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Final report - PARE Youth Research Project

January, 2014

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Glossary

<i>EULAR</i>	<i>European League Against Rheumatism</i>
<i>PARE</i>	<i>The EULAR Standing Committee of PARE</i>
<i>PARE organisations</i>	<i>Patient organisations member of the EULAR and co-opted members of the EULAR Standing Committee of PARE</i>

1. Introduction

1.1 Background

PARE organisations often try to organise activities for younger people with Rheumatic and Musculoskeletal Diseases (RMDs). Empowering youth groups all over Europe is important to improve health care for young people, but also in the context of capacity building to guarantee sustainability of PARE and the national patient organisations, now and in the future. For several reasons, it seems difficult to reach this specific target group.

There are however examples of youth groups that are very active and successful in bringing together young people with RMDs by using social media or by organising events that are different to the activities traditionally organised. From these examples we know that a group-specific approach to work for and by young people with RMDs is beneficial for campaigning in the interest of young people and for organising services that meet their needs and expectations.

1.2 What has PARE done so far?

In the last three years PARE has actively tried to become more inclusive in terms of young people with RMDs. By inviting young people, PARE has incorporated their perspectives in different events and activities. Young people with RMDs have been part of several working groups, extra bursaries have been provided to increase the number of young people at the autumn conference, dedicated sessions and workshops have been organised and also during the EULAR congress, opportunities for young people have been created to meet and to exchange knowledge and experiences.

1.3 Objectives of the project

This proposal addresses the need and wish of youth organisations and PARE organisations to take the next step and to improve the services to young people with RMDs by enhancing international collaboration, and by the integration of the perspective of young people with RMDs in EULAR. In order to be able to do this, we first need more insight into the needs of young people with RMDs and their organisations, and we need more insight into what is currently available in terms of activities and organisations for young people with RMDs across Europe. For the first project year, we work with a tentative age definition between 18 and 35 years.

Objectives – In the first year of this project, the task force will work on the following two objectives:

- a. Gather information about the way young people with RMDs are organised in different European countries;
- b. Explore the needs, obstacles, preferences and priorities of young people with RMDs and their organisations;

With the research findings about the needs of young people with RMDs (objective b), PARE hopes to be able to develop tailored programs, activities and networks that supports the

improvement of quality of life of young people and addresses their needs. By mapping out the current situation of youth activities and organisations in Europe (objective a), PARE will be able to compare the existing situation with the needs of young people and assess whether the current activities and organisation forms are effective and appropriate to support the interests of the target group.

On the basis of these findings, PARE will be able to develop a strategy for the future to improve the services for young people with RMDs: on an international as well as national level, and within its own organisation as well as beyond.

A separate outcome of the first year might be topics and questions for a research agenda.

2. Method

2.1 Approach of mixed methods and action research

To get an overview of youth activities for young people with Rheumatic and Musculoskeletal Diseases (RMDs) between 18-35 in Europe (objective 1) and to gain insights into their needs and obstacles (objective 2) we performed an explorative study using mixed methods. The first objective was addressed by a mapping study on youth activities on an organizational level. This method is explained in par. 2.2 and the results are presented in par. 3.1. The second objective required a combination of qualitative studies (interviews and focus groups) and a European survey through the internet. The used methods are explained in par. 2.3 and 2.4 and the results are presented in par. 3.2-3.4. The timeframe for this project is presented in Table 1.

RESEARCH PROCESS 2012-2013	
Aug-Oct 2012	Project coordinator is employed; Finalization of the project work plan and research approach; Development of research guide for national researchers.
Oct	National researchers (NR) are recruited to conduct the qualitative research.
Nov-Dec	NRs recruit participants and plan focus groups and interviews.
Dec/ Jan	NRs conduct the focus group and interviews. Reports are written and translated into English.
1-3 march 2013	Two days face-to-face meeting of the Task Force members, project coordinator and national researchers in Tallinn. Presentation of interview results and preliminary questionnaire design.
Mar-April	Development of the survey. Testing by Task Force members.
May – Jun	Final version is discussed by the Task Force members and discussed with the Advisory Group; The survey is translated into 18 European languages and checked for spelling and grammar by national youth representatives.
June	Programming of the survey using SurveyMonkey. Pilot testing by task force.
1 July	Launch of the survey; Launch of the project-website.
19 Sept	Survey closed. Change in project co-ordinator and researcher.
November	Preliminary findings presented and discussed in two workshops during the EULAR autumn conference for PARE.
Oct-Dec	Data cleaning and analysis. Writing the final report.

Table 1: Time table of the PARE youth research project

2.2 Mapping exercise

The mapping exercise addressed the first objective of the project and explored how the interests of youth with RMDs are currently organised in different countries in Europe. The PARE youth Task Force members discussed and decided on the relevant items that should be included:

- Is there a youth group or organisation?
- Is it independent or organised within a “mother organisation”?
- How is the age of young people with RMDs defined?
- How many members are involved?
- What kind of activities do they offer?
- How do they communicate? Is there a website?

The Task Force also discussed the organisations to be approached and decided to send out a questionnaire with open and closed questions to the official EULAR liaison persons of 40 organisations in Europe, 37 national EULAR member PARE organisations and three European disease specific umbrella organisations in the fields of Ankylosing Spondylitis, Scleroderma and Lupus. The request for providing the data and the analyses of the responses has been coordinated by the EULAR secretariats staff. In some cases a follow up via telephone was necessary. This mapping exercise took place during December 2012 and January 2013 in conjunction with the annual update of the PARE who-is-who project (EULAR directory of PARE organisations). The results are presented in par. 3.1.

2.3 Qualitative interviews and focus groups

To gain insights into the needs and obstacles of youth with RMDs in Europe (Objective 2) we followed an approach of *mixed methods*,¹² starting with qualitative interviews and focus groups, followed by a face-to-face meeting with expert young people with RMDs and an electronic survey (see par. 2.4). The qualitative research aimed at more in-depth understanding of the emotional and personal impact of the disease on daily lives of young people with RMDs. It was designed to inform the broader survey in the next phase of the project. The study was carried out in five countries, representing different European regions. Through interviews and focus groups we explored the experiences and the impact of the disease of young people with RMDs between 18 and 35 year. We also wanted to know more about the obstacles they have to face when participating in society and what their specific needs are.

National researchers - The interviews and focus group discussions were carried out by five national researchers (NRs) in five European countries: Cyprus, Estonia, Germany, Netherlands and Sweden. Recruitment of the national researchers has been done through the Task Force members hoping that this would create an opportunity for national collaboration between youth organizations, youth members and (health) researchers.

¹ Abma TA, The practice and politics of responsive evaluation. American journal of evaluation 2006;27(1):31

² Abma TA, Broerse JE. Patient participation as dialogue: setting research agendas. Health Expectations 2010;13(2):160-73.

The NRs all had an academic degree and four had personal experience with the disease. Three belonged to the target group and two others had extensive experience of working with young people with RMDs. The NRs were expected to carry out 4 interviews (2 members youth group and 2 non-members) and 1 focus group (ca. 8-10 youngsters, preferably 50% non-members). They made reports of the meetings and translated them into English.

Study participants – The NRs were encouraged to strive for maximum variation of the participants for gender, age, disease and severity.

The inclusion criteria were:

- A person between 18-35 years old
- Personal experience with a rheumatic or musculoskeletal disease for at least 2 years
- 50/50 men and women
- 50/50 “organized” and “unorganized”³.
- Willing to contribute to an interview or focus group that will be recorded.

Interviews and Focus groups - The interviews were based on a semi-structured interview guide, with questions and keywords to support the national researchers. The purpose of the guide was to establish a common objective and approach to guarantee the quality of the study. The focus groups had a 2-hour timeframe and all sessions were recorded. The NRs were responsible for moderation, sometimes supported by one of the Task Force leaders who could take on the role as note taker. The purpose of the meeting was explained to all participants who gave consent to the recording of the meeting and the use of the data.

The focus group was divided into three rounds, based on three research questions:

- What are the experiences of young people with RMD in Europe regarding the impact of their disease?
- What are the barriers they have to face when participating in society?
- What are their needs?

NRs were also asked to pay attention to the following themes: education, employment, health care and personal life (e.g. intimacy, relationships and children).

Analysis – The content analysis of the data was carried out by the project coordinator who gathered all English interview and focus group reports and presented her findings during a two days face-to-face meeting in Tallinn. The group consisted of four Task Force members, four national researchers, and three additional patient representatives, who could ensure representation of young people with children and different age groups.

On the first day the group focused on the analysis of the outcomes, based on a presentation by the project coordinator. Items and clusters were reformulated and restructured during a card sorting exercise. Many quotes derived from the qualitative reports were included in this exercise. On the second day, the group discussed concepts that should be validated by the survey and generated a set of items that reflected these concepts.

³ Definition: An “unorganised” person is someone who is *not actively* involved on a regular basis in activities arranged by a youth group linked to or/by a PARE member organisation. An “organised” person is an active member /of a group linked to/ or by a PARE member organisation.



Photos: Card sorting exercise during the face-to-face meeting: How the survey questionnaire was designed Participants at the face-to-face meeting in Tallinn

Quality measures – The project coordinator who was responsible for the instruction of the NRs and for the analysis, had training and experience in qualitative research and had personal experience with the disease. This was seen as advantageous for the project. She developed interview and focus group protocols for the NRs (see appendix 1). For the interviews as well as for the focus groups participants received information about the study (see appendix 2) and they gave their informed consent (see appendix 3). For the reporting back of the interviews and focus groups, the project coordinator developed two templates (see appendix 4 and 5).

2.4 Survey

After having obtained in-depth information about the experiences and perceptions of young people with RMDs, these findings were validated in the next phase by an electronic survey (see appendix 6) among a broad representation of the target group, again with an additional effort to include not-organized youngsters.

Survey development - The preliminary survey was discussed several times by the Task Force. The final survey was then discussed by the Advisory Board. After approval by all involved stakeholders, the survey was translated by an international agency into 17 languages. These were the languages of the national youth representatives that had showed an interest in distributing the survey among their members and on their websites. After the forward translation by a professional translator, a native speaking youth representative or health professional validated the translation for accuracy and comprehensiveness. The survey used SurveyMonkey software and was pilot tested by the Task Force members. Before the launch of the survey, Spanish organisations asked to be a part of the project and it was decided to translate the survey into Spanish. Local health professionals and clinicians helped with this. Our last meeting took place during the EULAR congress in Madrid. All interested PARE youth representatives were invited. First we had a short inspirational presentation of the project and survey, and then the youth representatives brainstormed how the survey could be promoted in different countries.



Photos: Youth research project meeting in EULAR Congress (Madrid 2013)

Participants - The link to the survey was distributed broadly using a variety of methods. For the promotion of the survey, Task Force members and other youth representatives created a logo and built a special project website (www.youngpare.org). Young volunteers were very committed and supported our Task Force a lot. Existing youth organisations and PARE organisations put the link of the survey on their websites. Also a number of health professionals supported the distribution of the link through their networks. Other means were publication of a short project overview and the survey link in the PARE newsletter e-Breakthrough, and Facebook was used. Locally, the Estonian team for example invited young people to participate through internet, Facebook, rheumatology society, physiotherapists' society, social workers, youth organisations, public events, Estonian Rheumatism Association network and other disease specific groups. In total the link was open for 11 weeks. Task Force members were actively involved in promotion and all the promotion was done on voluntary basis.

Data cleaning and analysis - The survey results were presented for analysis in 18 separate different-language Microsoft Excel tables. For easing analysis the format of all tables was unified. Texts of all 18 questionnaires and Internet-based dictionaries were used for ascertainment of comparability of the responses. From all tables, the records where Q1 (Do you have a rheumatic and/or a musculoskeletal condition) was answered as "No", and where the response to Q3 (Age) did not fall to the desired range (from 18 to 35), were removed. The

remaining responses were combined in to one table; column headings in English were used. With the aid of the questionnaires the responses were translated and coded. The records with no information but demographic data were dropped.

The final database was transferred to statistical program Stata 11.2 for further analysis. All variables were named and labelled according to Stata working principles. Some new variables were generated by grouping the existing ones.

For description of qualitative data frequency tables with percentage calculations were used. Bar plot was utilised for illustrative purposes. For qualitative data summary statistics describing central tendency and distribution (mainly mean and standard deviation) were applied; variable distribution was illustrated by histogram. The associations between variables were tested by either Chi-squared or Fisher exact test (in the case of qualitative data); distribution of quantitative variables in groups was compared using Wilcoxon rank-sum or Kruskal-Wallis tests. The difference was considered as statistically significant at probability level $p < 0.05$.

First preliminary data was used as an input and starting point for the youth workshops in EULAR Autumn Conference for PARE (November 2013, Reykjavik) together with European Patient's Forum (EPF) youth strategy example. Outcomes from the workshops are taken into account in conclusion and recommendation parts.



Photos: Youth workshops in EULAR Autumn Conference for PARE, Reykjavik, Nov 2013

3. Results

This chapter is structured as follows. First we present the final outcomes of the mapping exercise (3.1). Then we introduce the response numbers and characteristics of the interviews and focus groups participants (3.2) and the European survey participants (3.3). The combined findings of from the different research phases are presented in section 3.4. These findings are organized around six categories that were reviewed and agreed at the face-to-face youth meeting. These categories were used for survey design and validated by the survey.

3.1 Youth activities in Europe: current status

To identify to what extent PARE organisations have activities for and by the young patient group, a mapping exercise was performed. The results give insight in the infrastructures for youth with RMDs in PARE organisations. 40 PARE organisations participated: 37 PARE members and 3 European disease specific umbrella organisations.

