



MS International Federation Strategy 2017 – 2021

A strategy for the global MSIF movement



1. Introduction

Together we're stronger than MS is the new strategy for the MS International Federation (MSIF), the world's only global network of multiple sclerosis (MS) organisations.

Its focus is to mobilise all of us inside this global MSIF movement, organisations, people affected by MS, volunteers and staff to achieve our common mission: to bring the world together to improve the quality of life of everybody affected by MS and to end MS forever.

It is built on the conviction that if we work together we can achieve this faster and better than if we each work on our own.

This is not a strategy for MSIF's Secretariat alone but one that the whole MSIF movement is invited to own and participate in so that it carries the commitment of all the member organisations, who will play central roles in designing, resourcing and implementing projects to achieve our common aims.

The start of the strategy marks 50 years of the MSIF movement and we pledge to build a stronger, broader, global movement made up of effective MS organisations, engaged individuals and strategic international collaborations.

Together we will tackle the big challenges for people affected by MS in countries rich and poor.

2. our vision

A world without MS

3. our mission

We inspire, mobilise and bring the world together to improve the quality of life of everybody affected by MS and to end MS forever

People affected by MS:

We use this term to include people with MS, their caregivers, family members and friends closest to them.

4. our values

We are the global movement of people affected by MS and their organisations

1. People affected by MS are at the heart of everything that we do

- We are driven by the urgent needs of all people affected by MS.
- We ensure people affected by MS and organisations in the movement are central in decision making, strategy and evaluation.
- We strive to ensure no one with MS is left behind, wherever they live in the world.
- We ensure our work empowers and benefits people with MS and those around them – their families and friends.

2. We know international collaboration changes lives

- We work together to speed up the achievement of common aims.
- We value everyone's experience, contribution and priorities.
- We are stronger because we take the time to understand our different cultures.
- We remove barriers that stand in the way of effective collaboration.

3. We test, learn and adapt to continuously improve our impact

- We are passionate and persistent about our aims.
- We measure our impact to ensure we create positive change for people affected by MS.
- We reflect on everything we do, to learn from experience and plan for the future.
- We are open to new ideas from anywhere in the movement to further our aims.

5. Challenges for the MS community and the external environment



Things have improved but substantial inequalities remain

Since MSIF was founded almost 50 years ago, we've seen some remarkable developments that have led to big improvements in the quality of life of people affected by MS around the world.

Though there are still many gaps in our knowledge, our understanding of MS has increased dramatically through international collaboration and biomedical research. This has also increased our understanding of treatments and interventions that can positively change the experience of living with MS. There are many more treatment options for relapsing remitting MS today than just five years ago and there is a great deal more information available on MS.

Sadly, there has not been progress for all. For those with progressive MS, treatments exist to help manage symptoms, but there are currently no approved treatments available to alter the course of the disease.

Access to diagnosis is often lacking, particularly where there are challenging socioeconomic conditions. Often it is a long and difficult process. Access to treatments and health care varies from place to place as a result of low awareness, gaps in the health care systems or high cost of treatments amongst other factors.

Information relating to living with MS, though plentiful, is not always trustworthy, independent, or available in local languages. International consensus is lacking in many important areas. We have gaps in our understanding of the distribution of MS and its impact across the globe. People affected by MS still face multiple barriers to full participation in areas such as work, social and private life, in part due to stigma, or lack of awareness and understanding of MS.

An evolving MSIF movement

The number of organisations in the MSIF movement has grown by over 20% during the last strategic period, now reaching more than 100 countries. In line with this, our international collaborations have grown in ambition: the International Progressive MS Alliance, World MS Day, Kiss Goodbye to MS. We continue to improve cross cultural working, acting strategically, making joint international goals meaningful to national MS organisations, having people affected by MS at the heart of decision making processes, dealing with complexity and pooling resources to have greater impact collectively than alone.

The growth of digital tools has made the world borderless in many aspects. People seek solutions, wherever these exist, not just within the confines of their own country. As an international network of MS organisations we are well placed to respond to this new reality. It is essential we look outwards, collaborate with others and bring new ideas to solve the challenges we face together. Technology will continue to play an exciting role in this.

MS organisations face many challenges. Not only do they have to adapt to engaging with online communities alongside traditional work, but they have to do this in the context of an increasingly competitive fundraising environment as well as political and social change. As a movement we also need to contribute to, and advocate for, the necessary changes in governmental policy and provisions.

