

Palliative Care

**Voices** 

# INTRODUCTION

**An independent network of direct stakeholders:  
palliative care recipients and their carers  
contributing to global palliative care advocacy.**

**Set up in November 2017  
as part of a direct stakeholder engagement project with  
the Worldwide Hospice Palliative Care Alliance**

# SPEAKER

- Youth ambassador for Patch South Africa
- I am currently studying Psychology at the University of Cape Town. I have taken a short break due to health reasons.
- My activities include writing monthly articles for eHospice International.

# ISSUES TO ADDRESS

**Direct stakeholders in palliative care are not involved as they could be in palliative care advocacy, communications and governance**

**Direct stakeholders = Adults, children and youth who are currently living with conditions that require palliative care now or may require it in the future . Also those who are in older age and approaching the end of the life cycle.**

# RESEARCH-AIMS

Claire Morris, Global Advocacy Director at the Worldwide Hospice Palliative Care Alliance undertook research aiming to:

- investigate barriers, opportunities and power dynamics in relation to people, including young people, affected by serious chronic and life-limiting illness as advocates;
- strengthen the voice of direct stakeholders and increase their impact as advocates to improve access to quality palliative care worldwide;
- improve the power balance and look at who is speaking on behalf of whom to develop a more impactful social justice movement on palliative care;
- share learning widely.

# RESEARCH-DESIGN

**Research was undertaken through a mixed method approach with data gathered through:**

- **a rapid literature review**
- **semi-structured interviews with key informants including affected people and professionals; and**
- **an online survey targeted at palliative care organisations globally.**
- **The research was then utilised to co-produce a project and access funds to implement the recommendations.**

# RESEARCH-RESULTS

- The survey generated 24 responses from 18 countries.
- 91% (n29) of the respondents to the survey and the interviewees believed that people affected by life-limiting illnesses were critical to the development of palliative care globally.
- 100 % (n8) of those interviewed believed that people affected by life-limiting illness did not have an adequate voice in national and international policy making fora.
- As a result of the research, funding was accessed to implement a co-produced project involving direct stakeholders and palliative care paid advocacy and communications staff.

# HISTORY OF PALLIATIVE CARE VOICES

The Worldwide Hospice Palliative Care Alliance (WHPCA) created a direct stakeholder engagement project, informed by direct stakeholders. They recognise the value and importance of the direct stakeholder voice.

This project, funded by the Open Society Foundations (OSF), involves a grant programme to fund projects around palliative care patient advocacy in lower and middle income countries.

# HISTORY OF PALLIATIVE CARE VOICES

The money was initially intended for patient-led organisations/groups, but we have accepted organisations to apply on the agreement that money is spent on developing patient advocacy projects that are led and run by patients.

The other aim of the project was to set up an independent, international direct stakeholder network, which became Palliative Care Voices.

# WHAT WE HOPE TO ACHIEVE?

The aim of Palliative Care Voices is to give direct stakeholders, those receiving palliative care and current and former carers, the opportunity and platform to contribute to global palliative care advocacy.

Getting involved in campaigns and matching these people with opportunities as they wish.

The group also, although not a formal aim, allows people to come together, meet others and seek support from people who understand the palliative care 'journey'.

# WHO'S IN THE GROUP?

[At this early stage we do not have complete data]

