

# EURO-HSP ANNUAL MEETING

## JUNE 15, 2019

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# WELCOME AND INTRODUCTIONS

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President EURO-HSP



# MEETING OVERVIEW

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# What do we need to achieve today?

- Explore EURO-HSP's core purpose and the value it creates for its different stakeholders
- Discuss how EURO-HSP can increase its impact over the coming years
- Explore ways in which EURO-HSP can engage more effectively with its members and other stakeholders

# EURO-HSP General Meeting Agenda

- 09:00 Welcome, introductions and meeting overview
- 09:30 Situation analysis: Review of EURO-HSP SWOT analysis
- 10:15 Defining EURO-HSP's unique purpose and core values
- 11:00 Coffee
- 11:15 Agreeing EURO-HSP's mission and vision
- 12:00 Developing EURO-HSP's strategic plan for 2019-21
- 13:00 Lunch
- 14:00 Establishing effective governance and organizational structures
- 15:00 Coffee
- 15:15 Engaging effectively with EURO-HSP's members and other stakeholders
- 16:00 Euro HSP's Board of directors Meeting
- 17:30 Conclusions and next steps
- 17:00 Meeting close

# My role at this meeting

- Act as a strategist and offer ideas and insights based on my experience as an organizational coach
- Work with you to uncover your unique value and help clarify how you achieve your potential as an organization
- Act as a devil's advocate and an honest broker

# Meeting ground rules



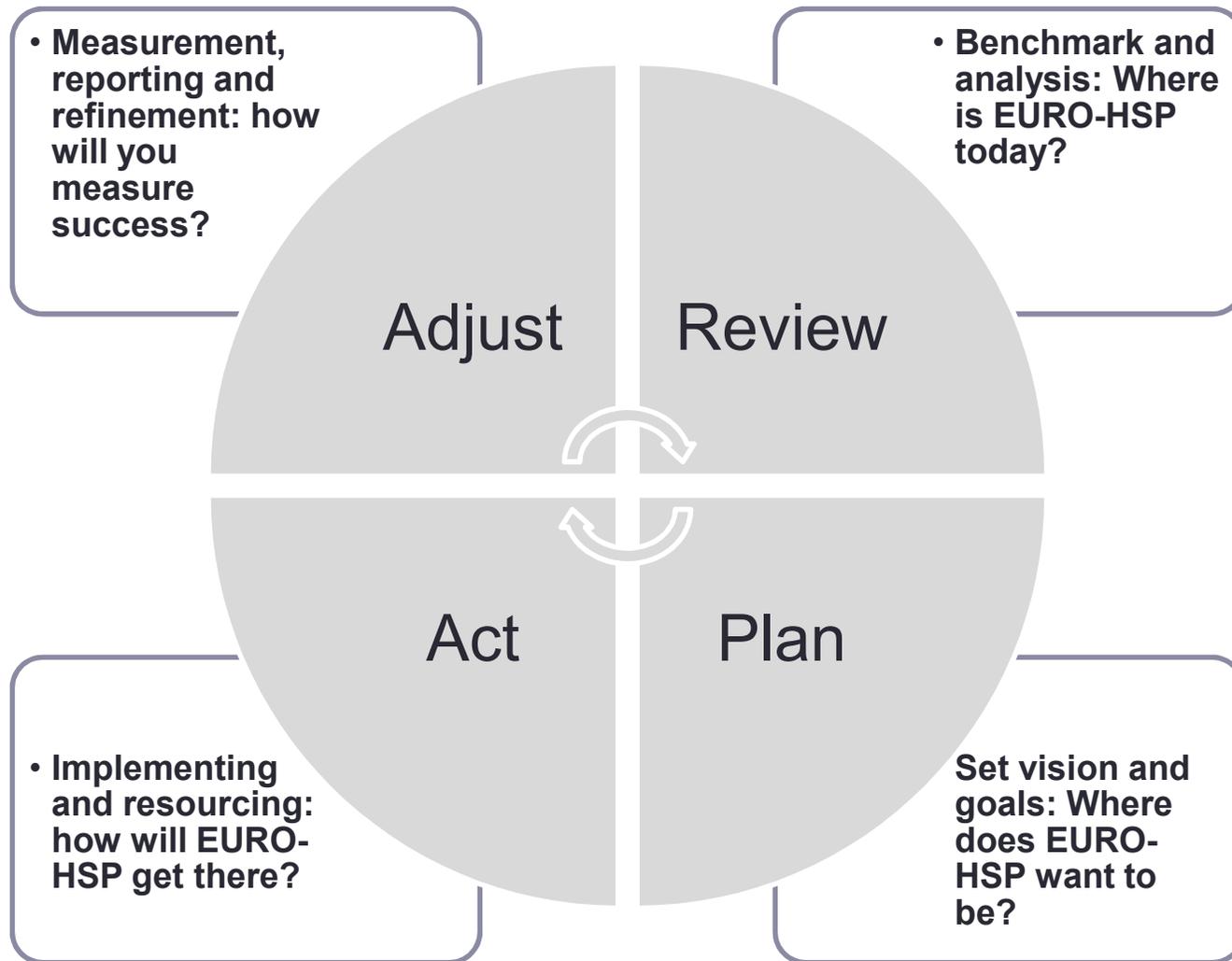
**One  
person  
talks at  
a time.**



# Increasing EURO-HSP's impact and sustainability



# Strategic planning cycle





# SITUATION ANALYSIS

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# Three important considerations

