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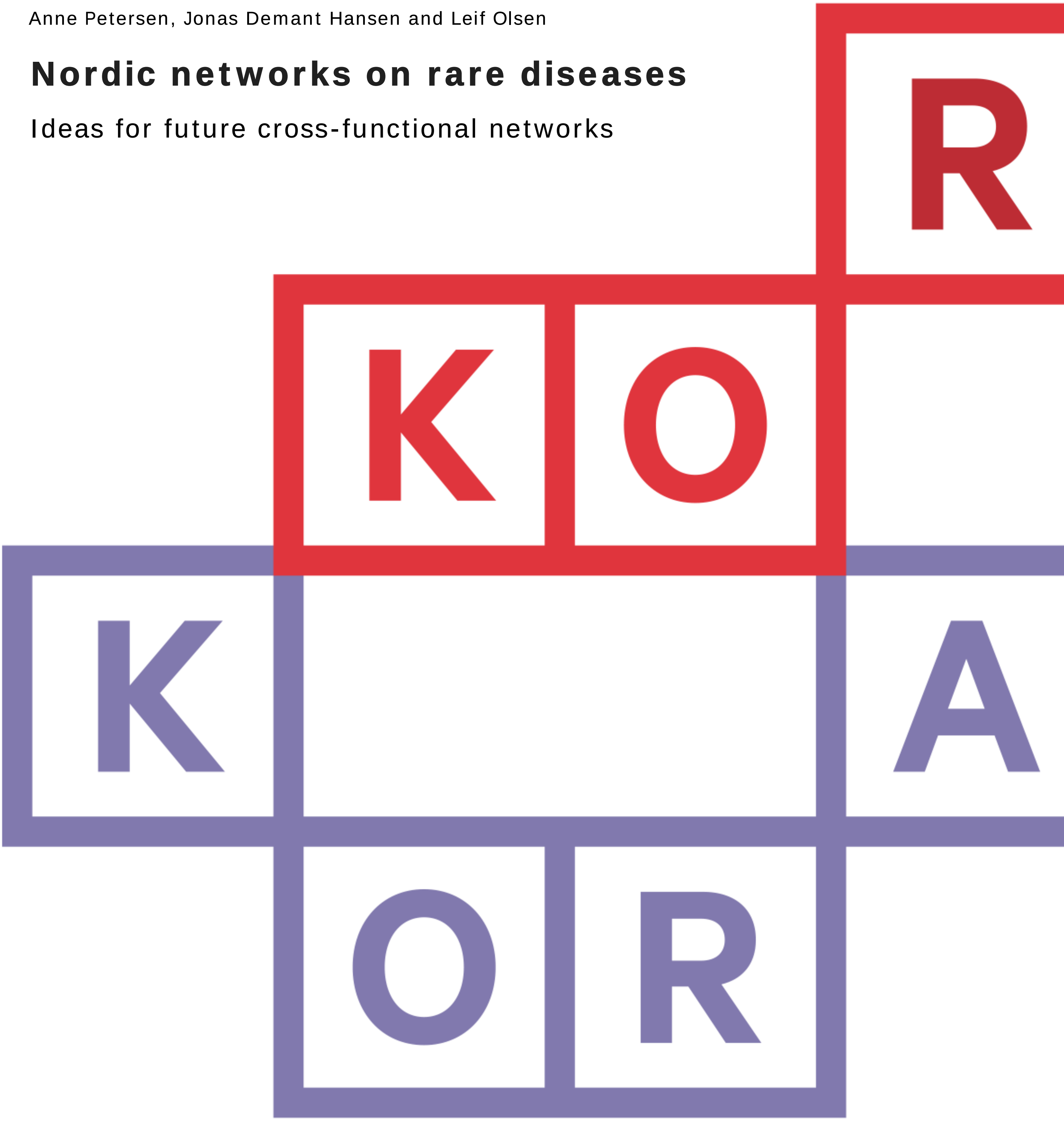
Nordic networks on rare diseases

Ideas for future cross-functional networks



Det Nationale Institut
for Kommuners og Regioners
Analyse og Forskning

Nordic networks on rare diseases – Ideas for future cross-functional networks

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Danish Institute
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Nordic Council of Ministers

Foreword

This memo is a collection of reflections on the need for Nordic collaboration and networking in the field of rare diseases. The thoughts were generated at a seminar for stakeholders involved with rare diseases, either as their job or as a part of their everyday life.

The memo as such is a bank of thoughts and ideas, and the purpose of the memo is to disseminate these ideas. A working group under the Nordic Council of Ministers was given the task of recommending what new efforts should be made in order to create and support cross-functional Nordic networks on rare diseases, and KORA was pleased to be hired to collect input from the stakeholders invited to the biannual Rarelink seminar on this topic.

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1 The product of the evaluation

The purpose of this assignment is to provide the working group under the Nordic Council of Ministers with an insight on the wishes and desires that the stakeholders' attending the 2015 Rarelink Seminar in Ågrenska have regarding a Nordic cross-functional network. In order to obtain this insight, KORA has conducted/facilitated:

1. A survey among the invitees to the seminar in Ågrenska to gain an insight into their perceptions of what a Nordic network should be, and how they perceive the existing Rarelink network
2. An inquiry into whether the participants in the seminar in Ågrenska find the recommendations from the Aalto report (2010) to be still relevant (Aalto 2010)
3. That the participants write up Nordic cross-functional networks that they find relevant to develop in the field of rare diseases
4. That the attendees analyse where there is a need for a Nordic cross-functional network, considering that there are international actors networking on rare diseases outside the Nordic countries.
5. A tracing of existing Nordic networks in the field of rare diseases.

This memo presents the findings of the five components above. The memo thus serves as a catalogue of thoughts and ideas on Nordic networks in the field of rare diseases.

2 Methods

In this chapter, we describe how insight was gained into the five components listed in Chapter 1. The same source informed all five components; the 65 invitees to/participants in the seminar in Ågrenska September 10-11th 2015, arranged by the Rarelink Steering Group. While tracing Nordic networks on rare diseases, we also searched the internet and received a working list of Nordic networks developed by The National Board of Social Services in Denmark.

We applied three different methodological approaches, in order to gain insight into the informants' thoughts on the five components listed in Chapter 1;

1. A questionnaire survey (component 1, Chapter 1)
2. Workshops (components 2-4, Chapter 1)
3. Desk research (component 5, Chapter 1).

By doing this, we approached the same stakeholders using different methodologies, in order to get as rich and broad a perspective on the current networks as possible, in addition to ideas for future networks. We had an overarching theoretical framework that structured what input we requested from the stakeholders.

In the following sections, we first provide an overview of our theoretical framework, and then describe how data was collected by conducting the survey and workshops, and by tracing existing Nordic networks on rare diseases using survey information and desk research.

2.1 Theoretical and methodological framework

Inspired by Pescosolido (2006), we based both our data collection and our analyses on four theoretical concepts developed to describe networks. These concepts are:

1. The **set of people** engaging in a network, e.g. the educational background they have, certain life experiences etc.
2. The **infra-structure** of the network, e.g. the size, density, types of relationships.
3. The **content**, i.e. what "moves across the network", for example scientific articles, lived experiences, therapeutic or diagnostic technology.
4. The **function** of the network, e.g. emotional support or knowledge sharing.

These four components are the primary building blocks of a network. Using these building blocks as a way of viewing networks, we are able to draw up a coherent picture of what is perceived as important to focus on when further developing networks.

In Chapter 1, we listed the five components into which we have gained insight. In the next three sections, we outline how these insights were gained.

2.2 The questionnaire survey – how we did it and how we analysed the data

The 65 stakeholders who were invited by the Rarelink Steering Group to participate in the seminar in Ågrenska September 10-11th 2015 were invited to answer a short questionnaire. Two weeks prior to the seminar, they received a link to the survey by email. One week later, they received an email reminding them to answer the questionnaire. Of the 65 stakeholders 44 answered, giving a response rate of 68 per cent.

The questionnaire contained 23 questions divided into four sections, inquiring about the stakeholders' background and experiences with networks on rare diseases:

- Background information on the respondent (job, organization, sector)
- Experience with existing networks and thoughts on future Nordic networks in general
- Experiences with the Rarelink Webpage
- Experiences with Rarelink conferences and seminars

The survey was constructed so as to operationalize the four analytical concepts structuring the analysis (see 2.1). Thus, the answers given in the survey provide information about the function, content, set of people and infrastructure of the current Nordic networks.

By sending out the survey prior to the seminar, preliminary information could be obtained about the stakeholders' views on strengths and challenges for Nordic networks in the field of rare disease. This information was used to guide the further enquiry in the workshops.

2.3 The three workshops – how they were conducted

In order to conduct/facilitate

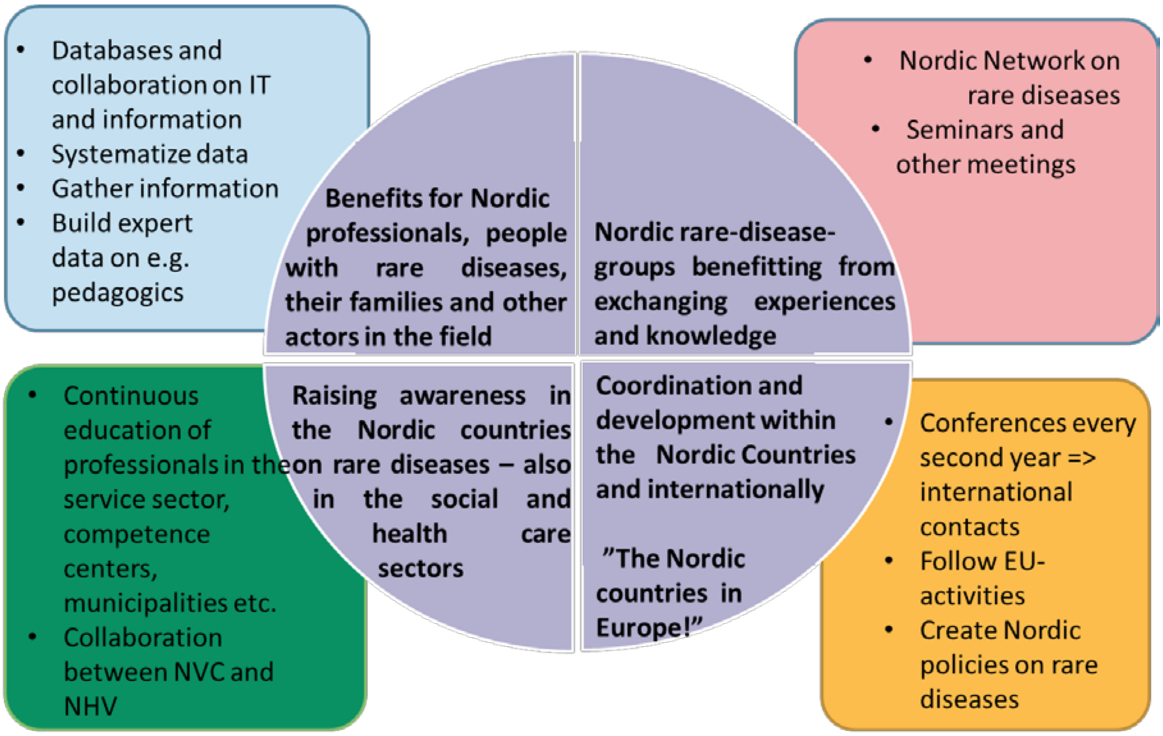
1. an inquiry into whether the participants in the seminar in Ågrenska find the recommendations from the Aalto report to be still relevant (Aalto 2010)
2. that the participants write down and discuss which Nordic cross-functional networks on rare diseases they think should be developed
3. that the participants analyse where there is a need for a Nordic cross-functional network, considering that there are international actors networking on rare diseases outside the Nordic countries,

we conducted three workshops during the seminar at Ågrenska. The first two workshops (referred to as no. 1 and no. 2) were conducted in smaller groups; four groups with nine or ten participants in each. KORA facilitated three of these groups, and one was facilitated by Vibeke Lubanski from The National Board of Social Services, Denmark. The third workshop was held in plenum and facilitated by KORA. The facilitation of the workshops was thoroughly described in a manual which was handed out to the facilitators prior to the workshops, in order to ensure that the workshops would provide the required insight regardless of who facilitated the workshop. All workshops were recorded by consent from the attendees.

In the following, we describe how the facilitation of the three workshops was performed and how the material was analysed subsequently.

Ad 1. We presented the attendees with the recommendations from the Aalto report (2010), asking the overarching question: Are these still the relevant aspects to focus on when building Nordic networks? While working our way through the figure (see Figure 2.1), we inquired as to how the attendees perceived the relevance of the different aspects. Afterwards we analysed the data, categorizing it according to whether it was perceived as relevant or not, what reasons were provided for something being relevant or not, and according to what the attendees focused on as relevant for the future.

Figure 2.1 The figure from the Aalto report (Aalto, 2010)



Ad 2. Prior to this workshop, the participants were given a short presentation of the four building blocks of a network (see 2.1).

After introducing the attendees to the components, they were handed a paper-table with the four building blocks and asked to design Nordic cross-functional networks on rare diseases. They were given five minutes to work on their own ideas, and afterwards ten minutes in pairs to comment on and co-create on each other's ideas. Following this, an hour was spent on presenting and developing ideas for future cross-functional Nordic networks on rare diseases in the groups.

We used the four building blocks (cf. Pescosolido, 2006) in the analysis of the participants' ideas for networks, and also use them in the presentation of the networks in this memo. We do this by passing the attendees' ideas on as they are (see Appendix table 2.1), and we have performed a content analysis merging similar network proposals into broader ideas for Nordic cross-functional networks (see 3.3).

Ad. 3. We asked the participants to let the following three questions reflect critically upon their thoughts on future cross-functional Nordic networks:

1. Is there a role for a Nordic Network in relation to your National networks?

2. Is there a gap in the existing Nordic networks for a cross-functional network to fill?
3. How should international, Nordic and national networks work together?

After a short introduction of these three questions, we facilitated a discussion between the participants. Some participants introduced ideas from the workshops that led to discussions of how the ideas should or should not be realized, considering that there are already many networks around the world. Again, we used the four building blocks introduced earlier in the facilitation of the discussion, for example by inquiring as to what the function of a Nordic network should be, who should be part of it etc. We also used the building blocks when analysing and presenting the analysis in this memo.

2.3.1 The tracing of Nordic networks on rare diseases

We applied four main criteria when tracing existing Nordic networks on rare diseases.

The first criterion is that the network should be explicitly oriented towards Nordic cooperation. For example, many patient networks and NGOs exist within each of the Nordic countries, and many of these might interact with stakeholders throughout the Nordic countries. But since most of these networks are primarily oriented towards a national agenda, they will not qualify for the list compiled here.

The second criterion is that the network should be formalised in such a way, that the organising core, e.g. steering group, working group, office etc., of the network is made up of representatives from two or more Nordic countries. This excludes, for example, a university department organising a seminar involving participants from several countries, unless more than one country is represented among the organisers.

The third criterion is that the network as well as the organising force should be relatively stable. This means that more project-based and temporary interaction has not made the list. For example, organising a once only event, e.g. a seminar, will not pass as a Nordic network, since the stakeholders only meet briefly.

The fourth criterion is that the main focus of the network must be rare diseases. This means, for example, that networks with a main focus on impairments that in rare cases are the result of a rare disease, so that the network does not routinely deal with aspects related to rare diseases, are not included in this list.

