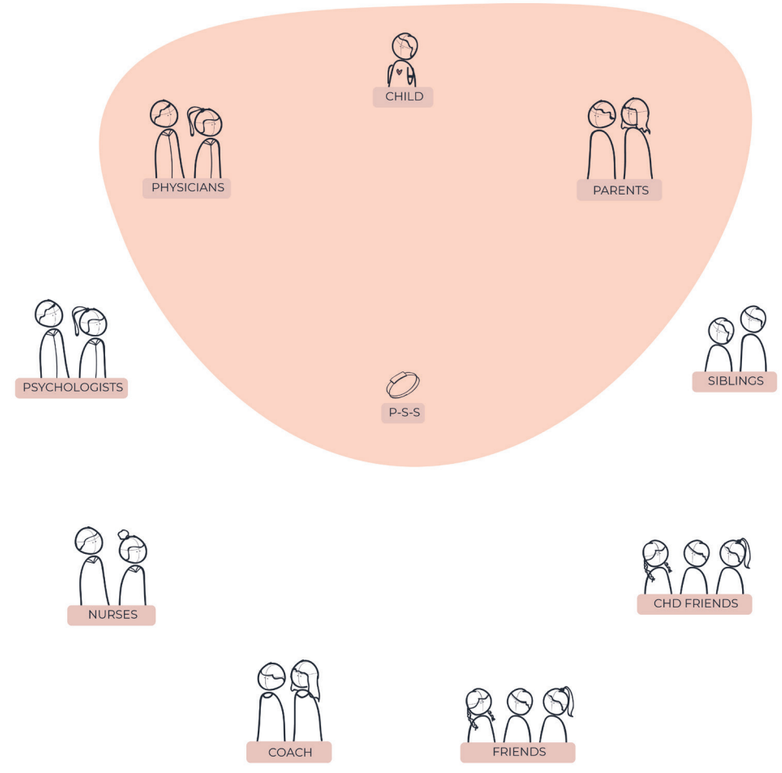
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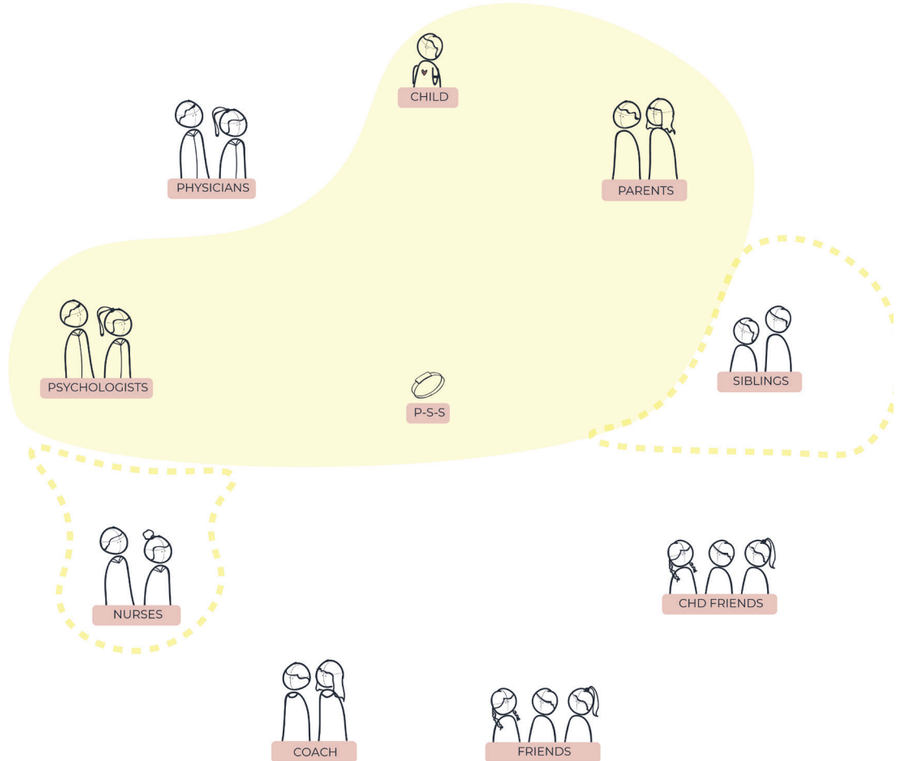
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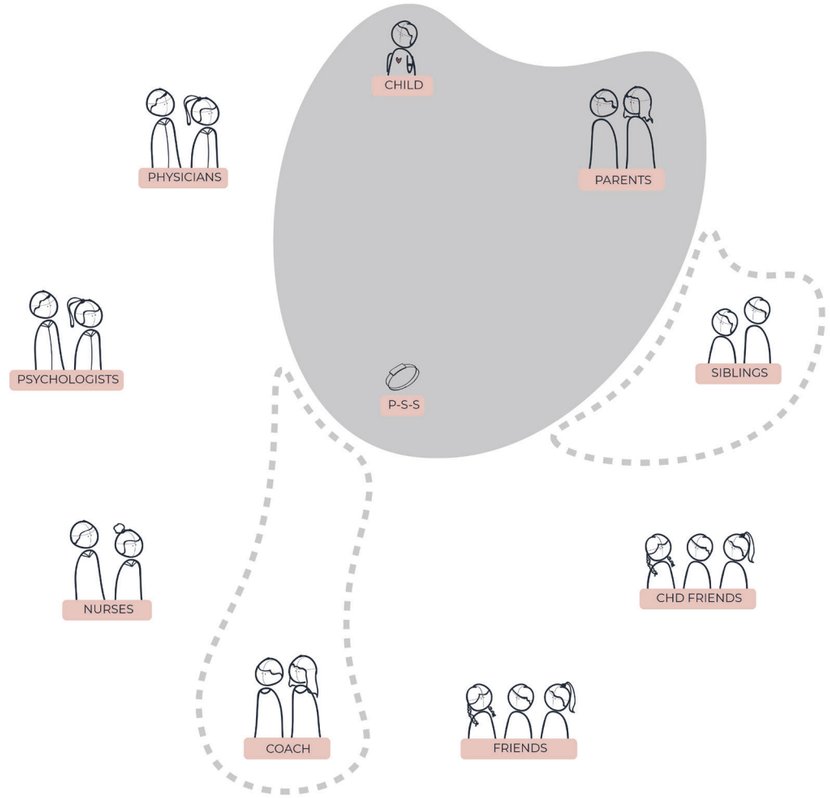
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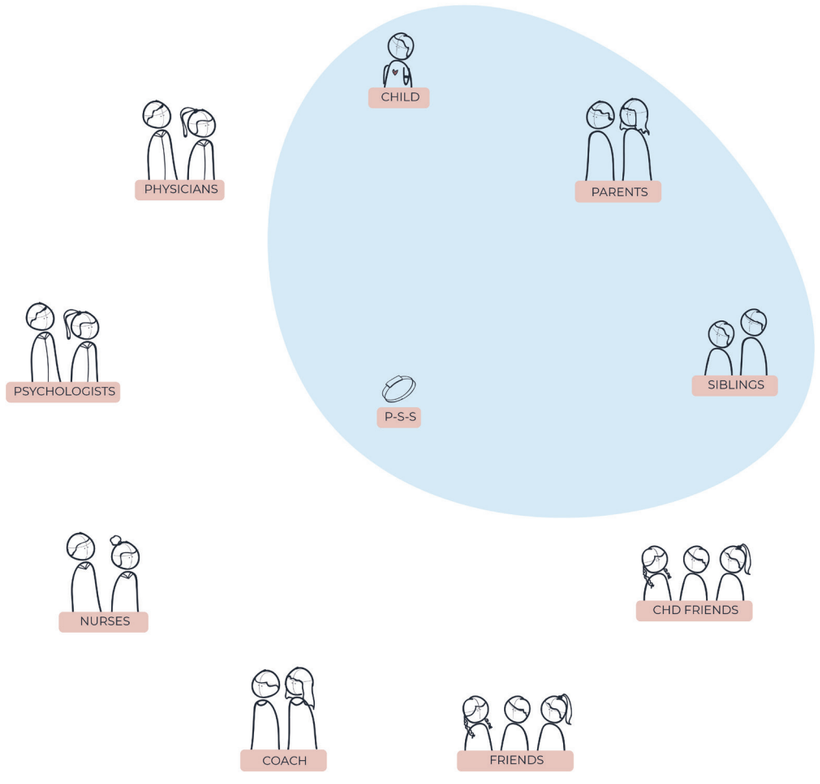
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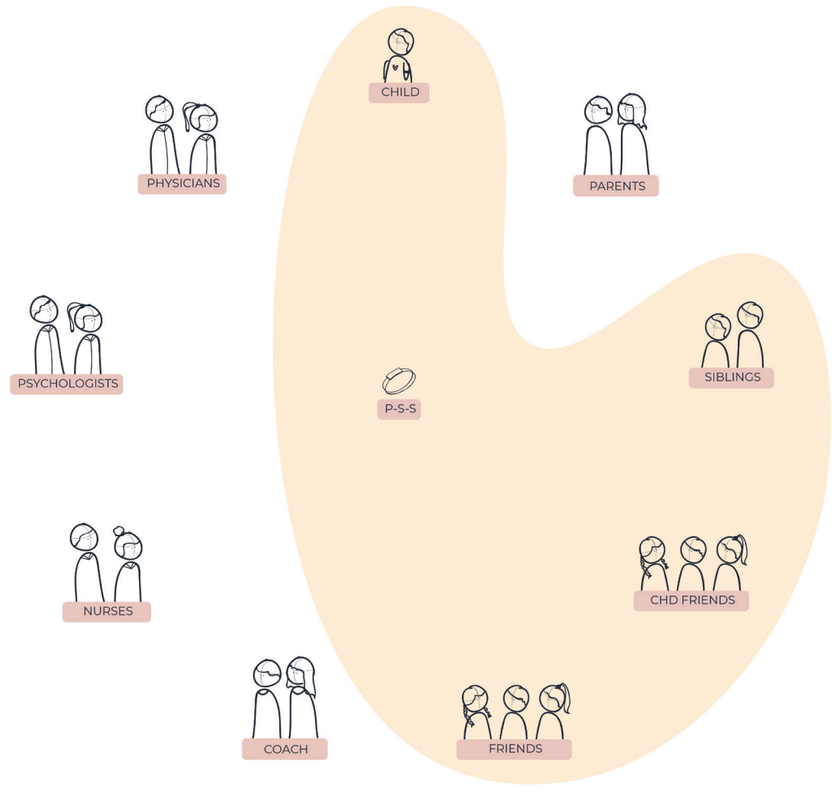
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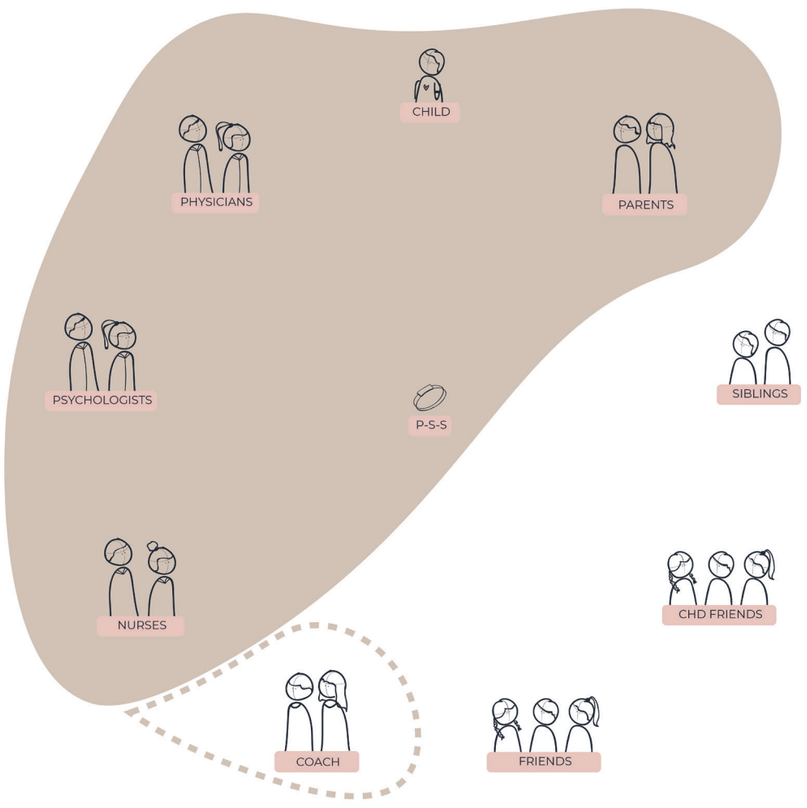
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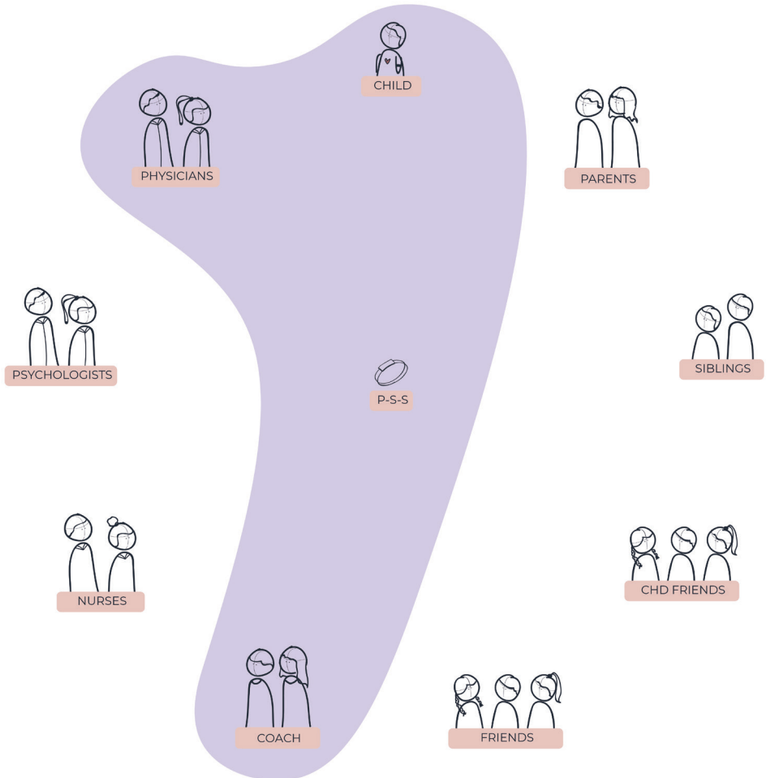
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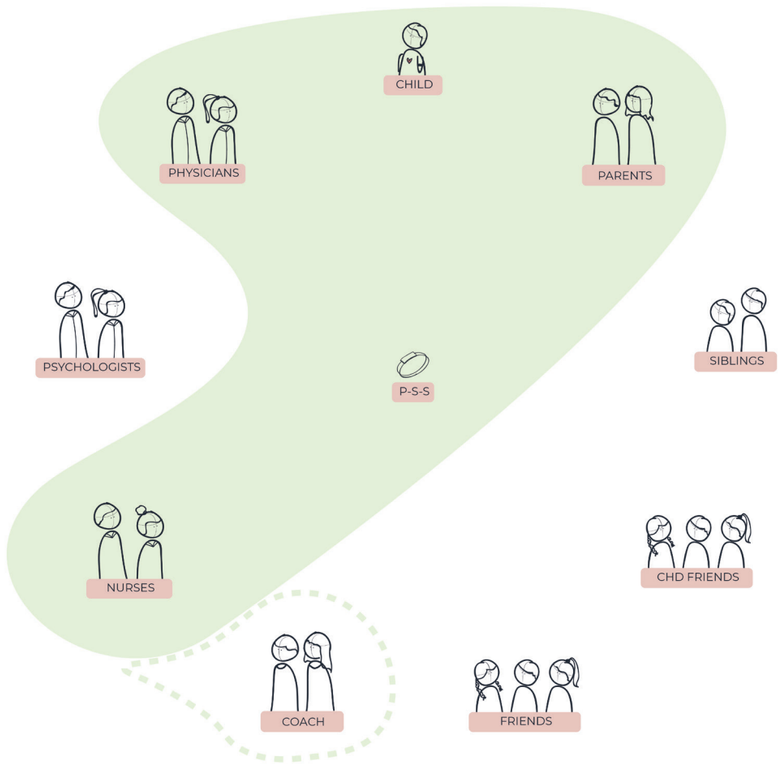
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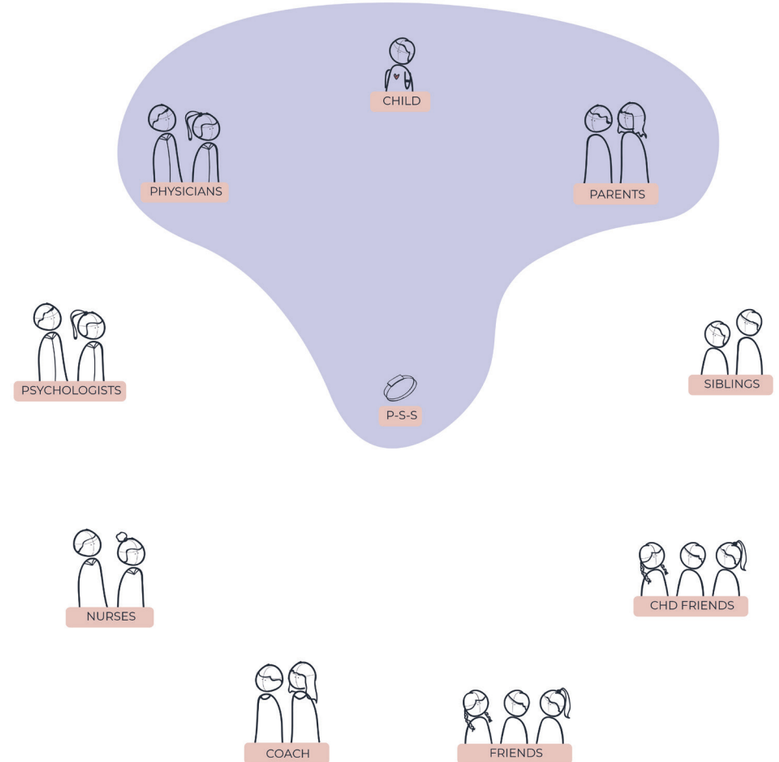
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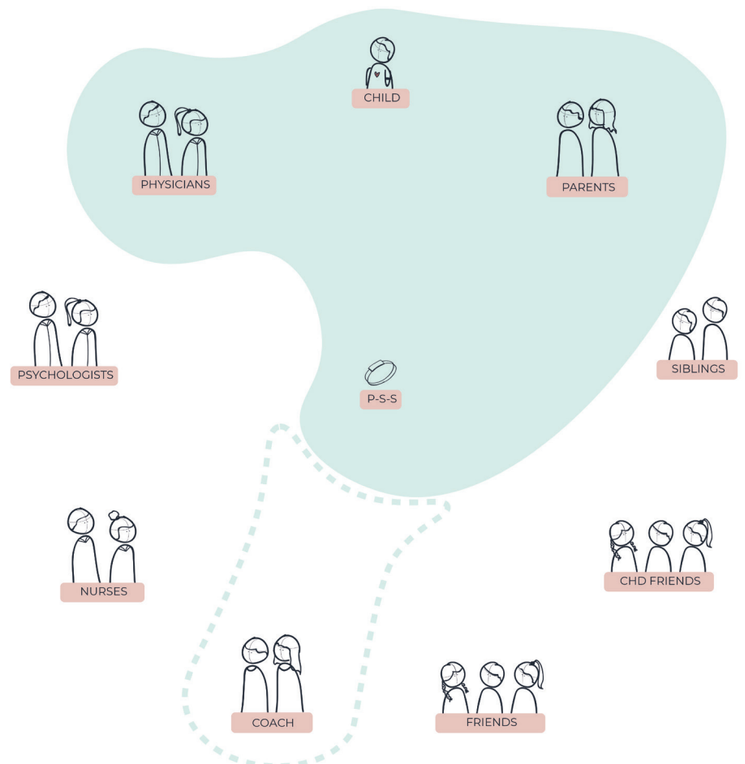
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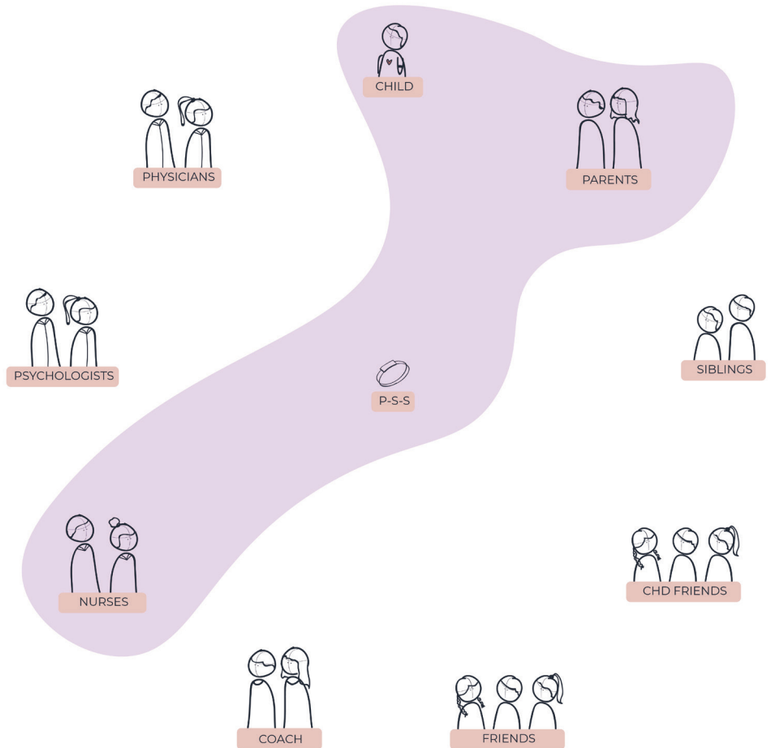
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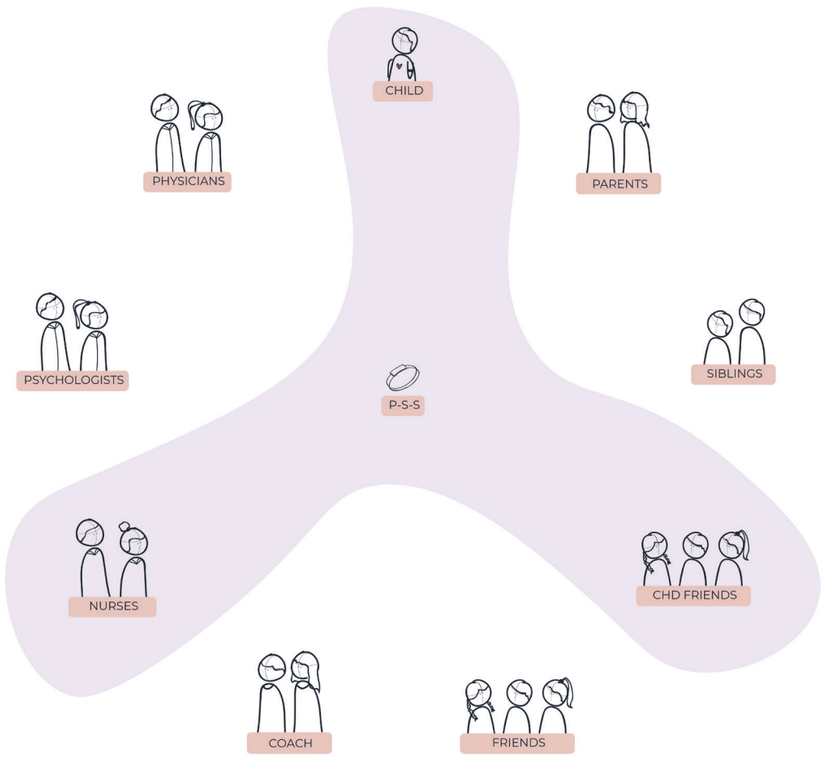
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Appendix V

PSS arrow's code Excel file

Sub-module	Function	Interaction order	Human goal	Emotion	AI	From	To	What device?	When does the interaction take place?		Why the action takes place?	What is expected from the interaction?	How will the interaction happen?	Ideas
1-PG	Sharing goals	1	Physical wellbeing	-	81	Child	PSS	Computer / tablet	Anytime	When they feel like it	State goals	Others to come up with a 'goal plan'	Create a goal based on the 6 dimensions of physical activity	
1-PG	Sharing goals	2	-	-	82	PSS	Paediatric Cardiologist	Computer / tablet	Anytime	Goals are set	Share goals and data from AT	Join goals chat	Notification 'new goal from AAAA'	
1-PG	Sharing goals	2	-	-	84	PSS	Coach	Computer / tablet	Anytime	Goals are set	Share goals and data from AT	Join goals chat	Notification 'new goal from AAAA'	
1-PG	Sharing goals	2	-	-	85	PSS	Sports Doctor	Computer / tablet	Anytime	Goals are set	Share goals and data from AT	Join goals chat	Notification 'new goal from AAAA'	
1-PG	Sharing goals	2	-	Admiration	94	PSS	Parents	Computer / tablet	Anytime	Goals are set	Share goals	Parents to know what is the child up to (encouragement)	Notification	
1-PG	Ideating plan to reach goal	3	Safety	-	88	Paediatric Cardiologist	Coach	Computer / tablet	Anytime	Goals chat is ready	Discuss posibilities and best way to support	Discuss CHD limitations and posibilities	Creation of chat with goal(s) to discuss	Button to 'publish plan' with child and parents
1-PG	Ideating plan to reach goal	3	Safety	-	89	Paediatric Cardiologist	Sports Doctor	Computer / tablet	Anytime	Goals chat is ready	Discuss posibilities and best way to support	Discuss CHD limitations and posibilities	Creation of chat with goal(s) to discuss	Button to 'publish plan' with child and parents
1-PG	Ideating plan to reach goal	3	Safety	-	90	Sports Doctor	Paediatric Cardiologist	Computer / tablet	Anytime	Goals chat is ready	Discuss posibilities and best way to support	Discuss CHD limitations and posibilities	Creation of chat with goal(s) to discuss	Button to 'publish plan' with child and parents
1-PG	Ideating plan to reach goal	3	Safety	-	91	Sports Doctor	Coach	Computer / tablet	Anytime	Goals chat is ready	Discuss posibilities and best way to support	Discuss CHD limitations and posibilities	Creation of chat with goal(s) to discuss	Button to 'publish plan' with child and parents
1-PG	Ideating plan to reach goal	3	Safety	-	92	Coach	Paediatric Cardiologist	Computer / tablet	Anytime	Goals chat is ready	Discuss posibilities and best way to support	Discuss CHD limitations and posibilities	Creation of chat with goal(s) to discuss	Button to 'publish plan' with child and parents
1-PG	Ideating plan to reach goal	3	Safety	-	93	Coach	Sports Doctor	Computer / tablet	Anytime	Goals chat is ready	Discuss posibilities and best way to support	Discuss CHD limitations and posibilities	Creation of chat with goal(s) to discuss	Button to 'publish plan' with child and parents
1-PG	Sharing goal plan	4	Safety	-	83	Paediatric Cardiologist	Child	Computer / tablet	Anytime	After being discussed with other specialities	Share best way to work towards them	Child knows what is advised to do	Display best way to achieve the goal, Child enters to 'goals chat'	
1-PG	Sharing goal plan	4	Safety	-	86	Coach	Child	Computer / tablet	Anytime	After being discussed with other specialities	Share best way to work towards them	Child knows what is advised to do	Display best way to achieve the goal, Child enters to 'goals chat'	
1-PG	Sharing goal plan	4	Safety	-	87	Sports Doctor	Child	Computer / tablet	Anytime	After being discussed with other specialities	Share best way to work towards them	Child knows what is advised to do	Display best way to achieve the goal, Child enters to 'goals chat'	
1-PG	Sharing goal plan	4	Safety	Relief	158	Paediatric Cardiologist	Parents	Computer / tablet	Anytime	After being discussed with other specialities	Share best way to work towards them	Parents knows what is advised to do and how to support	Display best way to achieve the goal, parents enter to 'goals chat'	
1-PG	Sharing goal plan	4	Safety	Relief	159	Coach	Parents	Computer / tablet	Anytime	After being discussed with other specialities	Share best way to work towards them	Parents knows what is advised to do and how to support	Display best way to achieve the goal, parents enter to 'goals chat'	

1-PG	Sharing goal plan	4	Safety	Relief	160	Sports Doctor	Parents	Computer / tablet	Anytime	After being discussed with other specialities	Share best way to work towards them	Parents knows what is advised to do and how to support	Display best way to achieve the goal, parents enter to 'goals chat'		
1-PG	Sharing	5	Physical wellbeing	Pride	161	Child	PSS	Computer / tablet	AF-PAP	Child reached the goal	Share accomplishment of the goal	Share with others	Click on checkmark of goal		
1-PG	Sharing	5	-	-	162	Coach	PSS	Computer / tablet / mobile phone	AF-PAP	Child reached the goal	Share accomplishment of the goal	Share with others	Click on checkmark of goal		
1-PG	Sharing	5	Resource provision	Admiration	163	Parents	PSS	Computer / tablet / mobile phone	AF-PAP	Share accomplishment of the goal	Share accomplishment of the goal	Share with others	Click on checkmark of goal		
1-PG	Sharing	5	-	-	164	PSS	Paediatric Cardiologist	Computer / tablet	Anytime	Others register goal reached	See goals achieved	Celebrate achievement	Notification, give option to comment on goals chat		
1-PG	Sharing	5	-	-	165	PSS	Sports Doctor	Computer / tablet	Anytime	Others register goal reached	See goals achieved	Celebrate achievement	Notification, give option to comment on goals chat		
1-PG	Goal remminder	6	Resource provision	-	95	PSS	Parents	Computer / tablet / mobile phone	Anytime	Too long with the same goal	Tips to support him better	Show support	Tell all the accomplishments of son and say that they could help them to get more by option A,B,C		
1-PG	Goal remminder	6	-	-	96	PSS	Child	Activity tracker / Computer / Tablet	AF-PAP	Too long with the same goal	Tips to achieve goal (from literature)	Child knows what is advised to do	Opportunity to recognize activity and give personalized tips		
2-SB	Exercise test discussion	1	-	-	97	Paediatric Cardiologist	Sports Doctor	Computer / tablet	B-PAP	Exercise test results are available	Discuss posibilities	Discuss CHD boundaries and posibilities	Creation of boundaries chat to discuss IF necessary	Button to 'Share with others'	
2-SB	Exercise test discussion	1	-	-	98	Sports Doctor	Paediatric Cardiologist	Computer / tablet	B-PAP	Exercise test results are available	Discuss posibilities	Discuss CHD boundaries and posibilities	Creation of boundaries chat to discuss IF necessary	Button to 'Share with others'	
2-SB	Sharing boundary	2.1	-	-	70	PSS	Parents	Mobile phone		2 days before meeting	Remminder about incoming meeting				
2-SB	Sharing boundary	2.1	-	-	71	PSS	Child	Computer / tablet		1 day before meeting					
2-SB	Sharing boundary	2.2	-	-	73	PSS	Parents	Mobile phone		10 minutes before appointment starts	Ask if micrphone can be turned on to				
2-SB	Sharing boundary results	2	Safety	-	99	Paediatric Cardiologist	Child	Computer / tablet	B-PAP	After meeting with family to discuss CPET results	Share diagnosis and tips for when the child doesnt feel good.	Ask question if they have	Enter and/or creation of the boundaries chat		
2-SB	Sharing boundary results	2	Safety	-	100	Paediatric Cardiologist	Parents	Computer / tablet / mobile phone	B-PAP	After meeting with family to discuss CPET results	Share diagnosis and tips for when the child doesnt feel good.	Ask question if they have	Enter and/or creation of the boundaries chat		
2-SB	Sharing boundaries	4.1	Safety		101	PSS	Child	Computer / tablet		Starting a new PA					
2-SB	Sharing boundaries	4.1	Safety		102	PSS	Parents	Computer / tablet / mobile phone		Starting a new PA					
2-SB	Sharing boundaries	4	Safety	Relief	103	Parents	Coach*	Computer / tablet / mobile phone	B-PAP	If parent and child agree	Share healthy posibilities with other stakeholders	Know how to better support him	Include in boundaries chat	Button to 'Share with others'	
2-SB	Sharing boundaries	4	-	-	104	Child	Coach*	Computer / tablet	B-PAP	If parent and child agree	Share healthy posibilities with other stakeholders	Know how to better support him	Include in boundaries chat	Button to 'Share with others'	
3-T	Self-discovery	1	Physical wellbeing	-	113	PSS	Child	Activity tracker	PAP	When entering safe threshold zone	Inform child of zone	Child be aware that the trainning started	Vibration pattern of short duration (1sec vib-2sec novib) repeating for 10 times + zone name on screen of AT		
3-T	Self-discovery	1	-	-	166	Child	PSS	Activity tracker	Anytime	When the child wears the bracelet	Collect HR and active minutes	Collect and use the data for the training option	Wear the device		
3-T	Self-discovery	2	Physical wellbeing	-	114	PSS	Child	Activity tracker	PAP	When entering symptom zone	Inform child of zone	Child be aware that if he feels palpitations, shortness of breath, tingling in your body etc it is related to CHD	Vibration pattern of short duration (1sec vib-2sec novib) repeating for 10 times + zone name on screen of AT		