1. Nature of strategic alliances
2. Concept of organizational identity
3. Increasing impact and ensuring sustainability



## Rationale for patient group collaboration at a European or international level

- Achieve common goals
- Increase power and influence
- Enhance organisation's credibility
- Provide entrée to other projects/ partnerships
- Gain access to funding and other resources
- Build organizational capacity
- Avoid duplication of effort

# Half of all strategic alliances fail

- Only 9% of companies consistently build strategic alliances well
- Poor or damaged relationships are the primary cause of breakdown.
- Relationships are characterized by:
  - Mistrust
  - Suspicion about partners motives
  - Festering conflicts
  - Strong feelings of disrespect
- Past relationship breakdowns can create huge hurdles for future collaboration

# Building alliances that create significant and sustainable value

Three steps to successful alliances include:

1. Building the right framework:
  - Clarity on alliance's vision, mission and value proposition (i.e. who you are as an organization)
  - Alignment on common goals and level of interdependence
  - Consensus on goals and strategy, roles and responsibilities, decision making processes and leadership
2. Preparing the organization
3. Forging relationships built on trust

# EURO-HSP's stated objectives

- EURO HSP is a Federation of national groups related with a Rare Disease called Hereditary Spastic Paraplegia or Strümpell-Lorrain disease

## Aims

- Collaborate with scientists and researchers to better understand, discover treatments and find a cure for the disease
- Better all social, political and cultural matters connected with the welfare of people affected by HSP
- Keep the broader society aware of the existence of HSP
- Expand international cooperation between patients, organisations and experts.

# EURO HSP's objectives

- Keeping up with and supporting medical research on HSP and related conditions;
- Central processing of information on such research and passing it on to the members of EURO-HSP
- Promoting and improving contacts between practitioners concerned and persons affected by HSP and other related conditions;
- Investigating social, political and cultural matters connected with the welfare of people affected by HSP and related conditions, as well as promoting and improving the exchange of information on such matters;
- Promoting co-operation on an international level between national associations for people affected by HSP and related conditions;
- Co-operating with or being members of other national and international organisations and institutions that have the objective of furthering the welfare of individuals affected by a physical disablement and, inter alia, those with a neuromuscular condition;
- Gathering funds and collecting, managing, using and distributing contributions, legacies and donations or their benefits, for the purpose of stimulating and promoting both medical research into HSP and related conditions and the welfare of people affected by them.
- Serving as a meeting point for any and all implicated groups (people with HSP, their families, investigators and scientists, doctors, nurses, health care workers, etc) where all aspects of dealing with optimal maintenance of health can be sought, including alternative methods with rational basis.
- Participating in media and media events in order to keep the general public as well as public and private institutions, European or International, aware of HSP issues and concerns.
- Other activities not specifically contemplated in these statutes that may favor the promotion, support, and social and labor inclusion of people affected by HSP and / or related conditions.



# Current members

- Denmark
- France
- Italy
- Netherlands
- Norway
- Spain
- Sweden
- Switzerland
- UK

# SWOT analysis

## STRENGTHS

- Patient driven organisation with the ambition to grow and provide value for its members
- Good relations with external stakeholders
- Enthusiastic individuals who wish to contribute to the success of Euro-HSP
- Established a best practice manual
- Member of EURORDIS
- Member of the European Reference Network for Neurological Diseases
- Scientific advances in the area of HSP

## OPPORTUNITIES

- Use this meeting to agree priority areas of focus for Euro-HSP over coming years
- Push for the establishment of a
- Increasing interest in patient engagement by different stakeholder groups
- Expand membership
- Help members to become stronger and more effective organisations
- Draw on the expertise of individual advocates who have skills in different areas (eg R&D)

## WEAKNESSES

- Limited resources and operational capacity
- Members not clear on added value of Euro-HSP
- Limited visibility
- Differences in members' capacity, realities and interests
- Challenge to recruit volunteers
- Long-term financial sustainability
- Few sources of funding to help sustain the organisation
- Lack of metrics to show impact
- Lack of physician willingness to share data

## THREATS

- Member discontent arising from lack of clarity on mission and lack of relevance of activities
- Unrealistic expectations on what Euro HSP can deliver for members
- Inability to grow due to lack of volunteers and financial resources