Just as MS varies from person to person and over time, so do the capacities of MS organisations. Yet we all share things in common and can learn from each other. In doing so, we can avoid duplication by adapting and replicating successful resources and programmes amongst the movement at lower cost. We have a responsibility and an opportunity to engage with and empower organisations and individuals affected by MS throughout the world to be the very best partners for and supporters of each other. Together we can continue to tackle the uneven access to treatment, care and support that is currently experienced by so many people affected by MS around the world, particularly in countries with challenging socioeconomic conditions and a high level of need.

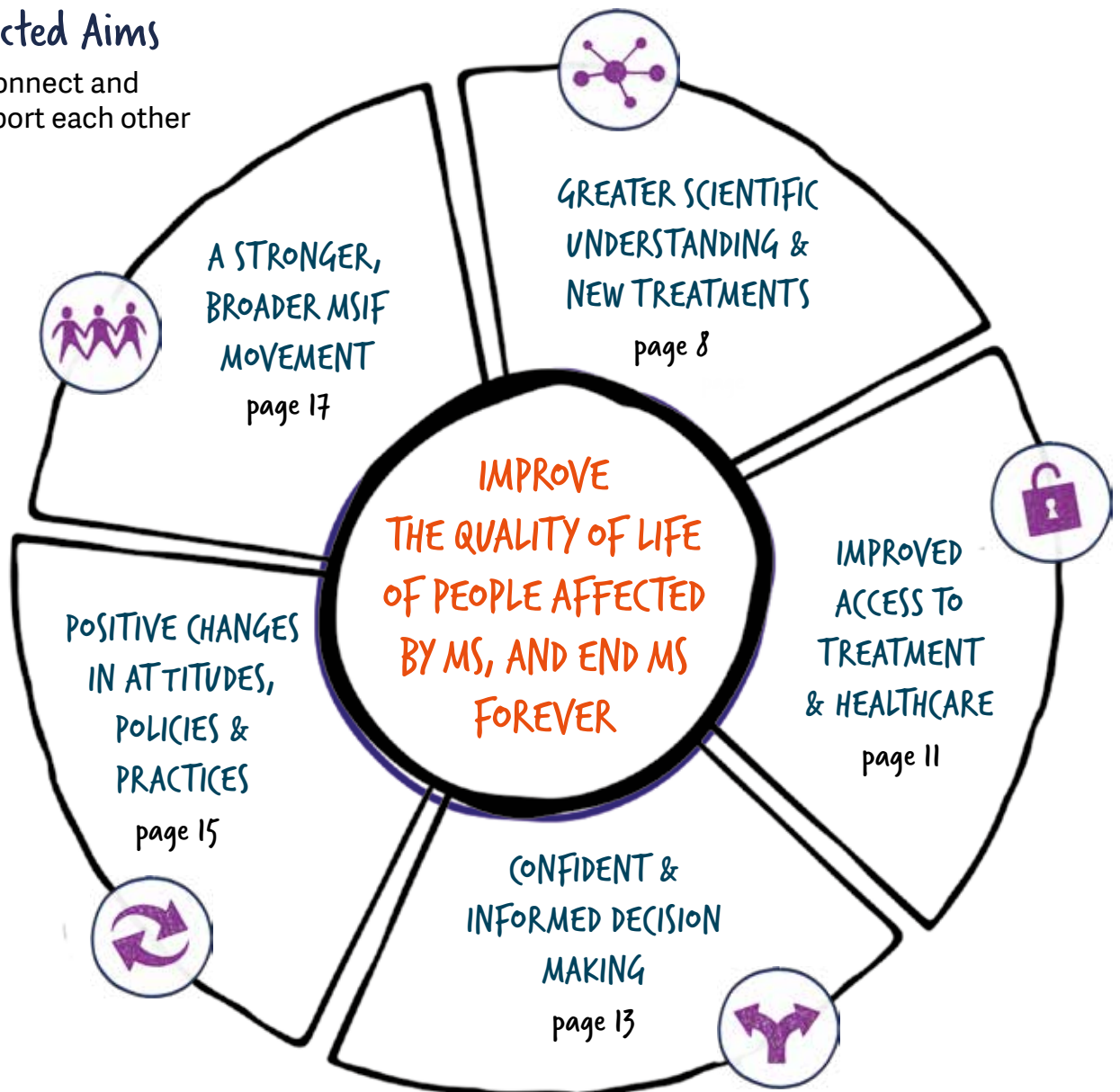


6. our aims

We - MSIF member organisations, people with and affected by MS, and the secretariat - will work together to achieve our common aims

Interconnected Aims

These aims connect and mutually support each other



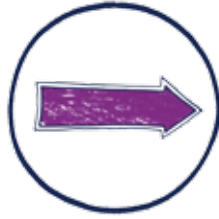
Aims: The impact we aim to achieve over the long term (10 - 15 years).

