

Support after stillbirth: Findings from the Parent Voices Initiative Global Registry Project

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Appendix 1

Parent Voices Initiative Registry online search terms

The following terms were used to systematically search online for stillbirth parent support organisations and individuals. The terms used in two pilot searches, in London UK and New Jersey USA, are also provided.

Systematic online search terms

Topic-specific terms:

- Stillbirth; stillborn; I had a stillbirth; I had a stillborn baby; gave birth to a stillborn baby; pregnancy loss; early pregnancy loss; I lost a pregnancy; miscarriage; late miscarriage; pregnancy complications; infant loss; lost my baby; pregnancy grief; pregnancy grief and loss; pregnancy bereavement; pregnancy bereavement counselling; postnatal; baby death
- perinatal/ stillbirth/pregnancy loss/neonatal death, died at birth, death of a baby, angel baby, perinatal death/perinatal bereavement, bereavement support

Support group terms:

- Parents; mums/moms; dads; support e.g. stillbirth parents; stillbirth mums/moms/mothers; stillbirths dads
- Forum e.g. stillbirth forum; stillbirth parent forum; stillbirth support forum
- Organisation e.g. stillbirth organisation/organisation; stillbirth parent organisation/organisation
- Group e.g. stillbirth group; stillbirth mums'/moms' group; stillbirth support group

- Program/programme e.g. stillbirth parents' program; stillbirth support program
- Near me e.g. stillbirth forum/organisation/group/program near me

Location terms:

- World region, country, region, state, city

Example search term: stillbirth parents support group near me Accra

Pilot search terms

The below search terms were used in two pilot searches of parent support in London, UK and New Jersey, USA. 'No new results' indicates that no new parent support organisations or individuals were found using these terms. This was used to indicate search saturation. The results of these pilot searches were checked by HB and SL, who work in those cities, respectively.

Search terms used in London pilot: stillbirth parent support group london; stillborn baby support groups London; I had a stillbirth London (no new results); I had a stillborn baby support group London; stillbirth grief and loss parent support group London (no new results); angel baby parent support group London (no new results); pregnancy bereavement parent support group London (no new results).

Search terms used in New Jersey pilot: stillbirth parent support group New Jersey; stillborn baby support groups New Jersey; I had a stillbirth New Jersey (no new results); I had a stillborn baby support group New Jersey; angel baby parent support group New Jersey; pregnancy bereavement parents organisation New Jersey (no new results); perinatal loss support group New Jersey (no new results).

Appendix 2

Outline of the online survey sent to organisations

A: Informed consent

Introduction to the survey: Stillbirths have been largely neglected in global public health policies and programs. The Stillbirth Advocacy Working Group (SAWG), the group leading this survey, was founded to help promote the inclusion of stillbirth in global health. The SAWG is co-chaired by the London School of Hygiene & Tropical Medicine (LSHTM) and the International Stillbirth Alliance (ISA). A key aim of the SAWG is to ensure that parents' voices are included in policies and programs for stillbirth prevention and support at a global level.

This survey is part of a project called the Parent Voices Initiative (PVI), which includes two projects aimed at increasing the participation of parents whose baby was stillborn in global efforts for stillbirth prevention and bereavement support after stillbirth. One of these projects, the 'Finding Parent Voices registry', is to create a list of groups and organisations ('stillbirth support organizations') in every country that provide support to parents whose baby was stillborn ('bereaved parents'). Within this survey, we aim to include both formal and informal groups and organisations; a separate survey has been developed to ask for information about 'point persons', individuals who may not be connected with a support group but who through their professional work, provide stillbirth-related support to parents; for example, midwives or doctors who provide informal or formal support including, but not limited to, advice, information, bereavement counselling, referrals, and future pregnancy planning for parents following a stillbirth.

The list will be a resource for parents and others affected by stillbirth all over the world. Your responses to this survey will help us in making this list. This survey will also help us to understand the challenges that parent support groups and organizations face in carrying out their work, and to develop tools for groups and organisations to use within their own communities and countries to advocate for better stillbirth prevention and bereavement support.

Participation: Your participation in this survey is greatly appreciated. This survey has 4 sections and should take about 45 minutes to complete. This survey asks about the aims of your group or organisation and any challenges that you face while providing stillbirth bereavement support. The survey also asks about employee and volunteer numbers, funding, the people that you support, and the services that you provide, so you may want to have this information to hand before you start. Your participation in this survey is voluntary and you have the right to stop filling in the survey at any time; just close your browser window if you wish to stop. Stopping will not affect your or your organisation's ability to be added to the list in the future.