# DISCUSSION

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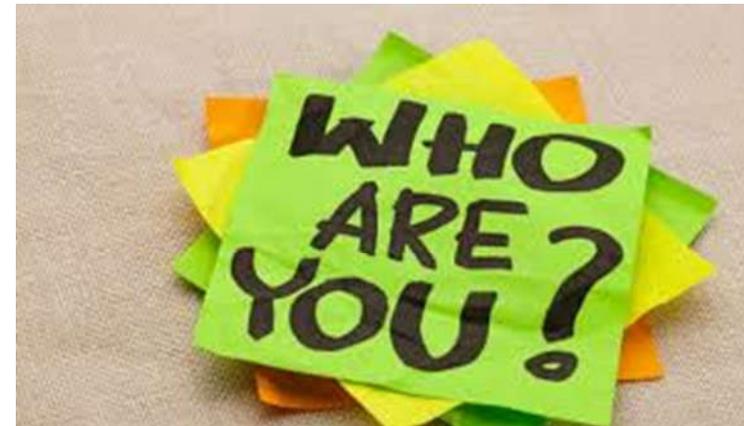
# EURO-HSP'S IDENTITY

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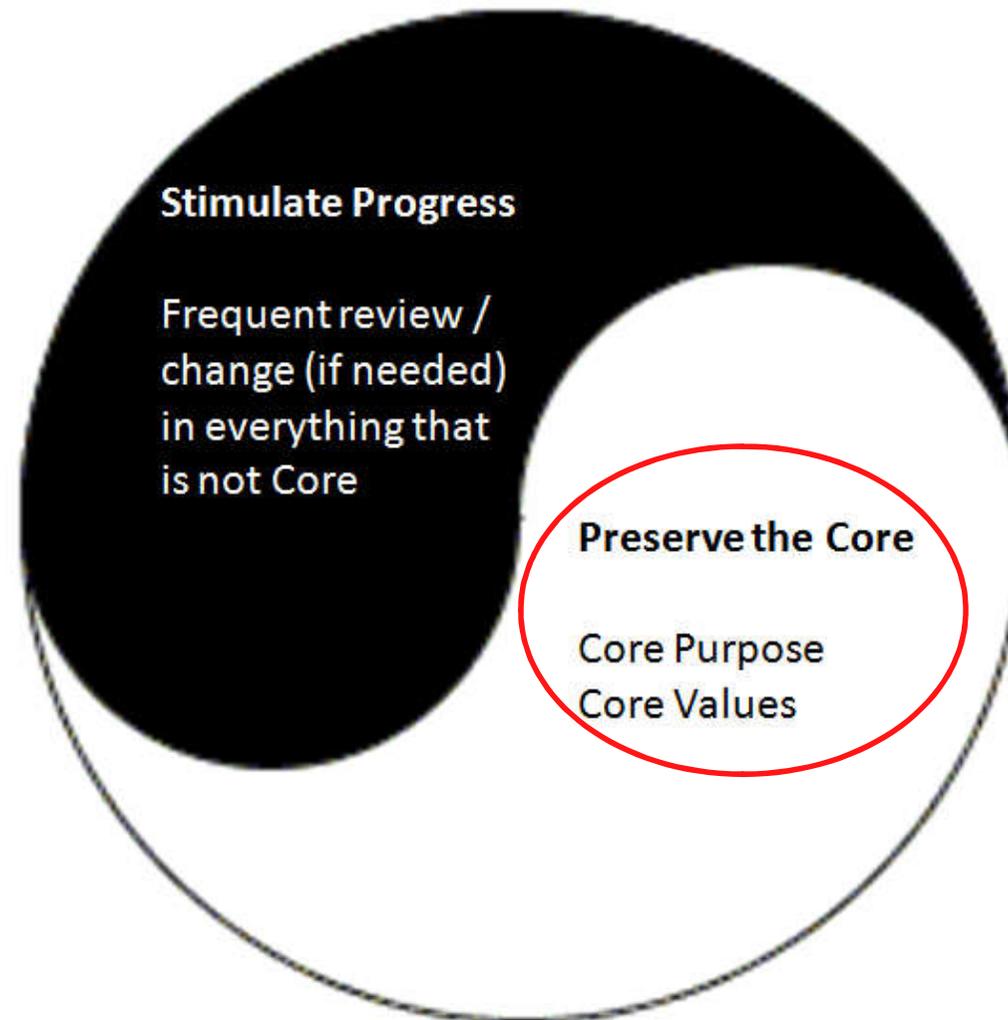


# What is organizational identity?

- **Organizational identity** has been defined as what is central, enduring and distinguishing about an organization and reflects a combination of its:
  - Unique value its capable of creating in the world in which it operates
  - Core values (what we stand for)
  - Distinctive characteristics
- If an organization is to thrive, its identity must be known