Put together, the four criteria give relatively stable and formalized networks, focussing on rare diseases and with the explicit purpose of functioning across the Nordic countries.

The list of Nordic networks was compiled by:

- a list obtained from the social service department in Denmark
- asking stakeholders answering our questionnaire, to list the networks that they are part of
- searching through various websites, databases and the Internet in general in order to identify networks of various forms and sizes
- way of the “snow ball method”, meaning that we have followed references to other networks when we came across these.

In searching on the Internet, we applied the following words and search terms:

- Nordic network
- Rare diseases
- Rare diagnosis
- Nordic cooperation
- Nordic conferences on rare disease
- Nordic seminars on rare disease
- Scandinavian networks on rare disease
- Nordic patient organizations.

3 Findings

In this chapter, we present the findings on each of the five components of the assignment in the order in which they were presented in Chapter 1. Thus, we first provide an overview of the survey respondents and their views on networks on rare diseases. Following this, we present the seminar attendees' thoughts on the recommendations from the Aalto report, as well as more general comments from the workshops. Section 3.3 presents our merging of ideas for Nordic cross-functional networks that the seminar attendees thought up, while section 3.4 presents the outcome of the plenum discussion of where there is a need for a Nordic cross-functional network, taking into consideration what other already established national and international networks exist. Finally, in section 3.5 we present the list of Nordic networks that met our inclusion criteria.

3.1 The survey

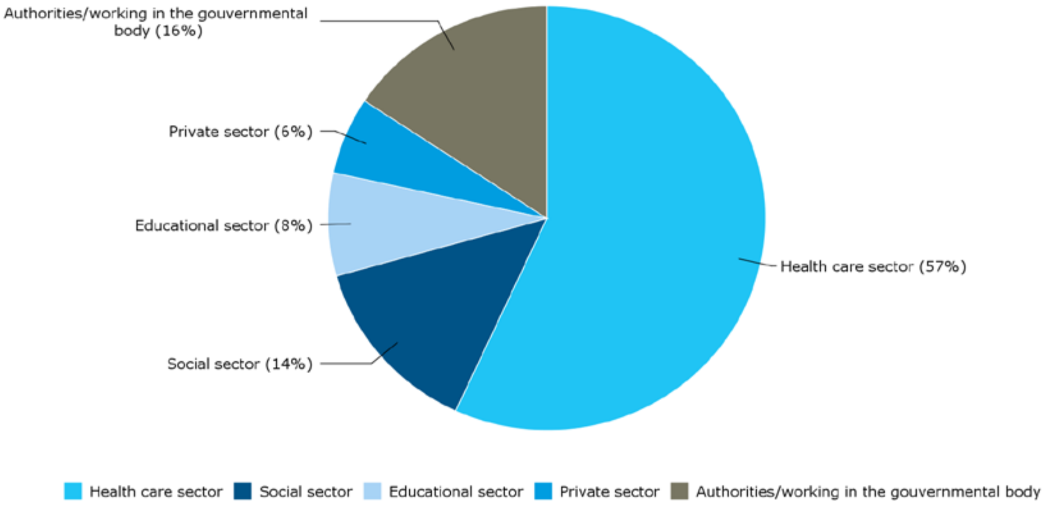
3.1.1 Who answered the survey?

Analysis showed that there is a high degree of consensus among the respondents, regardless of their sector affiliation and professional background. Therefore, the charts and figures presented in the following reflect the group of stakeholders as a whole.

Background information shows that a wide range of stakeholders are represented in the questionnaire – from practitioners and NGO's to researchers and administrators, which provides a relatively broad perspective on the field of rare diseases in the Nordic countries.

As seen in Figure 3.1, the health care sector is strongly represented in the survey, constituting 57 per cent of the respondents. The social sector constitutes 14 per cent, the educational sector constitutes 8 per cent, the private sector constitutes 6 per cent and, finally, people functioning as authorities in the governmental body made up 16 per cent of the respondents.

Figure 3.1 The responding stakeholders categorised according to the sector in which they work



3.1.2 Function – what do the stakeholders see as the primary purpose of a Nordic network dealing with rare diseases?

We asked the respondents what the primary function of a Nordic network should be, and asked them to rate four purposes of a Nordic network. They rated them as follows:

1. Facilitating knowledge sharing among professionals (Appendix 1, Figure 12),
2. Raising awareness of rare diseases among policymakers and the general public (Appendix, Figure 14)
3. Enabling the best day-to-day treatment, for example in practitioners' diagnosis of patients and seeking out of treatment (Appendix, Figure 15).
4. Facilitating emotional support among people with rare diseases (Appendix, Figure 13)

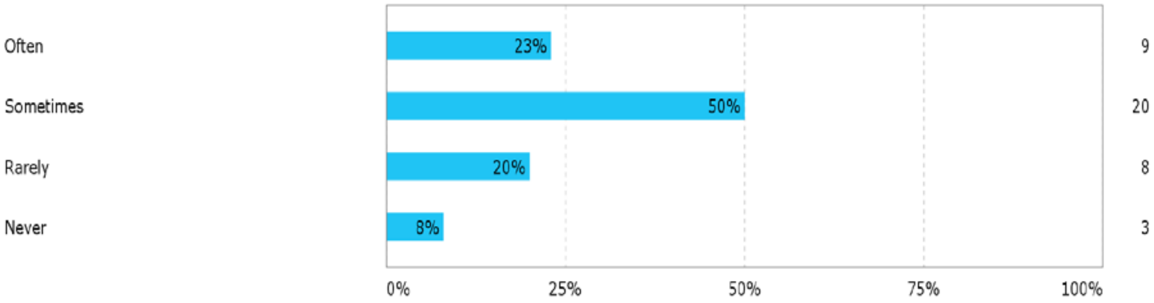
That the majority of the respondents are neither patients nor relatives should be considered an explanation for why there is less support for the purpose of mutual support among people with rare disease.

Comparing the four functions above, it should also be kept in mind that they do not mutually exclude each other – a single network can serve multiple purposes. Nevertheless, as can be seen in Appendix 1, Figure 15, respondents are less supportive of networks that require a higher degree of day-to-day activity. This might indicate that respondents prefer a network in which knowledge sharing and awareness raising are top priorities, but not necessarily pursued on a daily basis.

Infrastructure – the level of activity in the Nordic network

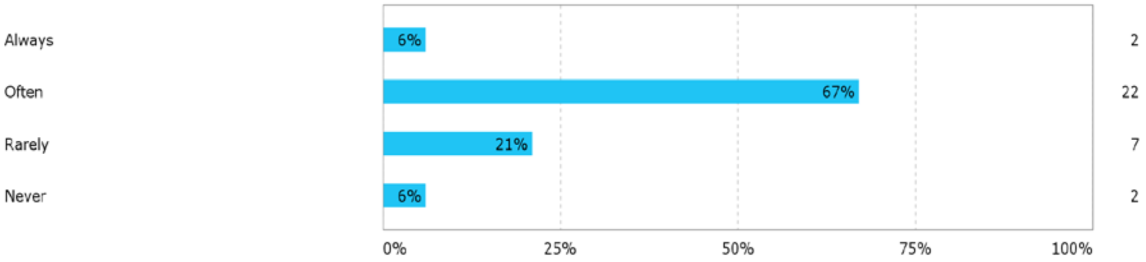
We asked the stakeholders how often they share relevant knowledge. As shown in Figure 3.1, more than a fourth of the respondents rarely or never share relevant knowledge with other stakeholders. This stands in contrast to the respondents' prioritization of knowledge sharing in a Nordic network and may imply that the infrastructure for sharing knowledge is insufficient.

Table 3.1 **The frequency of knowledge sharing among the stakeholders**



This indication of an underdeveloped infrastructure is supported by another response. We asked the stakeholders whether their needs are met by the current Nordic networks dealing with rare diseases. As shown in the figure below one fourth of the respondents answered that their needs are rarely or never met by the current networks.

Table 3.2 Illustration of whether the needs of the respondents are met by the current Nordic networks on rare diseases



3.1.3 How knowledge is shared?

The infrastructure enabling knowledge sharing in a network can consist of various forms of communication. For example, face-to-face meetings between professionals at seminars and conferences or one-way communication, e.g. use of databases containing articles or descriptions of diagnoses. We asked stakeholders where and how they search for knowledge on rare diseases, and their responses to this question can be summarised as follows:

1. Online databases/webpages (Appendix, Figure 7)
2. Direct contact with professionals (Appendix, Figure 8)
3. Direct contact with non-governmental organizations (Appendix, Figure 10)
4. Direct contact with people diagnosed with the disease in question (Appendix, Figure 9)

The most common means of obtaining knowledge is through databases/webpages. The second and third most common ways of obtaining knowledge are by contacting professionals or NGOs working in the field of rare diseases directly. Finally, according to the survey the fourth most used way of obtaining knowledge is by contacting persons diagnosed with a rare disease directly. This indicates that, among the respondents, knowledge from professionals and organised bodies in the field is preferred to knowledge from patients and their relatives.

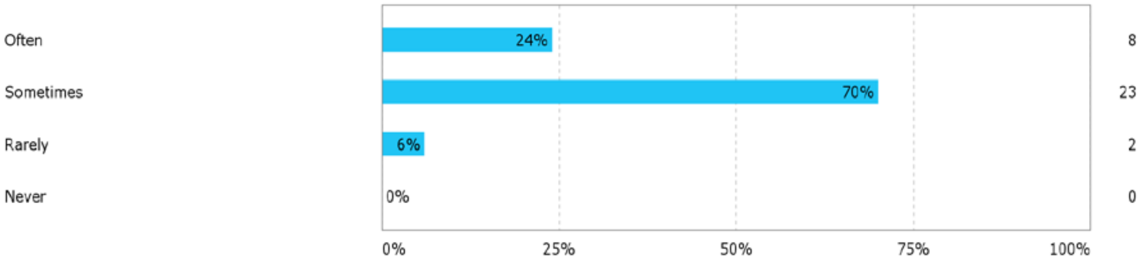
3.1.4 The stakeholders' experience with the Rarelink network

We asked the stakeholders about their experience of participating in the Rarelink network. Rarelink consist of two components: 1) conferences and seminars where stakeholders meet and exchange knowledge, and 2) a web-based database containing descriptions of diagnoses and contact information for relevant institutions working with rare diseases. We asked the stakeholders if they knew about these activities, and to which extent they have benefited from participating in them.

The survey results show that 84 per cent of the respondents know about the Rarelink website (Appendix 1, Figure 18), and that many of them visit the site quite frequently (Appendix 1, Figure 19). However, this was expected as the respondents were those invited to the Rarelink seminar.

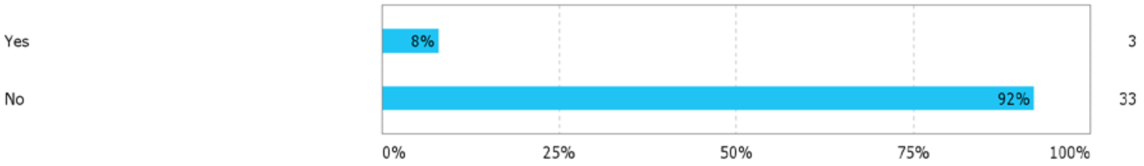
When asked about whether the stakeholders usually find the information they are looking for when visiting the website, 24 per cent answered often, 70 per cent sometimes, and finally 6 per cent answered rarely (Figure 3.3).

Table 3.3 The distribution of answers to the question of whether the stakeholders usually find the information they are seeking when visiting the Rarelink website



We also asked if the Rarelink webpage had helped the respondents make contact to other people in the field of rare diseases. Eight per cent answered yes, while 92 per cent answered no. This indicates that even though, as mentioned above, the preferred way of sharing knowledge among the stakeholders is via databases, databases alone are not a sufficient way to build networks and create new relations among stakeholders.

Table 3.4 The distribution of answers to the question of whether the website has helped the stakeholders make contact with other stakeholders in the field of rare diseases



While most of the respondents are familiar with the Rarelink webpage, only a little over half of the respondents have participated in the conferences, while one fourth of them have attended the seminars (Appendix 1, Figures 22 & 24). Those who have attended seminars have found them to be either beneficial or very beneficial.

3.2 The Aalto recommendations – still relevant?

3.2.1 General comments on the figure

The Aalto figure is too general to be a relevant guide

Across the workshops, the attendees found the recommendations from the Aalto report (2010) to be still relevant, but not exhaustive, as the figure is perceived to be too general. The figure does not provide any true or relevant guidance for activities, it was stated. Therefore, attendees said, it is difficult to disagree with the contents of the figure, but also difficult to be satisfied and see it as a guide for further development.

In some comments, changes in the figure's relevance was ascribed to evolvement in the rare disease field. For example, the fact that the Nordic School of Public Health (NHV) has been closed makes the collaboration between the two actors irrelevant (right lower box, figure 2.1). For other areas in which the participants stated that there had been some progression, further development was still found to be necessary, and thus no aspects were ticked off as irrelevant.

What makes it sensible to have a Nordic network?

The attendees agreed on there being an overarching need for a Nordic collaboration in the field of rare diseases, as also pointed out in the Aalto report (2010). Among the reasons they highlighted were that the geography, population density, cultures, healthcare systems, social systems, labour market and databases on health and social services have distinct similarities, making it possible to develop/sustain a meaningful Nordic collaboration on rare diseases – even when considering all the important work being done in the field of rare diseases outside of the Nordic countries. The similarities of the Nordic countries make it possible and beneficial to:

- Co-create holistic guidelines for best practice
- Compare (benchmark) services
- Pool expensive drugs and perform competitive bidding
- Assist each other in concrete matters in relation to diagnostics, treatment or other aspects of the patients' life with rare diseases.

Another important aspect is that size matters – both in favour of smaller and larger, said the attendees. In order for a network to be operational and productive it has to be 'fairly small' (depending of the function of the network). Considering that there are major similarities among the Nordic countries, it is considered a logical line of demarcation to keep it Nordic instead of, for instance, European, when it comes to cross-functional networks or an actual collaboration on therapeutic aspects.

Concerning databases, a Nordic network is preferred to what each country can muster on their own. The Nordic countries all have good national registers, and by joining forces they would reach a total population of approximately 26 million, making it possible to gain good data for “internal scientific use” as well as to, it was proposed, use the data as currency in negotiation with the pharmaceutical industry on the prices of drugs for rare diseases.

Two different ways of perceiving the main function of networks on rare diseases came out of the workshops. It was suggested that the focus should be on what the network can do for society instead of what a network can do for you. This makes the patient the centre of attention. Being part of such a network on rare diseases may not be contributing specifically to each stakeholder’s career, but creates better lives for patients and their relatives as well as generating support in society, it was argued. This proposed way of looking at networking was contradicted by the notion that there should only be a network if you need one, that is when you yourself can benefit from it. If not, participants will not be motivated to participate, or it will not be possible for participants to participate actively, as their organizations/employers will be less likely to support this. In other words, networks and collaboration could be amputated if it is not legitimate to focus on ‘what is in it for me’.

After having presented the general comments from the workshops in the above, we will now present the attendees comments on the figure box by box.

3.2.2 The Aalto recommendations box by box

In the four figures below, we have summed up the comments and ideas from the four workshops on the Aalto report relating to the different boxes.