Confidentiality: The information collected in this survey will be securely stored online at the London School of Hygiene & Tropical Medicine. All questions in Section B of this survey, except for B1, 2, 6, 14 and 15, will be made publicly available on the list of parent support organisations for stillbirths, which will be hosted on the website of the International Stillbirth Alliance. This is clearly marked on the survey questions. All other information that you supply will be anonymised and will not be included on the list. We will compile a project report in which all other data will be anonymised.

Please note that while all efforts to anonymise your answers to this survey will be made, there remains the possibility that your group or organisation will be identifiable from your answers. For example, if it is the only stillbirth-related group or organisation in a country or region or if it provides a specialised or very specific type of support, the group or organisation may remain identifiable.

Your information: Information made public on the list, as above, will remain online and will be reviewed and updated by the International Stillbirth Alliance every 3 years. This is clearly marked on the survey questions, and you do not have to answer these questions if you do not wish to. All other information collected through this survey will be stored securely at the London School of Hygiene & Tropical Medicine for up to 10 years, after which it will be destroyed. The information that you provide within this survey will only be used for the purposes of this study. Should you change your mind about participating in this study, you can withdraw your consent at any point until the point of publication by emailing parentvoices@lshtm.ac.uk.

Compensation: There is no compensation for participation in this survey. All participants will receive a link to the list and a copy of the project report once these are completed. The final section of this survey asks for your contact details so that we may do so.

Ethical approval: Ethical approval for this project has been granted by the London School of Hygiene & Tropical Medicine.

Funding sources: This project is funded by the Partnership for Maternal, Newborn and Child Health (PMNCH) and is undertaken by SAWG.

By ticking this box, I voluntarily agree to participate in this survey and I authorise the use and disclosure of the information I provide in this survey for use within the Finding Parent Voices registry, as well as for any related publications, presentations and/or research studies.

By ticking this box, I confirm that I give permission for the gathering, retention, display, and release of information provided in this survey under the terms detailed above.

B: Basic information, history & aims

We are interested in learning more about all groups and organisations that provide any type of stillbirth-related support to parents.

By ‘stillbirth-related parent support’, we mean any type of support (e.g. information, counselling, chatting etc.) to help parents whose baby has been stillborn. We recognise that this may not be necessarily a separate service but could be provided as part of support services in case of a newborn death, pregnancy loss and/or baby loss. We use ‘bereaved’ to indicate someone whose baby was born stillborn (e.g. bereaved parents or family members).

We are interested not only in organisations that focus on stillbirth-related parent support, but also organisations and groups that focus on other issues (such as pregnancy loss and newborn death), as long as some stillbirth-related parent support is provided as well.

We are interested in all types of groups and organisations, including non-profit organisations, research institutes, informal groups of social media, hospitals etc., as long as some of your work includes stillbirth-related parent support.

Please note that your responses to all questions in this section except for questions B1, B2, B6, B14

and B15, will be made publicly available on the list of stillbirth-related support groups and organisations.

- B1 What is your name?
- B2 What is your email address?
- B3 If your group or organisation has a name, what is it?
- B4 Which city and country is your group or organisation based in?
- B5 If your group or organisation has a website, Facebook page or other social media presence, please provide link(s):
- B6 What is your position within the group or organisation?
- B7 Does your group or organisation fall into any of the following categories? Please tick all that apply.
- Online group e.g. Facebook or other social media group, chatroom, meet-up, forum
 - Non-governmental organisation (NGO) or charity, or a group within an NGO or charity
 - Private hospital, or a group within a private hospital
 - Not-for-profit hospital, or a group within a not-for-profit hospital
 - Public hospital, or a group within a public hospital
 - Research institute/university, or a group within a research institute/university
 - None of the above
 - Other (please specify):
 - Don't know/unsure
 - Prefer not to say
- B8 Please estimate how many members/employees your group or organisation has right now (if any)?
- B9 What are the main aims of your group or organisation? These do not have to be stillbirth-specific only – we are interested in all of your aims. If your group or organisation has no stated aims, please mention this here as well.

B10 What types of stillbirth-related parent support does your group or organisation provide? Please tick all that apply.

- Provide information/advice on stillbirths to bereaved parents (parents whose baby was stillborn)
- Provide information/advice on stillbirth parent support for healthcare professionals
- Provide information/advice on stillbirth parent support for employers
- Provide professional post-stillbirth counselling for parents and families
- Provide informal post-stillbirth counselling for parents and families (e.g. peer support)
- Provide a space for bereaved parents and families to meet and support each other
- Provide a space for bereaved parents and families to tell their stories of their stillborn baby
- None of the above
- Other (please specify):
- Don't know/unsure
- Prefer not to say

B11 Who uses your services? Please tick all that apply.

