international
stillbirth alliance

Parent Voices Initiative

Mid-term report to PMNCH
Covering the period 27 April to 18 December 2020
Bid Ref: 2020/UHL/NMC/010

Summary

ISA is pleased to submit this mid-term report to PMNCH on progress in implementing the Parent Voices Initiative (PVI) (see Attachments 1-2 for the original proposal and the signed MOU with WHO). The objective 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 PVI includes two projects: 1) “Finding Parent Voices”, a Registry of all parent support organizations globally, to be hosted on the ISA website, and 2) “Raising Parent Voices”, development and testing of an Advocacy Toolkit to support parents in raising their voices so their views and needs are heard within their country's health goal-setting agendas. The Registry project is global while the Toolkit project is to be implemented in India and Kenya. Despite challenges related to the Covid-19 pandemic, we have made significant progress which we describe below. In the course of project implementation, we have also identified a number of important opportunities for follow-on work to maintain and expand the impact of the PVI, which we describe in the final section below. We would be grateful for the opportunity to discuss follow-on work with you, so that as this phase of the PVI comes to a close in June 2021, the momentum of our effort can be sustained.

Key findings to date:

- The first phase of the Registry project—an online search—is complete. A snowball search to supplement the online search is ongoing until the end of December. In the online search, we found 537 support entities from 197 countries, including 286 formal organisations, 164 informal organizations, and 87 point persons (these are the three types of support entities we are searching for). Through the snowball search, we have additionally identified 43 formal organizations, 6 informal organizations, and 36 point persons.
- We found at least 1 of each type of support entity (formal organization, informal organization, point person) in each SDG region except in the Oceania (excluding Australia/New Zealand) region, where we have so far identified none (see Attachment 10 for list of countries and regions).
- The majority (59%) of all search results are from the Northern America and Europe region and are in English.
- The PVI Toolkit project is progressing well through its planning stages (see below for details), with an MOU signed with India partners, and in process with Kenyan partners, and a draft toolkit with 8 modules completed for review by local partners

Administrative update:

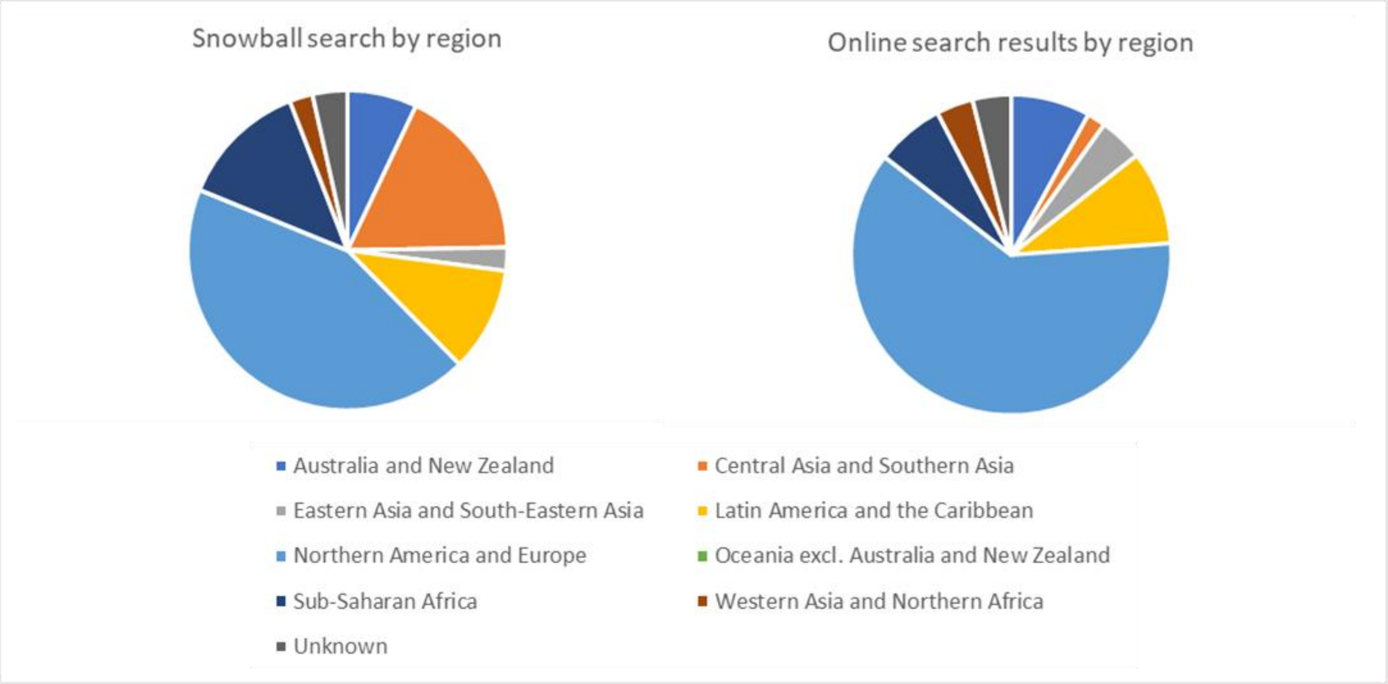
- Signed contracts with Senior Advisor Claire Storey, Toolkit Consultant Alka Dev, and Registry Consultant Vicki Ponce Hardy (see Attachments 5-8 for contracts)
- Operations Group established, including the above-named consultants and Project Managers Susannah Leisher and Hannah Blencowe, with biweekly meetings
- Advisory Group established (see Attachment 3 for updated list of members) and bimonthly meetings established
- MOU signed between ISA and PGIMER India (see below)

