

CARDIOLOGY
2025 ❤️

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

February 20th , 2025
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Children's Hospital
of Philadelphia®

Cardiac Center



Oslo
universitetssykehus

HOPE. HEAL. LEARN.



Disclaimer

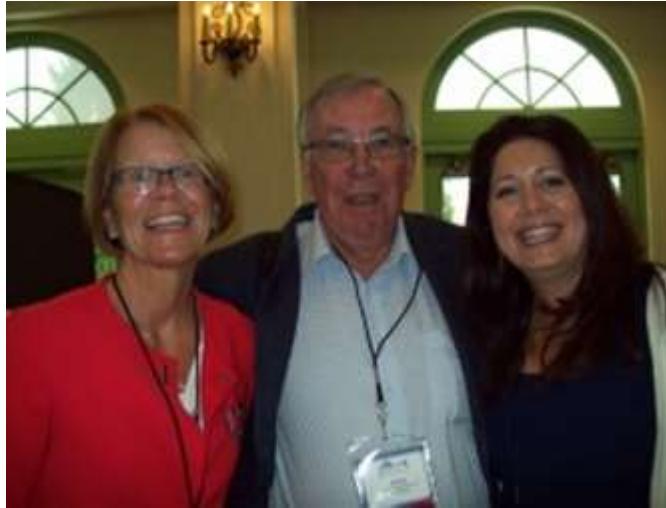
- I have no disclosures or conflicts other than all the people I've met and relations I've made the last 46 years.
- I would like to dedicate this session to dr.Bill Norwood,who passed away in December 2020.