As seen in Figure 3.2 there is strong support for sharing databases. Databases are perceived as a source of knowledge among the attendees. Therefore, easy access to relevant databases is a prerequisite, if databases are to be beneficial to professionals and people with rare diseases in the Nordic countries. Language barriers were mentioned several times during the course of the day. For databases to be operational across Nordic countries, it is necessary that all databases be in local languages as well as in English.

Some attendees saw a potential for combining knowledge-building and bettering available databases, and suggested that a Nordic network of relevant professionals should be created with the task of creating new/developing existing databases.

Finally, a common idea was that there should be a shared Nordic benchmarking system where institutions, initiatives, practice, guidelines – everything comparable going on – should be benchmarked against each other making it visible what the good institutions, initiatives etc. are. This will increase the possibility that the best will spread.

Figure 3.2 Comments from the four workshops on the upper left-hand side box in the Aalto report, *"Benefits for Nordic professionals…"*

Databases are knowledge – a tool to support development in the field. Access to data from other countries should be established/improved.

It has to be considered what knowledge is relevant to share for whom – and whether it is legal to share it?

Finland is listing experts on different diseases – creating a tool – that tool could be Nordic instead!

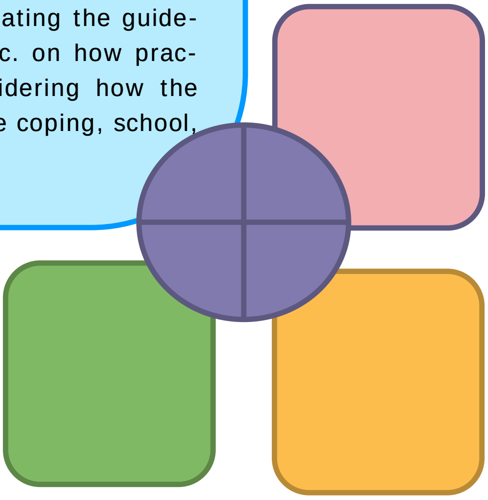
Databases should be in English as well as Nordic languages.

Nordic platforms/databases must share general information besides information on diagnosis.

Developing databases is in itself a way of creating knowledge – Nordic networks of clinicians, experts etc. should be joined in/through this task.

Analyzing data and benchmarking Nordic institutions/initiatives makes it possible to see where we err and do well – a way to bring silent knowledge out in the open for the benefit of everybody!

Create Nordic holistic (disease-specific) guidelines for best practice and for social services – and feed the networks creating the guidelines with follow-up information from databases etc. on how practice is changing. Holistic guidelines includes considering how the patient gets to the treatment, how their families are coping, school, work, social life… etc.



As can be seen in Figure 3.3 conferences are perceived as a creator of both energy and initiative, and as a passive agent that merely passes on information, not true action. In other words, conferences comprise a potential for change, if they are organised so that the energy generated is actually coupled with initiation of concrete initiatives for change. A way of coupling conferences with action, it was suggested, is for professionals attending the conference to join professionals from the country hosting the conference, in their respective organisations to discuss concrete cases and thereby share knowledge.

The cross-functional perspective is missing in conferences, it was noted, both in the sense that it is lacking and is missed. Another thing missing is insight into what solutions patients and their relatives invent – in everyday life for example – in order to live their life with their rare disease. This is an important source of knowledge for further development in the field.

There are many networks available today, and this, it was commented, weakens the ties between the set of people in a network. Depending on the function of the network, it is therefore necessary to consider carefully what infrastructure is needed to actually build or sustain the relationship between the set of people, as well as to nurse their relationship. A suggestion was that there should be only one primary and overarching facilitator of networks on rare diseases in the Nordic countries, providing the overview of the field and connecting those interested in a single network.

Finally, it was suggested that the way we think of networks should be turned upside down. Instead of thinking 'what is in it for me', the stakeholders should think about and build networks based on 'what is in it for society'. This way of perceiving networks will create goodwill in society, and, most importantly, it places the patient and their relatives at the centre. The networks would consider what assistance the patient and relatives need to *live their lives.* This approach will automatically bring together all involved parties in patient care pathways, and this will lead to insight and innovation, it was expected.

In Figure 3.4 the attendees perceived the Nordic countries as a meaningful entity for networking. However, Nordic networks should not be established where European or international networks already fulfil the function sufficiently. Nordic networks make sense where the similarities between the countries benefit the collaboration, e.g. by making it easier to transfer solutions from one country to another. A Nordic network makes sense where limiting the network to the Nordic countries makes the infrastructure of the network easier, or makes it easier to develop inspiring content to share. Representing more than just a single country should be an advantage in the struggle over issues where 'greater numbers', e.g. in terms of population, is simply an advantage. The suggestion that the Nordic countries should collaborate on buying expensive drugs for rare diseases can serve as an illustration of a situation where greater numbers count. Such collaboration would make it possible to bargain a better price, for example by using the unique currency that the Nordic countries share: some of the best registry data in the world.

However, when it comes to sharing data and knowledge among countries outside the Nordic countries, the moral standpoint that the Nordic countries are so resourceful that we are obligated to share our knowhow with other less privileged countries, was expressed.

There was an expectation among attendees that stakeholders affiliated with Rarelink already work for Nordic policy development. Concerning policy, however, some attendees stressed that Nordic policies must respect the EU rules and adhere to what is legitimate in EU. Finally, social media as Facebook or twitter may promote the creation of shared Nordic strategies on rare diseases, as postings on social media are easily accessible and can be highly inspirational.

Figure 3.3 Comments from the four workshops on the upper right-hand side box in the Aalto report, *“Nordic rare-disease-groups...”*

Conferences and seminars merely pass on information – they do not create change. Seminars and conferences are not enough!

Conferences and seminars create motivation for further involvement.

Meeting other attendees at conferences creates informal networks that you can draw upon afterwards.

The cross-functional perspective is missing in many of the existing gatherings.

Gatherings of experts at a conference should be coupled to experts going out into the field to work with patients in the country hosting the conference.

Exchange programmes in the Nordic countries are a good idea.

There is a gap to fill for a network on neglected rare diseases – those without networks! Focus on them.

There should only be one primary network facilitator, as more ‘players’ will only create confusion and reduce sharing.

Networking needs to be focused on ‘what is in it for society’ instead of ‘what is in it for me’; so that society can help people with rare diseases live their lives. It is a completely new way of thinking about networks.

Networks should have a holistic focus. By bringing different people together, they see what they did not know; they learn and innovate.

Maybe Facebook groups could be a good forum for patients to share experiences.

What do patients innovate in order to deal with their disease? – We should find out, share and develop.

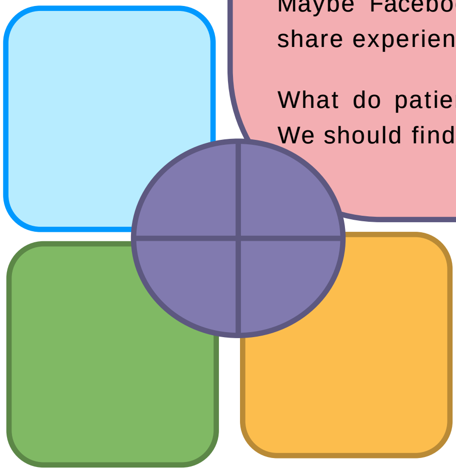
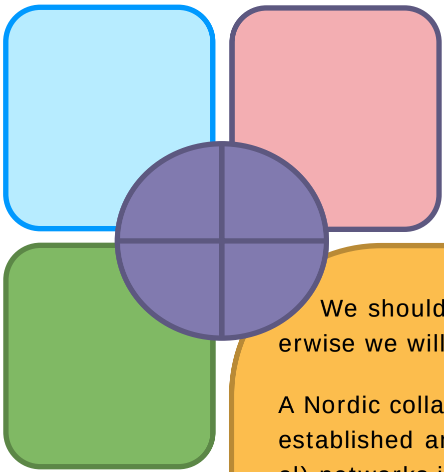


Figure 3.4 Comments from the four workshops on the lower right-hand side box in the Aalto report, *"Coordination and development..."*



We should have a specific focus in the Nordic countries – otherwise we will be swallowed up by the EU.

A Nordic collaboration should not be a parallel to anything already established and operating. An overview of European (international) networks is needed, in order to find the gaps.

Language barriers may or may not influence whether patients want services in other Nordic countries. Ask the patients!

Nordic countries should pool their expensive drugs for rare diseases, perhaps even with other non-Nordic countries. Join each other in competitive bidding. Bargain with the drug industry. Besides money, we should use good registry data on rare diseases as a currency.

This is about ethics. We have so many resources in the Nordic countries – we should develop, share/export our knowhow to less developed countries.

Too few people know about Rarelink! Do something about this!

The working group is already developing Nordic policies – are they not?

It is important to consider EU policies, when developing Nordic ones. We need to base our political work on regions, because this is a legitimate entity in the EU.

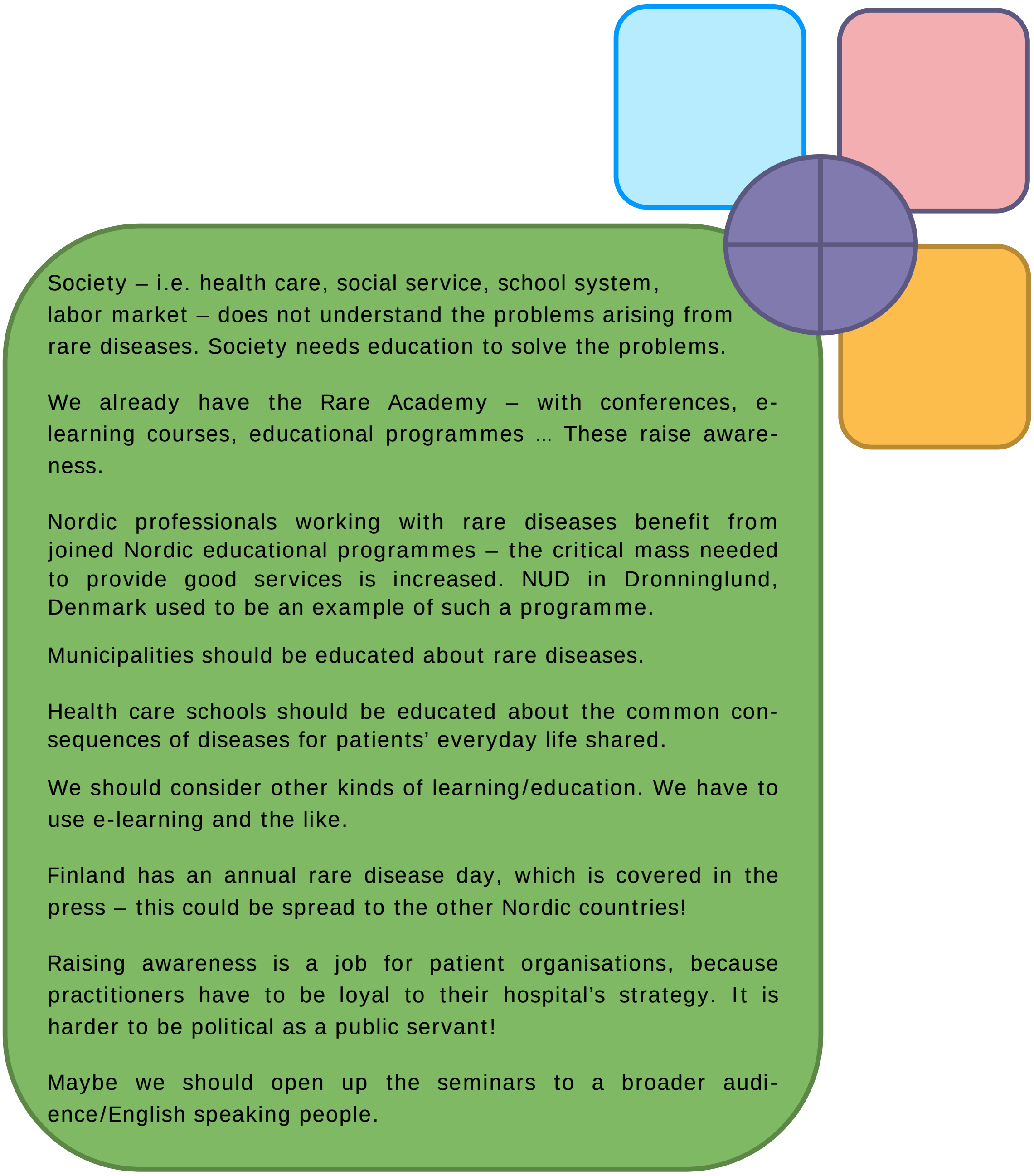
We should share experiences with strategies – this could be done as simply as through a Facebook page posting initiatives that other stakeholders pick up and implement in their own organisation/country. Nordic countries should share hashtags on rare disease postings.

As shown in Figure 3.5, there is a felt need for continuous education of society. Without education, patients with rare diseases will – continuously – face problems. Initiatives to educate are already taking place. In Norway, there is the 'Rare Academy' with a palette of educational initiatives, and Finish representatives told of how they have a national 'rare diseases day' that raises awareness. All these are initiatives that they would be happy to share with/export to other Nordic countries. However, there was a felt need that there should be education targeted to municipalities to both raise awareness and improve case management.

Rare diseases should be part of established health and social care educations in the Nordic countries, and besides this there should be inter-Nordic educational programmes, as there is and has been earlier. By having shared educational programmes, you increase the critical mass needed to provide good services. Educational programmes may need to take on new technologies – e-learning, for instance – and provide courses in English, rather than just Nordic languages.

Who should be responsible for raising awareness in society is debatable. The stakeholders with the greatest freedom to promote the agenda, it was put forward, are patient organisations. For professionals in the public sector, raising awareness is a political matter and public servants cannot take on such a task. They can assist in educating – sharing their knowledge – but they are not the optimum stakeholders to promote the agenda, it was argued.

Figure 3.5 Comments from the four workshops on the lower left-hand side box in the Aalto report, *“Raising awareness...”*



Society – i.e. health care, social service, school system, labor market – does not understand the problems arising from rare diseases. Society needs education to solve the problems.

We already have the Rare Academy – with conferences, e-learning courses, educational programmes ... These raise awareness.

Nordic professionals working with rare diseases benefit from joined Nordic educational programmes – the critical mass needed to provide good services is increased. NUD in Dronninglund, Denmark used to be an example of such a programme.

Municipalities should be educated about rare diseases.

Health care schools should be educated about the common consequences of diseases for patients’ everyday life shared.

We should consider other kinds of learning/education. We have to use e-learning and the like.

Finland has an annual rare disease day, which is covered in the press – this could be spread to the other Nordic countries!

Raising awareness is a job for patient organisations, because practitioners have to be loyal to their hospital’s strategy. It is harder to be political as a public servant!

Maybe we should open up the seminars to a broader audience/English speaking people.

3.3 Ideas for future cross-functional Nordic networks

The four workshops generated descriptions of 51 networks, of which some had distinct similarities, while others did not. In Appendix 2, table 2.1 a list of all the networks can be found, written as the participants did.

In and across the workshops, general comments on functions and infra-structure were made.

Infra-structure: As also indicated in the survey, a general comment on the infra-structure of a future network is that a network cannot function without people actually meeting in person, i.e. at the same physical location. In other words, video conferences cannot substitute real life meetings. However, once people having actually met and become familiar with each other, then other ways of communication will work as well, e.g. video conferences, email etc.

