

CARDIOLOGY  
2025 

# Replaced by an app; the future of Hope , Heal and Learn

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# HOPE. HEAL. LEARN.



# Disclaimer

- I have no disclosures or conflicts other than all the people I've met and relations I've made the last 46 years.
- I would like to dedicate this session to dr.Bill Norwood,who passed away in December 2020.





# PATHWAYS CRISSCROSSING OVER THE YEARS.....building bridges.



Cardiology 2007



Dr.Nancy Ghanayem



Cardiology 2018



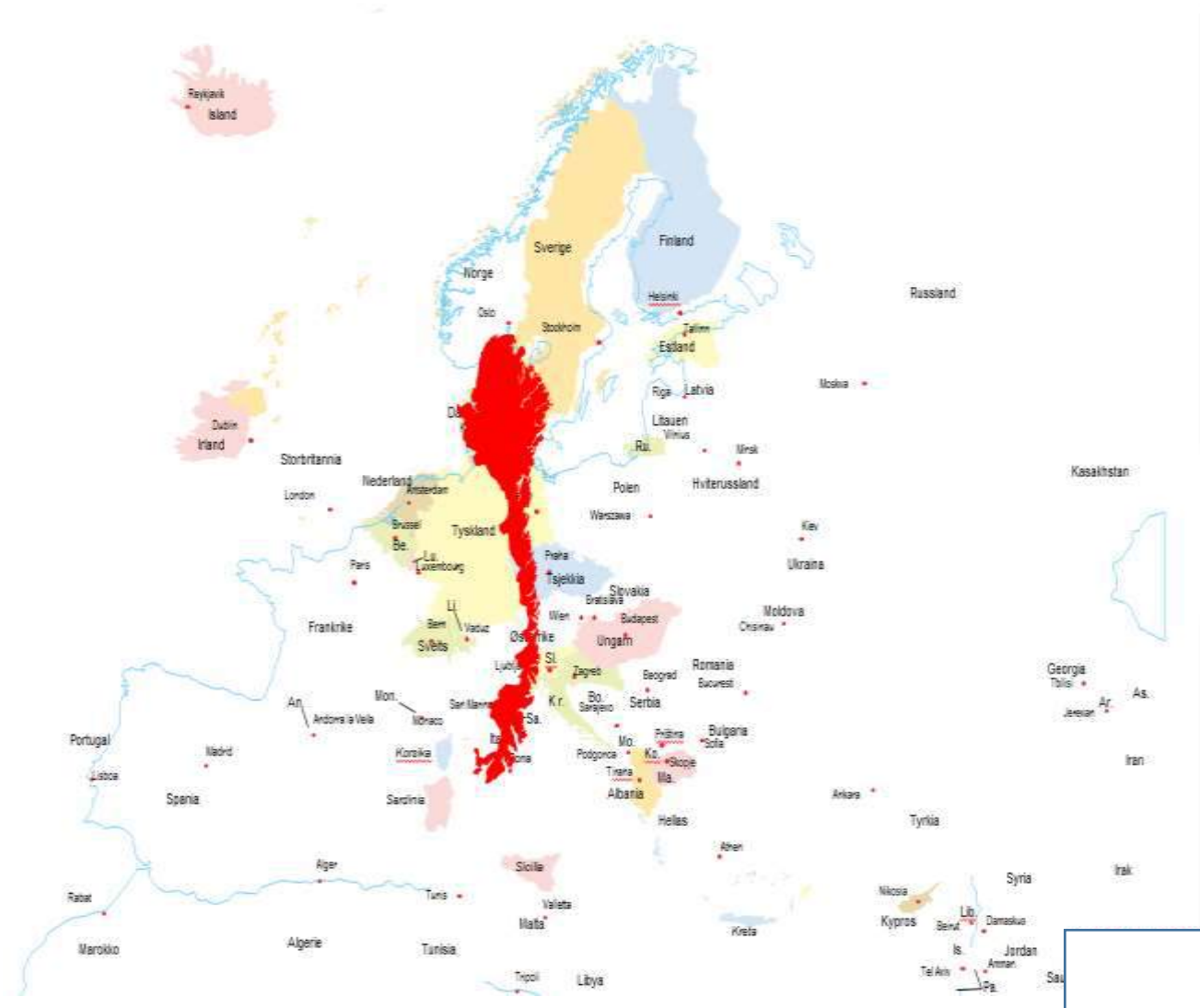
Judi Ruley , Social worker CHOP



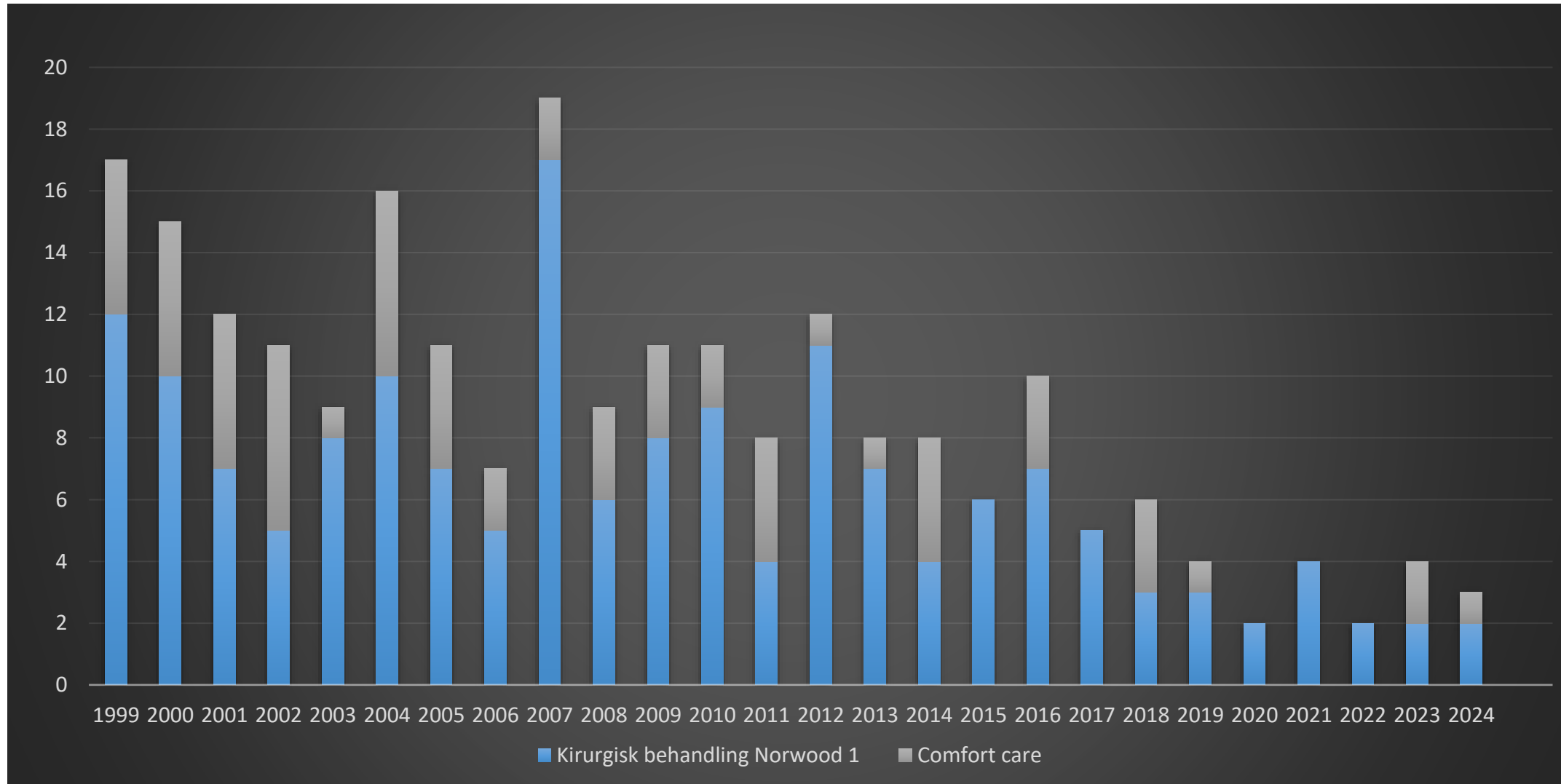
Cardiology 2020 M.Cohen

# NORWAY

- Population 5 554 000
  - 5 centers performing heart surgery
  - **1 out of 5 centers, Rikshospitalet** in Oslo - national responsibility for congenital heart disease ,transplantations and LVAD/ECMO
- 
- Births: 48000-50000
  - CHD : 500/ year
  - County's : 16-18
  - Socialized medicine
  - Maternity & Paternity leave 9-12 months



