

NAEVUS GLOBAL: BUILDING A STRATEGIC PLAN FROM 2025-2029

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Naevus Global's Strategy Working Group

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*Could only attend a few meetings

Elements of an organisation's strategy

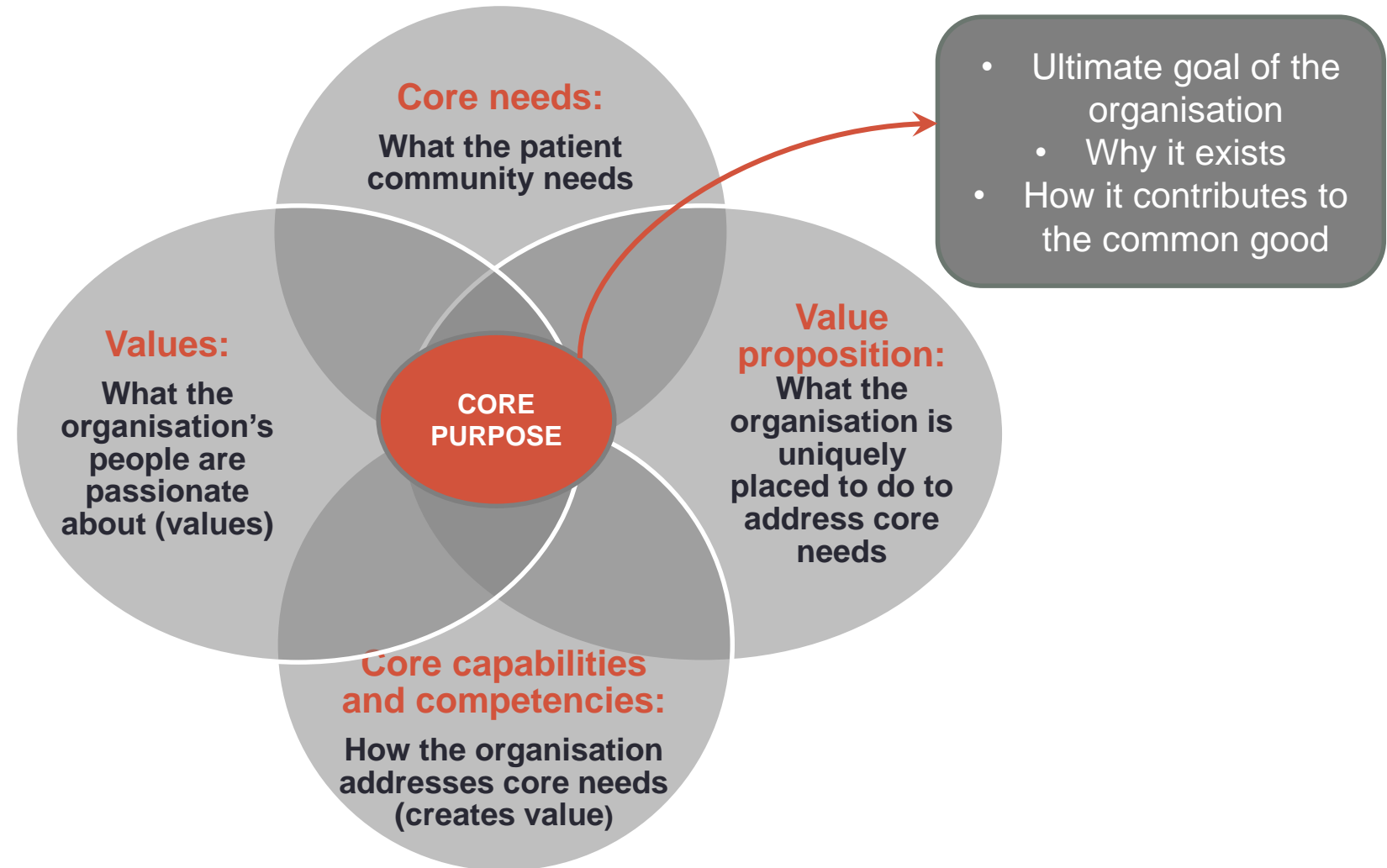
Unchanging/ slowly changing

- Core purpose (Vision and mission)
- Core values (Reflected in all your actions and decisions)
- Core capabilities and competencies (At what you need to excel to succeed within the world in which you operate)

Changing/ dynamic

- Situation analysis
- Strategic objectives and operational tactics
- Supporting resources and infrastructure
- Impact measurement

