Atlas of Multiple Sclerosis – the power of data!

Global webinar - September 2022, question and answer follow-up


The Atlas of MS – the power of data!

Advocating for better data - examples from India and Spain

“Numbers Matter” campaign - example from MSSI (MS Society of India)

The video of the talk from MSSI can be found here which includes some questions answered live at the event. Additional questions received in the chat have been answered by Sandeep and Javed from MSSI below:

Q1: How are you planning to reach people with MS in villages and remote areas? Will you be using an awareness campaign?

We will adopt two strategies to reach out to the rural population

- **Development of Information. Education & Communication (IEC) Material**: Leaflets, brochures, and posters will be printed in the local language to disseminate at Primary health care centres, which is the first referral point for the villages. This would help to create awareness in rural areas.
- **Support Groups in small towns to connect with Rural Population**: Decentralized approach will be adopted by creating small support groups in towns/blocks under the chapters. Support Groups will work in their assigned intervention areas to create awareness of MS and sensitize the healthcare providers at Primary health care and community healthcare centres

Q2: How did you engage patients to encourage them to add their data to the map and what benefits did you highlight as a reason to provide their data?

MSSI adopted two approaches to add data of registered MS persons (MSPs) on the map

- **Chapter’s level**: All chapters have their own regional networks, groups of MSPs, and other communication channels, they encouraged MSPs to provide data to the map.
- **National Level**: Reached the MSPs through campaigns, petitions, and social media and encouraged them to add their data to the map.

As far as benefits are concerned, we highlighted the importance of consolidated data and a National registry to mobilize the policymakers for better schemes/programmes for MSPs.

Q3: What software did you use to do the prevalence mapping, how easy is it to utilize and any specific learnings that you would share?

We used a basic web portal to register on the India MS map and shared the link in all groups for registration. This was a low-cost model just to capture basic information on the map. This is a user-friendly web portal to add information to the map.

Q4: What advice would you give to other countries that want to do something similar to the India MS Map?

We will recommend the following steps based on our learning

- **Database of MSPs**: Ensure you have complete details of MSPs enrolled in your country, if you are not having any database with complete information like their socio-economic profile, health status, etc, develop your database first in a simple excel file to understand your targeted population.
- **Analysis of country prevalence of MS**: Check whether Govt has any mechanism to capture the prevalence of MSPs in the country, if yes then you may take a call whether you need this mapping exercise or not as per your country's requirement. If there is no mechanism in your country to capture the data of MSPs, then it will be a good opportunity to create an in-country map.
- **Highlighting the need for prevalence Map**: First, analyse your internal data and highlight the key important finding like the preference for health services, affordability of treatment, which age group is highly impacted, gender ratio, employment status, etc to start a dialogue with civil society, Government, healthcare industry etc.
- **Campaign**: Based on identified need run a campaign to highlight the need for a national registry and engage other stakeholders in the campaign for a collective voice.
- **Development of basic web-based solution**: Identify the resources, initially start with a basic webpage and upgrade based on learning and requirement.

Q5: How much does a campaign like this cost in terms of people resources and external costs?

We had a very cost-effective model we spent around 500 USD on website development, if you have volunteers and full-time staff then you may save manpower costs in coordination, compilation, and dissemination of information.

Q6: How do you protect people's personal data when they include their information on the map?

MSSI has its own Data protection policy, it is recommended to have a data protection policy before gathering data from the beneficiaries. The data displayed on the map and the website was anonymous. The personal data collected via the online form is stored securely in line with our data protection policy.

Q7: Based on your own learnings what 2 or 3 suggestions or advice would you give to other organizations in countries who do not have a national registry about how they can tackle this issue?

A few suggestions based on our learning are as follows

- Make your own database first and analyse the data in depth to understand the target population
- Based on the findings of your data advocate with different stakeholders to bring their attention on the issues, you can also run a campaign
- Develop a proposal with a budget and identify resources to develop a web portal for MS registry or similar platforms

"EMData" example from EME (MS Society of Spain)

The video of the talk from EME can be found [here] which includes some questions answered live at the event. Additional questions received in the chat have been answered by Pedro from EME below:

Q1: Do you have any advice about how to engage patients to encourage them to provide data to your surveys and what benefits do you highlight as a reason to provide their data?

One of the goals of the EMData project, is to give feedback to many people who previously have taken part in surveys for us, but have never understood how that benefits them directly. EMData will be the place where new surveys will be launched and later shared again with the community.

Q2: What software did you use? How easy is it to utilise and any specific learnings that you would share?

Microsoft Azure and PowerBI. It's not easy to use for us but we are working with an IT provider for that.

Q3: Did you use any data mining and if so what learnings would you share with organisations thinking about doing the same?

Not yet. We are just collecting, cleaning and modelling data at the moment, but our intention is to do so in the future, once a larger amount of data is stored in the data lake.

Q4: What advice would you give to other countries that want to do something similar?

Start doing any kind of action around this topic. Showing the value of data to the community is a great starting point.

Q5: How much does a campaign like this cost in terms of people resources and external costs?

We don't have specific staff dedicated to the project and the total budget for the whole year is less than 10.000 euros. But these kinds of projects are very easy to escalate, starting from very modest actions.

Q6: How did you fund this project?

Own resources

Q7: How do you protect people's personal data when utilising other data sources or when they answer surveys?

We don't use or collect personal data, all the data are anonymized

Q8: Did you come across any weaknesses/something you were hoping to find and didn't?

Not yet... the outcomes are more than expected! :-)

Q9: Based on your own learnings what 2 or 3 suggestions or advice would you give to other organisations in countries who do not have a national registry about how they can tackle this issue?

To start supporting people with MS to collect data and show the value of sharing them.

Try to identify as much as data in the health system or past surveys in order to learn from them later.