Youth groups - The mapping exercise showed that 22 countries reported some form of activities for young people with RMDs. In 16 countries no activities were reported. The form in which the activities are organised varies. In 7 countries an independent youth organisation exist (Austria, Cyprus, Denmark, Estonia, Netherlands, Poland, Sweden). The term 'organisation' might be misleading, because sometimes the younger people are organized in other forms of groups, networks or communities. In 5 countries (Germany, Ireland, Norway, Slovakia, Switzerland) the youth organisation or group is a separate group or organisation integrated in the *mother organisation* (PARE member). In 10 countries separate activities are organized for youngsters by the mother organisation (PARE member) but there is no youth group (Flanders, Belgium, Greece, Iceland, Latvia, Macedonia, Romania, Serbia, Slovenia, UK). This is also the case for the Federation of European Scleroderma Associations (FESCA). Finally, in two countries, activities for youngsters are in preparation (Malta, France). Deta

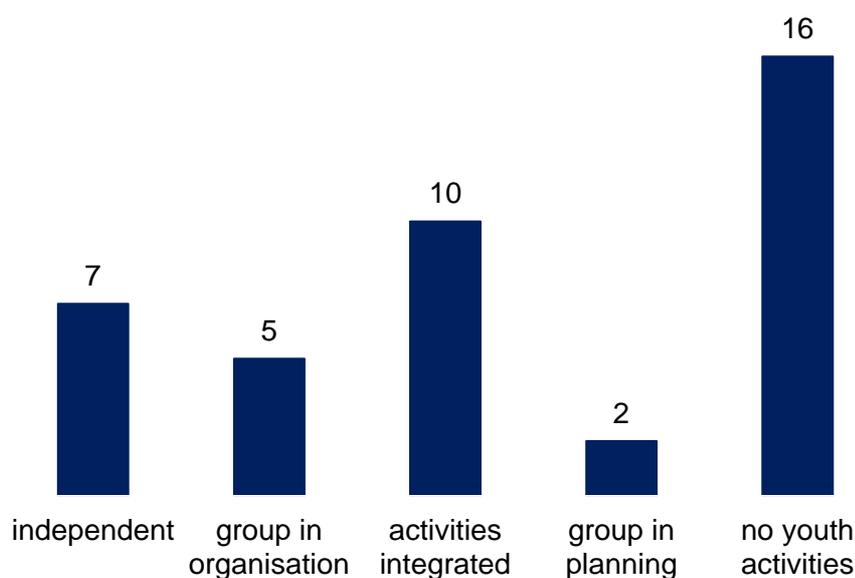


Figure 1: Number of organisations by different modes of youth activities (N=40)

Age range - This inquiry is a first attempt to map out existing youth work in Europe systematically and has also shown that the definition of “youth group”, and the range of ages involved, varies considerably from country to country (see table 3).

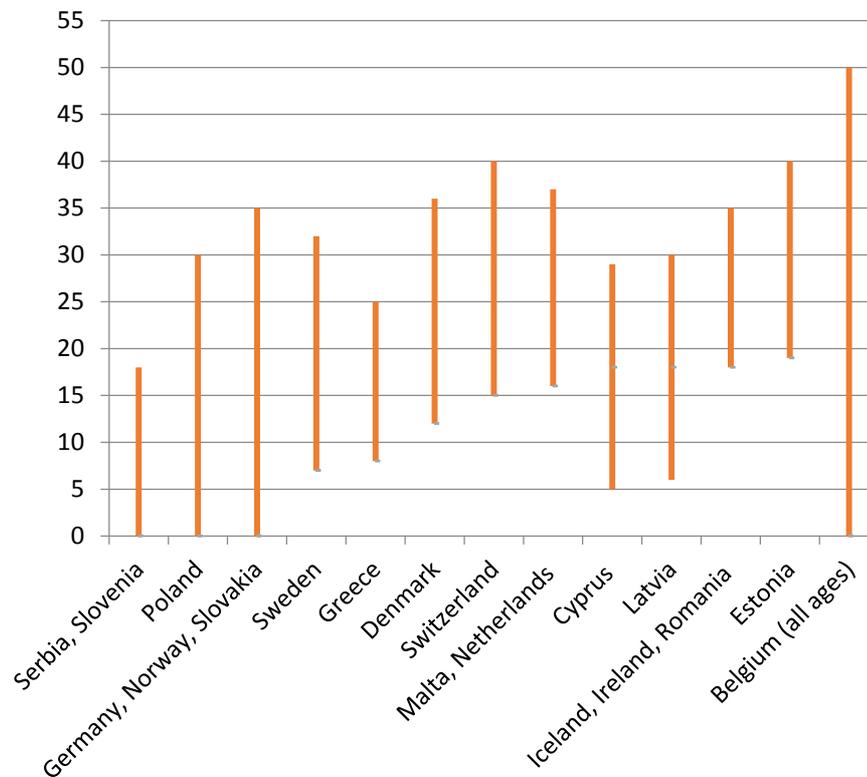


Table 2: Range of ages of youth group (N=19)

Members and activities - The participants of the mapping exercise provided information about the number of registered members (see table 4). Not all participating youth groups have registered members, for instance the community Youth-r-Well.com in the Netherlands has regular visitors of the website and their activities, but they don't pay a member fee and no formal registration takes place.

Members	Countries
0-10	Austria, France, Latvia, Macedonia, Malta, Romania, Slovenia, Switzerland
10-50	Estonia, Greece, Iceland, Ireland
50-100	Cyprus, Poland, Serbia
100-500	Denmark, Germany, Slovakia,
500-1000	
> 1000	Sweden

Table 3: Number of members per country

One group has an office with one employee. Many groups communicate through social media (Facebook, online contact, internet forums, and twitter) and have their own website or a webpage on the site of their mother organization.

The activities that were reported showed a great diversity: Workshops, educational activities, social events, weekend seminars, lectures, awareness-raising events, political lobbying, group therapy, independence breaks, positive futures workshops, family gatherings, youth weekends, annual conference, and psychological support after diagnosis, re-socialization, rehabilitation (self-management) courses and creative play.

The gathered data about youth groups is included in the annual EULAR directory of PARE organisations. For the future additional research is needed to complete the overview and to fill in the blank spots.

3.2 Interviews and focus group responses and characteristics

During the interviews and the focus groups, representatives of the target group identified many topics that are important from their perspective. In total 20 individual interviews and 2 focus group discussions with 7 participants took place. They gathered the experiences of 6 men and 21 women in the age of 19 to 34. For the characteristics of the participants see Table 4. We expected to reach to more young people (40), but our national researchers faced many problems with focus group interviews. Young people did not want to share their experiences with others and they preferred individual interviews.

Country		female	male	age range	non members	total	Diagnose
Cyprus	Interviews	3	1	25 – 34	1	4	RA 3
	Focus group	3	0	27-34	0	3	JIA 4
Sweden	Interviews	1	1	27,34	1	2	Fm 3
	Focus groups	4	0	24-32	3	4	SLE 6
Netherlands	Interviews	3	1	21 - 30	2	4	OA 1
Estonia	Interviews	5	2	23 - 34	3	7	PsA 1
Netherlands	Interviews	2	1	19 - 33	2	3	AS 1
	TOTAL	21	6	19 - 34	12	27	Others 2

Table 4: Characteristics of participants in interviews and focus groups; RA (Rheumatoid Arthritis), JIA (Juvenile idiopathic Arthritis), Fm (Fibromyalgia), SLE (Systematic Lupus Erythematosus), OA (Osteoarthritis), PsA (Psoriatic arthritis), AS (Ankylosing Spondylitis), MTD (Mixed Tissue Disorder), ReA (Reactive arthritis)

The interview questions covered the impact of the disease, the needs and barriers that young people experience in daily life. Through content analysis of the interviews, focus group reports, the discussions and outcomes of our face-to-face meeting, the Task Force came up with 6 main categories:

- Me, Myself & I
- Health care
- Education
- Work
- Social life
- Family and intimacy

3.3 Survey responses and characteristics

In total 3,501 response attempts were collected. Because of the respondent not having RMD or not belonging to the target age group from 18 to 35 years, 1,100 respondents were withdrawn from the database. The numbers of respondents without RMD or not belonging to the targeted age group are shown in table 5. Seventy two responses were not used in analysis due to excessive missing data. Therefore, the final analysis used data of 2,329 respondents (66.4% from all response attempts). Many respondents were in requested age group, but “healthy”. Surprisingly high number of respondents was over 35 years. The following flow chart gives a more detailed overview.

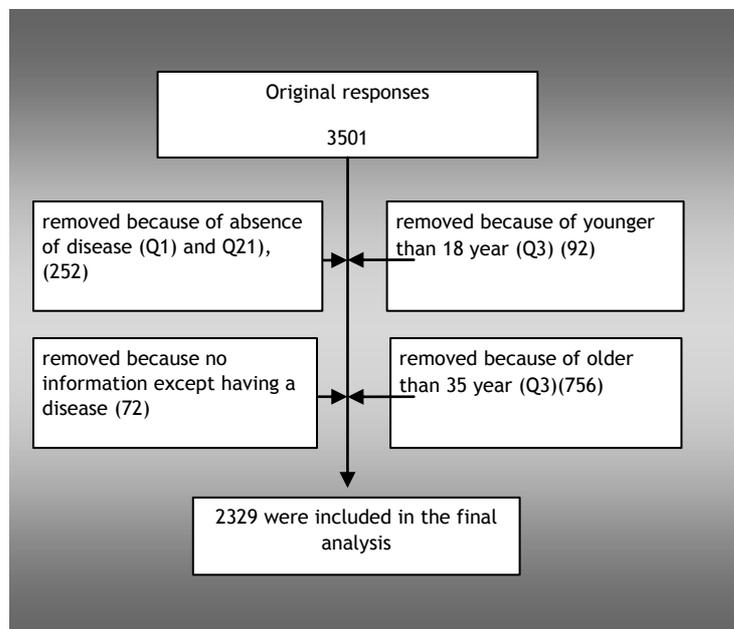


Table 5: Collected data and reasons for exclusion

Language	Collected	No RMD	Not in target age
Bulgarian	102	2	41
Dutch	376	10	29
English	684	55	89
Estonian	79	29	11
Finnish	65	5	6
French	893	70	353
German	253	12	60
Greek	97	12	17
Icelandic	110	4	23
Italian	130	7	38
Macedonia n	35	5	4
Polish	41	3	11
Portuguese	96	8	31
Romanian	46	1	19
Serbian	102	4	21
Slovak	82	5	20
Spanish	133	7	51
Swedish	177	13	24
Total	3501	252	848

Table 6: Number of responses withdrawn from analysis due to respondent not having a RMD or not belonging to targeted age group by response languages

The respondents represented 41 European countries. For analysis purposes, the countries were grouped in five regions. Figures demonstrate the distribution of responses by countries and regions and what was left for analysis (N=2,329). In 23 cases the data on respondent's country was missing.

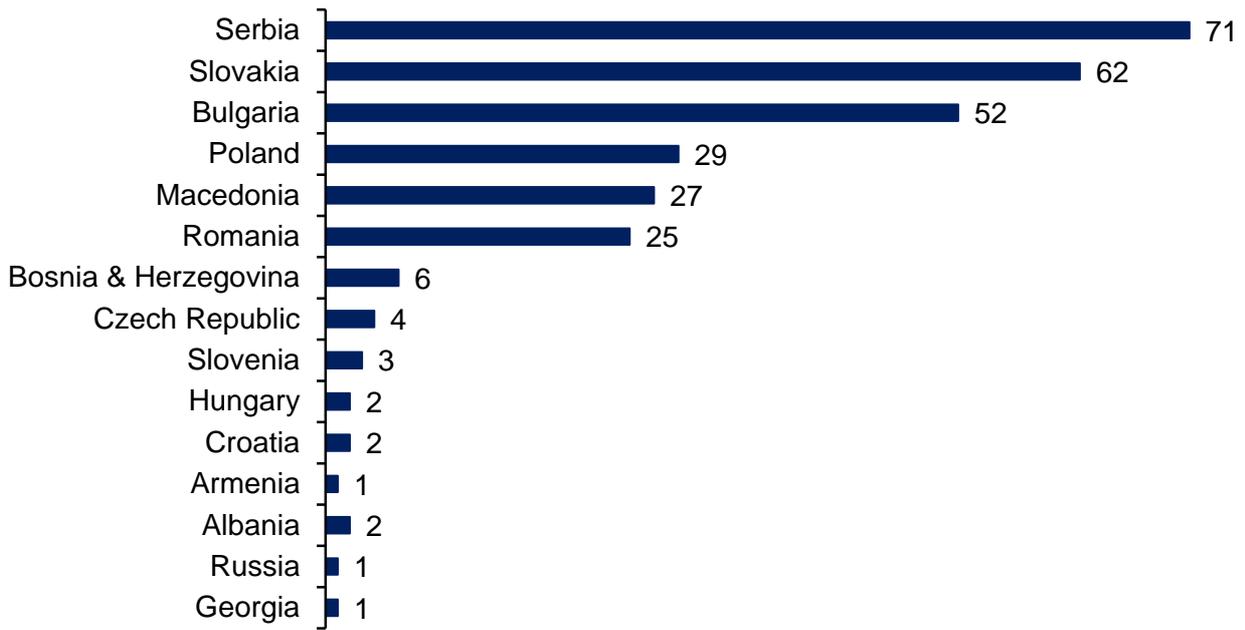


Figure 2: Number of participants by countries, East Europe (N=288)

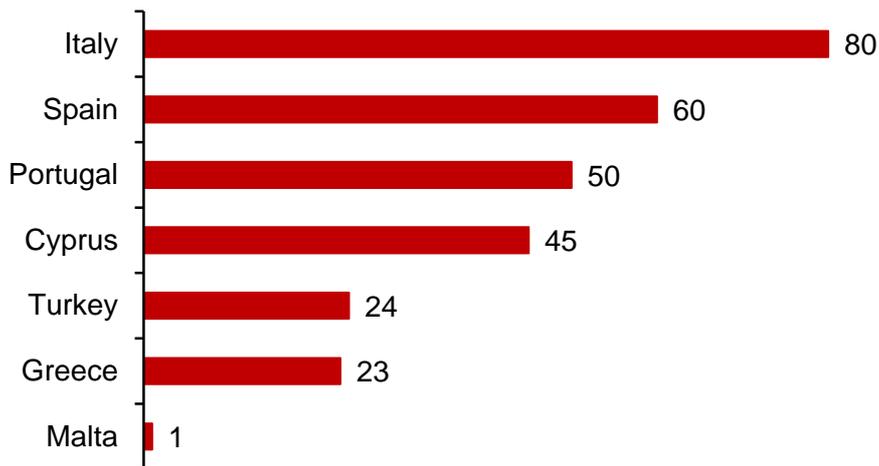


Figure 3: Number of participants by countries, South Europe (270)

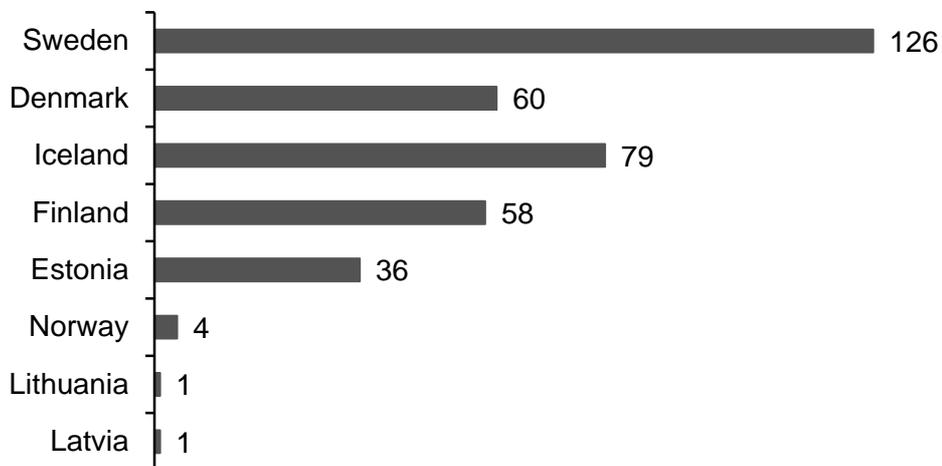


Figure 4: Number of participants by countries, North Europe (N=365)