Objectives: What we want to achieve within the strategic period of five years. These will be realistic, achievable and measurable.

Actions: The projects, activities and strategies we will develop to achieve the objectives. The pace and scope will be determined by member engagement.

Signposts of progress: Things we can track and measure. When we have achieved them, we will know we are making good progress towards achieving the aim.

7. Strategic directions



The next section provides background, objectives and actions that make up the proposed approach to progress towards achieving each aim.

Each aim and objective will have its own strategy to carry it out and we have a variety of ways of working in order to implement them in the most effective way. Annex 1 describes some of these ways of working, such as working groups and collaborative projects, and clarifies the terminology used. We need to be nimble and pragmatic in applying these to reach the most effective and appropriate way to approach each aim, objective or activity.

This set of strategic directions is not for the MSIF secretariat office in London. They are for the global MSIF movement as a whole, something we all can contribute to, engage with and uphold, collaboratively, across the Federation.

This document outlines the actions we aim to undertake. What we will take on and when we do it will depend on the capacities, capabilities, commitments and resources available within the MSIF movement to lead and develop these initiatives further.

The detailed plans and actions needed to achieve the objectives will be developed and phased across the five years of the strategy by working groups with members and the secretariat.

Our approach to monitoring, impact assessment, evaluation and learning will be developed further as we move from the strategy to planning phase. Being a federation, we will all need to provide information on this to be able to coordinate and communicate the combined and cumulative impacts of our MSIF movement.

Whilst being flexible, our ways of working will adhere to two principles:

Inclusive:

All members, large and small, well or less well-resourced and from any region have a genuine contribution to make. Each approach will have some way of bringing in representation from across the Federation.

Accountable:

Whilst the method of governance for each project may differ, all will be accountable in some way to the MSIF board, even when legal responsibility may rest with a member or group of members



Aim:

BETTER SCIENTIFIC UNDERSTANDING LEADING TO NEW WAYS TO TREAT, PREVENT AND STOP MS.

Background

We still have a lot to understand about MS. While several treatment options now exist for relapsing-remitting MS, and we know the role early treatment can play, there are currently no approved disease modifying treatments available for progressive MS. Better symptomatic treatment and rehabilitation, are also needed. As a movement, we have decided to focus on progressive MS, and will continue to do so, but there are many other pressing issues.

We are lacking an international strategic research framework for MSIF's member organisations (and the movement as a whole) and ways to measure the impact of the research they fund, to inform decisions on where to focus and align research activities across borders. People with and affected by MS must be an integral part of this process to ensure that their needs are reflected in research priorities. These activities will inspire more of MSIF's member organisations to raise funds for research. It is crucial members join in this, to make sure we maintain and grow the momentum of collaboration and hope that has been created in research.

There are large amounts of existing data from studies and registries across the world – all built, defined and collected in different ways. This has great potential. We need to find ways to share and exploit that data in order to speed up discoveries in MS research. Common data standards will also enable better data sharing in future research collaborations.

Many of the member organisations and MSIF have encouraged young researchers to move into and/or stay in the field of MS through awards, grants and fellowships. This is important to ensure the future of research in MS and continues to be a challenge. We want to understand better what the needs are across the world and how they can be best addressed in the movement.

Signposts of progress

- New outcome measures for progressive MS (an outcome of the International Progressive MS Alliance)
- Increase in number of researchers in the MS field
- More members raising money for research



Objective 1:

Make substantial progress in the search for treatments to slow, stop or reverse the accumulation of damage and disability associated with all forms of MS including progressive

Actions:

1. Collaborate within the International Progressive MS Alliance to remove barriers to the development of treatments.
2. Develop a global framework for research priorities (a common research agenda), for alignment of members and to focus collaboration.¹
3. Ensure people affected by MS are part of strategic research decision making processes across the Federation.



Objective 2:

Develop a methodology to measure the impact of research funded by members on the quality of life of people with MS

Actions:

1. Exchange practices used by members (and others) to inform and develop impact frameworks that all organisations can use with a particular emphasis on quality of life.



Objective 3:

Advance systems and processes for enabling data sharing and explore the need for and feasibility of global collaborations for registries or databases in relation to Patient Centred Outcomes (PCOs)

Actions:

1. Set specific objectives and develop a plan for collaborative work across the Federation in this area (particularly in relation to patient centred outcomes).²
2. Explore government funding (EU/US) for data sharing including Patient Centred Outcomes.
3. Update and further develop the Atlas of MS. Provide grants for support epidemiological research in regions with gaps.



