



Raising Parent Voices Advocacy Toolkit

Background: The Parent Voices Initiative (PVI) was developed by the Stillbirth Advocacy Working Group (SAWG) which is co-chaired by the International Stillbirth Alliance (ISA) and the London School of Hygiene & Tropical Medicine (LSHTM). This is funded by the Partnership for Maternal, New-born and Child Health. The purpose of the PVI is to raise the voice and participation of parents bereaved by stillbirth to strengthen advocacy for stillbirth prevention and post-stillbirth bereavement support. The India Providers Toolkit pilot project focused on improving communication between parents and health providers with the ultimate aim of fostering an environment conducive to stillbirth parents being able to advocate on their own behalf for bereavement support and stillbirth prevention. It focuses on health providers working within health facilities and communities, to provide them with information and suggested approaches for deeper and more open communication with parents after a stillbirth.

This toolkit covers breaking bad news, talking with parents about how and why their baby may have died, acknowledging their grief, making room for them to express their need for support, providing respectful bereavement care, facilitating dedicated space away from birthing women and new-borns, and discussing a safe plan for future pregnancies. The India Providers Toolkit was developed in consultation with health providers which was again revised to incorporate parent's perspective after consultation with the parents.

Phase II of the Above mentioned project continued Under Title "To adapt the stillbirth Advocacy toolkit developed for health providers in India (the Indian provider's toolkit) under the parent voices initiative to incorporate the perspective of Indian parents bereaved by stillbirth and their expectations from the health providers, laying the groundwork for toolkit implementation and scale-up in India and adaption to other SEARO countries. Investigators and Collaborators were from PGIMER, Chandigarh, India, Public Health Foundation of India, Gurugram, India, SWACH Foundation Panchkula India, LSHTM UK, Chair ISA, Advisor ISA

International Stillbirth Alliance's Raising Parent Voices Advocacy Toolkit for Health Providers in India was revised in two workshops conducted in Phase I of the "Raising Parent Voices advocacy toolkit". As per recommendations from the participants the toolkit was intended to be revised according to Indian context based on the parent's feedback. The Toolkits revision based on parents input in India was funded By WHO SEARO to achieve the following objectives.

Objective:

1. Translation of the toolkit in to Vernacular Language.
2. Consultation with parents in series of key informant interviews and focus group Discussion;
3. Adapt the toolkit to reflect the consultation

Ethical Clearance:

- The project was approved by the Institutional Ethical Committee.
- Changes In Participant information sheet and Informed consent form and Interview Schedule were approved
- Institutional collaborative Research Committee approved the Project
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Methodology: The Interviews were conducted with the following protocols which were developed by the Investigators after a series of meetings:

45 Stillborn Babies (decided not to interview mothers, fathers and mothers in law of the same baby/family)		
29 Mothers	8 Mother in Law (Present during the death of baby)	8 Fathers

- The PVI team agreed to hold interviews of bereaved parents and families of 45 Stillborn babies of which 29 mothers, 8 fathers and 8 Mother in Laws were to be Interviewed
- An Interview schedule along with PIS and ICF was developed to assess the parent's perspective and experience of care they received during their stay at the Hospital after diagnosis of Stillbirth.
- SWACH Foundation recommended two Interviewers who have a considerable experience of conducting field interviews specifically related to women's health. The Interviewers were trained by Local Consultant under supervision of the Investigators.
- A mixed Group of Parents were interviewed including Parents from SWACH data Pool and Parents visiting Postpartum Clinic of a tertiary hospital in north India. SWACH received all the data of Stillbirth from two districts of State Haryana, India. The tertiary Hospital in North India is situated in the Union Territory Chandigarh with a mix population coming from different socio-cultural backgrounds and receives patients from the north Indian states of J&K, Punjab, Haryana, Himachal and Uttar Pradesh.
- Inclusion Criteria -Parents who experienced Stillbirth during the period from January 2019 to March 2021.
- Exclusion Criteria: Parents who have Stillborn Baby with in less than 6 Months from the date of Interview, Home births and births not attended by health providers (e.g. born en route to facility), Currently Pregnant Mothers, Fathers and Grandmothers who were not present with mother at the time of stillbirth, Respondents who experienced Stillbirths during Peaks of COVID Pandemic were excluded.

Results: Before conducting the actual Interviews, 2 test Interviews were conducted to check the response from respondents and for training feedback for Interviewers. Parent's feedback and suggestions were recorded and analyzed after a total of 28 In-depth Interviews which were approximately 2 hour long each which was conducted using the Interview Schedule developed for mothers and modified for family members.

- 20 In-depth Interviews with the bereaved parents were conducted by telecommunication mode and were recorded and 8 face to face In-depth interviews were conducted and recorded.
- 100 % of the respondents acknowledged lack of support to raise their concerns and appreciated the initiative. As a result the interviewers received overwhelming responses from the respondents.
- Although 28 Interviews were conducted so far, the rest of the remaining 17 In-depth Interviews were to be followed up along with the Focused Group Discussion.
- The Interviewers prepared the transcripts of the Interviews which will now be used as the basis for the revision and redesigning of the toolkit after their analysis. Translation of transcripts and analysis of the data and re-designing of the toolkit was done.