



DYSNET

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Position Statement on Collaboration With Private Sector Organisations

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Summary:

DYSNET has developed guidance to help evaluate the suitability of potential collaborations with the private sector.

This guidance is based on several principles:

- benefits to DYSNET's member organisations and the dysmelic community at large must be a higher goal than benefits to either partner in the collaboration
- the potential collaborator must be financially viable and trustworthy
- the company or agency must be reputable

- the agency and its employees should conduct business with ethical standards compatible with DYSNET's own.

Criteria used to determine whether to collaborate include:

- the fit of collaboration to DYSNET's mission
- independence of scientific judgment
- effect of the potential collaborator's product(s) or service(s) on health
- the potential collaborator's conduct.

General recommendations for collaboration address:

- consistency of potential collaborator's broad mission with that of DYSNET
- the public nature of the collaboration
- openness and transparency around the collaboration project.

Introduction:

Private sector organisations support DYSNET because of shared brand values and because DYSNET is a trusted organisation and an important source of information for the European dysmelic population. The preservation of this status is a priority for the organisation and collaboration with private sector organisations must reflect this and help enhance the wealth of information curated by DYSNET.

For purposes of this Guidance, a collaboration is defined as an interaction between DYSNET and one or more private sector organisation in which both parties work together to carry out their missions.

The approach described here began with fits with the board of DYSNET's views on how best to assess and encourage partnerships with private organisations, and to further DYSNET's goal of providing accessible information to the dysmelic population worldwide as well as how to assess the suitability of public/private collaborations.

This document identifies principles that set forth guidance for evaluating potential collaborations. This document concentrates only on collaborations with private organisations, both for-profit and not-for-profit. Even with this guidance, the decision of whether to collaborate may still be unclear in some circumstances; no set of precepts can adequately cover all situations. Therefore all potential collaborations will be evaluated on a case-by-case basis in accordance with these guidelines and the individual circumstances.

Collaboration with the private sector:

Private sector organisations are not-for-profit or for-profit. Not-for-profit organisations include voluntary associations, foundations, civic groups, professional associations, universities, unions, and other similar types of groups. For-profit organisations include corporations, partnerships, proprietorships, and others intended to generate financial gain for their owners. The agendas and missions of private organisations may overlap to a greater or lesser degree with those of DYSNET. Collaborations with the private sector may involve, but are not limited to:

- **Technology development:** Examples of technology development activities include the development and evaluation of commercial products such as accessibility features on media outlets or in smart environments, the development of apps or other assistive technology of use to the dysmelic population. In this regard, DYSNET aims for collaborations as a user-testing and advisory group.
- **Professional education:** Examples of professional education include conference sponsorship and publication of proceedings, facilitation of best practice exchange, recommendations, or other materials to be distributed or taught to and by experts in the field of dysmelia and the dissemination of outcomes.
- **Applied research or evaluation:** Examples of research and evaluation include development or assessment of birth defect registries, cluster research and analysis of causes based on results, and dissemination of results.
- **Provision of impartial information:** Examples of provision of information include contributions to a document library curated by DYSNET in all major EU languages, supply of options for assistive technology and other disability-related products, an interactive network of experts and centres of excellence and the active dissemination of information through social media.

Reasons for considering collaboration include access to private sector skills and enhancement of the organisation by involving outside partners. Exemplary organisations in an industry can set an example for other organisations. Organisations often possess information or technology that is useful to the public. Engaging the private sector may be helpful in reaching a large segment of the public, generating broad societal support or winning over potential opposition. However, limited public resources or the expectation of gaining private resources alone should not be considered sufficient reason for collaborating with private organisations - the collaboration must also enhance DYSNET's knowledge base and community on more grounds than merely financial.

A potential private sector collaborator may have resources to commit, and DYSNET in turn may have access to specific populations or professional groups that the other cannot easily reach. In the best collaborations both groups bring credibility with selected segments of the population on certain issues and/or special technical expertise.

Criteria for assessing potential collaborators:

A. *DYSNET should have a clear view on how the potential collaboration fits within its overall mission and priorities and how it can assist the private partner's mission and priorities.*

If DYSNET originated the project, then it is likely to fit well with the organisation's mission and goals. If the project was the partner's idea, DYSNET should assess whether the project is central to the its goals and priorities or to what extent to collaboration can help further these. The organisation should consider the following questions:

- Why does the potential collaborator want to work with DYSNET?
- How does the project relate to the collaborator's mission and goals?
- Will the potential collaboration have a reasonably large impact relative to the resources required?

B. *DYSNET should address independence and objectivity of scientific judgment in the potential collaboration. Further, mechanisms should be identified that will ensure such objectivity and independence during the collaboration. The organisation should consider the following questions:*

- Will the project be designed so that it is scientifically defensible?
- Will DYSNET to have a controlling stake in the publication and dissemination of results and materials?
- Will DYSNET or the private sector partner have unilateral veto power over what can be disseminated?
- Can either party halt the project because they become uncomfortable with the results or interpretations?

Answers to these questions should be agreed on in advance and put in writing. The fact and appearance of independent judgment can be protected in many ways, including establishing independent review boards of health professionals and scientists who are not part of the project.