- Bereaved mothers (mothers whose baby was stillborn)
- Bereaved fathers (fathers whose baby was stillborn)
- Other bereaved family members (members of families where a baby was stillborn)
- Healthcare professionals
- Employers
- One or more specific ethnic group (please specify)
- People experiencing specific type(s) of deaths (e.g. stillbirths due to a specific cause) (please specify)
- Any special population group (please specify)
- Anyone who needs it (i.e. no specific group)
- None of the above

- Other specific group (please specify):
- Don't know/unsure
- Prefer not to say

B12 How do people find you/your stillbirth-related services? Please tick all that apply.

- Anyone can search online to access our group page or forum
- Word of mouth
- Posting on social media e.g. Twitter, Facebook
- Local advertisement e.g. in a local newspaper, we put up flyers at a local shop or hospital
- Fundraising or other activities and events
- Hospitals, health centres and healthcare professionals know about us and recommend us to bereaved parents or families
- Health and social service providers know us and recommend us to bereaved parents or families, or refer them to us
- We are healthcare professionals who deliver babies and so parents already know us
- We run local, regional, or national campaigns to reach parents and families who need support
- Local/national media have done stories or interviews about us (radio, tv, etc)
- Our founder/other staff are well known, and people hear about us from them
- None of the above
- Other (please specify):
- Don't know/unsure
- Prefer not to say

B13 How long has your group or organisation been providing stillbirth-related parent support (please provide the year that you started providing this support, if relevant)?

B14 Was your group or organisation set-up with the purpose of providing stillbirth-related parent support?

- Yes

- No, we offered other support first and later added stillbirth-related parent support
- Other (please specify):
- Unsure/don't know
- Prefer not to say

B15 What initially prompted your group or organisation to begin providing stillbirth-related parent support? Please tick all that apply.

- Personal experience: someone in your group or organisation had a miscarriage, stillbirth and/or newborn death (mother or father of the baby)
- Personal experience: someone in your group or organisation had a family member who had a miscarriage, stillbirth and/or newborn death
- Increased awareness of stillbirth of someone in your group or organisation through their work in social services, healthcare work, research, or another relevant area
- None of the above
- Other (please specify):
- Don't know/unsure
- Prefer not to say

C: Understanding of organisational needs

We would like to understand what challenges your group or organisation has faced while providing stillbirth-related parent support. None of the information that you provide from this point forward will be included in the registry and all information will be anonymised prior to analysis.

Please note that we are not a grant-making organisation, nor do we have the capacity to provide information on funding sources. We hope that the information gathered via this survey will help to identify gaps for stillbirth-related parent support groups and organisations, which could be used to advocate for improved financial support and opportunities at local and national levels.

C1: Staff & volunteers

C1.1 Is anyone formally employed (i.e. paid) by your group or organisation (please include yourself)?

- Yes
- No
- Unsure/don't know
- Prefer not to say

C1.2 → IF YES, how many people?

C1.3 Is anyone informally employed or involved (i.e. unpaid or volunteer, including board members) by your group or organisation (other than yourself)?

- Yes
- No
- Unsure/don't know
- Prefer not to say

C1.4 → IF YES, how many people?

C1.5 Which of these challenges related to staffing has your group or organisation faced when providing stillbirth-related parent support? Please tick all that apply

- High turnover of staff/volunteers
- Difficulties motivating staff/volunteers
- Difficulties training staff/volunteers
- Challenges related to salaries and/or benefits
- Lack of resources for staff/volunteers e.g. materials, time, space
- Lack of professional development opportunities for staff/volunteers
- Stillbirth is not considered a priority
- Other challenges related to staff/volunteers (please specify):
- No/none of the above
- Don't know/unsure
- Prefer not to say

C1.6 In your opinion, what would help most to overcome some of the challenges related to staff/volunteers (e.g. better staff incentives)?

C2: The people you provide support to

- C2.1 Roughly, how many bereaved parents and other family members did you support or interact with in the last year? (e.g. 20 mothers and 50 additional families)
- C2.2 Where do you provide your stillbirth support services? Please list all locations (e.g. towns, cities, areas, regions, or countries).
- C2.3 Which of these challenges has your group or organisation faced when providing stillbirth-related parent support? Please tick all that apply.
- It's difficult to reach the group(s) of people that we want to reach
 - It's difficult to reach the area(s) or region(s) that we want to reach
 - We can't provide support to all the people who want our support
 - It's difficult adapting our support for different groups e.g. mothers and fathers
 - It's difficult providing support due to stigma around stillbirth, baby loss and/or pregnancy loss
 - The people we support or want to reach change often
 - Other challenges related to the people you provide support to (please specify):
 - No/none of the above
 - Don't know/unsure
 - Prefer not to say
- C2.4 In your opinion, what would help most to overcome some of these challenges related to the people you provide support to (e.g. more effective advertising of support)?

