

Family Participatory Care: A Gateway to Nurturing Small & Sick Newborns



State of Newborn care Our Unit :2007



Babies often lying wet!!



Tubes/probes
often misplaced!!



IV swellings common!!



Alarms
ringing
incessantly!!

Common scene outside the neonatal unit.....
Parent Attendants lined waiting..... !!



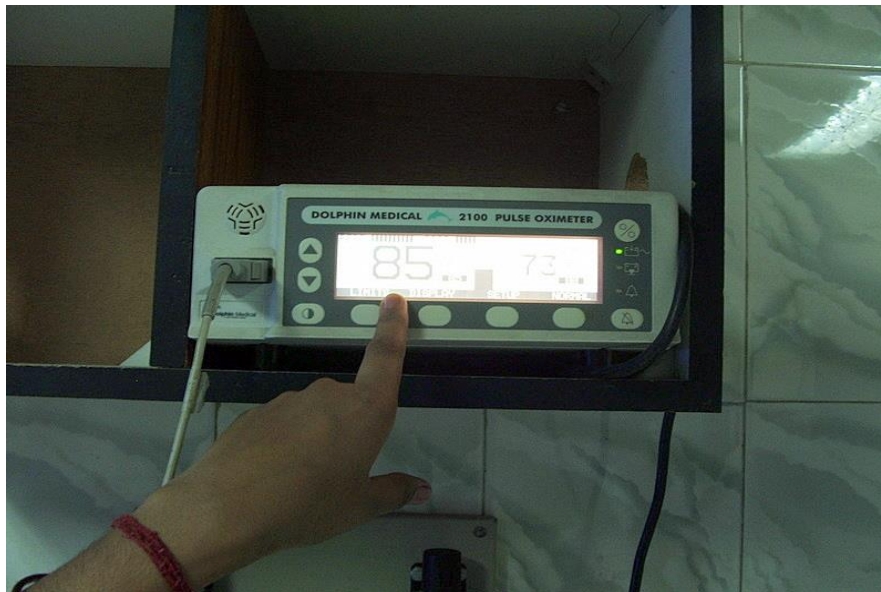


**“Can we start ‘engaging ’ the waiting
parent-attendants *as nursing aides* for
their own babies?”**

Allowing parents to come in ...



“Involving parents”: as nursing aides



“Using” parents: to overcome HR constraint



WHAT DID WE SEE?

P-A as nursing aides....

- Parents
- Babies
- Nurses

Passive/ Instructive
Participation

**FRINGE
BENEFITS!!!**



Modern Neonatal Care: Gaps

- Less Attention to
 - Sick babies' development
 - Psychosocial needs of family
- Parental involvement in care/decision making is: limited.
- Universal human workforce shortages: compromised QoC.
- Lack of continuum of care at home.

Family-Centered Care to Complement Care of Sick Newborns: A Randomized Controlled Trial

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[#]Management Studies, IIT; New Delhi, India.

TABLE III SUMMARY OF OUTCOMES IN THE TWO GROUP OF SICK NEWBORNS

Outcome variables	Control group (n=147)	Intervention group (n=148)	Mean difference (95% CI)	P value
Culture positive nosocomial infection rate	7.17	6.43	0.74 (-4.21, 5.6)	0.76
Culture negative nosocomial infection rate	9.86	10.56	-0.70 (-6.6, 5.2)	0.82
Duration of stay, median (IQR)	11 (7,18)	11.5 (7,17.5)		>0.05
Mortality, No. (%)	13 (8.8)	10 (6.8)	(0.04, 0.134)	0.5
Breastfeeding rate, No. (%)	100 (66.7)	119 (80.4)	(0.59, 0.74)	0.007

61% Males
 37% Fathers
 20% Grandparents
 41% > 50 years old
 25% Illiterate

No ↑ in Infection
 ↓ Hospital stay
 ↑ Breast feeding
 Feasible & Safe

Scope of Mother/Parental Involvement in a Nursery (SNCU)

Entry Protocol (Session I)



Scope of Mother/Parental Involvement in a Nursery (SNCU) contd....

Developmentally Supportive Care (SESSION II)



Scope of Mother/Parental Involvement in a Nursery (SNCU) contd....

Developmentally Supportive Care : Feeding (SESSION II)



Scope of Mother/Parental Involvement in a Nursery (SNCU) contd....

Kangaroo Mother Care (Session III)



Scope of Mother/Parental Involvement in a Nursery (SNCU) contd....

Preparation for Discharge and care at Home (SESSION IV)



Institutionalising Family Centred Care: The Process

**Induction at Admission
& Identification of
Primary Care Provider**



Daily Trainings Scheduled



**Demonstrations and
Practice**



Supervised Learning



Peer To Peer Learning



Discharge Counseling



Independent Doing



**Continuum of Care at
home**



Mother became our point of focus!!

About Implementation of FO

That was easy!!

- Mother already sold to the concept!
- Much easier to define what mother is expected to do and...she will do.

“Initially too much focus on training sessions and ensuring mothers must attend!!”

Mothers attending training sessions religiously but *mothers still not seen to be engaged in bedside care!!*



Focus shifted from ‘trainings’ to seeing mother’s involvement in bedside processes of care”

Need of supervision -----Role of provider!!

“Mothers involved in care but *sometimes seen to be engaged doing what was beyond her defined scope!!!....*”

??Task shifting by the provider



Lesson 2

- **Important to *define what mother will not do* eg.**
(Nothing pertaining to Oxygen regulation/IV canulae/ fluids/ Drugs/
Medications/Orogastric tube related feeding or else/
CPAP/ Endotracheal tube related)

Monitoring of Mother : ***Role of provider!!***

“Trainings not happening regularly!!....
Staff changes....new people... not aware of FCC”



Lesson 3

Need of periodic sensitization of staff (one and all !!)

(.....Role of provider!!)

So....

What was not so easy??

“Selling the concept to doc/ nurse !! “

A yellow ribbon banner with a blue outline, featuring a central rectangular box and two pointed ends.

Lesson 4

Provider needs to be focus of attention for effective implementation of the program!!