3-T	**Self-discovery**	**3**	Safety	-	115	PSS	Child	Activity tracker	PAP	When 80% symptom zone is explored	Alert to stop	Child to stop activity	Vibration (non-stop) till the device detects child is not moving	Dont stop till child comes down?			
3-T	**Self-discovery**	**4**	-	-	138	PSS	Child	Activity tracker / Computer / Tablet	AF-PAP	1 hour after child stopped trainning	If symptoms happened register them	Child to fill a brief questionnaire	Notification in AT, multiple choice selection of syptoms				
3-T	**Sharing**	**5**	Physical wellbeing	Pride	117	Child	Parents	Computer / tablet	Anytime	When they feel like it	Share milestones	Others congratuale him	Notification to share recent milestones achived, screen to select people and then send	Button to share achievements automatically with the persons you select			
3-T	**Sharing**	**6**	Physical wellbeing	Pride	116	PSS	Child	Activity tracker	AF-PAP	PAP is in safe threshold for 3 consecutive times (between different activities (active minutes)	Reward for mainting PAP in safe threshold for X consecutive times	Make child feel proud of achievement	Show map with goals achived and path to follow				
3-T	**Training progress**	**7**	Physical wellbeing	Pride	26	PSS	Child	Activity tracker / Computer / Tablet	1/week	Weekly during trainning	To send insights and trends	See overall picture	Visualisation of data and insight relevant for physical wellbeing	Option to have it more			
3-T	**Training progress**	**7**	Resource provision	Admiration	118	PSS	Parents	Computer / tablet / mobile phone	1/week	Weekly during trainning	Inform of trainning progress + tips to encourage (from literature)	Stimulate interaction between child and parents	Visual report showing days of the week and milestones achived + one tip to support child	maybe the tip topic can be focused on the day that is not very good	Visualisation of data and insight relevant for safety and resource provision	Option to have it more	
3-T	**Training progress**	**8**	-	-	121	PSS	Coach	Computer / tablet / mobile phone	1/week	Weekly during trainning	Inform of trainning progress	Discuss and adapt sport to childs capacities if necessary	Discuss in Goals chat				
3-T	**Training support**	**9**	Physical wellbeing	-	122	Coach	Child	Computer / tablet / mobile phone	Anytime	During trainning stage	Discuss and adapt sport to childs capacities if necessary	Give an advice to child that he can follow	Discuss in Goals chat				
3-T	**Training support**	**10**	-	-	119	PSS	Paediatric Cardiologist*	Computer / tablet	Anytime	If trainning is going poorly	Inform specialist of situation	Doctor initiate a conversation with child	Discuss in Goals chat	e.g. child is not even reaching the safe threshold, is it capacity, laziness or parents stopping it?			
3-T	**Training support**	**11**	Physical wellbeing	-	120	Paediatric Cardiologist*	Child	Computer / tablet	Anytime	During trainning stage	Know why traininig is not going very well and recomend tips	Child to listen advise, and/or try tips	Discuss in Goals chat				
4-RTWL	**Perceiving symptom**	**1**	Physical wellbeing	Frustration	1	Child	Parents	Mobile phone	PAP	Feels symptoms	Express perception/ feel of a symptom	Feel better	Child tells parent				
4-RTWL	**Perceiving symptom**	**1**	-	-	6	Coach	Parents	Mobile phone	PAP	Perceives a symptom	Express worry about PERCEIVED symptom	Know if child is out of danger	Coach tells parent in person or message	Notification			

4-RTWL	**Perceiving symptom**	**1**	Safety	Anxiety	7	Parents	PSS	Mobile phone	PAP	Perceives a symptom	Express worry about PERCEIVED symptom	Medical staff clarifying if child is out of danger	Parent register worry into the system	Create questionnaire to index data for medical staff (ask for context: activity, place, small description of symptom (or multiple option), intensity?, after or during PA)		
4-RTWL	**Understanding worry**	**2**	Safety	-	2	PSS	GP	Mobile phone	PAP	Parent registered a worry	Parent expressing worry about PERCEIVED symptom	Know if child is out of danger	Receive notification with brief description of worry and health data from child	Betada hasta saber que dice Arend		
4-RTWL	**Understanding worry**	**2**	Safety	-	3	PSS	Specialized Nurse	Mobile phone	PAP	Parent registered a worry	Parent expressing worry about PERCEIVED symptom	Know if child is out of danger	Receive notification with brief description of worry and health data from child			
4-RTWL	**Understanding worry**	**3**	-	-	8	Specialized Nurse	Paediatric Cardiologist*	Mobile phone / Computer	PAP	After interpretation of worry	If nurse is not secure about diagnosis	Clarity on what to advice	Nurse asks paediatric cardiologist for opinion	Notification		
4-RTWL	**Understanding worry**	**3**	-	-	9	Paediatric Cardiologist	Specialized Nurse	Mobile phone / Computer	PAP	After RE-interpretation of worry	Answer to diagosis	-	Paediatric Cardiologist replies to Nurse doubt	Notification		
4-RTWL	**Sharing worry interpretation**	**4**	Safety	Relief	10	Specialized Nurse	Parents	Mobile phone / Computer	PAP	When feedback arrives	Explain context (diagnosis)	Relief on worries	Nurse replies to parent's concern	Notification		
4-RTWL	**Sharing worry interpretation**	**4**	Safety	Relief	11	GP	Parents	Mobile phone / Computer	PAP	After interpretation of worry	Explain context (diagnosis)	Relief on worries	GP replies to parent's concern	Betada hasta saber que dice Arend		
4-RTWL	**Sharing worry interpretation**	**5**	Safety	Relief	4	Parents	Coach	None	PAP	After receiving diagnosis from medical staff	Asks to stop activity / reduce intensity (indicated by medical staff)	Reduce danger	Parent tells coach			
4-RTWL	**Sharing worry interpretation**	**5**	Safety	Relief	5	Parents	Child	None	PAP	After receiving diagnosis from medical staff	Asks to stop activity / reduce intensity (indicated by medical staff) / or continue with activity	Reduce danger	Parents tell child			
4-RTWL	**Finding what happened**	**6**	-	-	24	PSS	Child	Computer / tablet	AF-PAP	1 hr after parent sends worry	To triangulate event of worry	Child to fill brief prompt about perceived symptom by parent	Vibration notification to bracelete			
4-RTWL	**Finding what happened**	**6**	-	-	25	Child	PSS	Computer / tablet	AF-PAP	When he gets the notification	To triangulate event of worry	Child to fill brief prompt about perceived symptom by parent	Fill a brief prompt			
5-EL	**Danger alert**	**1**	Safety	-	12	PSS	Child	Activity tracker	PAP	Entering the danger zone	The heart is in danger	Child to stop activity	The bracelete will vibrate till the heart is in lower zone and/or parent/coach stop it	Vibration continuously		
5-EL	**Danger alert**	**1**	Safety	-	13	PSS	Parents	Mobile phone	PAP	Entering the danger zone	The heart is in danger	Make child stop activity	Emergency notification to mobile phone	Notification + sound	Option to call ambulance	

5-EL	**Danger alert**	**1**	Safety	-	14	PSS	Coach*	Mobile phone	PAP	Entering the danger zone	The heart is in danger	Make child stop activity	Emergency notification to mobile phone	Notification + sound	*If child is nearby (detect with PA schedule asked before, recognize patterns of activity at different times in the day)		
5-EL	**Danger alert**	**1**	Safety	-	15	PSS	Siblings*	Activity tracker	PAP	Entering the danger zone	The heart is in danger	Make child stop activity	Vibration notification to bracelete	*if registered in emergency contact group	Child and parents need to agree on who is in the emergency line		
5-EL	**Danger alert**	**1**	Safety	-	16	PSS	Friends*	Activity tracker	PAP	Entering the danger zone	The heart is in danger	Make child stop activity	Vibration notification to bracelete	*if registered in emergency contact group	Child and parents need to agree on who is in the emergency line		
5-EL	**Danger alert**	**1**	Safety	-	17	PSS	CHD Friends*	Activity tracker	PAP	Entering the danger zone	The heart is in danger	Make child stop activity	Vibration notification to bracelete	*if registered in emergency contact group	Child and parents need to agree on who is in the emergency line		
5-EL	**Danger alert by parents**	**2**	Resource provision	-	18	Parents	Coach	Mobile phone	PAP	After receiving notification	The heart is in danger	Make coach stop activity	Emergency notification to mobile phone/call	Shortcut to send message/call			
5-EL	**Danger alert by parents**	**2**	Resource provision	-	21	Parents	Siblings*	Mobile phone	PAP	After receiving notification	The heart is in danger	Make siblings stop activity	Emergency notification by vibration/call	*if registered in emergency contact group	Child and parents need to agree on who is in the emergency line		
5-EL	**Danger alert by parents**	**2**	Resource provision	-	22	Parents	Friends*	Mobile phone	PAP	After receiving notification	The heart is in danger	Make friends stop activity	Emergency notification by vibration/call	*if registered in emergency contact group	Child and parents need to agree on who is in the emergency line		
5-EL	**Danger alert by parents**	**2**	Resource provision	-	23	Parents	CHD Friends*	Mobile phone	PAP	After receiving notification	The heart is in danger	Make CHD friends stop activity	Emergency notification by vibration/call	*if registered in emergency contact group	Child and parents need to agree on who is in the emergency line		
5-EL	**Danger alert by parents**	**2**	Resource provision	-	56	Parents	Coach	Mobile phone	PAP	After receiving notification	The heart is in danger	Make coach stop activity	Emergency notification to mobile phone/call	Shortcut to send message/call			
5-EL	**Finding what happened**	**3**	-	-	19	PSS	Parents	Mobile phone	AF-PAP	60 min after HR is in the correct zone	Contextualize incident	Remind to fill and send mini-report*	Parent receives notification to fill a brief questionnaire	Notification	*Do it together with the child	Later give insigts on incidents if system identifies pattern	
5-EL	**Finding what happened**	**3**	-	-	20	Parents	Specialized Nurse	Mobile phone	AF-PAP	60 min after HR is in the correct zone	Inform medical staff of event	Nurse evaluate incident (reply)	Parents sends brief description of what happened	Brief description			

5-EL	**Finding what happened**	**3**	-	-	57	PSS	Child	Mobile phone	AF-PAP	60 min after HR is in the correct zone	Contextualize incident	Remind to fill and send mini-report*	Parent receives notification to fill questionnaire with parent	Notification	*Do it together with the parent	Later give insigts on incidents if system identifies pattern
5-EL	**Finding what happened**	**3**	-	-	58	Child	Parents	Mobile phone	AF-PAP	60 min after HR is in the correct zone	Contextualize incident	Fill mini-report	Child can send how he felt during the emergency	Notification		
6-EM	**Sharing feelings**	**1**	-	-	27	PSS	Parents	Computer / tablet / mobile phone	1/week	Weekly evaluation during trainning	Record and send PA worries and attitude of family members during trainning	Fill brief questionnaire	Notification each week to fill an online form	Option to register with more frequency		
6-EM	**Sharing feelings**	**1**	-	-	28	PSS	Child	Activity tracker / Computer / Tablet	1/week	Weekly evaluation during trainning	Record and send PA worries and attitude of family members during trainning	Fill brief questionnaire	Notification each week to fill an online form	Option to register with more frequency		
6-EM	**Sharing feelings**	**2**	-	-	29	PSS*	Child	Computer / tablet	Anytime	When collecting new data	See each others worries	Generate a healthy discussion between feelings	Child can see what are the main worries of the parent and discuss them with parent and/or psychologist	*if parent allows		
6-EM	**Sharing feelings**	**2**	Resource provision	-	30	PSS*	Parents	Computer / tablet / mobile phone	Anytime	When collecting new data	See each others worries	Generate a healthy discussion between feelings	Child can see what are the main worries of the parent and discuss them with parent and/or psychologist	*if child allows		
6-EM	**Understanding feelings**	**3**	-	-	40	PSS	Psychologist	Computer / tablet	1/week	Weekly evaluation during trainning	To analyse feelings of family members	Analyse and respond to family member	Specialist will receive relevant material related to his/her field	Notification		
6-EM	**Understanding feelings**	**3**	-	-	41	PSS	Social Worker	Computer / tablet	1/week	Weekly evaluation during trainning	To analyse feelings of family members	Analyse and respond to family member	Specialist will receive relevant material related to his/her field	Notification		
6-EM	**Asking for 2nd opinion**	**4**	-	-	42	Psychologist	Specialized Nurse*	Computer / tablet	Anytime	After receiving notification	Assign right person to solve matter	Analyse and respond to family member	Specialist will receive relevant matter to his occupation	Notification	*If psychologist feels that can't help with the situation and medical help is needed	
6-EM	**Asking for 2nd opinion**	**4**	-	-	44	Psychologist	Paediatric Cardiologist*	Computer / tablet	Anytime	After receiving notification	Assign right person to solve matter	Analyse and respond to family member	Specialist will receive relevant matter to his occupation	Notification	*If psychologist feels that can't help with the situation and medical help is needed	
6-EM	**Sharing feeling interpretation**	**5**	Safety	Relief	33	Psychologist	Parents	Computer / tablet	Anytime	If specialist receives query	To give relief and/ or a follow up to feeling	Decide who can handle the query or solve it	Notification of answer to mobile phone			
6-EM	**Sharing feeling interpretation**	**5**	-	-	34	Psychologist	Child	Computer / tablet	Anytime	If specialist receives query	To give relief and/ or a follow up to feeling	Decide who can handle the query or solve it	Vibration when message is received, then, seen at display			
6-EM	**Sharing feeling interpretation**	**5**	-	-	35	Social Worker	Child	Computer / tablet	Anytime	If specialist receives query	To give relief and/or a follow up to query	Solve query	After receiving query, the specialist analyse and then reply	Vibration when message is there		
6-EM	**Sharing feeling interpretation**	**5**	Safety	Relief	38	Social Worker	Parents	Computer / tablet	Anytime	If specialist receives query	To give relief and/or a follow up to query	Solve query	After receiving query, the specialist analyse and then reply	Notification		
6-EM	**Sharing feeling interpretation**	**5**	-	-	39	Specialized Nurse	Child	Computer / tablet	Anytime	If specialist receives query	To give relief and/or a follow up to query	Solve query	After receiving query, the specialist analyse and then reply	Notification		
6-EM	**Sharing feeling interpretation**	**5**	-	-	43	Specialized Nurse	Parents	Computer / tablet	Anytime	If specialist receives query	To give relief and/or a follow up to query	Solve query	After receiving query, the specialist analyse and then reply	Notification		
6-EM	**Sharing feeling interpretation**	**5**	Safety	Relief	45	Paediatric Cardiologist	Parents	Computer / tablet	Anytime	If specialist receives query	To give relief and/or a follow up to query	Solve query	After receiving query, the specialist analyse and then reply	Notification		

6-EM	**Sharing feeling interpretation**	**5**	-	-	46	Paediatric Cardiologist	Child	Computer / tablet	Anytime	If specialist receives query	To give relief and/or a follow up to query	Solve query	After receiving query, the specialist analyse and then reply	Notification	
7-UHDC	**Safe space for doubts**	**1**	Belonging	-	123	Child	CHD Friends	Computer / tablet	Anytime	When they feel like it	Have a safe space to talk with children of your age about CHD	Share concerns, tips, thoughts, activities	Creation of 'doubt chat'		
7-UHDC	**Safe space for doubts**	**1**	Belonging	-	124	CHD Friends	Child	Computer / tablet	Anytime	When they feel like it	Have a safe space to talk with children of your age about CHD	Share concerns, tips, thoughts, activities	Creation of 'doubt chat'		
7-UHDC	**Safe space for doubts**	**2**	Belonging	-	125	Child	PSS	Computer / tablet	Anytime	When they feel like it	Solve doubts related to CHD or wellbeing	Specialist answer	Ask question to open forum	Index questions	Add follow question
7-UHDC	**Safe space for doubts**	**2**	Belonging	-	126	CHD Friends	PSS	Computer / tablet	Anytime	When they feel like it	Solve doubts related to CHD or wellbeing	Specialist answer	Ask question to open forum	Index questions	Add follow question
7-UHDC	**Supervision**	**3**	-	-	127	PSS	Specialized Nurse	Computer / tablet	Anytime	System detects dangerous/bad behaviour in chat of friends	Supervision	Set the correct context for the conversation	Notification		
7-UHDC	**Supervision**	**3**	-	-	140	Specialized Nurse	Child	Computer / tablet	Anytime	After being notified of dangerous/bad behaviour	Supervision	Set the correct context for the conversation	The avatar of the S.N. will appear in the chat to say something regarding their discussion		
7-UHDC	**Sharing doubts**	**4**	-	-	128	PSS	Specialized Nurse	Computer / tablet	Anytime	Children ask questions	Inform forum doubts	Answer doubts of children	Notification		
7-UHDC	**Sharing doubts**	**4**	-	-	130	PSS	Psychologist	Computer / tablet	Anytime	Children ask questions	Inform forum doubts	Answer doubts of children	Notification		
7-UHDC	**Sharing doubts**	**4**	-	-	131	PSS	Social Worker	Computer / tablet	Anytime	Children ask questions	Inform forum doubts	Answer doubts of children	Notification		
7-UHDC	**Sharing doubts**	**4**	-	-	132	PSS	Pedagogical Assistant	Computer / tablet	Anytime	Children ask questions	Inform forum doubts	Answer doubts of children	Notification		
7-UHDC	**Sharing doubts**	**4**	-	-	133	PSS	Child Life Specialist	Computer / tablet	Anytime	Children ask questions	Inform forum doubts	Answer doubts of children	Notification		
7-UHDC	**Answering doubts**	**5**	-	-	129	Psychologist	Child	Computer / tablet	Anytime	After receiving notification and analysing doubt	Answer possible forum doubts	Clarify children doubts	Answer to forum question and notify the ones following the question		
7-UHDC	**Answering doubts**	**5**	-	-	134	Social Worker	Child	Computer / tablet	Anytime	After receiving notification and analysing doubt	Answer possible forum doubts	Clarify children doubts	Answer to forum question and notify the ones following the question		
7-UHDC	**Answering doubts**	**5**	-	-	135	Pedagogical Assistant	Child	Computer / tablet	Anytime	After receiving notification and analysing doubt	Answer possible forum doubts	Clarify children doubts	Answer to forum question and notify the ones following the question		
7-UHDC	**Answering doubts**	**5**	-	-	136	Child Life Specialist	Child	Computer / tablet	Anytime	After receiving notification and analysing doubt	Answer possible forum doubts	Clarify children doubts	Answer to forum question and notify the ones following the question		
7-UHDC	**Answering doubts**	**5**	-	-	139	Specialized Nurse	Child	Computer / tablet	Anytime	After receiving notification and analysing doubt	Answer possible forum doubts	Clarify children doubts	Answer to forum question and notifiy the ones following the questions		
8-UHDP	**Safe space for doubts**	**1**	Safety	-	141	Parents	PSS	Computer / tablet / mobile phone	Anytime	When parents have doubts and it is not an urgent matter	Solve doubts related to CHD, symptoms (what to look for) or wellbeing of their child in general	An answer to their concern	Write in the search engine		
8-UHDP	**Safe space for doubts**	**2**	-	-	155	PSS	Parents	Computer / tablet / mobile phone	Anytime	When parents write doubt	Connect to possible answer	Solve doubt of the parent without calling experts, otherwise, parent sending question to experts	Show first 10 possible answers (asked by others CHD families) and at the bottom have a button to send question to experts	button saying Not finding the answer you where looking for? send your question now	

8-UHDP	**Safe space for doubts**	**3**	Safety	Relief	142	Parents	PSS	Computer / tablet / mobile phone	Anytime	When possible answers are provided	Explore concerns related to CHD or wellbeing of their child in general	Connect with other families talking of the same topics/solve question	Show posible answers and if click on read, then a pop-up comes asking if it is interesing or useful, and if they would like to connect with the family who asked		
8-UHDP	**Safe space for doubts**	**4**	-	-	156	PSS	CHD Families	Computer / tablet / mobile phone	Anytime	Parents mark your question interesting/ useful	Connect families with same concerns	Create a chat if families want to connect	Notification, then family who posted the question will have to accept to connect with the new family		
8-UHDP	**Safe space for doubts**	**5**	-	-	154	CHD Families	Parents	Computer / tablet / mobile phone	Anytime	When new family contacts family that posted	Increase interaction with other CHD families	Accept request from other family to connect	Creation of chat between CHD families	Option to add more	
8-UHDP	**Safe space for doubts**	**6**	-	-	153	Parents	CHD Families	Computer / tablet / mobile phone	Anytime	After family that posted the question accepts request	Increase interaction with other CHD families	Express concerns, and solve more details of doubts they could have	Creation of chat between CHD families	Option to add more	
8-UHDP	**Safe space for doubts**	**7**	-	-	157	Parents	PSS*	Computer / tablet / mobile phone	Anytime	If question is not found	To find an answers from the specialist	Specialist answer	Parent will click the button of 'sending question'		
8-UHDP	**Sharing doubts**	**8**	-	-	143	PSS	Specialized Nurse	Computer / tablet	Anytime	When possbile answer is not satisfactory	Inform forum doubts	Accept the question and answer the question	Notification		
8-UHDP	**Sharing doubts**	**8**	-	-	144	PSS	Psychologist	Computer / tablet	Anytime	When possbile answer is not satisfactory	Inform forum doubts	Accept the question and answer the question	Notification		
8-UHDP	**Sharing doubts**	**8**	-	-	145	PSS	Social Worker	Computer / tablet	Anytime	When possbile answer is not satisfactory	Inform forum doubts	Accept the question and answer the question	Notification		
8-UHDP	**Sharing doubts**	**8**	-	-	146	PSS	Pedagogical Assistant	Computer / tablet	Anytime	When possbile answer is not satisfactory	Inform forum doubts	Accept the question and answer the question	Notification		
8-UHDP	**Sharing doubts**	**8**	-	-	147	PSS	Child Life Specialist	Computer / tablet	Anytime	When possbile answer is not satisfactory	Inform forum doubts	Accept the question and answer the question	Notification		
8-UHDP	**Answering doubts**	**9**	Safety	Relief	148	Specialized Nurse	Parents	Computer / tablet	Anytime	After receiving notification and analysing doubt	Answer possible forum doubts	Clarify parents doubts	Answer to forum question and notify the ones following the question		
8-UHDP	**Answering doubts**	**9**	Safety	Relief	149	Psychologist	Parents	Computer / tablet	Anytime	After receiving notification and analysing doubt	Answer possible forum doubts	Clarify parents doubts	Answer to forum question and notify the ones following the question		
8-UHDP	**Answering doubts**	**9**	Safety	Relief	150	Social Worker	Parents	Computer / tablet	Anytime	After receiving notification and analysing doubt	Answer possible forum doubts	Clarify parents doubts	Answer to forum question and notify the ones following the question		
8-UHDP	**Answering doubts**	**9**	Safety	Relief	151	Pedagogical Assistant	Parents	Computer / tablet	Anytime	After receiving notification and analysing doubt	Answer possible forum doubts	Clarify parents doubts	Answer to forum question and notify the ones following the question		
8-UHDP	**Answering doubts**	**9**	Safety	Relief	152	Child Life Specialist	Parents	Computer / tablet	Anytime	After receiving notification and analysing doubt	Answer possible forum doubts	Clarify parents doubts	Answer to forum question and notify the ones following the question		
9-PAFM	**Remember to do PA**	**1**	Physical wellbeing	-	137	PSS	Child	Activity tracker / Computer / Tablet	Anytime	Low level of PA for 7 conecutive days	Know if the child needs help in some way to increase PA	Child say if he IS OK or not	Vibration on AT to give notification, then ask about the sport he was playing	Instead of saying 'hey why your PA level is low?' focus more on the activity he is doing (more personal)	
9-PAFM	**Finding what is happening**	**2**	Resource provision	-	105	PSS	Parents	Mobile phone	Anytime	After 10 consecutive days of low levels of PA	To make others find out why PA level is low	Parents ask child why is he not very active and if OK then removes alarm	Notification of low levels of PA	Button to snooze	

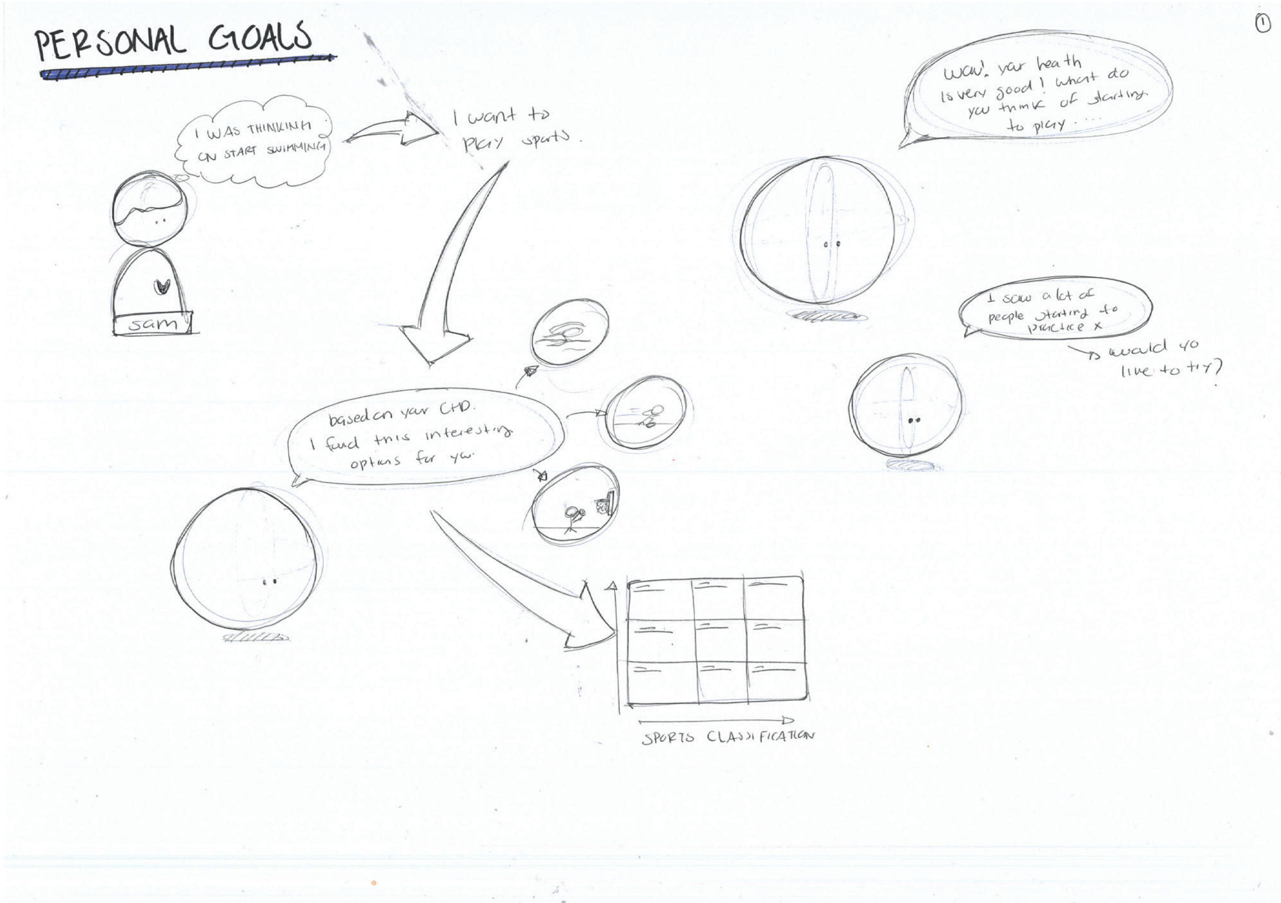
9-PAFM	**Finding what is happening**	**3**	-	-	106	PSS	Psychologist	Computer / tablet	Anytime	After asking parents, in case low levels remain low for 21 consecutive days	To know if child needs professional help with one aspect of his life	Contact the family and ask if everything is Ok	Accept request from PSS to follow 'concern' of the system and then contact family	Accept button and then see 'history' of feelings to see if something have been happeninig in the past 2 weeks	Show summary of feelings
9-PAFM	**Finding what is happening**	**3**	-	-	107	PSS	Social Worker	Computer / tablet	Anytime	After asking parents, in case low levels remain low for 21 consecutive days	To know if child needs professional help with one aspect of his life	Contact the family and ask if everything is Ok	Accept request from PSS to follow 'concern' of the system and then contact family	Accept button and then see 'history' of feelings to see if something have been happeninig in the past 2 weeks	Show summary of feelings
9-PAFM	**Encouraging PA**	**4**	Resource provision	-	109	Psychologist	Parents	Computer / tablet / mobile phone	Anytime	After receiving notification	To know why PA levels are low and offer tips to parent	Parent explain if something happened and expert recomends	Message notification + new chat with specialist		
9-PAFM	**Encouraging PA**	**4**	Resource provision	-	111	Social Worker	Parents	Computer / tablet / mobile phone	Anytime	After receiving notification	To know why PA levels are low and offer tips to parent	Parent explain if something happened and expert recomends	Message notification + new chat with specialist		
9-PAFM	**Encouraging PA**	**5**	Resource provision	-	112	Parents	Child	None	Anytime	After receiving notification from psychologist or social worker	To know if everything is OK with child	Know if parent can help child	Person-to-person talk		
9-PAFM	**Encouraging PA**	**6**	-	-	108	Psychologist*	Child	Activity tracker / Computer / Tablet	Anytime	if parents ask for it	To know if expert can help child	Child explain if he has a problem	Message notification + new chat with specialist		
9-PAFM	**Encouraging PA**	**6**	-	-	110	Social Worker*	Child	Activity tracker / Computer / Tablet	Anytime	if parents ask for it	To know if expert can help child	Child explain if he has a problem	Message notification + new chat with specialist		
99-PAC	**Remember to do PA**	**1**	Resource provision	-	31	PSS	Parents	Computer / tablet / mobile phone	B-PAP	When PA levels are low for 3 consecutive days	To remind them that they can set challenges	Send challenge invitation	Notification as a suggestion		
99-PAC	**Remember to do PA**	**1**	-	-	52	PSS	Siblings	Activity tracker / Computer / Tablet	B-PAP	When PA levels are low for 3 consecutive days	To remind them that they can set challenges	Send challenge invitation	Notification as a suggestion		
99-PAC	**Remember to do PA**	**1**	-	-	65	PSS	Child	Activity tracker / Computer / Tablet	B-PAP	When PA levels are low for 3 consecutive days	To remind them that they can set challenges	Send challenge invitation	Notification as a suggestion		
99-PAC	**Bringing people together**	**2**	Belonging	-	47	Child	Parents	Computer / tablet	B-PAP	After receiving notification from PSS	Invite to group challenge	Others to accept challenge	Invitation is send through APP and group of people invited need to accept	Suggest different activities (based on the 6 dimensions of PA?)	GROUP challenges, not individual
99-PAC	**Bringing people together**	**2**	Belonging	-	48	Child	Siblings	Computer / tablet	B-PAP	After receiving notification from PSS	Invite to group challenge	Others to accept challenge	Invitation is send through APP and group of people invited need to accept		GROUP challenges, not individual
99-PAC	**Bringing people together**	**2**	-	-	50	Parents	Child	Computer / tablet / mobile phone	B-PAP	After receiving notification from PSS	Invite to group challenge	Others to accept challenge	Invitation is send through APP and group of people invited need to accept		GROUP challenges, not individual
99-PAC	**Bringing people together**	**2**	-	-	51	Parents	Siblings	Computer / tablet / mobile phone	B-PAP	After receiving notification from PSS	Invite to group challenge	Others to accept challenge	Invitation is send through APP and group of people invited need to accept		GROUP challenges, not individual
99-PAC	**Bringing people together**	**2**	-	-	53	Siblings	Child	Computer / tablet	B-PAP	After receiving notification from PSS	Invite to group challenge	Others to accept challenge	Invitation is send through APP and group of people invited need to accept		GROUP challenges, not individual
99-PAC	**Bringing people together**	**2**	-	-	54	Siblings	Parents	Computer / tablet	B-PAP	After receiving notification from PSS	Invite to group challenge	Others to accept challenge	Invitation is send through APP and group of people invited need to accept		GROUP challenges, not individual
99-PAC	**Bringing people together**	**2**	Belonging	-	59	Child	CHD Families*	Computer / tablet	B-PAP	After receiving notification from PSS If parent and child agree	Invite to group challenge	Reply from CHD families	Invitation is send through APP and group of people invited need to accept	GROUP challenges, not individual	