C3: Stigma

- C3.1 Which of these challenges has your group or organisation faced when providing stillbirth-related parent support? Please tick all that apply.
- Mothers with stillborn babies face stigma from their family
 - Mothers with stillborn babies face stigma from healthcare providers

- Mothers with stillborn babies face stigma from society
- Fathers with stillborn babies face stigma from their family
- Fathers with stillborn babies face stigma from healthcare providers
- Fathers with stillborn babies face stigma from society
- It is taboo to talk about stillbirth in my country or area
- Other challenges related to stigma about stillbirth (please specify):
- No/none of the above
- Don't know/unsure
- Prefer not to say

- C3.2 In your opinion, what would help most to overcome some of these challenges related to stigma (e.g. more awareness of stillbirths)?

C4: Policies and laws

- C4.1 Please list any local or national policies or laws relating to stillbirths in your country that you are aware of (for example, laws around burials for stillborn babies).
- C4.2 Which of the following challenges has your group or organisation faced when providing stillbirth-related parent support? Please tick all that apply.
- There is no awareness of the need for stillbirth bereavement services in my country's health ministry/department
 - There is no funding for stillbirth bereavement services in my country's health ministry budget
 - Stillbirths are not counted in my country's health statistics
 - Stillborn babies are not given a birth certificate in my country
 - Stillborn babies are not given a death certificate in my country
 - Stillborn babies are not registered in my country
 - Stillborn babies sometimes can't be properly buried in my country

- Healthcare providers are sometimes afraid of legal action if a stillbirth happens
- Other challenges related to policies/laws about stillbirth (please specify):
- No/none of the above
- Don't know/unsure
- Prefer not to say

C4.3 In your opinion, what would help most to overcome some of these challenges related to policies and laws (e.g. registration for stillborn babies)?

C5: Funding

Disclaimer: Please note that we are not a grant-making organisation, nor do we have the capacity to provide information on funding sources. We hope that the information gathered via this survey will help to identify gaps for stillbirth-related parent support groups and organisations, which could be used to advocate for improved financial support and opportunities at local and national levels.

C5.1 Does your organisation or group have any funding for the stillbirth-related parent support that you provide?

- Yes
- No → IF NO, skip to Q C5.4
- Unsure

C5.2 What are your main funding sources? Please tick all that apply.

- Government
- Non-governmental organisations (NGOs)
- Hospitals
- Universities or foundations
- Individuals (e.g. individual donations)
- Members (e.g. memberships)
- Multilateral sources (United Nations, European Union, etc.)
- Fundraising activities that your group/organisation undertakes
- I spend my own personal funds for these activities
- Other staff/volunteers spend their own personal funds for these activities

- None of the above
- Other (please specify):
- Don't know/unsure
- Prefer not to say

C5.3 Approximately how much did you spend in the past 1 year on stillbirth-related parent support? Please indicate the currency (e.g. Rupees) and the time frame (e.g. April 2019 to March 2020). If none, please record 'none' here.

C5.4 Which of these challenges has your group or organisation faced when providing stillbirth-related parent support? Please tick all that apply.

- N/A – we don't require funding for our activities
- It is difficult to raise money
- It is difficult to know where or how to apply for funding
- There is a lack of funding sources
- We cannot raise enough money to achieve our aims
- Funding opportunities are too competitive
- Funding for our stillbirth-related parent support isn't seen as a priority by funders
- Other challenges related to funding (please specify):
- No/none of the above
- Don't know/unsure
- Prefer not to say

C5.5 In your opinion, what would help most to overcome some of these challenges related to funding (e.g. information on funding opportunities)?

C6: Other challenges

C6.1 Please provide details of any other challenges that your group or organisation has faced when providing stillbirth-related parent support, that you have not mentioned already.

C6.2 Please provide details of any other actions or resources that you feel would be useful to overcome these challenges.

C7: Successes

C7.1 In your opinion, what has gone especially well when your group or organisation has provided stillbirth-related parent support? Please give one or more examples with as much detail as you would like. If you can, let us know why you think these successes were possible (e.g. because of a highly skilled volunteer, or good planning, or an influential spokesperson, etc.). We want to learn not only from your challenges but also from your successes!