International Patient Alliance: Core purpose



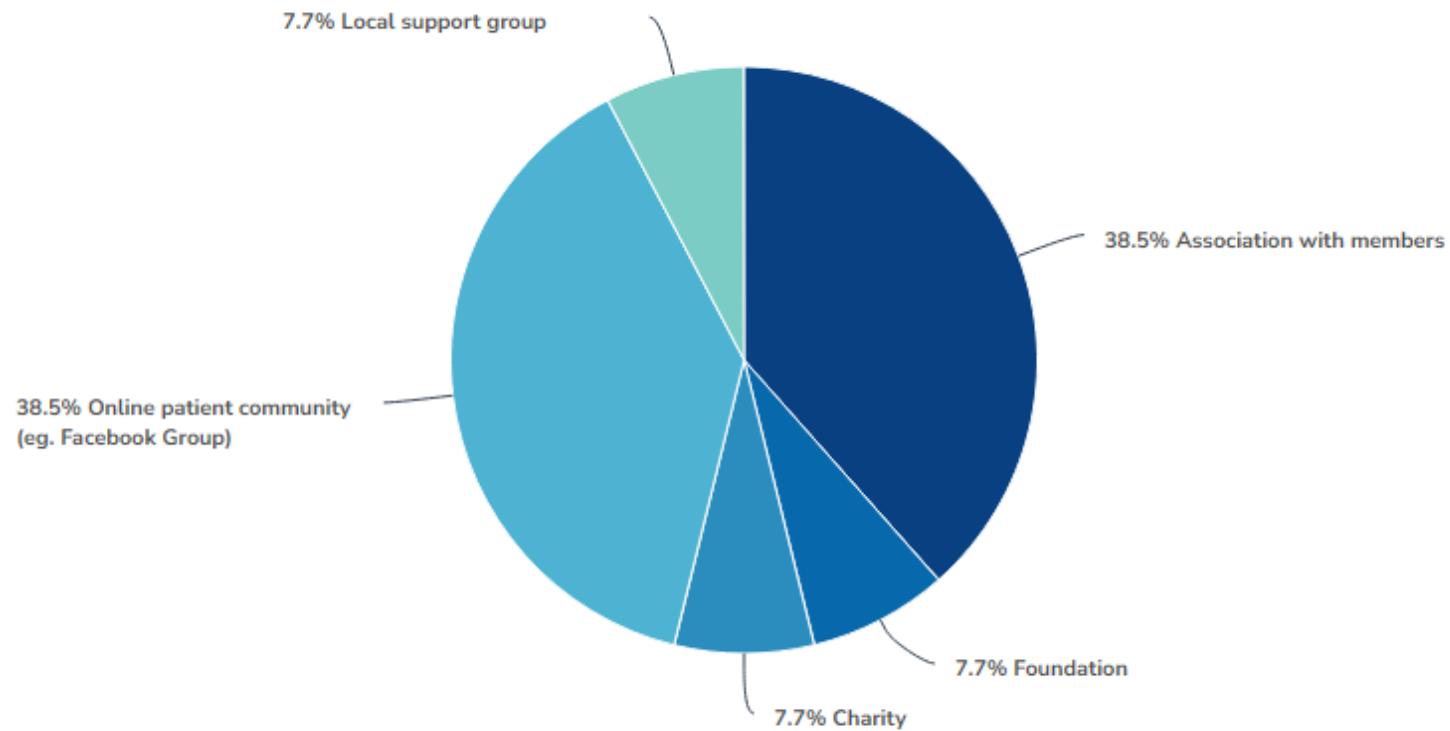
Steps taken to define core purpose

- Conducted a survey* to define the needs of:
 - Individuals affected by CMN
 - The CMN patient community
 - CMN patient organizations
- Conducted a value proposition exercise to define what Naevus Global is uniquely placed to do to address key needs
- Developed new vision and mission statements for Naevus Global based on the value proposition exercise
- Agreed values which are reflected in all that Naevus Global does

*Survey results at end of the presentation

RESULTS OF THE NAEVUS GLOBAL SURVEY

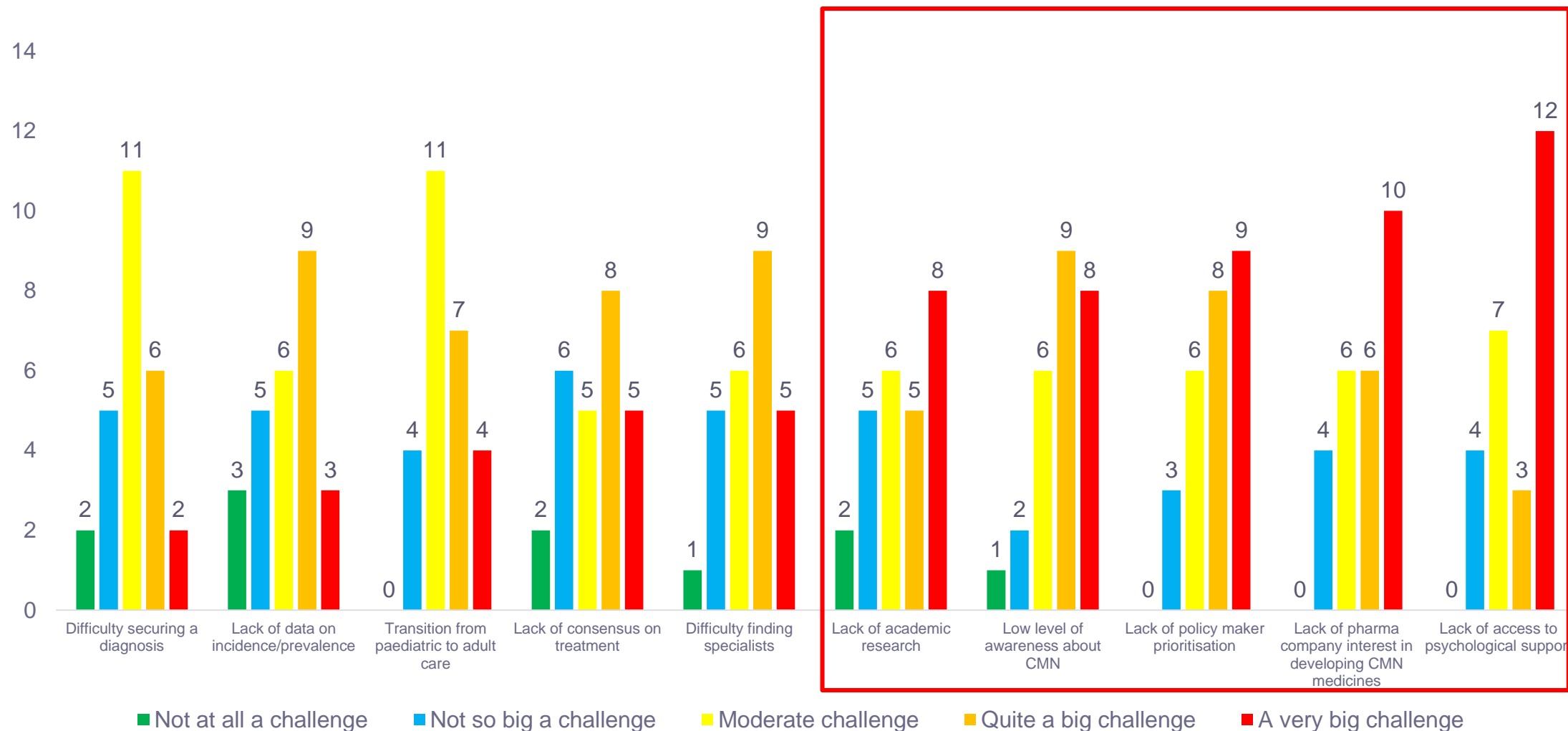
Conducted by Redmond Consulting in March 2024