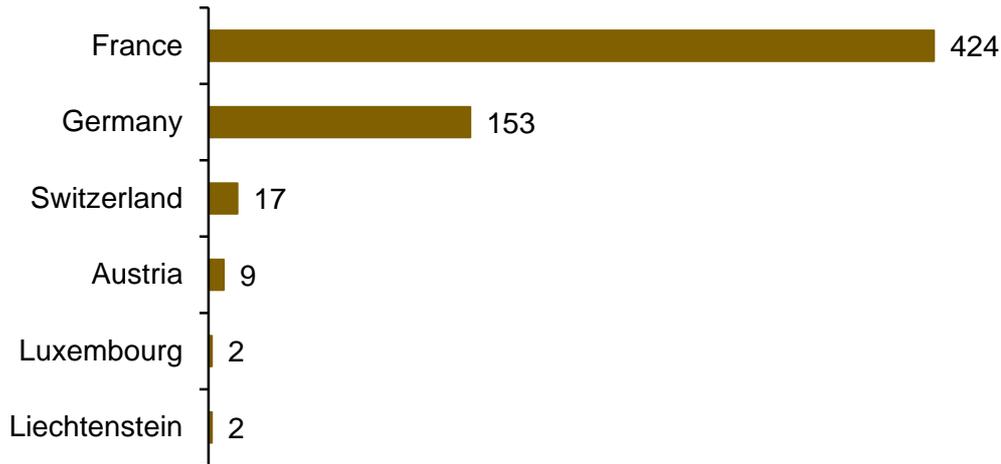


Figure 5: Number of participants by countries, Central Europe (N=607)

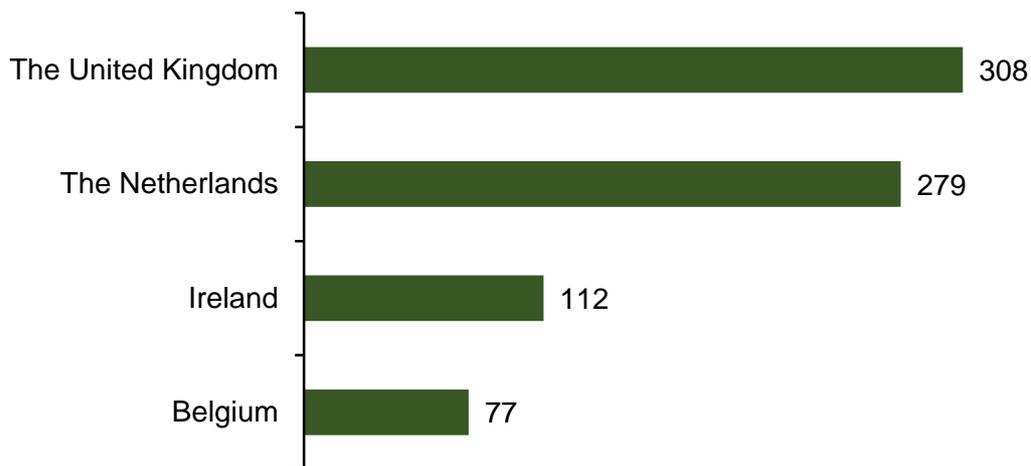


Figure 6: Number of participants by countries, West Europe (N=776)

The mean age of respondents was 28.0 (SD=5.1) years. The distribution of age showed a general tendency, where the number of responses increased with an increase in the respondents' age (Figure 7). There was remarkable peak at age 35 (257 (11.0 %) responses).

To have a better understanding of our target group needs, obstacles, preferences and priorities, we also compared data from different age groups (less than 25, 25-30 and more that 30 years), gender, living conditions, children etc.

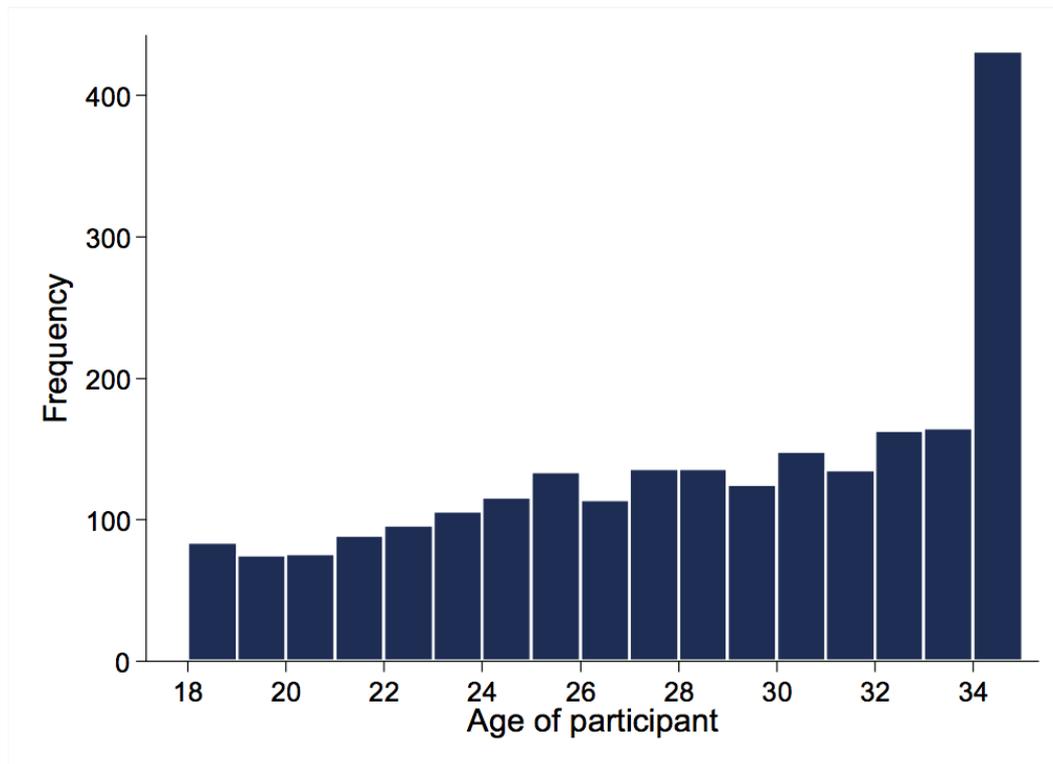


Figure 7: Distribution of the age of the participants

A majority of the respondents (72%) reported having one RMD, 184 did not fill in the number of RMDs, and other respondents reported from 2 to 6 conditions (Table 7)

Number of RMDs	Number of respondents	Percentage	Cumulative percentage
0	184	7.9	7.9
1	1,667	71.6	79.5
2	336	14.4	93.9
3	99	4.3	98.2
4	34	1.5	99.6
5	5	0.2	99.8
6	4	0.2	100.0
Total	2,329	100.0	

Table 7: Number of RMD reported by the respondents

We analyzed following diagnosis:

- Rheumatoid arthritis (RA)
- Fibromyalgia (FM)
- Ankylosing spondylitis (AS)
- Other rheumatic conditions (other RMD)
- Juvenile idiopathic arthritis (JIA)
- Psoriatic arthritis (PSA)
- Low back pain (LBP)
- Systemic lupus erythematosus (SLE)
- Osteoarthritis (OA)
- Systemic scleroderma (sclerosis) (SS)

The condition reported most often was rheumatoid arthritis, followed by fibromyalgia. The distribution of the reported conditions was quite different by regions (Table 8); most remarkable was the difference for fibromyalgia varying from 1% in East Europe to 33% in West Europe.

Region	RA	JIA	AS	OA	SLE	FM	SS	PSA	LBP	Other	Missing
East Europe	108 (38)	47 (16)	66 (23)	4 (1)	20 (7)	3 (1)	5 (2)	10 (4)	5 (2)	21 (7)	24 (8)
South Europe	75 (28)	32 (12)	51 (19)	8 (3)	30 (11)	56 (21)	6 (2)	25 (9)	22 (8)	34 (13)	20 (7)
North Europe	95 (26)	61 (17)	34 (9)	24 (7)	49 (13)	68 (19)	2 (1)	38 (10)	38 (10)	58 (16)	28 (8)
Central Europe	112 (19)	80 (13)	200 (33)	31 (5)	9 (2)	184 (30)	2 (1)	47 (8)	33 (5)	55 (9)	41 (7)
West Europe	220 (29)	57 (7)	103 (13)	31 (4)	38 (5)	253 (33)	8 (1)	60 (8)	71 (9)	131 (17)	49 (6)
missing	0	0	1	0	0	0	0	0	0	0	22
Total	610 (26)	277 (12)	455 (20)	98 (4)	146 (6)	564 (24)	23 (1)	180 (8)	169 (7)	299 (13)	184 (8)

Table 8: Number and percentage of reported Rheumatic or Musculoskeletal Disease by region

Main demographic characteristics by regions are presented in Table 9. Respondents were more from central-western Europe and there is difference in gender. Men are more active in Eastern Europe and women in North and West Europe.

Region	Frequency (%)	Female (%)	Member of organisation (%)	Mean age, years (SD)
East Europe	288 (12)	210 (73)	96 (33)	28.9 (5)
South Europe	270 (12)	231 (86)	89 (33)	29.4 (5)
North Europe	365 (16)	329 (90)	145 (40)	27.3 (5)
Central Europe	607 (26)	520 (86)	240 (40)	28.3 (5)
West Europe	776 (33)	702 (91)	220 (28)	27.3 (5)
Missing	23 (1)	14 (61)	1 (4)	28.3 (5)
Total	2,329 (100)	2,006 (86)	741 (34)	28.0 (5)

Table 9: Distribution and main characteristics of respondents by regions

Eighty six per cent of the respondents were women and 34% reported any form of involvement in activities of a patient group or organisation (39% of women and 30% of men, $p=0.006$). A majority of respondents involved in the organisations were women, older, and having fewer children than non-members.

One of our aims was to include unorganised young people who are often difficult to reach. Our final response analysis indicated that more than half of the respondents (66%) did not belong to any group. We also asked the respondents whether they would like to receive information about the local patient group. Almost all wanted to receive the information and in the follow up project we will continue working on this data together with the national PARE organisations.

Characteristic	Participation in patient organisation		
	no	Yes	p-value of difference
N	1323	791	
males, n(%)	200 (15)	86 (11)	0.006
mean age years (sd)	27.8 (5)	28.4 (5)	0.021
have children, n(%)	403 (31)	207 (26)	0.036

Table 10: Distribution and main characteristics of respondents by involvement in patients' organisation

3.4 Combined findings of the PARE youth research project

In this paragraph we present the combined outcomes of the interviews and the survey, and illustrate the results by the quotes that were derived from the interviews and focus groups. After analysing and interpreting the results at their face-to-face meeting, the youth Task Force clustered the results into the following six main categories:

- 1 Me, myself and I
- 2 Health care
- 3 Education
- 4 Work
- 5 Social life
- 6 Family life and intimacy

To have a better understanding of our target group needs, obstacles, preferences and priorities, we compared the data from different age groups (younger than 25, 25-30 and older than 30 years), gender, living conditions, children etc.

Our survey was translated into 18 languages, but we had responses from 41 countries. We made a country groups and compared the data between regions.

In every theme we will focus first on the outcomes from the qualitative research that we wanted to validate. The statistical analysis shows the differences between regions or specific categories of the young people and gives an insightful overview of the everyday life of the young people with a RMD.

3.4.1 Me, myself and I

Main outcomes from the interviews:

- Fear not to be accepted as a full member of society, to be taken serious.
- Preference not to talk about the disease and related consequences.
- "The good girl complex" - Underreporting of pain and barriers, as a result of not wanting "to cause trouble"
- I am a leader of my life and feel good
- Do not know how and to whom I can talk about my condition
- Support groups are a great source of information

The survey confirmed that more than half of the respondents are never (7%) or only sometimes (44%) satisfied with their life, feel that they cannot achieve important goals in their life (53%) or do not feel that they often have control over their lives (61%). 55% never or only sometimes feel optimistic about their future. These results are presented in the Figure (8).

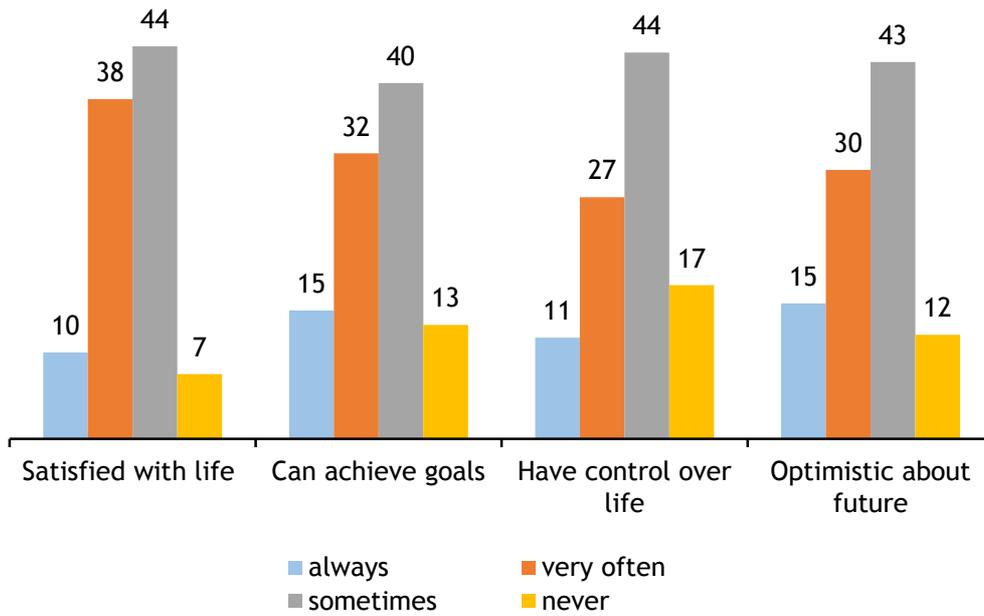


Figure 8: Percentages of respondents by the answers to the questions “I feel satisfied with my life”, “I feel that I can achieve important goals in my life”, “I feel that I have control over my own life”, and “I feel optimistic about my future”.

Only 32% of the respondents do not feel hampered to talk about their disease with others. Majority (69%) of the respondents prefer not to talk about the condition (Figure 9). A majority (58%) of the respondents does not talk about their condition with strangers (Figure 10). More than one third (36%) prefers not to talk about their condition at work or during a job interview. Almost a quarter of the respondents (22%) do not talk about their condition at school and with friends. 17% of the respondents do not talk about their condition with the family.