Function: A common phrase in the field of rare diseases is "The patient is the expert". But this should be understood as the patient being an expert on *his/her own situation*, i.e. the patient should not be seen as an expert on the disease itself, it was pointed out by some attendees. Expertise on the disease itself can only be obtained by professionals, via research and the like. When considering the function 'knowledge sharing', it is therefore important to be specific about what type of knowledge should be shared. Is it everyday experience? Or is it rather scientific knowledge, e.g. knowledge concerning medicine or technology? This again determines the set of people who will engage with and benefit from the network.

In the following sections, we present a merging of similar ideas for networks. The basis for merging ideas was that the function of the proposed network was similar.

3.3.1 Guidelines

Out of the 51 network ideas, 19 (see Appendix table 2.1: 4,8-10,13-15,17-19,21-24,28,33-35,40) networks either had creation of guidelines specifically as their function, or something representing the same, i.e. to develop, organise and harmonise methods or share best practices. Some attendees stressed that therapeutic guidelines already exist for some rare diseases, and that where satisfactory guidelines exist, e.g. European guidelines, these should be used instead of developing new Nordic ones. However, according to the attendees not all rare diseases have therapeutic guidelines, which is why therapeutic guidelines are also included in Table 3.5 below.

Besides developing guidelines, another function of a Nordic network related to developing guidelines is to harmonise practices/guidelines between the Nordic countries. The attendees were aware that it probably is not possible to determine at a Nordic level how the individual countries should organise their efforts on rare diseases, and suggested instead that the countries/organisations could be part of an inspirational network where benchmarking makes it clear what practices are most sensible to implement.

Table 3.5 Proposed network for creating guidelines for best practice

Network name	Function	Set of people	Infrastructure	Content
'From Diagnose to Life' Best practice guideline building network	Development of guidelines for • Best holistic practice • Models to create patient pathways • Disease group facilitation • Drug use • Use of social services • Use of rehabilitation • Diagnosing • Follow-up on programmes • Cross-sectorial collaboration.	The set of people should be selected according to diagnosis-specific groups, as different groups will have different needs in relation to guidelines. However, the set of people should be interdisciplinary and include: • Doctors • Nurses • Lab experts • Pedagogues • Social workers • Patients • Relatives of patients • Patient organisations • Nordic researchers, as the input has to be applicable to the the Nordic welfare systems provide • Centres of expertise • Decision makers, ministerial officials, directors. To create the basis for implementation of best practices. Not to develop the guidelines • A full-time secretariat running the networks.	Conferences focusing on how the guidelines operate => feedback for further development of the guidelines. Conferences with interchanging mono-professional and interdisciplinary sessions. Seminars. Meetings. Virtual meetings. Email. Workshops. A shared website.	Follow-up data providing information on how the guidelines are used, affect practice, their costs and the patient satisfaction with the practices. Thoughts on ethical issues concerning consequences of prioritisation – and lack of prioritisation! Comparing of experiences. Guideline ideas. Guideline drafts. Data on how the guidelines affect the area. Best practice descriptions. Big data: use of health services, total costs, patient satisfaction etc.

3.3.2 Collaboration solving problems in concrete cases

The function of six of the networks (see Appendix table 2.1:6,20,27,29,36,45) is to assist in concrete matters in concrete cases. These networks all imply an infra-structure where the set of people have easy access to each other – for example through *ad hoc* video conferences.

Two different networks take shape under this function. One has a medical, therapeutic focus, solving problems in relation to diagnosing or treating the patient. The other network has the patients' everyday life as its focus. These networks leads to different kinds of content that has to be shared, and they structure the participation of the set of people differently, as can be seen in Table 3.6 and Table 3.7.

Table 3.6 Proposed network for solving problems in relation to diagnosing or treating concrete patients

Network name	Function	Set of people	Infrastructure	Content
Nordpool – diagnostics	Diagnostic network.	Laboratories. Expert centres. Professionals and users together. Professions on their own.	Video-conferences Sample sharing. Difficult cases “Dr. House”. Gatherings for everyone. Gatherings for diagnosis-specific groups. Gatherings for specific profession.	Samples. Diagnoses.

Table 3.7 Proposed network for solving problems in relation to concrete problems concerning everyday life

Network name	Function	Set of people	Infrastructure	Content
Patient Pathways - The New Rare-link to Develop Holistic Models for Rare Diseases	Assist patients in overcoming barriers between services => empowering patients and professionals to overcome the barriers in patients’ life.	Professionals. Patients. Relatives. Patients with the same rare disease should be identified across borders, and interdisciplinary professionals working with these patients should be brought together to discuss how to assist the patient in the best way.	Meetings. Workshops. Video conferences. Seminars.	Educational programmes (professionals and patients attending the same programmes). Brainstorming – not conclusions. Thinking big and ambitiously on how to solve problems.

3.3.3 Collaboration on drugs

Three proposed networks (see Appendix table 2.1:5,7,47) focus on ensuring a better availability of drugs for patients with rare diseases. Two of the networks suggest that the Nordic countries join forces, in order to pressure the price of orphan drugs, and to pool the Nordic countries’ drugs, thereby increasing their availability, see Table 3.8. The third suggested network is actually a network of pharmaceutical companies, set-up to allow them to co-create drugs for rare diseases.

Table 3.8 Proposed network for Nordic collaboration on drugs for rare diseases

Network name	Function	Set of people	Infrastructure	Content
Nordpool – drugs	Provide availability of rare drugs. Increase competitive bidding. Lead to a critical but compassionate use of orphan drugs. Improve risk management (pooling of acquisition) during drug shortages, diseases etc.	Government. Communities. Health officials. Hospital pharmacists. National health institutes. Patient organisation representatives.	A common warehouse for orphan drugs.	Competitive bidding. Risk management. Therapy guidelines. Resource allocation. Prioritizing. Data on drug availability. Drugs shared to stakeholders if needed.

3.3.4 Education

Six network ideas (see Appendix table 2.1: 24,27,29,31,41,50) focus on educating professionals who are in contact with patients with rare diseases. Initiatives to do this already exist, and so the construction of the network builds on the existing Rare Academy, as can be seen in Table 3.9.

Table 3.9 Proposed networks for providing education on rare diseases

Network name	Function	Set of people	Infrastructure	Content
Rare academy - education	Educate people in the rare field. Spread information.	Cross-sectional professionals and patients together. Rarelink people – as they are highly dedicated • Steering group • Diagnosis group • Conference group • Marketing group. New construction: A working group with representatives responsible for educational initiatives in each Nordic country.	Conferences. Video conferences. Meetings. Gatherings for diagnosis-specific groups. Gatherings for specific professions. It-platforms.	Links translated into English. Existing material on rare diseases.

3.3.5 Empowering patients and professionals

Four networks (see Appendix table 2.1:3,8,12,29) are to empower either patients, professionals or both groups, see Table 3.10. The network will invent new approaches that focus on enabling patients, their relatives and professionals to take action in order to improve the lives of/approach to patients with rare diseases.

Table 3.10 Proposed network to empower patients, professionals or both groups

Network name	Function	Set of people	Infrastructure	Content
Empowerment up!	Create approaches that empower and facilitate self-direction for professionals, patients and patients' families.	Patient specialists	Meetings.	Experiences.
		Patients.	Seminars.	Brainstorms.
		People working with structures.	Working group with a secretary.	Task force material.
	Provide information and peer-support.	Competence centres.	Workshops.	Educational programmes (professionals and patients attending the same programmes).
		Stakeholders 'across all silos'.	Video conferences.	
		Patients with the same rare disease should be identified across borders, and professionals (interdisciplinary) working with these patients should be brought together to discuss how to assist the patient in the best way.		Thinking big and ambitiously on how to solve problems.

3.3.6 Facilitate research

Four networks (see Appendix table 2.1:1,2,23,43) focus on facilitating research on rare diseases. The network is meant to facilitate exchange of knowledge as well as data and other types of research material, and as such is a network for professionals only, see Table 3.11.

Table 3.11 Proposed network to facilitate research

Network name	Function	Set of people	Infrastructure	Content
Rare Disease Knowledge Network	Sharing knowledge among researchers.	Professionals.	Simple platform, relatively loose but formalised so it is not dependent on specific peoples' efforts.	Knowledge about RD, interventions, data.
	Facilitate interoperability of IT, registries, bio-banks.	Researchers in a chosen field, e.g. biolytics, pharmaceuticals.		Data exchange.
	Facilitate drug research.	Chiefs of all CRDS.	Virtual meetings.	
		Nurses of CRDS.	Traditional meetings.	
		At times, also politicians, ministry officials and big pharmaceutical companies.	Email lists.	

3.3.7 The mother hub

Two networks (see Appendix table 2.1:37 and 48) serve the function of an umbrella organisation, facilitating and promoting the functions and infrastructure of all other initiatives in the field of rare diseases. This network is described in Section 3.4.

3.3.8 Network proposals in singular ...

There were ideas for networks that were unique in that only one attendee thought of the idea. That no other attendees thought of the idea may be because the idea is original and relevant, as well as it may be because it is not found relevant by the other attendees. It is beyond this study to draw conclusions on this.

One idea is network No. 30 (see Appendix table 2.1), with the function to develop ways to handle ethical issues related to rare diseases, as outlined in Table 3.12.

Table 3.12 Proposed network to focus on ethics

Network name	Function	Set of people	Infrastructure	Content
Ethics in treatment of rare diseases	Discuss and develop ways to handle ethical issues in the field of rare diseases.	Experts on prioritisation. Patient organisations. Professionals.		Discussions on how to spend money – prioritisation! Ideas/discussions on how to handle effects/consequences of prioritisation!

Another idea is (No. 38 in Appendix table 2.1) that a network should be established with the purpose of mapping the field, as the overview gained by a mapping is a prerequisite for improving quality, see Table 3.13.

Table 3.13 Proposed network for mapping the field

Network name	Function	Set of people	Infrastructure	Content
Quality of knowledge	Improve quality of knowledge and services. Systematic Surveys of needs, services and outcomes. In short: to map the field.	Project leaders (researchers with a strong background in systematic review, registry data or surveys. “Peers”.	Workshops. Conferences. Publications.	White papers. Reports. Papers and procedures (project descriptions).

Finally, an idea (No. 46 in Appendix table 2.1) was put forward to seek out and list innovations made in relation to living with rare diseases. This list should be available to stakeholders in the Nordic countries, for the ideas to spread. See Table 3.14.

Table 3.14 Proposed network for listing innovations

Network name	Function	Set of people	Infra-structure	Content
Network for patient experiences and innovations	To share ideas among the countries.		Electronic.	List of ideas, experiences and innovations.

3.4 The gap to fill for a Nordic network in a world of networks on rare diseases

In this session, we asked the attendees to consider, critically, where there is a need for a Nordic network, i.e. a need that is not or cannot be fulfilled satisfactorily or better by a network other than a Nordic one. The findings from this session are a zooming in on some of the ideas generated in the earlier workshops, and as such the networks proposed in 3.4.2 should not be considered to be of a higher or lower priority among the attendees than the networks proposed in 3.3.

Before presenting the proposed networks, we will present some general comments put forward by attendees.

3.4.1 General comments

There is already a lot happening on a Nordic level, but these endeavours have arisen as bottom-up initiatives, and therefore there is no formalised responsibility or support for the initiatives, which makes them potentially vulnerable. Examples of such bottom-up initiatives are the conferences that the Rarelink group have hosted voluntarily. There is a need for formalising these initiatives, to secure support from decision makers in the different countries.

Discussing where there is a gap for a Nordic network when considering what is going on at the international level led to the conclusion that the discussion was uninformed. An overview of existing networks and possible collaborators is missing, and it was suggested that a first step towards further development of Nordic and international collaboration is to create such a list. Besides making strategic choices in the development of Nordic networks possible, the list could contribute to bringing people into contact with the existing networks, thus building on the these.

In the following, we move on to presenting the actual ideas for Nordic networks that were discussed during the session.

3.4.2 Five ideas for Nordic networks that fulfil the need for Nordic networks in a world of rare diseases

The workshop centred around five overarching ideas for a Nordic network:

1. **The mother hub.** The current Rarelink – or a similar constellation – should evolve into a kind of “Mother-hub” that has the overview of all initiatives in the field of rare diseases, and the Mother-hub should facilitate or sustain all other networks/collaborative initiatives in the field at an inter-Nordic level. That there is only one facilitator – one Mother-hub – has the advantage of simplicity, it was pointed out, making information, further collaboration etc. easier and accessible. See Table 3.15.

Table 3.15 The Mother-hub

Network name	Function	Content	Set of people	Infra-structure
The Mother-hub	A platform that informs about what goes on in the field of rare diseases and facilitate (all other) inter-Nordic initiatives in the field of rare diseases. Examples of initiatives are • Rare Academy that educates stakeholders in the rare disease field • Patient organization work.	Depends on the actual initiative and what should be done in relation to this. It could be • Contact between stakeholder and initiatives • Information • Oversight • Publications • White papers • Reports • Procedure descriptions • Project descriptions.	Representatives from all Nordic countries.	Workshops. Conferences. Web-page. Whatever each initiative in the field of rare diseases requires.

2. **Network for centres of expertise.** A future network should focus on developing the collaboration between the Nordic countries' national expertise-centres on rare diseases that are established in these years. It was noted that the Nordic countries seems to be establishing these centres differently from how other European countries do so. For one thing the Nordic countries' centres of expertise seem to
   - Apply a more holistic perspective, focusing more on social medicine, and secondly
   - The centres serve a coordinating function rather than a therapeutic function as it is seen in many other countries.

   By collaborating on the development of the centres and by having the centres of expertise share ideas/experience/knowledge on how to do things, all countries will be inspired to develop the field. This could be coupled to a benchmarking system, giving direction to the different Nordic countries' decision making on further development in the field. See Table 3.16.

Table 3.16 Network for centres of expertise

Network name	Function	Content	Set of people	Infra-structure
Network for Nordic centres of expertise	Develop the centres of expertise so that they can facilitate further development of the national initiatives on rare diseases.	Depends on the actual initiative and what should be done in relation to this. It could be • Contact information • Information on rare diseases • Experience with different approaches • Oversight of initiatives • Benchmarking of national initiatives and the centres' work.	Representatives from all Nordic countries, e.g. • Leaders of the centres • Experts • Practitioners • Patients and patient organization • Representatives with power from all countries (on invitation to gain support and financing).	

3. **No Cross-functionality without mono-functionality.** Cross-functionality in Nordic networks goes hand in hand with having mono-functional networks, it was stated. Being able to discuss matters related to rare diseases in mono-functional groups (e.g. amongst people with the same educational background, job function etc.) legitimates practitioners' participation in networks with a cross-functional focus, i.e. makes participation possible and ensures support from the organisations in which they work. Furthermore, when mono-functional groups get together to engage in cross-functional discussions, after having first discussed problems on rare diseases within their own group, it becomes possible to identify obstacles and possibilities as to what each mono-functional group can contribute with concerning a particular rare disease or rare diseases in general. This again can lead to the evolvement of approaches that build on the potentials of each mono-functional group.

Table 3.17 Network for mono-functional groups getting together

Network name	Function	Content	Set of people	Infrastructure
Network for mono-functional groups getting together.	Co-create solutions to obstacles in the field of rare diseases.	Depends on the actual initiative and what should be done in relation to this.	Mono-functional groups discussing the same matter. Mono-functional groups getting together in cross-functional groups discussing solutions to the problem.	Mono-functional meetings and cross-functional meetings. The cross-functional meetings could be at conferences.