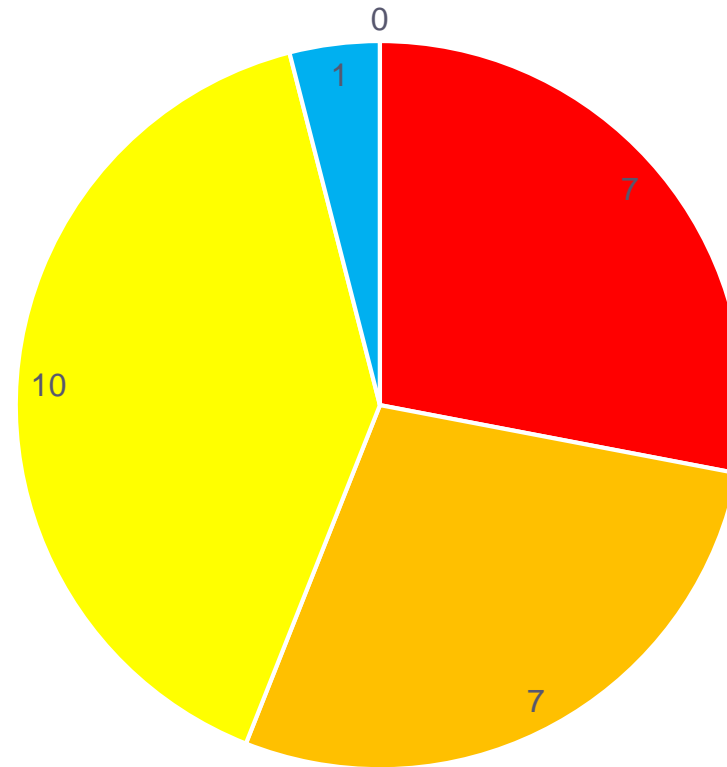
Value	Percent	Progress Bar	Responses
Association with members	38.5%	<div style="width: 38.5%; background-color: #003366;"></div>	10
Foundation	7.7%	<div style="width: 7.7%; background-color: #0056b3;"></div>	2
Charity	7.7%	<div style="width: 7.7%; background-color: #0070c0;"></div>	2
Online patient community (eg. Facebook Group)	38.5%	<div style="width: 38.5%; background-color: #00a0c9;"></div>	10
Local support group	7.7%	<div style="width: 7.7%; background-color: #76d7c4;"></div>	2