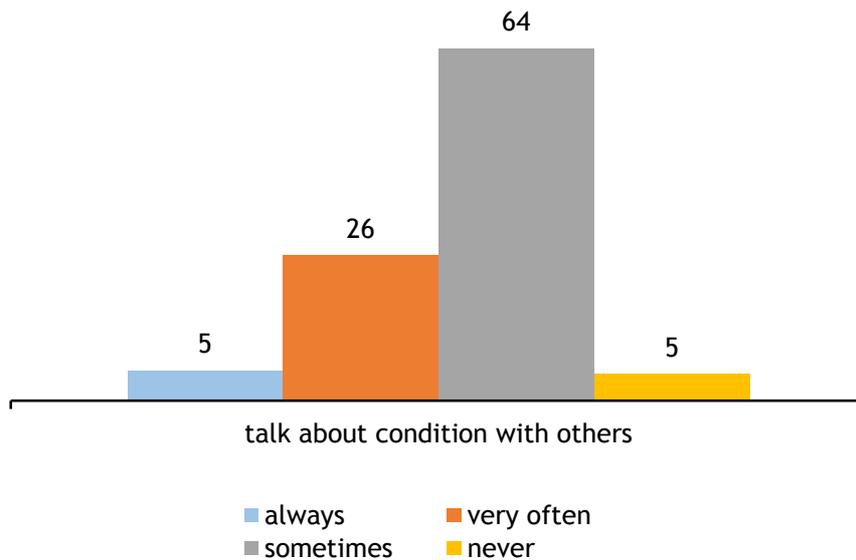


Figure 9: Percentage of respondents by frequency they talk about their condition with others

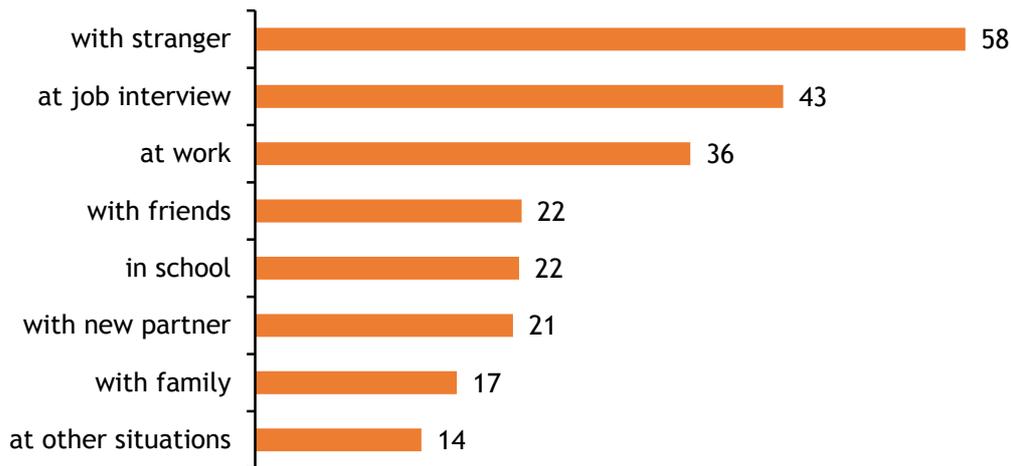


Figure 10: Percentages of the respondents preferring not to talk about their condition in specific circumstances

In total 85% of young people feel disadvantaged if others know about their disease (Figure 11). About a half (53%) of the respondents consider themselves being sometimes disadvantaged if others know about their condition. 31% feel that they are always or very often disadvantaged. Only 15% does not feel any difference.

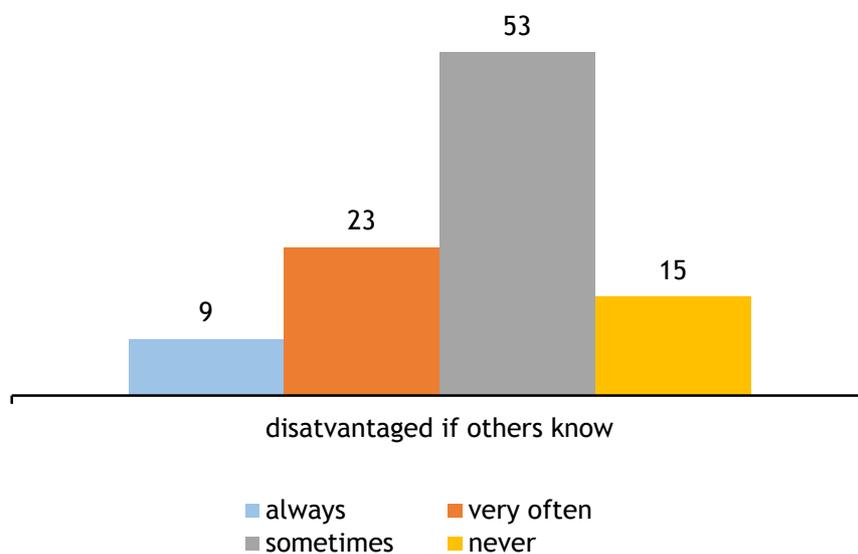


Figure 11: Percentages of the respondents by the perception of frequency of being disadvantaged if others knew about their condition.

Respondents who are members of the patients’ organisations talk about their condition more often than those who are not (Table 11).

The frequency of talking about the condition with others does not depend on the diagnosis among those who report one condition ($p=0.388$). Female respondents talk more frequently than men about their condition (Table 12)

Involvement in patients' organisation	Talk about condition with others, n (%)				Total
	always	very often	sometimes	never	
no	60 (5)	292 (22)	883 (67)	82 (6)	1,317 (100)
yes	54 (7)	261(33)	454 (58)	18 (2)	787 (100)
Total	114 (5)	553 (26)	1,337 (64)	100 (5)	2,104 (100)

Table 11: Frequency of talking about condition by involvement in patients' organisation ($p<0.001$)

Gender of respondent	Talk about condition with others, n (%)				Total
	always	very often	sometimes	never	
female	103 (6)	509 (27)	1,162 (63)	85 (4)	1,859 (100)
male	13 (5)	53 (18)	204 (71)	18 (6)	288 (100)
Total	116 (5)	562 (26)	1,366 (64)	103 (5)	2,147 (100)

Table 12: Frequency of talking about condition by gender ($p=0.006$)

Young people said:

- *"I don't know if it is possible to 100% accept that it is happening to me."*
- *"First couple of years were complicated, but it was as it was all together – disease, school, broken dishes, not managing things. It took a few years to learn to live with it."*
- *"Masculinity ideals, creates great distance, we talk all about being young and sick, but it also means something to be a man and to have a rheumatic disease. You get to hear that it's a bitch disease..."*
- *"I think the biggest influence my disease has had on me is that I am very tolerant"*
- *"I am mentally trying to get used to the idea that things might go differently of what I expected for the rest of my life."*
- *"Sometimes you just need to pull yourself together and manage. It helps if you think positive and try to do as much as you can."*
- *"There are plenty of times when I let my limits go, just because I have something like 'I am a student, I'm only young once, I want to try the things I can do"*

- *“There have been times where I had to give up a lot, but when its better I do everything. I don’t feel that there are many things undone.”*
- *“Rather the problem is that there is feeling that I cannot leave anything undone now. Cause there is the feeling that maybe soon the disease is bad again and then I cannot do anything.”*
- *“This has given courage to me to face my disease. At the beginning I was afraid to talk about it and it is easier to people in the same situation. They understand. When I talk to other people, they only react how horrible it is. It is very different who you talk about it. In the association I understand them and they understand me.”*
- *“There could also be events for children, where they are explained in a simple way. Maybe there could be materials about how to tell children. It’s a complicated thing.”*
- *“I need to learn to talk about rheumatism when it does something to me. It is difficult, but I may find a way”*
- *“The feeling of doubt that you get from other people – teachers, friends, doctors, is a big barrier that can make you cautious and closed.”*
- *“Rheumatism is a hidden disability, that you don’t look sick, and what are you talking about or how will I know that you are feeling good or bad. There is a lot of this kind of attitude.”*
- *“I tell to people now what I have. But I choose. I think not knowing creates rumours, attitudes, thoughts etc.”*

3.4.2 Health care

Outcomes from the interviews:

- Finding the right diagnosis, treatment and medication are outstanding factors for one’s health and quality of life.
- Lack of access to rheumatologists causing difficulties in getting specialist care.
- Inequalities of health care, for instance differences in access to specialist and physiotherapeutic options and activities between (larger) cities and countryside.
- More information about the disease, medication and communication between health professionals.
- Patient groups are a great source of medical information and support.
- Belonging to the patient group gives me better access to rheumatologists and information.

Table 13 compares the mean age at symptoms beginning, mean time from symptoms to diagnosis and accessibility of rheumatologist by regions. The difference between mean age at symptom onset is not significant between regions, whereas the mean time between first symptoms and diagnosis and access to rheumatologist differs significantly; the longest time from symptoms to diagnosis and lowest percentage of respondents with good (always or very often) access to rheumatologist characterise West Europe.

Region	Mean age at onset of disease symptoms, years (SD)	Mean time from first symptoms to diagnosis, years (SD)	Access to rheumatologist always or very often (%)
East Europe	17.5 (8)	2.0 (3)	203 (71)
South Europe	17.9 (9)	3.6 (5)	196 (73)
North Europe	16.7 (8)	3.3 (4)	241 (66)
Central Europe	17.9 (8)	4.0 (5)	393 (65)
West Europe	17.1 (7)	4.7 (5)	423 (55)
missing	27	11	0
Total	17.4 (8)	3.3 (5)	1,456 (63)

Table 13: Mean age at onset of disease symptoms, mean time to diagnosis and accessibility of rheumatologist by regions.

There is no statistically significant difference between age at symptoms beginning ($p=0.0622$) by regions; there is a statistically significant difference between the time to diagnosis ($p<0.001$) and between access to a rheumatologist ($p<0.001$) by regions.

Access to the rheumatologist exists almost always for 63% of the respondents. About 10% ($n=209$) report having no access to the rheumatologist. Almost all respondents (98%) reported their condition being diagnosed by the rheumatologist. Access to the rheumatologist was associated with the diagnosis among the patients who reported one RMD ($p<0.001$, Table 14), with the highest percentages having access always or very often for the young people with juvenile idiopathic arthritis, and remarkably worse access for the fibromyalgia patients in comparison with other named conditions.

Data shows that patients with more common diseases have better access to the rheumatologists. Patients with fibromyalgia and low back pain are more likely to have limited access to the rheumatologists.

Condition	Access to a rheumatologist				Total
	always	very often	sometimes	never	
RA	274 (62)	88 (20)	69 (16)	10 (2)	441 (100)
JIA	123 (67)	40 (22)	18 (10)	2 (1)	183 (100)
AS	187 (54)	81 (24)	66 (19)	11 (3)	345 (100)
SEL	66 (61)	23 (20)	17 (16)	3 (3)	109 (100)
FM	38 (13)	44 (15)	125 (42)	92 (30)	299 (100)
PSA	74 (64)	22 (19)	18 (16)	1 (1)	115 (100)
Other	61 (37)	21 (13)	49 (30)	34 (20)	165 (100)
Total	823 (50)	319 (19)	362 (22)	153 (9)	1,657 (100)

Table 14: Accessibility of rheumatologist by conditions (osteoarthritis, systemic sclerosis and low back pain were added to “other” category)

A similar pattern can be observed when comparing the mean time between onset of first disease symptoms and the diagnosis ($p < 0.001$). This period is the shortest for the people with juvenile arthritis and the longest for the people with fibromyalgia. This is shown in table 15.

Condition	Mean time from symptoms to diagnosis, years (SD)	Number of respondents
RA	1.7 (3)	439
JIA	0.9 (2)	183
AS	4.7 (5)	344
SEL	2.6 (4)	108
FM	5.5 (5)	300
PSA	3.0 (4)	114
Other	5.0 (6)	167
Total	3.4 (5)	1655

Table 15: Mean time from first symptoms to diagnosis by conditions (osteoarthritis, systemic sclerosis and low back pain were added to “other” category)

During interviews many respondents stated that due to belonging to a patient organisation, they were more informed and had better access to the rheumatology care. Members of patient organisations have somewhat better access to the rheumatologists than non-members (Table 16). The survey results confirmed our initial theory.

Involvement in patient organisation	Access to rheumatologist, n(%)				Total
	always	very often	sometimes	never	
no	599 (46)	252 (19)	322 (25)	142 (11)	1,315 (100)
yes	423 (54)	143 (18)	167 (21)	55 (7)	788 (100)
Total	1,022 (49)	395 (19)	489 (23)	197 (9)	2,103 (100)

Table 16: Access to rheumatologist by involvement in patient organisation ($p=0.001$)

There is no statistically significant difference between the age and beginning of symptoms ($p=0.0622$) but there is a statistically significant difference between the time to diagnosis ($p<0.001$) and access to the rheumatologist ($p<0.001$) (Table 17)

Region	Mean age at symptoms (SD)	Mean time from symptoms to diagnosis (SD)	Access to rheumatologist always or very often (%)
East Europe	17.5 (8)	2.0 (3)	203 (71)
South Europe	17.9 (9)	3.6 (5)	196 (73)
North Europe	16.7 (8)	3.3 (4)	241 (66)
Central Europe	17.9 (8)	4.0 (5)	393 (65)
West Europe	17.1 (7)	4.7 (5)	423 (55)
Missing	27	11	0
Total	17.4 (8)	3.3 (5)	1,456 (63)

Table 17: Mean age at symptoms beginning, Mean time to diagnosis and accessibility of rheumatologist by regions.

Young people said:

- „I have had three mothers – my mother, my rheumatologist, my psychologist.“
- “When I got lupus diagnosis, it was a relief, as it was a solution. I was even happy. It gave finally some explanation to things.”
- Money is a problem. One thing is to exercise alone at home, but other thing is in a group with a trainer. It would be good if there was support for doing sports.”
- „I have gone through depression, anti-depressants, psychologist etc. This goes with the diagnosis, but maybe it does not. I don’t know.“
- “I remember the first time I was diagnosed with RA, I was given a book “ABC of Rheumatic disease” to read. I thought that my life is over, but then it started slowly getting better again. I read what I cannot do or might become, what can happen to my body.... how much you have to bear. It was very depressing, very very depressing.”
- “In itself, the care from the hospital is good, but mainly focused on drugs. They take study or social life not really into account.”
- “I could not get out of bed or could only crawl. Then I went to my family doctor, who sent me to a county hospital rheumatologist. She asked me what I take, I said baby pills, the doctor said to stop and come back in 2 months. But I said that I am in pain and I can’t handle it anymore. I waited another month and it got worse and my mouth took me again to the family doctor and said that I wanted to go into town to see a doctor. When I got there, I was put immediately to hospital and they did tests and already suspected lupus. In hospital when I got medication, then immediately the next days my fingers were moving and it was getting better. “
- “I got pregnant, but the doctor did not tell me that with my medication it is not allowed and I did not know to ask. I lost this chance.”

