

World Stroke Organization Global Stroke Bill of Rights

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Background

In 2014 the World Stroke Organization (WSO) launched the Global Stroke Bill of Rights (GSBoR), which was developed by a working group of survivors and caregivers from across the world and informed by two online surveys.

Methods

In 2017, WSO gathered feedback on the use of the GSBoR via a web-based questionnaire completed by people who had signed the GSBoR and people who had been signposted to it, but had not signed. The questionnaire had eight questions, both closed and open, and received 30 responses.

Global Stroke Bill of Rights

As a person who has had a stroke I have a right to:



Receive the best stroke care

- A rapid diagnosis so I can be treated quickly.
- Receive treatment by a specialised team at all stages of my journey (in hospital and during rehabilitation).
- Receive care that is well coordinated.
- Access treatment regardless of financial situation, gender, culture or place that I live.
- Receive treatment that is right for me as an individual considering my age, gender, culture, goals and my changing needs over time.



Be informed and prepared

- Be informed about the signs of stroke so I can recognise if I am having one.
- Be fully informed about what has happened to me and about living with stroke for as long as I require it.

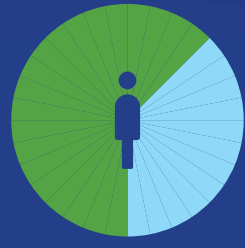


Be supported in my recovery

- Be provided with hope for the best possible recovery I can make now and into the future.
- Receive psychological and emotional support in a form that best meets my needs.
- Be included in all aspects of society regardless of any disability I may have.
- Receive support (financial or otherwise) to ensure I am cared for in the longer term.
- Be supported to return to work, and/or to other activities I may choose to participate in after my stroke.
- Get access to formal and informal advocacy to assist me with access to the services I need.
- Be connected to other stroke survivors and caregivers so I may gain and provide support in my recovery from stroke.



www.world-stroke.org



1. Have you referenced or referred to the GSBoR since signing it? **60% Yes**

2. If you have referenced or referred to the GSBoR, please give brief details about how you have used it. **63% gave details**

What: to promote the right to best possible care; to highlight gaps in care

Why: as a source of information for advocacy; in an academic thesis

How: websites and social media; resources for patients; interviews

Who: patients; emergency medical teams; doctors; the general public

When: exhibitions; training; World Stroke Day; in a stroke unit; conference

3. How useful have you found the GSBoR in helping to raise awareness of stroke among the population?



4. How useful have you found the GSBoR in helping to secure stroke policy changes in your country?



5. How useful have you found the GSBoR in increasing the number of stroke advocates in your country?



6. What have you found particularly successful when using the GSBoR?

- Voice and credibility** Clear objective, accessible language, WSO endorsed
- Global nature** At a local level highlights the need for global policy changes
- Rights based approach** Promotes quality stroke care as a right
- The potential** To strengthen our advocacy messages

7. What barriers have you experienced in trying to use the GSBoR?

- Bureaucracy** Lack of national government endorsement
- Capacity** The major barrier to its realisation is financial
- Lack of awareness** In some countries it is not widely known
- Language and culture** There needs to be further translations

8. Do you have any recommendations relating to the GSBoR?



80% recommended greater promotion and more translations.

Conclusion

- The majority of respondents view the GSBoR as a useful document.
- It is most useful in awareness raising.
- It is least useful in influencing stroke policy and increasing the number of stroke advocates.
- The GSBoR is versatile; its tone and credibility allows it to be used with a range of stakeholders, in different settings and with a specific focus.
- Its global nature and rights based approach mean that it is aligned with international declarations and treaties on non-communicable diseases.
- While there are barriers to its use, the questionnaire feedback indicates that developing strategies to address these barriers is worthwhile.



World Stroke Organization

To find out more about the Global Stroke Bill of Rights please visit:

www.worldstrokecampaign.org