Totals: 26

CMN community challenges

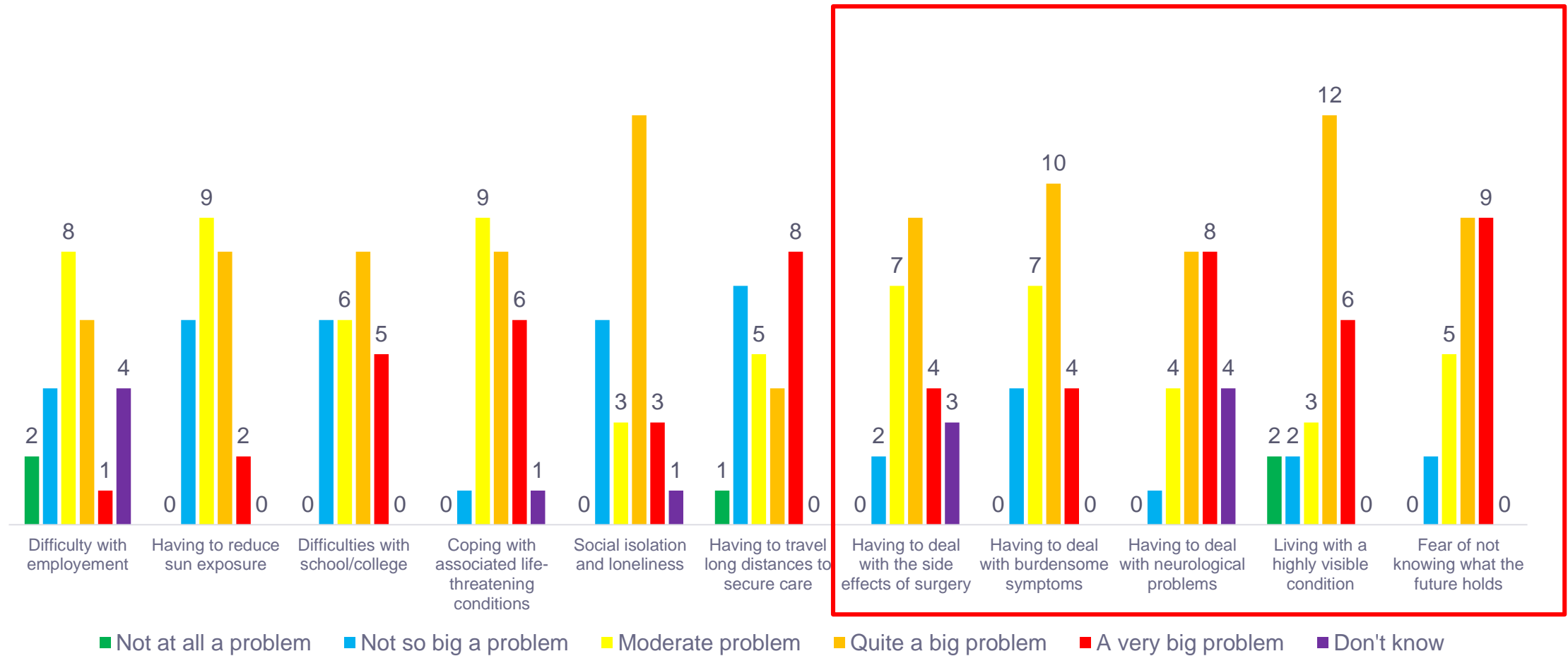


CMN patient community influence on decision making

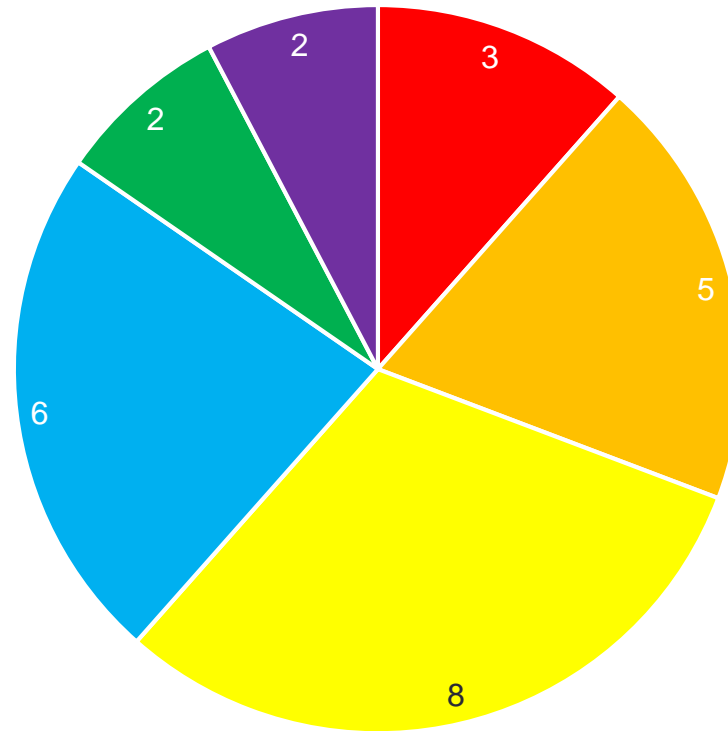


■ Not strong at all ■ Not very strong ■ Moderately strong ■ Very strong ■ Extremely strong

Problems experienced by people with CMN and their families

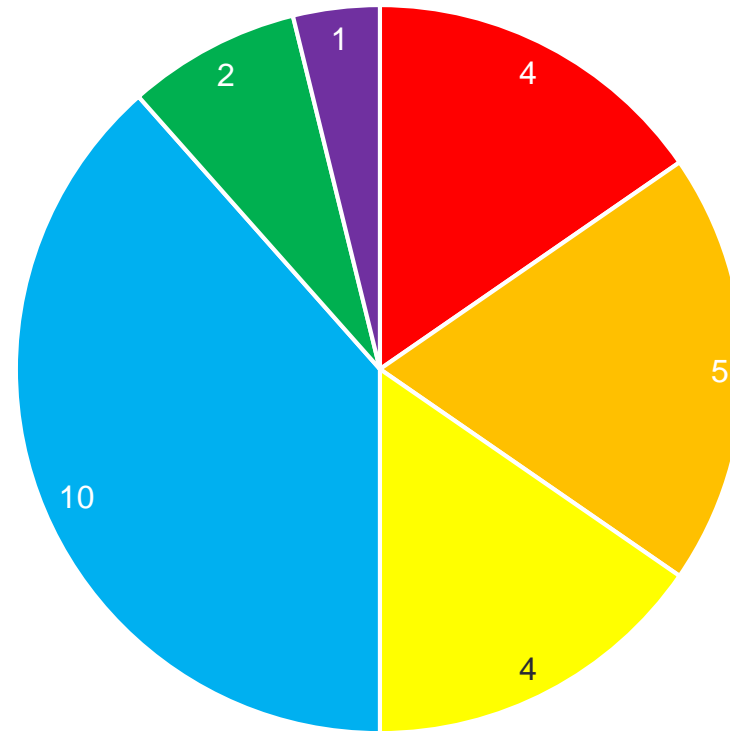


Quality of patient information available on CMN/NCM



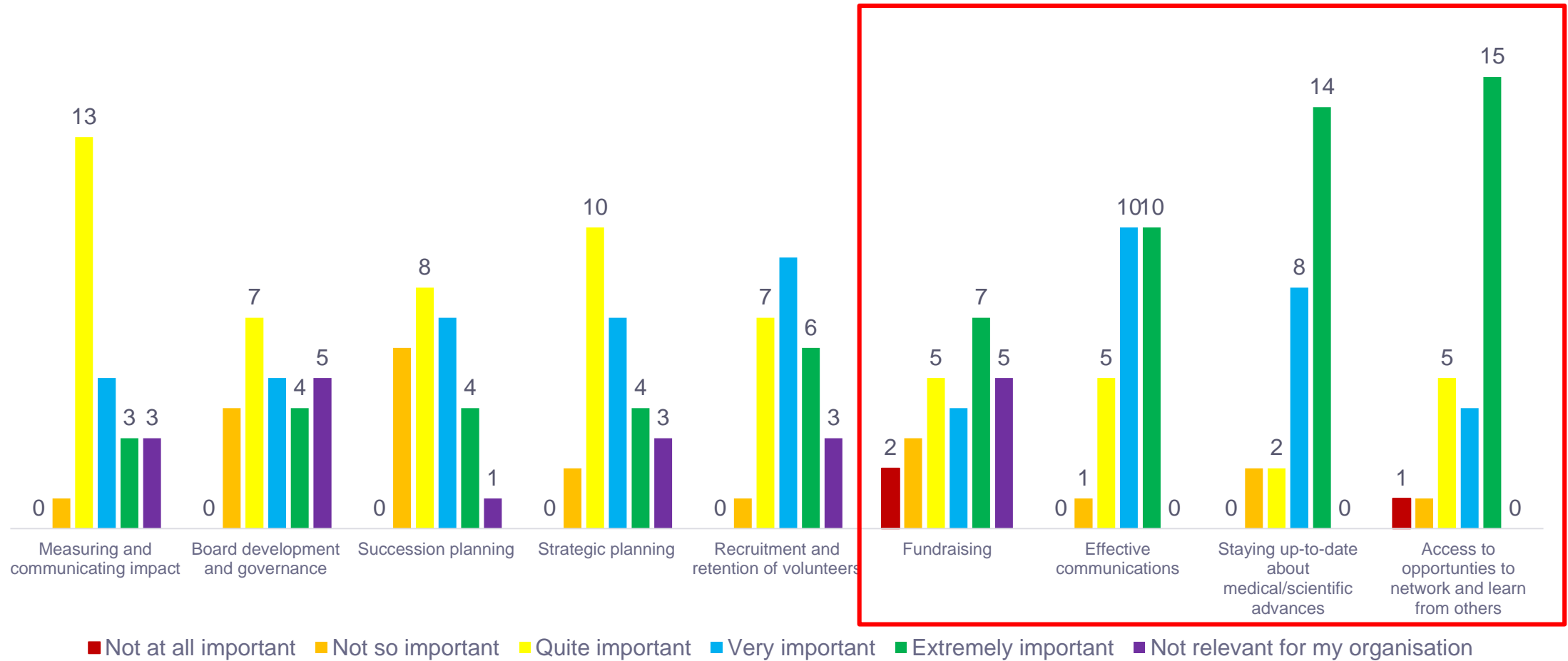
■ Poor ■ Fair ■ Good ■ Very good ■ Excellent ■ No information available

