

Brief: Situational Analysis to map the development of multiple sclerosis (MS) patient organisations in Argentina, Brazil, Chile and Mexico

Aims

The MS International Federation (MSIF) is seeking experienced consultants to conduct a situational analysis to map the current opportunities and challenges facing the development of MS patient organisations in Argentina, Brazil, Chile and Mexico.

The analysis will support MSIF in determining where and how it can best invest resources in a programme that will strengthen the capacity of MS organisations to further address the needs of people with MS in these countries.

Background

The 2013 *Atlas of MS*¹ identified that more than 53,000 people in Brazil, Argentina and Mexico alone have MS with many thousands more directly affected as family and community members.

MSIF has Member organisations in a number of countries in Latin America, including Argentina, Brazil and Mexico; we don't currently have a Member organisation in Chile but are in contact with MS groups working there.

These organisations work in challenging contexts. Varying levels of economic stability alongside the presence of other, more widespread diseases mean that already stretched resources are often focused on addressing other, more immediate needs, leaving the MS population and their families underserved by the state.

Gaps in the health system such as a concentration of diagnostic tools in urban areas and low numbers of MS specialists lead to an urban-rural access disparity and high levels of under/misdiagnosis respectively. A lack of a multi-disciplinary approach to MS treatment means that it is frequently left to MS organisations to provide psychosocial support services.

Whilst working hard to fill this vacuum, MS organisations are often facing a number of internal, organisational challenges found throughout civil society in this, and other regions. Challenges around governance, structure and strategic direction;

¹ <http://www.msif.org/about-us/advocacy/atlas/>

being unable to afford and therefore invest in staff/volunteer skills and training and lacking financial credibility to attract funding and remain sustainable.

In much of the Latin American region the lack of MS information paired with low levels of awareness often contributes to a lack of informed decision-making with regards to treatment and disease management; social stigma and exclusion and discrimination in education and the workplace. Treatment affordability is an issue meaning low treatment uptake. The standard of clinical trials for biosimilars is also a frequently raised issue in the region.

However, the MS research community is burgeoning in the region with a number of young researchers benefitting from MSIF's Research Awards Programme. When attending the most recent LACTRIMS (Latin American MS Research Congress) in Lima, Peru in November 2014, the interconnectedness of the research community was evident with region-wide collaborative working taking place in many research areas.

This interconnectedness is also reflected by high levels of social media and mobile phone penetration increasing the number of ways MSIF, its Members and other MS groups can reach out to the MS population.

Objectives

The analysis should cover the following areas:

Country context

- Identify the key challenges and opportunities related to developing MS organisations in each country through providing an insight into the socioeconomic, geographic² and political situation
- Provide an overview of current disability-related legislation in each country including the areas of education and employment and the country's commitment to adhere to national/international/regional disability rights conventions/charters/codes
- Provide an insight into communications within each country (and the wider region) to include use of social media; internet and mobile usage
- Provide an insight into the availability and sources of printed and online MS information in each country and related decision-making with regards to treatment and management
- Provide an insight into the level of general public awareness of MS and how this impacts on people with and affected by MS socially, within the family, in education and the workplace
- Provide an insight into the level of MS awareness amongst general health practitioners in each country

² Given the size of the potential countries, it is likely that the analysis will be carried out in 2-3 cities in each country

The non-governmental organisations (NGO) sector

- Review and describe the traits and trends of the NGO sector in each country, including the legal framework within which NGOs operate; the relationship between NGOs and the corporate sector, the state and the media and the funding opportunities available
- Provide an overview of the volunteering culture
- Provide insights into the work being carried out, and methods used, by international charitable organisations in each country in initiating non-governmental action in general and patient support (in the health sector) in particular

Funding issues

- Provide an overview of the funding regulations relating to NGOs
- Provide an overview of potential funding sources for NGOs
- Provide an overview of pharmaceutical³ and related industry engagement with and funding for the MS patient and research communities, outlining any guidelines that are followed or policies that have been put in place by either industry or the MS communities

Treatment and access issues

- Give an overview of the diagnostic tools and methods, treatment and care options⁴ (the current management models) available to people with MS, with the associated costs and types of financial support (benefits/subsidisation) provided by government in each country
- Outline other challenges in each country which have an impact on people's access to diagnosis and treatment, including but not limited to where people live (rural or urban areas), gender and the number of MS practitioners⁵

Possibilities for engagement and assessment

- Engage with MSIF's Members (where applicable) and other MS organisations/groups in each country to find out more about their projects and programmes; their funding sources; organisational management and structure and development over time (considering factors such as income, membership and community engagement and staff/volunteer numbers)
- Explore the past impact and potential reach of existing MSIF and Member organisation projects and materials in the region, to include but not limited to Spanish translation of MSIF e-newsletter, previous initiatives, *MS in focus*, World MS Day and MSIF's research awards etc

³ Including international and national companies

⁴ Including residential and respite care and options for caregivers of people with MS

⁵ Neurologists, nurses, therapists and other health professionals with a knowledge of and experience in treating people with MS

- Assess Members and other MS organisations/groups willingness to be involved in a programme of organisational development and which area(s) of organisational need, including but not limited to oversight/vision, management resources, financial resources, human resources or external resources, they indicate would be a priority for them to develop
- Engage with the medical and research community⁶
- Explore links with LACTRIMS (<http://www.lactrims2014.com/>) and other professional MS/neurological bodies

Local partners

- Map potential local educational, management, training and development opportunities and local consultants that could potentially support the delivery of the programme

Epidemiological data mapping is not required as part of the situational analysis. Consultant(s) will be encouraged to review the *Atlas of MS* for an overview of current regional data and an introduction to the availability and accessibility of resources for people with MS in Latin America as part of their preparation for the analysis.

