

# Defining the MPS Society vision

Findings from our stakeholder survey



# Defining the MPS Society vision

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## 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.

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## 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

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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

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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

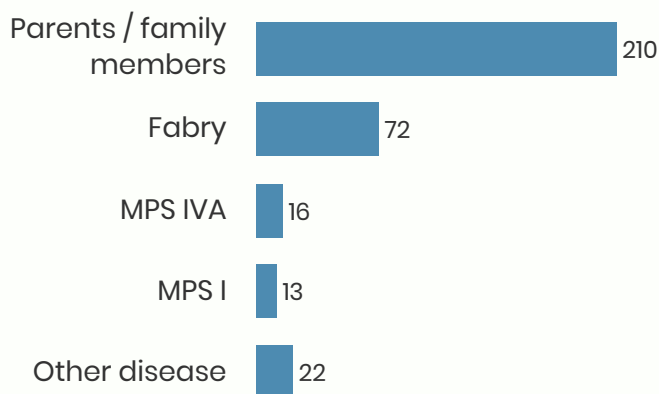
28-30 June 2019, Hilton, Coventry, UK

[Watch here](#)

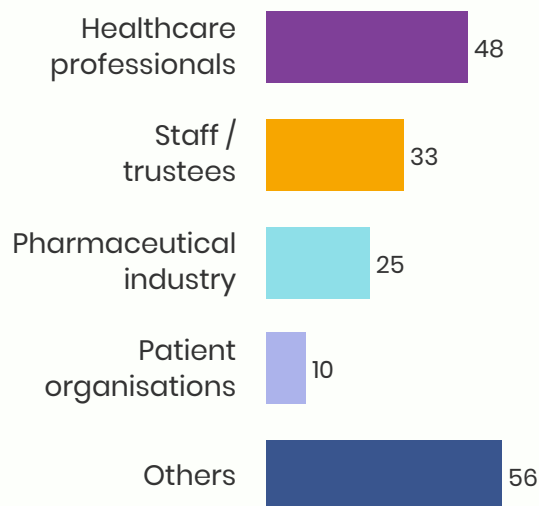
## Stakeholder responses

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"*

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

*"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

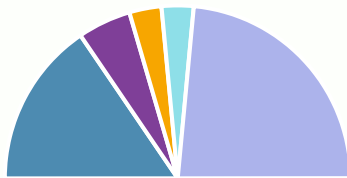
Daily life with their condition  
 Mobility  
 Finding employment

### 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



- Keep up the good work
- Don't know
- More opportunities to connect
- More information
- Other suggestions

**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

### Current challenges

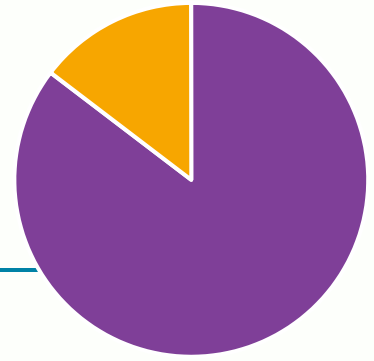
In addition to their health challenges:  
 Transition  
 Meeting others  
 Finding work

**58%** felt we do enough for their age group

### 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



● Specialist centres ● Other

## 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

### Access to treatment

*"Equitable access to allied healthcare and mental health services"*

### New and effective treatment

Cost of treatment  
Improved disease modifying therapies  
Measuring efficacy

*"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.

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## 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

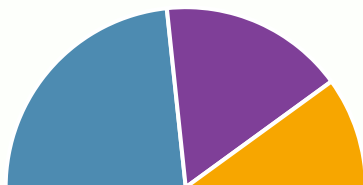
*"Working more in partnership with healthcare trusts to improve clinical co ordination"*

*"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"*

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## How can they support the work of the MPS Society?



● Collaboration   ● Raising awareness   ● Other

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.

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# Pharmaceutical industry perspective

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## 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"*



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## 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.

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## 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

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## 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.

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## How can we improve support to the pharmaceutical industry?

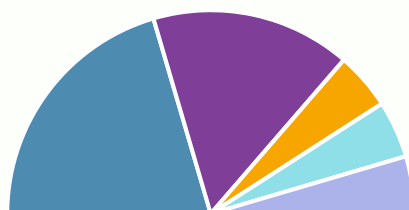
**Continue as we are**  
The most frequent response was to keep doing what we do

**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

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## How can they support the work of the MPS Society?



● Funding ● Collaboration ● Information  
● Work with MPS Commercial ● Other

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

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## 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

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## 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"*

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## 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

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## 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"*

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## 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

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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



## 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



## Challenges in MPS, Fabry and related diseases

- Cost of treatment
- Access to treatment
- Ageing patient population



## 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



## How can they support the work of the MPS Society?

- Continued close collaboration
- Engagement and communication

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## Our national and international roles

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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

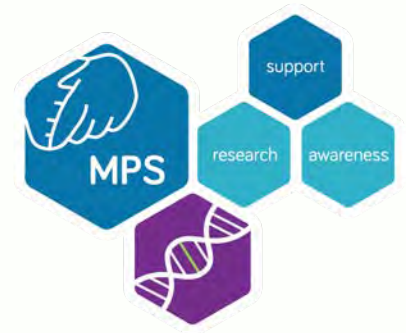
Founded in 1982, the Society for Mucopolysaccharide Diseases (the MPS Society) is the only national charity specialising in MPS, Fabry and related diseases in the UK. It represents and supports affected children and adults, their families, carers and professionals.

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### The Vision Stakeholder Survey was conducted by MPS Commercial

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