4. **Patients and professionals thinking together.** A network where patients and professionals get together, think new ideas and develop the area is missing on a Nordic level. However, there should only be a network if there is a need for a network, so the first thing to do before developing a network is to identify what these stakeholders can

agree to collaborate on and how. Research may be such a theme as there is something in it for everyone; experts want to do research, patients want knowledge to increase. Creating holistic best-practice guidelines could be another function to gather around.

Table 3.18 Patients and professionals thinking together

Network name	Function	Content	Set of people	Infrastructure
Patients and professionals thinking together	Get together and think! Think about where the current approaches do not suffice – and think new ideas for practice. Think about where the current approaches do suffice and more – and develop guidelines for a holistic best practice.	Experiences, information, knowledge from practice. Cases on concrete problems in the field of rare diseases.	Key stakeholders in the field of rare diseases • Professionals from all sectors/relevant organisations • Patient organisation • Researchers.	Meetings.

5. **Creating a Nordic strategy on rare diseases.** A shared Nordic strategy should focus on 'what is in it for society', as this approach furthers the involvement of decision makers – the prerequisite for making and implementing a shared Nordic strategy. Furthermore, a Nordic strategy on rare diseases will open up for more networks that, with the formal power invested from a common strategy, will be able to work on different agendas related to rare diseases.

Table 3.19 A Nordic strategy on rare diseases

Network name	Function	Content	Set of people	Infra-structure
Strategy building network	Create a common Nordic strategy – either to be an actual shared strategy or alternatively, to guide the countries in making their own strategy.	Analyses of the current rare diseases situations in the five countries: • What are the weaknesses, strengths, barriers, obstacles in the field • Visions and goals for the field.	Key stakeholders in the field of rare diseases • Experts from all sectors/relevant organisations • Patient organisations • Decision makers: • Ministers • Directors of relevant offices/organizations .	Meetings.

3.5 The list of Nordic networks on rare diseases

In the following, we present the list of Nordic networks that met our selection criteria, see Section 2.3.1.

Table 3.20 List of Nordic networks traced according to our selection criteria

Network	Function	Set of People	Infrastructure	Content	Comments
Network cooperating on spreading and sharing knowledge about speech disorders and stuttering.	Knowledge sharing, education.	University of Uppsala, Svenska. Logopedförbundet (SE). Statped (N). Socialstyrelsen (DK).	Stakeholders/sets of people plan and facilitate conferences and seminars where professionals meet and exchange knowledge and experience.	Different stakeholders attend the Nordic conferences – practitioners, researchers and patient organisations – and share information and ideas.	For information about the conferences, go to: http://www.stammen.dk/nordisk.html
	Knowledge sharing.	University of Uppsala. Swedish Logoped Association (Svenska Logopedförbundet) (SE). Statped (N) (Statped is a national service for special needs education made up of four regions and a main office located in Oslo). Social Agency (Socialstyrelsen) (DK).	The conferences are the result of an inter-Nordic cooperation between stakeholders from Sweden, Norway and Denmark.	Planning and organising Nordic conferences on the stuttering and speech disorders.	

Network	Function	Set of People	Infrastructure	Content	Comments
The Nordic leader forum	Among other things the forum plans and executes activities for the benefit of persons with deafblindness. The activities are based upon a joint Nordic approach.	The Nordic Leaders' Forum on Deafblindness consists of leaders of services responsible for staff training, professional development and service provision for persons with deafblindness and their networks • Socialstyrelsen, (DK) • Helse Nord-RHF (N), • Statped (N), • Stiftelsen Signo (N), • Specialpedagogiska skolmyndigheten (S), • Nationellt Kunnskapscenter för Dövblindfrågor (S), • Midstod (National Institute for the Blind, Visually Impaired and Deafblind) (IS), • Kuurosokeat (The Finnish Deafblind Association) (FI), • Nordens Velfærdscenter (NVC) functioning under the Nordic council of ministers.	A secretariat is responsible for the planning and for the content of the meetings.	Apart from conferences for stakeholders, the leader forum meets once a year to share knowledge and exchange ideas.	The Nordic Leaders forum is supported by the Nordic center for welfare and social issues (NVC), established by the Nordic Council of Ministers.
PCN – Pro Communication Nordica	PCN is a Nordic network of professionals and organisations working with aids for disabled deaf and deafblind people. Their goal is to develop the Nordic cooperation in this area.	PCN has a board composed of eight members from all the Nordic countries Member organisations: • Signo (Norway) • Mo Gård (Sweden) • SPSM (Specialpedagogiska Skolmyndigheten, Sweden) • CFD (Denmark) • Dövas Servicestiftelse (Finland).	PCN is based solely on volunteer labour and has no employees.	Coordination and exchange of professional experience and knowledge. Development of social and cultural events. Strategic development of community services for deaf and deafblind people in the Nordic countries.	

Network	Function	Set of People	Infrastructure	Content	Comments
RareLink	Knowledge sharing.	Helsedirektoratet (N) Ågrenska - Nationellt kompetenscentrum för sällsynta diagnoser' (SE) National Board (GB) The network of rare diagnoses in Finland (Harvinaiset-verkosto) (FI) The State Diagnostic and Counselling Centre (Greiningar) (IS)	Steering group with representatives.	Joint Nordic website with collection of links. Organising seminars and conferences for stakeholders working in the field of rare diseases.	
Network for rare diseases	Knowledge sharing.	Omsorgsdepartemantet (N) Socialstyrelsen (SE) Socialstyrelsen (DK) Social- och hälsovårds- ministeriet (FI) Välfärdsministeriet (IS).			The project is under the Nordic Council of Ministers
NOMO Project	Knowledge sharing. Coordinating initiatives. Facilitating Nordic group for coordinating the standardization initiatives.	The National Institute for Health and Welfare (Finland). NAV,(Norway) Nordic Welfare Centre (NVC) Hjälpmedelsinstitutet); SIS (SE) NAV (NO) Delta Center (NO) Institute for health and welfare (FI) Icelandic Health Insurance (IS)	Annual meetings, work groups, research networks.	The project has been completed but is still producing and publishing articles.	
Nordic purchasing group		Icelandic Health Insurance (ICE) NAV; (NO) National Agency for Inclusion; SIS (Swedish Standard) (SE)	Annual meetings.		

Network	Function	Set of People	Infrastructure	Content	Comments
Sällsynta Brukarorganisationers Nordiska Nätverk (SBONN).	Nordic co-operation between national umbrella organisations and other networks dealing with rare diseases. The purpose of SBONN is to strengthen the exchange of experience and the development of ideas and knowledge across the umbrella organisations and networks in Scandinavia.				
Rare Diseases Nordic Network of Patient Organisations	The mission of the Rare Diseases Nordic Network of Patient Organisations is to strengthen the exchange of ideas, knowledge, learning and understanding between the rare disease patient organisations in the Nordic countries.	The Rare Diseases Nordic Network of Patient Organisations represents 197 rare disease organizations and more than 49,000 members in five countries.	The administration of the Rare Diseases Nordic Network of Patient Organisations will rotate among member countries annually.	Meetings, seminars and other activities.	Read the letter of intent here: http://sjaeldnediagnoser.dk/wp-content/uploads/2014/02/Letter-of-intent-nordic-EN-endelig-Maj-2014.pdf

Network	Function	Set of People	Infrastructure	Content	Comments
Nordisk gruppe til koordinering af standardiseringsind-satsen	Coordination and knowledge sharing regarding standardisation	Nordens Välfärdscenter (NVC) Myndigheten för delaktighet (formely Hjälpmedelsinstitutet) (SE) Delta Center (NO) Institutet för hälsa och välfärd (THL); (FI) Invalidiliittory/Invalidförbundet (FI) Sjúkratryggingar Íslands (ICE)			
Skandinavisk netværk om børn som pårørende/Scandinavian network on children as relatives	Knowledge sharing	Barns Beste (NO) Nationellt kompetenscentrum anhöriga (SE), Socialstyrelsen (SW) Socialstyrelsen (DK)	The network has meetings 1-2 times a year.	Arranging conferences, sharing knowledge.	

4 References

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Appendix 1 – Survey Results

Figure 1

What is your relation to the field of rare diseases? Feel free to choose more than one answer

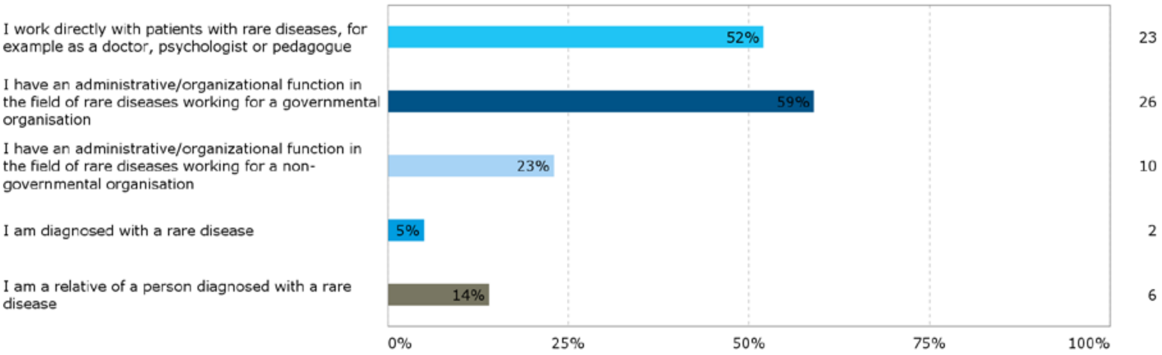


Figure 2

If you work in the field of rare diseases, which sector do you work in? Feel free to choose more than one answer.

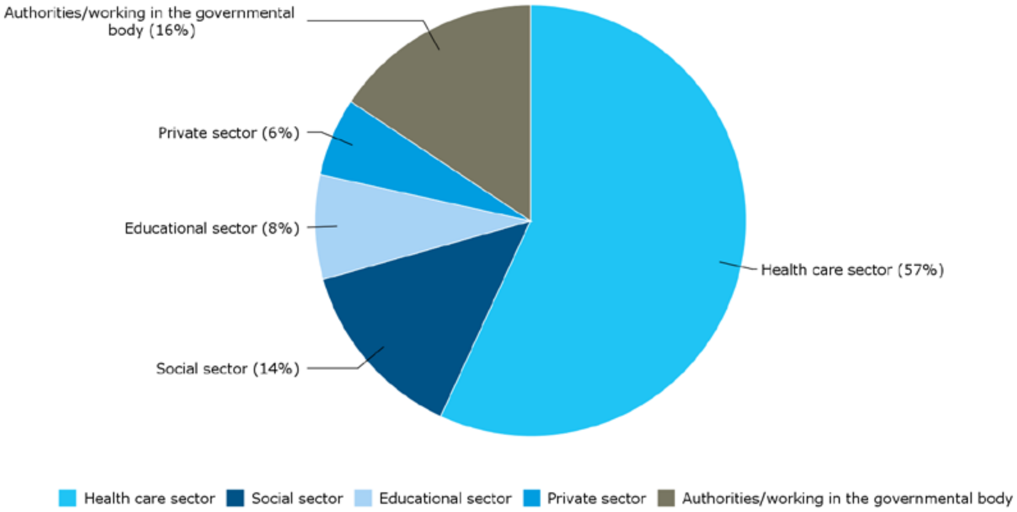


Figure 3

In the context of dealing with rare diseases, which of the Nordic countries do you represent? Feel free to choose more than one answer.

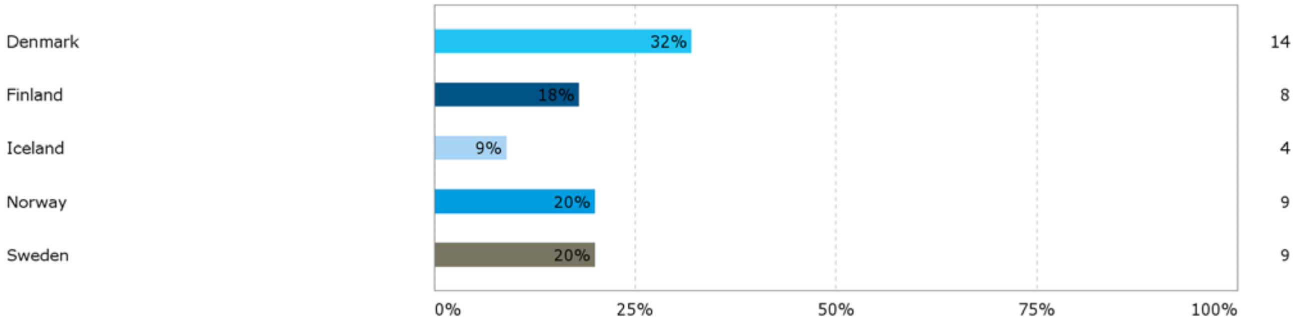


Figure 4

Are you involved in any Nordic networks dealing with rare diseases?

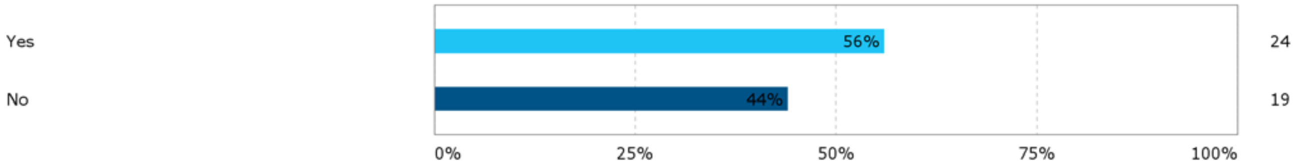


Figure 5

Do the current Nordic networks dealing with rare diseases meet your needs?

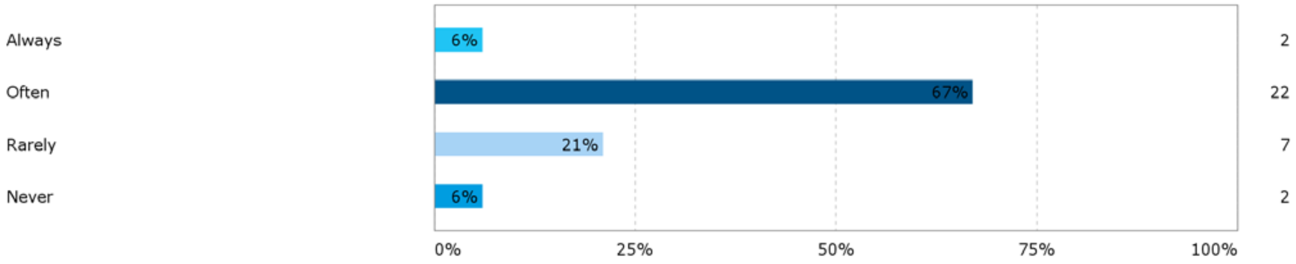


Figure 6

How frequently do you share relevant knowledge/information with stakeholders in the field of rare diseases in other Nordic countries?