Quality of peer support available for individuals affected by CMN/NCM

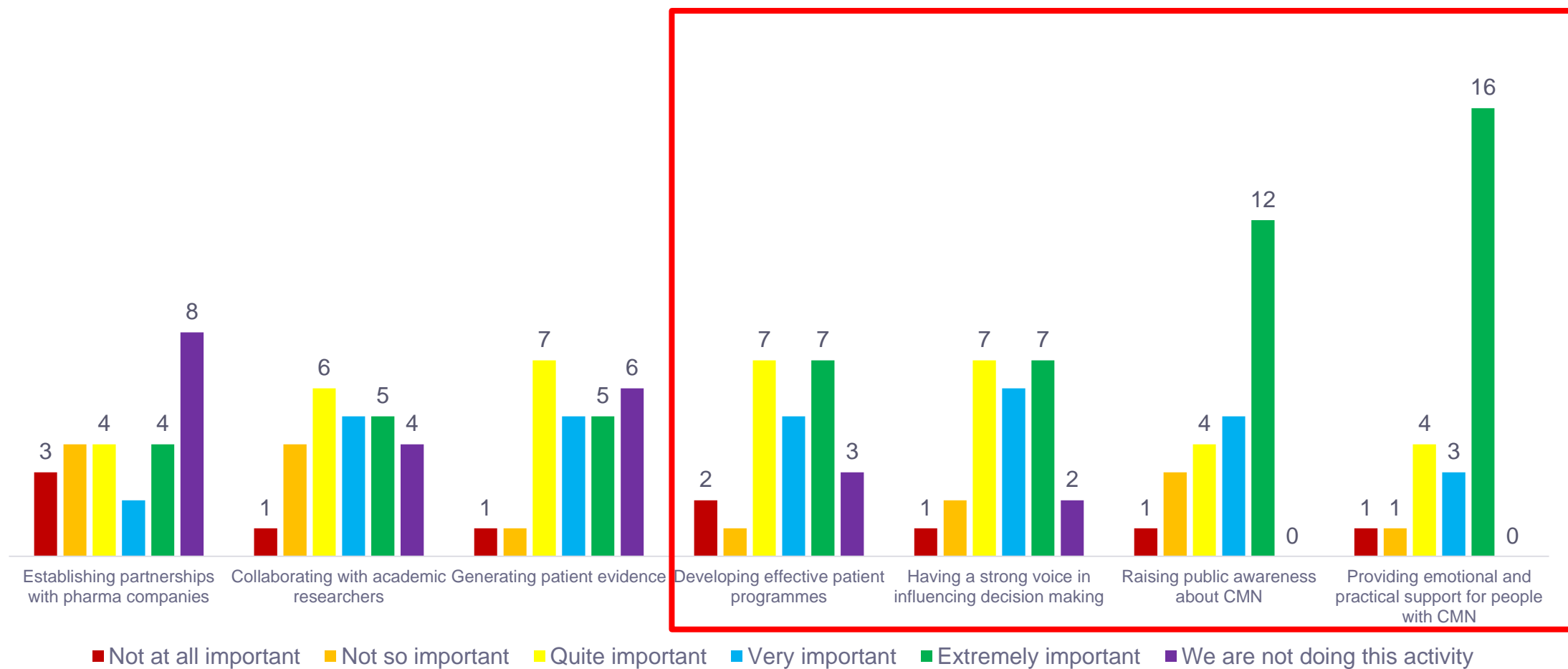


■ Poor ■ Fair ■ Good ■ Very good ■ Excellent ■ No peer support available

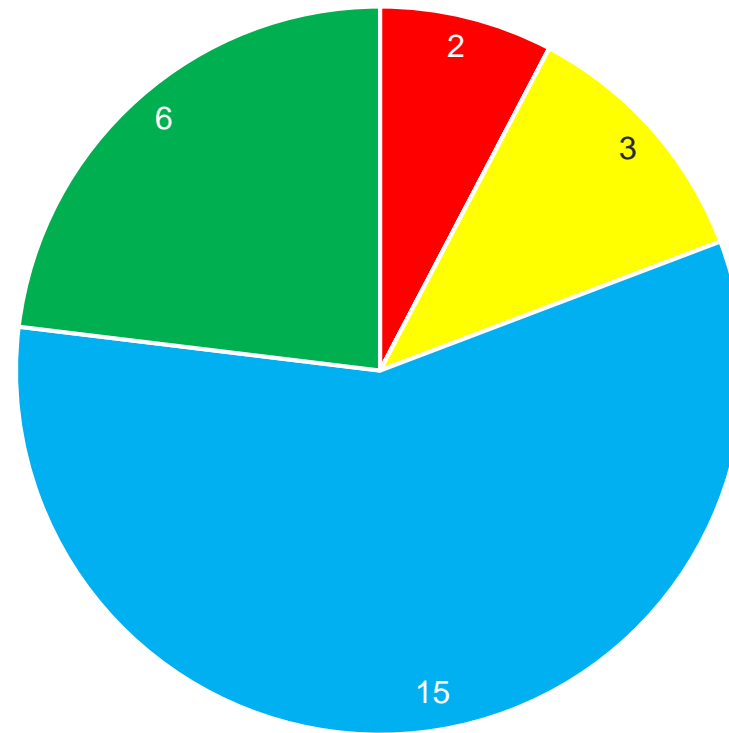
CMN organisational challenges



Challenging activities for CMN organisations



Satisfaction with involvement with Naevus Global



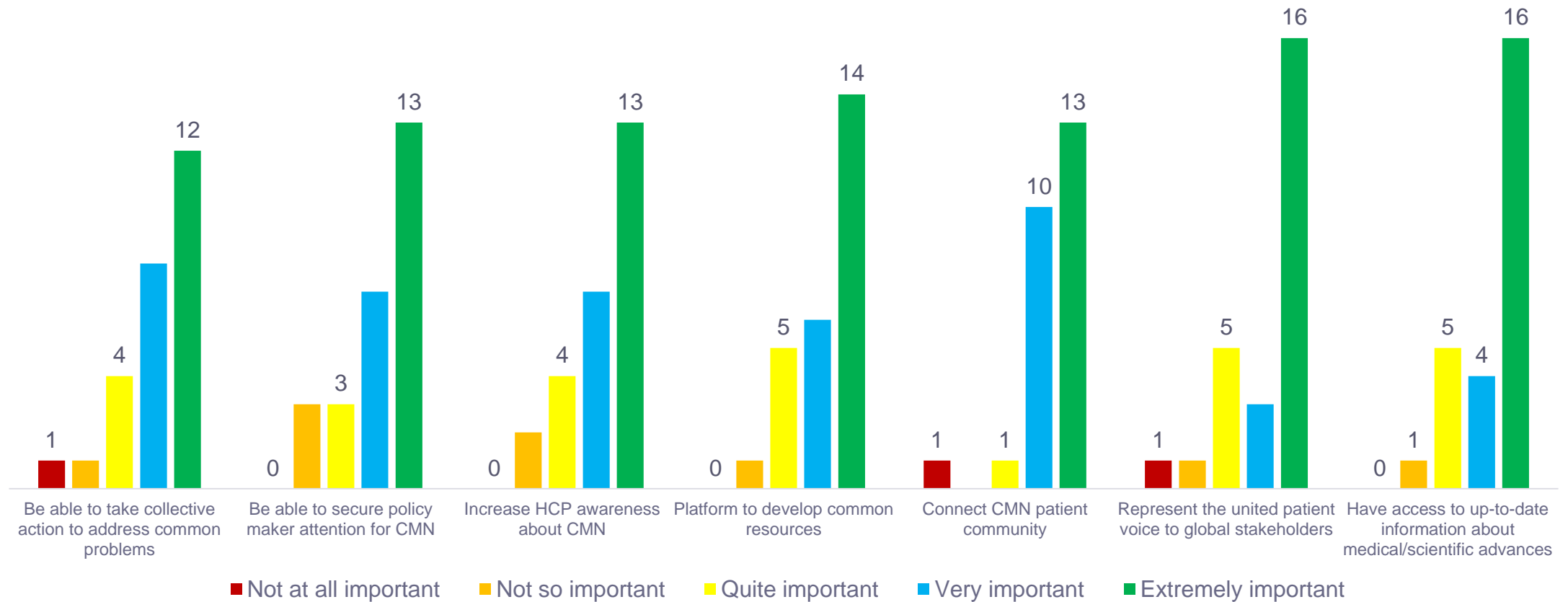