Challenges w.r.t. health care providers

- Accepting P-A as a co-partner in care !
- Diminished authority?
- Watch Dog Effect!!
(Uneasiness because of being constantly watched!)
- Tendency to task shift!!
- Expected to deliver a standard of care that an empowered parent now is aware of and expects from him !!!

About Implementation of FCC.....

Identifying Champions & Getting health care provider on board is the most important!!!

Monitoring

In hospital

- Nurses performance.
- Adverse events /HAI

After Discharge

- EBF rate at 3/ 6 months
- KMC continuing rate
- No. of rehospitalisations
- Post D/S mortality
- Growth & Devt.

Measures & Attributes of Implementation (June'16-July'17)

1. Measure of Implementation

- Workspace readiness
(Infrastructure-Facilities)
- Parent/Attendant preparedness (Practices)
- Staff preparedness (Attitudes)

2. Feasibility

- 61% Males
- 37% Fathers
- 20% Grandparents
- 41% > 50 years old
- 25% Illiterate

3. Acceptability

Qualitative study (2016)

- Primary gains:
(Empowerment, Skills, Continuum of Care)
- Improved patient- staff relation

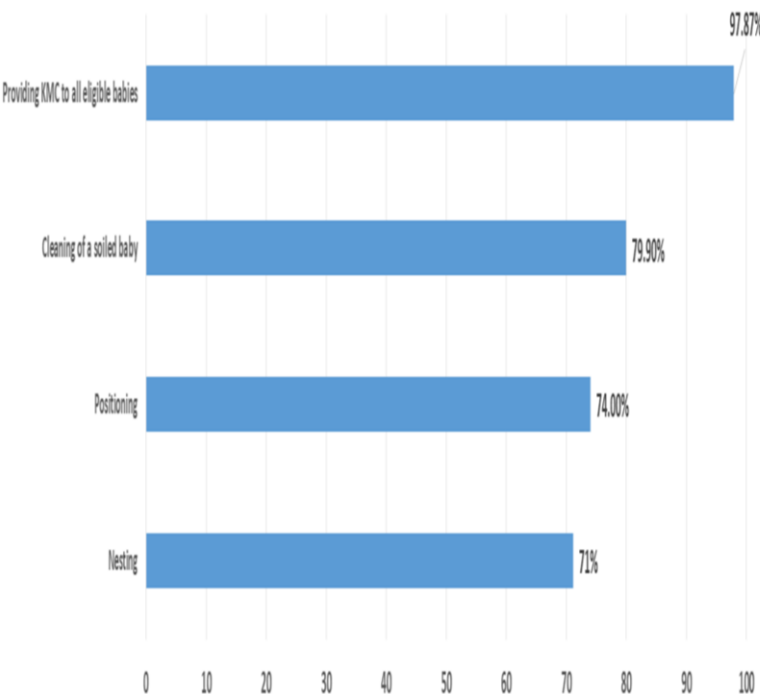
4. Measure of Quality of Care

Participatopn of Mothers in Care in processes of care

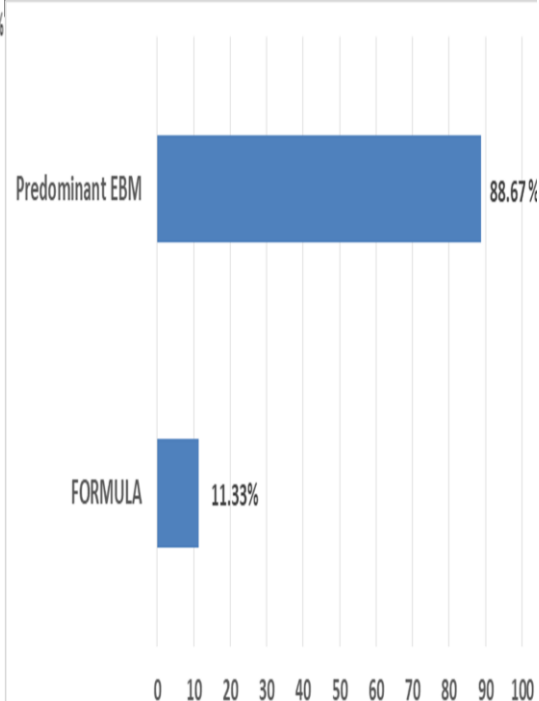
- Nesting,
- Positioning,
- Cleaning,
- Skin to Skin Care

[illegible]

Involvement of Parent- Attendants : Measure of Quality of Care (June'16-July'17)