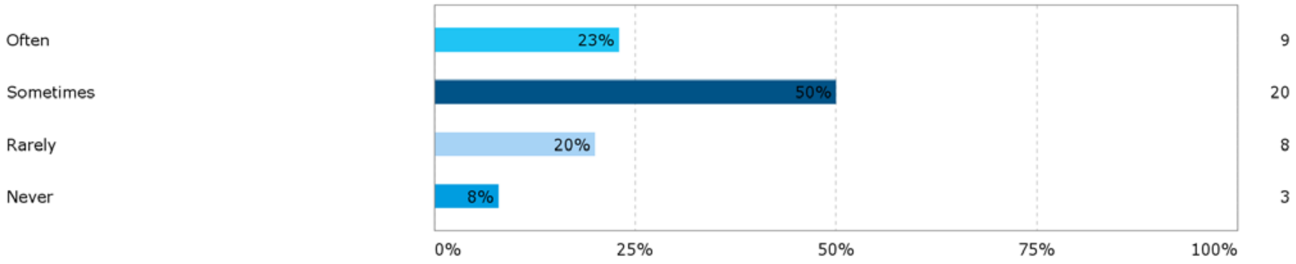


Figure 7

How frequently do you use the following options, when you search for knowledge or information about rare diseases?

- Online databases/webpages?

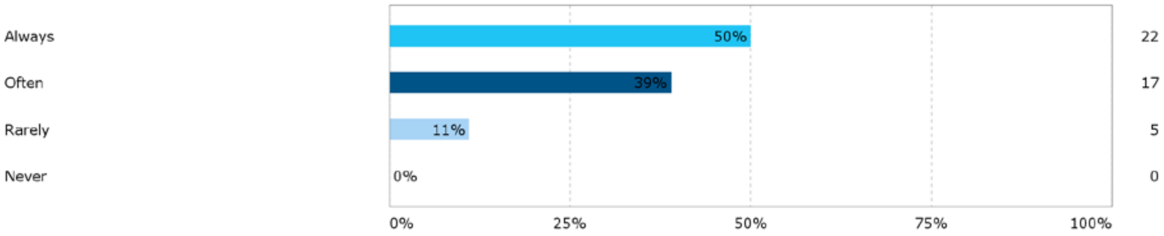


Figure 8

How frequently do you use the following options, when you search for knowledge or information about rare diseases?

- Direct contact with professionals?

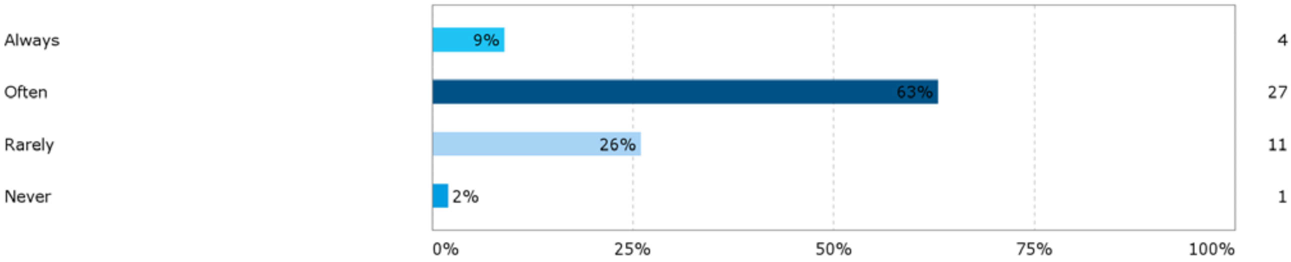


Figure 9

How frequently do you use the following options, when you search for knowledge or information about rare diseases?

- Direct contact with people diagnosed with the disease in question?

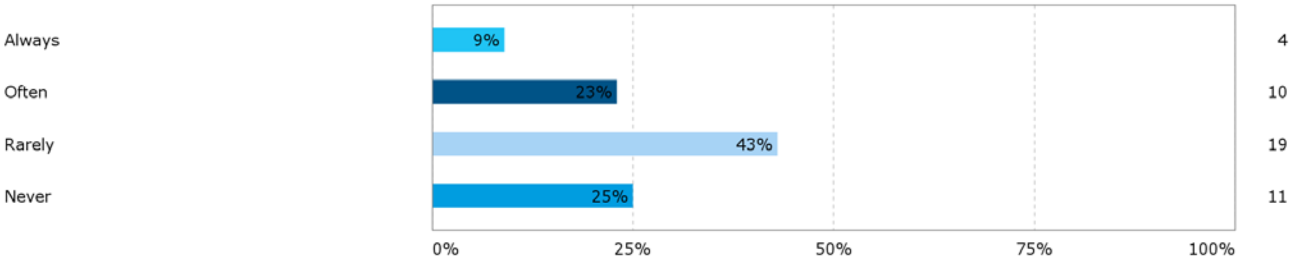


Figure 10

How frequently do you use the following options, when you search for knowledge or information about rare diseases?
- Direct contact with non-governmental organisations?

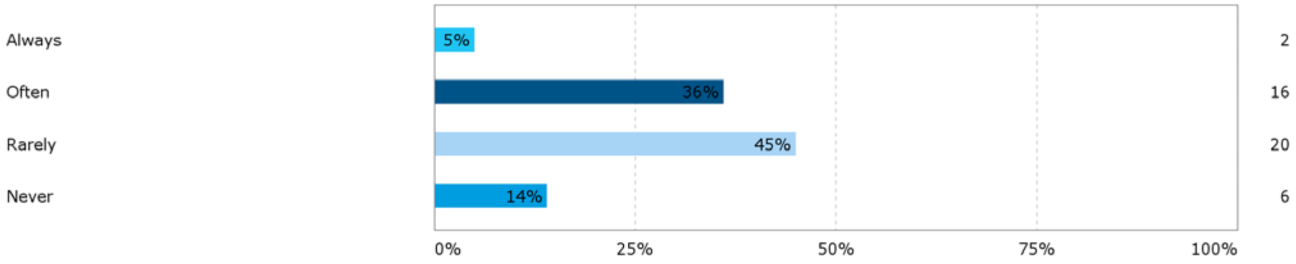


Figure 11

How frequently do you use the following options, when you search for knowledge or information about rare diseases?
- Other?

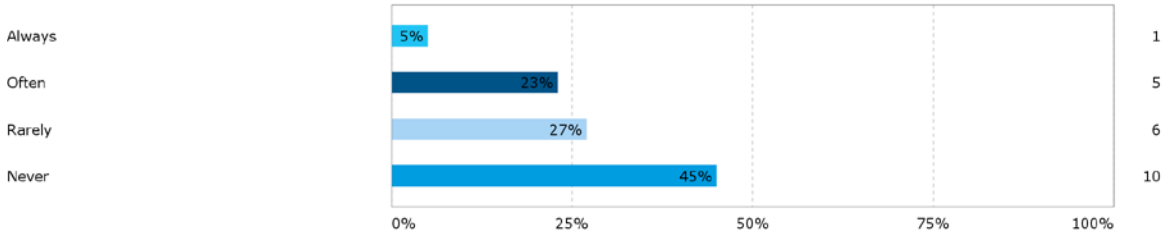


Figure 12

From your perspective, what should the primary purpose of a network dealing with rare diseases be?
- Facilitating knowledge sharing among professionals working with rare diseases

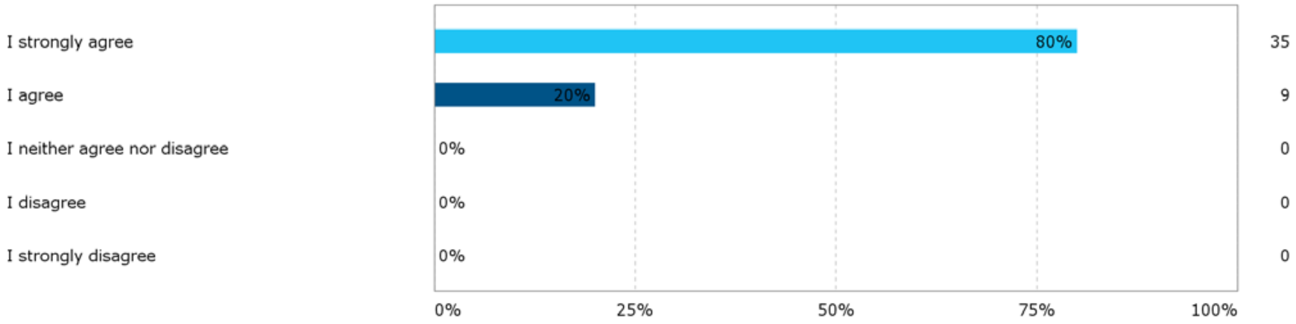


Figure 13

From your perspective, what should the primary purpose of a network dealing with rare diseases be?
- Facilitating mutual support for people diagnosed with a rare disease

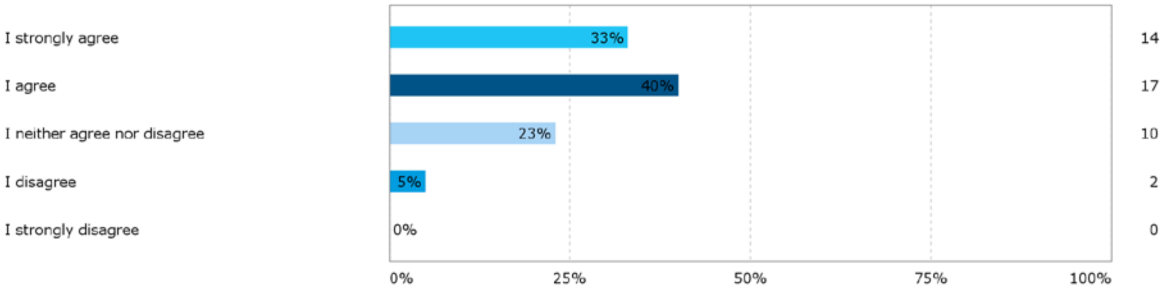


Figure 14

From your perspective, what should the primary purpose of a network dealing with rare diseases be?
- Raising awareness of rare diseases among policy makers and the general public

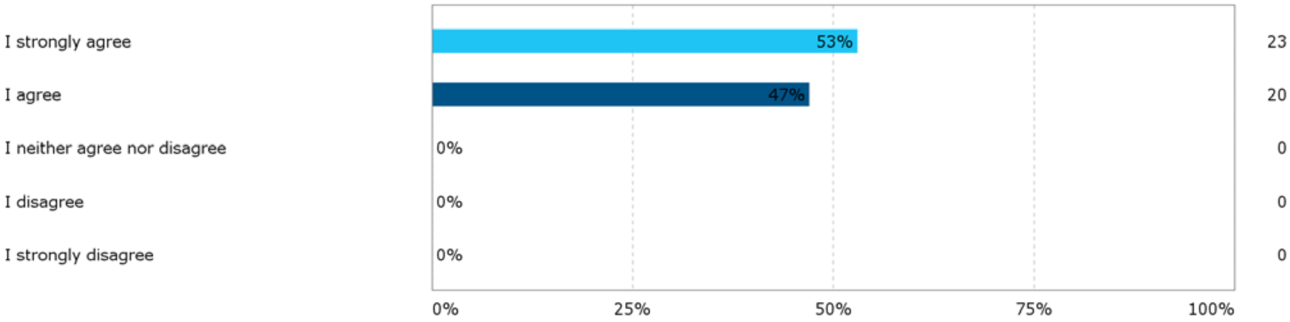


Figure 15

From your perspective, what should the primary purpose of a network dealing with rare diseases be?
- Enabling the best day-to-day treatment for patients. For example, in the diagnosis of patients or seeking out of the right treatment.

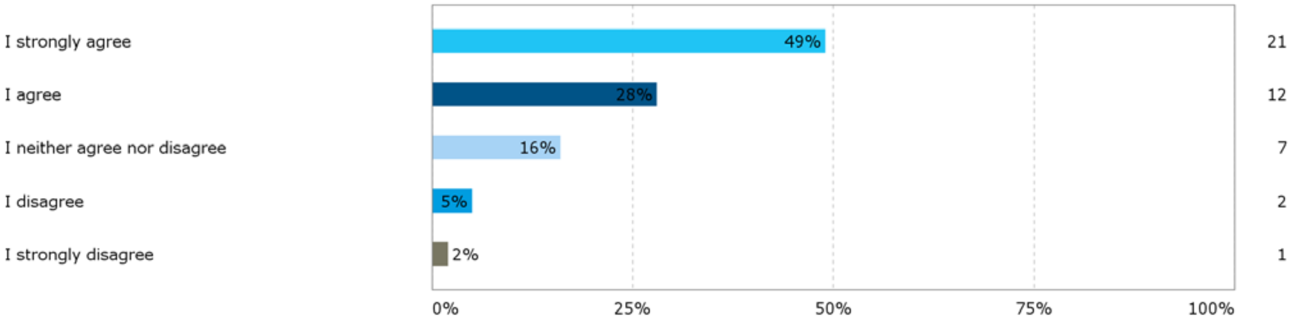


Figure 16

From your perspective, what should the primary purpose of a network dealing with rare diseases be?
 - Other

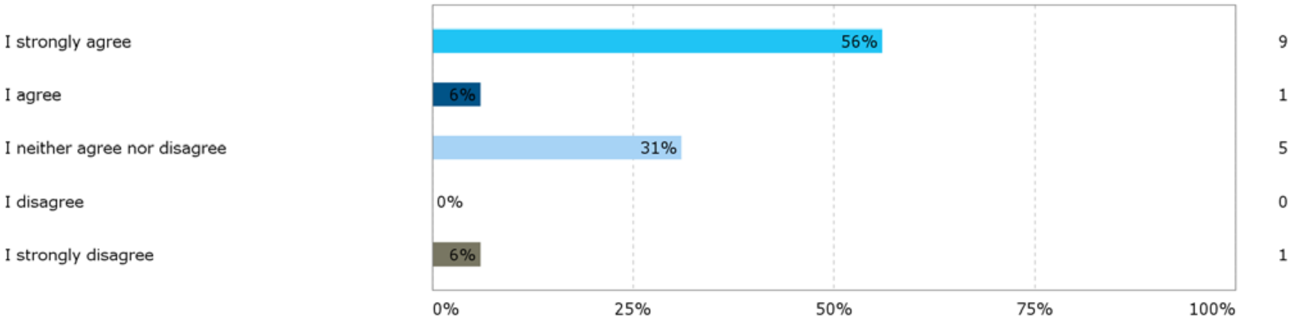


Figure 17

Are you aware that there is an agreement called “Nordisk Tjeneste Udveksling” (Nordic Exchange Service)?
This service, which is under the auspices of The Nordic Council of Ministers, enables you to visit other Nordic countries and stay in an organisation for a period, in order to learn and exchange knowledge.

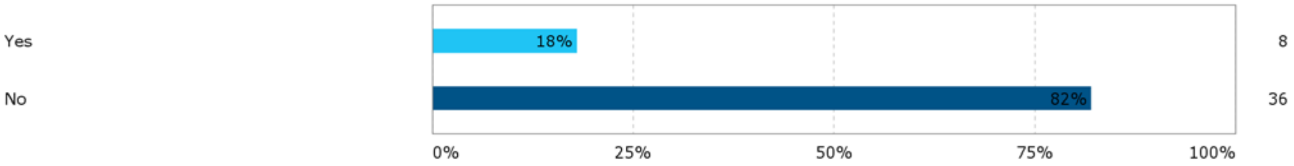


Figure 18

Do you know the webpage/online collection of links called 'Rarelink'?

