Defining the MPS Society vision

Findings from our stakeholder survey

Defining the MPS Society vision

Overview

In the ever changing rare disease landscape, the MPS Society needs to ensure it continues to serve the best interests of our patient community. The need to re-evaluate our purpose and priorities gave rise to the MPS Society Vision Project to develop our strategies and plans for the coming years. To inform this project, we commissioned our research team in MPS Commercial to gather the views of our stakeholders.

The survey

In September 2018 we invited our stakeholders to take part in an on-line survey. The survey sought their views on a number of key issues.

- Views on the MPS Society today
- Current challenges for our stakeholders
- How we can best serve the long-term needs of the patient community
- How all stakeholders can support each other

More than 5000
Stakeholders contacted

Over 500
Replies received

What the survey told us

The survey confirmed the need for us to continuously appraise the changing needs of our membership and the wider rare disease community. It has provided vital feedback on our services and identification of areas of focus to provide new and innovative ways to meet the needs of our members. We have gained valuable insights into how we can best support and work with our wider stakeholders.

Aging patient population

A key theme from our membership and other stakeholder responses was the need to support individuals at all ages and through all of life's transitions. As an increasing number of our membership are young adults finding their place in society, we need to support the unique challenges they may face in finding suitable employment or provision for education, independence or care beyond childhood.

Equally, many of our members are facing growing older with their condition and parents may be facing the time when their age or ill health will mean the need to find alternative care provision for their adult children.

New treatments

Issues around the discovery of new treatments and access to approved new therapies were raised by all stakeholders. New and improved disease modifying treatments are needed in an environment where funding for research and reimbursement of innovative therapies can be difficult to achieve.

Collaboration

All stakeholders agreed that to support the long-term needs of the patient population, collaboration, sharing of information and joint initiatives are of great importance. Our members would like to work with us to support others who face similar challenges and to offer their skills. All our stakeholders wish to continue the communication and partnerships necessary to address the changing needs of the patient group and the opportunity for all to access the best available treatment, care and opportunities.

Next steps

The results of the Vision Survey have formed an integral part of our ongoing review of the future direction of the MPS Society. Our new vision and strategy was launched at our national conference in June.

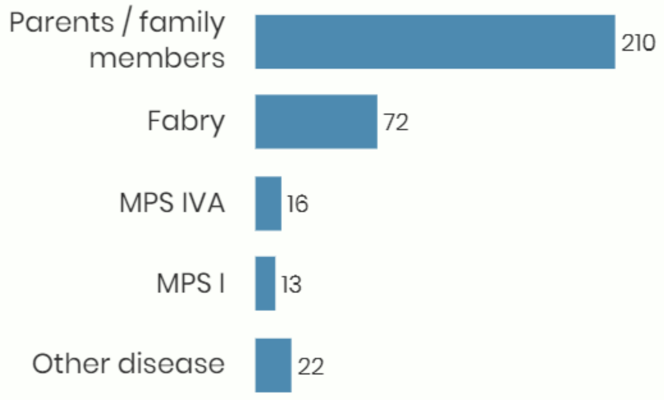
MPS National Conference 2019

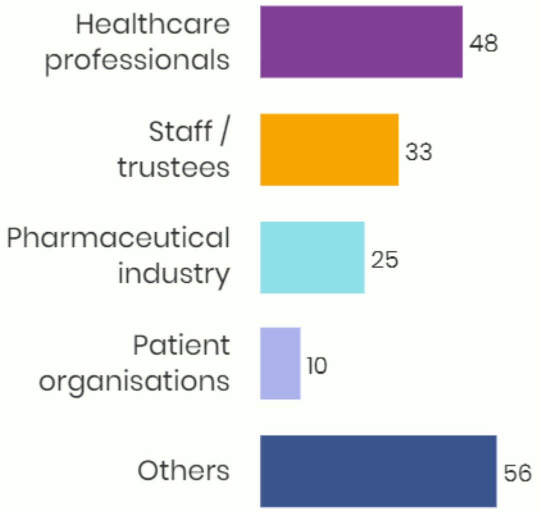
IN MEMORY OF CHRISTINE LAVERY

28-30 June 2019, Hilton, Coventry, UK

Stakeholder responses

The majority of responses received were from the members of the MPS Society. The staff and trustees of both the MPS Society and MPS Commercial also took part. More than 170 of our wider stakeholder group responded including some replies from fundraisers, volunteers, patient support services, researchers, government agencies and educationists (listed as 'others' on the graph).