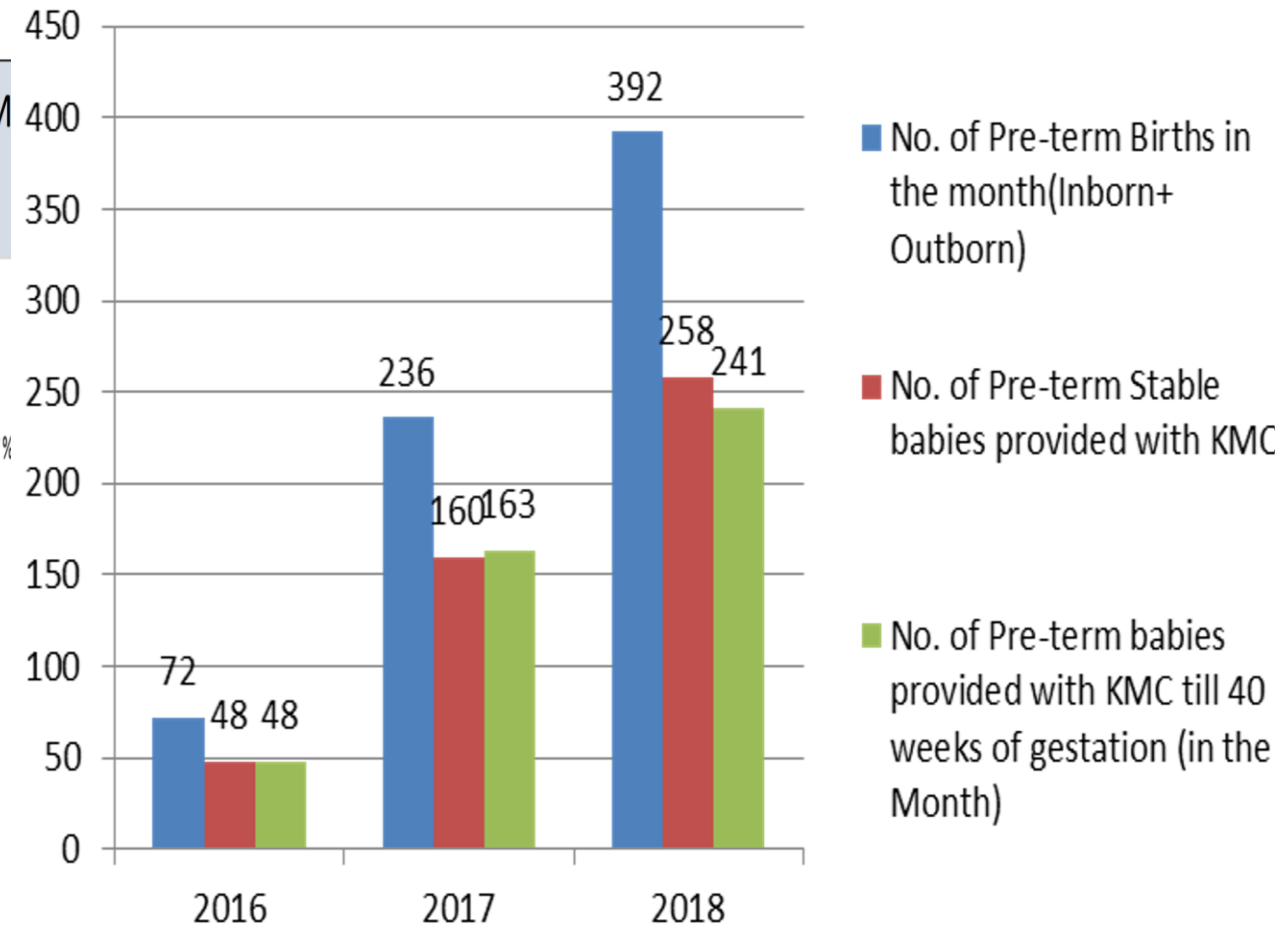
Average Exclusive / Predominant EBM
usage in Outborn NICU
(July'16-July'17)



KMC Data

October 2016 – November 2018

Dr Ram Manohar Lohia Hospital & PGIMER, New Delhi- 110001



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Sarin and Maria BMC Health Services Research
<https://doi.org/10.1186/s12913-019-4017-1> (2019) 19:184

BMC Health Services Research

Open Access

Check for updates


RESEARCH ARTICLE

Acceptability of a family-centered newborn care model among providers and receivers of care in a Public Health Setting: a qualitative study from India

Enisha Sarin¹ and Arti Maria^{2*}

Abstract
Background: Family-centered care (FCC), based on collaborative participation of the family along with a team of health care providers, is found to increase the well-being of sick infants in neonatal critical care units. Over the last 4

Parent- Attendants' Experiences




Pratibha
(February '17)

Now I would be able to do everything on my own.

When new baby comes in the doctor tells me to teach them how to wash hands and how to enter the nursery.

They are not aware of anything but I have learnt everything so I teach that to other people. In that way I would also remember everything and make sure that I have not missed out anything.

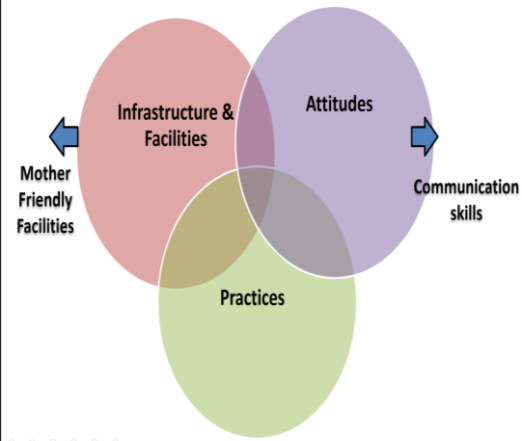
So, I am not teaching them but I am learning the things again and again".



Mr. Zaid
(February'17)

"We always perform handwashing while going to baby, cleaning house using Dettol, we don't allow outsider to visit , only family members are allowed, that too after bathing".