# Built to last – Successful Habits of Visionary Companies (Collins & Porras, 1994)

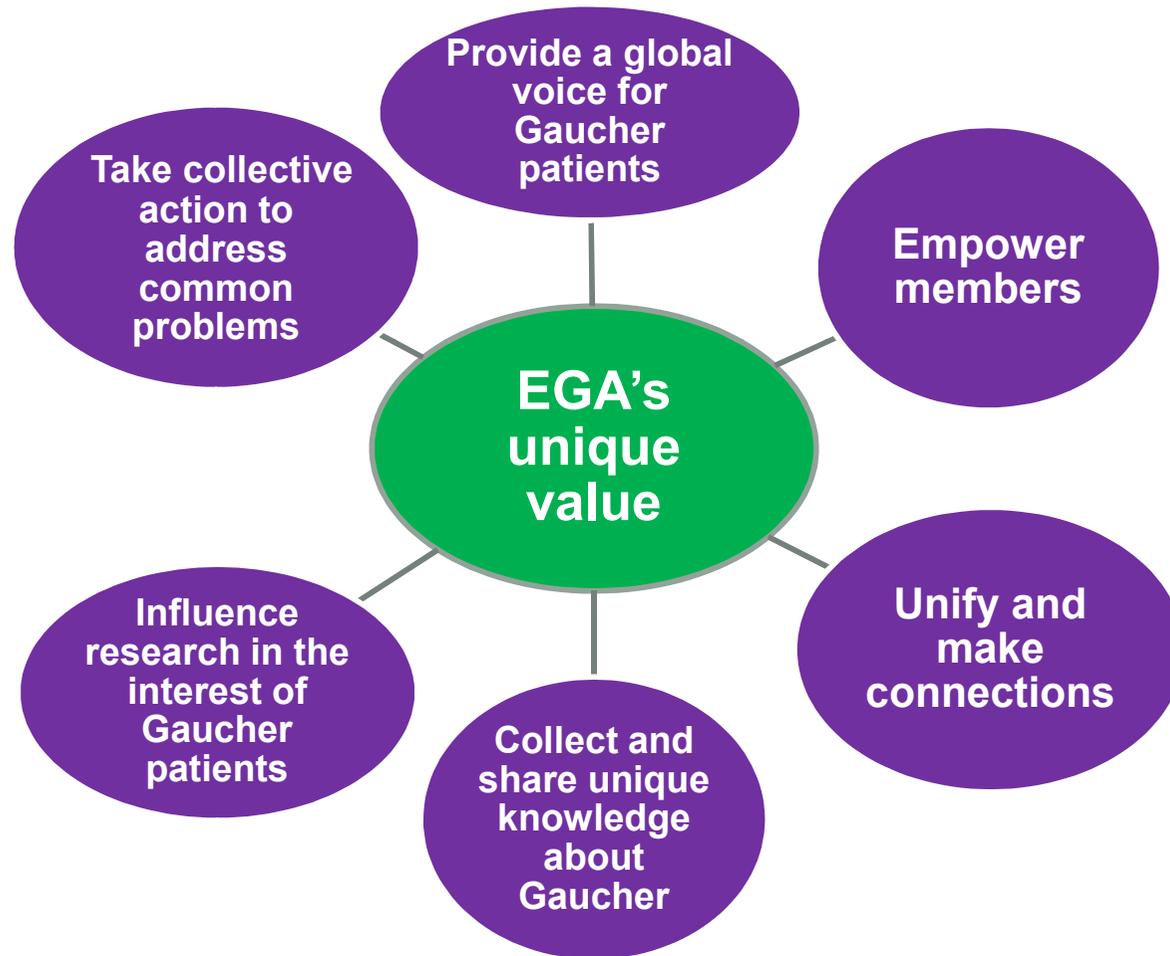


# Organizational value

- **Organizational value** is the distinctive, contribution an organization is capable of making to customers, to others and to society generally (often called unique value proposition)

What value does Euro-HSP create for:  
Its members?  
Wider HSP patient community?  
Health professionals?  
Pharmaceutical industry?  
Society as a whole?

## Example of the unique value of a international organisation representing people with a rare disease



# Organizational values

- **Organizational values** are core beliefs that underpin all that an organization does and are manifested in its actions

What are EURO-HSP's core values?

# Examples of potential core values

- Authentic
- Representative
- Collaborative
- Courageous
- Innovative
- Visionary
- Genuine
- Ethical
- Accountable
- Integrity
- Professional