# HLHS in Norway 1999-2024



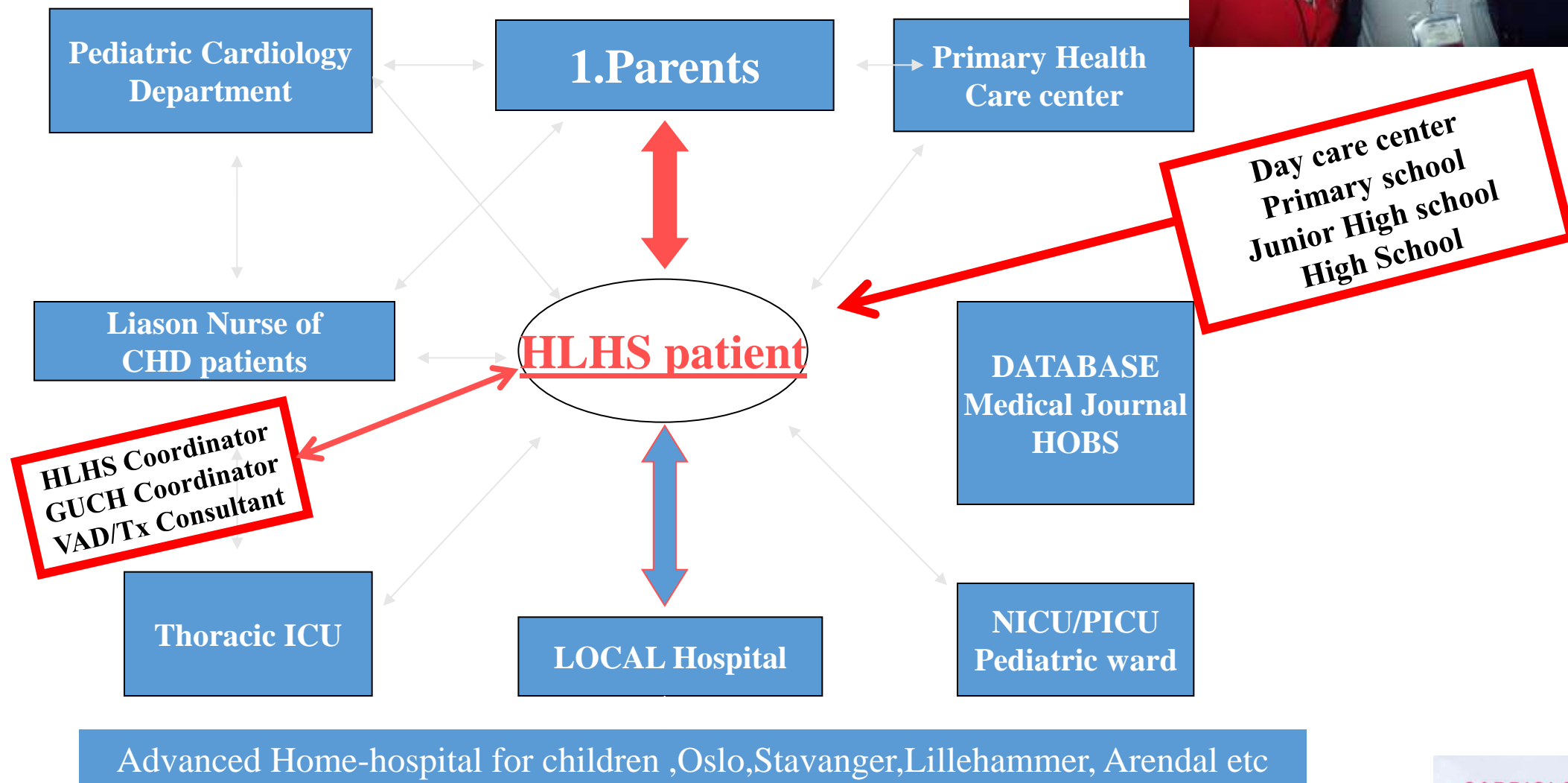
# Patient course and «pathway» to Fontan at Rikshospitalet, Oslo