Responses from our members


Responses from our other stakeholders

Feedback summary

Our stakeholders described us as supportive, knowledgeable, vital, influential and professional.
They agreed that the most important things we do are: provide support to our members, advocacy, support research, provide information, increase disease awareness and give the patient community a voice.

Our members

We have supported our members in countless ways through our advocacy and information service, conferences, meetings and campaigns. Some would like more information on clinical trials and more opportunities to meet each other

Healthcare professionals

They value the support we offer their patients and the contribution this makes to overall patient care. They would like us to attend more clinics, provide more patient information and increase awareness of our services

Staff and trustees

We want to support our members changing needs, raise awareness and support research and access to treatment. We hope to achieve this through continued collaboration with all our stakeholders.

Pharmaceutical companies

They value our knowledge, advice and the services we provide them and the patient community. We should continue to share information and our collaborations with industry and other patient organisations

Patient organisations

We have offered support and guidance to other organisations. They would like more collaboration on advocacy and raising awareness and increased sharing of information

Other stakeholders

We provide this group with the patient perspective. They expressed the need to build stronger relationships with decision makers and continue the dialogue on the challenges our members face

MPS Society membership perspective

THE MPS Society today

The most important things we do

Support/advocacy

Research

Information/awareness

Bring people together

Our members described the MPS Society as helpful, supportive and knowledgeable.

55% used the advocacy service at least once in the last two years

82% used our information resources

37% attended an event, conference or meeting

52% raised funds for the MPS Society

How we have supported our members

We received 370 replies to this question. Here are just a few of the responses from our members:

> *"I know there is always someone at the end of the phone (or email) if I'm having problems. I have had help with benefits, tenancy rights and lots more in the past"*

> *"Helped me to transfer my care to a dedicated team at Royal Free Hospital. Which saved my life"*

> *"Gave us the confidence to have a further child to complete our family. You cannot imagine the value of this! Support and friendship of other Sanfilippo families"*

> *"Helped me get access to enzyme replacement therapy"*

Do all our members feel represented?

68% felt we do enough for their age group

Some of our adult members, including the young adult community (16-19 years) felt we could do more for them

80% of adult members felt their condition was supported

Those with MPS, Fabry and related diseases generally felt well supported

90% felt their child's condition was supported

Most parents felt that their child's condition was well supported

Challenges faced by our members

Fabry

Managing pain and fatigue

Staying in employment

Explaining condition to employers

Parents

Managing child's condition

Child's education

Access to treatment

MPS and related disease

Daily life with their condition

Mobility

Finding employment

Other common themes

Transition/getting older

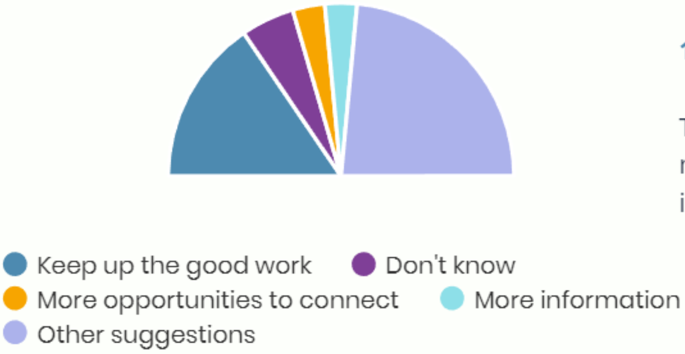
Social integration

Healthcare and treatment

While those with Fabry can find working and managing symptoms challenging, those with MPS and related diseases expressed more difficulty in finding employment.

Concerns over healthcare and treatment included access to trials and treatment and children moving to adult services.

Members suggestions on how to improve



31% felt that we are doing all we can to support them

10% could think of nothing else we should be doing

The most common requests were for more ways to meet and connect with each other and for more information, particularly on clinical trials.

Would our members like to be more involved with the society?