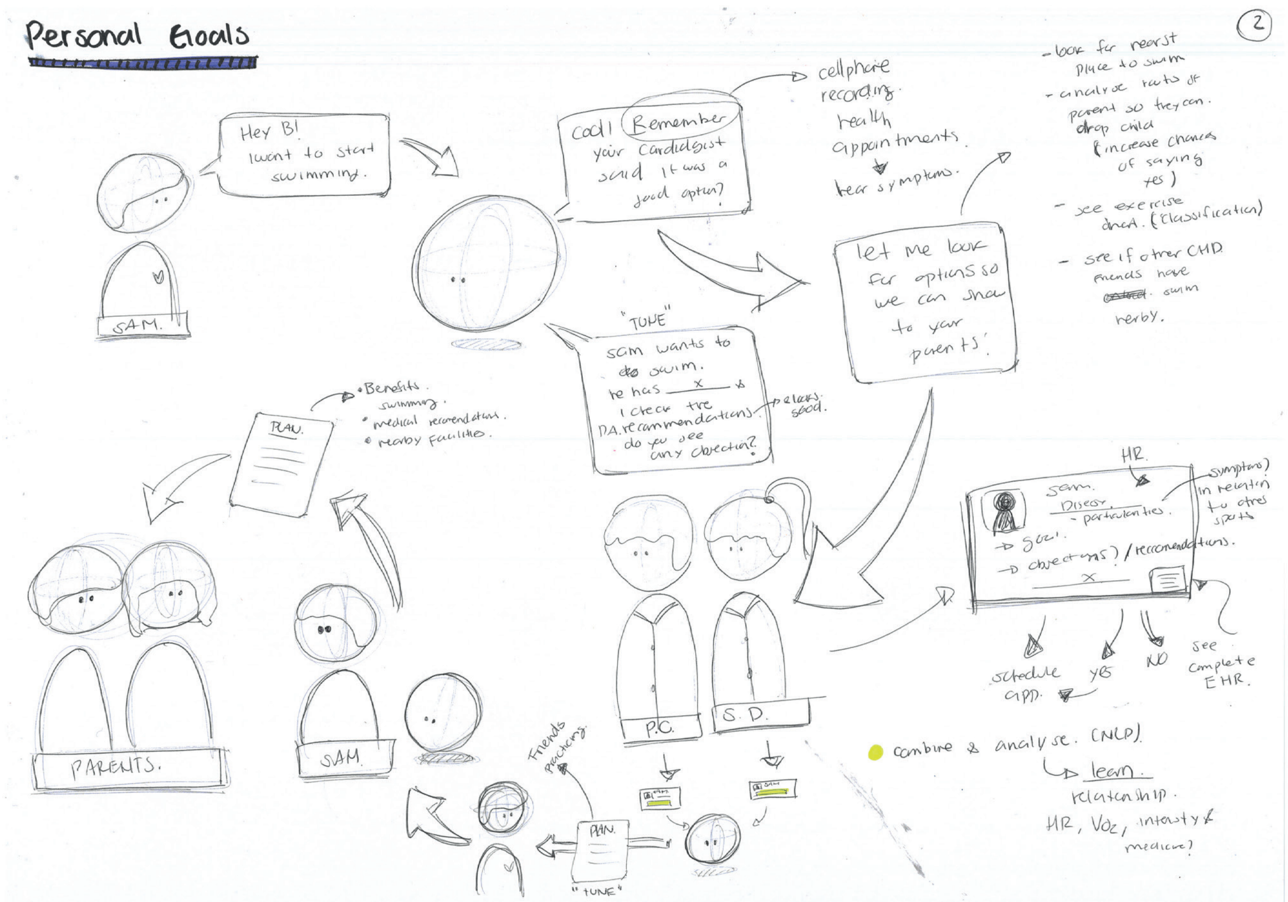
99-PAC	**Bringing people together**	**2**	Belonging	-	60	Child	Friends	Computer / tablet	B-PAP	After receiving notification from PSS	Invite to group challenge	Others to accept challenge	Invitation is send through APP and group of people invited need to accept	GROUP challenges, not individual	
99-PAC	**Bringing people together**	**2**	Belonging	-	61	Child	CHD Friends	Computer / tablet	B-PAP	After receiving notification from PSS	Invite to group challenge	Others to accept challenge	Invitation is send through APP and group of people invited need to accept		
99-PAC	**Bringing people together**	**2**	-	-	62	Parents	CHD Families*	Computer / tablet / mobile phone	B-PAP	After receiving notification from PSS If parent and child agree	Invite to group challenge	Reply from CHD families	Invitation is send through APP and group of people invited need to accept		GROUP challenges, not individual
99-PAC	**Bringing people together**	**3**	-	-	49	Parents	PSS	Computer / tablet / mobile phone	B-PAP	When they accept the challenge	Creation of challenge group	All the participants of the challenge in one place (chat)	Accept the challenge with one button		
99-PAC	**Bringing people together**	**3**	-	-	55	Siblings	PSS	Computer / tablet	B-PAP	When they accept the challenge	Creation of challenge group	All the participants of the challenge in one place (chat)	Accept the challenge with one button		
99-PAC	**Bringing people together**	**3**	-	-	63	Friends	PSS	Computer / tablet	B-PAP	When they accept the challenge	Creation of challenge group	All the participants of the challenge in one place (chat)	Accept the challenge with one button		
99-PAC	**Bringing people together**	**3**	-	-	64	CHD Friends	PSS	Computer / tablet	B-PAP	When they accept the challenge	Creation of challenge group	All the participants of the challenge in one place (chat)	Accept the challenge with one button		
99-PAC	**Bringing people together**	**3**	-	-	67	CHD Families	PSS	Computer / tablet	B-PAP	When they accept the challenge	Creation of challenge group	All the participants of the challenge in one place (chat)	Accept the challenge with one button		
99-PAC	**Increasing PA**	**4**	Belonging	Joy	32	PSS	Parents	Computer / tablet / mobile phone	B-PAP	Challenge is accepted*	To gather the group of people who will participate in the game	Set game rules, interact between each other in a safe space	Creation of chat of friends, make them chose each team a name and a creation of a logo	*If invited to participate	A group with the players is created, only in this context they can interact with eachother
99-PAC	**Increasing PA**	**4**	Belonging	Joy	36	PSS	CHD Families	Computer / tablet / mobile phone	B-PAP	Challenge is accepted*	To gather the group of people who will participate in the game	Set game rules, interact between each other in a safe space	Creation of chat of friends, make them chose each team a name and a creation of a logo	*If invited to participate	A group with the players is created, only in this context they can interact with eachother
99-PAC	**Increasing PA**	**4**	Belonging	Joy	66	PSS	Child	Activity tracker / Computer / Tablet	B-PAP	Challenge is accepted	To gather the group of people who will participate in the game	Set game rules, interact between each other in a safe space	Creation of chat of friends, make them chose each team a name and a creation of a logo		A group with the players is created, only in this context they can interact with eachother
99-PAC	**Increasing PA**	**4**	Belonging	Joy	68	PSS	Friends	Activity tracker / Computer / Tablet	B-PAP	Challenge is accepted*	To gather the group of people who will participate in the game	Set game rules, interact between each other in a safe space	Creation of chat of friends, make them chose each team a name and a creation of a logo	*If invited to participate	A group with the players is created, only in this context they can interact with eachother
99-PAC	**Increasing PA**	**4**	Belonging	Joy	69	PSS	CHD Friends	Activity tracker / Computer / Tablet	B-PAP	Challenge is accepted*	To gather the group of people who will participate in the game	Set game rules, interact between each other in a safe space	Creation of chat of friends, make them chose each team a name and a creation of a logo	*If invited to participate	A group with the players is created, only in this context they can interact with eachother

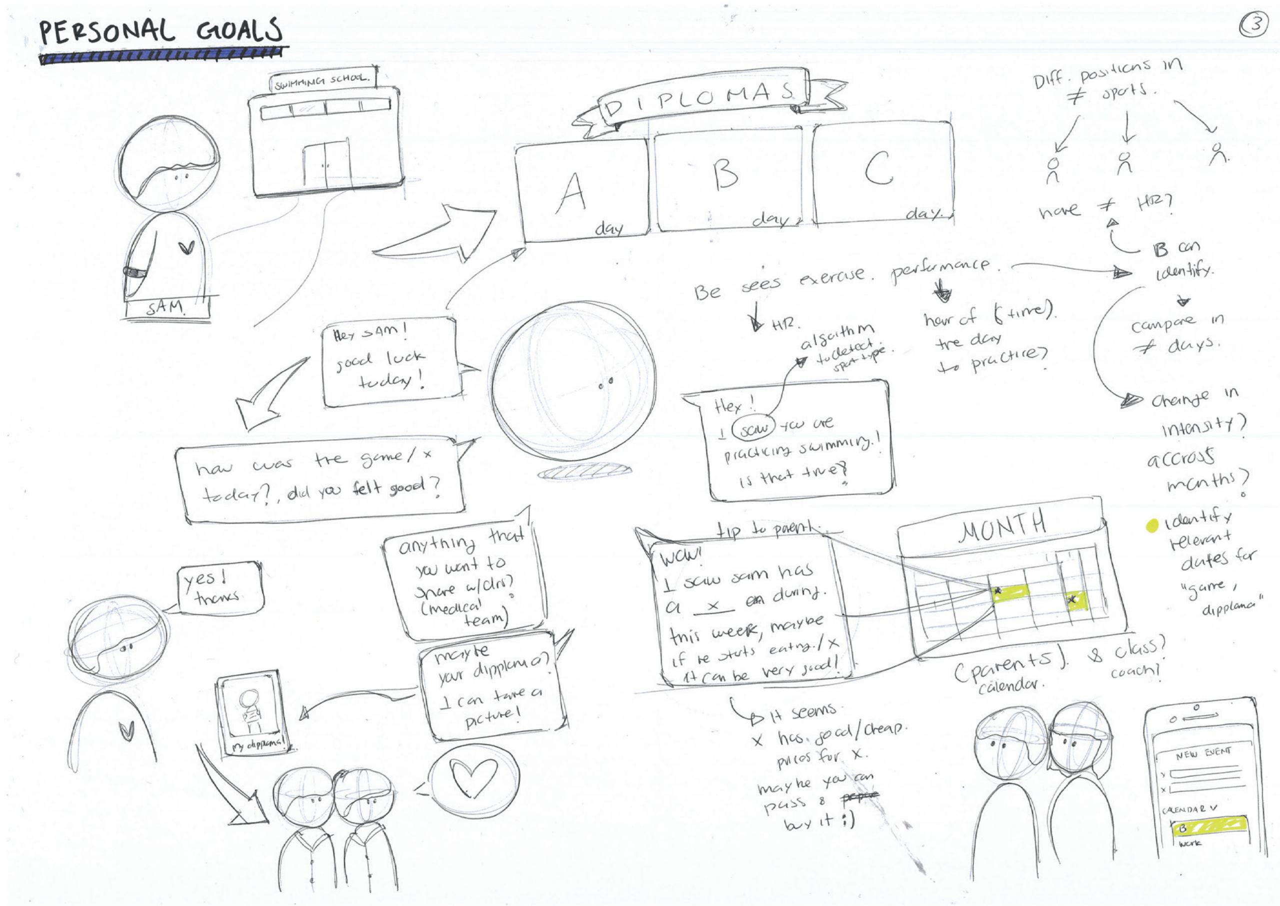
99-PAC	**Increasing PA**	**4**	Belonging	Joy	72	PSS	Siblings*	Activity tracker / Computer / Tablet	B-PAP	Challenge is accepted*	To gather the group of people who will participate in the game	Set game rules, interact between each other in a safe space	Creation of chat of friends, make them chose each team a name and a creation of a logo	*If invited to participate	A group with the players is created, only in this context they can interact with eachother
ES	**Finding what is happening**	**1**	-	-	37	PSS	Parents	Computer / tablet / mobile phone	1/week	Weekly during trainning	Ask to say if child had symptoms during the week	Remember to register symptoms	Notification and then see in display		
ES	**Finding what is happening**	**1**	-	-	78	PSS	Child	Activity tracker / Computer / Tablet	1/week	Weekly during trainning	Ask to say if he had symptoms during the week	Remember to register symptoms	Vibration when message is received, then, seen at display		
ES	**Perceiving symptom**	**2**	-	-	74	Child	PSS	Computer / tablet	Anytime	Perceives a symptom and/or remembers occurrance (not related to PAP)	Keep record of symptoms for improving treatment	Register symptoms	Online questionnaire		
ES	**Perceiving symptom**	**2**	-	-	76	Parents	PSS	Computer / tablet / mobile phone	Anytime	Perceives a symptom and/or remembers occurrance (not related to PAP)	Keep record of symptoms for improving treatment	Know if child is out of danger	Online questionnaire		
ES	**Giving support**	**3**	Physical wellbeing	Pride	75	PSS	Child	Activity tracker / Computer / Tablet	1/week	Weekly during trainning	To send insights and trends	See overall picture	Visualisation of data and insight relevant for physical wellbeing	Option to have it more	
ES	**Giving support**	**3**	Resource Provision	Admiration	77	PSS	Parents	Computer / tablet / mobile phone	1/week	Weekly during trainning	To send trends	See overall picture	Visualisation of data and insight relevant for safety and resource provision	Option to have it more	
ES	**Giving support**	**4**	-	-	79	PSS	Paediatric Cardiologist	Computer / tablet	Anytime	Detection of dangerous symptom	The heart is in danger	Analyse and respond to family member	Specialist will receive relevant matter to his occupation		
ES	**Giving support**	**4**	-	-	80	Paediatric Cardiologist	Parents	Computer / tablet	Anytime	Detection of dangerous symptom	The heart is in danger	Bring child to hospital if necessary	After receiving query, the specialist analyse and then reply		

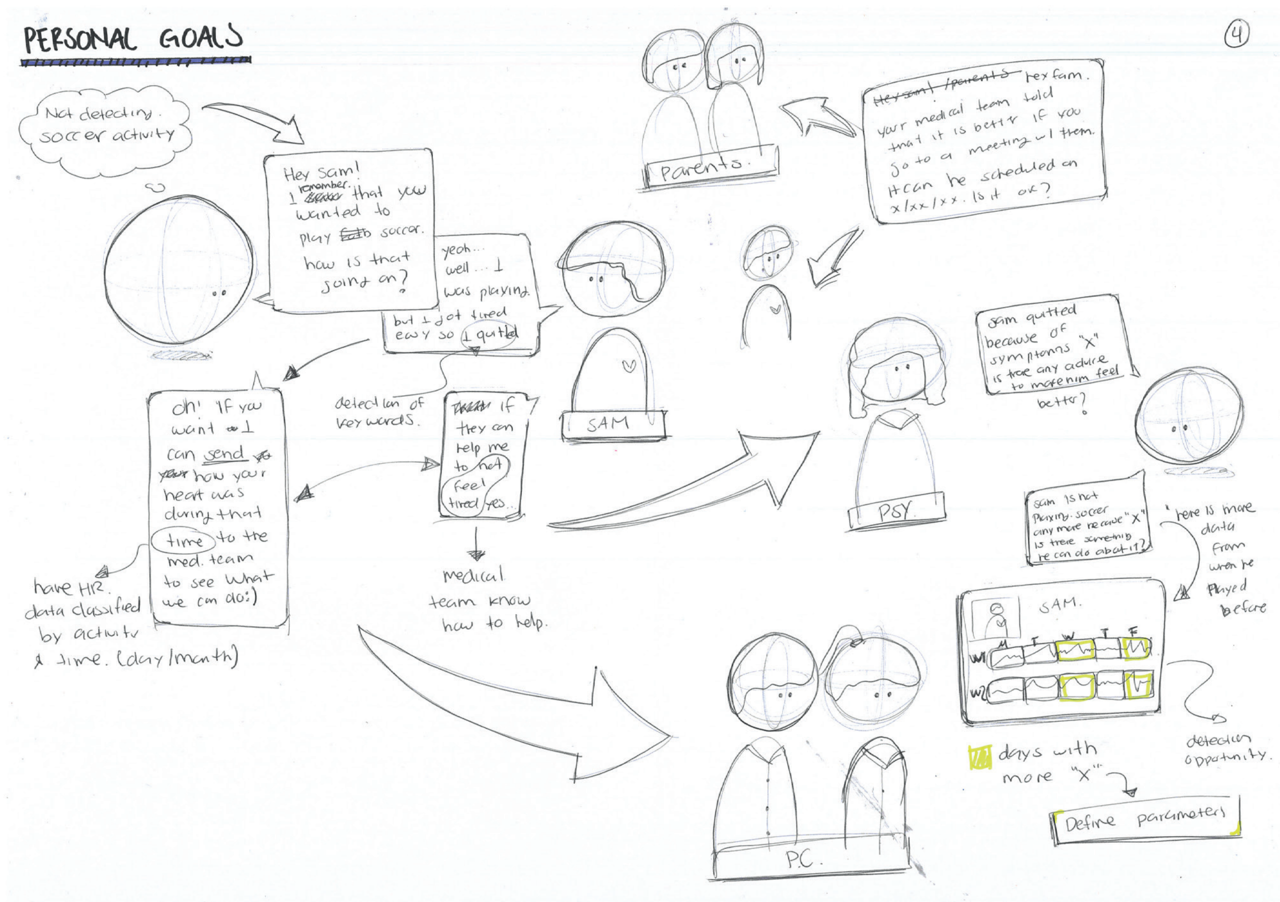
Appendix W

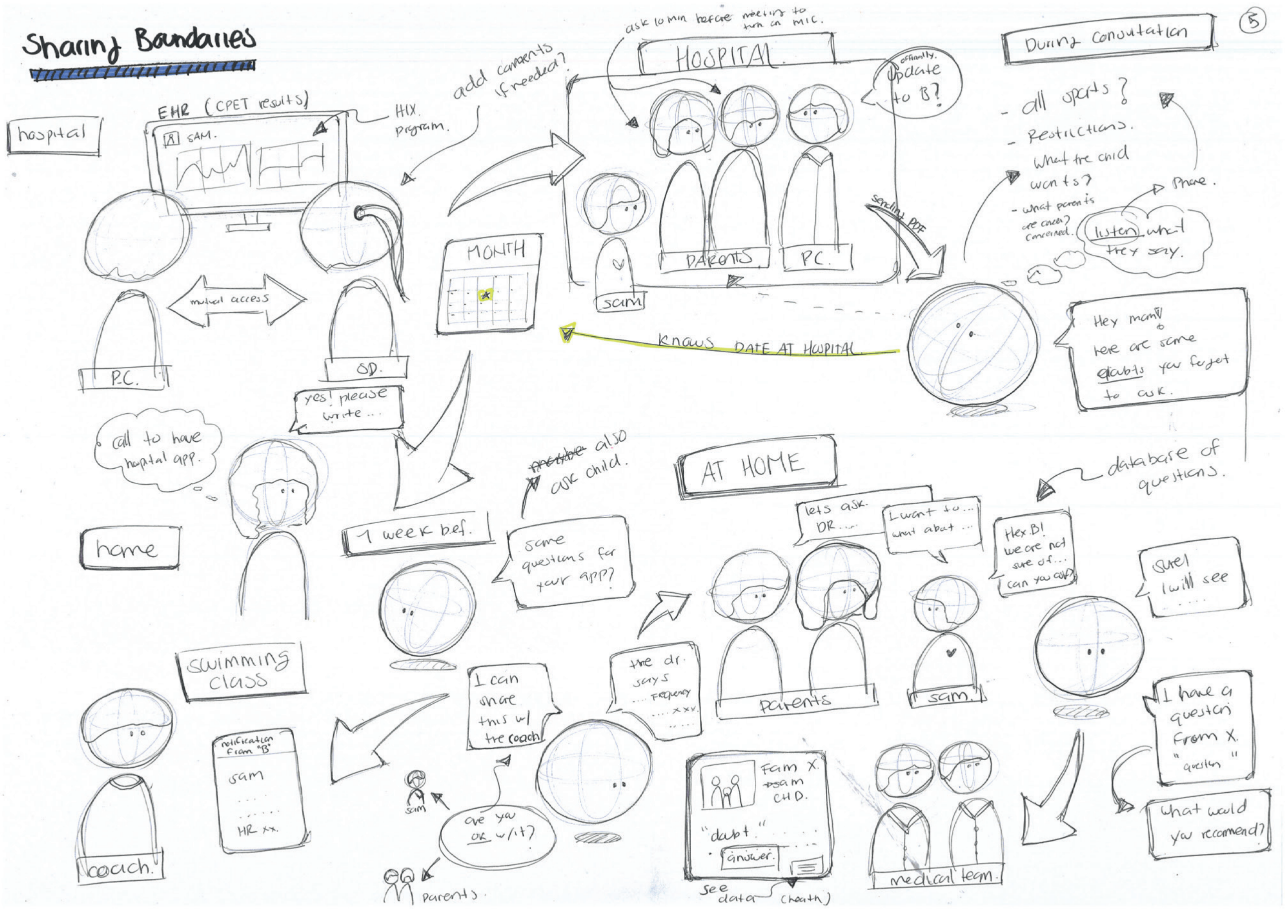
Agentive ideation

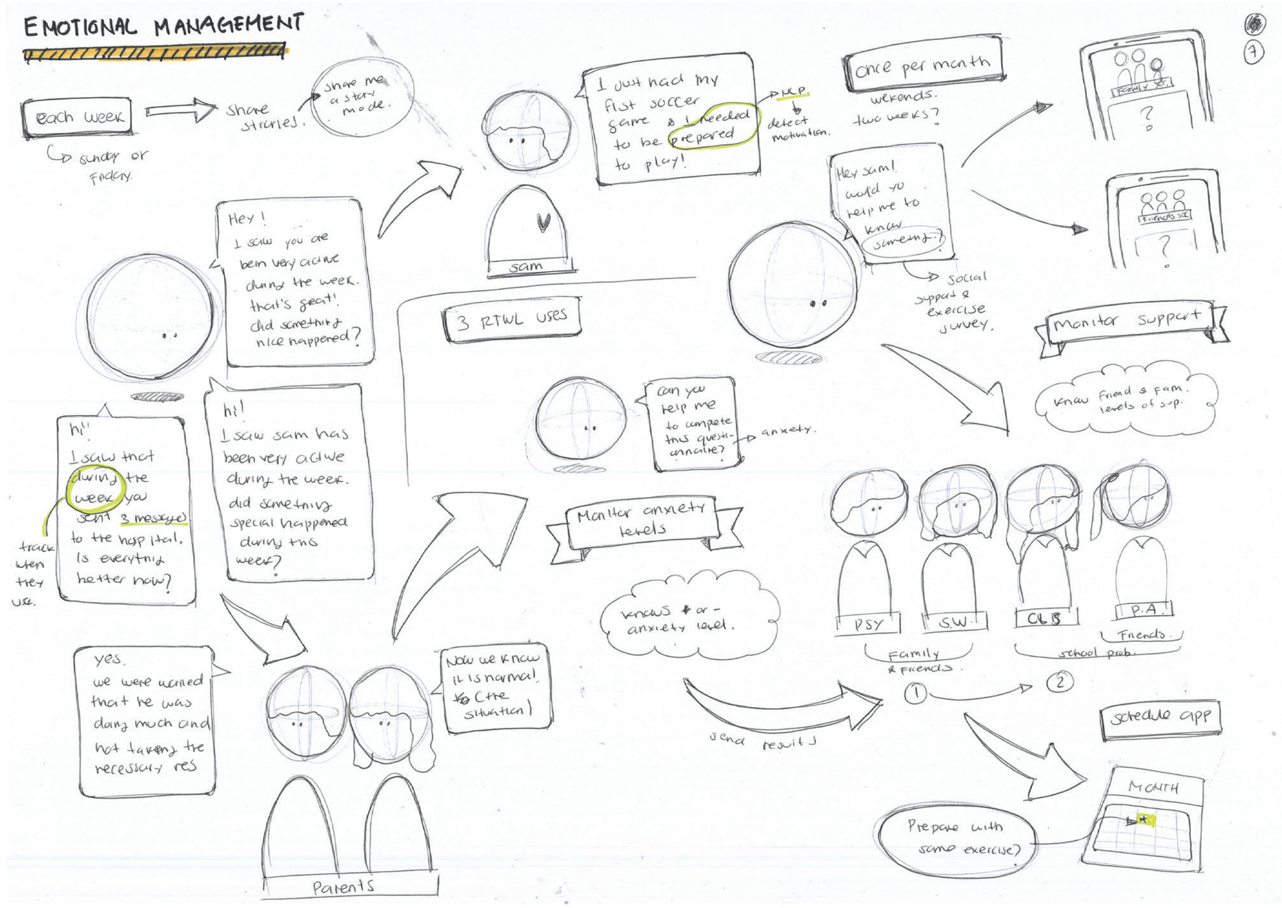

PERSONAL GOALS
1
I WAS THINKING ON START SWIMMING
I want to play sports
Wow, your health is very good! what do you think of starting to play ...
I saw a lot of people starting to practice x
would you like to try?
SAM
based on your CHD, I find this interesting options for you
SPORTS CLASSIFICATION

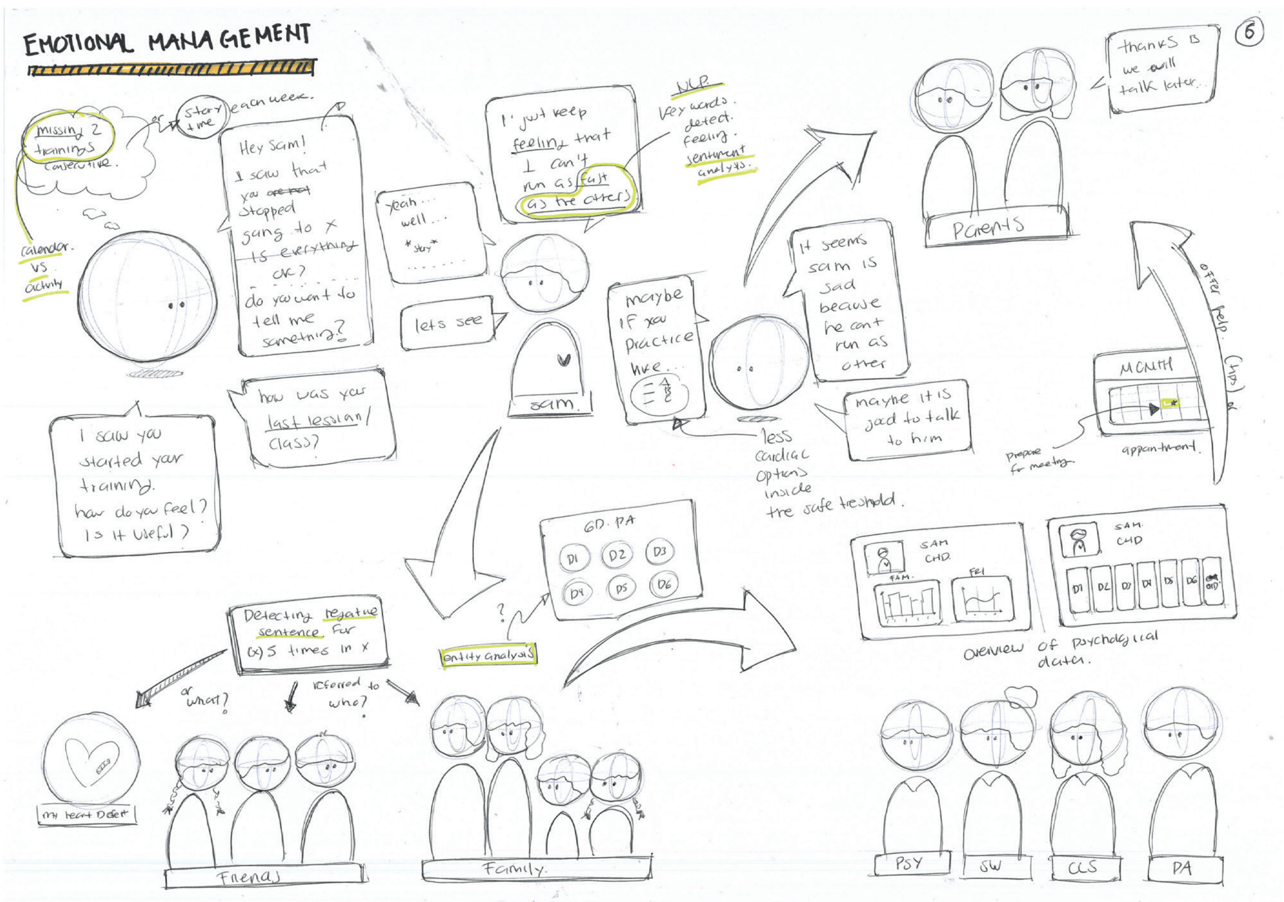

Personal Goals
2
Hey B! I want to start swimming.
SAM.
Cool! Remember your cardiologist said it was a good option
cellphone recording health appointments
let me look for options so we can show to your parents
"TUNE"
Sam wants to swim. he has x I check the PA recommendations do you see any objection?
PARENTS.
SAM.
P.C.
S.D.
schedule app.
yes
NO
see complete EHR.
combine & analyse. (NLP)
learn relationship
HR, Voz, intensity & medicine?

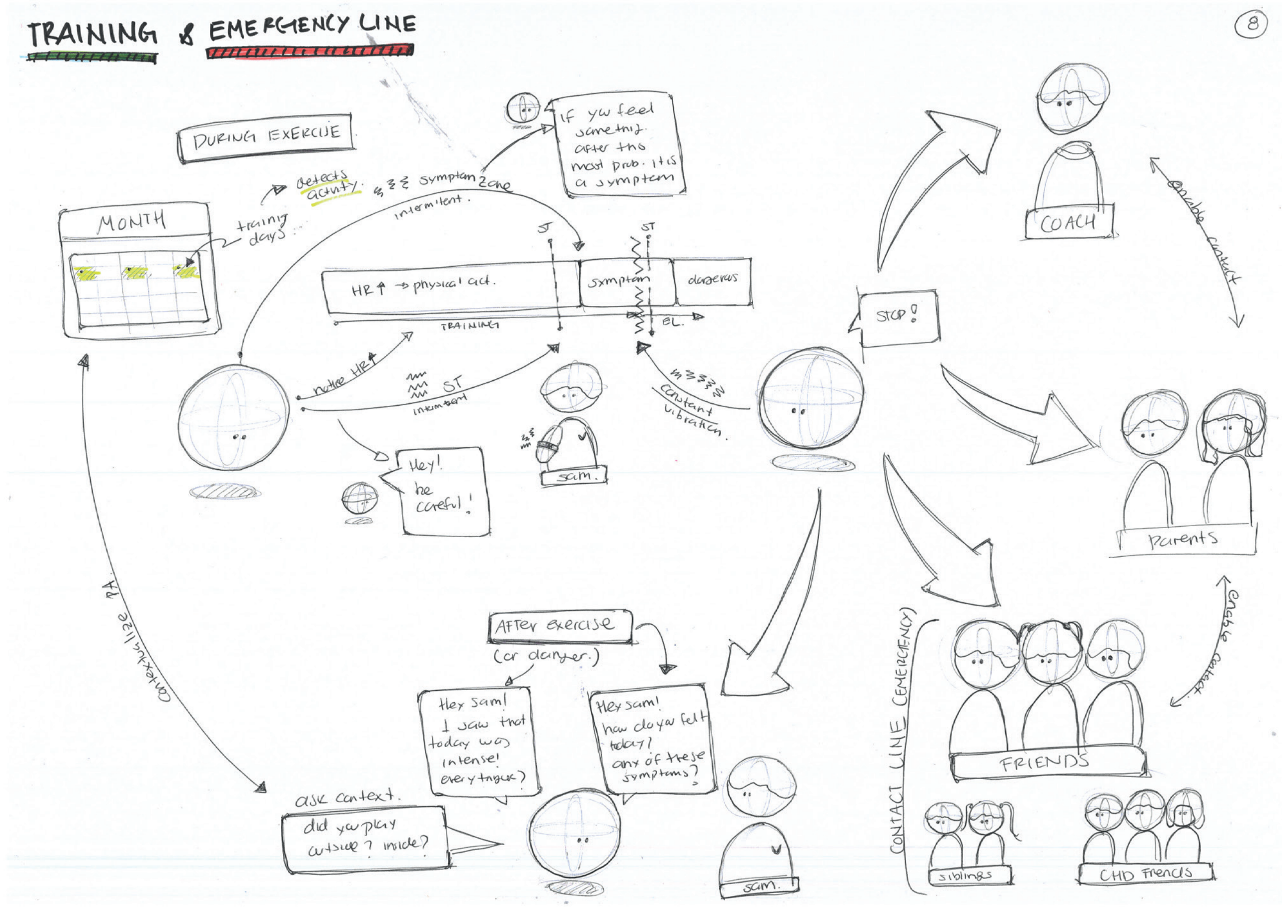

PERSONAL GOALS
3
SWIMMING SCHOOL
DIPLOMAS
A
B
C
SAM
Hey Sam! good luck today!
how was the game / x today?, did you felt good?
yes! thanks
anything that you want to share w/dr? (medical team)
maybe your diploma? I can take a picture!
Hey! I saw you are practicing swimming! is that true?
Tip to parent
WOW I saw Sam has a x on during this week, maybe if he starts eating / x it can be very good!
MONTH
(parents calendar)
(class coach)
Diff. positions in ≠ sports
compare in ≠ days
change in intensity? across months?
identify relevant dates for "game, diplomas"


PERSONAL GOALS
4
Not detecting soccer activity
Hey Sam! I remember that you wanted to play soccer. how is that going on?
yeah... well... I was playing but I got tired easy so I quitted
Oh! If you want I can send how your heart was during that time to the med. team to see what we can do:)
detection of key words.
medical team know how to help.
have HR data classified by activity & time. (day/month)
Parents.
SAM
PSY
PC.
SAM.
days with more "x"
Define parameters

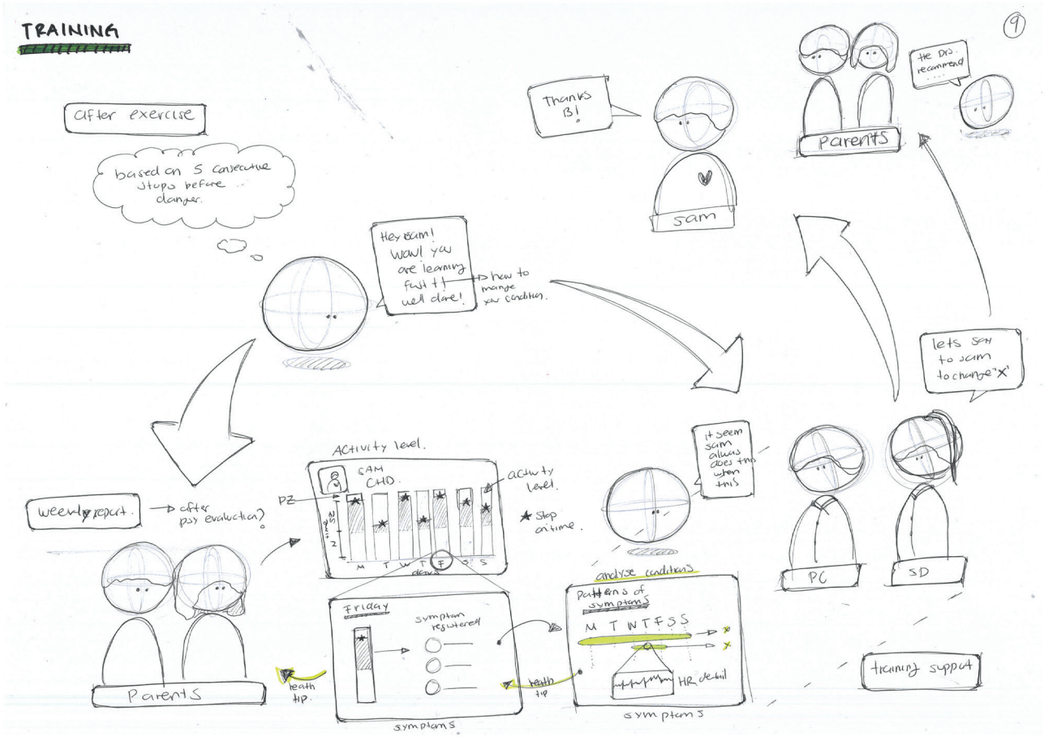

Sharing Boundaries
5
hospital
HOSPITAL
During Consultation
PARENTS
PC
P.C.
OD.
MONTH
AT HOME
home
1 week bef.
swimming class
Parents
sam
coach
medical team
database of questions