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



Cardiology 2007



Dr.Nancy Ghanayem



Cardiology 2018



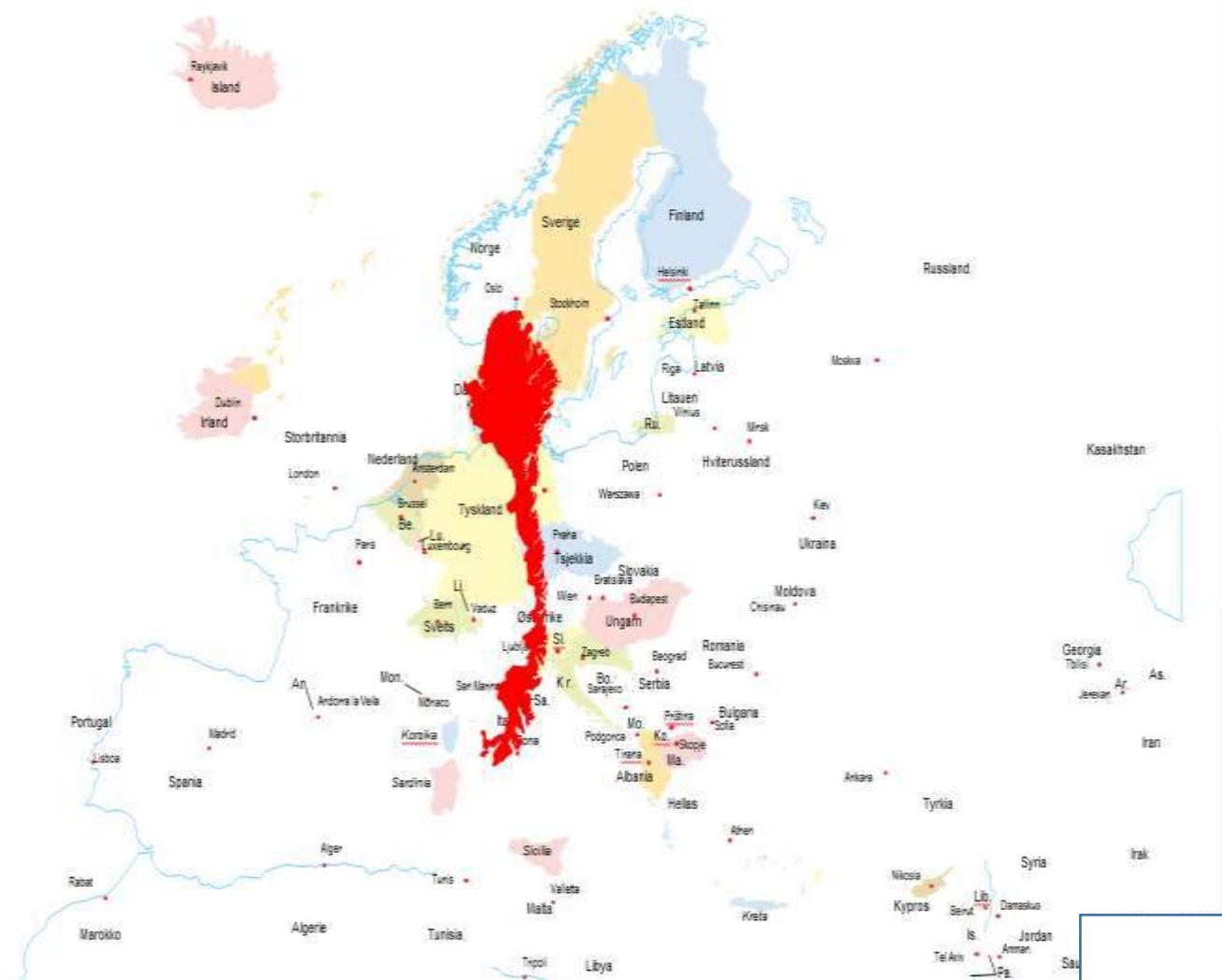
Judi Ruley , Social worker CHOP



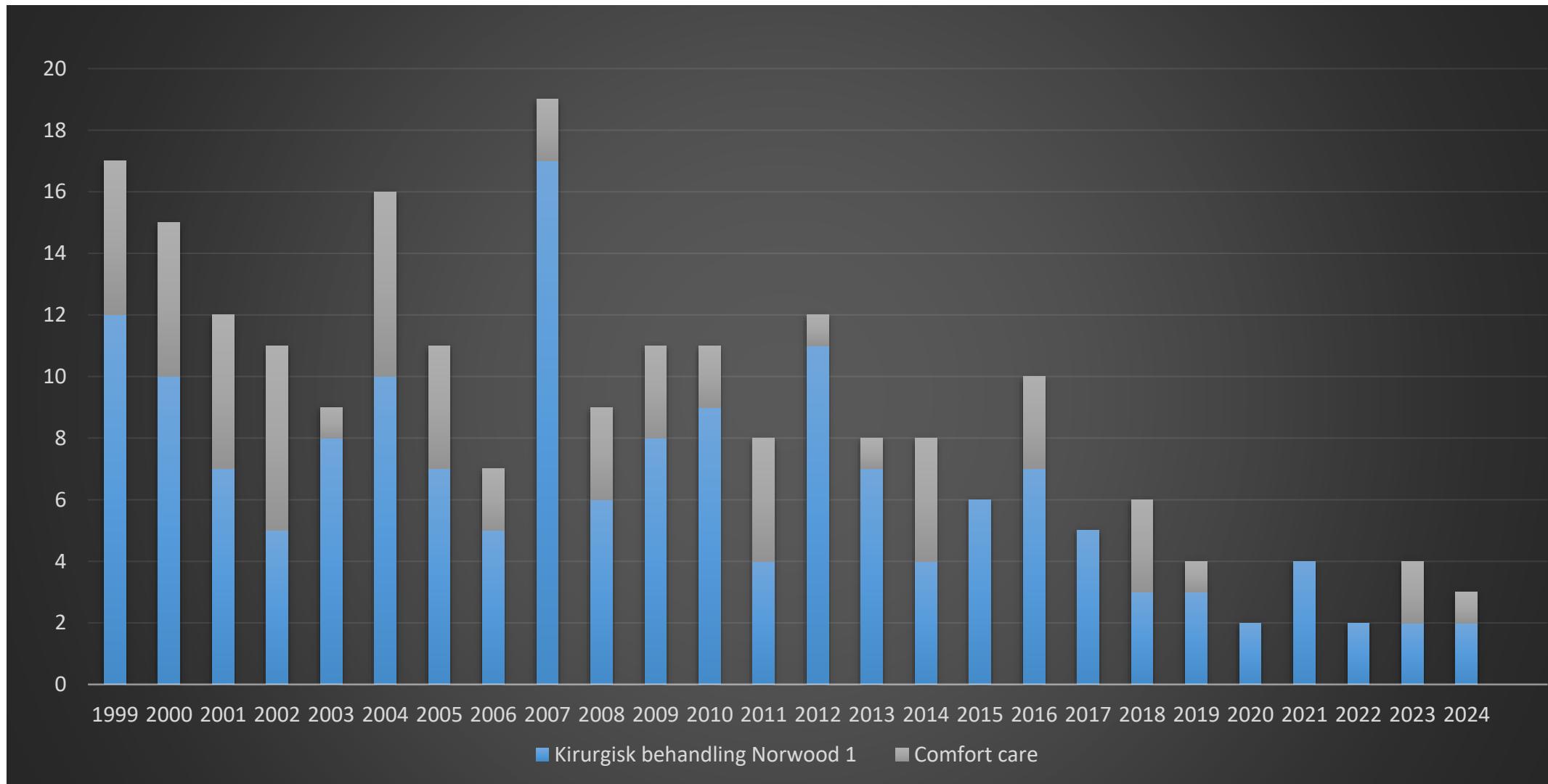
Cardiology 2020 M.Cohen