■ Very dissatisfied ■ Dissatisfied ■ Neither satisfied nor dissatisfied ■ Satisfied ■ Very satisfied

Naevus Global's HX TrustID scores

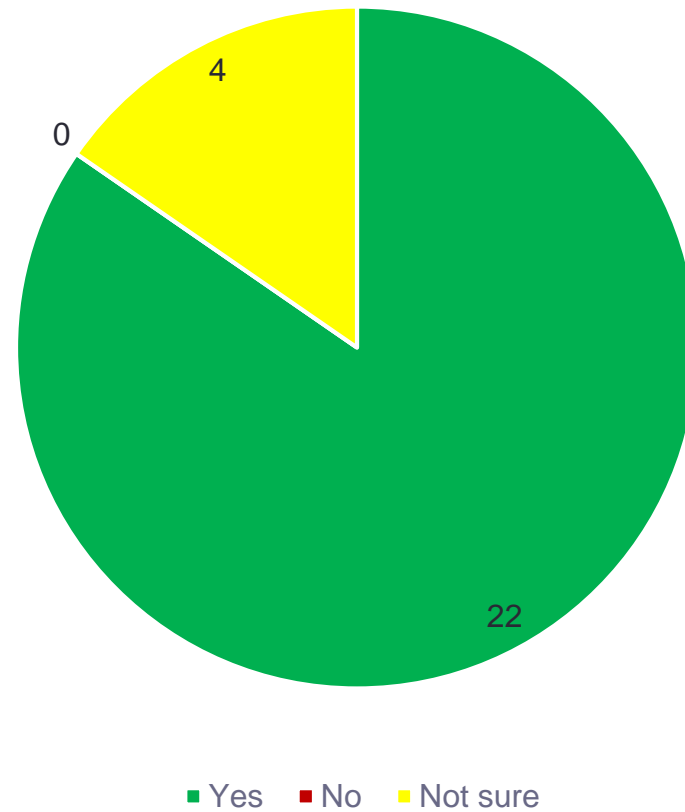
Item	Score
Humanity	57.8%
Transparency	69.2%
Capability	65.4%
Reliability	73.1%
Composite HX TrustID score	66%

[gx-ffot-hx-trustid-customer-survey-guide-2022.pdf \(deloitte.com\)](#)

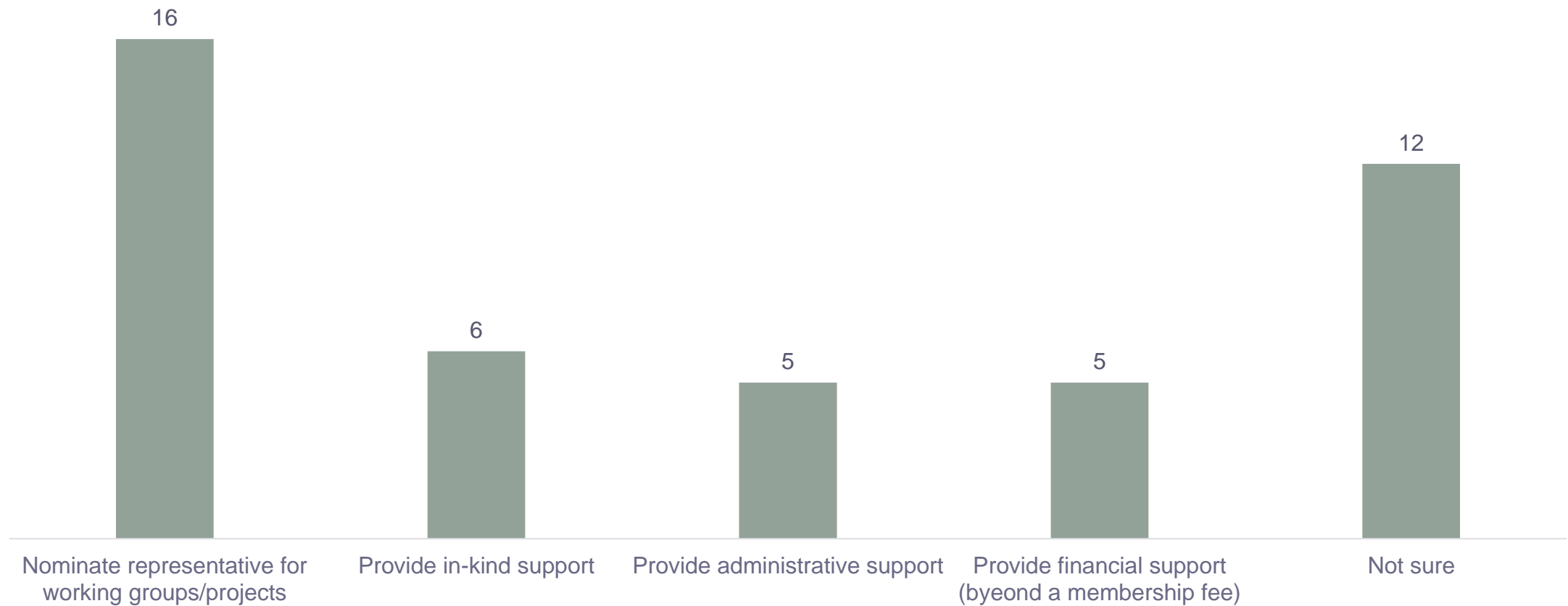
Potential benefits that Naevus Global can deliver for the community