3.4.3 Education

Main outcomes of the interviews:

- RMDs influence studies and causes delay
- There is not enough understanding and awareness among teachers and professors
- Support is very important

Engagement of the respondents at the time of the survey is presented in Table 18. A majority of the respondents (32,6 %) are working full time, followed by working part time (20,1%). Type of engagement varies in different parts of Europe.

Region	Studying part time, n (%)	Studying full time, n (%)	Working part time, n (%)	Working full time, n (%)	Un-employed, n (%)	Sick leave, n (%)	Other, n (%)
East Europe	18 (6)	59 (21)	26 (9)	122 (42)	55 (19)	10 (4)	19 (6)
South Europe	11 (4)	32 (12)	42 (26)	96 (36)	64 (24)	15 (6)	19 (7)
North Europe	38 (10)	84 (23)	85 (23)	113 (31)	37 (10)	53 (14)	31 (9)
Central Europe	24 (4)	71 (12)	103 (17)	201 (33)	118 (19)	73 (12)	63 (10)
West Europe	65 (8)	116 (15)	208 (27)	219 (28)	108 (14)	94 (12)	64 (8)
Total	156 (7)	362 (16)	464 (20)	571 (33)	382 (17)	245 (11)	196 (9)

Table 18: Engagement of the respondents by region

The majority of respondents (69%) had more than 13 years of education (Table 19).

Region	Years of education		
	9 or less (%)	10 to 12 (%)	13 or more (%)
East Europe	13 (5)	71 (27)	179 (68)
South Europe	26 (11)	46 (19)	171 (70)
North Europe	20 (6)	90 (25)	242 (69)
Central Europe	49 (8)	156 (27)	379 (65)
West Europe	67 (9)	143 (19)	534 (72)
Total	175 (8)	506 (23)	1,505 (69)

Table 19: Years of education by region

Sixty five per cent of the respondents (N=1,467; 65%) had a RMD during their studies. From them, 74% reported having delays during their studies (32% always or very often, 42% sometimes). Almost one quarter had never had a delay during their study because of their disease. We did not find a significant difference in delay of studies when we compared gender, age, marital status or living conditions.

What kind of support would have helped young people during their studies? Most of the respondents said that more awareness about rheumatic diseases among teachers would have been very helpful (51 %). This is an important finding because many other needs are directly connected to this: a flexible schedule (46%), adjustable table/chair (30 %), financial support (29%), etc.

The importance of different assistive measures during studies is depicted in Figure 12.

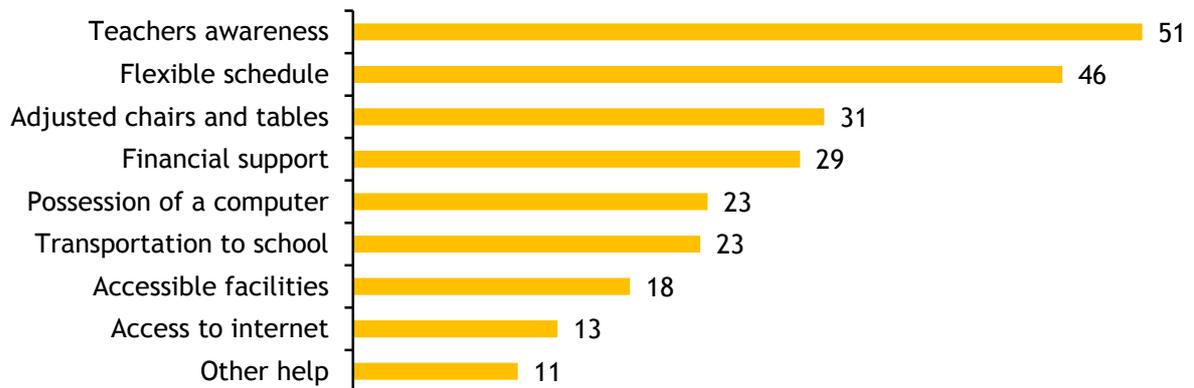


Figure 12: Percentage of respondents who considered specific assistive measure being helpful at school.

Only twenty-nine per cent of those who had RMD during their studies (29%) reported that they were managing/had managed at school without assistance.

More than half of the respondents who had RMD during their studies (58%) reported no teasing at school because of their condition, whereas one-tenth was teased always or very often.

Young people said:

- *“It is up to you”, I was determined to finish school so I did, with better grades than most, but then I crashed and had to stay in bed for over a year”*
- *“I`m lucky that I have an alternative, I have a pretty good brain that I have used from the beginning. I don`t need my body to do something in everyday life.”*
- *“The disease prolonged my education period. I could not do some subjects, when teachers were not flexible, sometimes I was so sick and could not go to seminars, then I could not finish the subject.”*
- *“People might suspect you are simulating or faking. I believe I have experienced it also. In university some professors did not believe and said that young people don`t have this kind of disease.”*
- *“I have experienced a lot of disbelief in education and in the medical system.”*

3.4.4 Work

Outcome from the interviews:

- It is important for young persons with RMDs to be able to work.
- Fear that the employer “might immediately think that you are sick and can’t do anything”
- Many respondents are afraid to reveal their condition and to lose their job because of that.
- RMDs have a huge impact on work ability.

With the survey we wanted to have a closer look on the work issues that came out from the interviews. How much does having one or more RMDs limit the work ability? How many young people are afraid that employers “might immediately think that you are sick and can’t do anything”?

Young people with RMD have many challenges in their life, but most of them have worked and want to work. A majority of the respondents (88%; N=1,952) had been employed at some point of their life. We wanted to know if work ability is affected by the condition and how many young people face it.

In total 95 % of the respondents admit that a RMD has a negative impact on their work ability. More than a half of the respondents (53%) reported their work ability being always or very often affected by the condition, 42% had work ability sometimes affected, and only 5% of the respondents do not feel limited because of their condition (Figure 13). We also looked at gender differences. Work ability is more affected in women (always/often – 54% female vs. 45% male respondents). We could not find a correlation in ability to work and age.

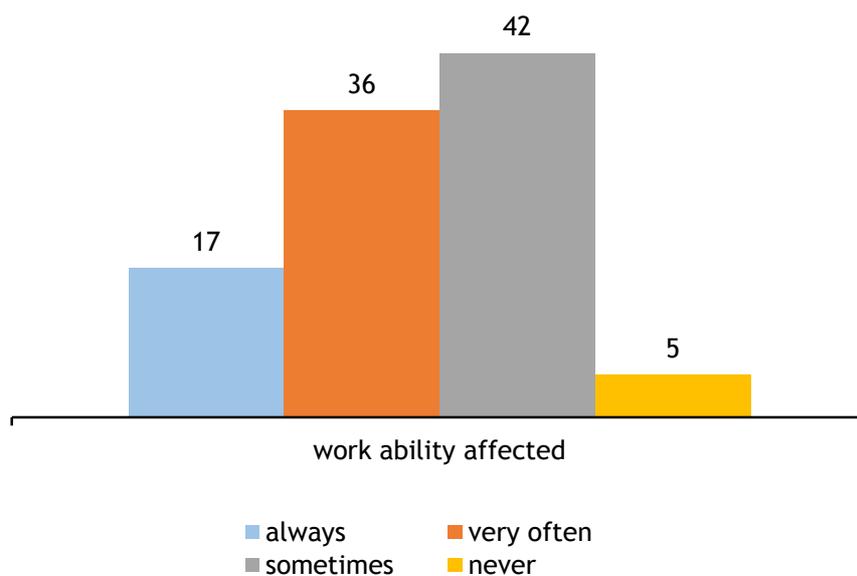


Figure 13: Work ability detailed overview

How do young people manage themselves? Approximately half of the respondents (48%) were always or very often able to support themselves financially; one-fifth reported being never able to support themselves. The main income sources of the respondents are shown in Figure 14.

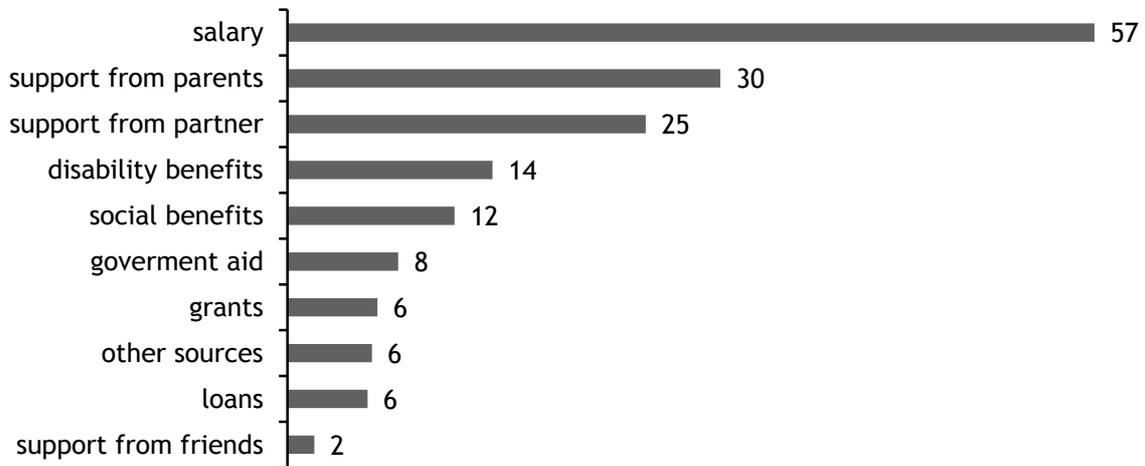


Figure 14: Percentage of respondents who considered specific financial source(s) as their main income

During interviews many participants mentioned that they do not talk about the disease with their boss. We wanted to know the situation in Europe: Do young people inform their boss about their condition before starting a new job?

Distribution of the ever employed respondents by the answers to the questions “Do you inform your boss about your condition before starting a new job?” and “Have you been forced to quit a job due to your condition?” is shown in Figure 15.

35% of respondents always or very often inform their boss about their condition. 38% hide their condition. 55% of the respondents had to stop their paid job partly or entirely due to the disease.

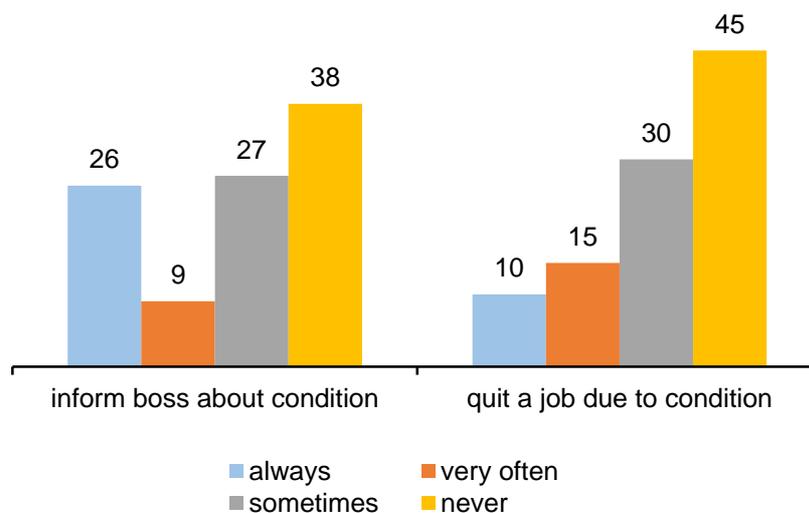


Figure 15: Distribution of the percentages of respondents by answers to the questions “Do you inform your boss about your condition before starting a new job?” and “Have you been forced to quit a job due to your condition?” (N=1,952)

We also analyzed whether there is a difference if you have children. 32% of the respondents with children reported that they always or very often had to quit their job, compared to 21% of respondents without children.

More optimistic people reported much less barriers in work life, only 37% feel that their work ability is always or very often affected. 65% of less optimistic people face the same situation.

Young people said:

- *"I have worked alongside my studies. I really love working, I think work is very important."*
- *"I suffer from fatigue, but working 32 hours is fine for me, I would also like to work 40 hours."*
- *"I've never had to take a day off from work due to illness or fatigue. I have to say that I would never do that".*
- *"Fatigue influences a lot. It is one of lupus symptoms. And it does not help that you sleep. You are all the time like in a bubble and cannot work at all."*
- *"I noticed at first that colleagues said things behind my back, for example if I called in sick. Once during a personal assessment, I was told that there are some functions that I could not fulfil. I thought we were to judge what I could and could not, and not Judge my sick leave."*
- *"Problematic was the combination of attending school, doing the internship, I had a second job and my household: that didn't work out."*
- *"I changed job a number of times, and because I got more responsibility and more freedom, I always managed to work full time. Until a few years ago. My disease progressed, I didn't feel well and I also noticed that I was tired to prove to myself and others that I could do a full-time work week of 60 hours. Over the years you start to realize that you might want a lot, but it does not work out as you want."*
- *"It would be much harder to work in the office. It would not be possible to just lie down for a couple of hours in the office. Of course it would depend of work place."*
- *"It is necessary that employer is flexible and you can take a day off if you can't move or get dressed."*
- *"I have luckily worked always at home. During the whole duration of my sickness"*

3.4.5 Social life

Main outcomes from the interviews:

- Suffering from crossing physical limits or not crossing these limits.
- Not being able to go out with the friends
- Finding alternatives and "real" friends
- Emotionally very hard to cope
- Revise dreams and visions
- Fatigue and pain are the main obstacles that limit daily life
- Patient support (groups) groups are very important

Majority (93%) of the respondents report that RMD interferes with their social life. The social life of 7% respondents is not affected by the RMD. There is statistically significant difference of RMD interfering with social life by regions (Table 20)

Region	RMD interferes with social life, n (%)				Total
	always	very often	sometimes	never	
East Europe	15 (6)	74 (28)	141 (53)	36 (13)	266 (100)
South Europe	33 (13)	82 (33)	111 (45)	23 (9)	249 (100)
North Europe	37 (11)	101 (30)	172 (51)	25 (8)	335 (100)
Central Europe	69 (12)	227 (39)	251 (43)	32 (6)	579 (100)
West Europe	133 (18)	289 (39)	287 (39)	26 (4)	735 (100)
Total	287 (13)	773 (35)	962 (45)	142 (7)	2,164 (100)

Table 20: RMD interfering with social life, difference by regions $p < 0.001$

Almost half of the respondents in all condition categories except for fibromyalgia report that RMDs very often or always interfere with their social life (Table 21). More than half (52%) of fibromyalgia patients answered that their condition very often interferes with their social life and one-fifth even answered that always.