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



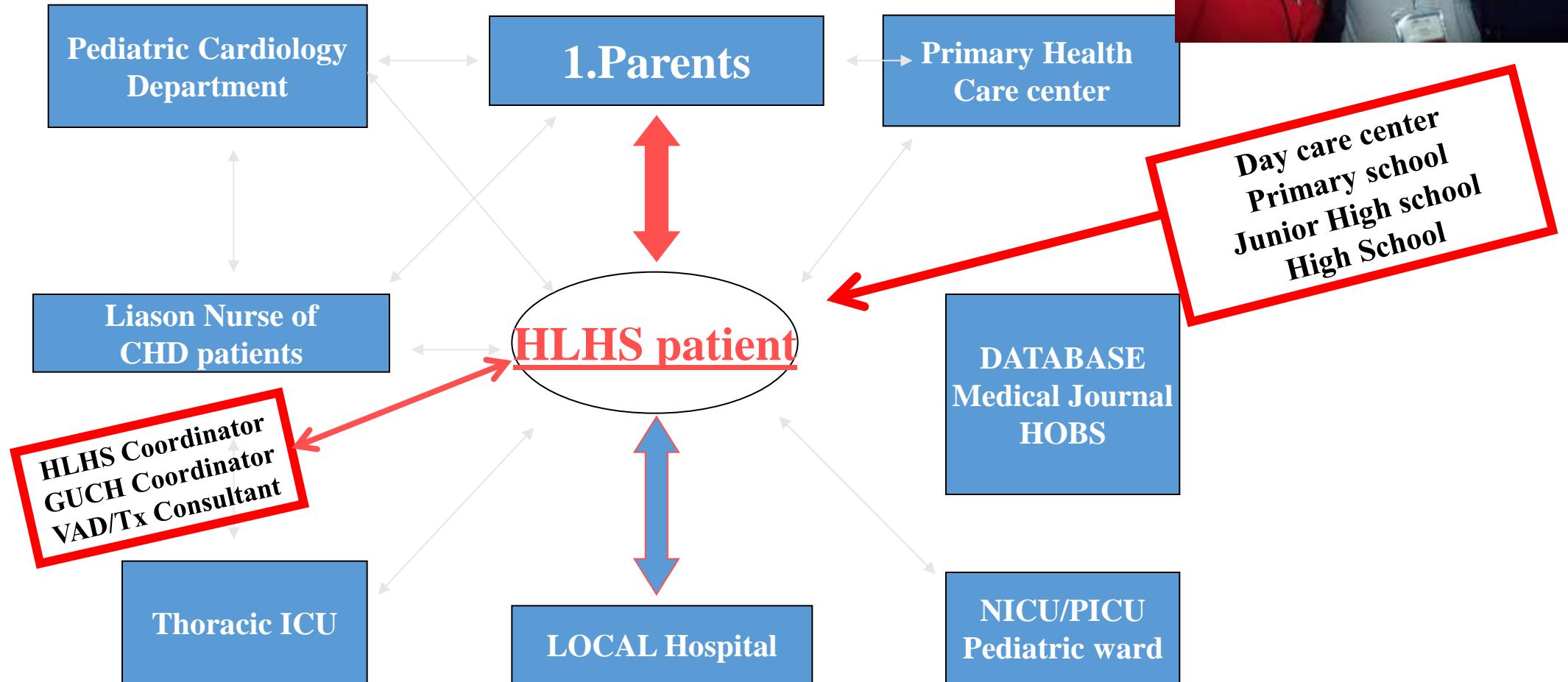
Patient course and «pathway» to Fontan at Rikshospitalet, Oslo

- 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



Source: Surg Infect © 2004 Mary Ann Liebert, Inc.