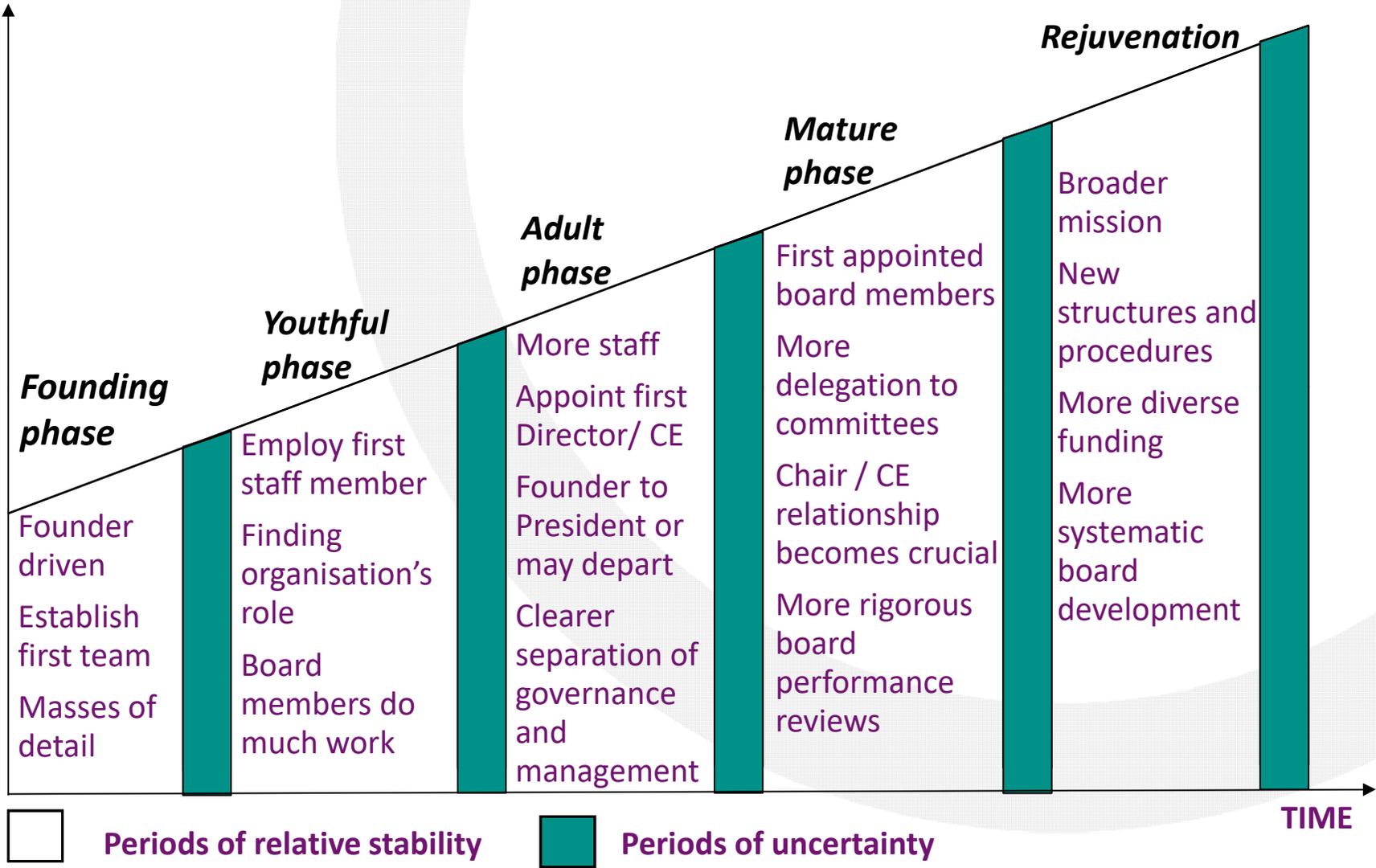




# ESTABLISHING EFFECTIVE GOVERNANCE AND ADMISITRATIVE STRUCTURES

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# Board development in federal organisations





# DISCUSSION

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# MEMBER AND STAKEHOLDER ENGAGEMENT

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# Effective member engagement

Key questions:

- How can we engage more effectively with our members?
- How can we help our members feel a stronger sense of belonging to EURO-HSP?