EMOTIONAL MANAGEMENT
7
Each week
once per month
sam
3 RTWL uses
Monitor support
Monitor anxiety levels
PSY
SW
CLS
P.A.
Parents
schedule app
MONTH

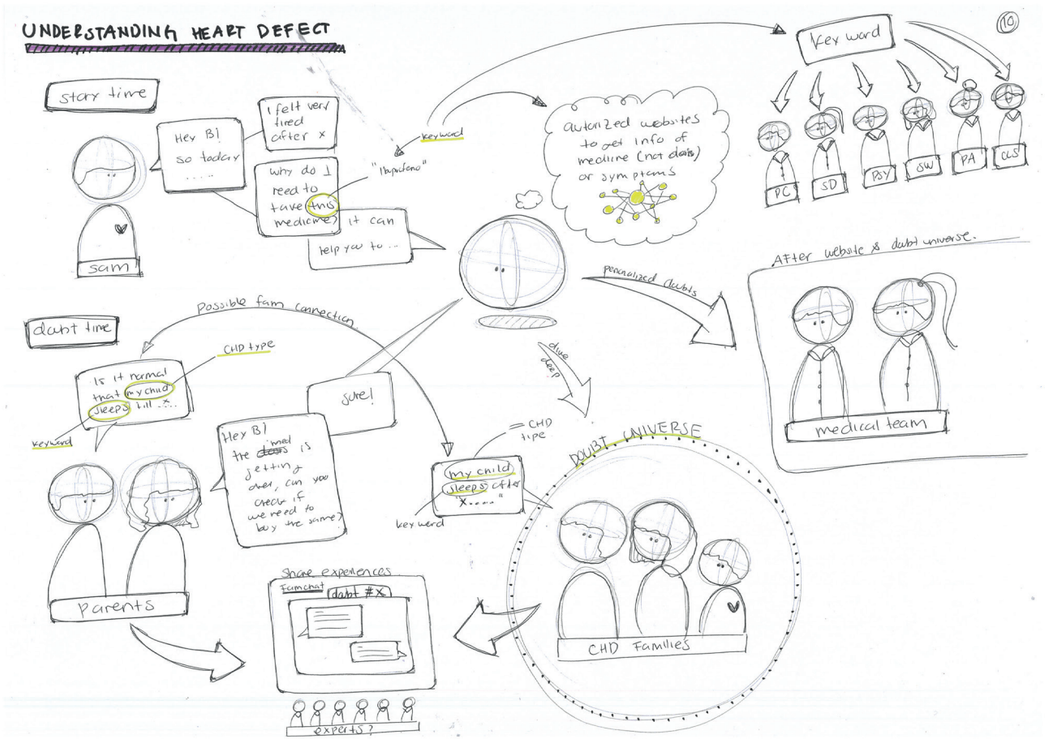

EMOTIONAL MANAGEMENT
6
Parents
sam
MONTH
Friends
Family
PSY
SW
CLS
PA


TRAINING & EMERGENCY LINE
8
DURING EXERCISE
MONTH
COACH
Parents
After exercise
FRIENDS
sam
CONTACT LINE (EMERGENCY)
siblings
CHD friends

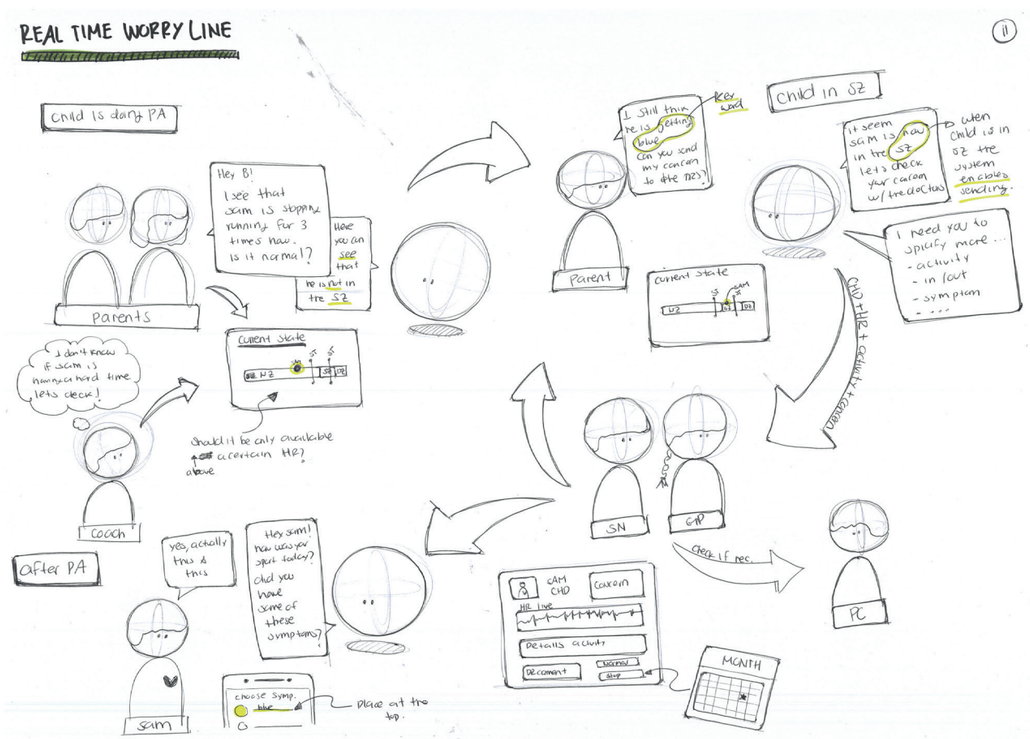
TRAINING



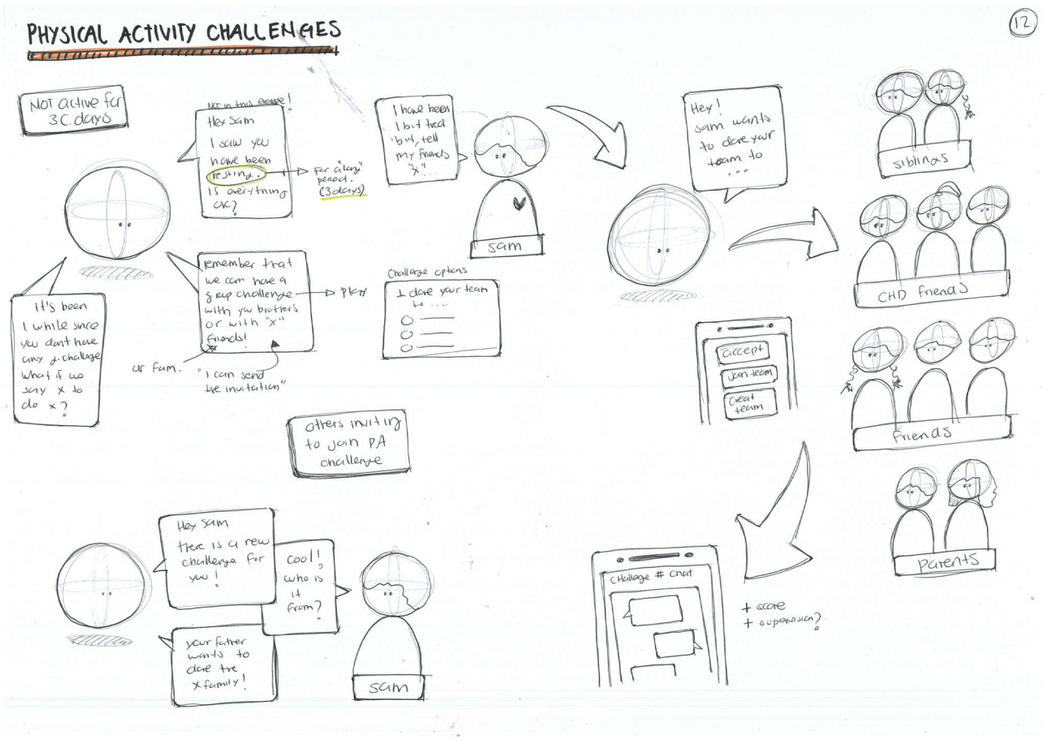
UNDERSTANDING HEART DEFECT

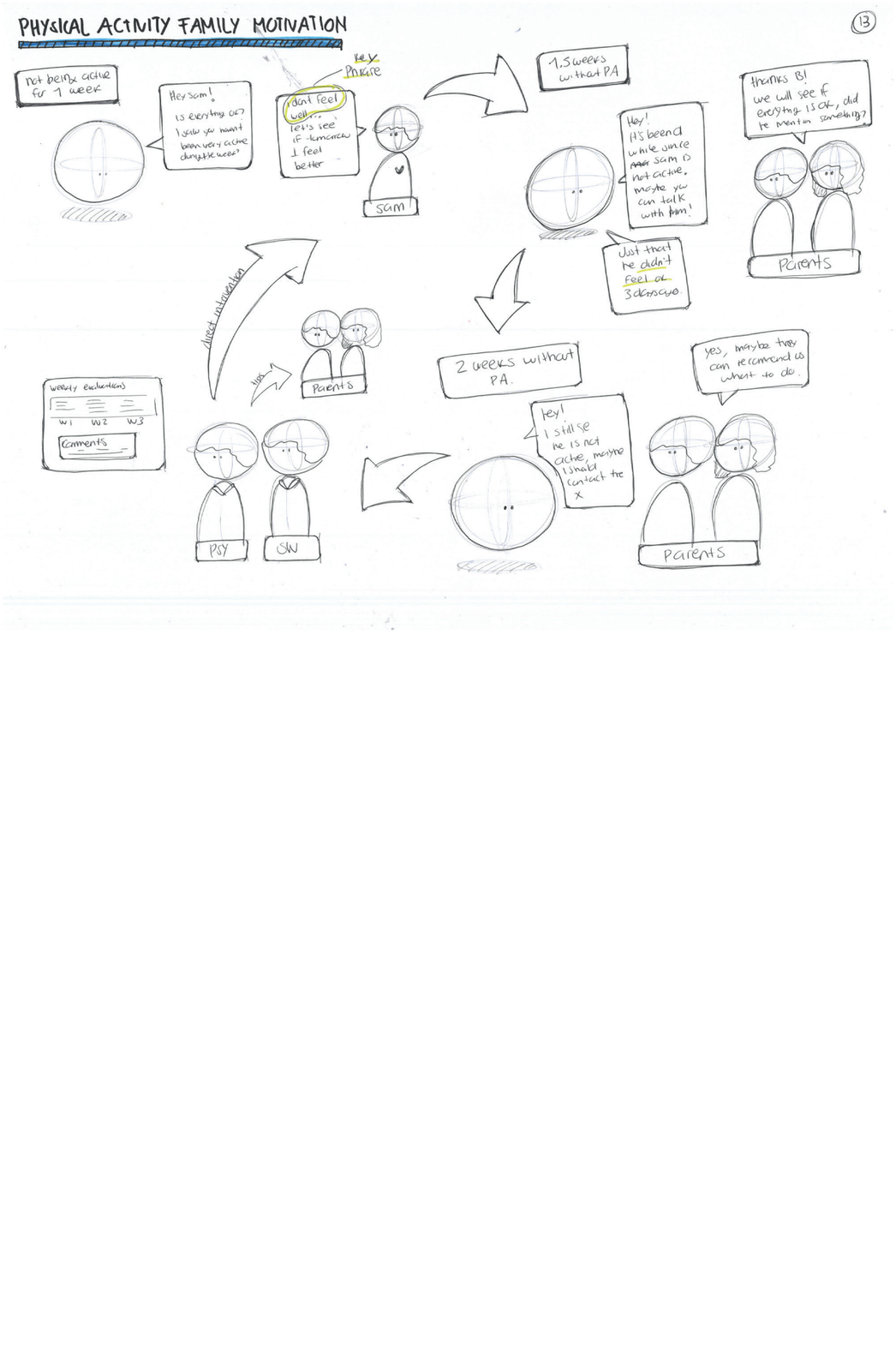


REAL TIME WORRY LINE



PHYSICAL ACTIVITY CHALLENGES




PHYSICAL ACTIVITY FAMILY MOTIVATION
13
not being active for 1 week
Hey sam!
is everything OK?
I saw you haven't been very active during the week?
Key Phrase
I don't feel well...
let's see if tomorrow I feel better
sam
1,5 weeks without PA
Hey!
It's been a while since sam is not active, maybe you can talk with him!
Just that he didn't feel ok 3 days ago
thanks B!
we will see if everything is ok, did he mention something?
Parents
direct intervention
Parents
2 weeks without PA.
weekly evaluations
W1 W2 W3
comments
Hey!
I still see he is not active, maybe I should contact the x
yes, maybe they can recommend us what to do.
PSY
SW
Parents

Appendix X

Technology map table

DEPEST	Source	Trends	Key concept 1	Key concept 2	Key concept 3	Key concept 4	Key concept 5	Key concept 6	Key concept 7	Key concept 8	Key concept 9	Key concept 10
Technological	Accenture	DARQ Power	Distributed ledger technology	artificial intelligence	extended reality	quantum computing						
Technological	Deloitte	Moving health care outside hospital walls	virtual health/telehealth	Synchronous care	Physician-to-physician communication	improve monitoring and alerts for chronic disease patients	Virtual social work	Remote patient monitorin				
Technological	Deloitte	"Being digital"	blockchain	cloud-based computing	virtual health	AI and robotics	digital reality,	Internet of Medical Things (IoMT)	data sharing via digital solutions	personalization	self-service	patient experience
Technological	Fjord	Silence is gold	Take a lack of responsiveness as a hint to be quieter, not noisier.	Radically simplify your feedback surveys	Invest in content design	Measure the cognitive effort						
Technological	Fjord	Data minimalism	Empower people to know how, where and why their data was used	minimal viable data pattern	Allow people to act when data about them is wrong							
Technological	Fjord	Ahead of the curb	Design for moving from A to B	Go for gains, not pains	As mobility becomes an ecosystem, many aspects will connect or merge	Partners trump platforms						
Technological	Fjord	Space odyssey	Let online behaviours inform offline	The experience of seamlessly moving between digital and physical channels is evolving	Link space and business strategy	Create a connected ecosystem						
Technological	Fjord	Synthetic realities	In a world of synthetic realities, authenticity – something consumers value highly		distinguish your brand by having a clear purpose	Explore synthetic realities as a creative tool	Harness the power of AI-generated images for learning					
Technological	Gartner	Augmented intelligence	enhance cognitive performance	assistive role in advancing capabilities								
Technological	Gartner	Chatbots	guidance	tips								
Technological	Gartner	Machine learning	personalized customer treatment	supply chain recommendations	dynamic pricing	medical diagnostics	anti-money laundering					
Technological	Gartner	AI governance	policies to fight AI-related biases	negative implications of AI								
Technological	Gartner	Intelligent applications	intelligent automation	data-driven insights	guided recommendations							
Technological	Gartner	Sensing and mobility	Internet of Things	AR cloud	autonomous driving levels 4 and 5	flying autonomous vehicles	3D sensing cameras	light cargo delivery drones				
Technological	Gartner	Augmented human	biochips	emotion AI	Personification	immersive workspace	biotech					
Technological	Gartner	Postclassical compute and comms	5G	Next-generation memory	Low-earth-orbit datellite systems	nanoscale 3D printing						
Technological	Gartner	Digital ecosystems	DigitalOps	Knowledge graphs	syntethic data	decentalized web	decentralized autonomous organizations					
Technological	Gartner	Advanced AI and analytics	Adaptive machine learning	Edge AI	Edge analytics	Explainable AI	AI PaaS	Transfering learning	generative adversarial networks	graph analytics		
Technological	Gartner	Hyperautomation	robotic process automation (RPA)	intelligent business management software (iBPMS)	artificial intelligence	machine learning	digital twin of the organization (DTO)					
Technological	Gartner	Multiexperience	augmented reality (AR),	virtual (VR)	mixed reality	multichannel human-machine interfaces	sensing technologies					
Technological	Gartner	Human augmentation	Sensory augmentation	biological function augmentation	brain augmentation	genetic augmentation						
Technological	Gartner	The empowered edge	Edge computing	Internet of Things (IoT)								
Technological	Gartner	The distributed cloud	cloud computing.									
Technological	Gartner	Autonomous things	drones	robots	ships							
Technological	Gartner	Practical blockchain										
Technological	Mckinsey	digital health ecosystem	Health coach	challenges and rewards	premium check-ups	treatment paths	best doctor	telemedicine	second opinion	healthcare concierge	food service	social integration
Technological	PwC HRI	Digital therapeutics	Connected care	biopharmaceutical	real-time therapeutic insights	behavioral changes	Focus on outcomes, not just endpoints	Evaluate the impact	Explore partnership			
Technological	Trend Hunter	Deepfake Production	catalyst for the betterment of the human race.	AI								
Technological	Trend Hunter	Gamified Stay	material goods are less valuable than shareable memories.	Experience								
Technological	Trend Hunter	Rewarded Action	game dynamics and incentivization to day-to-day tasks	competitive and engaging world.	Gamification							
Technological	Trend Hunter	Holographic Assistant	hyper-individualized products and services	Personalization								
Technological	Trend Hunter	Behavioral Installation	immersive entertainment	Multisensation								
Technological	Trend Hunter	Active Silence	focused business models,	simplistic thinking	streamlined UX	Simplicity						
Technological	World Economic Forum	Social Robots	Droid friends	Droid assistants								
Technological	World Economic Forum	Tiny Lenses for Miniature Devices										
Technological	World Economic Forum	Disordered Proteins as Drug Targets										
Technological	World Economic Forum	Collaborative Telepresence	virtual gatherings will feel like they are physically together									
Technological	World Economic Forum	Advanced Food Tracking and Packaging										
Technological	World Economic Forum	DNA Data Storage										

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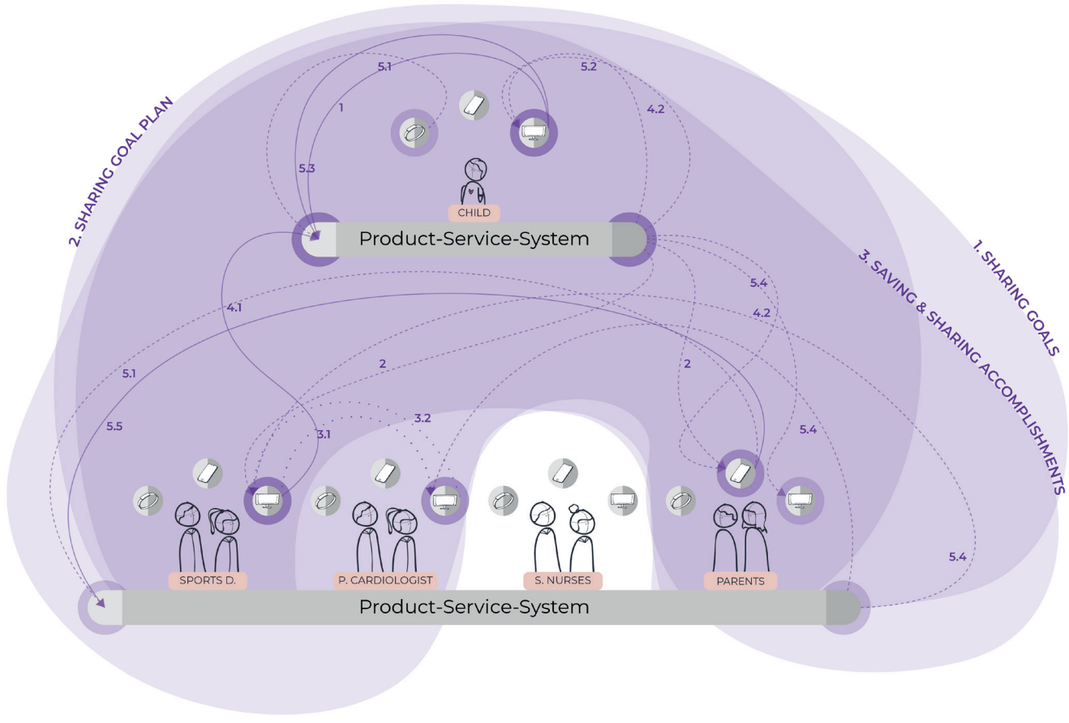
Technological	World Economic Forum	DNA Data Storage										