**Current membership: 70 members**

**Number of patients (confirmed): 20**

**Number of carers (confirmed): 12**

# WHICH COUNTRIES ARE REPRESENTED?

Bangladesh: 1

Bhutan: 1

Ireland: 1

Mexico: 1

Norway: 1

Pakistan: 1

Philippines: 1

Vietnam

United Kingdom: 27

USA: 6

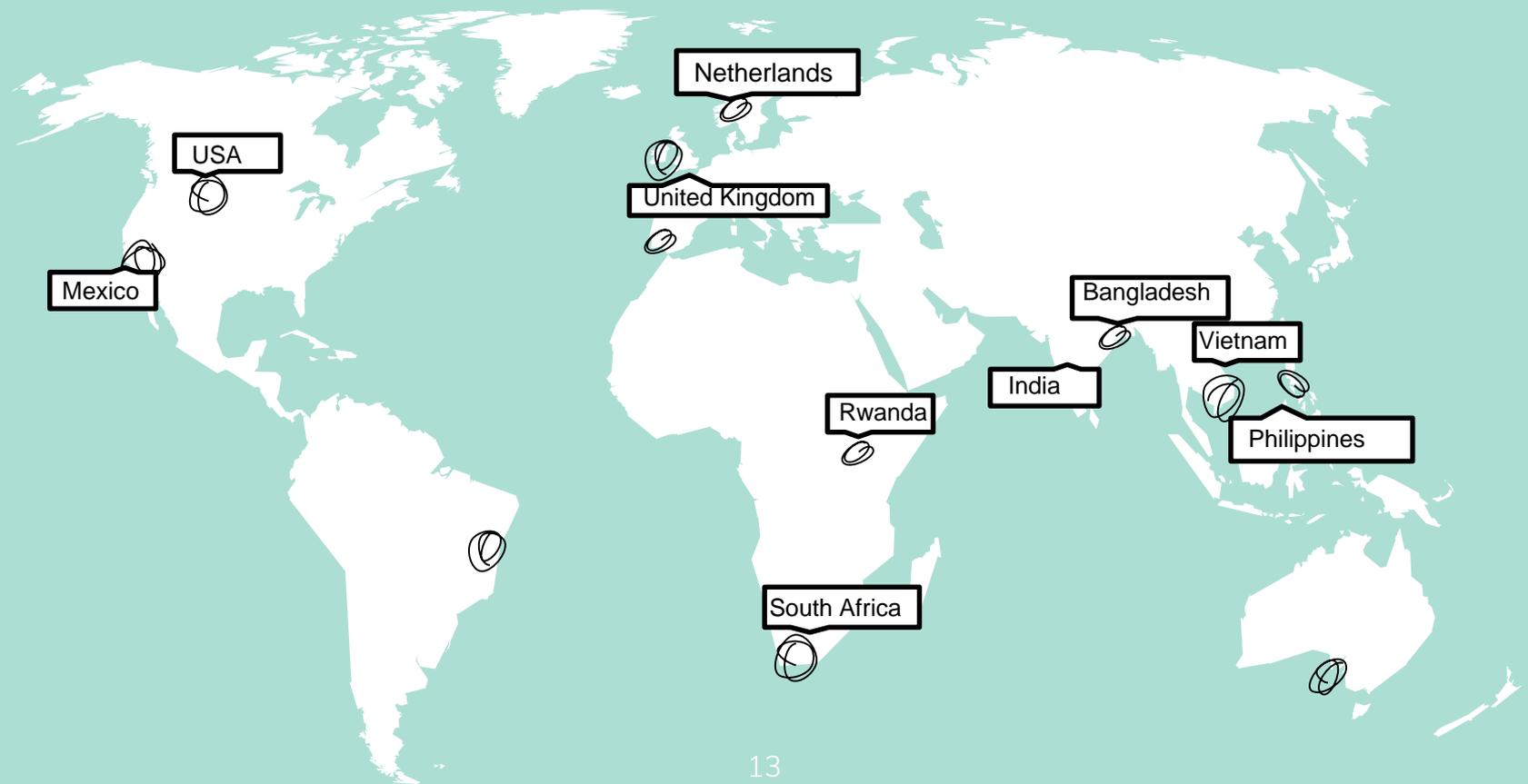
India: 4

South Africa: 3

The Netherlands: 2

Rwanda: 2

Unknown: 2



# EXAMPLES OF CONDITIONS REPRESENTED

Organ failures  
(intestinal, respiratory, cardiac)

Cystic Fibrosis

Ehlers-Danlos Syndrome

Rare Genetic Conditions

Mitochondrial Disease

Cancers  
(including brain tumours, lymphoma,  
leukaemia, breast cancer,  
colorectal cancer, pancreatic cancer)

Unknown; life-limiting  
conditions

Costello Syndrome

Severe Cerebral Palsy

Spinal Muscular Atrophy

Edward's Syndrome

# ACHIEVEMENTS SO FAR?

**Very early stages...**

**However,**

**Three direct stakeholders, including me, had our words read out at the recent World Health Organisation Executive Board. The impact of these statements was huge, they really made a difference.**

**There was much interest in the words of directly affected people.**

# ACHIEVEMENTS SO FAR?

Dr Stephen Connor of the WHPCA read out the words of Lucy Watts, the founder of Palliative Care Voices.

Following this, he was asked by Dr Tedros, Director General of the WHO, to pass on his details to Lucy so they could speak directly. That telephone call was a huge success.

Lucy shared her story in more detail and they discussed palliative care and universal health coverage.

He was very appreciative and eager to know more about Palliative Care Voices.

He then said he wanted to work 'together' to improve access to palliative care around the world.

# HOPES FOR THE FUTURE?

We hope in future to have more content to utilise in media and campaigns: stories, quotes, some videos and to really utilise all options and opportunities to have the direct stakeholder voice heard.

We hope to support and enable palliative care recipients and current and former carers to be able to get involved and to share their experiences on a global stage.

We will continue to grow the group, do as much advocacy work as we can and to develop the network and its members to really make it a success.

# CONCLUSION

- People, including youth, affected by life-limiting conditions can have significant impact on palliative care development but they are not being fully enabled to participate in advocacy.
- The barriers to affected people's participation are numerous and not universally understood but individuals and organisations could enable greater involvement of people affected by life-limiting conditions
- Advocacy projects can be co-designed with direct stakeholders and direct stakeholders want to and can be enabled to demand quality palliative care for all

# PalliativeCare Voices

WHERE TO FIND US?

**The group:**

<https://www.facebook.com/groups/145292306095465/>

**The public FB page:** fb.me/palliativecarevoices

**Twitter:** @PallCareVoices