- Inutero diagnosis and follow-up( 50 %)
- Comfort Care ( 28%)
- Norwood stage 1/Sano – Day 5
  - Home-monitoring program + HOBS app
- Norwood Stage 2( BDCPC) – 4-6 months
- Norwood Stage 3( ex-TCPC) – 15 kg





# Coordinating HLHS Follow-up



# Individual plan – TEAM effort

- Primary Health Care Nurse
- GP local
- Physical therapist
- Primary teacher
- Educational and psychological service
- Special Educator
- Parents







Diary



### Home-monitoring:

- Weight x 1 / week at the Primary Health Care Center
- Weight gain **min. 150 gr / week**
- Pulsoximeter reading  $> 70 < 90 \%$

Fluid intake increased by the HLHS-coordinator weekly  
( 15% of weight)

- Phone contact / SMS once a week/ E-mail contact**



**HOBS- Heart Observation app**



# (The Norwegian Association for Children with Congenital heart Disease)



4 Magazine



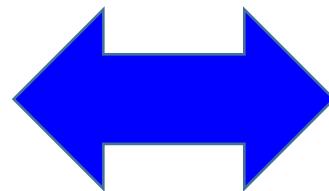
- Folder for each age
- Emergency Sheet
  
- Folder for diagnose
- Day care info
- Primary School info
- Junior High School info
- High School info
- Advice to teachers/ parents



Collaborating with the Ombudsman / Government



Google 1978



We live in a computer world. Either you go with the flow or you fall off the train.  
This is a tech world. ....Mildred Kirschenbaum 100 years old





Image 1. «My Child»



Image 2. «Normal for my child»



Image 3. «Information»



Image 4. «Contact»



Image 5a. «Assessment»

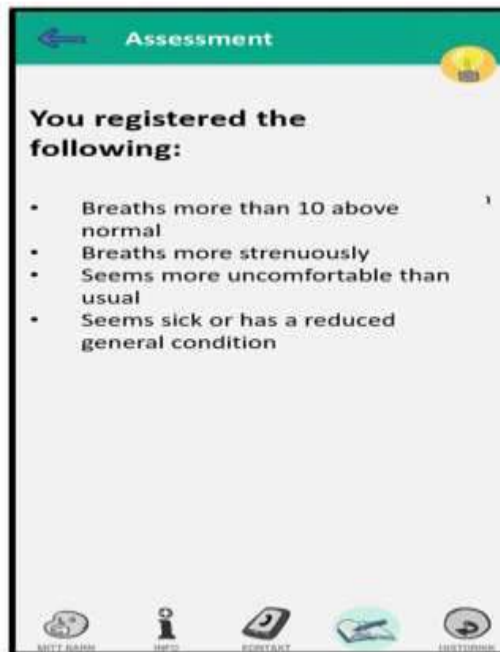


Image 5b. «Assessment respons»



Image 6. «Summary»



# Development and Usability of the Heart OBServation app



## Results from development and evaluation of features

### Background

Every year approximately 125 infants are born in Norway with severe congenital heart disease (CHD). Around 10% of these children die during the two first years of life. Recent research documents that 1% of these children die unexpectedly after a gradual deterioration at home. Many parents find it difficult to recognize worsening of symptoms.

### Aim

We aim to describe development and features of a mobile application, aiming to support parents' management of their child's condition.

### Method

Oslo University Hospital, collaborated with parents and local health professionals to develop The Heart OBServation app (HOBS). We used an iterative approach and investigated the usability by completing semi structured interviews of 9 families and arranged two focus group interviews with 8 nurses. We performed framework analysis to explore usability.

### Development and Research Team

**Elin Hjorth-Johansen**, MScN, PhD-Candidate Neonatal Intensive Care Unit (NICU), Oslo University Hospital (OUH). **Anna Harmens** RN, South-Eastern Norway Regional Health Authority. **Henning Harmens**; System developer, Hena AS/Knirkefritt. **Britt Elin Fredriksen**; RN, CCRN, CNS, OUH. **Gunnar Wik**, MD, Hospital of Southern Norway. **Siw Helen Westby Eger**; MD, PhD, OUH. **Ingeborg Martinsen**; MScN, NICU, OUH. **Ragnhild Hillestad Andersen**; RN, NICU, OUH. Senior Researcher **Elin Børåsund**; RN, PhD, Department of Digital Health Research, OUH. Professor **Anne Moen**, RN, PhD, Department of nursing science, University of Oslo. Professor **Henrik**