Hence Implementing FPC

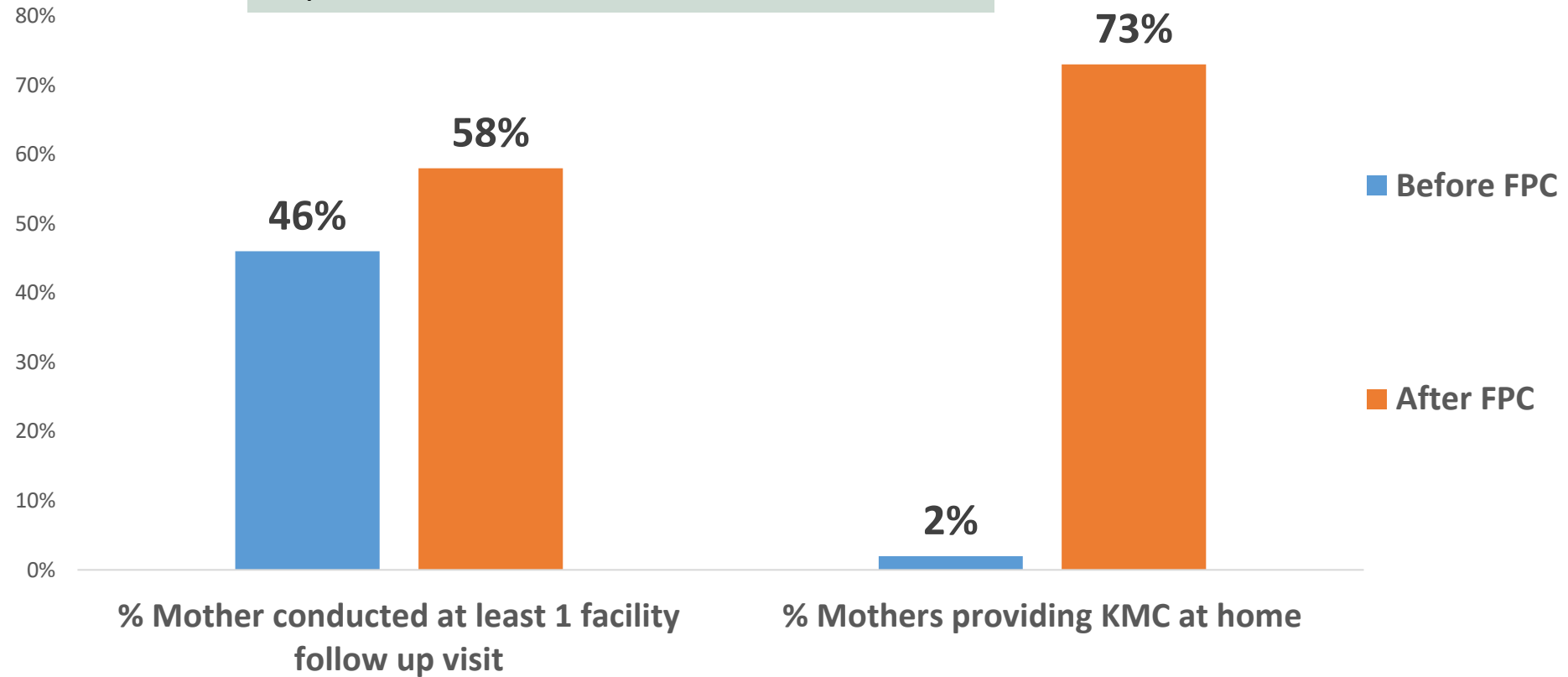


FPC Model

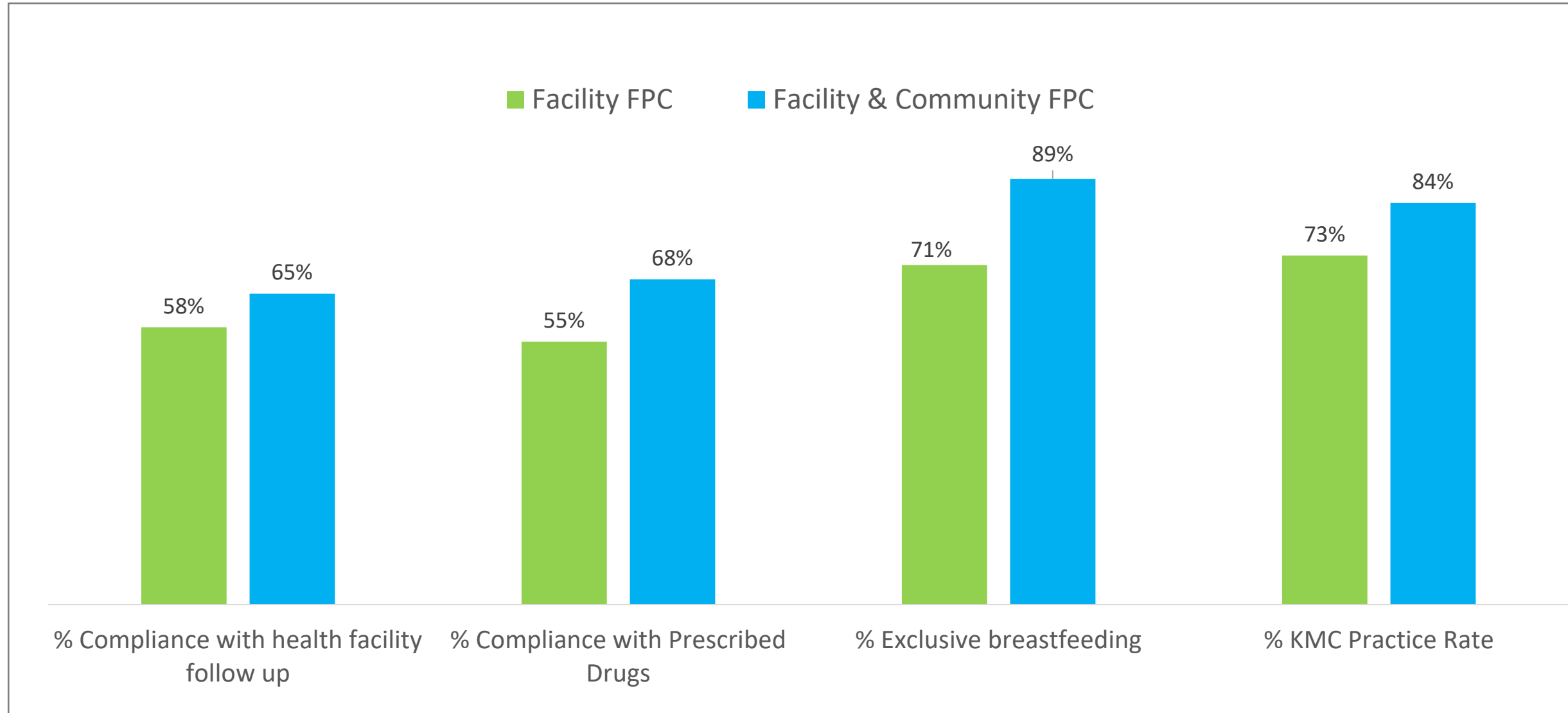


Results achieved in 5 Model FPC centres

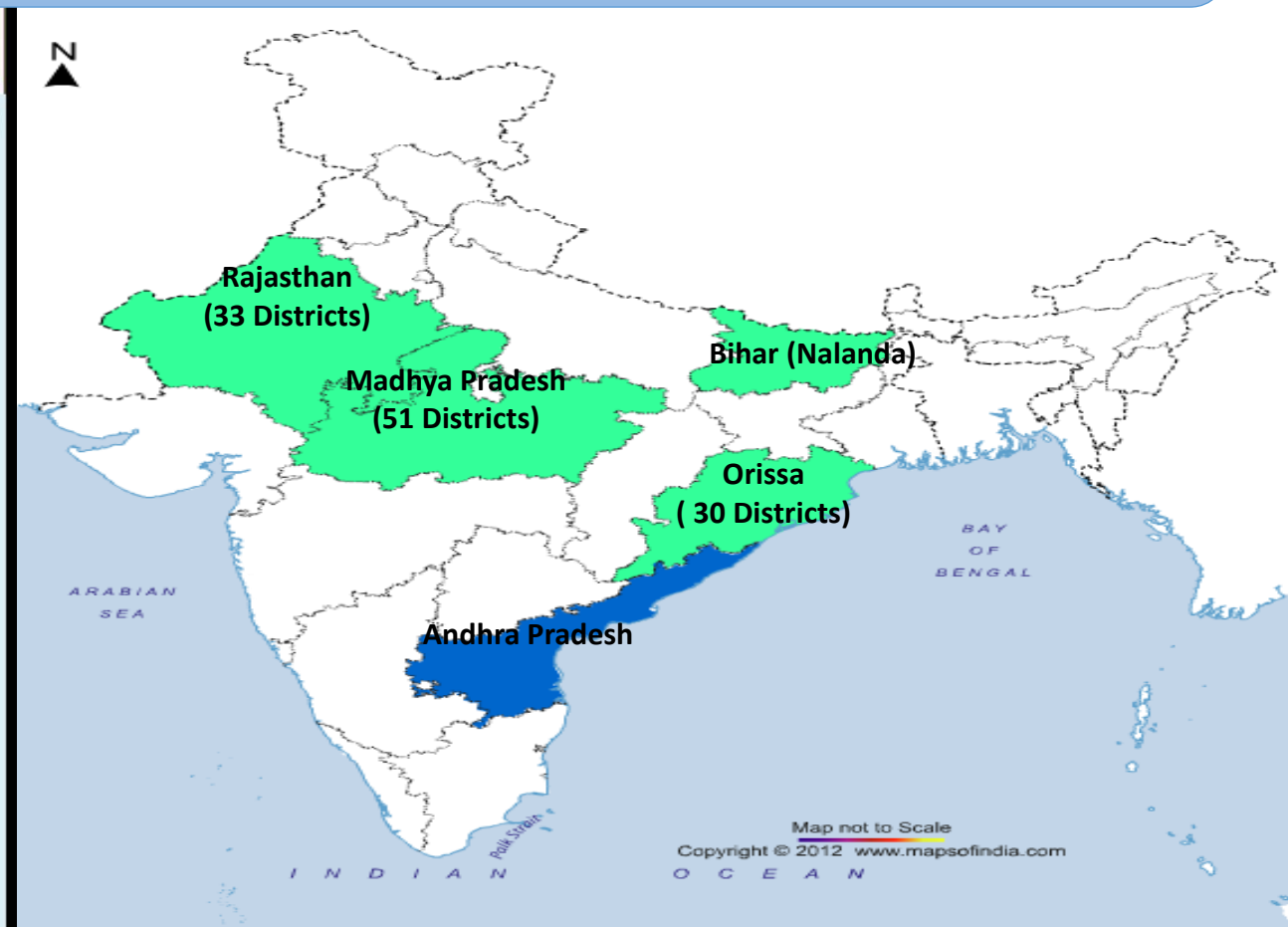
Adherence especially KMC Significantly improved



Improved Adherence with addition of community component in 5 FPC centres



Translation in Public Health Country Scale up 2014- till date



Phenomenal Scale up of FPC in India!!!

- **FPC Scaled up in 69 FPC centres with country budgets in one year**

■ **5 Model Centres since Jan 2016**

■ **69 FPC Centres since April 2017**

Qualitative & Quantitative Assessment of FPC in 38 facilities in India

Objective:

- ❖ Assess the current status of FPC implementation
- ❖ Bottlenecks & challenges in quality implementation of FPC.

• Tools

- a) Health Provider-Interview
- b) Facility checklist
- c) Data verification
- d) Client satisfaction & knowledge