D: Stillbirth-related advocacy

When we talk about ‘stillbirth advocacy’, we mean any activity that is aimed at influencing people who make decisions that could help prevent stillbirths and support bereaved families. This might include people who work on or make decisions on health budgets, health policies, or healthcare services. Examples of activities that would fall within ‘stillbirth advocacy’ include responding to a request for public input to a local or national health plan, giving a radio interview, or speaking at an event to explain stillbirth to the public. This is also sometimes called ‘lobbying’.

D1 Does your group or organisation engage in stillbirth advocacy?

- Yes → IF YES, skip to Q D3
 No → IF NO, skip to Q D2
 Unsure/don't know
 Prefer not to say

D2 IF NO, is this due to any of the following? Please tick all that apply.

- This is not in our mission/aims
 We do not have the capacity
 We haven't considered this before
 This wouldn't be effective (please explain)
 This could cause problems for our group/organisation (please explain)
 We haven't been asked or approached to engage in this way
 None of the above
 Other (please specify):
 Don't know/unsure

Prefer not to say NOW SKIP TO SECTION E

D3 IF YES, please describe these activities.

D4 Which of these challenges has your group or organisation faced when engaging in stillbirth advocacy? Please tick all that apply.

- There aren't many opportunities to engage in stillbirth advocacy
 It's difficult to reach the right audience
 It feels like nobody is listening
 Changes that are made because of our advocacy are too small or take too long
 It's hard to get our message across
 We don't have the necessary skills or experience among our staff/volunteers
 None of the above
 Don't know/unsure
 Prefer not to say
 Other challenges related to stillbirth advocacy (please list):

D5 In your opinion, what would help most to overcome some of these challenges related to stillbirth advocacy (e.g. linking with other people involved in stillbirth advocacy)?

E: Follow-up information

E1 Please provide contact information (name, email address, phone number) for any other people, groups, or organisations working in stillbirth-related parent support that you feel should be included in this registry – especially those who may be difficult for us to find via a google search.

E2 Please provide details of any lists of stillbirth-related parent support organisations that you know of that you think should be included in this list.

E3 Will a registry or list of stillbirth-related parent support organisations be useful for your group or organisation and/or for the people whom you support? Please explain.

E4 We plan to interview some of the organisations that have completed this survey, to gain a deeper understanding of the information that you have provided. Would you or someone else in your group or organisation be willing to be contacted for a follow-up interview?

⇒ If yes, please provide contact details (name, email address, job title):

E5 We are developing a plan to keep the list of parent support organizations updated in the future. Would you or someone else in your group or organisation be willing to be contacted a year from now to update the information you have provided?

⇒ If yes, please provide contact details (name, email address, job title) (if different to above):

E6 We plan to publicise the list of parent support organizations once it is completed. Would you or someone else in your group or organisation be willing to be contacted in a few months to help us with this?

⇒ If yes, please provide contact details (name, email address, job title) (if different to above):

F: Thank you so much for your participation in this survey. Your answers are very appreciated and will help to raise parent voices for stillbirth prevention and parent support.

For a copy of your responses, please email Vicki Ponce Hardy at parentvoices@lshtm.ac.uk. If you have any question, concern or query regarding your responses or the survey, or you would like to edit your responses, please do not hesitate to get in touch.

Appendix 3a Interview guide for interviews with organisational leads

1. Introduction to the interview (5 minutes)

This interview will be recorded, I'll start recording now.

I'll be conducting this interview with you. I am a consultant on this project and have been gathering and analysis data for this project since last spring. Can I confirm you are X, from X.

I will first give you some background information to the study and will then confirm your consent verbally for participating in this interview. Thank you for sending through your signed consent form. Do you have any questions before we start?

This interview is part of a project called the Parent Voices Initiative, which aims to raise the voices and participation of parents bereaved by stillbirth around the world, as a way of strengthening advocacy for better stillbirth prevention and bereavement support after stillbirth. We aim to make a list, or 'registry', of parent support point persons, groups and organisations of all sizes that provide support to parents bereaved by stillbirths in every country. We hope that the list will be a resource for parents and others affected by stillbirth all over the world. We have collected information for this list via an online search and a survey, which you have already taken part in.

As part of this project, we also aim to identify common challenges, successes and key gaps for point persons and organisations who provide stillbirth parent support. Your participation in this interview will help us do this. The interviews that we conduct will form part of a project report and will feed into our advocacy for stillbirth prevention, as well as the development of tools for point persons and organisations to use within their own communities and countries to advocate for better stillbirth prevention and bereavement support.

