

# SURVIVE and THRIVE

Transforming care for every  
small and sick newborn



# Measuring parent and community engagement



## Why measuring is so important



18.2.97 12<sup>30</sup>  
Lukas



23.2.97 we lost our  
daughter Lena



15.03.97  
Erstes Kängurubin

*“It is important to learn from data. To change minds in every day practice and to improve the care of small and sick newborns, it is key to listen to parents experiences and collect all information and data.”*

– Silke Mader, parent, advocate and founder  
European Foundation for the Care of Newborn Infants  
and The Global Alliance for Newborn Care

## Why are these data needed?

- Assessments of parents' knowledge, attitudes and beliefs, and their desired role during their newborn's inpatient care, are central to an effective approach to **family-centred care**.
- Programme assessment using evidence-based, family-centred care guidelines can improve the quality of family-centred care.

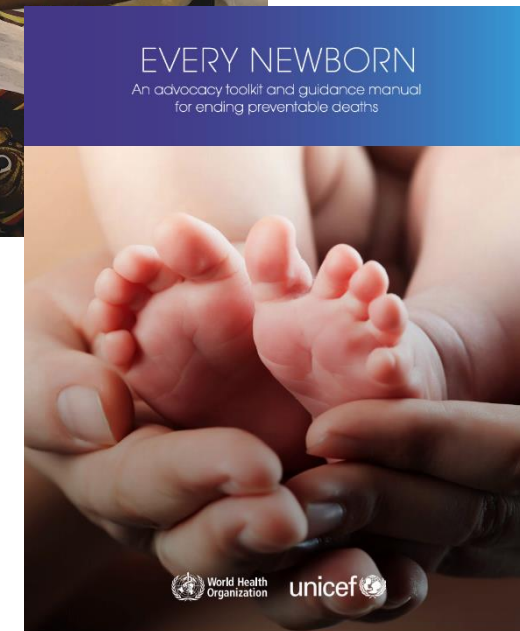


Source: Davidson JE, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Crit Care Med. 2017;45(1):103–128.

## Which data can be used now?

### Family-centred care tools measuring...

- **Parent and community engagement** in care of small and sick newborns
- **Provider perceptions and parent satisfaction** at discharge from neonatal units using surveys and benchmarking reports
  - Options specific to LMICs available
- **Advocacy activities and results** at the societal and policy levels



See sources in Notes.

## What data are needed?

### Potential questions to measure types of support received:

- Were measures taken to ensure that parents and caregivers developed the appropriate skills to care for their newborn in facility and after discharge?
- Do they report a positive care experience in the facility?
- Do they share information regarding any situations of disrespect and abuse?
- Are there facilities to help parents stay close to their newborn (rooms for overnight stays, toilets, showers, provision of food)?



## What data are needed?

Potential questions to measure types of support received:

- Are there educational materials available to parents and caregivers?
- Was the newborn separated at any point from their mother without explanation?
- Are there community groups to provide support to parents and families?
- How do facilities link parents to these groups and to community health workers for support after discharge?



## What data are needed?

### Potential questions to measure types of support received:

- Do community behaviours and practices towards inpatient care-seeking differ between female and male newborns?
- What information do parents receive about care for their newborn in the hospital and after hospital discharge?
- How well informed are community-level services and health workers about the care and developmental needs of small and sick newborns?
- Were compassionate support and mental health services available for grieving families in the event of a newborn's death?