Objective 4:
Fill strategic gaps in the pipeline of the MS research workforce throughout the world

Actions:

1. Assess gaps in pipeline of MS research workforce and consider how to strategically address those by MSIF or members' fellowships.
2. Focus the MSIF fellowship programme on grants for researchers from emerging countries and align to the global research framework and aims of this strategy. Widen networks and mentoring opportunities of research fellows within the MSIF movement.



Objective 5:
Increase the overall amount of funds invested by the movement in MS research globally

Actions:

1. Involve and support new member organisations in raising funds for research.
2. Develop fundable packages, such as projects that emerge from objective 1 (progress in the search for treatments).
3. Use data obtained from objective 2 (measuring impact) in reporting to donors, funders, etc.

¹This process can be informed by data generated by the Progressive MS alliance's funding data platform (landscape tool). The framework may include topics that were identified at the 2015 research coordination meeting: prevention (for example in relation to development of MS, progression of disability, and/or progression of underlying damage), repurposing, risk reduction, paediatric MS, stem cells, cognitive issues, symptomatic deterioration, symptomatic treatments, early treatment, disability progression, symptom deterioration, or palliative care.

²Such an objective might include the facilitation of online platforms that enable countries in resource poor settings to participate in or replicate existing databases/ registries (e.g. NARCOMS, UK's MS Register, Australia's AMSLS) to gather epidemiological data)



Aim:

IMPROVED ACCESS TO EFFECTIVE TREATMENTS AND HEALTH CARE.

Background

Irrespective of the progress in the development of effective treatments for MS, many people face barriers in getting these treatments and medical care such as rehabilitation. This may be due to insurance systems, the high prices for the drugs or unwillingness or inability of governments to prioritise the treatment of MS in their reimbursement programmes. It may also be a result of the increasing complexity of treatment options and lack of understanding on what to will work best, when and for whom – the advent of personalised medicine for a complex, chronic condition.

MSIF's Atlas of MS documents the inequality of access across the globe – but we need to know more. In most countries there are regional discrepancies in the diagnosis of MS – the first step on the ladder to getting early treatment. The lack of awareness about MS amongst General Practitioners in the first line of health care or amongst neurologists in many countries, in particular in rural or scarcely populated areas, is a major factor in this and impacts on the effective management of MS, especially considering the complex array of treatment options and need for personalised medicine . What is clear is that the barriers are complex and vary greatly from country to country.

MS organisations have lobbied their governments for reimbursement of MS drugs. They have provided information to people with MS about how to understand their treatment options and to negotiate the state or private insurance systems.

At an international level, MSIF has never dealt with this in a systematic way. The greatest needs are in resource poor countries and settings, but even the richest countries in the world face a true crisis in this area.

Agreeing this aim is ambitious and will require crucial inputs from MSIF's member organisations: initially their brightest and best staff and allied experts to share the experience they already have in this areas, to help research and understand the field, explore the gaps and forge strategies for the MISF movement with the full commitment and solidarity of the membership.

The direction towards this aim assumes that we will not wait until we have fully developed the strategy before taking some action as some of the areas which we can tackle are already clear.

Signposts of progress

- Increase in number of general clinical health professionals with knowledge and skills on MS
- Increase in number of countries with reasonable access to treatment (to be defined)

Objective 1:

Develop an approach to address the barriers to access to treatments



Actions:

1. Collect available evidence on barriers to access and undertake research strategically to address gaps in understanding.
2. Bring member organisations together to share strategies and agree recommendations as a guide to influencing change.
3. Hold an international 'think tank' meeting with the best and brightest minds from all relevant sectors to inform the development of new strategies.³

4. Informed by actions 1, 2 & 3 above, develop strategies to address access issues with a particular, but not exclusive, focus on resource poor settings.

Objective 2:

Improved access to diagnosis, as early as possible



Actions:

1. Convene a group to develop a strategy to improve access to diagnosis in different settings.
2. Increase number of healthcare professionals (multi-disciplinary teams) specialised in MS through a new, global clinical fellowships programme and, in partnership with EMSP, provide online training to help staff specialise in MS (nurse pro) in areas outside Europe.
3. Develop and update international frameworks and tools to inform and support national level advocacy on this issue:

- Update the Principles to promote the quality of life of people affected by MS for 2017
- Update and further develop the Atlas of MS for 2019

Objective 3:

Provide information on treatments and the holistic management of MS to inform decision making by people with MS



Actions:

1. Review available information and contribute to initiatives (e.g. ECTRIMS, MS Brain Health) to document and clarify treatment decision making.
2. Tailor the resources resulting from the above for a lay audience. Internationalise and translate. (See Aim 3: Supporting Informed Decision Making.)