Coordinating HLHS Follow-up



Advanced Home-hospital for children ,Oslo,Stavanger,Lillehammer, Arendal etc

Individual plan – TEAM effort

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





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



4 Magazine



Collaborating with the Ombudsman / Government

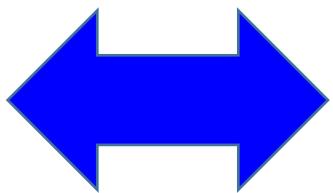


- Folder for each age
- Emergency Sheet

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



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

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Image 1. «My Child»



Image 2. «Normal for my child»



Image 3. «Information»



Image 4. «Contact»

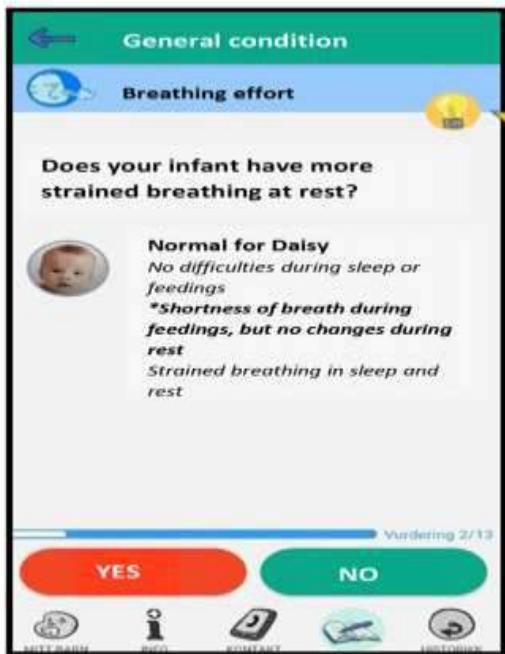


Image 5a. «Assessment»

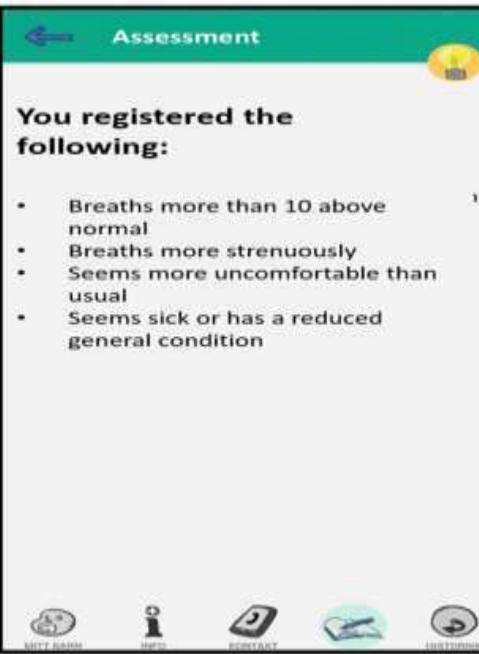


Image 5b. «Assessment response»

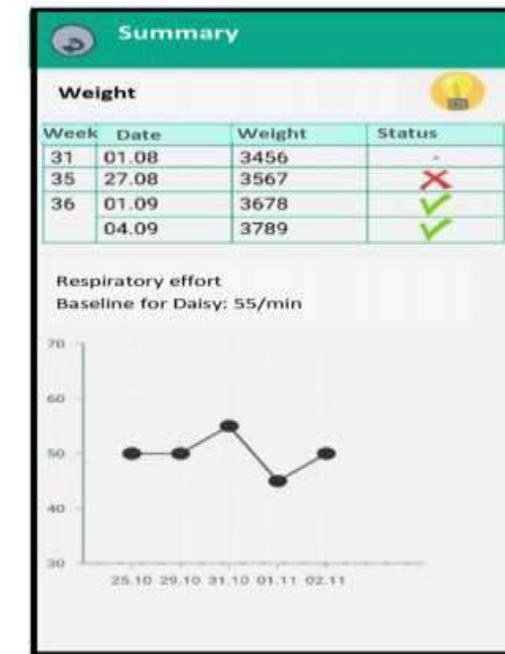


Image 6. «Summary»

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 10% 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 with 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 Bjørnsund**; RN, PhD, Department of Digital Health Research, OUH. Professor **Anne Moen**, RN, PhD, Department of nursing science, University of Oslo. Professor **Henrik**



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