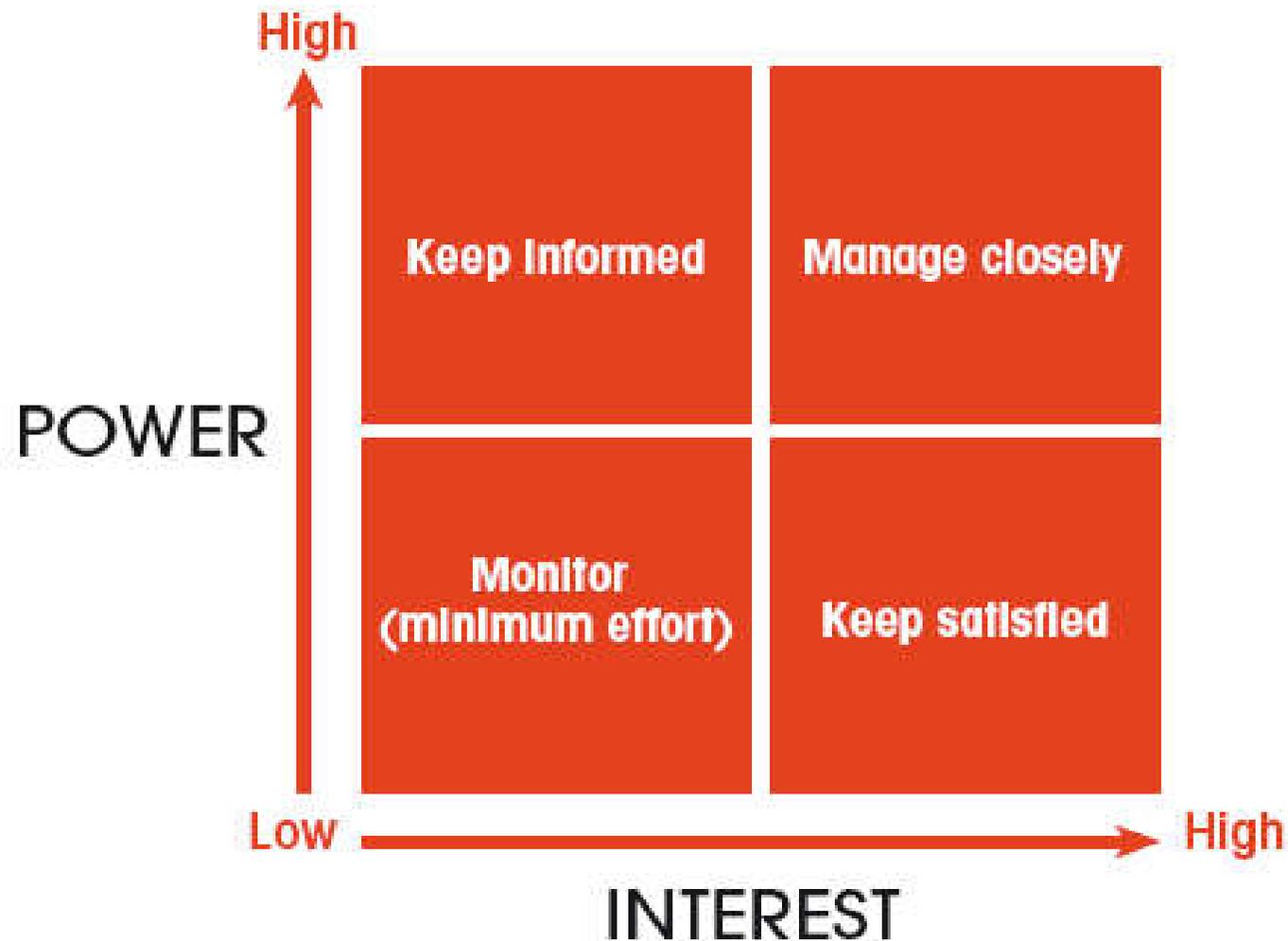
# A stakeholder can be defined as...

...a person, group, organisation or system that affects or can be affected by an organisation's actions

...stakeholders are important since they have the power either to block or advance an action