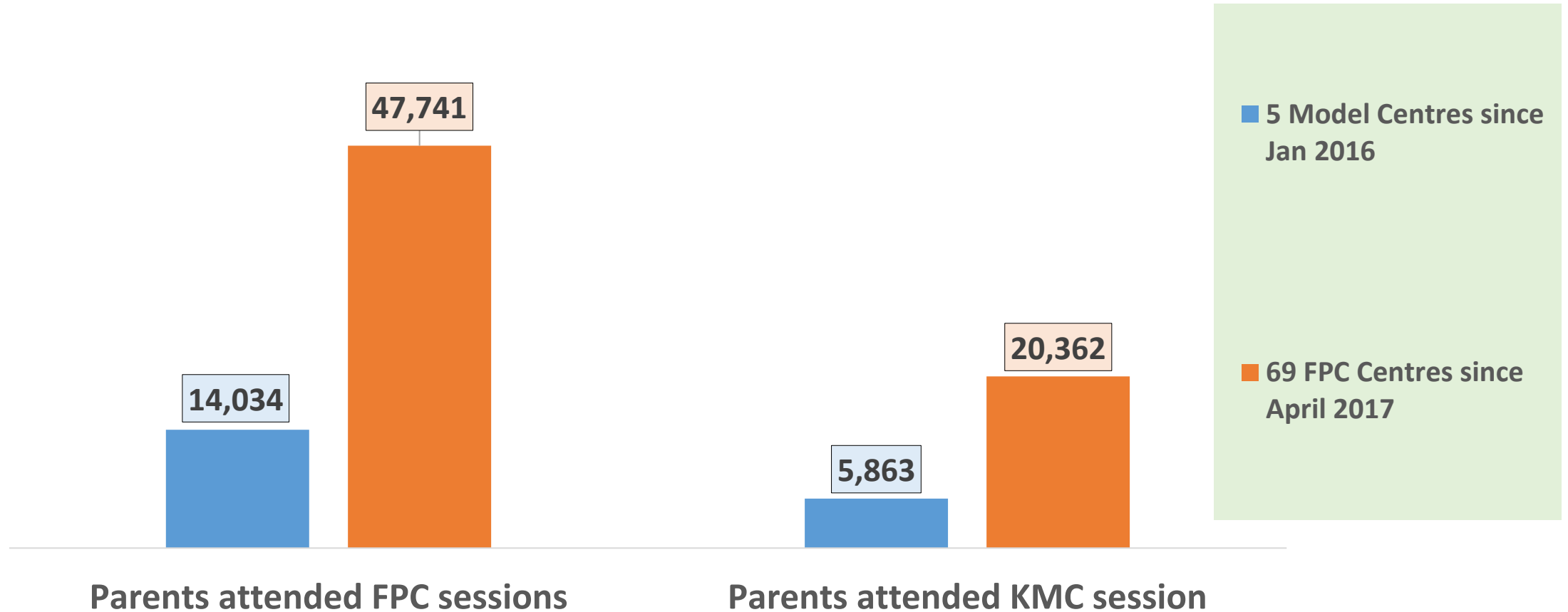
69 Facilities
Training
conducted

43
submitting
reports

38
Assessed

Phenomenal Scale up of FPC in India!!!

- **FPC Scaled up in 69 FPC centres with country budgets in one year**



FPC Assessment-QoC (providers feedback N=38)

S N	Qualitative Opinion of Doctors and Nurses (N=38)	Improved	No Change	Not Sure
1.	Quality of care since starting FPC in the facility	97%	-	3%
2.	Breast feeding practices in the facility	97%	3%	
3.	KMC practices in the facility	100%	-	
4.	Nosocomial infections in the facility	34%	39%	27%
5.	Follow up of discharged cases in the facility	74%	26%	

Follow up at community for SNCU discharged babies

Care at SNCU



At home, care by mother



1. Adherence (compliance with discharge instructions)
2. Continue support for KMC & LBW feeding
3. Play & stimulation (ECD)
4. Prompt detection of danger signs & timely referral to appropriate facility

Outcome: Follow up of 9500 NB after D/S shows mortality<1%

Summary of Findings

- **Most moms suggested FPC should start!!!!.**
- **Enabling logistics available at most places.**
- 72% eligible NB were receiving FPCat final units
- 53% of Doctors /Nurses)were trained on FPC.
- Most facilities had regular FPC sessions but training not well structured.
- **Breast feeding & KMC practices have increased**

Assesment of implementation in 85 neonatal units of 3 states with state funding by NIPI revealed;

13,213 (75%) mother& family members received capacity-building FPC sessions;

5,548 (86%) newborns below 2,000 grams were provided with kangaroo mother care until discharge;

initial assesment: exclusive BF rates-86%, continuing KMC at home:75%;

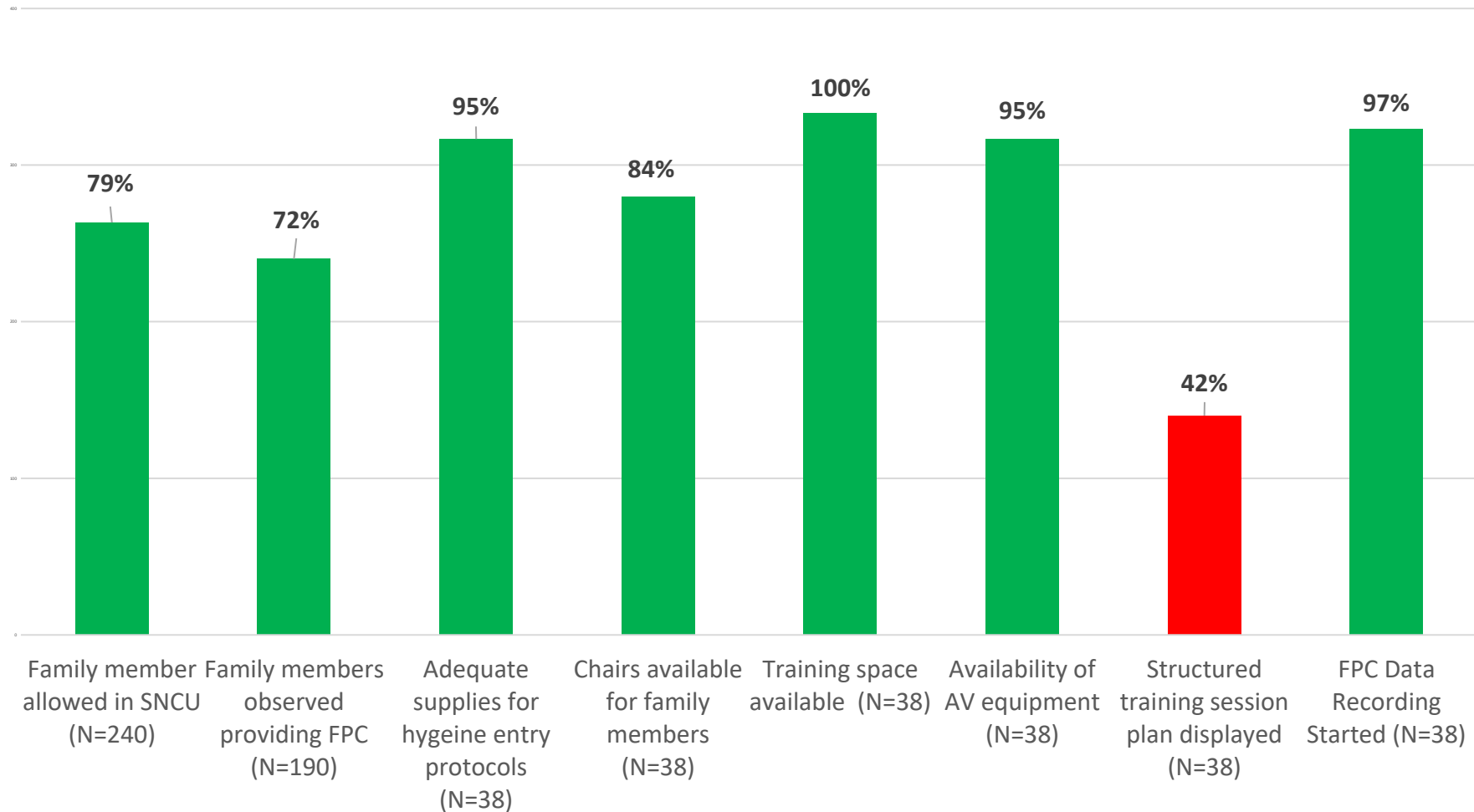
post-discharge mortality reduced from 7% to 2.7% in the implementing districts.