Appendix Y

PSS Individual visualization of functions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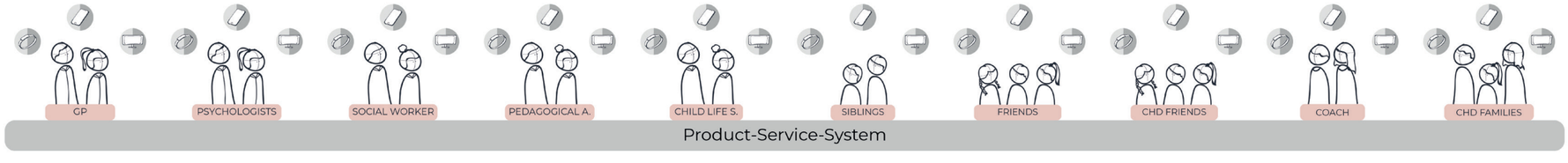
1. SHARING GOALS
3. SAVING & SHARING ACCOMPLISHMENTS
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
1
5.1
5.2
4.2
5.3
4.1
5.1
2
2
5.4
4.2
5.5
3.1
3.2
5.4
5.4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SOCIAL WORKER
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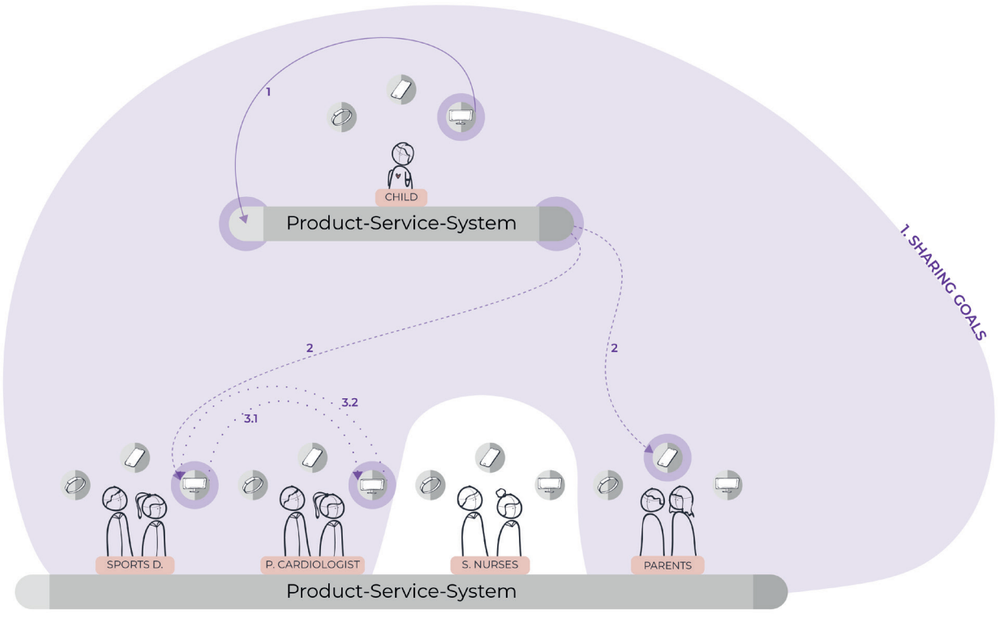
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System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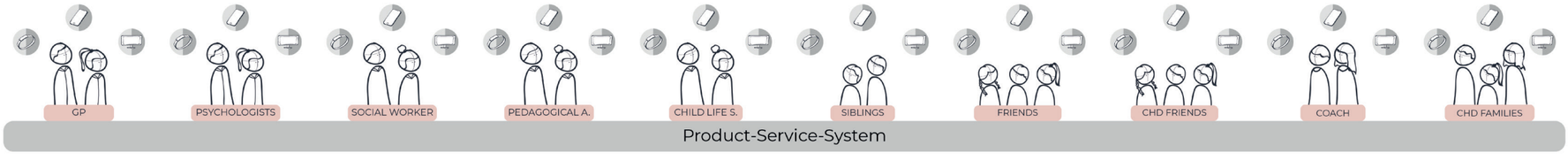
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
1
2
2
3.2
3.1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CHD FRIENDS
COACH
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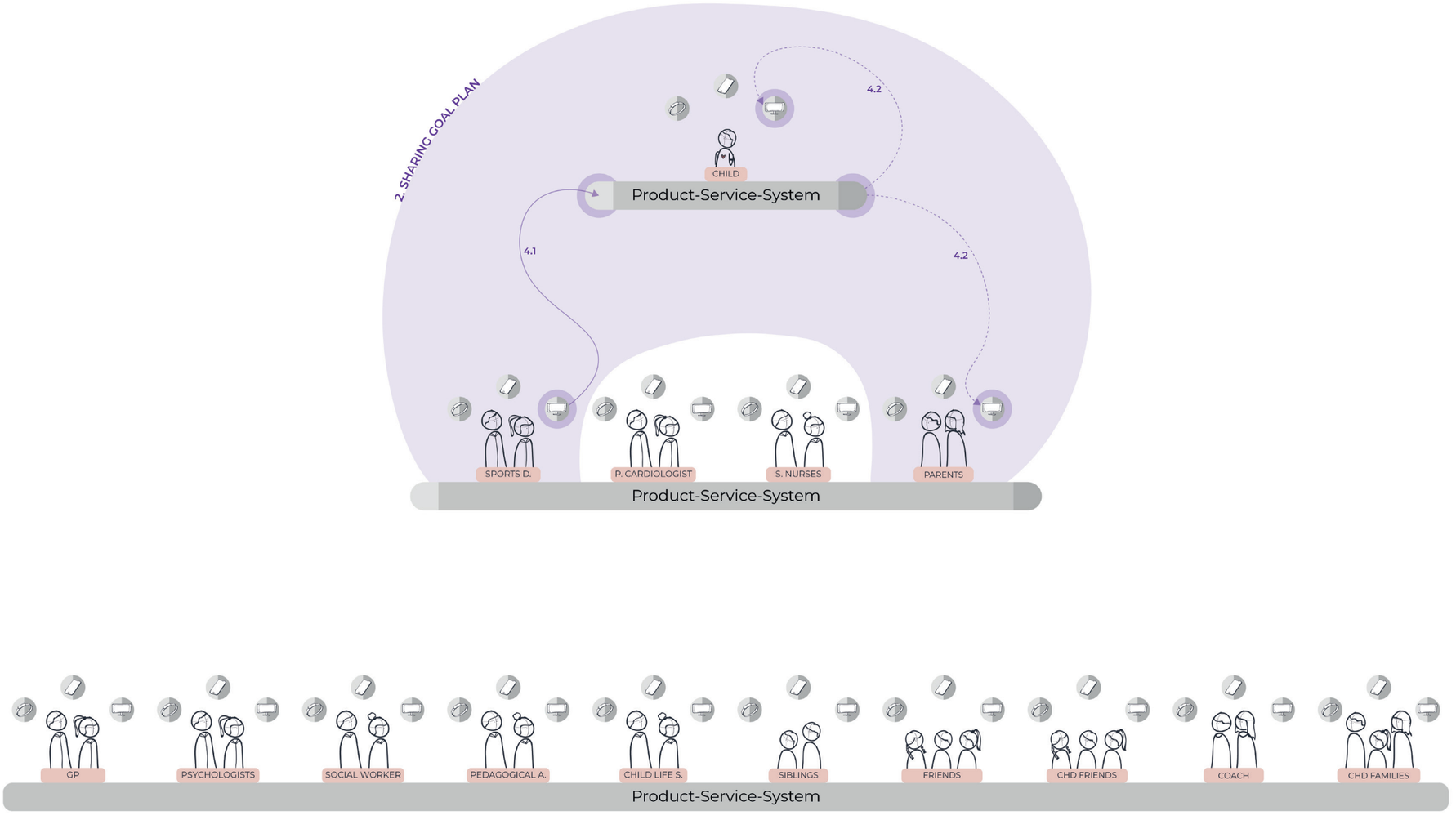
Product-Service-System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4.2
CHILD
Product-Service-System
4.1
4.2
SPORTS D.
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S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
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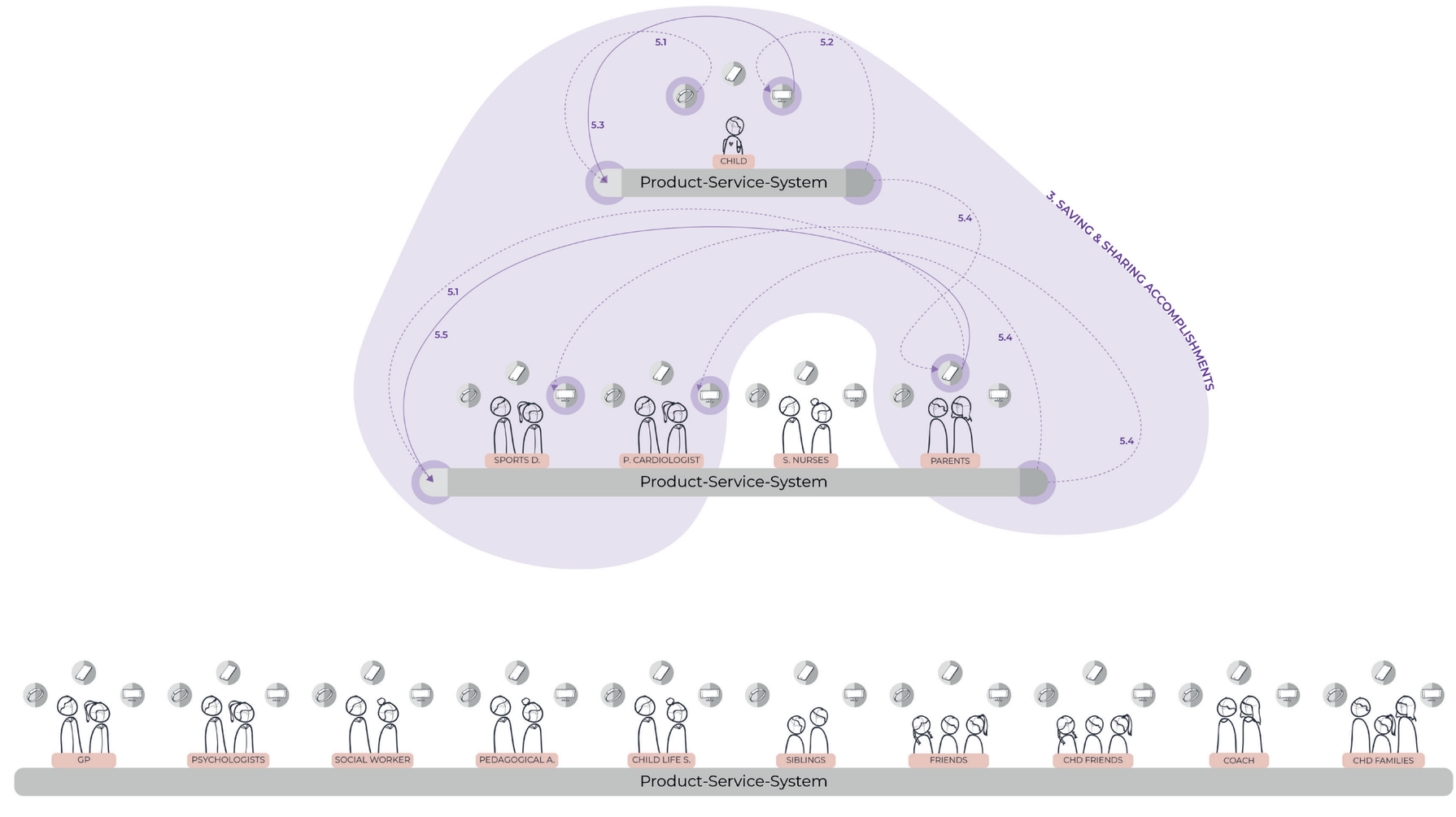
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System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5.4
SPORTS D.
P. CARDIOLOGIST
S. NURSES
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Product-Service-System
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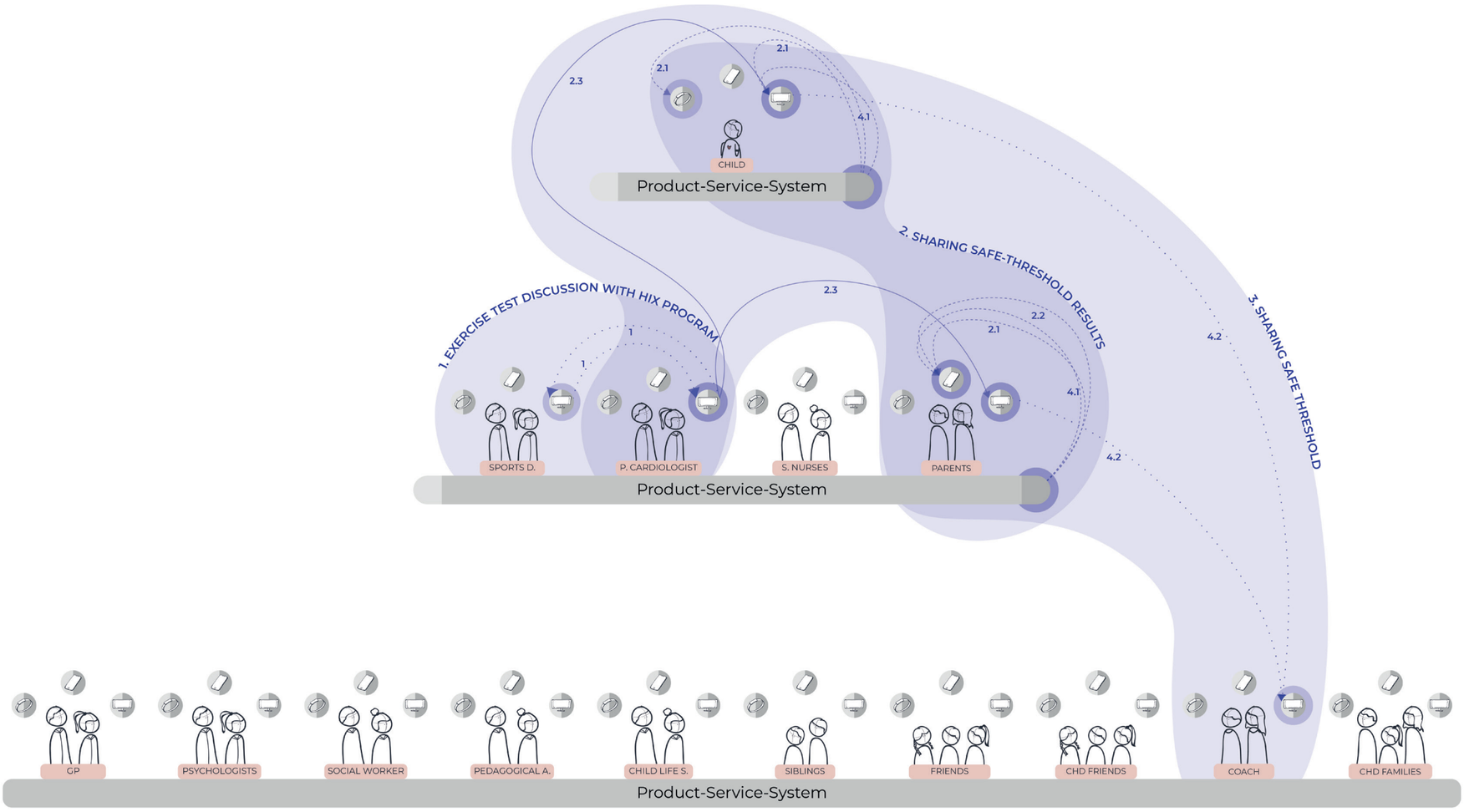
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3. SHARING SAFE THRESHOLD
1. EXERCISE TEST DISCUSSION WITH HIX PROGRAM
2.3
1
1
2.2
2.1
4.1
4.2
4.2
SPORTS D.
P. CARDIOLOGIST
S. NURSES
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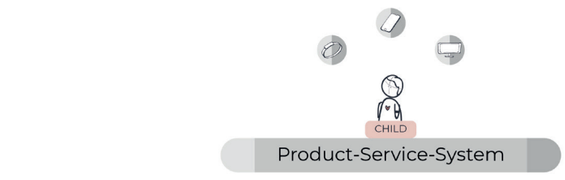
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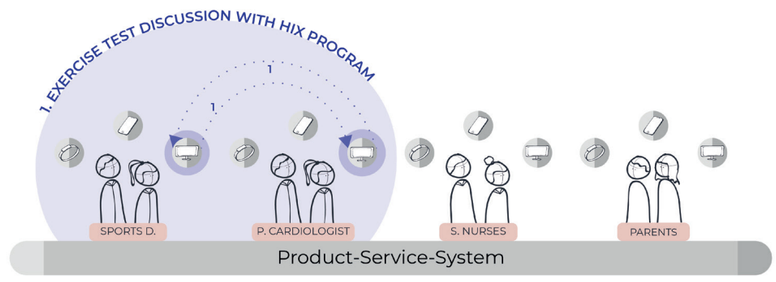
Product-Service-System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SPORTS D.
P. CARDIOLOGIST
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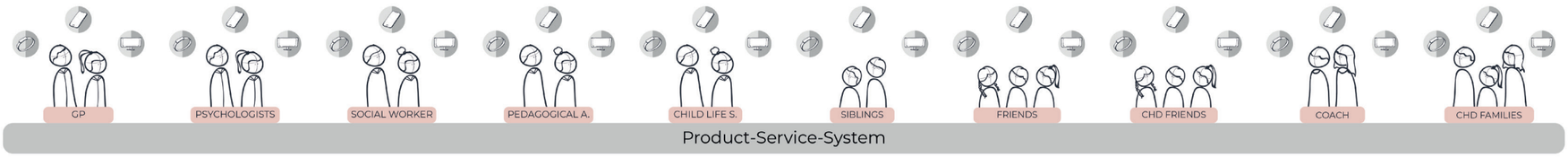
PARENTS
Product-Service-System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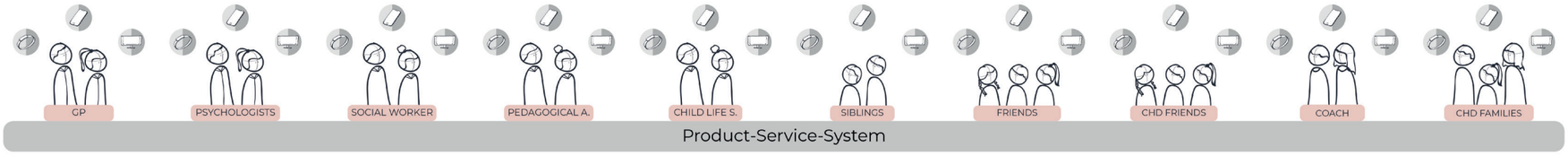
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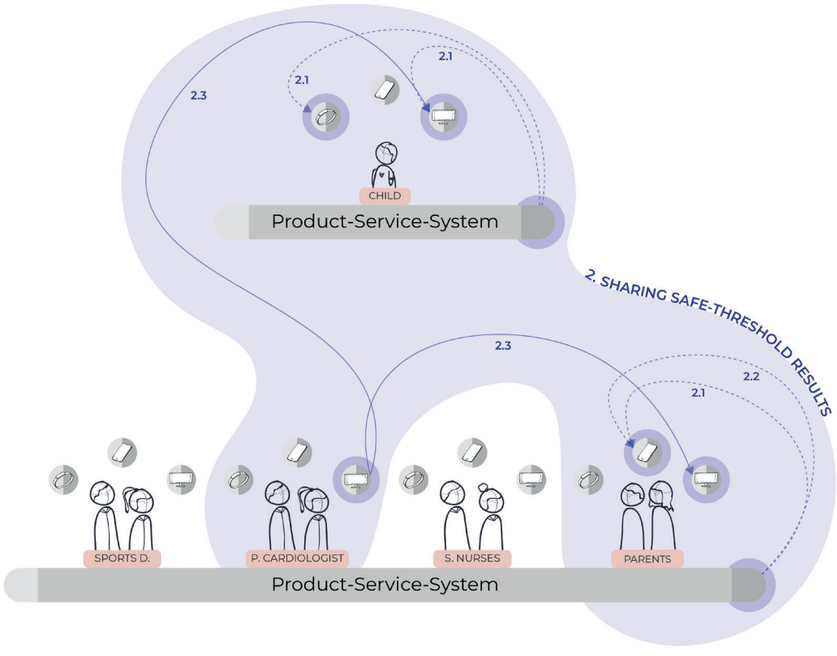
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2.1
2.1
CHILD
Product-Service-System
2. SHARING SAFE-THRESHOLD RESULTS
2.3
2.2
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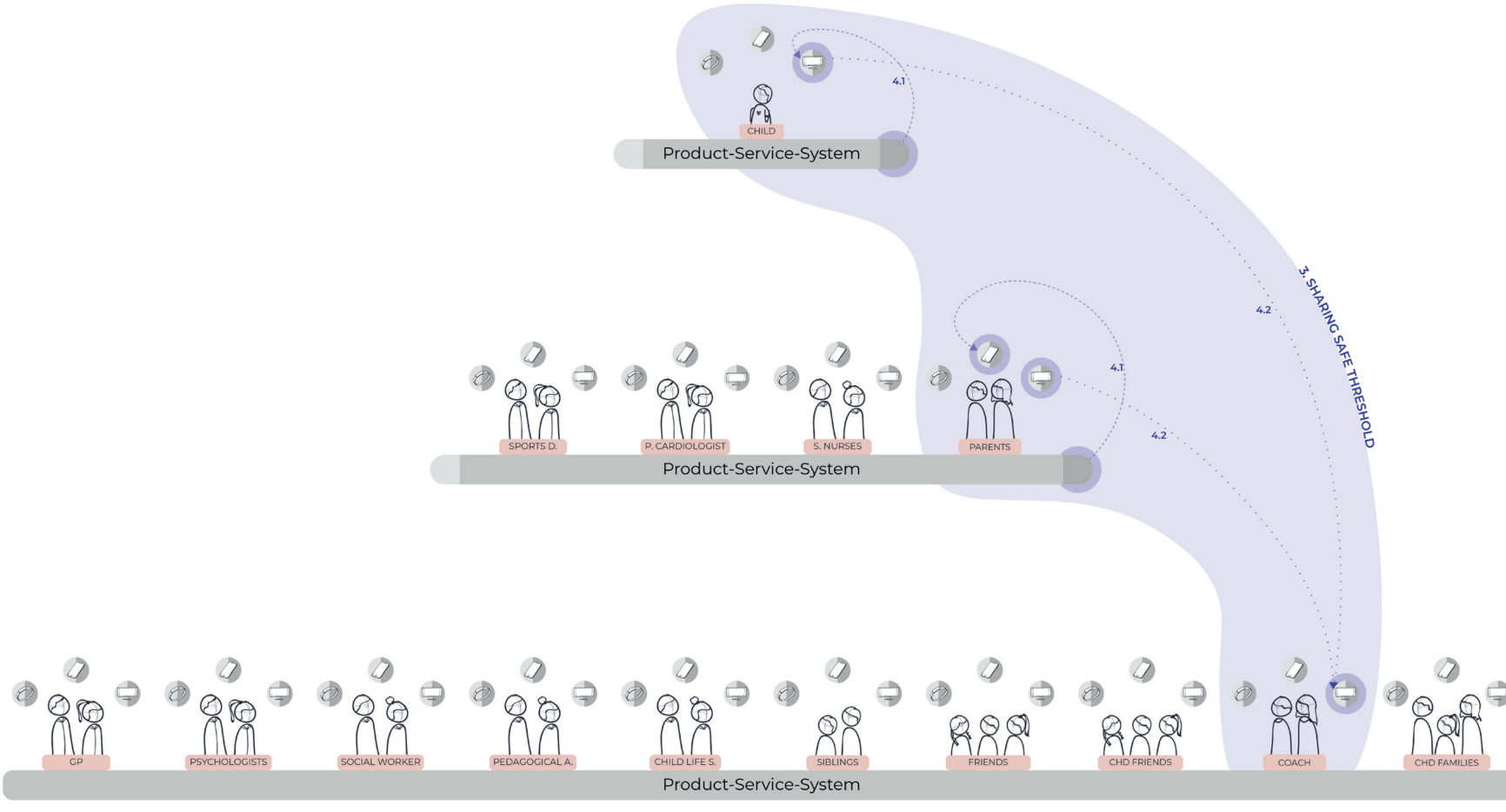
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Product-Service-System
3. SHARING SAFE THRESHOLD
4.2
4.1
4.2
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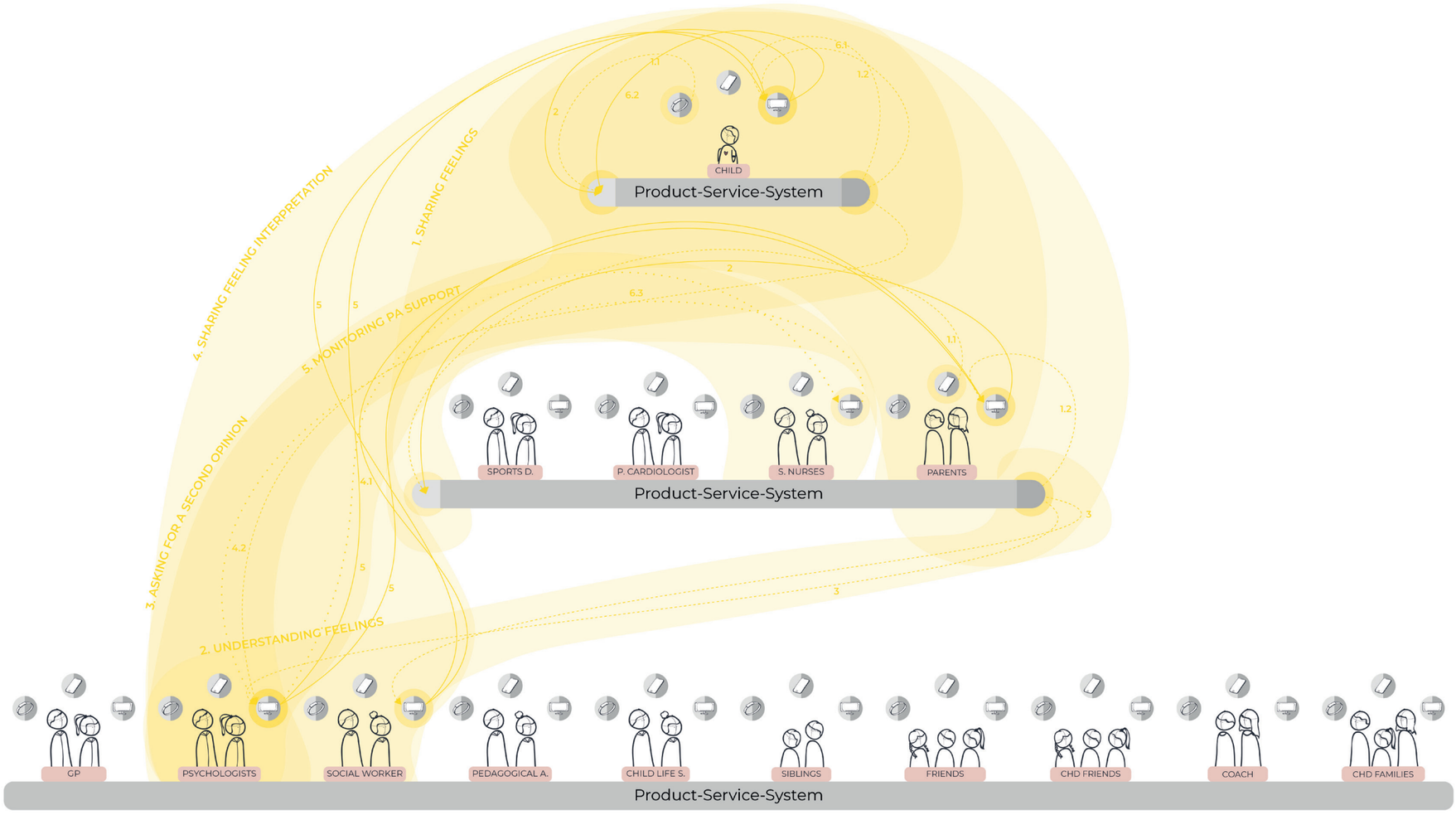
1. SHARING FEELINGS
2. UNDERSTANDING FEELINGS
3. ASKING FOR A SECOND OPINION
4. SHARING FEELING INTERPRETATION
5. MONITORING PA SUPPORT
1.1
1.2
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4.1
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6.1
6.2
6.3
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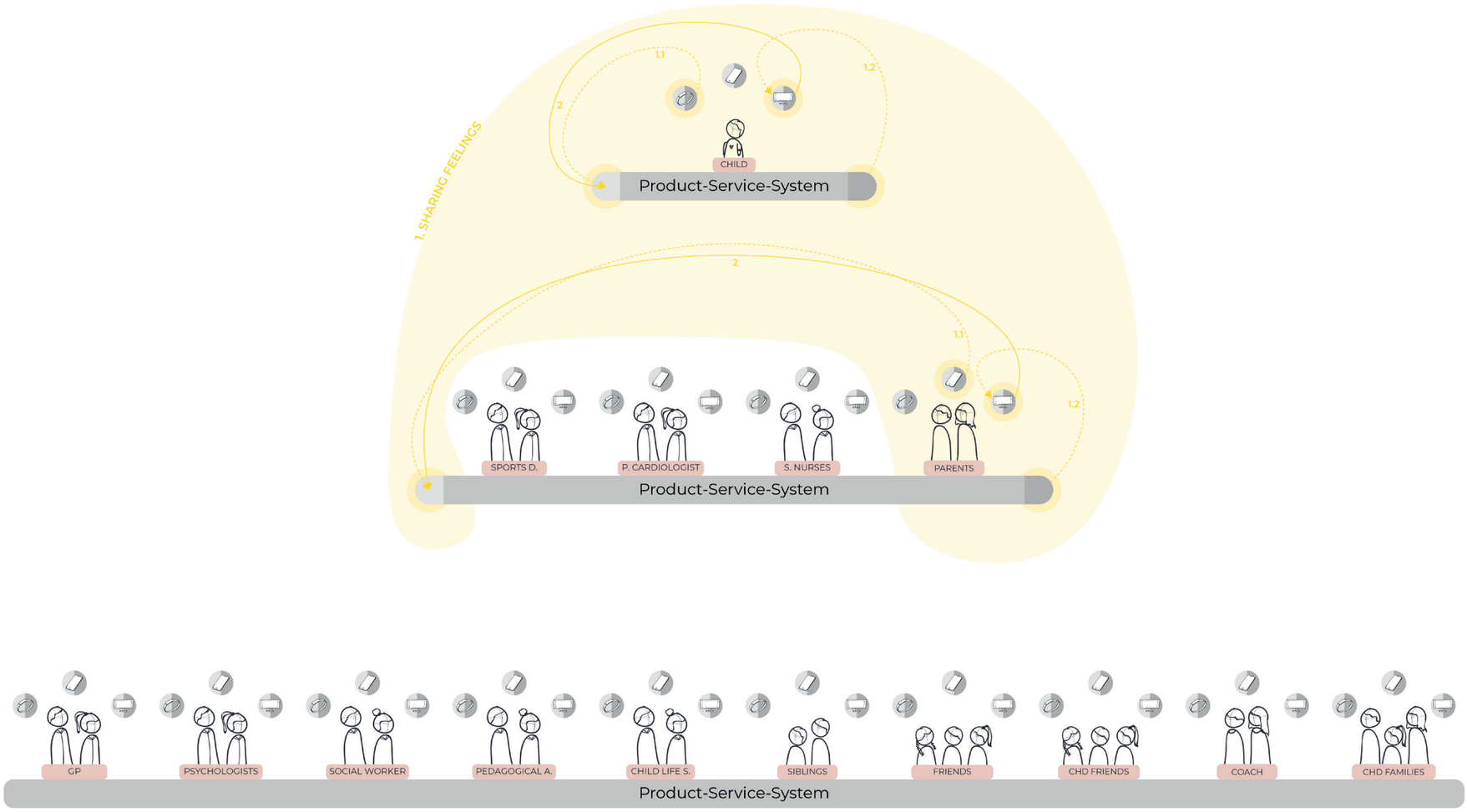
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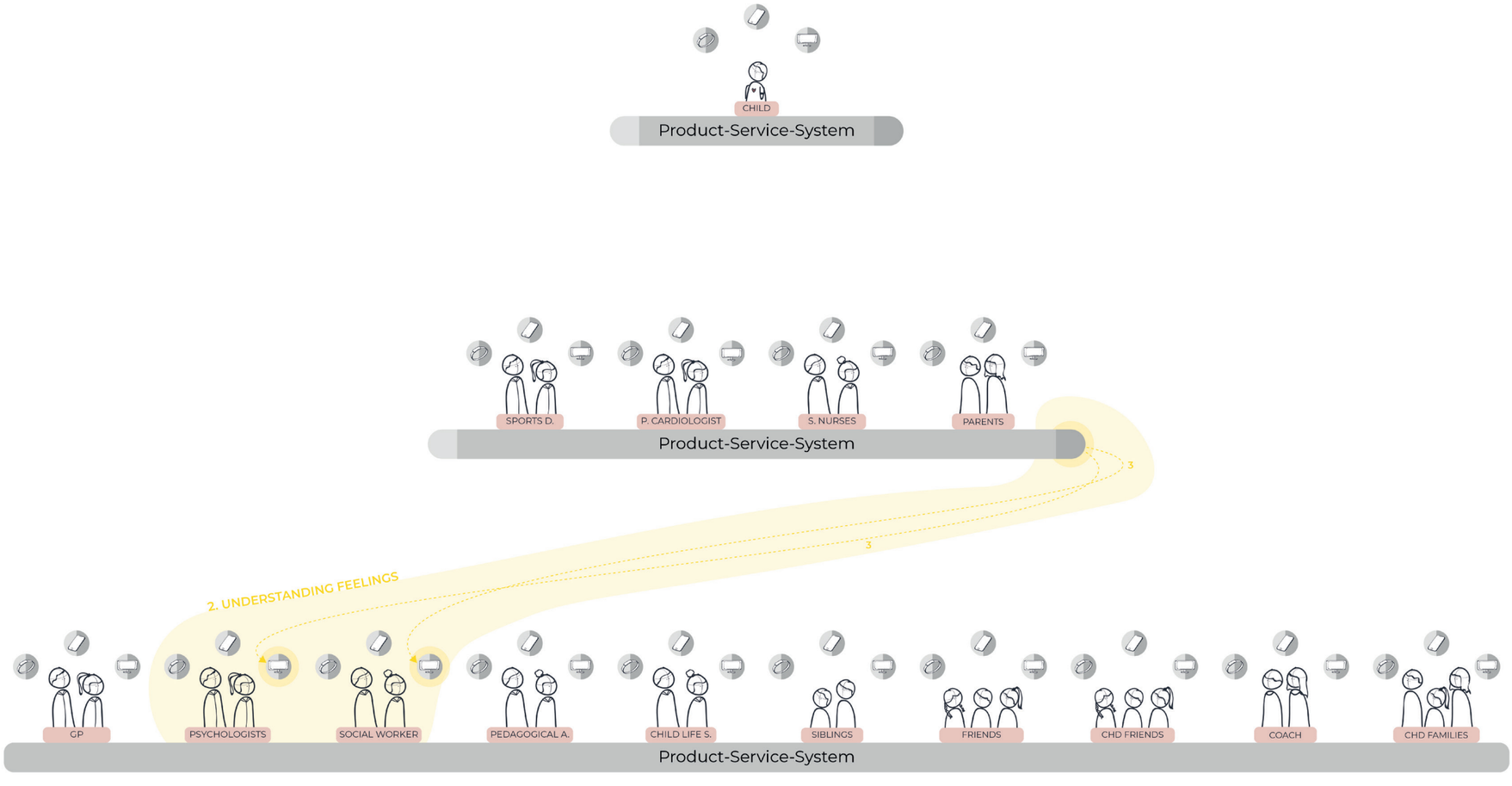
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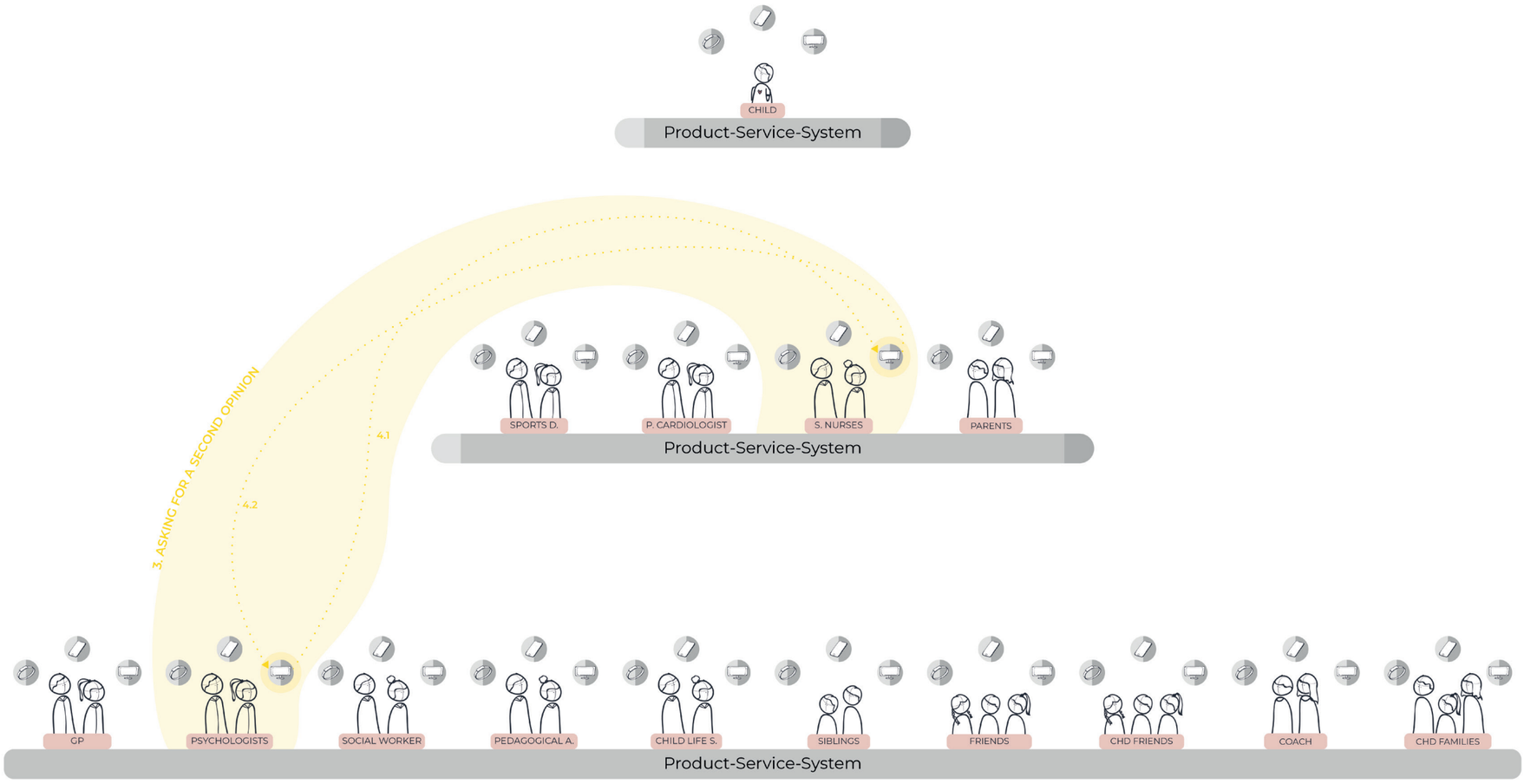
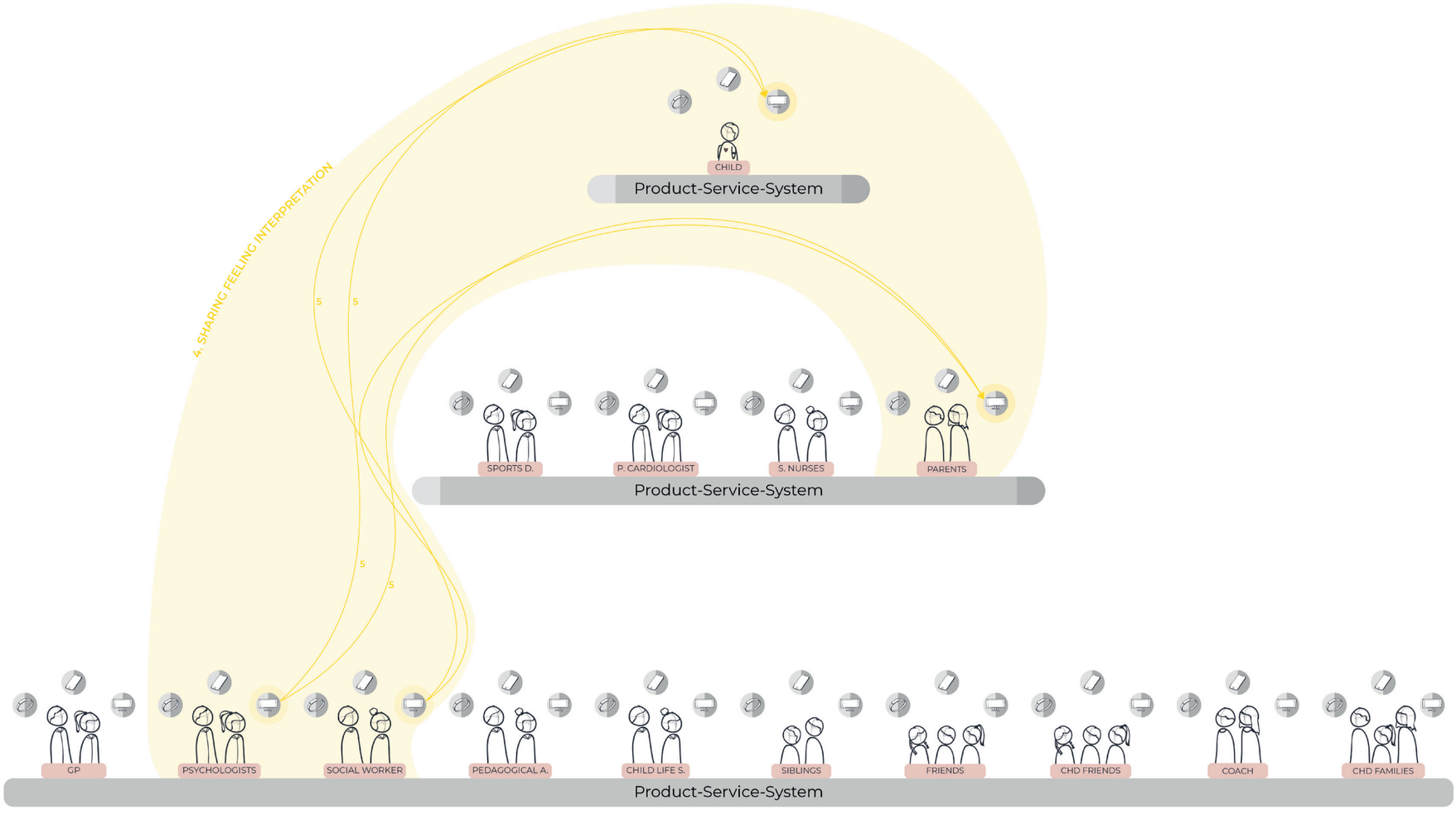
CHD FAMILIES
Product-Service-System


CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
3. ASKING FOR A SECOND OPINION
4.1
4.2
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