...stakeholders can be internal or external to an organisation

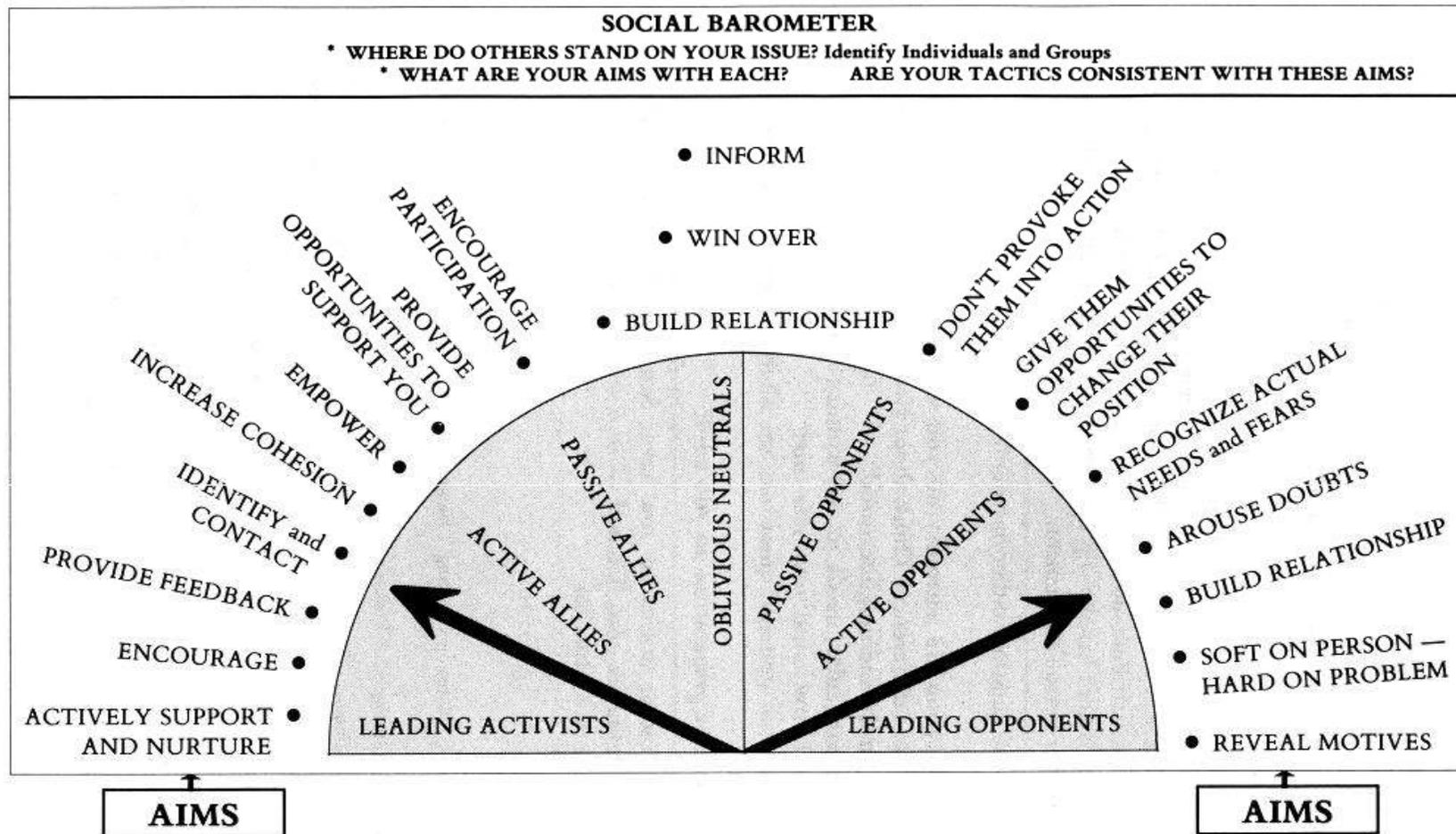
# Prioritising stakeholders



# Stakeholder management

- What is your current relationship with this stakeholder? What is their opinion of your organisation?
- Who influences their opinions generally, and who influences their opinion of you? Do some of these influencers therefore become important stakeholders in their own right?
- Who else might be influenced by their opinions? Do these people become stakeholders in their own right?
- If they are not likely to be positive, what will win them around to support your project?
- If you don't think you will be able to win them around, how will you manage their opposition?
- What information do they want from you?
- How do they want to receive information from you? What is the best way of communicating your message to them?

# Engaging with stakeholders: Defining allies and enemies



# Stakeholder management matrix

Stakeholder name	How powerful?	Nature of relationship?	Stance on issue?	Chance of blocking action?	What do you want from stakeholder?	Strategy for managing stakeholder?
Actor A	M	None	Neutral	M	Win over	Inform/ build relationship
Actor B	H	Enemy	Leading opponent	H	Neutralise	Arouse doubts/reveal motives
Actor C	M	Ally	Passive supporter	L	Increase cohesion	Coalition building
Actor D	M	None	Passive opponent	M	Don't provoke into action	Recognise concerns/Provide facts to help change their position

Adapted by Kathy Redmond from various tools available on the Internet



# DISCUSSION

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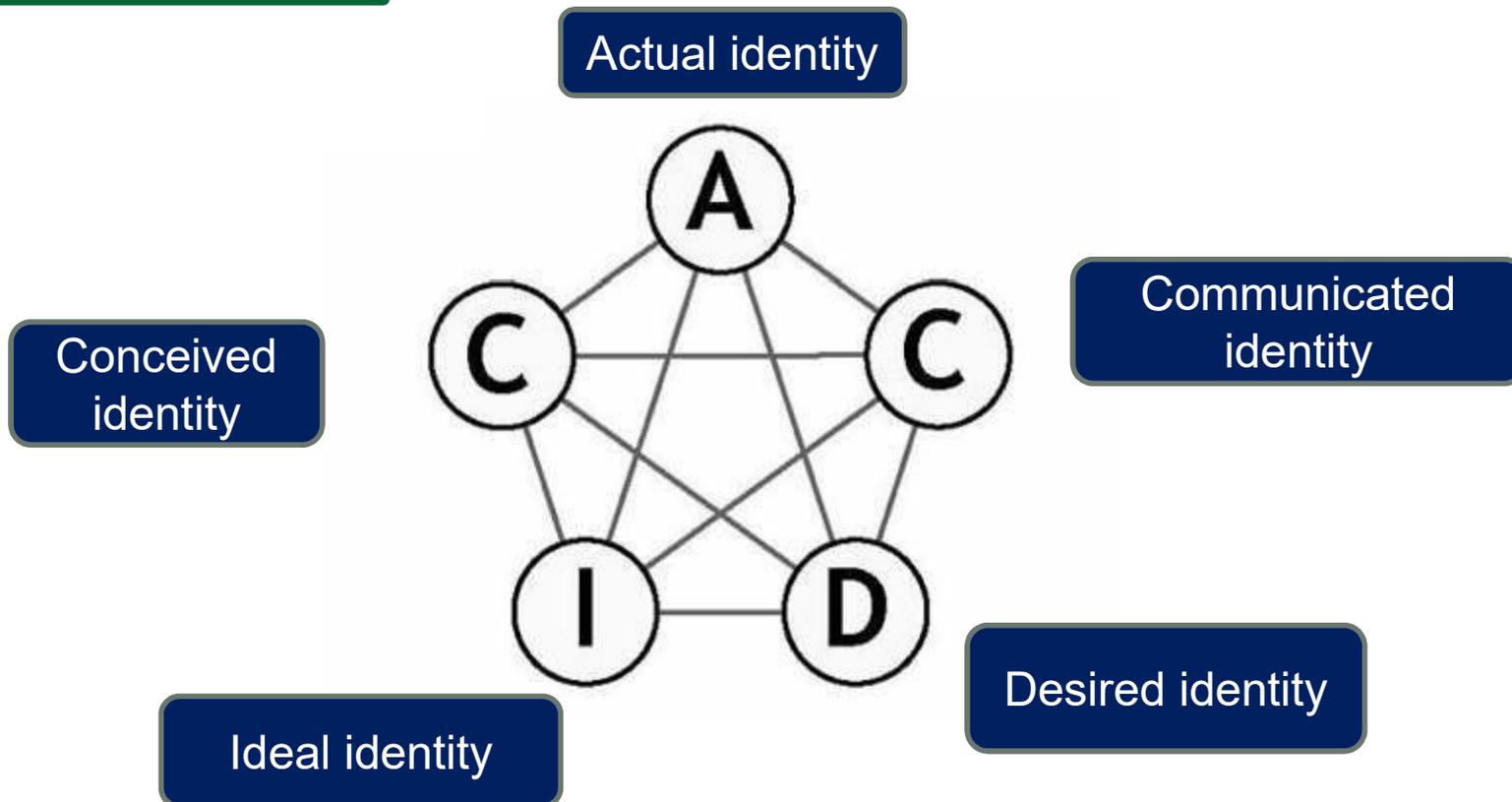