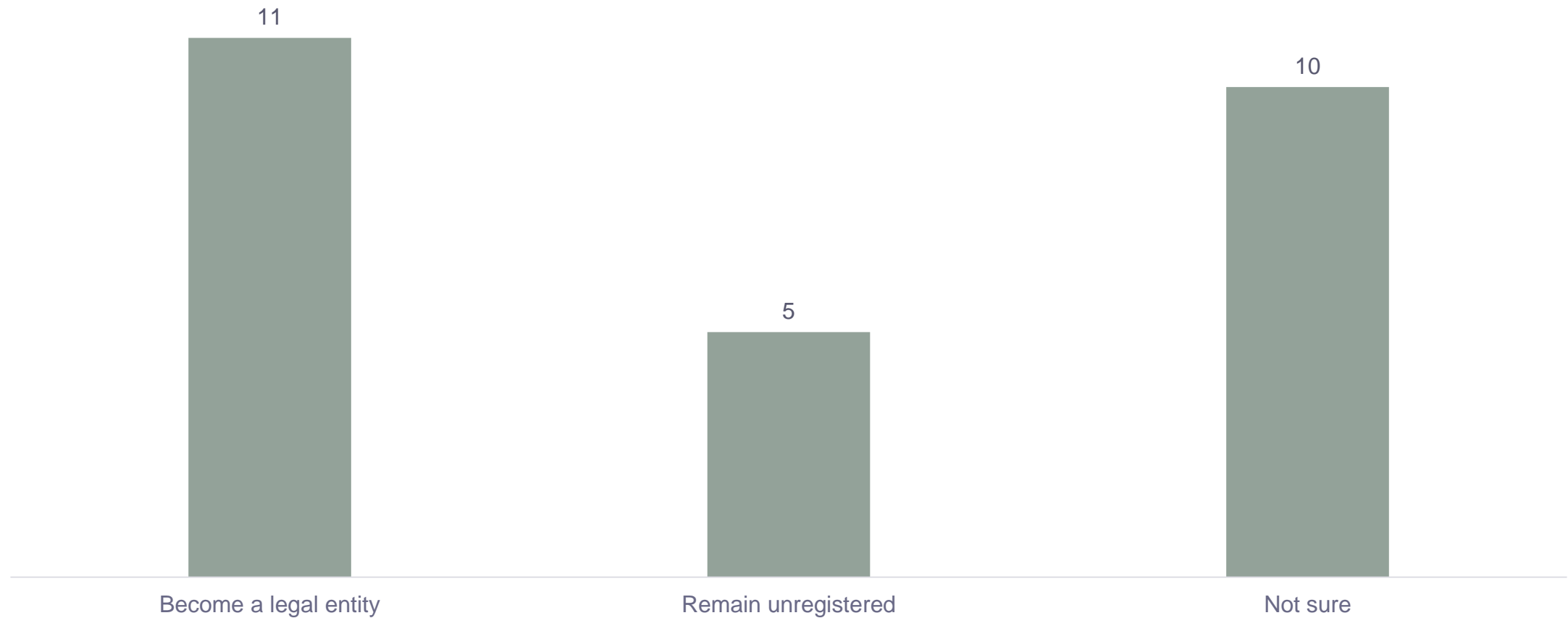
Interest in being a member of Naevus Global



How CMN patient community is willing to contribute to Naevus Global



Opinion on whether Naevus Global should become a registered legal entity



NAEVUS GLOBAL'S UNIQUE VALUE PROPOSITION

What Naevus Global is uniquely placed to do to address community needs

- **Empower CMN patient organisations** across the world to be more effective in their activities
- **Connect the global CMN patient community** by providing a platform for knowledge exchange, brainstorming on how to address common problems, sharing of resources and the co-development of common resources
- **Co-ordinate joint action** to address common problems (e.g. raise awareness about the burdens of CMN and the need for greater policy prioritisation of these conditions, promote research on CMN/NCM, address access problem etc.)
- **Provide a united and representative patient voice** in global decisions that impact on people with CMN

Benefits of joining Naevus Global: Unlocking the collective power of the community

- Membership of Naevus Global will provide members with the opportunity to:
 - Have a **voice in decisions** that impact the CMN patient community globally
 - Be involved in **joint actions** to address common problems
 - **Gain access** to information, know-how, opportunities and resources
 - **Raise global awareness** about and give greater visibility to the burdens of CMN
 - **Reduce duplication and fragmentation** of effort releasing resources to focus on national issues
- Overall this will increase members' impact, influence and sustainability

PROPOSED NEW VISION AND MISSION

Proposed vision for Naevus Global

What is a vision statement?