Outputs

A written report in English which includes:

1. an overview of common findings
2. an overview of key findings in each country
3. an analysis of the current and future strengths, weaknesses, opportunities and threats (SWOT Analysis) of developing a capacity building programme in the selected countries
4. database of contacts⁷ within each country
5. recommendations⁸ on where and how MSIF could most effectively invest resources in an organisational capacity-building programme
6. an outline⁹ of the potential measures of success for such a programme including suggested tools/methodology to be used to capture such information

⁶ Including young researchers (with a view to MSIF engaging with them in the future with regards to our research awards) and newly trained/qualified MS health professionals (to provide an insight into past and current levels of MS specialist training)

⁷ Resulting from the situational analysis, including but not limited to staff/volunteers of other NGOs in the region, funder contacts, relevant health officials, MS organisation staff and volunteers and health professionals within the MS research community and linked to LACTRIMS

⁸ The recommendations should be presented in no more than four pages

⁹ The outline should be presented in no more than four pages

Timeline and methodology

It is envisaged that the consultancy will be carried out over a period of 3-5 months (ideally between April and September) in 2015.

Consultants must be available to participate in an initial briefing¹⁰ with MSIF at the start of the consultancy; meeting(s) to discuss preliminary report(s) and a meeting to discuss the final report.

Consultants will be expected to conduct interviews, surveys and group discussions with key stakeholders (including people with and affected by MS) and carry out desk-based research, document review and data analysis as appropriate.

MSIF is open to using a group/team of consultants (e.g. each consultant carrying out the analysis in one country) provided that a uniform review and reporting procedure is in place. Alternatively, one consultant could carry out the analysis in all four countries.

If feasible and appropriate, consultant(s) can connect with an in-country representative from the MS movement who may be able to assist in gathering relevant information and provide local insight towards the situational analysis.

Budget

The indicative budget for the analysis is between **GBP £75,000 and £85,000**.

The budget should cover the consultant(s) fees for days worked, to include but not limited to, preparing for and carrying out the analysis; drafting and finalising the report (including any meetings/Skype calls with MSIF) and any related project management fees.

Travel and accommodation costs and any other expenses incurred in carrying out the analysis should also be included in the budget. Consultant(s) will be responsible for managing the budget once agreed with MSIF.

Conflict of interest

In order to avoid any perceived conflict of interest, perceived or otherwise, consultant(s) should note that, in order to be eligible to tender for the work, they (or their company/agency/organisation) should not have been employed by (as a permanent or temporary member of staff) or have carried out services for (in an advisory or consultancy capacity) national or international healthcare companies, or their subsidiaries, within the past 18 months.

¹⁰ Location to be agreed with selected consultants

Consultant(s) Specification

As detailed above, the analysis is open to individuals or groups of consultants who have previously worked together, and who will be able to apply the same methodology to all four countries, including a uniform review and reporting procedure and one joint final report.

It is essential consultant(s)

- are fluent in Spanish and Portuguese¹¹
- are proficient in written and spoken English
- have excellent interpersonal skills
- are either currently living and working¹² in the countries where the analysis will be carried out and are therefore familiar with the country contexts
- are familiar with the NGO sector in each country, including the legal framework and related funding regulations, within which NGOs operate
- are familiar with health/disability sector
- have at least 5 years of proven work experience in the field of organisational development and NGO capacity building
- have at least 5 years of proven experience in conducting objective and candid qualitative research/situational analyses/assessments/feasibility studies, including developing the necessary methodology and assessment tools
- have an existing network of contacts and established working relationships across the NGO and fundraising sectors in the relevant countries
- employ tact and diplomacy when working with patient organisations in the four countries
- are aware and sensitive to the needs of people with and affected by MS
- are independent and impartial when interpreting the results of the analysis and providing recommendations for MSIF
- are willing and able to travel to potentially to challenging areas
- have the ability to work with minimal supervision as well as effectively within a group (if applicable)

It is desirable that consultant(s)

- are familiar with MS and its symptoms, diagnosis and treatment and care options
- are competent in using digital and social media tools

¹¹ If a group of consultants carry out the analysis then the consultant responsible for Brazil must be fluent in Portuguese

¹² or have lived/worked in the countries within the last two years

Application process

Please outline¹³, in English, in **no more than five pages** how you would respond to the brief and carry out the analysis to best meet the aims and objectives, indicating the methodology you would use and how you would distribute your time in each country (if applying as a group please indicate how the work would be distributed between consultants).

Please include a timeline for the analysis in your outline indicating your/your group's availability to carry out the analysis between April and September 2015.

Please also submit an outline of your budget to carry out the analysis including all consultant(s) and management fees; travel and accommodation costs and other expenses.

CVs for all consultants you anticipate involving in the analysis should also be included.

Please email the outline, timeline, budget and CVs to development@msif.org by **midnight GMT Friday 20 March 2015**.

Shortlisting will be based on consultant(s) response to the brief, experience and skills and availability. Value for money will be taken into consideration when reviewing tenders for the work.

Reference(s) from previous work and a telephone or in-person meeting will be arranged for those consultants shortlisted.

Attachments

- The MS International Federation and our capacity building work
- What is MS?

¹³ consultants submitting an application as a group should submit ONE application between them but include the CVs of all the consultants to be involved