Condition	RMD interferes with social life, n (%)				Total
	always	very often	sometimes	never	
RA	24 (6)	127 (29)	243 (55)	45 (10)	439 (100)
JIA	8 (5)	53(30)	103 (58)	13 (7)	177 (100)
AS	34 (10)	125 (36)	160 (47)	24 (7)	343 (100)
SEL	13 (12)	30 (27)	58 (53)	9 (8)	110 (100)
FM	61 (20)	155 (52)	81 (27)	4 (1)	301 (100)
PSA	4(4)	40 (35)	59 (51)	12 (10)	115 (100)
Other	28 (17)	37 (22)	85 (51)	16 (10)	166 (100)
Total	172 (10)	567 (34)	789 (48)	123 (8)	1,651 (100)

Table 21: RMD interfering with social life, difference by conditions $p < 0.001$

The main obstacles for participation in social activities are pain and fatigue (Figure 16), which interferes with social activities according to approximately 80% of the respondents.

Environmental factors like lack of accessible places and transportation are of less importance.

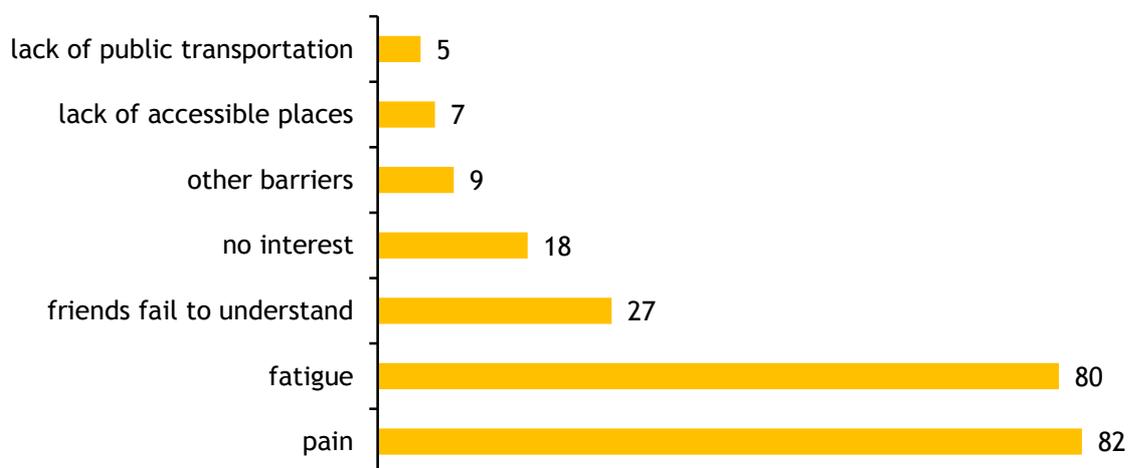


Figure 16: Percentage of respondents who considered specific factor(s) as their obstacles for social life

Ninety two per cent (92%) of the respondents report that their RMD has an impact on their mental health and only 8% report no impact at all by their condition (Figure 17).

Although a high proportion of the respondents (42%) admit that their disease very often or always affects their mental health, the number of people who indicate that they always or very often need psychological support is remarkably lower: 17% (Figure 18). The association between perceived impact on mental health and need for psychological support is illustrated by Table 22.

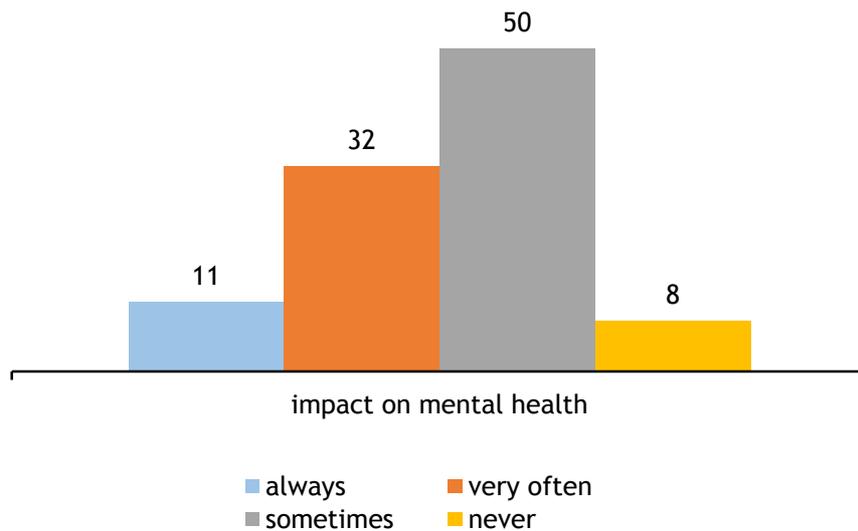


Figure 17: Percentage of respondents by perceived impact of RMD on mental health

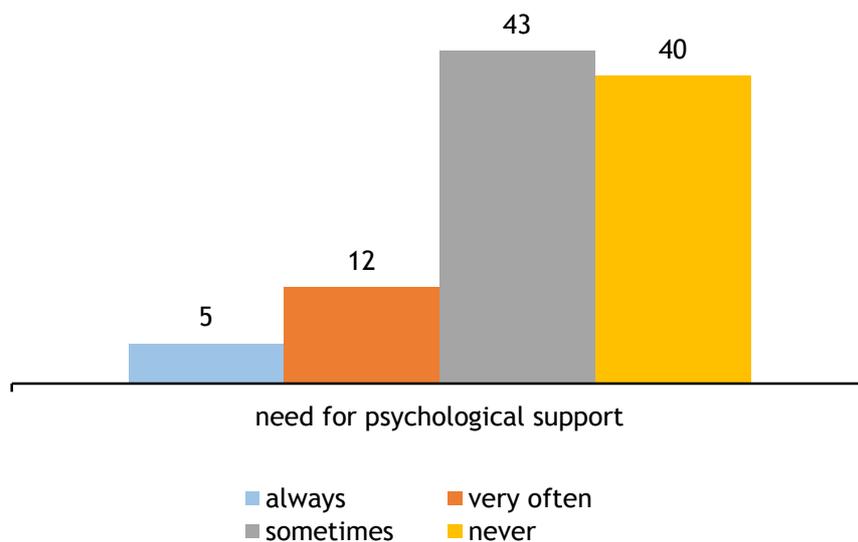


Figure 18: Percentage of respondents by perceived need for psychological support

Impact on mental health	Need for psychological support				Total
	always	very often	sometimes	never	
always	73 (31)	78 (34)	63 (28)	15 (7)	229 (100)
very often	33 (5)	141 (21)	377(55)	125 (19)	676 (100)
sometimes	4 (1)	43 (4)	463 (43)	561 (52)	1,071 (100)
never	0	2 (1)	18 (11)	146 (88)	166 (100)
Total	110 (5)	264 (12)	921 (43)	847 (40)	2,142 (100)

Table 22: The impact on mental health and need for psychological support

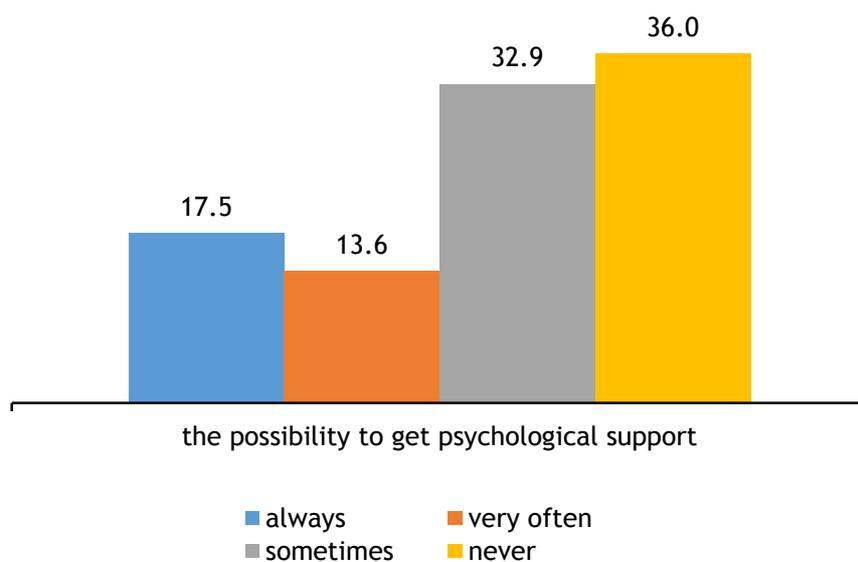


Figure 19: Percentage of respondents by possibility to get of psychological support

The association between perceived need for and possibility to get psychological support is illustrated by Table 23.

Need for psychological support	Possibility to get psychological support				Total
	always	very often	sometimes	never	
always	55 (50)	10 (9)	28 (26)	17 (15)	110 (100)
very often	42 (16)	87 (33)	82 (32)	54 (20)	265 (100)
sometimes	112 (12)	124 (15)	395 (43)	274 (30)	905 (100)
never	154 (19)	64 (8)	185 (23)	408 (50)	811 (100)
Total	363 (17)	285 (14)	690 (33)	753 (36)	2,091 (100)

Table 23: The need for and possibility to get psychological support

The possibility to get psychological support is similar for members and non-members of patients' organisations (Table 24)

Involvement in patient organisation	Possibility to get psychological support, n(%)				Total
	always	very often	sometimes	never	
no	210 (16)	173 (14)	413 (32)	486 (38)	1,282 (100)
yes	150 (19)	106 (14)	268 (35)	249 (32)	773 (100)
Total	360 (18)	279 (14)	681 (32)	735 (36)	2,055 (100)

Table 24: Possibility to get psychological support by involvement in patient organisation ($p=0.051$)

Sixty-seven per cent of the respondents want to get information from their national patients' organisation. The percentage is the same among both members and non-members of the patients' organisation ($p=0.761$). There is no difference between male and female respondents ($p=0.887$). There is statistically significant ($p<0.001$) difference between the wish to have information from national organisations by region (Table 25).

Region	Want information from national organisation, n (%)		
	no	yes	Total
East Europe	54 (21)	205 (79)	259 (100)
South Europe	33 (14)	207 (86)	240 (100)
North Europe	96 (29)	234 (71)	330 (100)
Central Europe	208 (37)	352 (63)	560 (100)
West Europe	307 (43)	411 (57)	718 (100)
Total	698 (33)	1,409 (67)	2,107 (100)

Table 25: The wish to get information from national organisation region

Young people said:

- *“This has given courage to me to face my disease. At the beginning I was afraid to talk about it and it is easier to people with same situation. They understand. When I tell to other people, they only react how horrible it is. It is very different who you talk about it. In the association I understand them and they understand me.”*
- *“I find it very easy to tell that I have arthritis, I do that often with a joke, that makes it easy for people and myself. I find it very difficult to show that I am sometimes sad.”*
- *“Sometimes happens that I cannot stand on the dance floor but I still do and then the next day cannot stand anymore. That is the consequence that I accept. The disease really doesn’t stop me.”*
- *“There are very close people to me who do not understand that one day you feel that you can run a marathon and the next moment you cannot even step out of your own bed.”*
- *“Yes, it is very restricted, but you get used to it too. Even if I believe that I am doing well, I cannot participate in everything I would like. If it goes bad, I can participate very little. You also change your opinion about what you think is good. Some people find it very frustrating if they cannot go to every party, and I'm lucky if I can go to one.”*
- *“I have got a lot of information thanks to the events of the association where I have been. I know there is a lot I don’t know yet.”*

- *“The emotional support that I get in the association is very important.”*
- *“My disease keeps me busy every day, absolutely.”*
- *“Emotional support has been very important – I have got it from mother, husband and friends”*

3.4.6 Family/Intimacy

- Engaged and both financially and emotionally resourceful parents are key-factors for coping disease-related obstacles
- Mothers are the front figures.
- Child wish/Pregnancy is dependent on healthcare assistance.
- Relationships are important - husbands and boyfriends
- Sexuality – hardly reported.
- Feelings of loneliness
- The impact of the disease is highly dependent on what type of support the patients receive in their daily life.
- Partners and family members do not understand the disease

Survey gave data that majority (71%) of the respondents had no children; the proportion of not having children was similar for male (73%) and female (70%) respondents ($p=0.380$). Of those having children, 87% had one or two children; the biggest number of children was 7. Living situations of the respondents are described in Table 26. Half of the respondents (50%) lived with a partner, almost one-fourth with parents. Living situations differed between regions.

Region	Living situation				
	Alone (%)	With partner (%)	With friend (%)	With parents (%)	Other (%)
East Europe	34 (12)	124 (43)	13 (5)	104 (36)	11 (4)
South Europe	32 (12)	119 (45)	6 (2)	98 (37)	11 (4)
North Europe	80 (22)	214 (59)	15 (4)	43 (12)	11 (3)
Central Europe	141 (23)	327 (54)	28 (5)	103 (17)	6 (1)
West Europe	126 (17)	368 (48)	40 (5)	197 (26)	35 (4)
Total	413 (18)	1,152 (50)	102 (5)	545 (24)	74 (3)

Table 26: Living situation of the respondents by regions

When the respondents need help they prefer the assistance of parents or a partner (Figure 20). Over 60% of the young people with RMD receive support in everyday life from parents and/or partners.

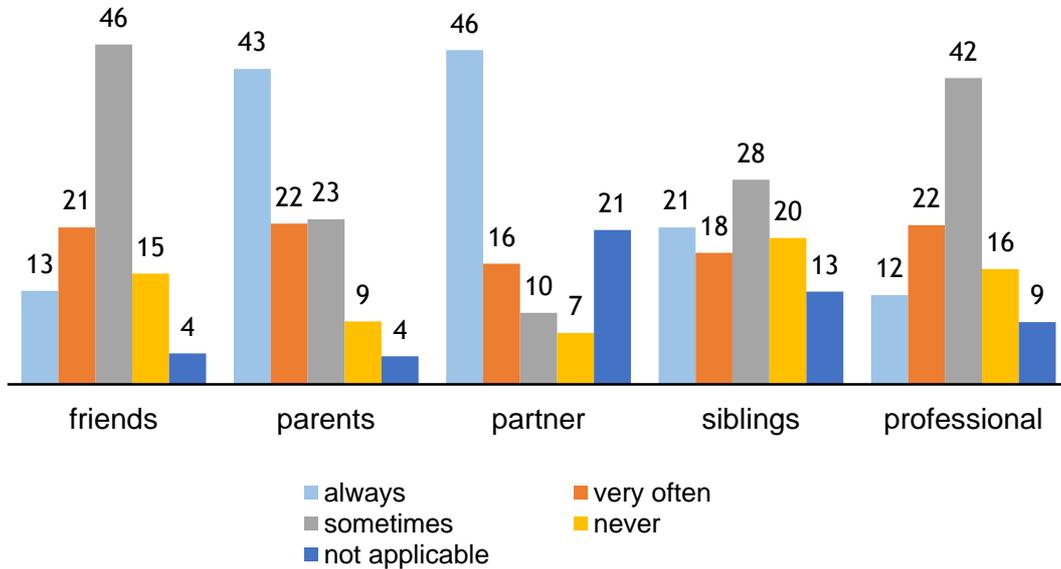


Figure 20: Percentages of respondents by receiving of person(s) for assistance

Almost 83% of the respondents admit that their RMD interferes their sexual life, out of them more than one-third (35%) experience sexual life problems because the condition always or very often (Figure 21).