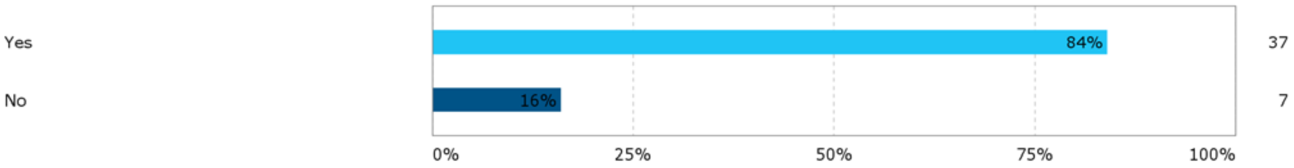


Figure 19

How many times during the last year have you visited the Rarelink website?

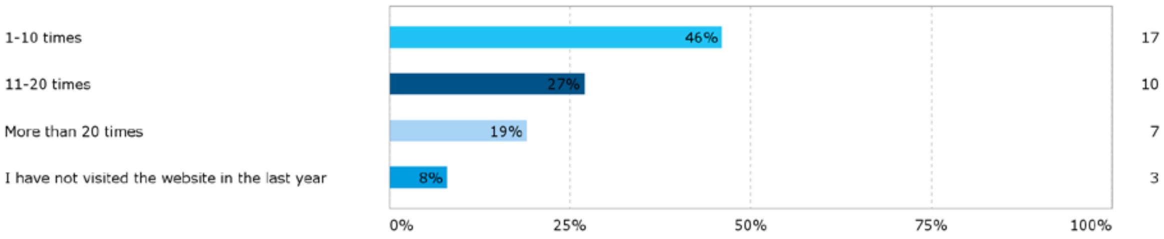


Figure 20

Do you find the information that you are seeking, when you visit the Rarelink website?

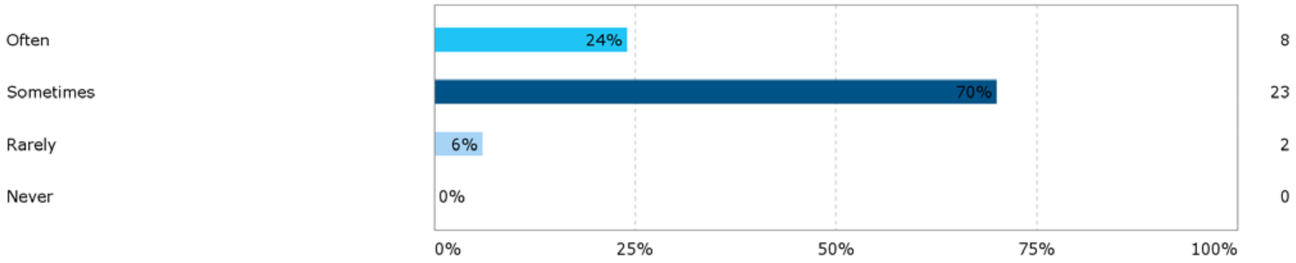


Figure 21

Has the website helped you make contact with other people or organisations in the network of people working with rare diseases?

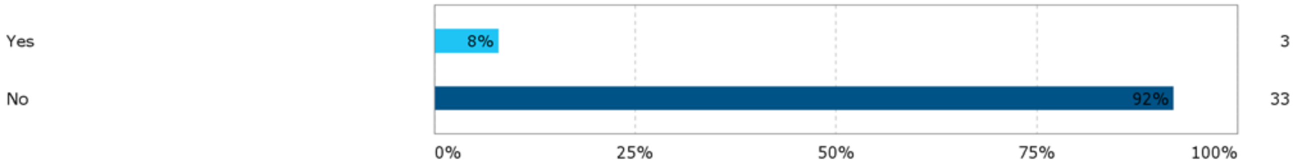


Figure 22

Have you participated in any of the conferences held by Rarelink?

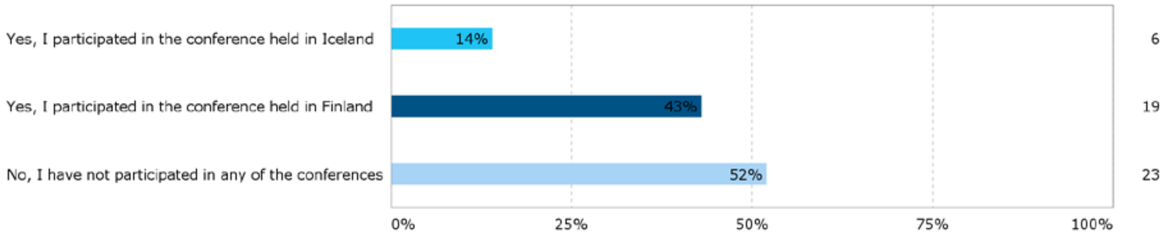


Figure 23

Did you find the conferences to be ...

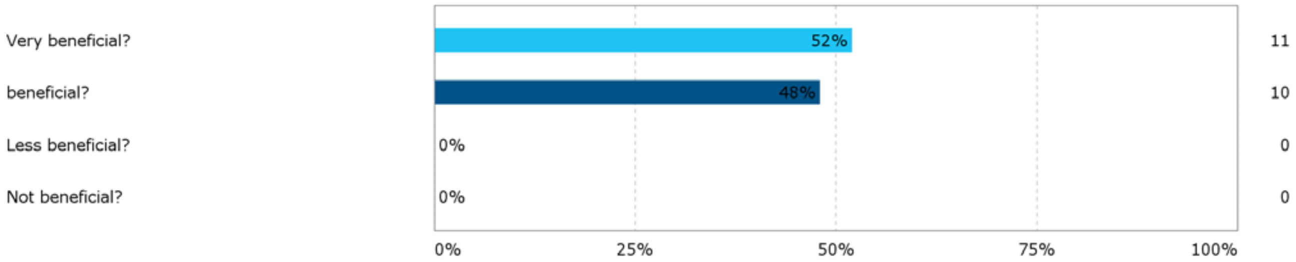


Figure 24

Have you participated in any of the seminars held by Rarelink?

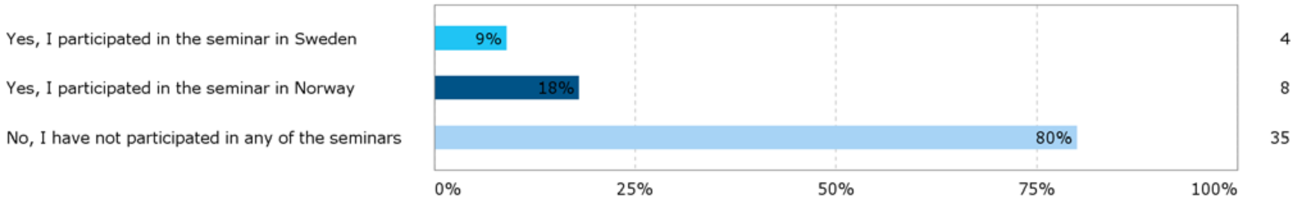


Figure 25

Did you find the seminars to be ...

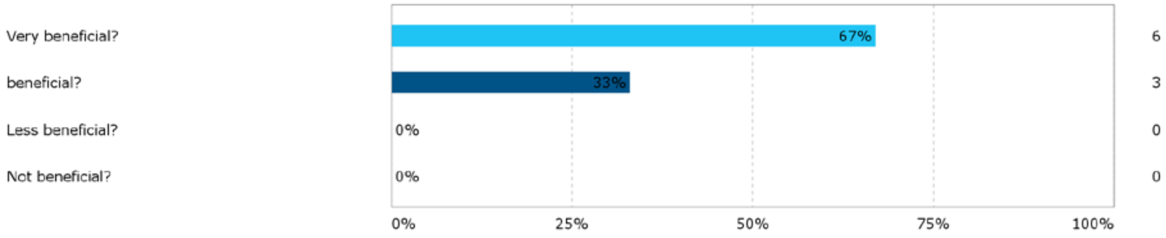


Figure 26

To which extent do you agree with the following statement:
The annual gatherings held by Rarelink have strengthened my ties to people from other Nordic countries in the field of rare diseases?

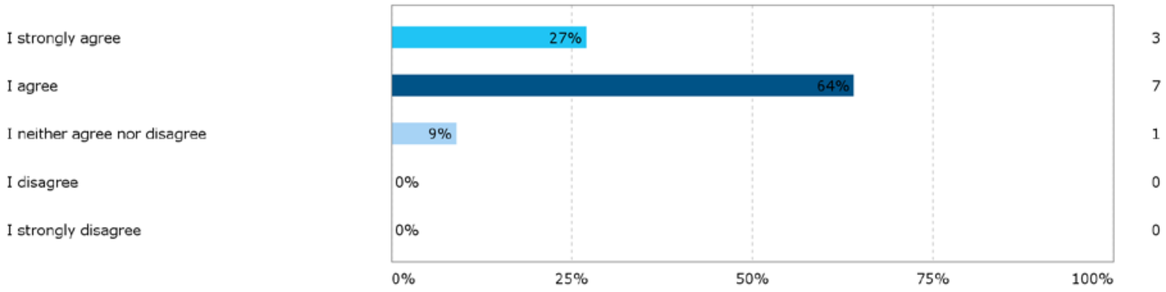


Figure 27

In your opinion, what should the primary purpose of the conferences and seminars be?
- Facilitating knowledge sharing among professionals working with rare diseases

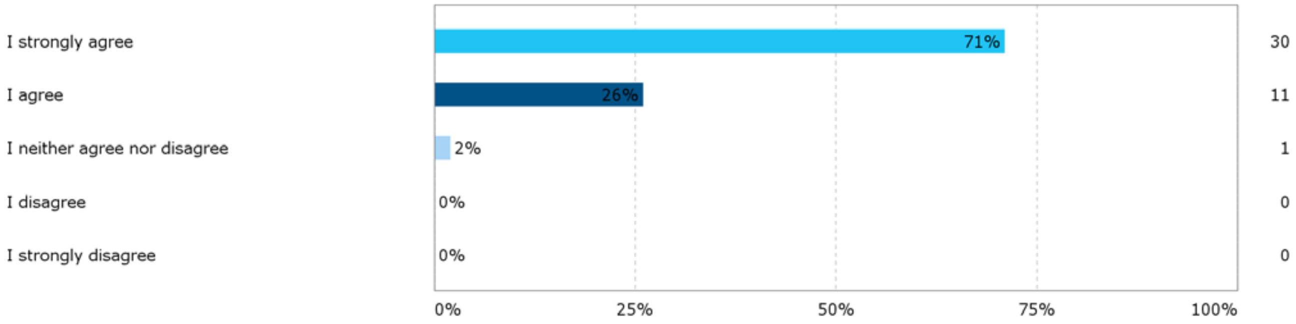


Figure 28

In your opinion, what should the primary purpose of the conferences and seminars be?
- Facilitating mutual support for people diagnosed with a rare disease

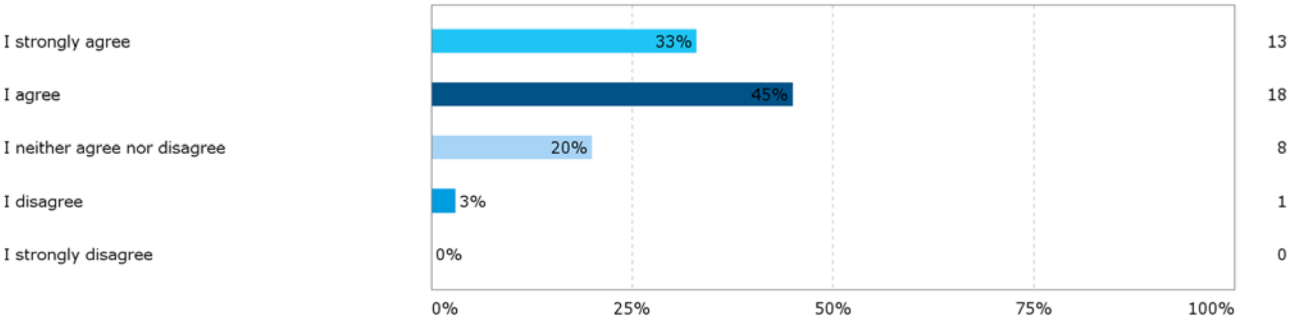


Figure 29

In your opinion, what should the primary purpose of the conferences and seminars be?
- Raising awareness of rare diseases among policy makers and the general public

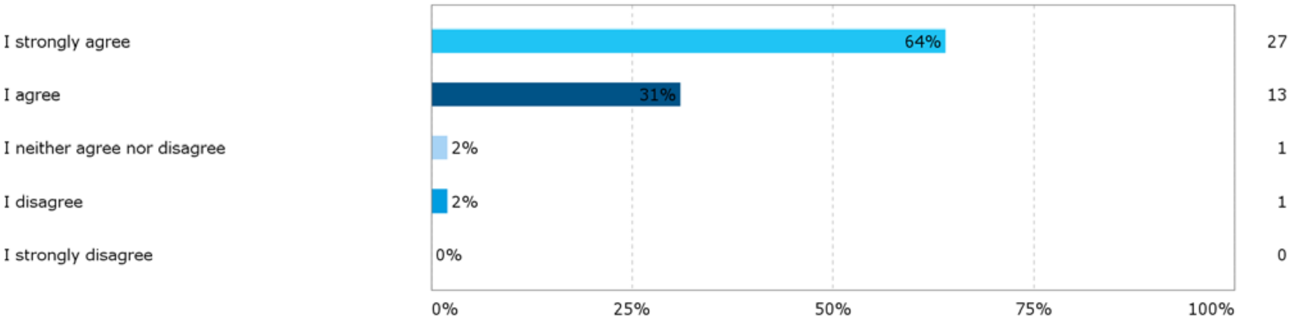
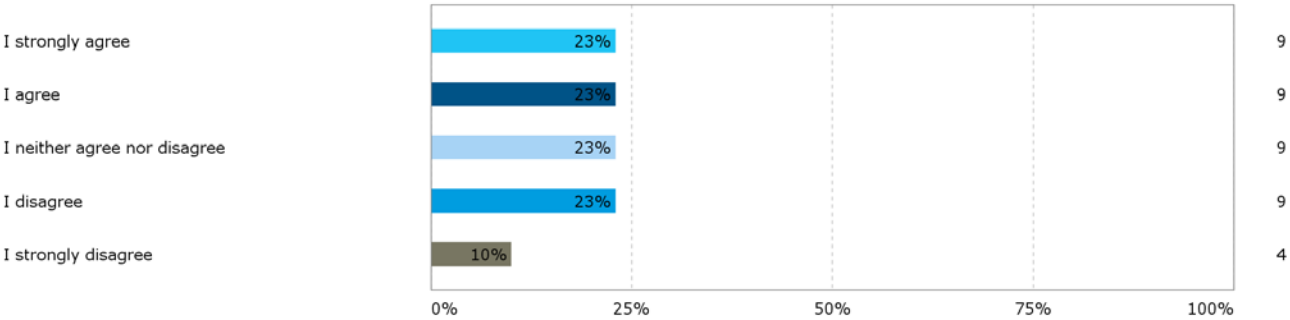


Figure 30

In your opinion, what should the primary purpose of the conferences and seminars be?
- Treating specific patients. For example, diagnosing or seeking out the right treatment for patients.