4. SHARING FEELING INTERPRETATION
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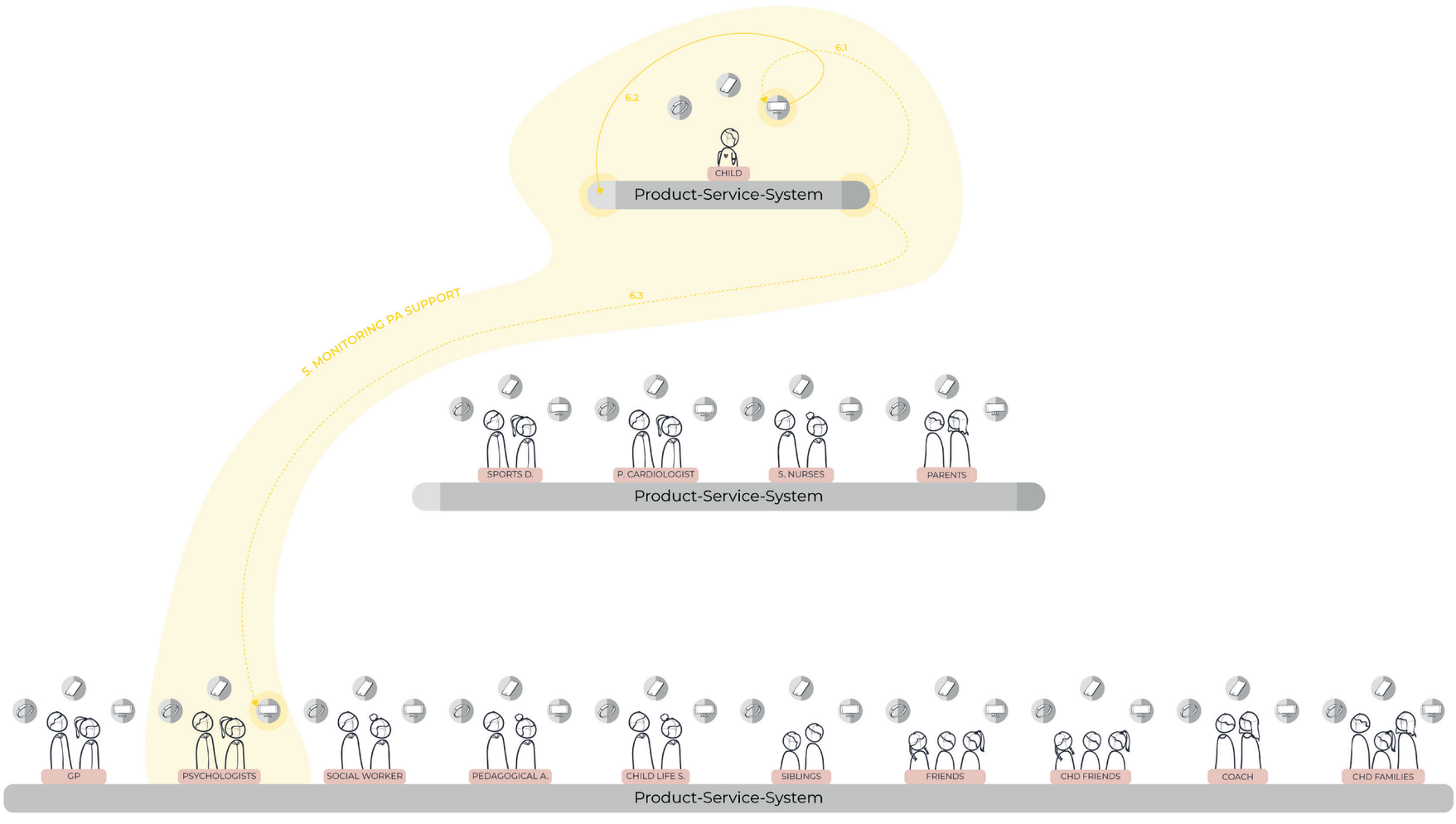
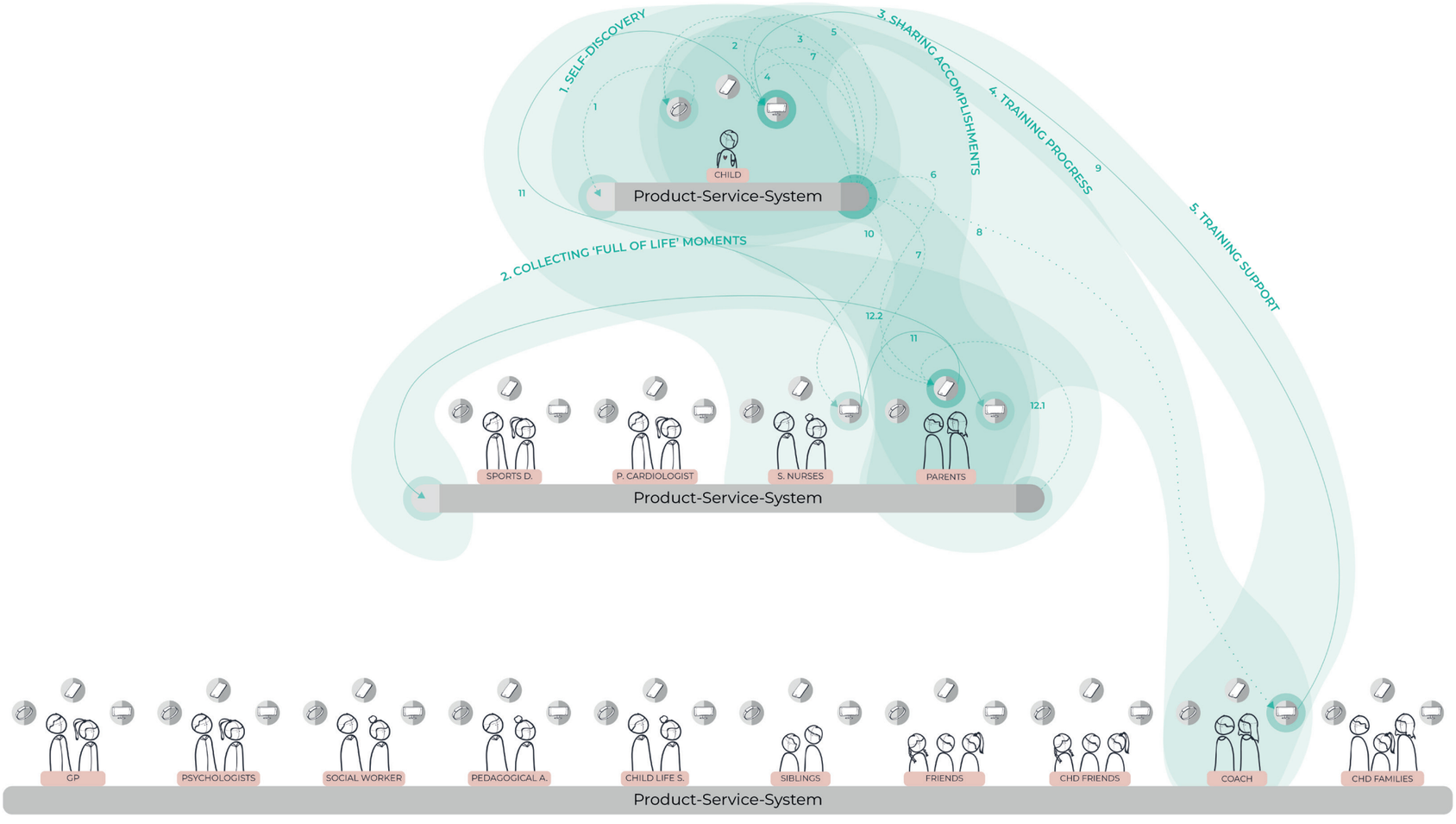
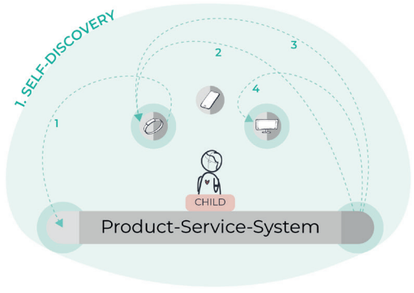
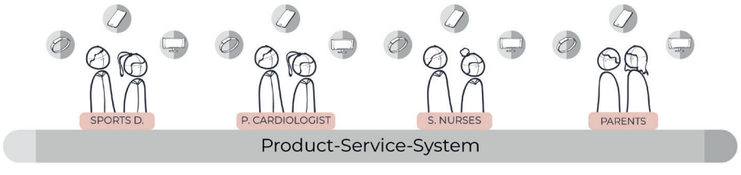
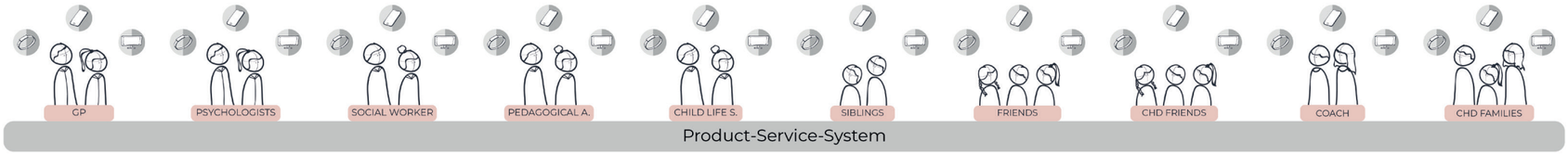
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System

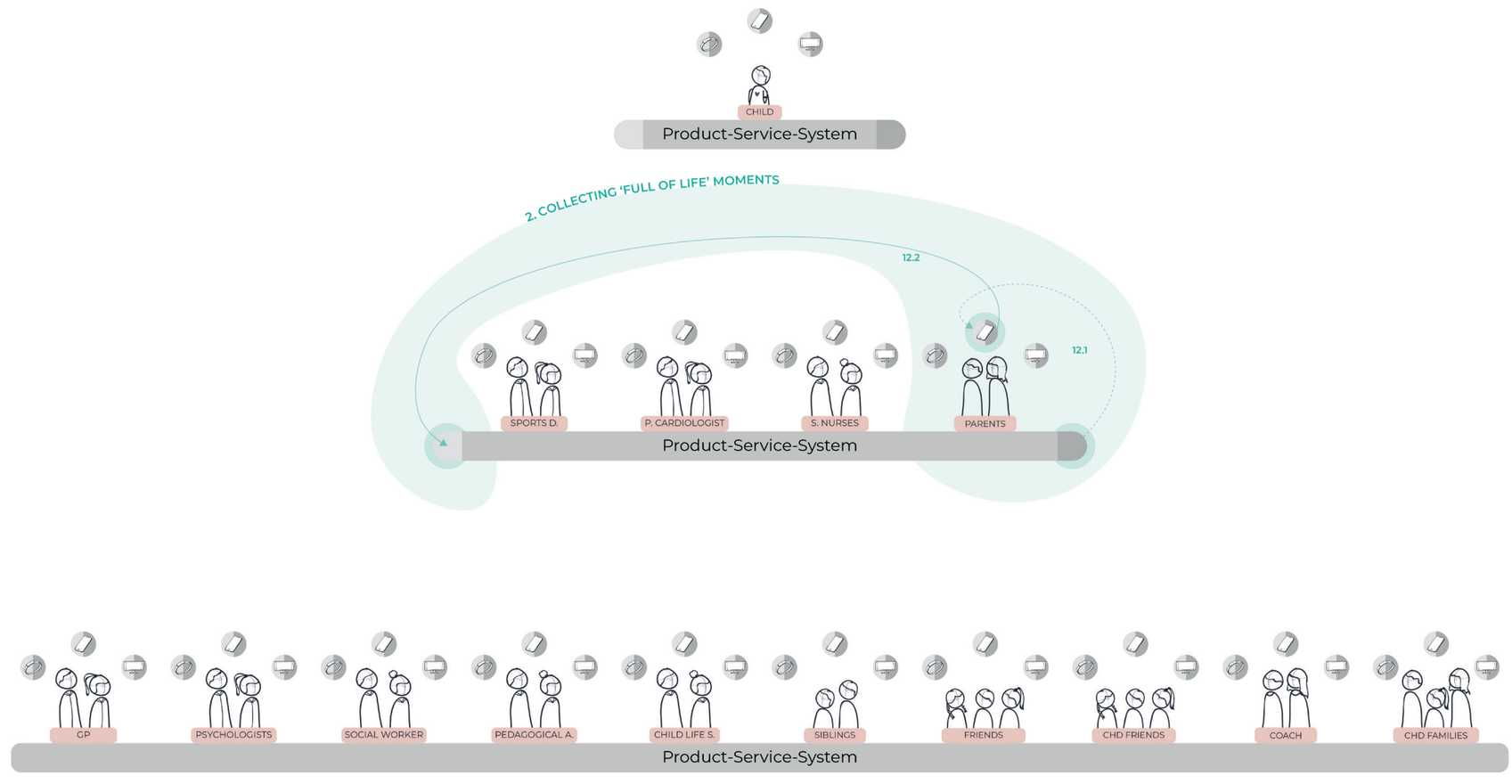

6.1
6.2
6.3
5. MONITORING PA SUPPORT
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System

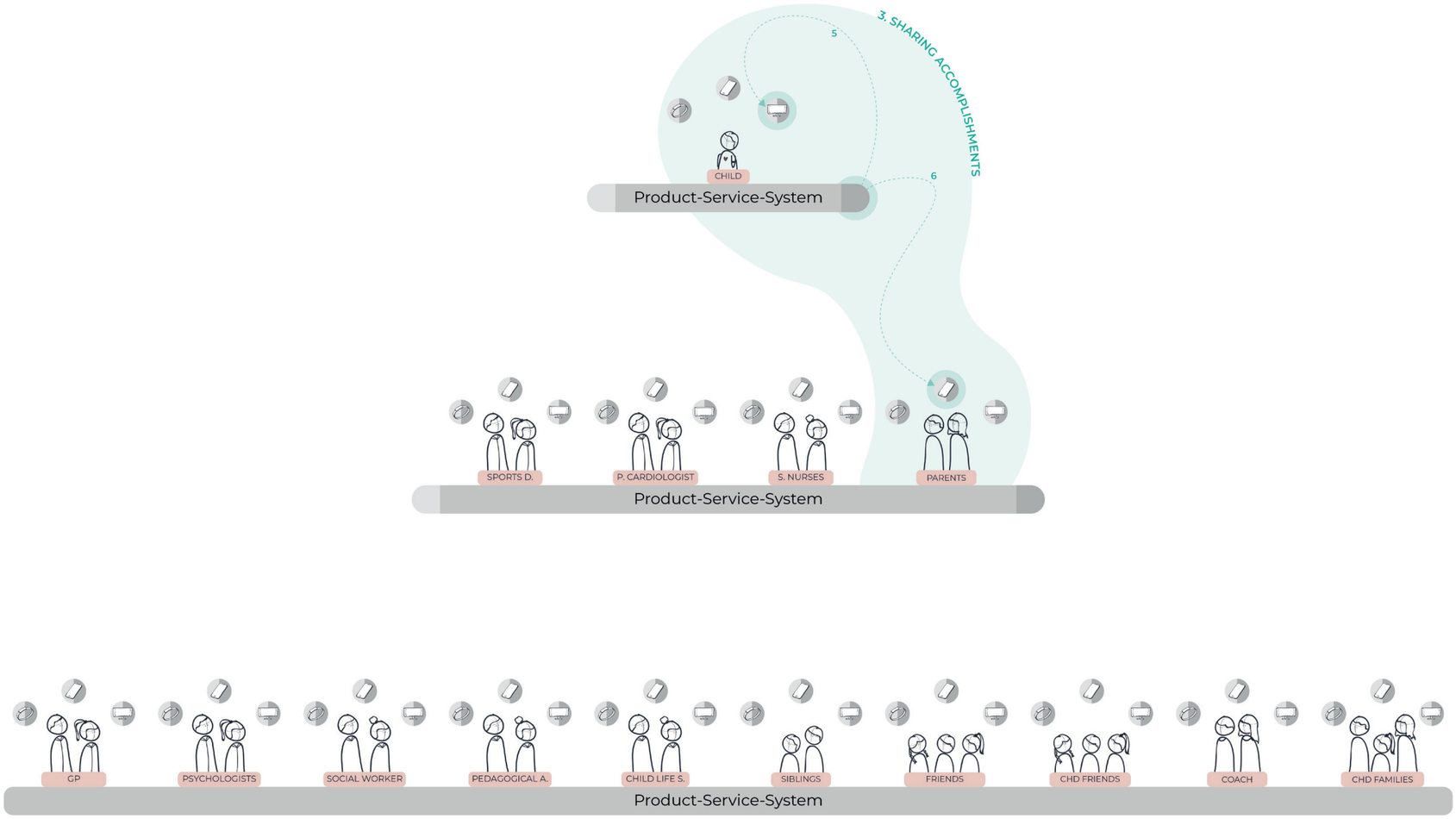

1. SELF-DISCOVERY
2. COLLECTING 'FULL OF LIFE' MOMENTS
3. SHARING ACCOMPLISHMENTS
4. TRAINING PROGRESS
5. TRAINING SUPPORT
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


1. SELF-DISCOVERY
CHILD
Product-Service-System


SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System


GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


CHILD
Product-Service-System
2. COLLECTING 'FULL OF LIFE' MOMENTS
12.2
12.1
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


3. SHARING ACCOMPLISHMENTS
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6
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
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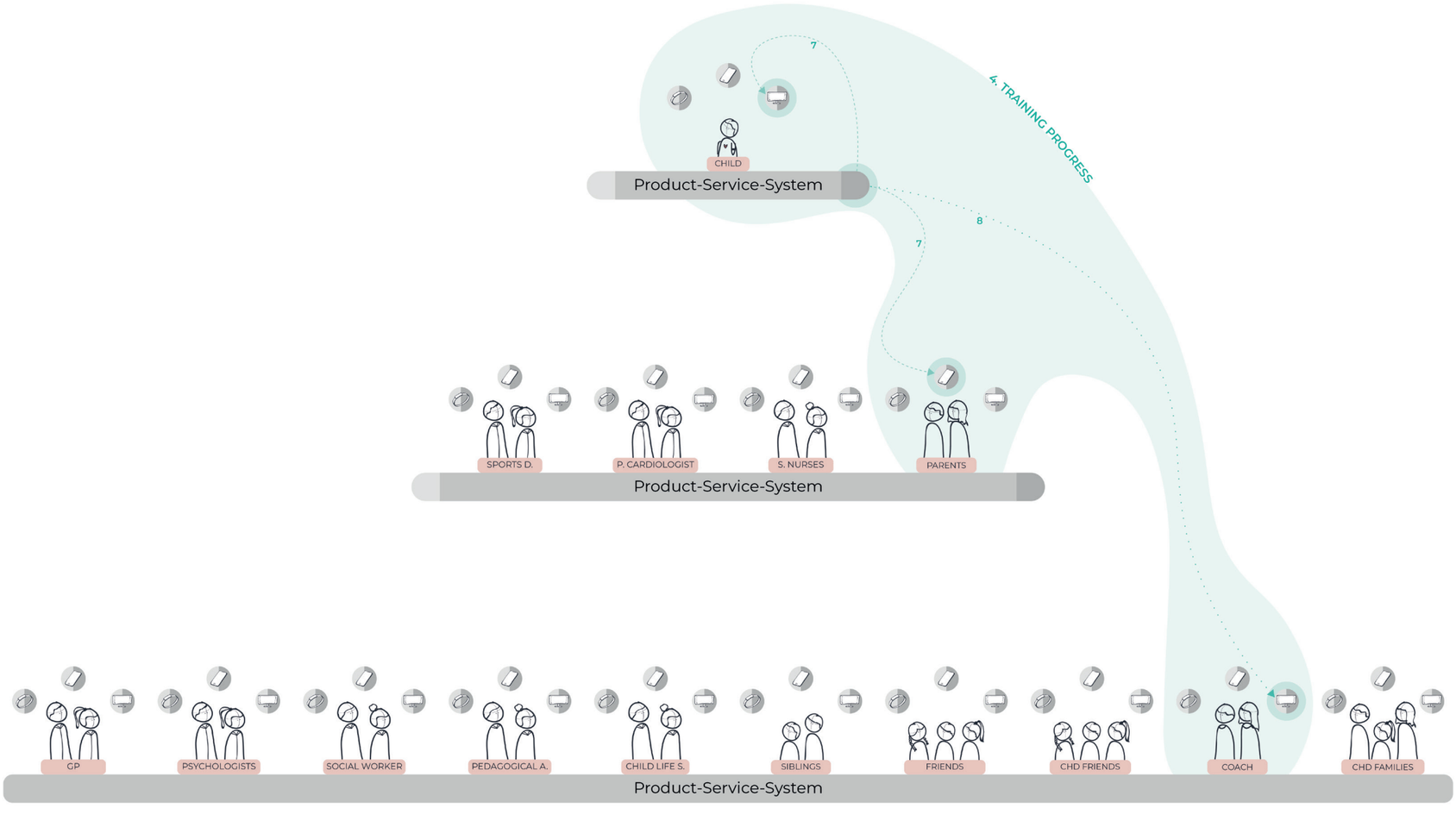
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


4. TRAINING PROGRESS
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CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
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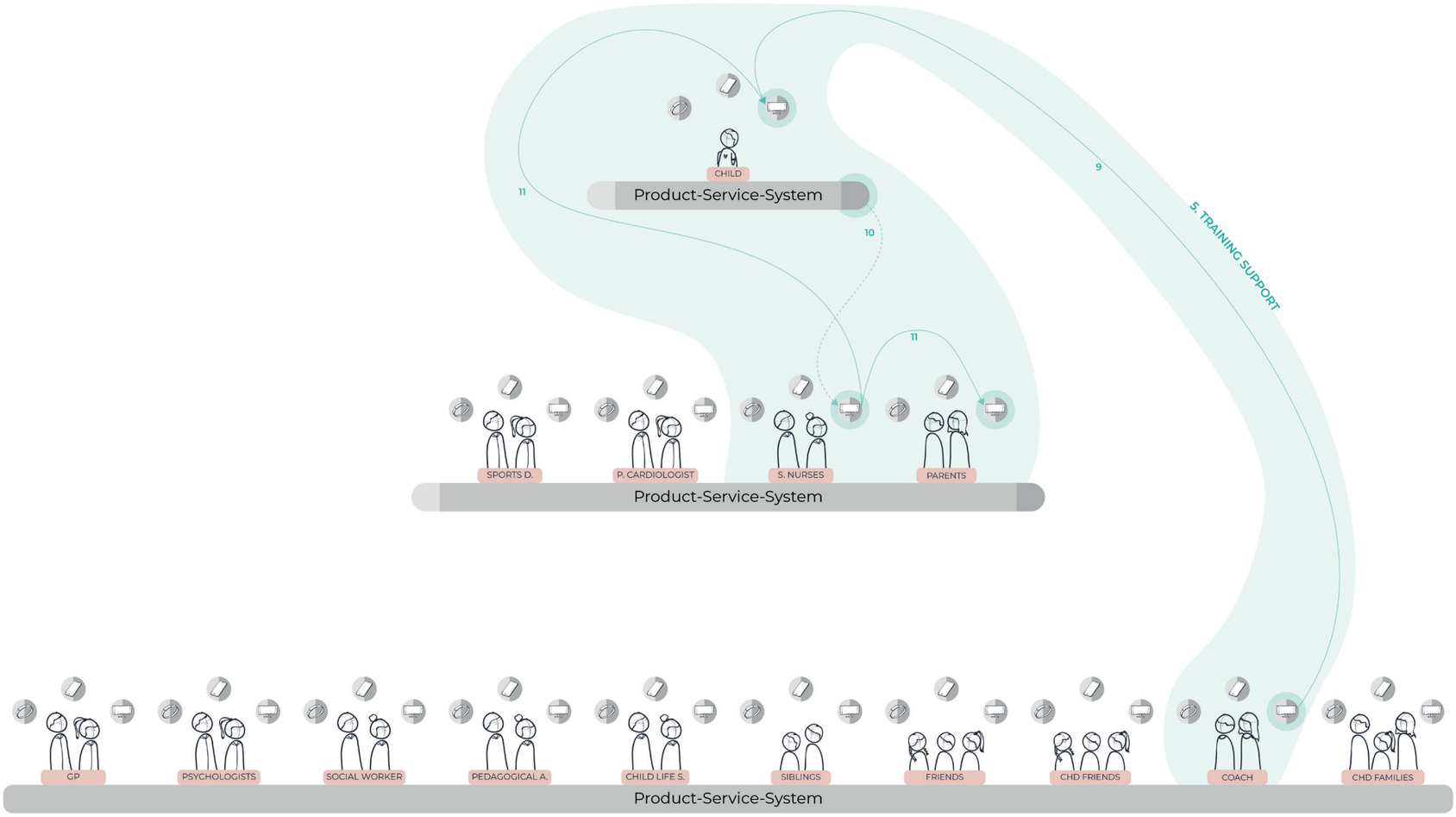
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


5. TRAINING SUPPORT
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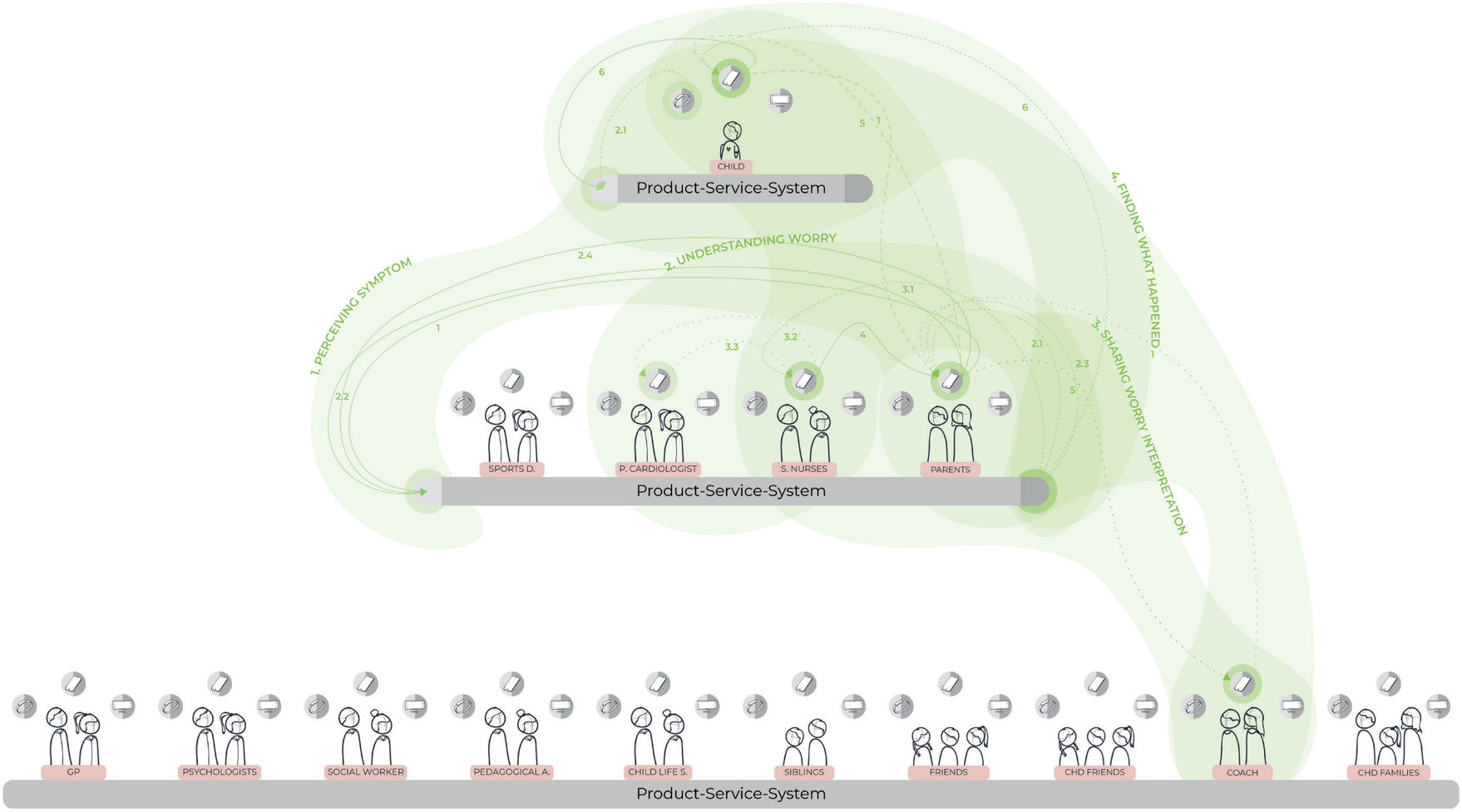
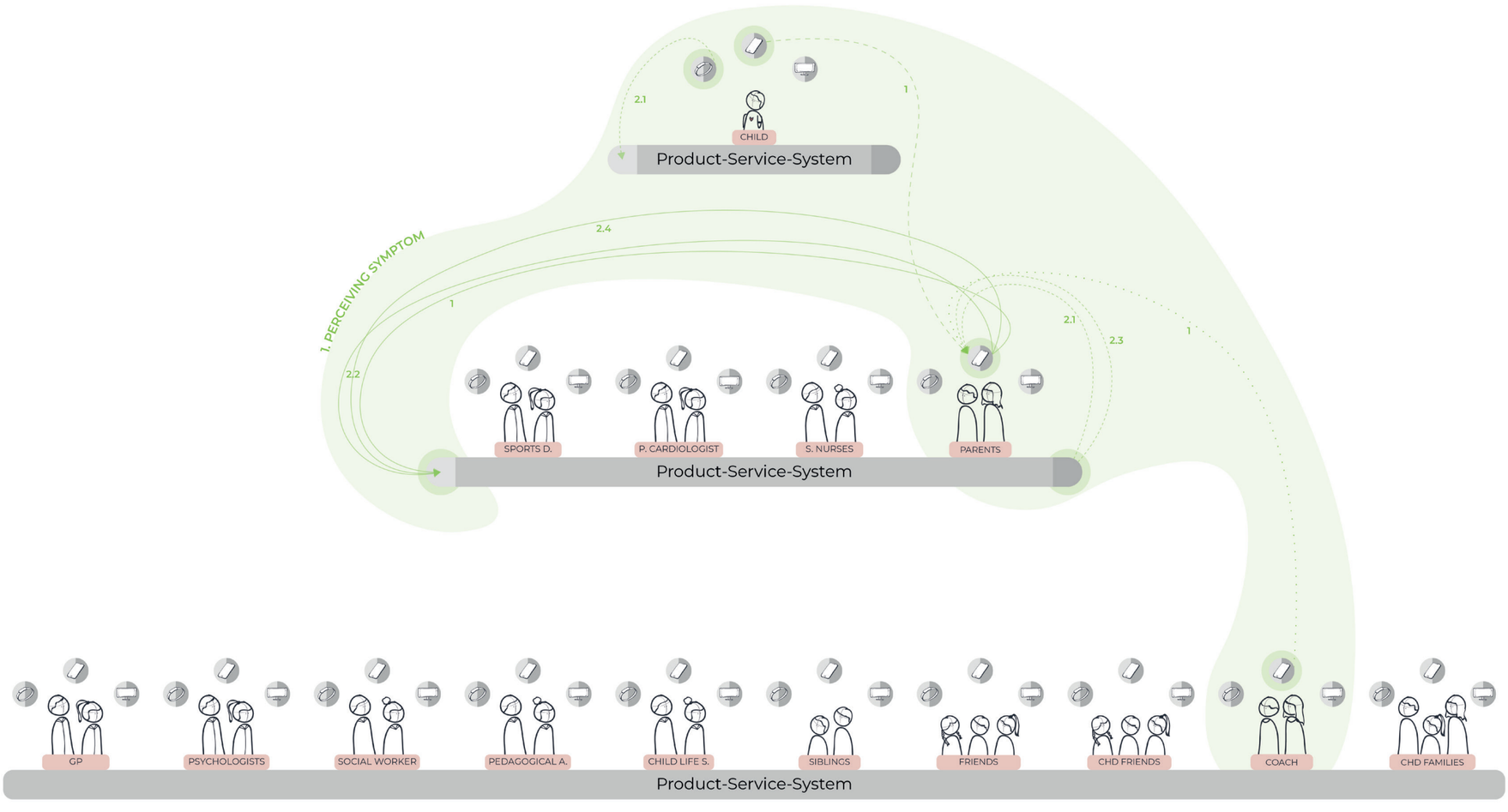
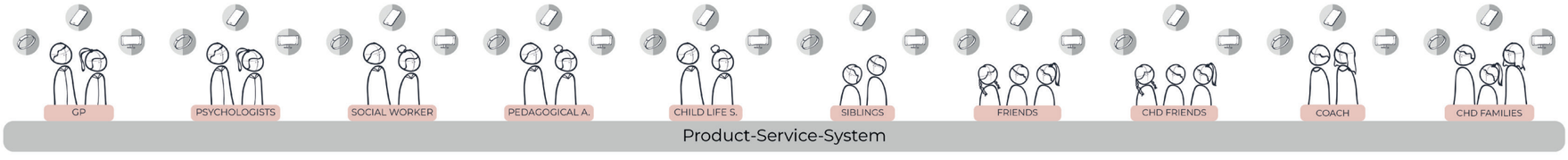
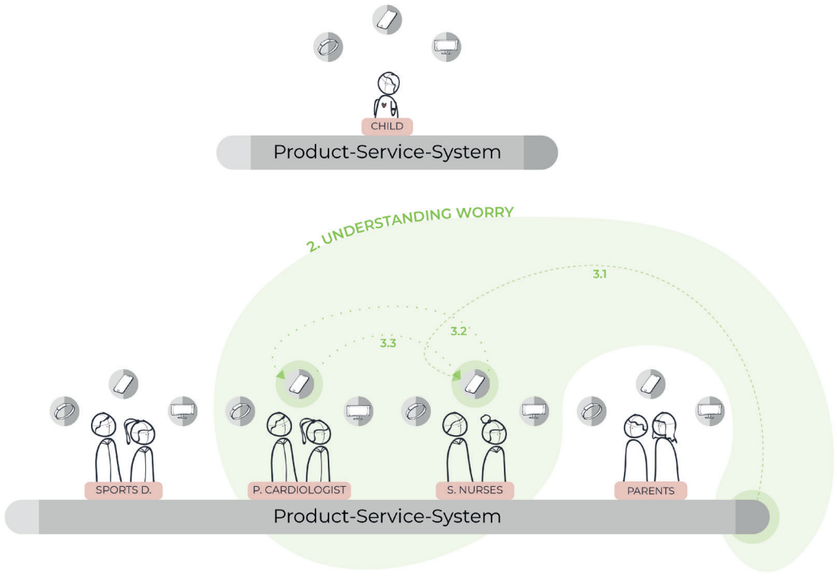
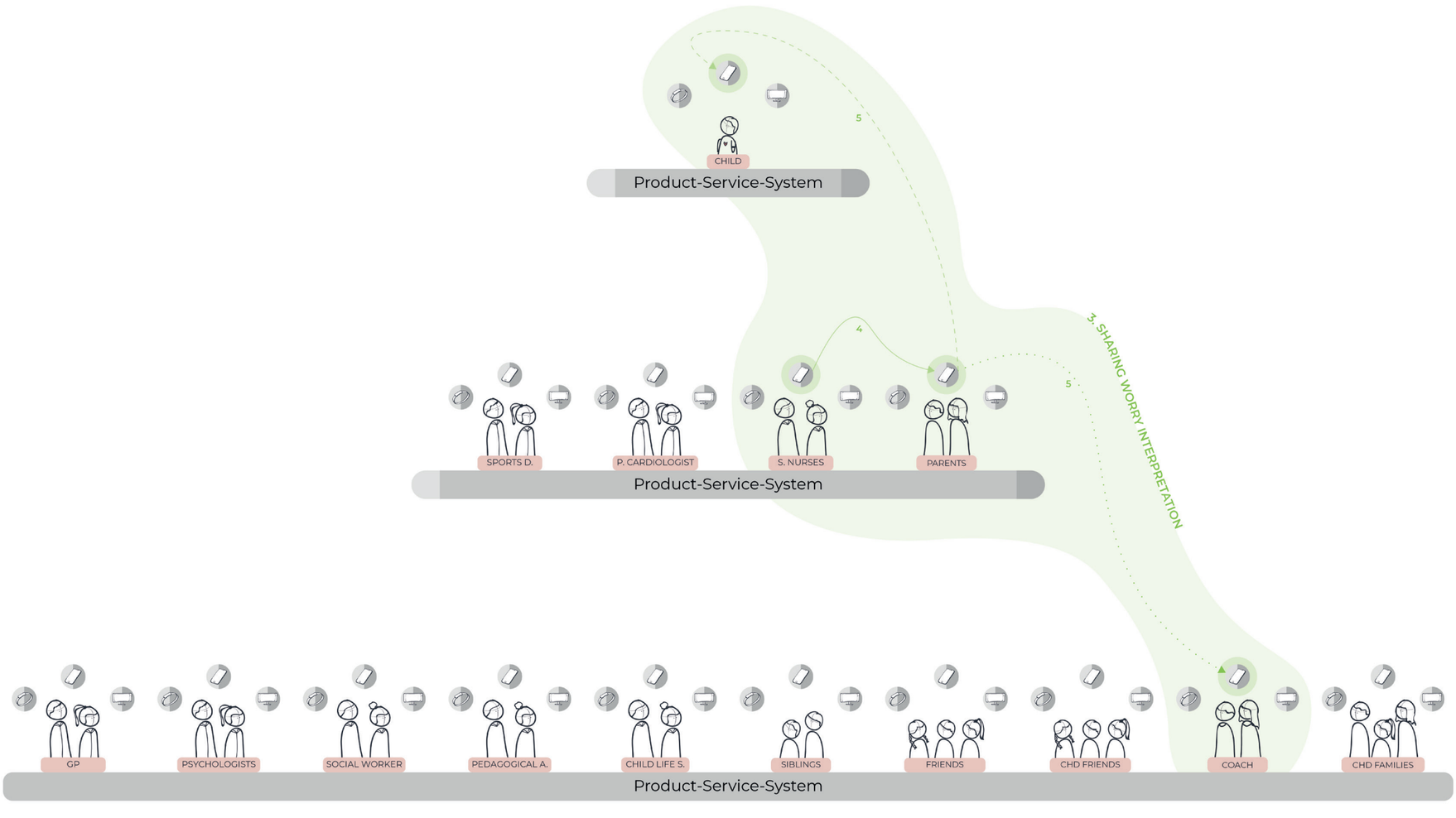
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