- A statement that communicates **the future** or **desired state** an organisation wants to achieve
- These statements are often **highly ambitious** and help inspire and gain commitment to an organisation's cause

Proposed vision statement for Naevus Global

- **Naevus Global channels the collective expertise of its patient networks to expand patient support groups, optimise and integrate the patient journey, and influence global decision making as it concerns CMN, so that people affected enjoy an empowered life with acceptance.**

Proposed mission statement for Naevus Global

What is a mission statement?

- Defines what the organization is **fundamentally there to do** (purpose)
- Sets an organisation **apart from others** (unique value proposition)
- Explains to both insiders and outsiders **why an organisation exists**
- Mission statements tend to be **short, clear and written in the present tense**

Proposed mission statement for Naevus Global

Naevus Global is an international network of patient experts committed to enhancing the lives of those affected by CMN. We connect and empower global patient support groups by sharing knowledge and experience to amplify our unified voice in global decision making.

Organisational values

Values are core beliefs that underpin all that an organisation does and are manifested in all of its actions

Shared values:

- Provides the glue that helps keep an organisation together
- Create better understanding and foster communication between people within an organisation
- Help people within an organisation work better together and feel better about what they do
- Help create an attractive and effective work environment

Naevus Global's values that are visible in all that the organisation does

Community values

As the global CMN patient community we...

- put the needs and interests of **people affected by CMN first**
- are as **inclusive** as possible and foster **connectivity** within our growing community
- create a strong sense of **belonging** where people feel **supported** and **empowered**

Organisational values

As an international alliance of CMN patient organisations we are:

- **innovative** in our approach and **global** in our outlook
- **highly collaborative** and always act with **integrity**
- determined to be **impactful** and ensure our work is of **high quality**
- **transparent** about our actions and **accountable** for all that we do

Values questions to ask when making decisions or reflecting on organisational performance

- Are we putting the needs and interests of people affected by CMN first?
- Are we being as inclusive as we can be?
- Will this action foster a sense of belonging and help our community feel supported and empowered?
- What can be do to ensure that information, resources and connections are shared as widely as possible within our community?
- Are we being as innovative as we could be?
- Are we global enough in our outlook?
- Are we doing the right thing?
- How can we be as transparent as possible about our decisions and actions?
- Are we having a big enough impact? Is there more we could be doing?

DEVELOPING STRATEGIC OBJECTIVES THAT ARE LINKED TO NAEVUS GLOBAL'S VISION AND MISSION

What are strategic objectives?

- Strategic objectives (sometimes also called imperatives) are clear statements of specific long-term outcomes that an organisation wants to achieve in different areas:
 - Are closely linked with the organisation's value proposition
 - Need to be achieved in order for the organisation to grow and deliver on its vision
 - Should be ambitious
 - Should be anchored to shorter-range tactical goals and that must be met to achieve the desired long-term outcomes
- Strategic objectives provide clear direction for the organisation:
 - Facilitate decision making about whether to pursue opportunities
 - Help define what the organisation should focus on and where resources need to be allocated

Naevus Global Vision 2030

1. The CMN patient community globally will feel more empowered and capable of advocating on behalf of people with CMN
2. Global decisions that impact on people with CMN will be informed and influenced by the united voice of the CMN patient community
3. There will be an increase in, awareness about and better co-ordination of research can improve the lives of people with CMN
4. There will be greater awareness about the burdens of CMN and the need for different stakeholders to take action to tackle the most important unmet needs

Note: To deliver these objectives we need to build a strong and sustainable organisation with appropriate legal structure, governance, communications, sufficient resources etc

Linking objectives to tactics

Strategic objectives (focus)	Examples of short term goals	Example of potential tactics to achieve short term goals
Community empowerment	By the end of 2026 we will have established a platform for the community to share knowledge and experience	<ul style="list-style-type: none"> • Annual/biennial in-person meeting of community • Regular webinars to facilitate experience exchange • Raise awareness of opportunities via GlobalSkin, EURORDIS, RDI etc • Platform for sharing resources • Newsletter with scientific updates/webinars with researchers following key congresses • Toolkit on starting patient organisations • Establish a community mentorship program
United patient Voice	By the end of 2026 we will create a communications network to share opportunities for input in global decision making	<ul style="list-style-type: none"> • Establish a communication channel • Create a calendar with conferences worldwide • Engagement with key researchers • Provide patient input into research projects • Presence at World Congress on Rare Skin Diseases
Patient-focused research	By the end of 2026 we will compile a list of existing relevant CMN research and connect them to the patient journey	<ul style="list-style-type: none"> • Conduct a mapping exercise of existing CMN research • Consensus meeting with researchers/clinicians to identify key gaps • Categorize research materials
CMN awareness	By the end of 2026 we will organize one common campaign to raise awareness about about CMN	<ul style="list-style-type: none"> • Global CMN Awareness Day 28th of September • Identify opportunities to raise awareness amongst various stakeholders • Develop common messages on CMN for Rare Disease Day • Have a stand at key relevant international conferences • Develop a template for streamlined branding to share our network's resource materials

NEXT STEPS

Next steps

- Establish a Steering Committee which will have the task of developing proposals for Naevus Global's:
 - Legal structure (Whether or not to become a legal entity or remain unincorporated)
 - Governance framework (Leadership, co-ordinating body, decision making powers, etc)
 - Membership criteria and application process
 - Roles and responsibilities (leadership, co-ordinating body and members)
 - Action plan based on agreed strategic objectives
 - Plan for resourcing the organisation (people and finances)
- Hold a follow-up meeting with interested organisations to discuss proposals

Difference between a unincorporated and incorporated organisation

Unincorporated organisation

- An unincorporated organisation is legally understood to be a collection of individuals (or organisations) who have agreed to come together to pursue a common purpose
- An unincorporated organisation has no legal identity outside of the people who are on its management committee
- Members of an unincorporated organisation are personally liable for the organisation's actions
- Unincorporated organisations cannot enter into contracts or own property in their own right. A member must enter a contract in their own name

Incorporated organisation

- Incorporated organisations have their own legal identity and therefore have a legal standing that is similar to that of a person
- Members of incorporated organisations are not personally liable for the organisation's actions
- The organisation can enter into contracts in its own name

<https://valonline.org.uk/unincorporated-v-s-incorporated-legal-structures/>
<https://www.acnc.gov.au/for-charities/start-charity/you-start-charity/who-can-apply-be-registered/unincorporated>