³The strategy might include actions such as: an MSIF position on need for robust regulatory action around approval of generic and biosimilar compounds (perhaps centred on Latin America to complement capacity building efforts in Aim 5), drug access schemes similar to e.g. HIV and making their prescribing safe; providing guidance to health providers on use of low-cost off label drugs; join coalitions on these issues; work with intergovernmental organisations such as the WHO; explore design of innovative patient access schemes for new compounds or technologies; strengthen the evidence of the effectiveness of treatments and their cost benefit in order to persuade policy makers to increase access to these treatments.



Aim:

ACCESS TO ACCURATE AND TRUSTWORTHY INFORMATION
AND RESOURCES TO MAKE INFORMED DECISIONS TO LIVE
WELL WITH MS.

Background

In many countries there is a lack of trustworthy information available, making it difficult for people affected by MS to make informed choices about the resources they need and about how to access them. Repurposing and translating existing materials and making them easily available will help address this gap. It will also avoid duplication of effort across the MSIF movement.

The growth of digital tools available has made the world borderless in many aspects. People seek information and solutions wherever they exist and not only from their national MS organisation or within the confines of their own country. As an international network of MS organisations we are well placed to respond to this new reality. Digital tools give us exciting new ways to influence, reach, inform and engage with people across the globe. We will focus our efforts on maximising the potential of digital tools and ensure that all materials and information are easily accessed via mobile and tablet devices. We will also continue to provide members with print-ready publications for those people who prefer to consume information in printed format.

Additionally, we can all work together to increase the competence of our volunteers and staff and strengthen MS organisations to enable them to make best use of these resources so that people affected by MS around the world can make informed decisions.

Agreeing this aim is ambitious and will require crucial inputs from MSIF's member organisations: initially their brightest and best staff and allied experts to share the experience they already have in this areas, to help research and understand the field, explore the gaps and forge strategies for the MSIF movement with the full commitment and solidarity of the membership.

The direction towards this aim assumes that we will not wait until we have fully developed the strategy before taking some action as some of the areas which we can tackle are already clear.

Signposts of progress

- MS organisations and individuals will report using and adapting information and materials available from Members and the Secretariat



Objective 1:

Comprehensive information to be available for people affected by MS, for use and adaptation by member organisations and others anywhere in the world

Actions:

1. Develop a system to identify, collate, repurpose, develop and translate materials for use around the world – covering, over time, key issues relating to MS.
2. Establish a central (digital) location where resources are accessible from anywhere in the world.
3. Develop a global digital strategy to cover the international increasingly borderless world and the role members and MSIF play in this whilst promoting MSIF and member information as trustworthy, and raise awareness of relevant MSIF global initiatives.
4. React to emerging therapies or media attention with consensus statements or digital resources, signposting to member statements were available.

Objective 2:

Enhanced competence of membership staff and volunteers involved in care, services, information & communication in order to provide the highest quality support for people affected by MS possible

Actions:

1. Create networks of communication staff/volunteers across the membership to share best practice and experience in their areas of expertise (e.g. digital, information and resource development, branding, and press and public relations.)
2. Convene workshops of communication staff/volunteers to share best practice.
3. Create networks of care and services staff/volunteers across the membership to share best practice and experience in their areas of expertise and collaborate on development of tools. This will include pediatric MS, caregivers and service provision.
4. Convene workshops of care and services staff/volunteers to share best practice and experience.





Aim:

POSITIVE CHANGES IN POLICIES AND PRACTICES, ATTITUDES AND BEHAVIOURS THAT ARE OBSTACLES TO LIVING WELL WITH MS.

Background

People with and affected by MS (their caregivers, family members etc) face social and economic challenges, wherever they are in the world. Disability benefits, employment opportunities, and accessible buildings and transport are just a few of these. A Lack of awareness of MS and unhelpful attitudes and behaviours of others - health professionals and employers, even family and friends - can add to the burden of stigma and discrimination. Digital tools give us exciting new ways to influence, reach, inform and engage with people across the globe to improve awareness and influence change.

While most work to improve this is undertaken by in-country MS organisations, as a movement we can provide tools and evidence to support these efforts, such as the Atlas of MS and the 'Principles to Promote the Quality of Life of People with MS. Tackling some issues may benefit from a global approach, mobilising people affected by MS and the whole MSIF movement to work together.

Signposts of progress

- All members of MSIF participate in World MS Day
- Atlas of MS published

One of the most significant obstacles to good quality of life across the world is lack of access to treatment and care. Therefore, much of our activities at international level to progress towards this aim will be focussed towards the objectives in the 'access to treatments and healthcare' aim.

Action:

1. Pursue the activities towards aim:

-  Improved access to effective treatments and healthcare.