# BACKUPS

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# Exploring organizational identity

**AC2ID  
Test**





## MPE's mission

- To provide education, information and support to member groups and to advocate at European, national and local levels for the best possible research and equal access to the best possible treatment and care

# Who are EURO-HSP's stakeholders?

People living with HSP	Organisations representing people living with HSP
EU policy makers	Regulators
National governments	Pharmaceutical companies
Health technology assessment agencies	Research funding agencies
Payors	Media
International/regional professionals societies	General public

# Value vs values

- **Value** - the proprietary, or distinctive, contribution an organization is capable of making in the marketplace — that is, to customers, to others and to society generally
- **Values** – core beliefs or principles that underpin all that an organization does and that provide a compass for decision making. While circumstances may change, ideally values do not.

# Mission vs Vision: what's the difference

Mission statement: Defines the fundamental purpose that sets an organization apart from others (unique value proposition) and explains to both insiders and outsiders why an organization exists. Mission statements tend to be short, clear and written in the present tense.

Vision statement: a statement that also defines an organization's core purpose but is more focused on the desired state an organization wants to achieve. These statements are often highly ambitious and help inspire and attract commitment to an organization's cause. Vision statements tend to be timeless – even if the organization changes its strategy, the vision and values will often stay the same

# Some more definitions...

- **Organizational image:** refers to collective perceptions of an organization – what both insiders and outsiders think about an organization. What outsiders think of the organization is often referred to as reputation
- **Identity dysfunctions:** Organisations are at risk of two identity dynamic dysfunctions - narcissism (too inward looking and ignoring what outsiders think) and hyper-adaptation (adapting too much to what outsiders think and abandoning true identity). Both of these can damage the image outsiders have of the organization
- **Organizational identification:** where people feel a sense of oneness with and belonging to their organization
- **Organizational commitment:** a psychological state that describes members' relationships with the organization and influences their emotional attachment, loyalty and willingness to stay with an organization
- **Organizational culture:** the basic assumptions and beliefs that are shared by members of an organization, that operate unconsciously and define in a taken-for-granted manner an organisation's view of itself and its environment. Culture can reinforce an organisation's identity.
- **A stakeholder** is a person, group, organization or system that affects or can be affected by an organisation's actions. They are important because they have the power to block or advance an action. Stakeholders can be internal or external to an organization.

# Identity types: AC3ID

**TABLE 1-The AC<sup>3</sup>ID Test of Corporate Brand Management**

<b>Critical Concern</b>	<b>Identity Type</b>	<b>Concept</b>	<b>Time Frame</b>
<i>What we really are</i>	Actual	<i>corporate identity</i>	<i>Present</i>
<i>What we say we are</i>	Communicated	<i>corporate communications</i>	<i>Past/Present</i>
<i>What we are seen to be</i>	Conceived	<i>corporate image</i>	<i>Past/Present</i>
<i>What the brand stands for</i>	Covenanted	<i>corporate brand</i>	<i>Past/Present</i>
<i>What we ought to be</i>	Ideal	<i>corporate strategy</i>	<i>Future</i>
<i>What we wish to be</i>	Desired	<i>CEO vision</i>	<i>Future</i>