Appendix 2 – The ideas for networks generated in workshop II

Appendix table 2.1 The ideas for cross-functional networks on rare diseases generated in the four workshops II

	Name of the network	Function	Set of People	Infra-structure	Content	What is that level of activity?	Comments
1	**Scandinavian Centres for Rare Diseases**	Facilitate exchange of experts Facilitate interoperability of IT, registers, biobanks Facilitate drug research.	Chiefs of all CRDS Nurses of CRDS Geneticists At times also politicians, ministry officials and big pharmaceutical companies.	Interactive • Virtual meetings • Traditional meetings • Email lists.	Should facilitate collaboration in a wide array of functions Should avoid being too theoretical and 'company interests'.		
2	**Biobanks: Registers for rare diseases**	Research.	Researchers in a chosen field, e.g. biolytics, pharmaceuticals.	Interactive	Data exchange.		
3	**Rare disease patient organisations**	Empowerment, self-direction, information, peer-support.	Patient specialists.	Interactive • Meetings.	Peer support • Experiences.		
4	**Disease(group)-specific guideline groups**	Create guidelines on: • Disease group facilitation • Drug use • Use of social services • Use of rehabilitation • The above in combination.	Patient organisation representatives Doctors Social workers III sector (rehab. medicine etc.) Interdisciplinary and reimbursement agencies.	Interactive • Meetings • Virtual meetings • Email.	• Experiences • Follow-up data from the effectiveness of interventions • Big data – use of health services, total costs, patient satisfaction etc.		

	Name of the network	Function	Set of People	Infra-structure	Content	What is that level of activity?	Comments
5	**Drug acquisition and use**	Increase competitive bidding Lead to a critical but compassionate use of orphan drugs Improve risk management (pooling of acquisition) during drug shortages, diseases etc.	Government Communities Health officials Hospital pharmacists National health institutes Patient organisation representatives.	Inter-Nordic.	Competitive bidding Risk management Therapy guidelines Resource allocation Prioritising.		
6	**Nordpool – diagnostics**	Diagnostic network.	Laboratories Expert centres.	Sample sharing.	Samples Diagnoses		Should be Europe-wide instead
7	**Nordpool – drugs**	Provide availability of rare drugs.	Governmental bodies.	Ensure a common warehouse for orphan drugs.	Administrative sharing of data on drug availability Drugs shared between stakeholders if needed.		
8	**Empowerment –holistic models for rare diseases**	Suggest models to create patient pathways Empowerment.	All relevant kinds of professionals and patients and people working with structures.	Work-group with secretary Presentations at seminars.	Brainstorms Task force material		
9	**Guidelines**	For diagnosis For patients Follow-up on programmes.	Professionals, e.g. clinicians Administrators	Meetings Video conference.	Best practice descriptions.		

	Name of the network	Function	Set of People	Infra-structure	Content	What is that level of activity?	Comments
10	**Living with rare diseases – in diagnosis specific groups**	Raising knowledge and awareness Creating a holistic view => leading to Nordic guidelines in the future.	Practitioners Patients Patients' families Project leader Cross-sectorial Cross-level • Specialists • Community practitioners.	Meetings Email Video profession Project leader	Knowledge Experiences Best practices Recommendations.		
11	**Rarelink**	Accessible information on optimum lives for persons with rare diseases Bringing together people and information.	Qualified with experience with rare diseases from all Nordic countries.	A steering group with a representative from each country should ensure: • Diagnose database • Conferences • Meetings.	Holistic approach focus Qualified information.	Meetings regularly Updating website Conferences and seminars every second year.	
12	**Empowerment programme**	Exchange of experiences Broader perspective empowering: • Patients • Patients' families • Professionals.	Competence centres Across silos – all countries.				Building a Nordic network among already existing ones.

	Name of the network	Function	Set of People	Infra-structure	Content	What is that level of activity?	Comments
13	**Nordic Network on Rare Diseases**	Develop areas on Nordic Cooperation.	Medical professionals People with lived experience Nordic authorities, (directorate level?) Clinicians.	Meetings Video conferences.	Highly specialised services Registers? Guidelines for best practice Experiences.	Three-four meetings a year?	
14	**Network on treatment quality**	Exchange current practices and harmonise guidelines/daily work.	Lab. experts Clinicians Patient representatives International experts A hired project leader to run the network.	Mutual learning Databases On request Workshops.	Guidelines E-services.	Regular meetings Possibility of daily contact.	
15	**Network for leaders of rare disease centres**	Exchange current practices and harmonise guidelines/daily work.	Centre leaders Patient representatives Government officials.	Mutual learning Databases On request Workshops	Guidelines E-services.	Regular meetings Possibility of daily contact.	
16	**Network for patient organisations**	Facilitate exchange of information.	Representative stakeholders.	Mutual learning: • Databases • On request • Workshops.	Guidelines E-services.	Regular meetings Possibility of daily contact.	

	Name of the network	Function	Set of People	Infra-structure	Content	What is that level of activity?	Comments
17	**Network of professional groups**	Exchange current practices and harmonise guidelines/daily work.	Relevant stakeholders: • Professionals • Patient groups • etc.	Mutual learning • Databases • On request • Workshops.	Guidelines E-services.	Regular meetings Possibility of daily contact.	
18		Sharing best practice in different professional and patient organisations		Workshops Conferences			
19		Develop guidelines on treatment (both medical and non-medical).	Patient representatives Professional representatives.	Databases.			Nordic and European.
20		Solve difficult cases.	Varies.	Web-meetings.	Difficult cases “Dr. House”.		
21		Develop, organise and harmonise methods,	Centres of expertise Multi-professional.	Meetings Conferences.	Knowledge.		
22	**SBONN**	Share knowledge, good practices, affect policies, search for things that can be moderated for use by people with rare diseases use – also in other cultures.	Umbrella-associations of patient organisation from Nordic countries, representing both experiences of living with rare diseases and professional points of view.	A platform where material can be shared (e.g. “cloud services” in Gmail) Meeting twice a year Skype meetings between meetings.	Material about rare diseases Knowledge about practices in use and models, if there are any.		

	Name of the network	Function	Set of People	Infra-structure	Content	What is that level of activity?	Comments
23	**Around it all**	Information (also research) exchange Guide-lines/recommendation exchange/development Debate of hot topics.	Depends on the actual function and required content • Decision makers • Patient organisation • Clinicians and experts • (Researchers) • Centres of knowledge.	A common website Seminars.			
24	**Rarelink with subgroups**	Collection of diagnosis Create contacts Rare-academy Develop guidelines (Orphanet codes).	Representatives from all Nordic Countries and with mixed backgrounds • Steering group • Diagnosis-specific groups • Academy-group • Etc.	Conferences Physical meetings 2-3 times a year Video conferences (when necessary) Email.	Information Contact information on user organisations Educational material.		
25	**Adult metabolic group**	Improving holistic care.	People working with adult inborn errors of metabolism • Physicians • Nurses • Dieticians • Psychologists • Social workers • Administrative/political persons on invitation.	Network of contact information, e.g. closed group on Google (Meetings and profession).	Information/knowledge/experiences on • Diagnosis • Treatment • Follow-up • Financing • Legal issues • Problems • Etc.		Nordic-Estonian.

	Name of the network	Function	Set of People	Infra-structure	Content	What is that level of activity?	Comments
26	**Nord-rare**		Centres of rare diseases Patient organisations of rare diseases Government actors responsible for rare diseases.	Virtual platforms Conferences Meetings.	Knowledge Data Services.		
27		Competence development Assist on diagnostics in cases of doubt Tele-medicine Solve problems.	Everyone together – professionals and users or Professions on their own.	Gatherings for all Gatherings for diagnosis specific groups Gatherings for specific professions Structure model to organise profession.			

	Name of the network	Function	Set of People	Infra-structure	Content	What is that level of activity?	Comments
28	**'From Diagnose to Life' Best practice guideline building network => Harmonising practices across the Nordic Countries, but with the countries keeping the authority to decide how their system should work'.**	Development of guidelines for best holistic practice.	The set of people should be picked according to diagnosis-specific groups, as different groups have different needs regarding a best holistic practice – presupposes that diagnoses are clustered according to similarities on treatment and/or impairment. The set of people should be interdisciplinary and include: • Doctors • Nurses • Pedagogues • Social workers • Patients • Research competencies – Nordic researchers, as the input from the researchers has to be applicable to a Nordic context, i.e. the hurdles and possibilities that the Nordic welfare systems provide • Relatives of patients • Reimbursement people, minstrel officials, directors (to create the basis for realisation of the guidelines and implementation of the best practices. Not to develop the guidelines) • A full-time secretariat running the networks (responsibilities for developing the different networks, and hence guidelines, should be placed on countries, and should be close to clinicians/everyday practice)	There should be a follow-up function providing the network with information on how the guidelines are used, affect practice, their costs, the patient satisfaction with the practices Conferences – focusing on how the guidelines operate => feedback on how they work for further development of the guidelines.	Thoughts on ethical issues concerning consequences of prioritization – and lack of prioritization! Comparing of experiences Guideline ideas Guideline drafts Data on how the guidelines affect the area.		Best practice guidelines already exist on diagnosis and treatment for many rare diseases, but do not include the diagnoses' consequences for the lives of patients and relatives The different Nordic systems might not want to apply the guidelines/they may not be compatible with the existing political and administrative systems => it should be voluntary and countries should take them in at the pace that fits them It is the optimal timing to create such guidelines now that there are national centres Guidelines => legitimation of drug prescription => drug industry seeks out/builds markets.

	Name of the network	Function	Set of People	Infra-structure	Content	What is that level of activity?	Comments
29	**Patient Pathways - The New Rarelink to Develop Holistic Models for Rare Diseases**	Assist patients In overcoming barriers between services => empowering patients and professionals to overcome the barriers in patients' life	Professionals Patients Relatives Patients with the same rare disease should be identified across boarders, and interdisciplinary professionals working with these patients should be brought together to discuss how to assist the patient in the best way and to be educated to do this.	Meetings Workshops Video conferences Seminars	Educational programmes (professionals and patients attending the same programmes) Brainstorming – not conclusions Thinking big and ambitious on how to solve problems	Activity varies with the process.	We cannot create a society for people with rare diseases – we have to find ways to fit them into society.
30	**Ethics in treatment of rare diseases**	Discuss and develop ways to handle ethical issues in the field of rare diseases	Experts on prioritisation Patient organisations Professionals		Discussions on how to spend money – prioritisation! Ideas/discussions on how to handle effects/consequences of prioritisation!	Meeting three times a year	
31	**Rarelink – continued**	Rare-Academy – to educate people in the rare field.	Rarelink people – as they are very dedicated • Steering group • Diagnosis group • Conference group • Marketing group.	Conferences Video conferences	Links translated into English.		Money is needed to run the different activities.

	Name of the network	Function	Set of People	Infra-structure	Content	What is that level of activity?	Comments
32	**Rarelink – continued**	Platform for building new networks Develop the website platform	Rarelink people • Steering group • Diagnosis group • Conference group • Marketing group • Experts on the different diagnoses.	Virtual – the platform on the Internet.	Update Translate into English? Questions from patients answered by experts in the field through the platform.		It has to be scientific, solid information of quality that you can trust There are other websites offering something similar to this, but the Q&A, and especially the security, is missing.
33	**Rarelink – continued**	Knowledge sharing.	Rarelink people • Steering group • Diagnosis group • Conference group • Marketing group + more governmental representatives.	Conferences Video conferences Meetings/real life.	Knowledge sharing, mapping of existing guidelines.	Annual meetings in the framework of existing networks.	Rarelink is already facilitating the creation of new new networks.
34		Discussing cross-sectorial, cross-educational problems in the field of rare diseases Sharing/developing guidelines.	Different professions Work groups made up of clinical experts and patients and relatives • experts in social services.	Meetings Conferences with interchanging sessions that are mono-professional and interdisciplinary.	Guidelines.	Ongoing meetings.	It is important that you get a chance to discuss with your own profession, in between discussing across professions The conferences has to focus on themes and sub-themes, and the people matching these should be invited.

	Name of the network	Function	Set of People	Infra-structure	Content	What is that level of activity?	Comments
35		Develop working methods.	Centres of expertise Patients.	Meeting face to face, e.g. at conferences Video conferences.	Discussions on developing the methods Discussions on medical issues Discussions on other issues.		
36	**Doctor-house** Network for diagnosing difficult cases	Diagnosing difficult cases.	Doctors.	Web Video conferences			A structure is needed, for example to ensure that doctors are prepared.
37	**Mother hub**	Facilitator for anyone, anything, any idea/initiative in the field of rare diseases Facilitating all the different strands of initiatives in the field of rare diseases.	Anyone and anything in the field of rare diseases.	Workshops, conferences, publications.	Meeting structures for patients in dialogue with doctors, specialists and centres of expertise Whatever each initiative in the field of rare diseases requires.		Today, this mother hub is known as Rarelink but maybe the name should be changed The responsibility for running the Mother hub should be very clear.
38	**Quality of knowledge**	Improve quality of knowledge and services. Systematic Surveys of needs, services and outcomes. In short: mapping the field.	Project leaders (researchers with a strong background in systematic review, registry data or surveys. “Peers”.	Workshops, conferences, publications.	White paper, reports, papers and procedures (project descriptions).	Few face-to-face meetings. One way communication of papers, reports etc.	
39	**Rarelink continued**	Knowledge sharing.	Existing network (Rarelink) + government representatives.	Meeting/real life Conferences.	Knowledge sharing.	Meetings within the framework of the existing.	

	Name of the network	Function	Set of People	Infra-structure	Content	What is that level of activity?	Comments
40		- Creating and developing guidelines.	- Work groups consisting of clinical experts and experts in social services.	- Work group meetings.	- Sharing knowledge about guidelines.		
41	**Rare academy – education**	Educational modules of rare diseases – existing material.	Cross-sectional professionals and patients.	Info Videos	Existing material on rare diseases.	Very active in the beginning.	
42	**Rarelinking**	Names Field of works in rare diseases Experiences Connecting people.	Many different professionals in the field of rare diseases Experts from the social and educational field, NOGs.	Like Linkedin.	Practical knowledge.	Use the existing tools/social media.	
43	**Rarelink knowledge network**	Sharing knowledge among researchers.	Professionals/researchers.	Simple platform, relatively loose but formalized so it is not dependent on specific people.	Knowledge about RD, interventions, data.	A platform, not too many meetings.	
44	**Nordic Rarelink**	Collect data, research cooperation.	Engaged professionals.	Meetings, web portal.	New knowledge.	Seminars, informal communication.	
45	**Network of the RD-centre at university hospitals.**	Share knowledge of RD expertise from each other's hospitals.	Small groups.	Meetings, teleconferences.	To build a strong "list" of available expertise in all Nordic countries.		
46	**Network for patient experiences and possible innovations**	To share ideas among the countries.		Electronic organisations.	List of ideas, experiences and innovations.	The networks needs some kind of leader or organiser to collect and structure information.	

	Name of the network	Function	Set of People	Infra-structure	Content	What is that level of activity?	Comments
47	**Network for medical agencies to join forces and become stronger players when producing/developing orphan drugs**						
48	**Rarelink**	Steering group/committee with overview/responsibility for coordinating other activities.	Decision makers.	Meetings/video conferences.			
49	**Rare-web**	Develop website, new dynamic platform.	Continue todays organisation Working groups.	Steering group, diagnosis Group, statistics, other.			
50	**Rare academy**	Collect and spread courses, information etc.	New construction, working group with responsibility for each Nordic country	Meetings, technical platforms, IT etc.	Establish and maintain the activity, publishing etc.		
51	**Rare conferences and meetings**	Arrange conferences and meetings.	New construction (working group)		Working together making conferences		

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