In addition, where we have the capacity to do so, we believe we should take opportunities to tackle some of the other, non-treatment and care related aspects of quality of life as follows:



The infographic features a yellow background with several icons: a megaphone, a warning sign, a speech bubble, a magnifying glass, and a graduation cap. The text is written in a handwritten style.

Objective 1:
Provide flexible, evidence based international frameworks and tools for national, local and individual action to influence policies and practices, attitudes and behaviours

Actions:

1. Develop tools for advocacy by members in their countries:
 - update the 'Principles to Promote the Quality of Life of People with MS' (2017)
 - update and further develop the Atlas of MS (2019)
2. Once the Principles have been updated prioritise which of the issues within it would benefit from an international approach and explore possible strategies.
3. Coordinate World MS Day as a global framework for national action, as a platform for advocacy, mobilization, and awareness raising.
4. Explore how to build on and expand our experience of making use of digital tools in support of this objective.



Aim:

A STRONGER, BROADER MSIF MOVEMENT MADE UP OF EFFECTIVE MS ORGANISATIONS, ENGAGED INDIVIDUALS AND STRATEGIC INTERNATIONAL COLLABORATIONS

Background

The MSIF movement is made up of our member organisations and all the people with and affected by MS connected to them, the secretariat and all the committees and advisory bodies of the Federation. The MS movement is, of course, much broader than this – involving anyone connected to MS and whilst we will work with those in the wider MS movement and outside of MS wherever it makes sense to partner or make coalitions to achieve our objectives, this aim is about how to strengthen the MSIF movement so we can have the greatest impact together possible.

The MSIF movement has evolved greatly over the last 50 years, becoming more globally representative. The number of members and associated groups now cover over 100 countries in the world. We have steadily been deepening the way we work together. We are making strategic progress, in different areas such as World MS Day, Kiss Goodbye to MS and in strengthening fundraising skills across the membership, or the MS movement in the Arab region. We are learning much from the collaboration on tackling progressive MS.

The constantly evolving technology will help deepen the connections and communications within the MSIF movement and open up space for new forms of organisations and programmes relating to health, fundraising and advocacy for MS. It may also disrupt the NGO sector, health industry and the work of some MS organisations. We all need to respond and adapt to these changes.

There is wide variety in the maturity, capacity, professionalism and effectiveness of national MS organisations in the MSIF movement, and in the contexts in which they operate. The needs in countries with challenging socio economic situations are high. MS organisations in those settings face particular challenges. As a movement we need to support each other and improve the best in any setting, building on our experience and innovating to strengthen our MSIF movement, putting more of the national resources to work to achieve aims that have a worldwide impact for all people affected by MS – and fulfil the ambitious mission we set ourselves.



Objective 1:

Enhanced competence, influence and effectiveness of member organisations and MSIF

Actions:

1. Further develop the definition of the qualities MS organisations should strive towards⁴
2. Increase the exchange of skills and experience between and amongst member organisations and MSIF through sharing guidance available amongst the membership, skills-networks, workshops⁵, conferences⁶, and global networking meetings.
3. Support members to adapt and duplicate the very best programmes found amongst the movement.
4. Foster leadership development and innovation in the MSIF movement through grants and awards.⁷
5. Enhance the capacity and skills of MSIF and its Secretariat to facilitate communication, cooperation and collaboration throughout the Federation.



Objective 2:

Stronger MS organisations in countries with challenging socioeconomic conditions and a high level of need

Actions:

1. Continue to review and develop our capacity building and evaluation methodology.
2. Continue the Arab region capacity building programme.
3. Continue to develop the capacity building programme in Latin America.
4. Identify the approach to be taken on China and possibly other Asian countries.
5. Produce or repurpose relevant resources⁸ aimed at recently established and developing groups and organisations.

⁴ E.g. in relation to: governance; service provision; communication; central role of people affected by MS;

⁵ In fundraising, communications and other common areas of work

⁶ Including a World MS Conference in 2018, at the invitation of the Italian MS Society

⁷ Through grants and training opportunities for CEOs and other leaders, and accelerator grants to support or scale up innovative projects.

⁸ For example 'How To' Guides

Objective 3:

Ensure effective and inclusive collaborations with clear roles for MSIF and member organisations to support the aims and objectives of the strategy



Actions:

1. Review the MSIF membership structures to ensure they enhance commitment, collaboration and participation in the Federation and promote national cooperation.
2. Continue and enhance fundraising and member involvement with the Progressive MS Alliance.
3. Further develop and strengthen initiatives such as Kiss Goodbye to MS and World MS Day.
4. Initiate any new collaborations and models of working as needed which further the strategy.



