
CONFERENCE ABSTRACT

WSO SSO Global Mapping Project

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Introduction

Stroke support organisations (SSOs) are non-governmental organisations focused on advocacy and long-term stroke support, and aim to drive better outcomes in stroke prevention, treatment, and long-term care. A key priority of the World Stroke Organization (WSO) in strengthening global capacity for stroke care is the development of SSOs by establishing, supporting, and strengthening a global network, particularly in low and middle-income countries (LMICs). In May 2019 the SSO Committee of the WSO proposed a mapping project of all SSOs known to WSO globally which was completed in February 2021.

Aims Objectives Theory or Methods

The objectives were to: (a) increase understanding of the organisational background of SSOs globally; (b) obtain a snapshot of SSO service delivery, awareness, and advocacy activities globally, focused on the 2018 calendar year; (c) obtain data for further analysis of the scale and reach of SSOs and their activities; and (d) obtain data for further analysis of SSO capacity to produce evidence of value. A questionnaire focused on organisation profile and activities across the stroke care pathway was sent by email to identified SSOs and any gaps in the data were followed up by email and telephone.

Highlights or Results or Key Findings

92 SSOs from 58 countries participated. There is considerable potential for SSOs to drive improved stroke outcomes globally as they work along the entire stroke care pathway and at all levels in support of integrated care. From the smallest to the largest, SSOs reach beyond their borders to build collaborative capacity and network with other stroke organisations at the regional, national, and international level. SSOs also support resilient communities by investing in interventions at the community level and mobilising large numbers of people affected by and engaged with stroke. They also utilize predominantly volunteers in the delivery of their stroke awareness and support activities. However, SSOs report that sustainability of human and financial resources, and inadequate national strategies for stroke prevention, treatment and recovery are major challenges to increasing their impact. To address these challenges, they call for increased partnership between their organisations and government, clinicians, and academics.

Conclusions

This project has shown that SSOs are operating globally delivering activities across the stroke care pathway and are working in ways that support integrated care. Findings suggest that for SSOs to maximize their contribution to driving improved stroke outcomes, capacity building, increased partnership and collaboration require considerable investment.

Implications for applicability/transferability sustainability and limitations

These insights can guide further analysis and focused research aimed at benchmarking the activities of SSOs along the stroke care pathway with evidenced based guidelines, and to explore capacity building activities for SSOs. Recruitment strategies were limited, likely resulting in several SSOs being left out of this inaugural report.