**MY CHILD**

**Feature description**  
**My Child:** Individualize HOBS to the infant regarding diagnosis, treatment, needs, and birth information. Controls settings in Normal for my child, Assessment of condition, and Information. Contains feature to take a picture of illustration of the congenital heart disease before and after surgery

**Evaluation**  
**Parents' experiences:** Easy and intuitive to fill out. Wants introduction and support to secure correct input.  
**Requests:** None  
**Nurses' experiences:** Clear, simple, and comprehensive. Entail guidance to choose the right topics to teach.  
**Requests:** None

**NORMAL FOR MY CHILD**

**Feature description**  
Settings in my child control categories to fill out. Infant's appearance is selected by parents regarding, respiration, circulation, elimination, eating, sleeping, and satisfaction. Description is not accurate but meant to raise an approximate picture of the child.

**Evaluation**  
**Parents' experiences:** Easy and intuitive to fill out. Raises awareness of child's normal appearance.  
**Requests:** Nuance some categories (vomiting, eating habits, and appearance).  
**Nurses' experiences:** Gives systematic, specific overview to required observations. Focuses on respirations and circulation, which parents usually do not pay attention to. Enables a retrospective view of what was normal for the child.  
**Requests:** Video of respiratory distress should be included for guidance. More nuanced categories in eating, skin appearance, and vomiting

**ASSESSMENT**

**Feature description**  
Parents record respirations, circulation, elimination, eating, sleeping, and satisfaction due to setting in My child. They answer yes or no to questions about symptoms. Parents may take pictures of wounds and compare them with former pictures. Tip buttons may advise them how to do assessments.

**Evaluation**  
**Parents' experiences:** Nice to have a checklist if needed. Gives awareness of what to look for and what it means. Not necessary to use it every time because they remember. Value the opportunity to compare pictures of wounds.  
**Requests:** Clear description of how to interpret and what to do about observations and findings, what parents should look for at home.  
**Nurses' experiences:** Gives awareness of what to look for and how to do it.

**INFORMATION**

**Feature description**  
Parents receive individualized information based on settings in "My child" in a reading list.

**Evaluation**  
**Parents' experiences:** Relevant, available, and easy to understand.  
**Requests:** Parents missed information about: Sick siblings, pulseoxymeter.  
**Nurses' experiences:** More available in HOBS than in handouts. The possibility to gather written information is absent.  
**Requests:** keep leaflets as an opportunity

**CONTACT**

**Feature description**  
Parents can gather telephone number to local contacts during hospitalization. Information about who to call and when is added to each service level.

**Evaluation**  
**Parents' experiences:** Used in different ways, but most important to gather number and information at one place.  
**Nurses' experiences:** Important information to receive. Traffic light makes it visual as more or less acute. Valuable information about who to call when

**Requests:** Include information about important information to emergency calls.

**SUMMARY**

**Feature description**  
Measures of general condition are presented as bar chart and measurements of heart rate, breathing rate and saturation in curves. Weight gain is calculated to be sufficient or not and visualized by a red cross or green thick.

**Evaluation**  
**Parents' experiences:** Appreciates the confirmation of good weight gain. Less interested in curves than a single assessment.  
**Requests:** Automatic sharing of information

**Important revisions completed:**

- New feature: Interactive discharge checklist adapted to each infant based on settings in My Child (picture to the right)
- Video of strained breathing to support guidance included in "Normal for my child"
- Nuanced categories in baseline
- Clarified and updated information in requested topics
- Added important

Before discharge please complete and receive guidance in the topics in the checklist below. Please tick off completed tasks.

- Discharge check of settings in My Child
- Updated Normal for My Child
- Done assessments together with a nurse
- Discharge talk with a doctor
- Received contact information
- Has information about next follow-up
- Has picture of the surgery wound
- Know how to use a pulseoxymeter
- Know how medications are given
- Have necessary prescriptions
- Can find information about

### Conclusion

The features of HOBS was well received as usable to provide tailored information, increase awareness of the child's normal condition and to support parents to assess worsening of symptoms. Some features was revised and an interactive discharge function was added to ensure guidance and empower parents during discharges.

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# Conclusion

- It's impossible, said the doubt
- It's dangerous, said the fear
- It's unnecessary, said the common sense
- I'll do it anyway, said the heart.....



Thank you for your attention