Objective 4:

Strengthened communication and networking amongst the MSIF membership and across the Federation

Actions:

1. Develop communication tools to widen international contacts and collaboration beyond CEOs and board members of national organisations.
2. Provide opportunities for the membership to learn about each other's areas of work and best practice.

8. How to do it - Resources, funding and implementation

This strategy represents an evolution of how we do things. It is not a strategy just for the MSIF Secretariat to implement alone. The strategy's aims, goals and ambitions are owned by the whole of the MSIF movement. This strategy relies on staffing and financial resources for which provision will be made in MSIF's budgets. It also relies on member organisations' participation and contributions in terms of staffing, expertise, and, in some cases, financial resources.

This strategy is therefore important not just for what it sets out for us all to do, but for how we will do it. It is an evolution because we have already begun to work in this more collaborative way, pooling resources and sharing expertise towards shared goals – in World MS Day, in the Progressive MS Alliance, and in Kiss Goodbye to MS.

Outline of resource and funding mix

The resources that will underpin the strategy are the following:

- Contributions of staff or volunteer time from member organisations
- Reallocation of existing resources in member organisations, for example in making a national project into one which can benefit the MSIF movement
- Financial contributions from member organisations
- Funds, staff and activities covered in MSIF's budgets⁹, and reallocation of existing resources.
- Member organisations committing to being a Lead Agency in order to carry out, lead or make a major contribution to one of the projects.

⁹ Funded by membership dues, contributions from Vanneau Trust, healthcare industry, kiss goodbye to MS, and funding from TRIMS and other sources.

9. Indicative timeline

2017

- International Progressive MS Alliance Collaborative Network Awards start
- Quality of Life Principles Launch
- Second year Kiss Goodbye to MS – more members join
- Fundraising webinars
- MSIF 50th anniversary
- World MS Day – Quality of Life
- Atlas of MS and data collection on access starts
- Annual Research staff Network meeting
- Access advocacy workshop for member organisations
- Review of MSIF membership structure underway
- Work groups established for aim 1, 2, 3
- 2 information resources adapted for international/national use
- Initiation of second Arab region country-focused programme
- Arab region workshop during MENACTRIMS

2018

- Annual Research staff Network meeting
- Kiss Goodbye to MS
- International Progressive MS Alliance 3rd Scientific Meeting
- MS World Conference - Italian MS Society
- World MS Day – Research
- Review of Researchers pipeline completed
- Access 'Think tank' meeting
- Possible start of first new collaborative project arising from aim 2
- Approach on accelerator and innovation grants agreed
- Clinical fellowship programme designed
- Digital hub developed
- 2 information resources adapted for international/national use
- Possible start of first new collaborative project arising from aim 1
- Latin America Region workshop during LACTRIMS
- MSIF membership structure review completed

○ 2019

- Kiss Goodbye to MS
- Interim results of Progressive MS Alliance Collaborative Network Awards
- Annual Research staff Network meeting
- Atlas of MS update launched
- World MS Day – linked to the Atlas of MS
- Clinical fellowship programme launched
- 2 information resources adapted for international/national use
- Arab region workshop during MENACTRIMS

○ 2020

- Kiss Goodbye to MS
- Annual Research staff Network meeting
- World MS Day (theme to be determined)
- 2 information resources adapted for international/national use
- Latin America Region workshop during LACTRIMS

○ 2021

- Kiss Goodbye to MS
- Annual Research staff Network meeting
- World MS Day (theme to be determined)
- Alliance results of Collaborative Awards
- 2 information resources adapted for international/national use

ANNEX 1: Definitions

- 1. Convene:** to bring together the national MS organisations and their associated staff, volunteers and or people with and affected by MS, MSIF's governing bodies and or other experts or organisations for any purpose, such as:
 - exchange and sharing of best practice (example: fundraising workshops)
 - taking collective decisions about any aspect of the MSIF movement (example: MSIF networking meetings)
 - exploring and planning how to work together or collaborate on specific projects (examples: Pediatric MS Strategy Meetings; Kiss Goodbye conference calls).

Convening is a central role of MSIF but members can and do also convene.

- 2. Collaborate:** to work with another person or group in order to achieve or do something. To a certain extent, everything in this strategy involves an element of collaboration. However, we define a collaborative project as something more than this, see point 6 below).
- 3. Lead agency:**
 - a. A member organisation that carries out a project, programme or initiative and wants to do it in such a way that it contributes to the whole MSIF movement.
Example: the German MS Society organising the 2013 Berlin World Conference
 - b. A member organisation that takes a leading role in coordinating or implementing the whole or a part of a task or project on behalf of the MSIF movement.
Example: the Italian MS Society operating as a lead agency on the Data Sharing & Patient Centred Outcomes project.