1. PERCEIVING SYMPTOM
2. UNDERSTANDING WORRY
3. SHARING WORRY INTERPRETATION
4. FINDING WHAT HAPPENED –
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


1. PERCEIVING SYMPTOM
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


CHILD
Product-Service-System
2. UNDERSTANDING WORRY
3.1
3.2
3.3
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System


CHILD
Product-Service-System
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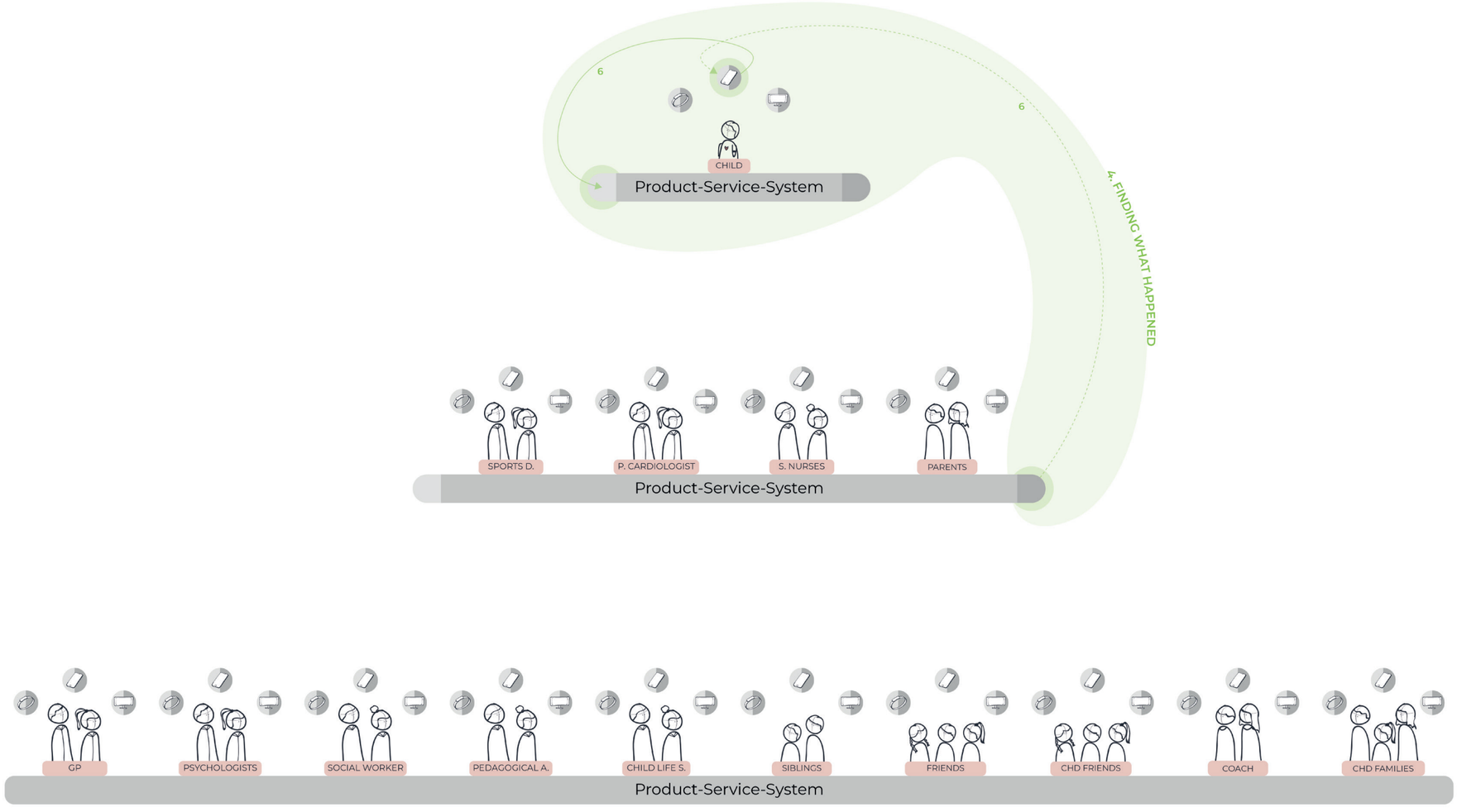
3. SHARING WORRY INTERPRETATION
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System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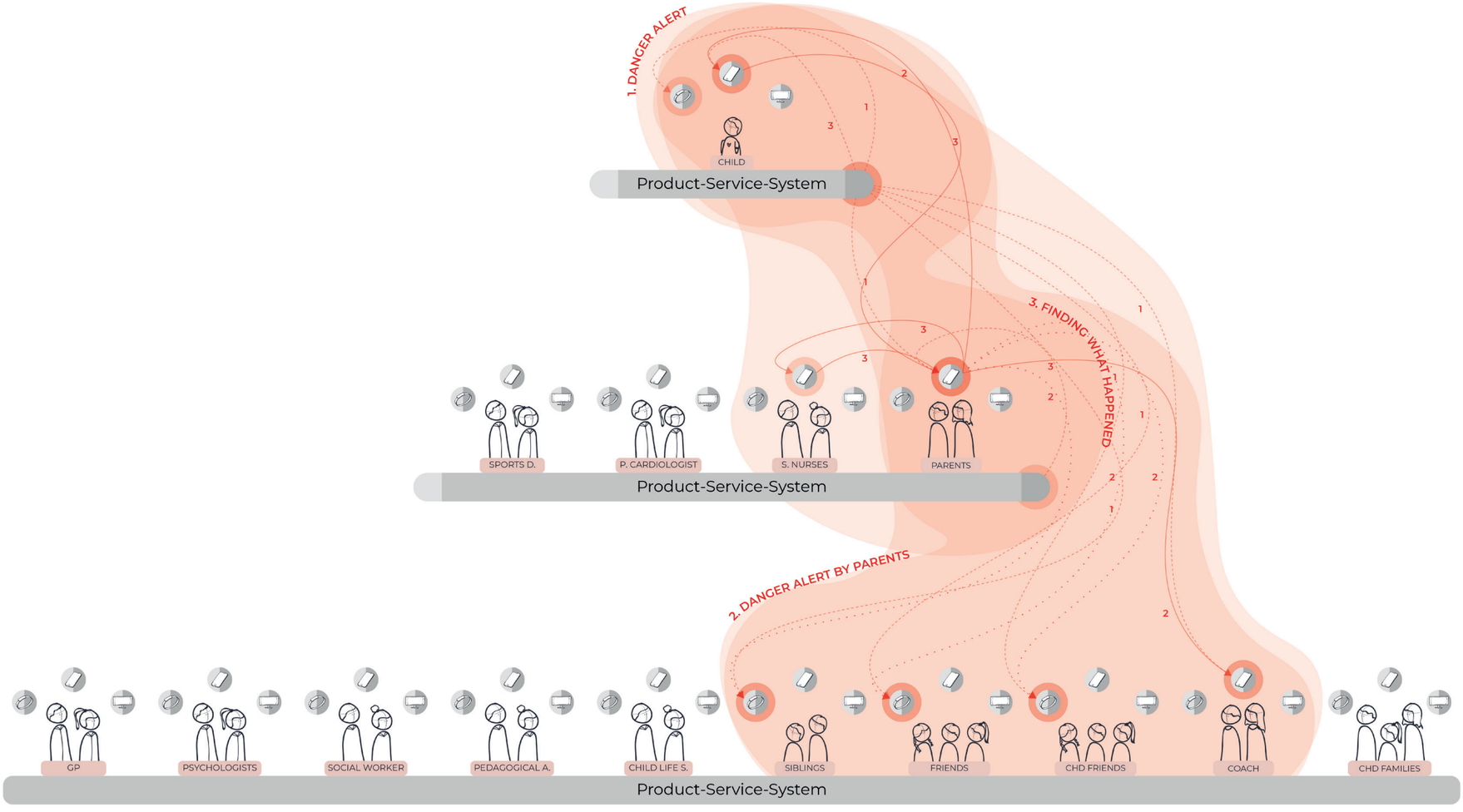
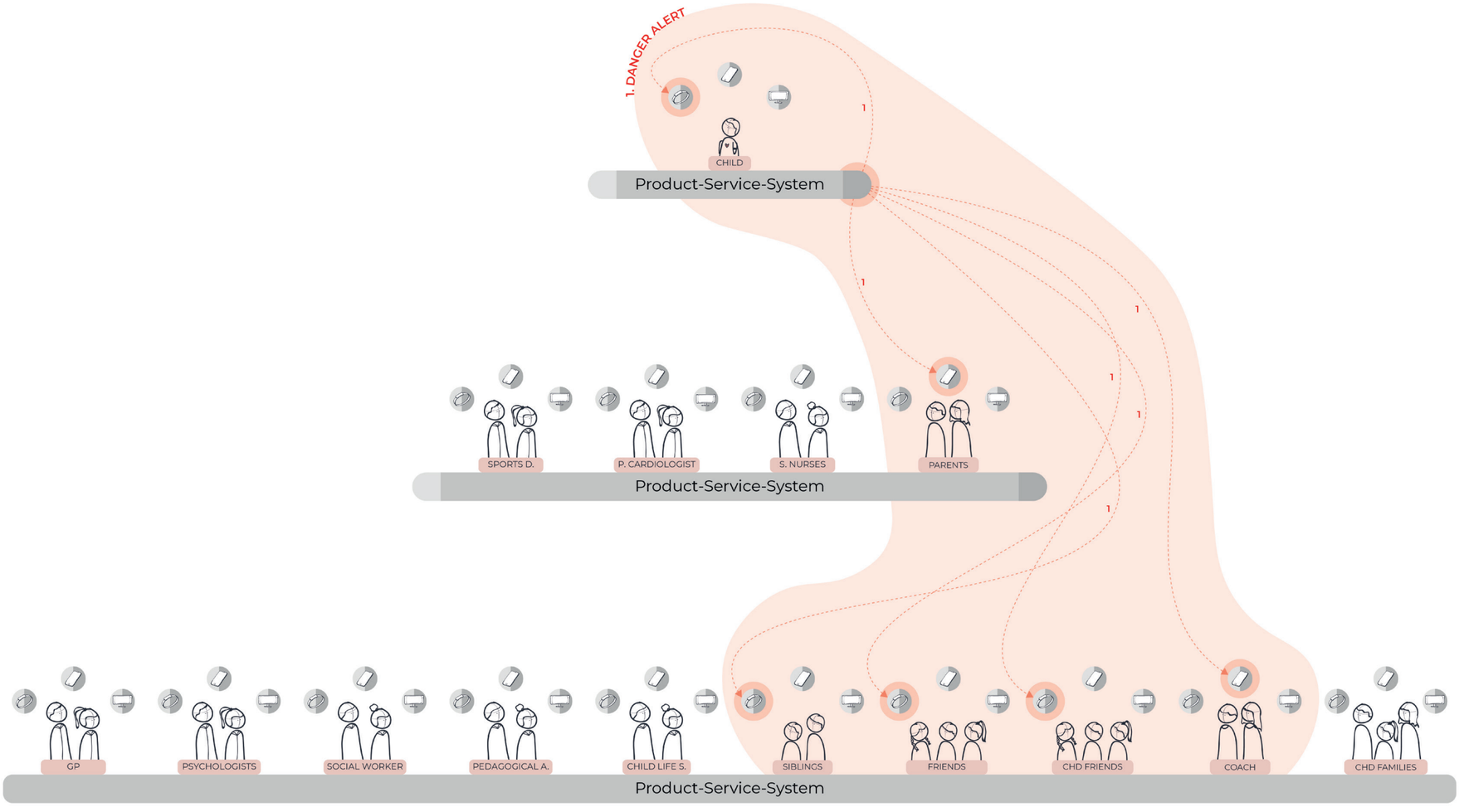
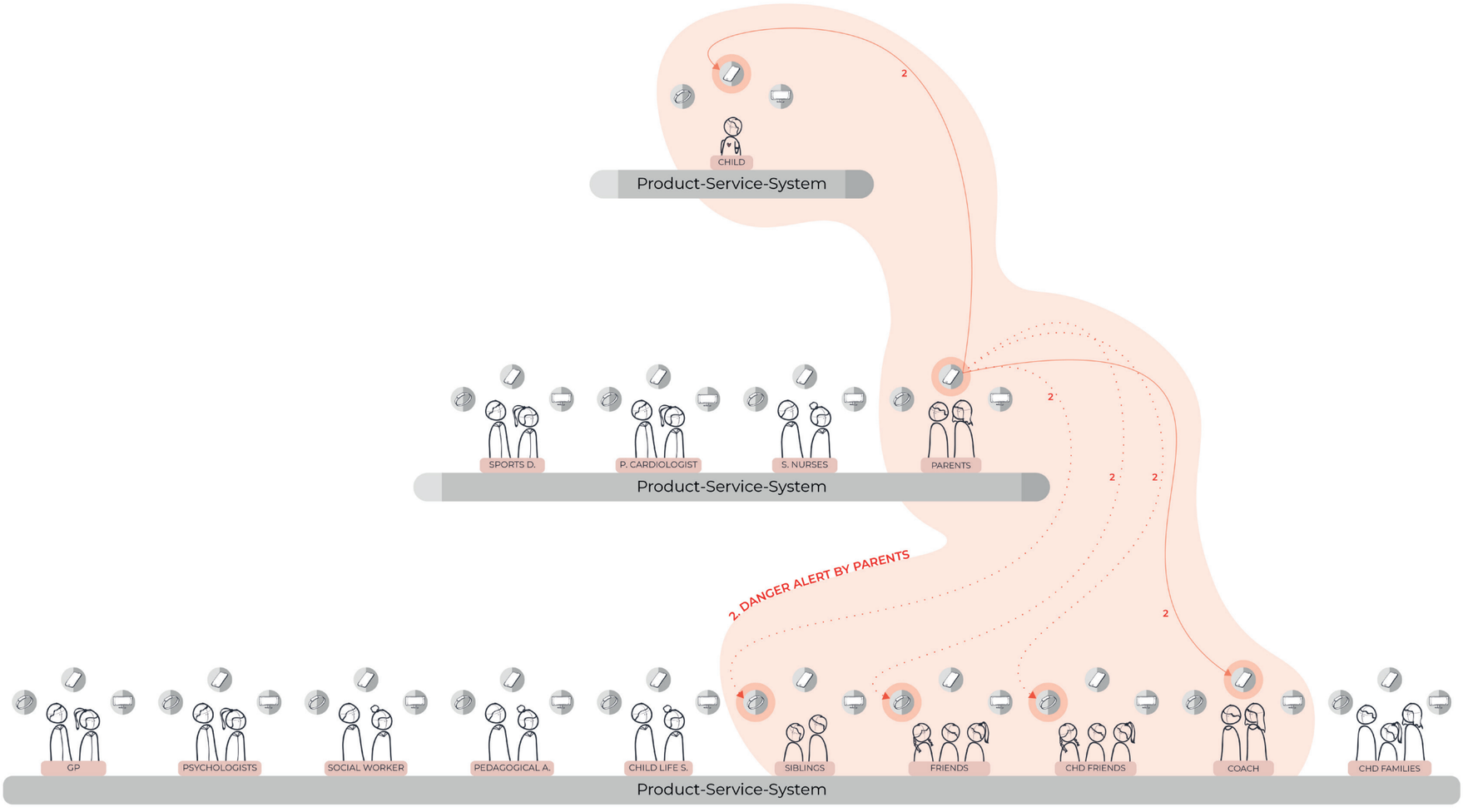
6
CHILD
Product-Service-System
4. FINDING WHAT HAPPENED
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


1. DANGER ALERT
CHILD
Product-Service-System
3. FINDING WHAT HAPPENED
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
2. DANGER ALERT BY PARENTS
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


1. DANGER ALERT
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


2
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
2
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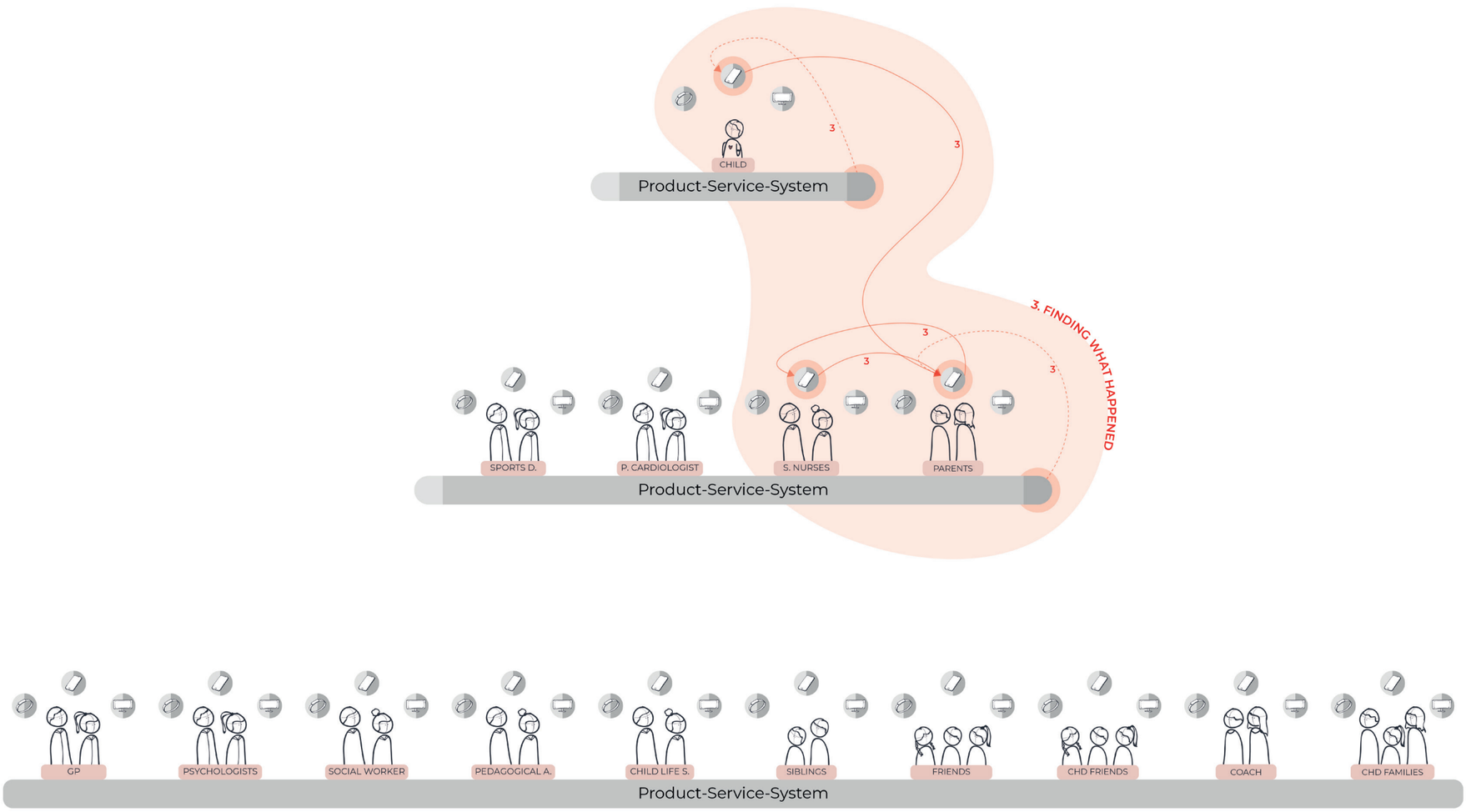
2
2
2. DANGER ALERT BY PARENTS
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


3
CHILD
Product-Service-System
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3. FINDING WHAT HAPPENED
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
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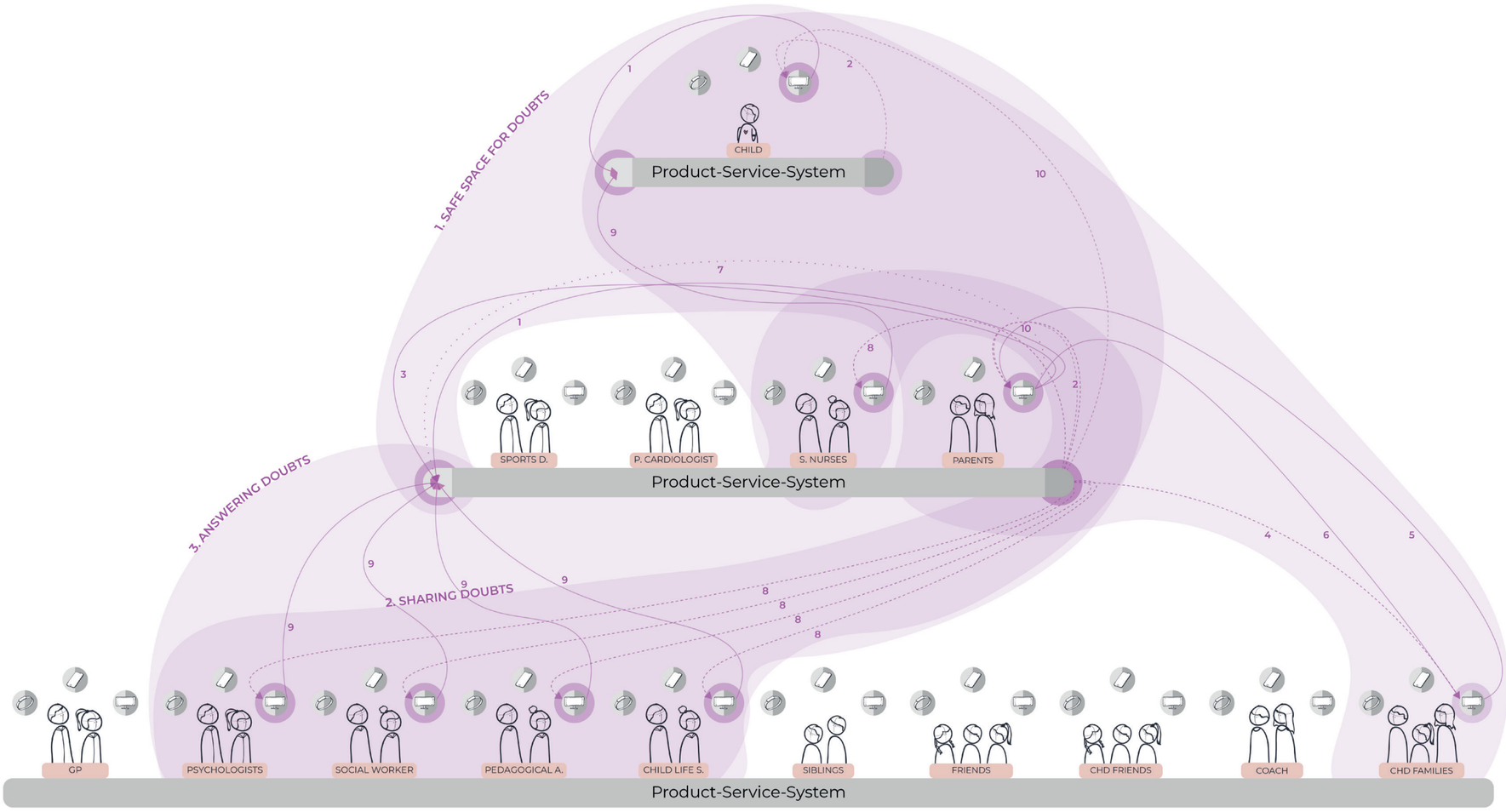
COACH
CHD FAMILIES
Product-Service-System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2. SHARING DOUBTS
3. ANSWERING DOUBTS
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
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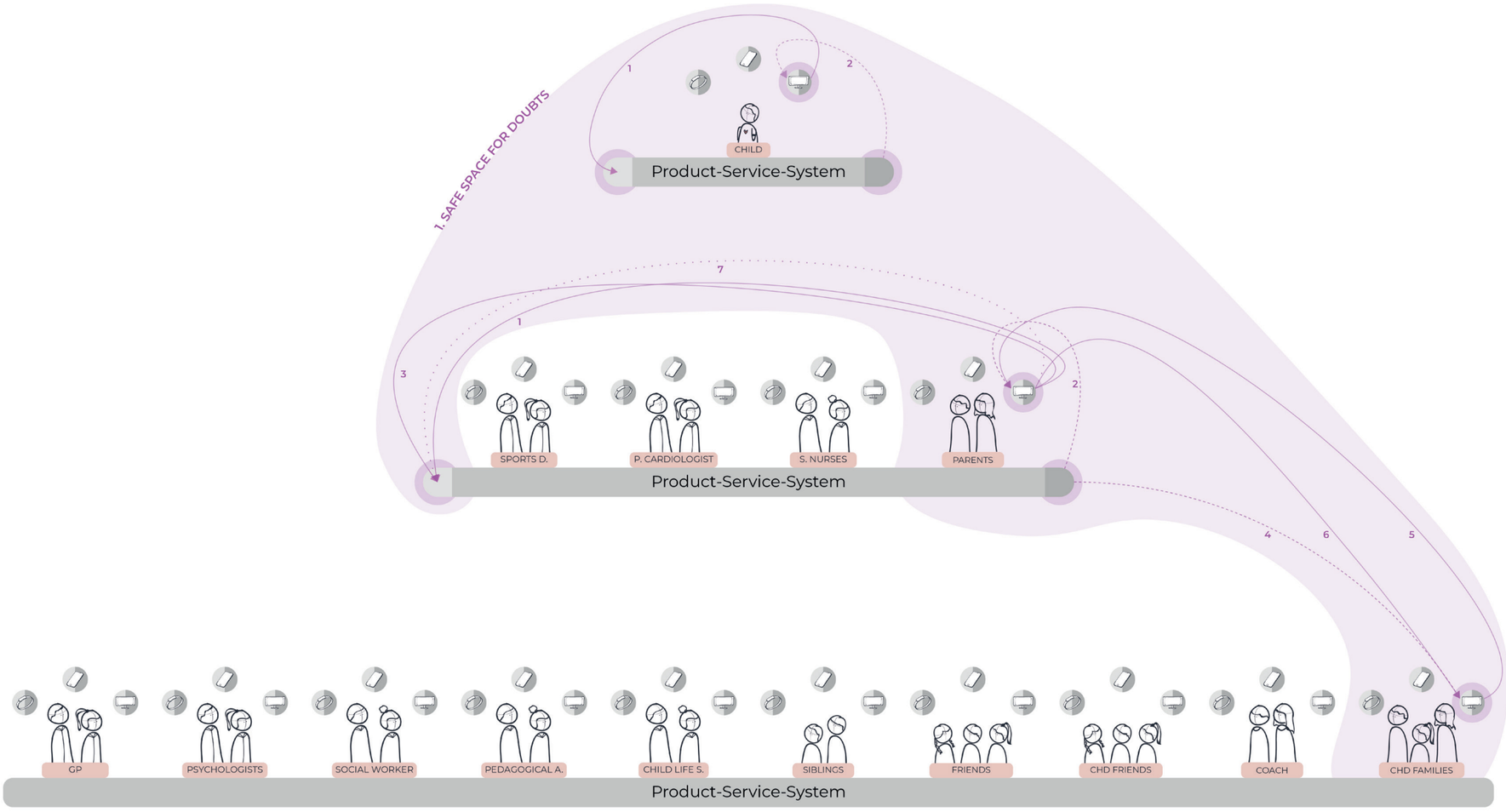
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


1. SAFE SPACE FOR DOUBTS
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
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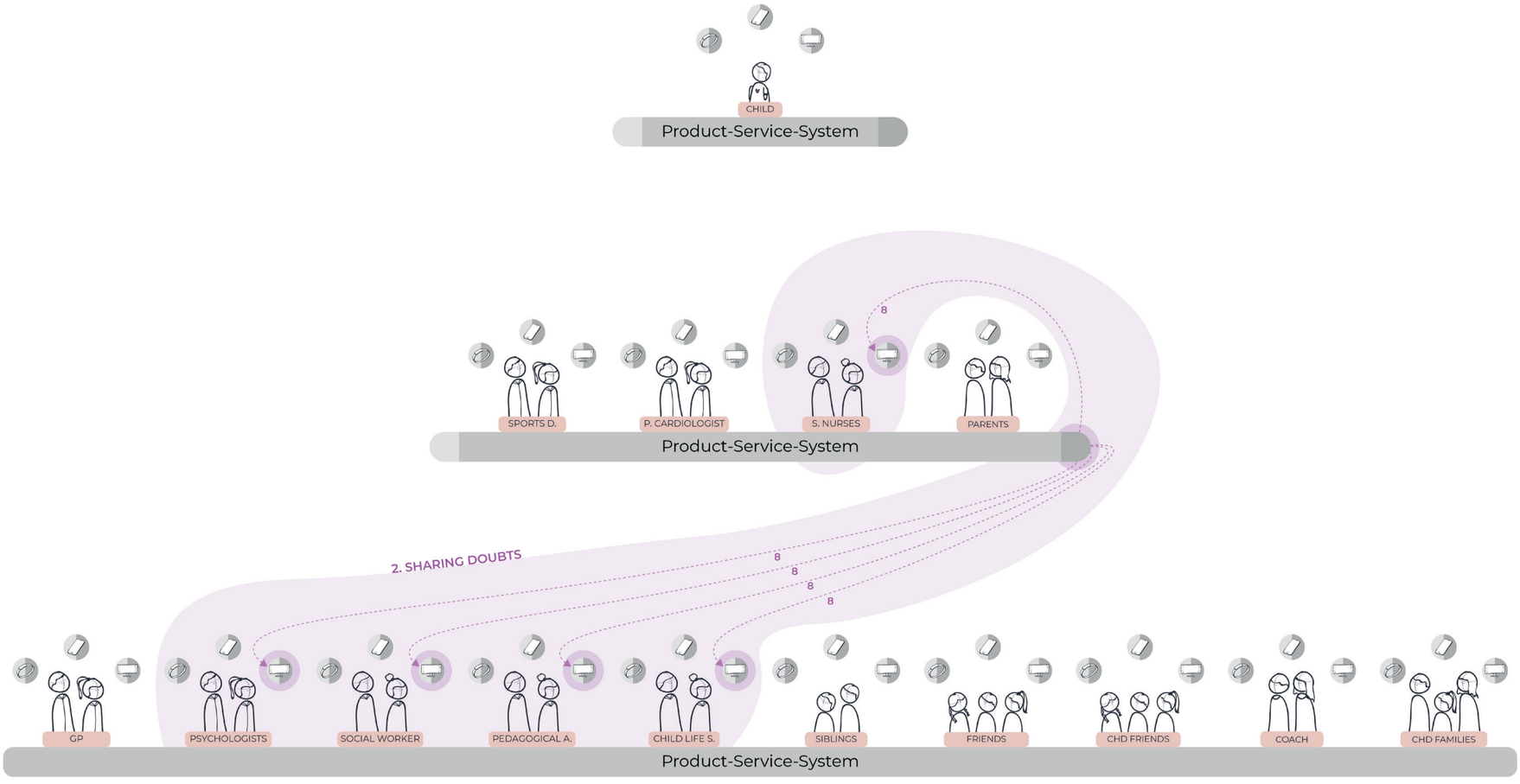
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System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Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
8
Product-Service-System
2. SHARING DOUBTS
8
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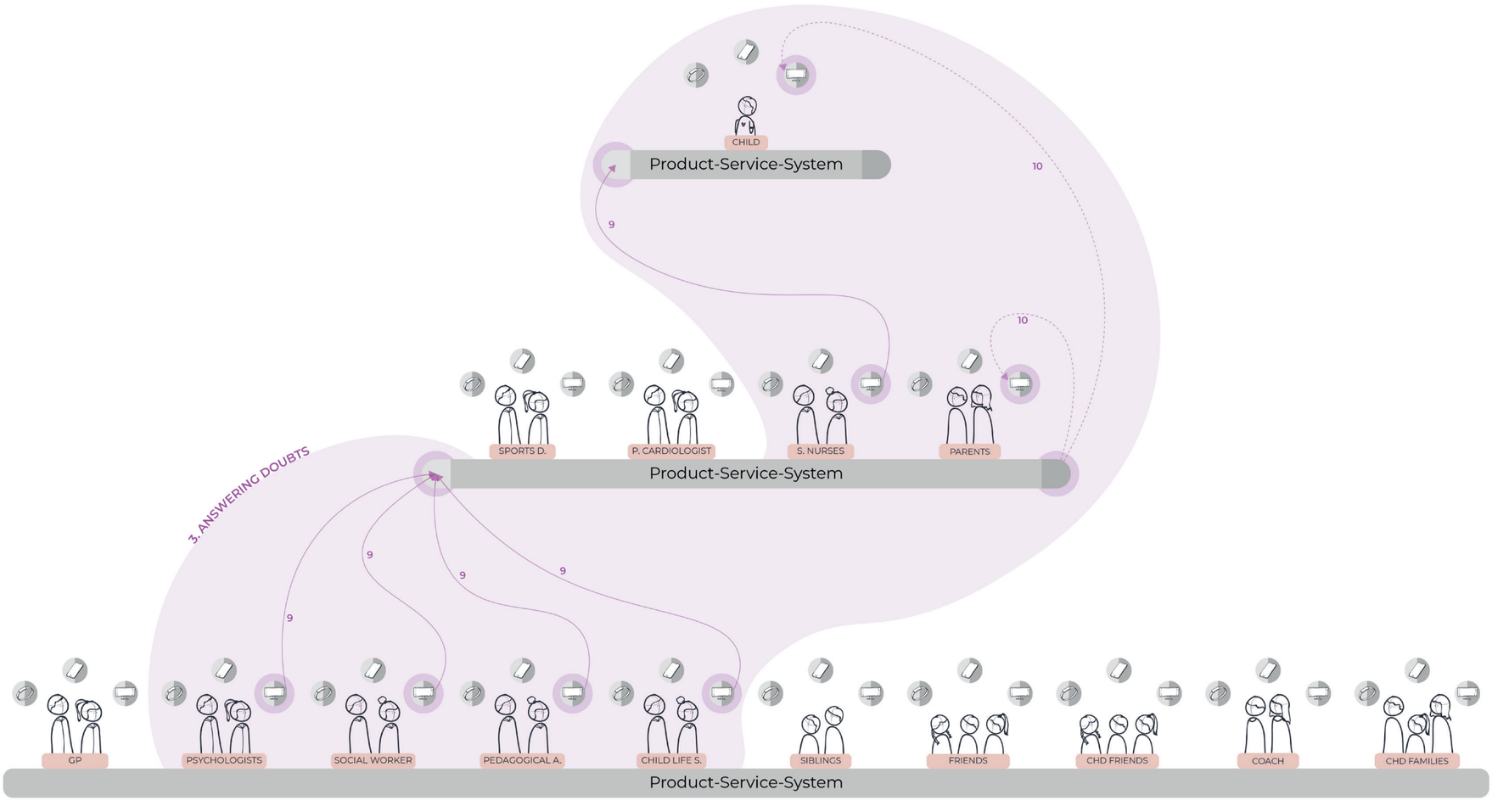
8
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