This interview will take around 1 hour and will cover basic information about your role and your organisation's role in providing support to parents affected by stillbirth, plus questions around challenges that your organisation faces when providing stillbirth parent support, as well as any gaps or needs that your organisation experience when trying to provide this support. I will also ask

you about your organisation's successes in stillbirth support. There are no right or wrong answers.

At this point, I would like to reiterate that your participation is completely voluntary and that you are free to stop this interview at any point. If you would like to pause or stop at any time, please let me know. Can I confirm that you are still happy to take part in this interview?

Do you have any questions before we start the interview?

2. Role (5 minutes)

The interviews are a chance to probe on survey responses, so the interviewer can refer to the questions below alongside survey responses as a guide.

I am going to start by asking you about your role. I see from your survey responses that your role is X. Can you tell me some more about your role and how your role involves supporting parents affected by a stillbirth?

And can you tell me some more about your organisations role in supporting parents affected by stillbirth?

2. Needs analysis (35 minutes)

The interviews are a chance to probe on survey responses, so the interviewer can refer to the questions below alongside survey responses as a guide.

I'll now ask you some questions about any needs, challenges or gaps that you face or experience when providing stillbirth parent support. This will follow a similar pattern to the survey, and I'll ask you about challenges related to staffing, reach, funding, policies in your country, and stigma.

Firstly, can you tell me about the challenge that you see as being the biggest or most important when it comes to providing stillbirth parent support?

I'll now ask you about:

From your survey responses, I see that you have marked X as a significant challenge. Can you tell me more about this?

How does this challenge affect your stillbirth parent support services?

What would it take to overcome this challenge?

Staff (Probe based on survey responses)

Reach (Probe based on survey responses)

Funding – I see from your survey responses that your group does/doesn't receive any funding, is that right?

Can you tell me a bit about the funding that supports your/your organisation's stillbirth parent support services? (probe – for example, can you tell me about how often you receive funding, whether it is sufficient, does it cover costs etc.)

Can you tell me a bit about why you/your organisation doesn't have funding for stillbirth parent support services? (probe for why not – never tried to gain funding, no funding source available, funding not needed)

How does this funding/lack of funding affect your stillbirth support services?

Policies in your country (Probe based on survey responses)

Stigma (Probe based on survey responses)

Successes:

- I see that you mentioned X as a success in providing your/your organisation's stillbirth parent support services. Can you tell me more about this?
- What do you see as your organisation's biggest success in providing stillbirth parent support?

Gaps:

- In addition to the challenges that you've already mentioned, can you tell me about any other challenges that you/your organisation have faced in trying to provide stillbirth support?

3. Advocacy (10 minutes)

Thank you so much. I'll now move us on to the next part of the interview, during which I'll ask you about stillbirth-related advocacy. When I talk about 'stillbirth advocacy', I mean any activity that is aimed at influencing people who make decisions that could help prevent stillbirths and support bereaved families. This might include people who work on or make decisions on health budgets, health policies, or healthcare services. Examples of activities that would fall within 'stillbirth advocacy' include responding to a request for public input to a local or national health plan, giving a radio interview, teaching or training healthcare professionals, or speaking at an event to explain stillbirth to the public. This is also sometimes called 'lobbying'.

- I see from your survey responses that you/your organisation have/have not engaged in advocacy related activities before, is that right?
- In your survey responses, you talked about participating in X activity, can you tell me a bit more about this?
- I see that you ticked X as a challenge to participating in stillbirth advocacy activities, can you tell me a bit more about this?
- What do you think would help overcome this?
- I see that you mentioned that X would help to overcome challenges related to stillbirth advocacy activities, can you tell me a bit more about this?
- Can you tell me a bit about why you/your organisation haven't taken part in advocacy related activities before? (probe for why not – never thought about it, don't know how to, no resources)
- Can you tell me a bit about what might help you to take part in activities like this (if you want to)?

4. Registry (5 minutes)

- As you know, we are developing a registry of stillbirth parent support groups, organisations, and point people around the world.
- What elements of a registry do you think would be most helpful, both for you/your organisation and for the people that you support? For others around the world?
- In your opinion, is there anything missing that you think we should consider when developing this registry?

5. End of interview (5 minutes)

- That brings us to the end of the interview. Thank you so much for your participation.
- Before we finish, I would just like to confirm that you are/are not willing to be contacted in the future regarding further participation in the registry, for example updating your information in the registry, and/or help with publicization of the registry?
- Do you have any questions or comments at this stage?
- If any questions come up after the interview, please feel free to get in touch with me at parentvoices@lshtm.ac.uk.

Appendix 3b Interview guide for interviews with point persons

1. Introduction to the interview (5 minutes)

This interview will be recorded, I'll start recording now.