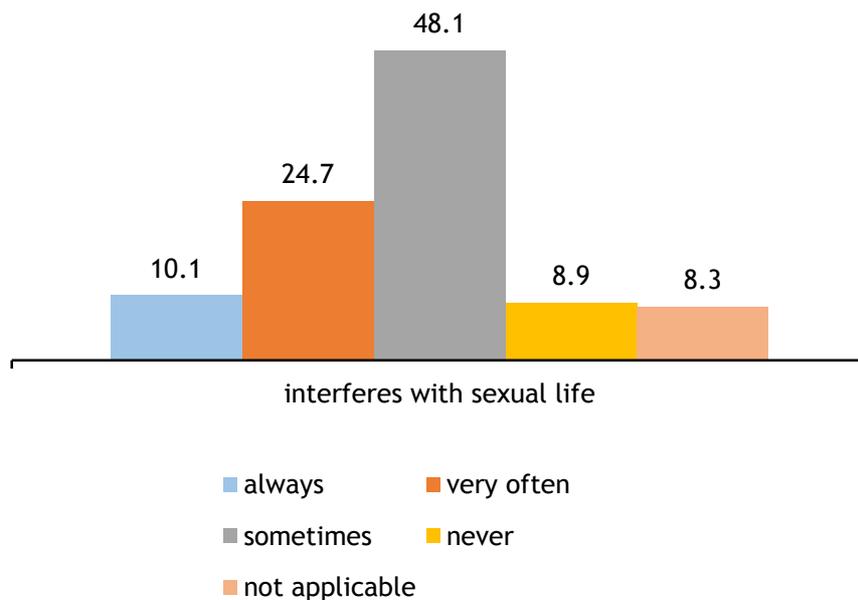


Figure 21: Percentages of the respondents by frequency their condition interferes with their sexual life

The condition has more effect on the sexual life of female respondents (Table 27).

Gender of the respondent	Condition interferes with sexual life, n (%)					Total
	always	very often	sometimes	never	not applicable	
female	187 (10)	480 (27)	844 (47)	139 (8)	146 (8)	1,796 (100)
male	21 (7)	32 (12)	152 (55)	46 (17)	25 (9)	276 (100)
Total	208 (10)	512 (25)	996 (48)	185 (9)	171 (8)	2,072 (100)

Table 27: Interference of RMD with sexual life by gender, ($p < 0.001$)

The distribution of percentage of respondents for whom the RMD interferes with their sexual life was quite similar for all conditions except fibromyalgia (Table 28, among respondents who had one condition)

Condition	Condition interferes with sexual life, n (%)					Total
	always	very often	sometimes	never	not applicable	
RA	30 (7)	78 (19)	229 (55)	60 (14)	20 (5)	417 (100)
JIA	10 (6)	31 (18)	87 (50)	16 (9)	30 (17)	174 (100)
AS	26 (8)	75 (23)	179 (46)	28 (9)	19 (6)	327 (100)
SEL	7 (7)	20 (19)	57 (54)	10 (10)	10 (10)	104 (100)
FM	42 (14)	99 (35)	117 (41)	9 (3)	19 (7)	286 (100)
PSA	8 (8)	21 (20)	46 (45)	16 (16)	12 (12)	103 (100)
Other	10 (6)	35 (22)	84 (52)	15 (9)	18 (11)	162 (100)
Total	133 (9)	359 (23)	799 (51)	154 (10)	128 (7)	1,573

Table 28: Interference of RMD with sexual life by condition, ($p < 0.001$)

The main problems interfering with sexual life are pain/discomfort (72%), fatigue (60%), lack of sexual interest or desire (32%) and not feeling to have an attractive body (30%). A more detailed overview is shown on Figure 22

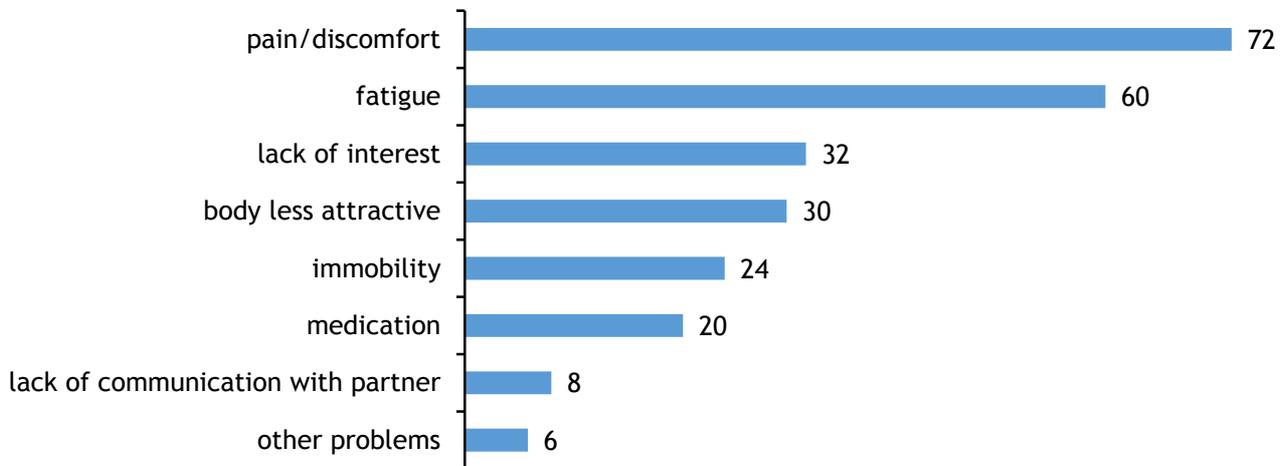


Figure 22: Percentages of the respondents who consider specific problems as obstacles for their sexual life

Almost half of the respondents (43%) would like more information on the sexual issues. The members of the patients' organisations are more interested in this type of information than non-members ($p=0.004$, Table 23).

Involvement in patients' organisation	Want info about sexual issues, n (%)		
	no	yes	Total
no	766 (58.8)	536 (41.2)	1,302 (100.0)
yes	405 (52.3)	369 (47.7)	774 (100.0)
Total	1,171 (56.4)	905 (43.6)	2,076 (100.0)

Table 23: The wish to have more information on sexual issues by involvement in patients' organisation

Young people said:

- *“Partner and parents do not understand what I am going through.”*
- *„I always learned from my parents: the disease doesn't own you, but you have the disease.”*
- *“My parents are very important, other people come and go in my life, and they are family and so those who know me from zero to now have experienced my arthritis as well.”*
- *“At a given moment, when I had stopped the medication, my husband said that only then he really realized what an impact this had on my body and my life.”*
- *“Arthritis is never specifically discussed in my family.”*
- *“It has become a lot easier since I have my husband. He does all heavier things”*
- *“My main aiding equipment is my husband and if he is not there, then I don't eat things that I cannot open. Otherwise you just have to be creative and find solutions”*
- *“I couldn't find a better man. My husband does everything in the household, he never complains, it is of course nice if I can do things by myself if I am physically able to, but in principle he says "if you occasionally have some extra energy, just go out with your girlfriends”.*
- *“My husband knows what it is. And he has been with me to some events and there he has got a lot of information also. It is very important that he knows. Cause at the beginning when I did not have the diagnoses, then he thought I am faking it. And when he found out about the diagnoses he got down and was surprised what kinds of diseases exist.”*
- *“My first son was born deaf and my in-laws blamed my pharmacological treatment for their grandson`s disability. I was deeply hurt by this and felt very guilty for a long time, even though I stopped all medication three months prior to his conception.”*
- *“I will not let my rheumatism limited my relationships and don't have any problem with sex.”*
- *“I notice there are obstacles in bed because I have often pain or tiredness. In that case it requires some extra efforts to become more active than you sometimes want.”*

4. Conclusions

This is the first and the largest European study into the experiences, obstacles and needs of the young people between 18 and 35 years with a rheumatic or musculoskeletal disease (RMD). The study has been carried out by, with and for people from the target group. The results reveal a variety of circumstances affecting the lives of young people with RMDs in Europe. With these results, we not only have a solid base-line picture of the current needs and obstacles of this rather invisible patient group, but we also have a good starting document to develop a youth strategy for the future and a practical plan of actions for EULAR, youth groups and PARE organisations.

Strengths of the study

The strength of the study is the emergent project design that combined mixed methods with an approach of action research by the youngsters themselves. This has resulted in a high response rate of the survey. Over 3500 people filled in the online-survey, which was available in 18 languages. After excluding non-eligible responses, 2329 responses were included, representing the perceptions of young people with a RMD coming from 41 European countries. A further strength of the study is the fact that there were a significant number of non-organized respondents (66%) and this was one of our objectives. This indicates that the outreach of the survey may have contributed to a valid representation of the target group. In spite of not having a traditional paper questionnaire, we reached many young people. A separate website (www.youngpare.org) was created to promote the survey. National organisations were asked to upload the information on their websites and Facebook pages. Survey results indicate that we reached more people than we expected by using modern communication channels. If we want to reach out to the target group, we have to utilize social media actively.

The mapping exercise taught us that only in 22 countries (55%) there are some youth activities. Despite the fact that RMDs have a high impact on young people, in many countries, patient organisations do not work specifically in their interests. The findings from the qualitative research showed that local groups support young people a lot and they are a good source for information, peer education and mental support. Many non-organised young people (65%) showed interest in receiving information about local patient groups.

Based on the presentation of our findings at the Autumn Conference in Reykjavik (November 2013), we recommend to follow the example of the European Patient Forum. They have developed a youth strategy and have a steady youth working group. Their youth activities are carried out with the help of dedicated staff officers.

Limitations

One limitation of this study is the relatively low number of participants in the focus groups. It might be argued that it is difficult to gather young people with RMDs to come together for research purposes to talk about their condition. The survey also indicated that many young people do not want to disclose themselves. They clearly prefer to meet on the internet or face-to-face during more enjoyable activities. Other limitations were the restricted experiences of the young Task Force members in carrying out research. The lack of a control group has been

brought forward as an obstacle to compare our findings with healthy youngsters. However, we believe that the data as presented in this report is appropriate, gives sufficient information to stimulate follow-up research and could be used nationally. Due to limited resources we were not able to prepare separate country reports and we will focus on these in our follow up projects.

Another limitation might have been that the mapping exercise through data collected via email through PARE liaison persons did not result in a complete overview of current youth activities and youth involvement. This offline exercise involved not only information about youth activities in a specific country but also other organisational updates. This poses the potential of gaps in information as well as changes which may have taken place in the meantime. There is a need to update and verify this information again to monitor youth activities and groups frequently, preferably every year. This information should be integrated into the EULAR Directory of PARE organisations and should be fed back into the PARE Youth task force.

The current research design could not allow us to analyze the correlation between different variables or to compare the data with the general population. Further research is needed in prioritized areas to obtain more information. Scientific research methods should be used again and implemented more stringent to gather an even better scientifically sound database. However the quality of the available data guaranteed a solid baseline to get an understanding of the needs, obstacles, preferences and priorities of young people and to plan follow up steps for further integration of young people`s perspectives into EULAR PARE.

Finally, the project had to face a change of coordinator after the data collection. This required prompt improvisation in the last stages of data analysis and writing the report.

Mapping exercise

From the mapping exercise we learned how young people with RMDs are organized in different European countries. The most important conclusions are:

- 22 (55%) of the PARE member organisations have some kind of activities that are dedicated to young people.
- 18 (45%) of the PARE member organisations do not provide services to young people. Two of them are planning to establish a youth group.
- There is a huge difference in the age limits that defines "youth" in all European countries, varying between 0 till 55.
- Activities for young people with RMDs vary a lot and are offered through 3 different ways: By independent youth organisations (7), by a youth group that is part of a mother organisation (5) or as specific focus in the ordinary activities of the mother organisation (10).
- There are special contact people for young people in many countries, almost all of them work on a voluntary basis.

From the research, we learned more about the impact that young people with RMDs between 18 and 35 years experience as a consequence of their disease. The most important conclusions are:

- Talking about the disease is a huge issue in many European countries. 68% of respondents prefer not to talk about their condition. 36% of younger people do not tell their employers about their disease, 22% does not talk about their disease at school or with friends and 17% does not talk about it with their family.
- 85% of the young people with a RMD feel disadvantaged if others know about their disease
- 10% of the young people have no access to a rheumatologist in their country.
- 92% of the young people are facing negative impact on mental health.
- 65% of the young people had a RMD during their studies and 74% of them experienced a delay in their educational career.
- Delay in educational career could be avoided by raising awareness about RMD among teaching staff (51%), flexible schedule (46%), adjustable table/chair (30%) and financial support (29%).
- 95% of the young people reported a significant impact of their condition on work ability.
- 55% of the young people had to stop their paid job partly or entirely due to their disease.
- 20% of the young people are not able to support themselves.
- 93% of the young people reported a significant impact of their condition on social life. Main barriers for them were: pain (82%), fatigue (80%), friends fail to understand their needs (27%) and no interest (21%).
- RMDs impacted the sexual life of 83% of the young people. Most common causes are pain and discomfort (72%), fatigue (60%), lack of sexual interest or desire (32%) and not feeling to have an attractive body (30%).
- Over 60% of the young people with RMDs receive support in everyday life from parents and/or partners.

Collected data confirm that having a RMD has a huge impact on many domains of life. Education, work, social life, family life, intimacy and health care are all affected by having a disease. The ability and willingness to disclose the disease is a great problem in many countries, partly because of the expected negative consequences of others knowing about the disease.

A majority of the young people does not want to talk about their disease for different reasons, not only because they are afraid of not getting a job or to stay at work, but also because they experience or expect negative responses from others. Therefore many young people do not talk about their disease at school, with friends or family. Fatigue, functional disabilities and the unpredictable nature of the disease are symptoms that many respondents experience, although often not taken seriously by people in the direct environment. Lack of understanding often leads to feelings of depression and loneliness. Finally, for many respondents it is hard to find appropriate and tailor-made information that addresses their every day concerns, such as information about opportunities to enjoy sexuality, the decision to have children and consequences for pregnancy, medicine use and breast feeding.

To reach out to young people, we have to use modern communication channels and support online networking.