25% would like to help with fundraising
16% are not in a position to become more involved at the moment
12% would like to support other members

"Involve members in working groups to develop member services"

"Enable a forum to bring professional skills to help the society"

Perspectives of our young adult members

23% of our members are aged 16-24 years

We wanted to understand more about their needs

58% felt we do enough for their age group

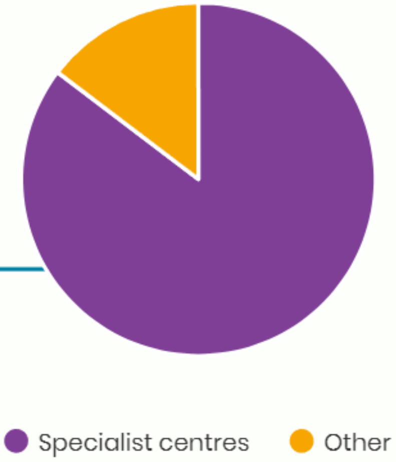
Current challenges

In addition to their health challenges:
Transition
Meeting others
Finding work

How can we improve services for them?

Help them connect more with each other and more use of social media/internet forums.

Healthcare professional perspective



THE MPS Society today

Most healthcare professionals who responded were from specialist metabolic centres. They described the MPS Society as informative, supportive and helpful.

The most important things we do

Patient support/advocacy
Research
Information/awareness

They also described us as

"Engaging with all partners in healthcare to improve care"

"Influencing the NHS and the government"

"Bringing families and professionals together"

Our impact on their organisation

Patient support

"A resource for helping patients with non-medical issues, advice and support"

Collaboration

"Valued relationship - proud that our labs are linked to the Society"

Patient care

"Very important part of my practice which has led to improvements in patient care"

Challenges in MPS, Fabry and related diseases

Funding

Funding for treatment, overall patient care and research

New and effective treatment

Cost of treatment
Improved disease modifying therapies
Measuring efficacy

Access to treatment

"Equitable access to allied healthcare and mental health services"

"Sustained funding for access to disease modifying therapies"

How can we support the long-term needs of MPS, Fabry and related diseases?

Patient support

Supporting patients at different life stages
Updated patient information
Continue our support to families

Awareness

Increase awareness of the MPS Society and our services
Increase disease awareness and education

Support for research and the development of learning tools for healthcare professionals were also mentioned.

How can we improve support to the healthcare profession?

Attend clinics

They would like us to attend more clinics at specialist centres

Information

More patient directed materials on the diseases e.g. story books aimed at young people

Collaboration and communication

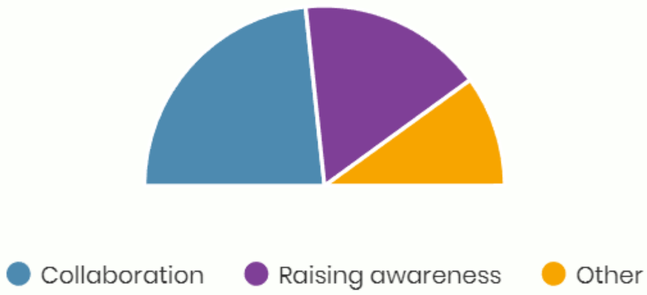
More frequent communication and partnering

"Working more in partnership with healthcare trusts to improve clinical co ordination"

"Empower patients to drive the care they need in partnership with the healthcare team"

"Stay updated on common interest projects, MPS Society can be more aware of clinic developments to inform patients/families"

How can they support the work of the MPS Society?



Most felt that the best way we can work together is through collaboration and raising awareness of the MPS Society and the services it provides to patients.

Regular meetings and updates with our advocacy team was suggested.

They can support us by attending and presenting at our conferences and workshops.

Pharmaceutical industry perspective

The MPS Society today

They described the MPS Society as vital, passionate and influential.

The most important things we do

Provide link to patients
Support patients/advocacy
Support for clinical trials

Other comments included

"Leaders in patient advocacy"

"Networks with other stakeholders to influence change"

"Keep MPS conditions on the NHS agenda"

"Real world data generation"

Our impact on their organisation

Knowledge/advice
Disease knowledge
Provide insight
Advice on pre-clinical and clinical programmes

Collaboration
Partner for patient support and research

Patient contact
Gateway to the patient community

Support for patients and families involved in clinical trials was also mentioned.

Challenges in MPS, Fabry and related diseases

Funding and access to treatment

Reimbursement and affordability
Large Fabry population

New treatments

Finding the next generation of treatments
Demonstrating their value

Ageing patient population

Providing new/different services as patients age

How can we support the long-term needs of MPS, Fabry and related diseases?