I'll be conducting this interview with you. I am a consultant on this project and have been gathering and analysis data for this project since last spring. Can I confirm you are X, from X.

I will first give you some background information to the study and will then confirm your consent verbally for participating in this interview. Thank you for sending through your signed consent form. Do you have any questions before we start?

This interview is part of a project called the Parent Voices Initiative, which aims to raise the voices and participation of parents bereaved by stillbirth around the world, as a way of strengthening advocacy for better stillbirth prevention and bereavement support after stillbirth. We aim to make a list, or 'registry', of parent support point persons, groups and organisations of all sizes that provide support to parents bereaved by stillbirths in every country. We hope that the list will be a resource for parents and others affected by stillbirth all over the world. We have collected information for this list via an online search and a survey, which you have already taken part in.

As part of this project, we also aim to identify common challenges, successes and key gaps for point persons and organisations who provide stillbirth parent support. Your participation in this interview will help us do this. The interviews that we conduct will form part of a project report and will feed into our advocacy for stillbirth prevention, as well as the development of tools for point persons and organisations to use within their own communities and countries to advocate for better stillbirth prevention and bereavement support.

This interview will take around 1 hour and will cover basic information about your role or roles in providing support to parents affected by stillbirth, plus questions around challenges that you face when providing stillbirth parent support, as well as any gaps or needs that you experience when trying to provide this support. I will also ask you about your successes in stillbirth support. There are no right or wrong answers.

At this point, I would like to reiterate that your participation is completely voluntary and that you are free to stop this interview at any point. If you would like to pause or stop at any time, please let me know. Can I confirm that you are still happy to take part in this interview?

Do you have any questions before we start the interview?

2. Role (5 minutes)

The interviews are a chance to probe on survey responses, so the interviewer can refer to the questions below alongside survey responses as a guide.

I am going to start by asking you about your role. I see from your survey responses that your role is X. Can you tell me some more about your role and how your role involves supporting parents affected by a stillbirth?

2. Needs analysis (30 minutes)

The interviews are a chance to probe on survey responses, so the interviewer can refer to the questions below alongside survey responses as a guide.

I'll now ask you some questions about any needs, challenges or gaps that you face or experience when providing stillbirth parent support. This will follow a similar pattern to the survey, and I'll ask you about challenges related to staffing, reach, funding, policies in your country, and stigma.

Firstly, can you tell me about the challenge that you see as being the biggest or most important when it comes to providing stillbirth parent support?

I'll now ask you about:

From your survey responses, I see that you have marked X as a significant challenge. Can you tell me more about this?

How does this challenge affect your stillbirth parent support services?

What would it take to overcome this challenge?

Your role (Probe based on survey responses)

The people you provide support to (Probe based on survey responses)

Funding – I see from your survey responses that you do/don't receive any funding additional to your pay, is that right?

If you do receive additional funding, can you tell me a bit more about that? (probe – for example, can you tell me about how often you receive funding, whether it is sufficient, does it cover costs etc.)

Policies in your country (Probe based on survey responses)

Stigma (Probe based on survey responses)

Successes:

- I see that you mentioned X as a success in providing your stillbirth parent support services. Can you tell me more about this?
- What do you see as your biggest success in providing stillbirth parent support?

Gaps:

- In addition to the challenges that you've already mentioned, can you tell me about any other challenges that you have faced in trying to provide stillbirth support?

3. Advocacy (10 minutes)

Thank you so much. I'll now move us on to the next part of the interview, during which I'll ask you about stillbirth-related advocacy.

When I talk about 'stillbirth advocacy', I mean any activity that is aimed at influencing people who make decisions that could help prevent stillbirths and support bereaved families. This might include people who work on or make decisions on health budgets, health policies, or healthcare services. Examples of activities that would fall within 'stillbirth advocacy' include responding to a request for public input to a local or national health plan, giving a radio interview, teaching or training healthcare professionals, or speaking at an event to explain stillbirth to the public. This is also sometimes called 'lobbying'.

- I see from your survey responses that you have/have not engaged in advocacy related activities before, is that right?
- Can you tell me a bit about why you haven't taken part in advocacy related activities before? (probe for why not – never thought about it, don't know how to, no resources)
- Can you tell me a bit about what might help you to take part in activities like this (if you want to)?

4. Registry (5 minutes)

- As you know, we are developing a registry of stillbirth parent support groups, organisations, and point people around the world.
- What elements of a registry do you think would be most helpful, both for you/your organisation and for the people that you support? For others around the world?
- In your opinion, is there anything missing that you think we should consider when developing this registry?