Toolkit update:

- Toolkit Consultant & Senior Advisor have met at least biweekly to discuss purpose and scope of toolkit and desired profiles and expectations of partner organizations in India and Kenya.
- Draft toolkit with 8 modules has been completed for review by local partners in India and Kenya.
- Two institutions in India have agreed to participate in development, finalization, and piloting of the toolkit in local settings: a tertiary urban hospital and a rural community-based facility. Both sites will include both providers and parents. The urban hospital is the Post Graduate Institute for Medical Education and Research (PGIMER) based in Chandigarh and the rural effort will be led by the Public Health Foundation of India (PHFI). Representatives from both institutions are also advising on the toolkit and its applicability for the Indian context. In the Indian context, the toolkit will be used by providers to integrate grief counselling and bereavement support for mothers and fathers into current maternal health care practices and facilitate discussions about stillbirth by providers. The goal is that facilitating providers' ability to listen to women, acknowledge, recognize and discuss stillbirth will provide space for parents' voice at a later stage, and we agree that the complete lack of formal support organizations in India necessitates starting with providers in this context. In India, in-depth information will be gathered on the experience of different types of providers (doctors, nurses, midwives, and counsellors) in supporting mothers during and after a stillbirth. It is likely that eventually there would be need for something that is more targeted toward parents, as this work advances in India.
- ISA has signed an MOU with PGIMER in India (see Attachments 13-14) to support both urban and rural workshops (to simplify communication, PHFI is working under this MOU). PGIMER has begun recruitment for a local consultant to support the workshops.
- A parent-focused counselling group/organization, Still A Mum, has been identified in Kenya to pilot the toolkit with parents and counsellors, yielding in-depth information on the value of this toolkit for sharing information, grief and bereavement counselling, as well as any additional advocacy efforts desired by parents. In-depth information will be gathered on the experience of parents and counsellors in working with the toolkit. Anecdotally, parents have also expressed a desire to participate in advocacy efforts to improve the quality of care around stillbirths so the toolkit could have more information on this.
- A draft MOU for Kenya is under review with Still A Mum.
- Due to Covid-related travel restrictions, we are reimagining the Toolkit project with the possible scenario that no international travel will be possible. Workshops in both countries are tentatively planned for February – April 2021, with results and toolkit updates finalized in May and June.

Registry update:

- Data gathering tools were drafted in July.
- The search strategy was designed and tested in August in two settings: London, UK, and New Jersey, USA, as these were settings known to the team.
- Data gathering tools were piloted with 2 organizations and 3 point persons in August, and tools were refined and finalized.
- Ethics permission was applied for and received from LSHTM in September (see Attachment 9).
- The online search was completed in October; the snowball search is ongoing.
- The second phase of the Registry project is now under way: an online survey sent to all support entities identified in the first phase that have contact information (see Attachment 11 for survey tool). The survey has been sent to 316 formal organizations (44, 14% responded to date), 130 informal organizations (11, 9%), and 105 point persons (14, 13%). The survey will close at the end of December.
- Preliminary analysis of search and survey data is complete.
- Interviews (the third phase of the registry project) will be conducted in January and February 2021, with analysis and the project report to be completed by the end of February (see Attachment 12 for sample interview guide).
- Discussions will be under way shortly with our IT support to prepare for hosting the registry on the ISA website.
- A draft paper summarizing results of the Registry project is planned to be submitted in March 2021.



Revised timeline

- The project was granted a no-cost extension to June 30, 2021, due to Covid-related delays (see Attachment 4).