For an organisation to be a lead agency it should have the competence, capacity and desire to take on this role. It is understood that a lead agency role may be most successful if a project at the heart of the organisation's own strategy and work.

Each time a lead agency takes on a role, it needs to be decided:

- To whom it is accountable, e.g. to a MSIF Steering Committee (see below), directly MSIF's Board or to the MSIF CEO.
- What delegated authority it has in decision making.
- What resources it will contribute (e.g. staff, expertise, travel costs or financial resources) and or require.
- What financial responsibility it has and what risk is involved in accepting this responsibility.
- How it will coordinate the involvement of (or consulting with) other members.
- In what time frame will it operate.

Those decisions and the agreement between MSIF and the lead-agency need to be formalised in a Memorandum of Understanding, which should be agreed by the member organisation's CEO or national board.

4. Steering Committee: a committee that has a high level of decision making authority in relation to the overall direction, content and or implementation of a project and are appointed by and report to MSIF's Board. Can include people affected by MS and or functionaries selected from member organisations, MSIF staff/Board members, members of relevant MSIF committees and or outside experts.
Example: the Steering Committee for the Principles for Quality of Life and updates and of the Atlas of MS.

5. Working Group: a group of membership staff or others selected for their skills, experience, expertise and or perspective to advice or work with the Secretariat (or a Lead Agency) on developing or implementing a specific activity or project. Working groups are key in ensuring global or regional perspectives are taken into account.
Example: working groups for World MS Day; the Atlas of MS; the Principles; the Latin America capacity building programme

6. Collaborative project: a project in which several member organisations undertake to work together on behalf of the MSIF movement, with a high degree of:

- collective input of staff or other resources
- delegated authority

Collaborative projects can take on many forms, but broadly can be led and coordinated in the following ways:

- a. by a lead agency
- b. by a collective body (Steering Committee) of the participating members, complemented with representation from the wider movement.
- c. by the Secretariat

Example: The Progressive MS Alliance; production of the guide on 'Stem cell therapies in MS'

7. Joining Coalitions: Joining groups of organisations in fields beyond MS, to collaborate for common purposes, such as better legislation or socio-economic opportunities, or health policies. This can be ad hoc for a specific purpose or long term.
Example: Joining the campaign for universal access to affordable medicine in 2014/15. Several national MS organisations work in coalitions with neurological or disability organisations.

8. Deploy staff: Allocate and fund a member staff to a role inside the MSIF Secretariat.

9. Members / Membership: The member organisations of MSIF, including Full, Associate Members and Supporting Organisations.

- 10. Corresponding organisation:** Small, informal support groups or newer organisations in countries without an MSIF member, often run by volunteers and don't (yet) meet criteria for membership. They are not members but MSIF provides advice and links them with member organisations to share best practice. Corresponding organisations act as our points of contact for people with and affected by MS in the country and are listed on the MSIF website. There can be several Corresponding organisations in a country.
- 11. MSIF's Secretariat:** MSIF's CEO and the staff team reporting to him and supported by the board and relevant committees.
- 12. Federation:** The member organisations of MSIF, including Supporting Organisations, MSIF's Secretariat, and all its governance and advisory structures.
- 13. MSIF Movement:** the member organisations of MSIF, including Supporting Organisations, and Corresponding Organisations, the people affected by MS and others, such as staff and volunteers, connected to them; MSIF's Secretariat, and all its governance and advisory structures.
- 14. MS Movement:** the wider MS stakeholder community, including the MSIF movement. May include any combination of individuals affected by MS, non-member MS organisations, companies, researchers, clinicians or other interested parties.
- 15. People with MS Advisory Committee:** advisory committee to the MSIF Board, consisting of persons with MS. It focuses on the needs and aspirations of people with and affected by MS and consults as appropriate with the persons with MS appointed by member organisations as contact persons.
- 16. International Medical and Scientific Board (IMSB):** body that advises MSIF, consisting of medical or research specialists, with two representatives nominated by each member organisation, some additional representatives selected by the Chair on the basis of specific expertise, as well as the chairs of ACTRIMS, ECTRIMS, LACTRIMS, MENACTRIMS and PACTRIMS (the regional congresses of MS health professionals), and the members of the International Research Staff Network.
- 17. Staff/Skills Network:** a strongly connected group comprising of mostly membership staff with particular functions or responsibilities, but also others (volunteers or other relevant experts), who connect to exchange experience and skills or explore cooperation.
Example: International Research Staff Network: the network of research staff from those member organisations that raise funds for research purposes. The network was formally established at the International Research Coordination Meeting in early 2015.