5. End of interview (5 minutes)

- That brings us to the end of the interview. Thank you so much for your participation.
- Before we finish, I would just like to confirm that you are/are not willing to be contacted in the future regarding further participation in the registry, for example updating your information in the registry, and/or help with publicization of the registry?
- Do you have any questions or comments at this stage?
- If any questions come up after the interview, please feel free to get in touch with me at parentvoices@lshtm.ac.uk
- Thank you again for your participation.

Appendix 4 Research team and reflexivity

VPH (female) conducted all interviews. No other researchers were present. AB translated two interviews from Spanish to English. SM provided oversight of the interview analysis and VPH and AB analysed the interview transcripts. At the time of research, VPH held an MSc Public Health and was a consultant for the International Stillbirth Alliance, AB held an MSc Nutrition for Public Health and was a consultant for the International Stillbirth Alliance, and SM held a PhD from the University of Surrey and was Associate Head of School, Health and Social Care at The Open University. VPH and AB completed training in qualitative research methodologies during their MSc degrees. SM has extensive experience as a senior qualitative academic researcher.

Each interview participant had, prior to the interview, completed a survey (see Annex A2 for details). Otherwise, no relationship was established between VPH and each participant prior to the interviews taking place. At the start of each interview, VPH read each participant a structured introduction to the interview (see Annex A3ab). This did not disclose any personal details or goals about VPH but did provide some context to the research and broad research aims. Several participants queried VPH about why they were personally invested in completing the research and VPH provided answers relating to familial experience of loss as well as academic research interest.

Appendix 5 Study design

Further information on study design and rationale can be found in the main paper (pages 4 and 5). Of the participants contacted for interview who did not respond, no reasons were provided for their non-response and non-participation in the interview. Demographic data about interview participants were not collected. Participants were provided with their previously completed survey answers and a brief guide to the interview process, aims, and themes. Participants were asked questions based on their survey answers and were then probed and prompted for further information within each pre-defined theme. Interviews were recorded on Zoom (video and audio). Repeat interviews were not conducted and transcripts were not returned to participants. Participants did not provide feedback on the findings. Data saturation was discussed between VPH and other study authors during the interview period.

Appendix 6

COREQ (Consolidated criteria for Reporting Qualitative research) checklist

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	Annex p19
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	Annex p19
Occupation	3	What was their occupation at the time of the study?	Annex p19
Gender	4	Was the researcher male or female?	Annex p19
Experience and training	5	What experience or training did the researcher have?	Annex p19
<i>Relationship with Participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	Annex p19
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Annex p19
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Annex p19
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	2-4
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	2-4
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	2-4
Sample size	12	How many participants were in the study?	5-7
Non-participation	13	How many people refused to participate or dropped out? Reasons?	5-7
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	Annex p19
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	Annex p19
Description of sample graphic	16	What are the important characteristics of the sample? e.g. demo data, date	5-7

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	3, Annex 3ab
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	Annex p19
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	3, Annex p19
Field notes	20	Were field notes made during and/or after the interview or focus group?	Annex p19
Duration	21	What was the duration of the inter views or focus group?	53
Data saturation	22	Was data saturation discussed?	Annex p19
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	Annex p19
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	2-5
Description of the coding tree	25	Did authors provide a description of the coding tree?	4
Derivation of themes	26	Were themes identified in advance or derived from the data?	3, 4
Software	27	What software, if applicable, was used to manage the data?	4
Participant checking	28	Did participants provide feedback on the findings?	Annex p19
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	7-14, Annex p19
Data and findings consistent	30	Was there consistency between the data presented and the findings?	7-14
Clarity of major themes	31	Were major themes clearly presented in the findings?	7-14
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	7-14

Appendix 7

Pseudonymised interview participant numbers and corresponding regions

Interview participants were assigned a pseudonym number, shown below:

Pseudonym	Region
Organisational lead 1	Latin America & the Caribbean
Organisational lead 2	Northern America & Europe
Organisational lead 3	Australia & New Zealand
Organisational lead 4	Sub-Saharan Africa
Organisational lead 5	Northern America & Europe
Organisational lead 6	Sub-Saharan Africa
Organisational lead 7	Australia & New Zealand
Organisational lead 8	Australia & New Zealand
Organisational lead 9	Northern America & Europe
Organisational lead 10	Northern America & Europe
Organisational lead 11	Sub-Saharan Africa
Organisational lead 12	Sub-Saharan Africa
Point person 1	Latin America & the Caribbean
Point person 2	South-east Asia
Point person 3	Northern America & Europe
Point person 4	Northern America & Europe
Point person 5	Northern America & Europe