Collaboration
To provide a unified approach to healthcare
With other patient organisations internationally
With umbrella organisations

Engagement
Continued engagement with patient community
Strategies for patient/stakeholder engagement

Learning more about clinical trial strategy and the need for priority and focus were also mentioned.

How can we improve support to the pharmaceutical industry?

Continue as we are

The most frequent response was to keep doing what we do

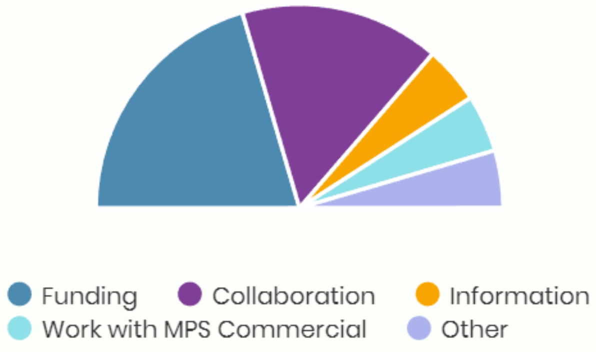
Collaboration

Work together on patient-centric projects
Clarify rules of engagement between patient organisations and industry

Information

Share information through regular meetings
Publish more of our data

How can they support the work of the MPS Society?



The pharmaceutical industry can support us through sponsorship, grants and collaborative projects.

Information exchange, keeping us up-to-date on their programmes and by appointing MPS Commercial for clinical trial logistics, patient research and communications activities were also mentioned.

Patient organisation perspective

The MPS Society today

Other patient organisations described the MPS Society as caring and knowledgeable.

The most important things we do

Information
Patient services
Research

Our impact on their organisation

Most responses related to the support and mentoring we have given other organisations:

> *"Supportive to another small patient organisation"*
>
> *"MPS mentored our organisation when we were initially founded and has continued to willingly share expertise. Significant joint commitment to improving the lives of those patients with LSDs"*
>
> *"I certainly look to the MPS Society in the UK for guidance in terms of organizational management and support"*

Challenges in MPS, Fabry and related diseases

Access to treatment and earlier diagnosis were mentioned most frequently. Other challenges included:

Raising awareness and funds
Research funding
Cost of treatment

How can we support the long-term needs of MPS, Fabry and related diseases?

Responses included:

> *"Promote research, awareness and support the changing needs of the population"*
>
> *"Include more organizations from different countries and maintain systematized contact. The symposiums should have translators"*
>
> *"Regional meetings and collaboration"*

How can we support each other?

Collaboration

Joint advocacy
International fund
Awareness campaigns
Working with umbrella organisations

Information and advice

Sharing information
Mentoring
Keeping each other informed of challenges, activities and programmes

Government agency perspective

We received a small number of responses from government agencies.

The most important things we do

Represent patients concerns
Advocate for better services
Lobby at a very high level
Engage with the commissioning processes
Provide valuable disease information

Challenges in MPS, Fabry and related diseases

Cost of treatment
Access to treatment
Ageing patient population

How can they support the work of the MPS Society?

Continued close collaboration
Engagement and communication

Our impact on their organisation

Resource to inform on the conditions and the effect they have on patients and families
Provide helpful comment on plans and strategies

How can we support the long-term needs of the patient population?

Communicate the challenges
Be part of the conversation and solution
Build strong relationships with decision makers

Our national and international roles

Respondents described our national role as supporting our members and their families, both as individuals and the disease community as a whole.

Our international role was described as collaboration and the sharing of knowledge and learnings. Other patient organisations responded that we should help to build networks, international awareness and fundraising activities, provide resource to smaller organisations and work to create best practices for patient advocacy groups.

The MPS Society

Founded in 1982, the Society for Mucopolysaccharide Diseases (the MPS Society) is the only national charity specialising in MPS, Fabry and related diseases in the UK. It represents and supports affected children and adults, their families, carers and professionals.

Registered address:
MPS Society
MPS House
Repton Place
White Lion Road
Amersham
Bucks
HP7 9LP
UK

mps@mpssociety.org.uk
www.mpssociety.org.uk

T: 0345 389 9901

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info@mpspact.com
www.mpscommercial.com

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