C. *DYSNET should assess the effect of the private partner's products or services on the health and quality of life for the dysmelic population and whether they are compatible with DYSNET's mission.*

With regard to the partner's product or services, DYSNET should consider the following questions:

- What is the overall impact of the potential collaborator's products or services, their distribution, mode of delivery, and their use to the dysmelic community on an international level?
- Will the potential collaborator's products or services further the well-being of dysmelics on an international scale?
- What is the impact of the potential collaboration on the health and quality of life for people affected by dysmelia?

Under no circumstances will DYSNET undertake to collaborate with organisations whose products or services has been proven to have harmful effects, regardless of whether these are accompanied by beneficial results. In negotiating the collaboration, the potential partner can be asked to provide a list of products or services. Common knowledge should suffice to determine the extent to which a product or service has a harmful component. If there is doubt about a product's safety, a more thorough review should be conducted.

D. *DYSNET should assess the behavior of the private partner in conducting business and determine whether the partner's behavior is consistent with DYSNET's mission and ethics and the principles guiding private sector collaboration.*

Questions regarding a variety of aspects about the potential collaborator's behavior should be asked. These include, but are not limited to:

- What is the history of the organisation's previous collaborations with DYSNET or another non-profit entity?
- Do the potential collaborator and DYSNET adhere to similar scientific, ethical, and legal principles and practices?
- Will the potential collaborator comply with or be compatible with DYSNET's policy and regulations?
- What are the potential collaborator's practices in promoting its products or services and its interests?
- Could DYSNET stand behind the collaborator's practices?
- Does the potential collaborator's motivation for pursuing the collaboration fit with DYSNET's mission and priorities?
- How has the potential collaborator behaved in the past if or when its product or service was found to be harmful?

In the specific case where an organisation is owned by another (e.g., subsidiaries owned by a parent company) and either the parent company or one of the subsidiaries produces a product or delivers a service that is harmful, the issue of whether the organisation supports the interests of the parent company or other commonly owned organisations should be addressed. The independence of the potential partner and whether the interests of the other commonly owned organisations will be supported by the collaboration should be addressed. Questions to ask include:

- Is there evidence that the potential partner has conducted activities that support the interests of other organisations?
- How independently is the organisation able to conduct its business from the parent organisation and affiliated organisations?

Most of these questions about partner's behavior in conducting business can be asked directly of the partner or assessed during the negotiation phase of the collaboration. In addition, a media search could be made to determine whether there have been press reports about the partner's behavior.

General recommendations for collaboration:

A. *DYSNET should assess not only the specific area of mutual interest but the public impact of the partner's broad public mission and image.*

In any collaboration, partners should share a common goal. But DYSNET should also be aware of the unshared aspects of the partner's activities. Areas of similarity of mission and interest are often well described in planning meetings, since these similarities are the basis for potential collaborations. However, the overall perception of the partner will inevitably color the public's view of the appropriateness of the collaboration. Will the collaboration enhance or detract from DYSNET's mission, image, and credibility?

B. *DYSNET should aim to participate as an indirect collaborator (e.g. as an independent adviser for a project) as well as in direct partnership.*

An indirect relationship occurs when the organisation collaborates with an entity through an intermediary partner with whom the organisation executes an agreement. Indirect relationships vary; for example, DYSNET may serve as a member of an

advisory group for a project or may be a member of a large group conducting a project through a third party, such as a professional association.

DYSNET - in order to further its standing as the leading authority on dysmelia in the world - should actively pursue indirect partnerships in which the organisation can participate in an advisory capacity. This can entail, but is not limited to, being brought on as an impartial user-testing group or as a member of an advisory panel.

Indirect relationships should not be established solely to distance DYSNET from a specific partner, thereby avoiding an external perception of an inappropriate collaboration. An indirect relationship often provides relatively little protection from the perception that the agency is inappropriately working with a private organisation.

C. *Private partners should be informed that the existence of the collaborative relationship will be made a matter of public record. How this will occur should be worked out early, especially if implied endorsements are likely.*

In the spirit of transparency, both DYSNET and the partner should be willing to make public the existence of a collaboration. Appearing to 'do wrong' while 'doing right' is still really 'doing wrong.' Officials who appear to be doing wrong erode confidence in the organisation. Citizens often have no other way to judge actions other than by appearance. Public disclosure of the relationships can help reduce concerns about potential conflicts of interest.

DYSNET should assess how its name and participation in a collaborative project will be used and whether such usage is consistent with the organisation's public role. A private partner may be eager to link its name with DYSNET. Both partners should understand how the collaboration might be publicised, and DYSNET should have the chance to review and approve how its name and participation will be used.

If DYSNET publicly endorses a product or service, it must be made clear that the organisation is the beneficiary of a collaboration with a commercial partner, where such an agreement has been entered into. Endorsements should only be given when - in the opinion of DYSNET - the product or service will enhance the quality of life of people affected by dysmelia. No endorsement will be given in return purely for financial reward - either to the organisation as a whole or individual board members and officers.

D. *Staff who will be developing collaborations with the private sector should receive orientation and guidance from DYSNET's board concerning the organisation's principles, criteria, and recommendations for collaborating with the private sector.*

These principles, criteria, and recommendations provide general guidance for collaborating with the private sector. Their success in implementation is dependent upon consistent use by all staff. Because they are open to interpretation, staff who are likely to develop collaborative relationships should become familiar and conversant in the principles, criteria, and recommendations.