Financial report

- Total award US$38,873
- $19,436.50 (50%) transferred to ISA from PMNCH on 6 May 2020, with $19,436.50 (50%) remaining to be transferred to ISA upon request to PMNCH
- First payment made to Registry Consultant on 24 August 2020 in the amount of $1637
- First payment made to Advocacy Consultant on 9 December 2020 in the amount of $2000
- No other expenses incurred to date. Current balance at ISA is thus $15,799.50

Follow-up

ISA is very grateful for this opportunity to carry out these two important and unique projects that will support parent voice in stillbirth prevention and bereavement support globally. As we have worked, we have identified a number of possible follow-on activities to build on and sustain the remarkable interest in and demand for this work. We would welcome a chance to discuss further any of the following ideas for a follow-on **Parent Voices Initiative-Phase 2**.

- **Keep the Registry updated**. To ensure it remains useful, it will be critical to fund an annual review and update, to add new entries and correct existing entries.
- **Expand access to the Registry for non-English speakers**. The bulk of the stillbirth burden lies in sub-Saharan Africa and South Asia, so to make the Registry most useful in these regions, it must be updated by native speakers of other languages common in these regions, for instance French for Francophone Africa. This will require translation of Registry tools.
- **Develop and evaluate country-specific guidelines on stillbirth support services**. We have identified a number of groups who would like to provide stillbirth parent support but don't know how to. This is especially important for countries (eg India) and regions (eg Oceania) where we have identified very few support resources.
- **Expand the Registry and Toolkit projects to include support for newborn death**. This is a key next step in order to acknowledge the continuum of loss, including both stillbirth and newborn death. For the Registry this would require a modest update of Registry tools first, while for the Toolkit project, adaptation would be more complex.
- **Learning from PVI**. We would like to fund research on the impact of the Registry and Toolkit projects in order to identify how these could be improved and adapted for different settings and audiences; research should include mixed-methods analysis to understand how and why the Registry and the Toolkit are used.
- **A stillbirth glossary**. Our work has already identified challenges in merely talking about stillbirth, due to the wide range of terms used. A first step needs to be a listing and qualitative analysis of definitions and words used for stillbirth, bereavement, and parent support in different countries, cultures and languages. This glossary could be very useful for all kinds of stillbirth-related work, especially in high-burden regions.
- **Toolkit production**. We anticipate needing support to incorporate high-quality graphics into the Toolkit to facilitate its use with a lay (or less educated) audience, especially parents in rural communities. This would also require the services of a skilled designer with experience in this type of product. Simple B&W and high-quality printable pdfs would also be helpful so that the Toolkit is easily downloadable for users.
- **Adaptation of the Toolkit for other stakeholders**. Our aim is to make the Toolkit modular, so that different modules can be removed or added to tailor the Toolkit for different audiences and settings. Currently our focus is on doctors, nurses, and counsellors in India and parents in Kenya, but we would like to support adaptation of the Toolkit for other groups including midwives,

traditional birth attendants, hospital administrators, journalists, and educators in medical and nursing schools, as well as for different local populations, including indigenous and other racially and ethnically excluded groups.

- **Expand access to the Toolkit for non-English speakers**. As with the Registry, it will be critical to ensure access by those in high-burden regions or working with non-English speakers, by translating the Toolkit, eg into Spanish and French. This would require skilled translators used to the vocabulary used in the Toolkit.
- **Increase uptake of the Toolkit**. We are concerned that the Toolkit cannot be widely used without a companion training course that is built around it. We wish to develop such a course and have it adapted so that it could be self-directed and online. This would be a major undertaking but is likely a key follow-on project.
- **Toolkit "Third Leg of the Stool" for Indigenous Australians**. We are in discussions with the Indigenous Advisory Committee of the Stillbirth Centre for Research Excellence (CRE) at the University of Queensland, Australia, who wish to undertake the Toolkit project with Indigenous care providers and bereaved parents, starting in South Australia. We are very excited by this opportunity to expand the PVI to address stillbirth inequity among the underserved and high-burden communities who exist even within high-income countries. While we hope that the CRE will be able to provide some funding for this project, it is not certain.
- **Global exchange on the PVI**. The ISA conference will be held in November 2021 in Brisbane, Australia, and we very much hope to hold a workshop prior to the conference on the PVI, including bringing parents and others from India and Kenya to Brisbane, and if the Indigenous Australia Toolkit project is funded, to include them as well. The aim of the workshop would be to share experiences and lessons learned to date and to plan for how to expand utility, access and impact of both the Registry and the Toolkit.

Attachments

1. Original proposal from SAWG to PMNCH
2. MOU between ISA and WHO
3. Advisory Group members
4. Agreement for no-cost extension
5. Contract - Claire Storey
6. Contract - Alka Dev
7. Contract - Vicki Ponce Hardy
8. Contract addendum – Vicki Ponce Hardy
9. Registry Ethics approval
10. List of SDG regions & countries
11. Registry online survey guide
12. Registry interview guide
13. MOU between ISA and PGIMER
14. MOU between ISA and PGIMER - signature page