FPC Assessment-Quality of Care

(providers feedback N=38)

S N	Qualitative Opinion of Doctors and Nurses (N=38)	Improved	No Change	Not Sure
1.	Quality of care since starting FPC in the facility	97%	-	3%
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4.	Nosocomial infections in the facility	34%	39%	27%
5.	Follow up of discharged cases in the facility	74%	26%	

FPC Assessment-Facility observation



Summary of Findings

- Almost all the mothers suggested FPC should start everywhere !!!!!.
- All units were functional for FPC (72% eligible newborns receiving FPC)
- 53% of clinical staff (Doctors and Nurses) were trained on FPC.
- Enabling logistics available at most places.
- In most of the facilities FPC sessions happening regularly but training not well structured.
- Breast feeding & KMC practices have increased.

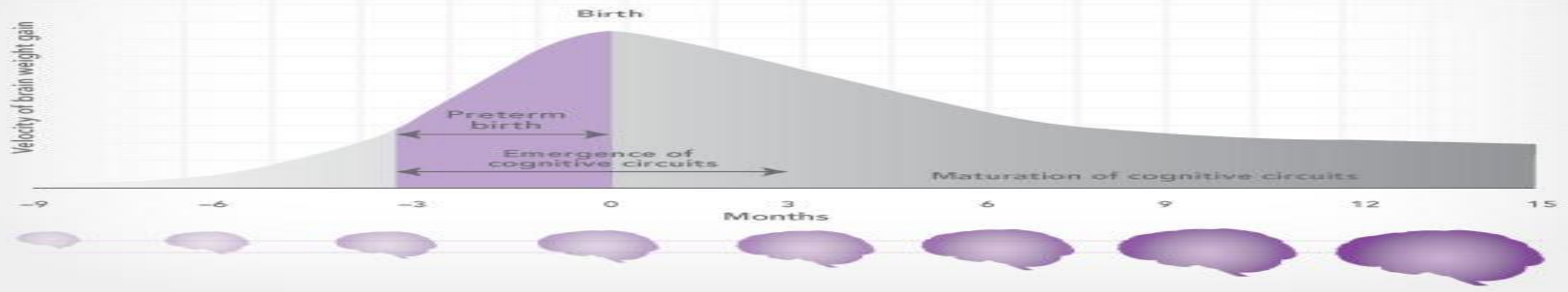
Learnings & challenges!

- ❖ FPC is doable in public health framework
- ❖ **Winning strategy for improving KMC & empowering families**
- ❖ Convincing key stakeholders: single most important step!
- ❖ Identifying a champion at each institutional level
- ❖ **Integration with FBNC**
- ❖ **Scale up support**

Neuro-developmental Outcome at 1 year with FCC

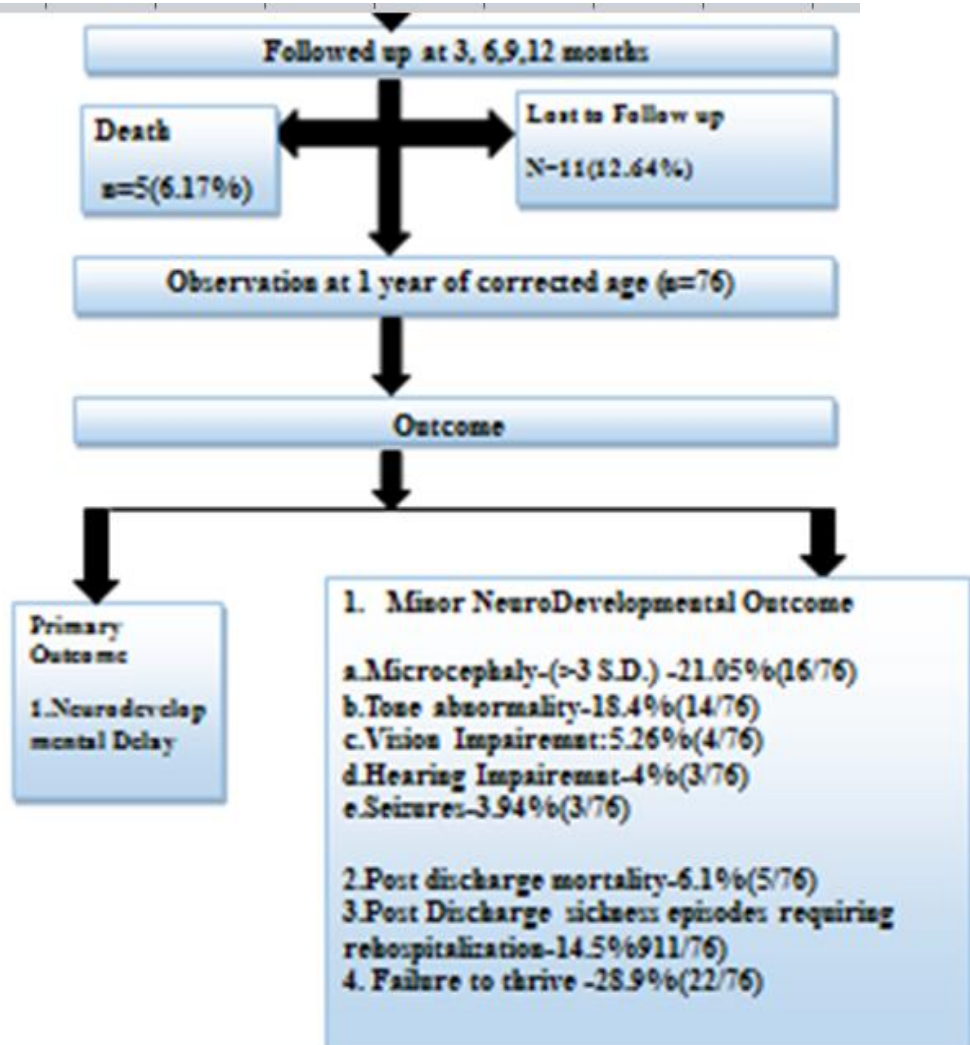


The most rapid period of brain weight gain occurs immediately before and after 40 weeks' gestation¹