CHILD
Product-Service-System
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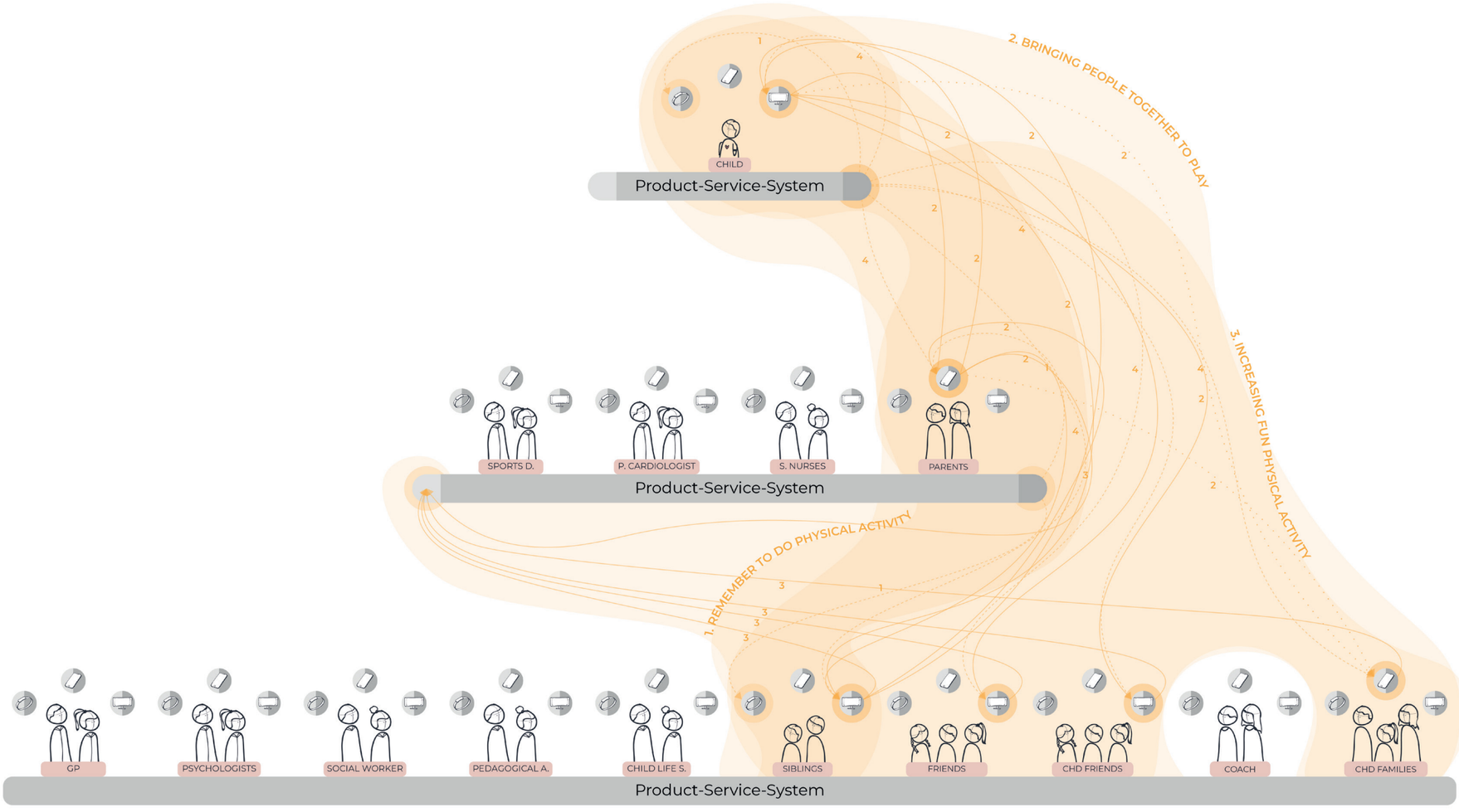
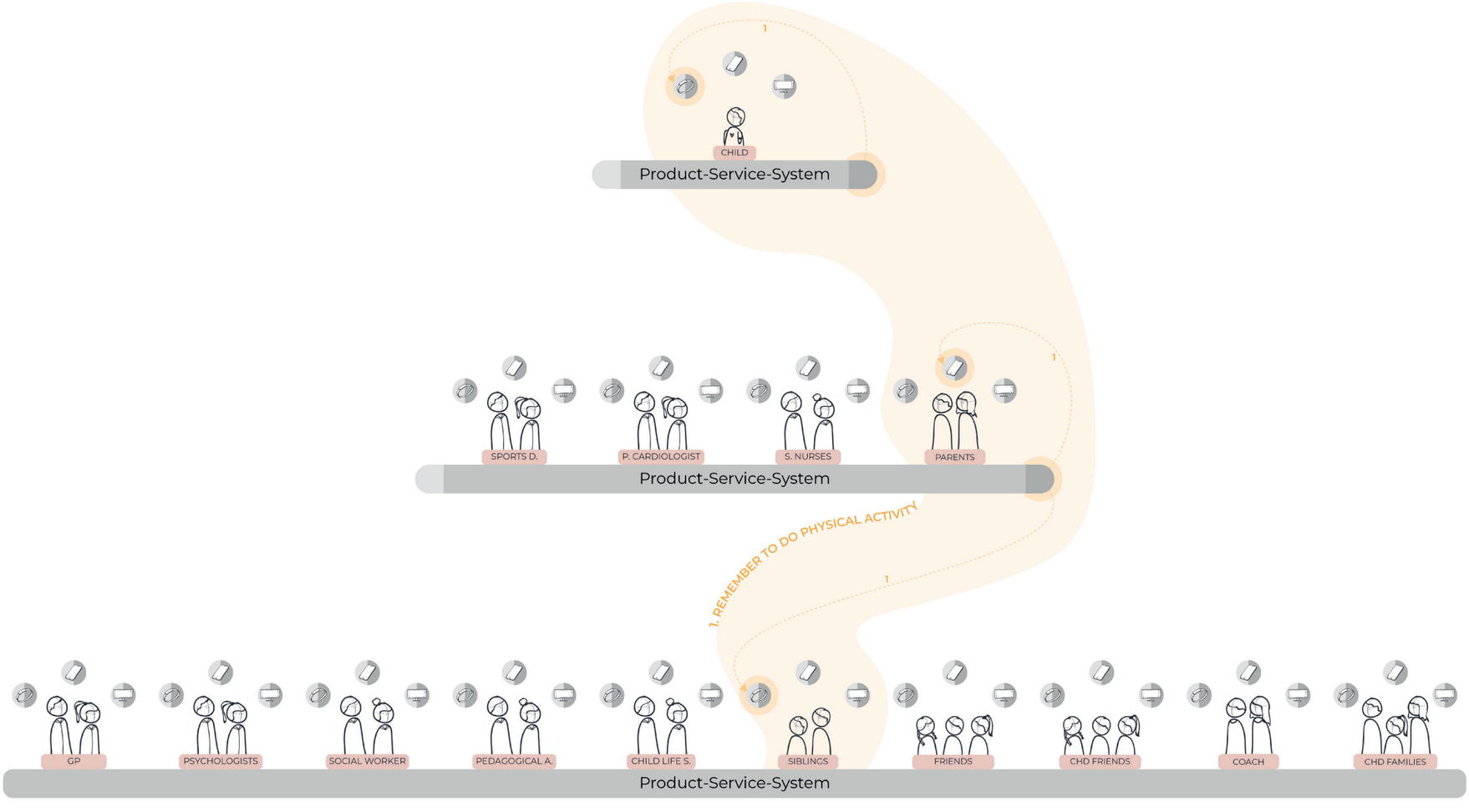
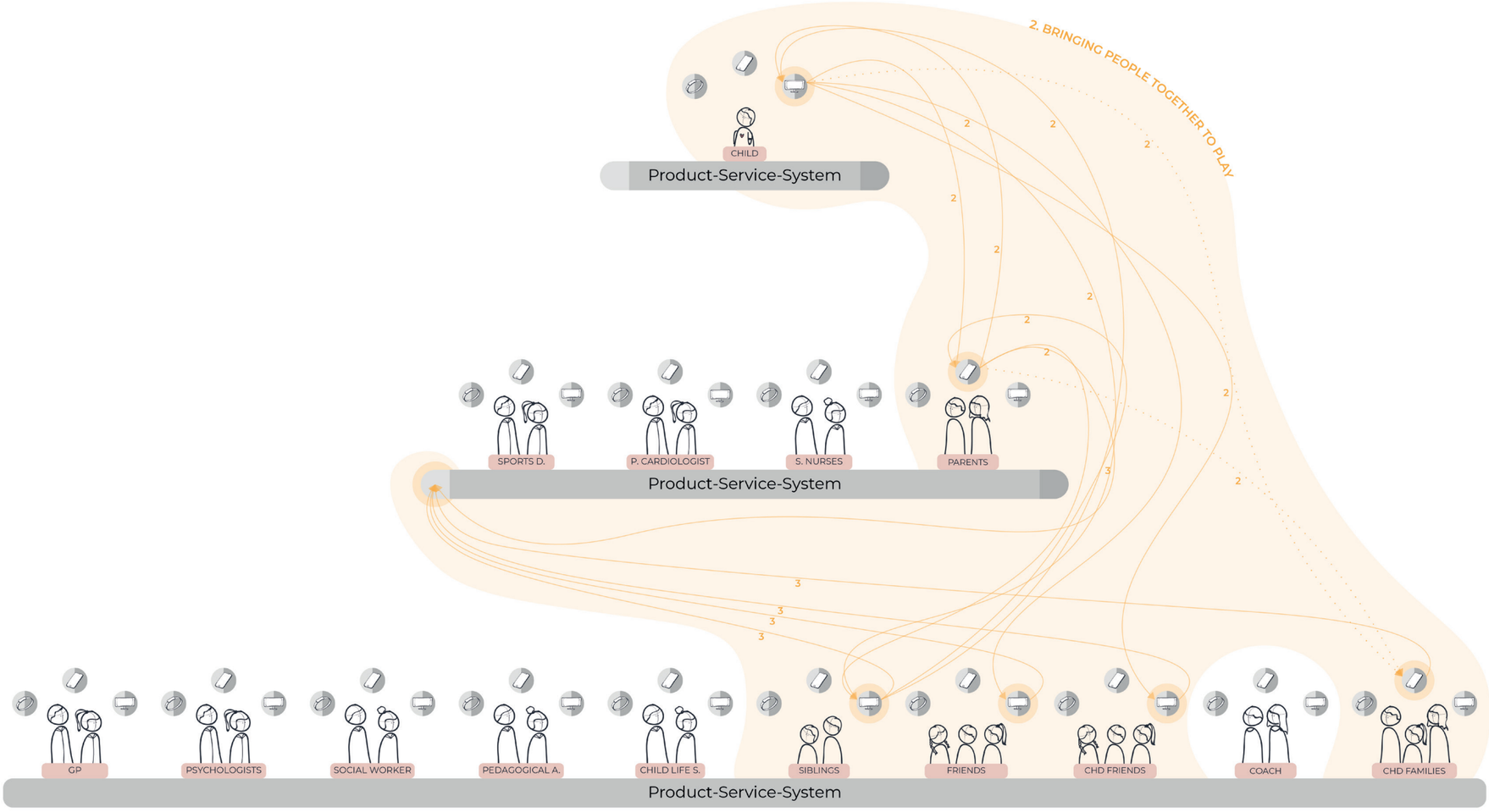
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
3. ANSWERING DOUBTS
9
9
9
9
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


2. BRINGING PEOPLE TOGETHER TO PLAY
3. INCREASING FUN PHYSICAL ACTIVITY
1. REMEMBER TO DO PHYSICAL ACTIVITY
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


1. REMEMBER TO DO PHYSICAL ACTIVITY
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


2. BRINGING PEOPLE TOGETHER TO PLAY
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
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FRIENDS
CHD FRIENDS
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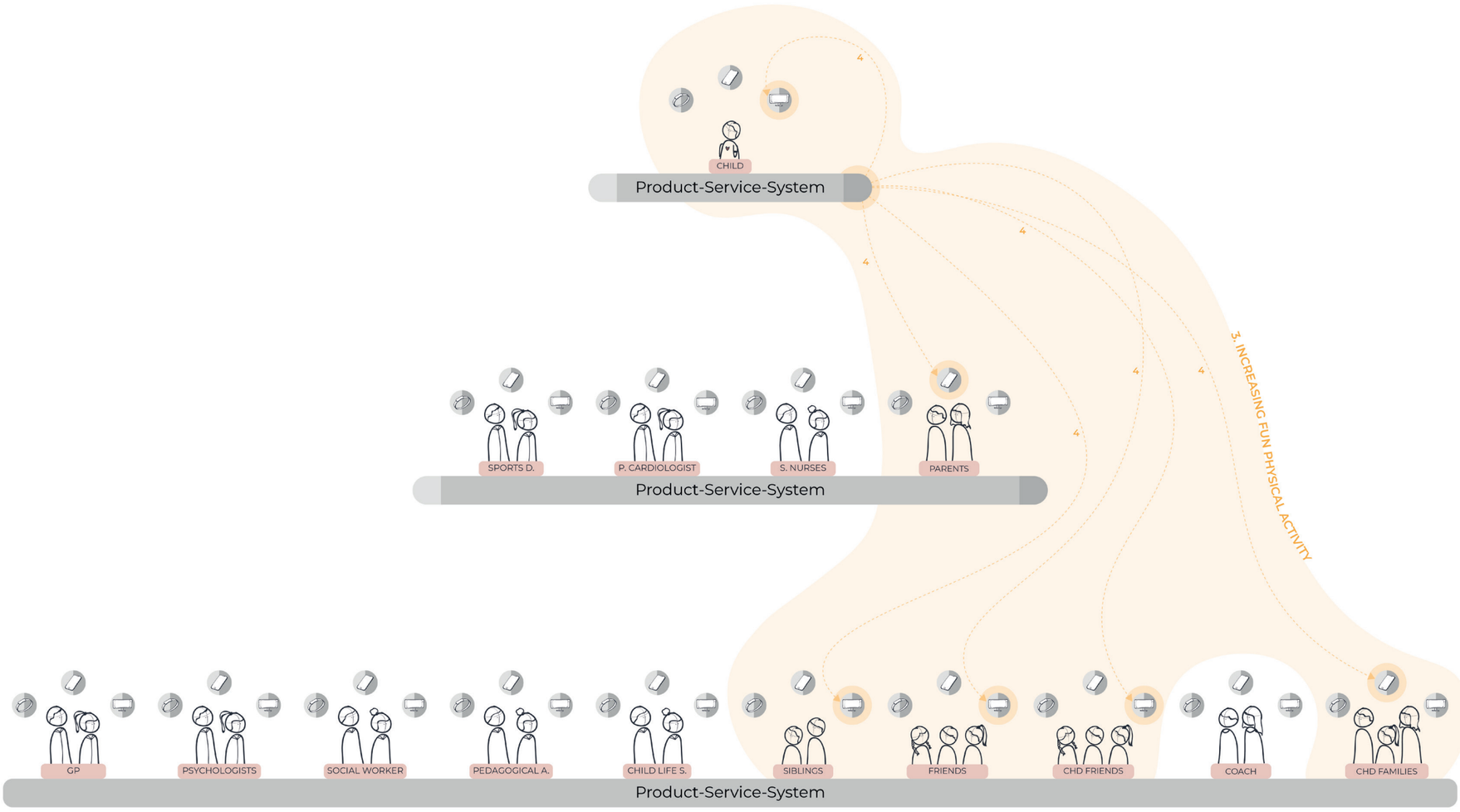
CHD FAMILIES
Product-Service-System


3. INCREASING FUN PHYSICAL ACTIVITY
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
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CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
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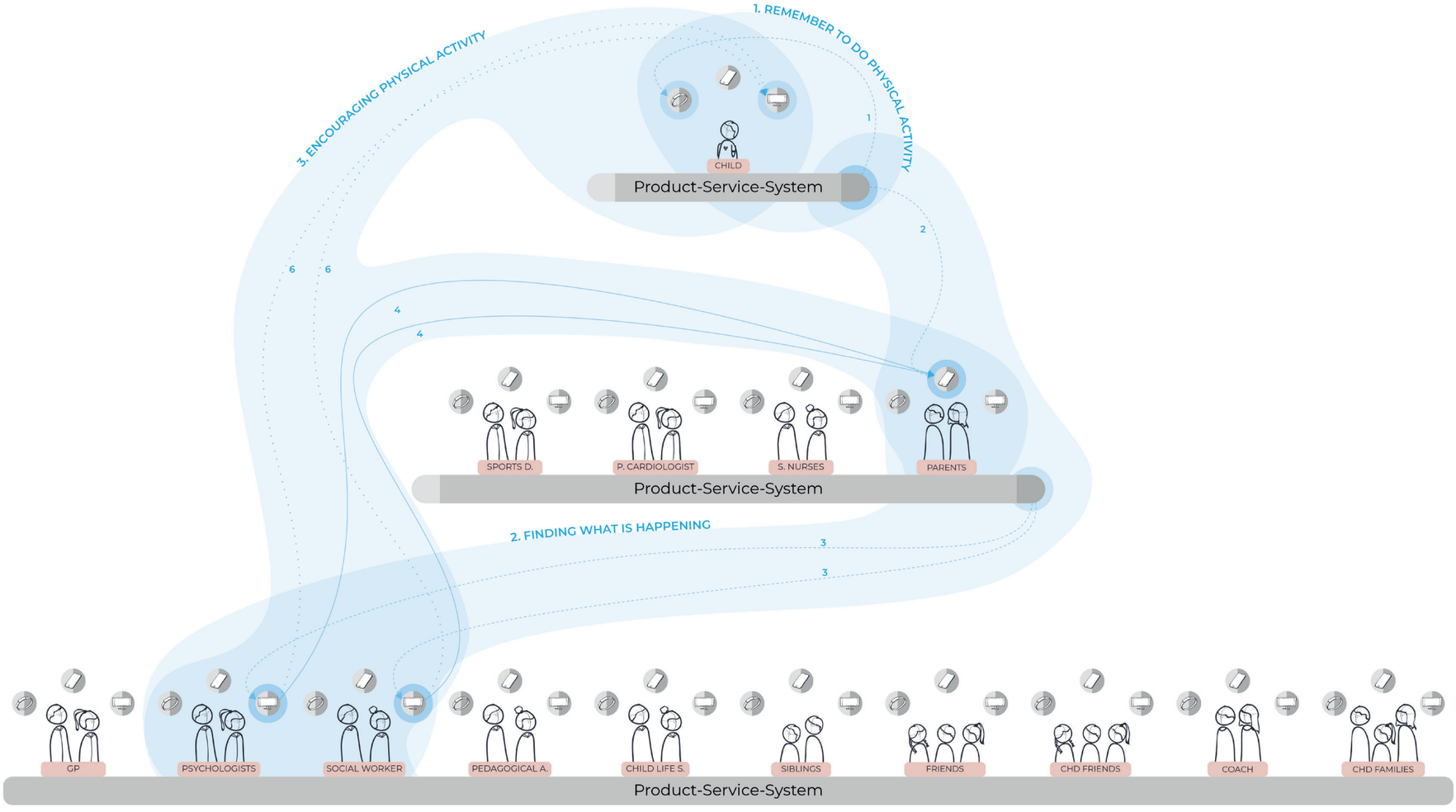
CHD FAMILIES
Product-Service-System


1. REMEMBER TO DO PHYSICAL ACTIVITY
3. ENCOURAGING PHYSICAL ACTIVITY
2. FINDING WHAT IS HAPPENING
1
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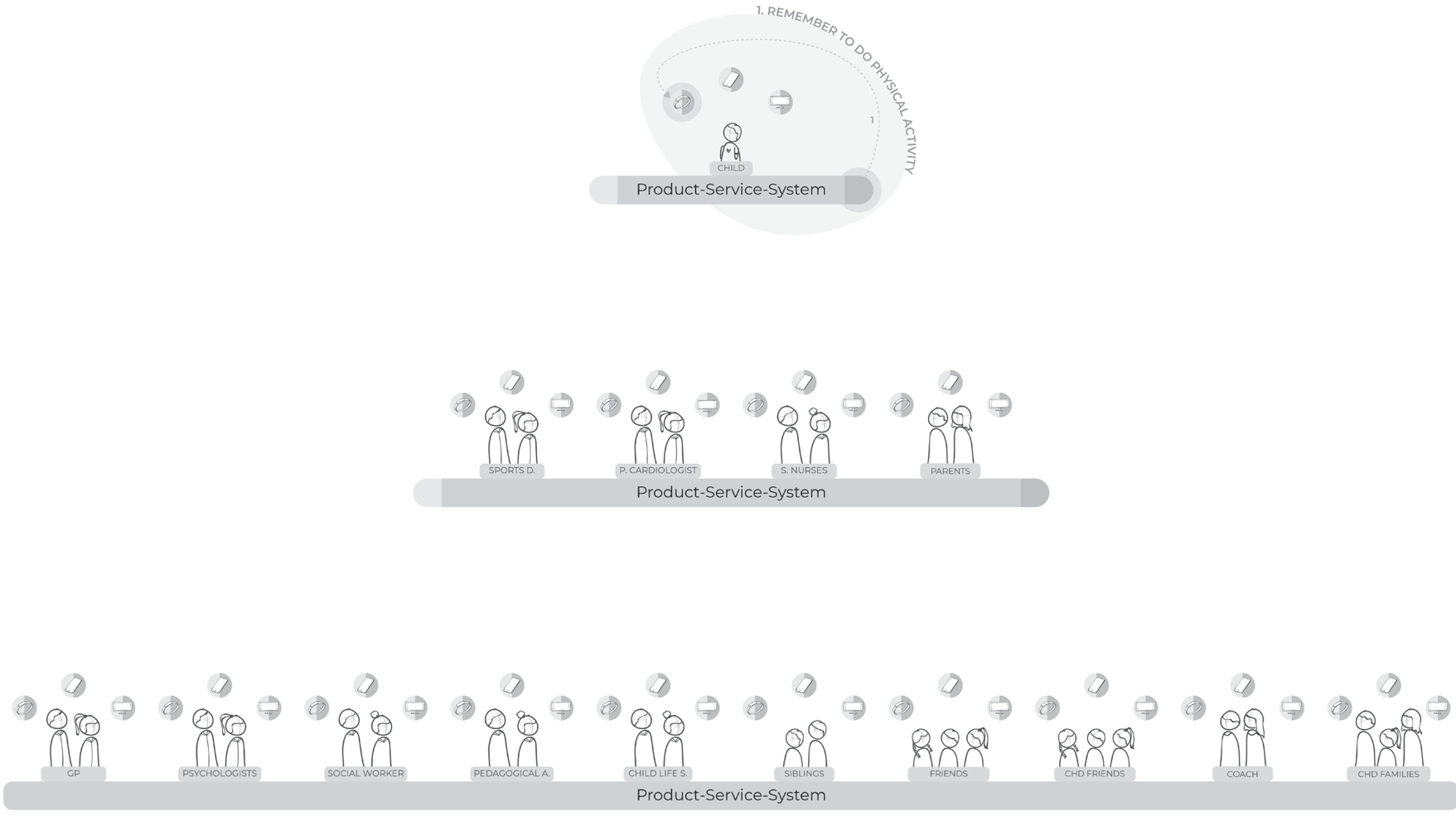
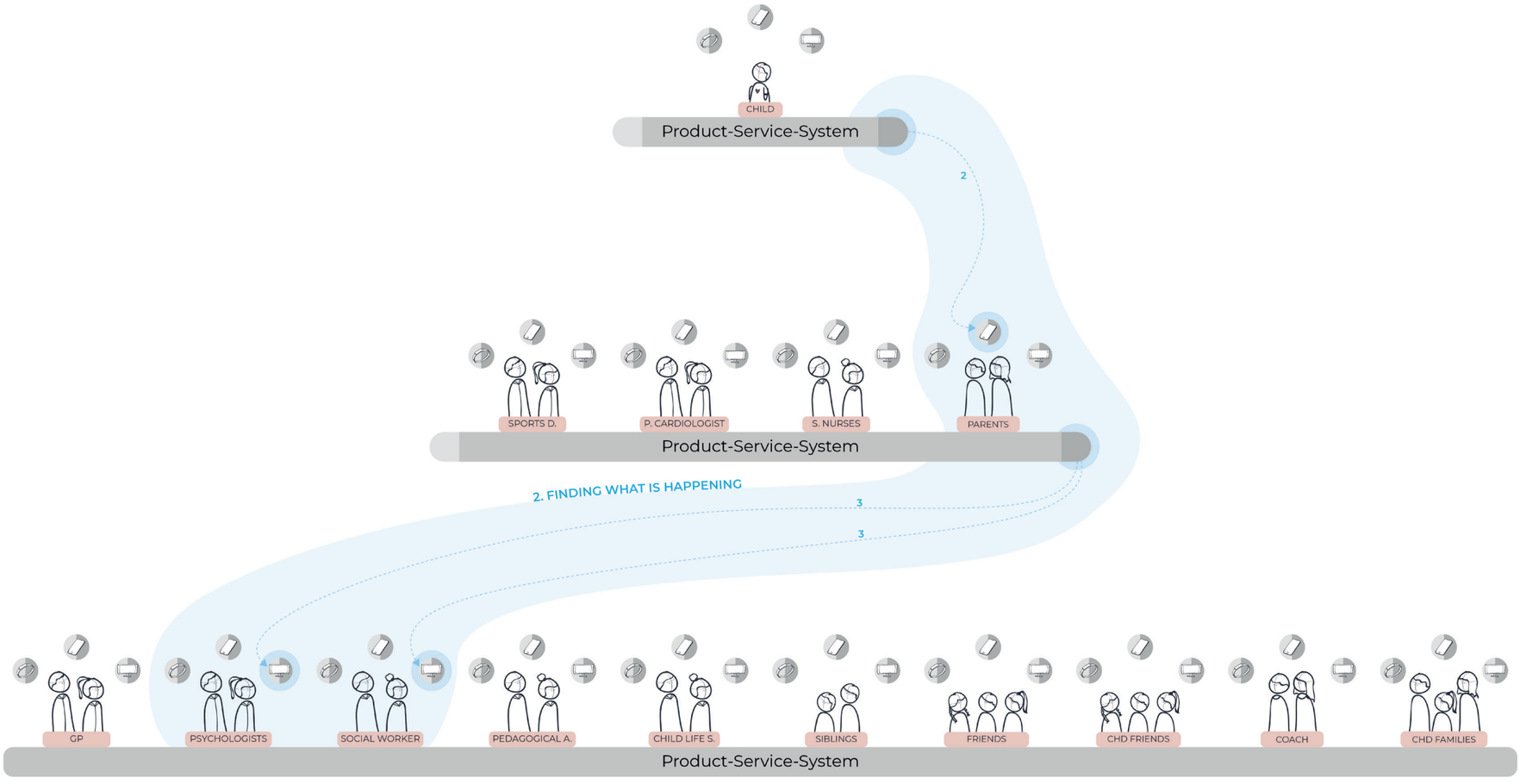
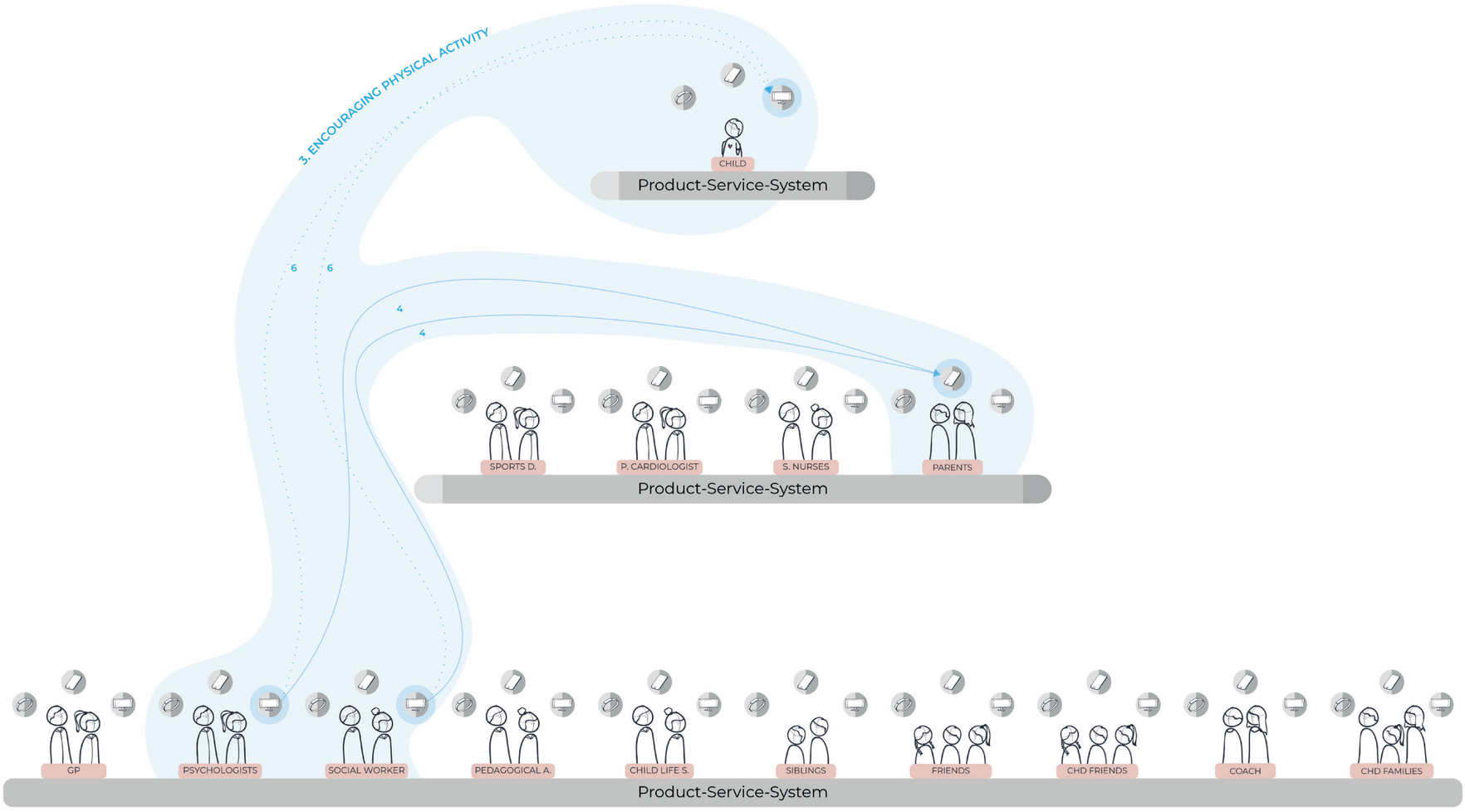
6
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


1. REMEMBER TO DO PHYSICAL ACTIVITY
1
CHILD
Product-Service-System
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


CHILD
Product-Service-System
2
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
2. FINDING WHAT IS HAPPENING
3
3
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System


3. ENCOURAGING PHYSICAL ACTIVITY
CHILD
Product-Service-System
6
6
4
4
SPORTS D.
P. CARDIOLOGIST
S. NURSES
PARENTS
Product-Service-System
GP
PSYCHOLOGISTS
SOCIAL WORKER
PEDAGOGICAL A.
CHILD LIFE S.
SIBLINGS
FRIENDS
CHD FRIENDS
COACH
CHD FAMILIES
Product-Service-System