Neuro-developmental Outcome at 1 year with FCC: Conclusions

Primary Outcome: DQ <70 & SQ <70



Developmental Quotient < 70	n (%) (N=76)
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Normal neurodevelopment)	58 (76.3)
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Abnormal Neurodevelopment)	18 (23.7)
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Social Quotient <70	n (%) (N=76)
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No Social Delay	57 (75)
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Social delay	19 (25)
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- Slightly **lower rates** of adverse neuro-developmental outcomes in the present study set against **a backdrop of FCC compared to** pre FCC period from the same unit or similar population datasets from district SNCUs
- Cause effect relation cannot be established but the study generated a hypothesis that is worth testing through RCTs

Optimising Early Childhood Development

At Community : Empowerment: Linkage
for Continuity of Care

At Facility : Nurturing Care
*Through learnt competencies:
Involvement in Processes of Care*

Family Centred Care

Small or Sick Newborn
at Facility

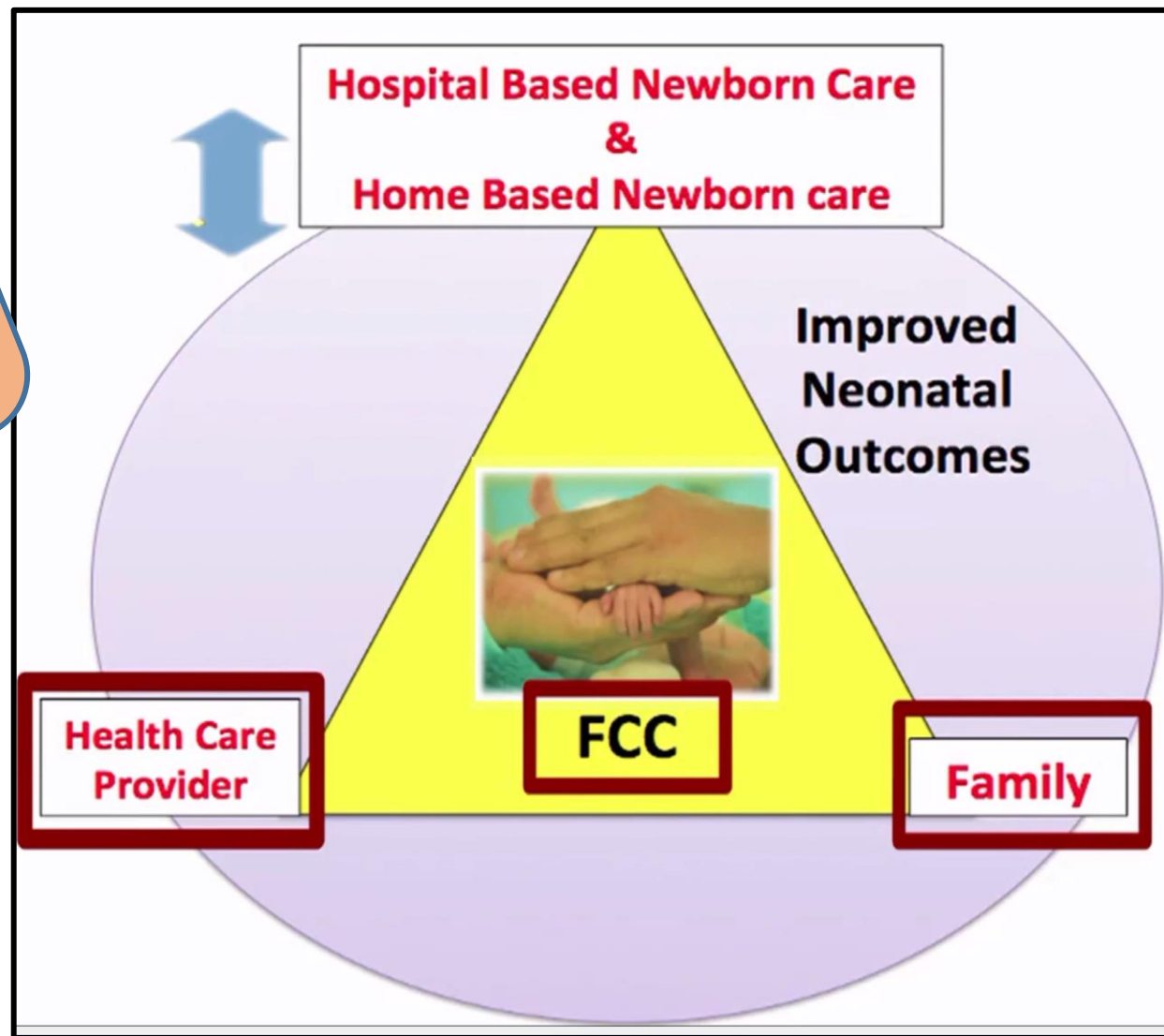
LINKAGE BETWEEN
FCC & ECD

Family Centred Care is.....

- A humane way to care: A Gateway to Nurturing Small & Sick NBs
- Creates opportunity for lifelong bonding.
- A family's right to a respectful care : Need to protect, support & promote!
- A winning strategy for KMC scale up
- Operational feasibility & acceptability in Indian health care setting seems promising.



**Transformative
Participation**



Family Centred Newborn Care holds the key for developing social accountability of health & may help achieve Sustainable Development Goals.

Acknowledgement

- NIPI
- USAID-ASSIST & INCLEN
- National and state governments
- Babies & families for participation & consent for pictures
- Our unit staff /doctors and RML Hospital