5. Recommendations

The PARE youth research project has finished the first phase, the identification and research part. In the second phase we hope to continue on the basis of these research findings to improve the support of PARE and youth organisations and to further integrate their perspective in EULAR. For this the Task Force has developed a new project application.

The collected data confirm that having a RMD has a huge impact on the life of young people. How can EULAR, the Standing Committee of PARE and the national organisations help to reduce this burden and raise the quality of life of this target group?

Based on the findings from this PARE research project, we recommend the development of a youth strategy and to undertake the following actions:

- The impact of RMDs on young people is often neglected. Therefore all stakeholders, including EULAR, the national patient organisations, health providers and policy makers should give more attention to this specific target group.
- To establish a sustainable youth group in PARE with sufficient secretarial support to develop a youth strategy and to implement the recommendations, support youth groups and national member organisations, and to guarantee continuity in the future.
- To organize a strategic meeting in 2014 with representatives of all European youth groups who actively contributed to the survey, to develop a youth strategy and a plan of actions based on the survey results.
- To explore the reasons or obstacles of PARE organisations not to have a youth group.
- To engage with national youth groups and organisations to develop, share and organize programs that can be implemented on a national level to encourage and empower young people to start talking about their disease.
- To agree on a preferred age range for the definition of young people with RMDs.
- To support the development and use of modern communication channels (social media, www.youngpare.org, etc.) for networking, education and support of youth groups.
- Many actively participating PARE representatives have asked for detailed country reports to use on national and local level. We therefore recommend to further analyze the outcomes of the European youth survey and to produce country fact sheets.
- To mediate contact with unorganized youth, who participated in the survey and showed interest to receive additional information about youth groups.
- To support the establishment of new youth activities, new youth groups and online platforms.

6. Acknowledgements

We would like to thank all the people that in many different ways have contributed to the success of the PARE youth research project.

Task Force

- ✓ Anna Ageberg (Sweden)
- ✓ Dragan Chichikj (Macedonia)
- ✓ Laura Hickey (Ireland)
- ✓ Linda van Nieuwkoop (Netherlands)
- ✓ Ingrid Pöldemaa (Estonia, chair, project coordinator Sep`13 – Jan`14)
- ✓ Björn Teutriene (Germany)
- ✓ Maarten de Wit (Netherlands, convenor)
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- ✓ Judy Ammerlaan (Netherlands), health professional representative
- ✓ Nele Caeyers (Belgium), patient representative
- ✓ Nemanja Damjanov (Serbia), rheumatologist

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- ✓ Ingrid Kihlsten, Sweden. Project Coordinator/researcher of the (PARE Youth Research) project (until Aug 2013) and BA in Public Health Science, Master student in Sexology, Malmo University.
- ✓ Maarten de Wit, Netherlands, PhD in collaboration with Linda van Nieuwkoop.

Researcher (survey)

- ✓ Marika Tammaru, Estonia, East Tallinn Central Hospital, Head of Research Department, MD, Phd Tartu University

Secretarial support

- ✓ Florian Klett, EULAR PARE Programme manager

Volunteers

- ✓ Susanne Poot, the Netherlands (website www.youngpare.org)
- ✓ Jean-Noël Dachicourt, France (creating logo)
- ✓ Kristi Mustkivi and Serle Roletsky, Estonia (TF meeting preparation)
- ✓ Angela Lore, Italy (TF meeting)
- ✓ Youth representatives in PARE and other European organisations

Appendix 1

Interview guide

These are the three main research questions:

- What are the experiences of young people with RMD in Europe regarding the impact of their disease?
- What are the barriers they have to face when participating in society?
- What are their needs?

The interviews served as an assessment of what is experienced as disease-related barriers in relation to one's needs in order to increase the quality of one's life.

The following topics that have been generated from contributions of youth representatives from 7 countries, and a workshop that was conducted in Athens (2011) with youth participants.

2a Background questions

- Can you please tell me a little bit about yourself?

Make sure to note: *Age, Occupational status, Education, Living conditions, Diagnosis, Disease duration.*

2b Topic Education

- How does your disease make an impact on your educational situation or possibilities?
- Are there any disease related barriers for you to get the education you want? What would you need in terms of support?
- Do your classmates and/or the principal/teacher know about your condition? (Disadvantage, advantage?)

2c Topic Employment

- How does the disease affect your possibilities on having an employment?
- Are there any barriers?
- What type of support would you need in order to maintain a job position?
- Do colleagues and/or the manager know about your condition? (Disadvantage, advantage?)

2d Topic Personal

- How does your disease affect your personal life?
- On your relationships?
- Are there any disease related barriers or problems that arise in your personal life with family and friends?
- What would you need in terms of aid and support to cope better with these barriers and/or obstacles?

Possible key topics: Information, Pregnancy, social network, building and/or maintaining intimate relationships, empowering activities, social support, health, stress, and diet.

2e Topic Health care

- How does your medical situation look like?
- Do you have access to sufficient health care?
- Have you/do you experience barriers in receiving sufficient health care?
- What are these barriers and can/how could that be changed?

*Possible key topics: Medication (access to the right medication)
Diagnosis (getting a diagnosis, access to GP's and health professionals)
GP/Health Professionals (Communication, support, pain management, medication, cooperation between doctors),
Joint prevention.*

Appendix 2

Information letter

Dear

In this letter we would like to provide information about the research for which you were asked to participate and the organisation standing behind it. The EULAR PARE Standing Committee gathers representatives of rheumatic and musculoskeletal user groups around Europe to work together towards improving the quality of life for the more than 120 million people in Europe living with these conditions. The committee's vision is of people with rheumatic and musculoskeletal diseases in Europe being empowered to lead full and independent lives. To achieve this, the committee organises a range of high-quality activities and programmes. This study is an international collaborative research that will be conducted in five European countries (Germany, Sweden, Netherlands, Cyprus, and Estonia). We would like to know more about the consequences of having a rheumatic disease for young people between 18 and 35 years. This concerns the question of how the disease make an impact on your daily life, what obstacles you are experiencing and what you kind of support that would meet your needs to have increased quality of life. We collect this information through interviews with young people and a group meeting with about 8 people. You are invited to give voice to your life experience by participating in a group meeting [day] [date] in [location]. The evening starts at [time] and lasts about 2 hours. All participants receive a small present and reimbursement of travel expenses. If you do not have the opportunity to participate in the group meeting, we will ask you if you are willing to participate in an interview. The time and place we can determine in consultation. All the information from the interviews and the group meeting will be handled very carefully. That means that your privacy is assured and that all information used in the report and any publication will be displayed completely anonymous. If you would like more information about this study, or if you are interested to participate, please send an email to [name national researcher], [e-mal]. You can also call [phone number].

Thanks in advance for your interest in this investigation and we hope you want to take part,
Yours sincerely,

[Name task force member], [position and name of organisation]

[Name national researcher], researcher

Appendix 3

Consent form

Pare Youth Project

-A study to investigate the barriers and needs of young people living with RMD

Project Coordinator:	Ingrid Kihlsten, ingkih@gmail.com
----------------------	-----------------------------------

Project Convenor: Maarten de Wit, martinusdewit@hotmail.com

National Researcher: (name), (number email)

If you have a concern about any aspect of this study you should speak to the researcher or contact the project coordinator and we will do our best to answer any questions or concerns that you might have

Please read the following statements and initial box
--

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.
2. I confirm that I have had sufficient time to consider whether or not I wish to participate in the study.
3. I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without giving any reason
4. I understand that all data will be kept strictly confidential to this research.
5. I consent to my quotations being used anonymously in reports and publications.

Signed: _____ Date: _____

Full name in block capitals: _____

Signed (National researcher): _____

Full name in block capitals: _____

Appendix 4

Template for reporting back about the focus group meeting

Name of the national researcher

Name of the national PARE task force member

Date of focus group

Location of the focus group

Duration of the focus group

Number of participants

Number of male

Number of female

Lowest age

Highest age

Average age

Number of “organised”

Number of “un-organised”

List the specific rheumatic conditions if available

Description of recruitment procedure

Please report the main experiences of the participants regarding the impact of their disease

Please report the main barriers for participating fully and independently in society

Please report the main needs of the participants

Appendix 5

Template for reporting back on individual interviews

(Please complete the report for each individual interview separately)

Name of the national researcher

Name of the national PARE task force member

Date of the interview

Location of the interview

Duration of the interview

Sex (Male/Female)

Age

Occupation

Member of disease-related organisation or youth group (Yes/No)

Rheumatic condition

Diagnosis:

Duration:

Description of recruitment procedure

Please report the main experiences of the interviewee regarding the impact of the disease

Please report the main barriers for participating fully and independently in society

Please report the main needs of the interviewee

Appendix 6

Survey questionnaire (18 languages)

PARE YOUTH RESEARCH PROJECT - INSTRUCTION TO TRANSLATORS

The translators for this project are required to be native speakers of the target language, proficient in the reading the source language, experienced in translating documents and have experience within the health services field.

The survey is reaching out via SurveyMonkey, to young people between the ages of 18-35 years living in 23 European countries. (Text in parentheses and in red) are only clarifications and are not needed to be translated. You can have a look on the digital version here: <https://www.surveymonkey.com/s/YDC78L8>

We have through extensive collaboration with the target group, youth in Europe between the ages of 18-35 years, tried to give the survey a cultural sensitivity. Many surveys suffer measurement errors due to poor translation procedures, inappropriate content, insensitivity of items, and a lack of knowledge of the cultural norms by researchers. Unfortunately, due to limited time and resources in the project we are unable to double-check the validity of each questionnaire. However, in the extent that it is possible, we will try to test all questionnaires by one representative from each country before it is sent out.

One issue that has been discussed within our research team is whether it is more appropriate to use the word "disease" than "condition". This is something that you will be the judge of when translating. However the aim of the research is *to explore the conditions for youth living with a disease rather than exploring the disease itself* (in a medical sense). It can be important for you to know that rheumatic and musculoskeletal diseases vary greatly, in terms of how these affect the physical and mental ability of each individual and depending on the societal norms and support systems for that individual; so you know that our research population is very heterogeneous. It is therefore a challenge to make one survey for many different types of living conditions and contexts.

The aim should be to achieve linguistic equivalence in terms of taking the semantic, conceptual and normative equivalence closely into account. It is important that not only the words and sentences are translated but also accordingly to the language of the target group; according to the social script of the linguistic and social culture. For example, some cultures are less willing to share personal information or discuss certain topics than other cultures, and by paraphrasing a sensitive question one could make a sensitive item less intrusive. It is important that the reader does not feel threatened by a question, thus it might risk that they decide to leave the survey.

Best wishes and good luck,

[name Project co-ordinator PARE Youth Research Project]

(FIRST PAGE, Introduction text)

Hi there!

Thank you for lending us 10 minutes of your time! Your participation is very important. This survey is about the needs and experiences of young people between 18-35 years living with rheumatic and musculoskeletal diseases in Europe. We have made this survey together with youth representatives from all over Europe, and we hope that you will find the questions in this survey relevant to you!

Do not worry, all responses are anonymous. That means that no one can track who wrote what. The results will be used in a report that will help to guide future youth work across Europe, and might also be used for scientific purposes.

The final report will be published in November 2013 on our homepage (XXX) and EULAR's homepage www.eular.org.

If you have any questions about the survey, or if you want to contact us, you are welcome to send an email to the Project Co-ordinator, Ingrid Kihlsten, at ingkih@gmail.com

Thank you for taking the time to complete this survey!

"Thank you for your interest!"

"You have to answer this question."

"Forward/Next"

"Back"

"Finished"

"Click the 'Next' button to start the survey!"

DEMOGRAPHIC VARIABLES

1) Do you have a rheumatic and/or a musculoskeletal condition?
<Yes, No>

2) Gender
<Male, Female>

3) Age
(A list of numbers from 0-35+).

(If the respondent clicks 35+ they will be conducted to a frame saying):

"In this research project we have chosen only to include young people between 18-35 years old. Thank you for your interest!"

4) In which country do you live?

Albania

Andorra

Armenia

Austria

Azerbaijan

Belarus

Belgium

Bosnia & Herzegovina

Bulgaria

Croatia

Cyprus

Czech Republic

Denmark
Estonia
Finland
France
Georgia
Germany
Greece
Hungary
Iceland
Ireland
Italy
Kosovo
Latvia
Liechtenstein
Lithuania
Luxembourg
Macedonia
Malta
Moldova

Monaco
Montenegro
The Netherlands
Norway
Poland
Portugal
Romania
Russia
San Marino
Serbia
Slovakia
Slovenia
Spain
Sweden
Switzerland
Turkey
Ukraine
United Kingdom

5) Do you have children?

Yes
No

6) How many children do you have?

(A list of numbers)

7) What is your current living situation? *The question aims to investigate how the respondent live/what their housing conditions are like)*

Single
Shared housing with a partner
Shared housing with friends
With parents
Other

EDUCATION

8) Years of education *(We want to know how many years in total that the respondent has attended any form of formal education, from primary school to university)*

9 years or less
10 -12 years
13 years or more

9) What are you engaged with now? *Please tick the appropriate boxes*

Studying part time
Studying full time
Working part time
Working full time
Unemployed
Sick leave
Other

10) Did you have a rheumatic/musculoskeletal condition during your studies?

- Yes
- No

11) Has your rheumatic/musculoskeletal condition caused a delay in your studies?

<Always, Very often, Sometimes, Never, Not applicable>

12) What kind of support would help/would have helped you manage your studies?

(This questions is constructed to include both respondents that are currently enrolled and the ones that have finished their education/studies)

Please tick the appropriate boxes.

- I manage-/d without support
- Accessible facilities in school
- Financial support
- Adjusted chairs and tables
- Flexible schedule
- To have a computer
- Access to internet
- Information about my condition to teachers
- Transport to school

13) Have you experienced any teasing in school due to your condition?

<Always, Very often, Sometimes, Never>

WORK

14) Has your condition affected your ability to work?

<Always, Very often, Sometimes, Never>

15) Have you ever been employed? ("No" will jump to question 18)

- Yes
- No

16) Do you inform your boss about your condition before starting a new job?

<Always, Very often, Sometimes, Never>

17) Have you been forced to quit a job due to your condition?

<Always, Very often, Sometimes, Never>

FINANCES

18) Are you able to financially support yourself?

<Always, Very often, Sometimes, Never>

19) What is your main source of income? **Please tick the appropriate boxes.**

- Salary from work
- Government aid
- Social benefits
- Disability benefit
- Loans

Grants
Support from partner
Support from parents
Support from friends
Other

HEALTH

20) Have you been diagnosed by a medical doctor for a rheumatic/musculoskeletal condition?
<Yes, No>

21) What type of condition do you have?
Rheumatoid Arthritis
Juvenile Idiopathic Arthritis
Ankylosing Spondylitis
Osteoarthritis
Systemic Lupus Erythematosus
Fibromyalgia
Scleroderma
Psoriatic Arthritis
Lower Back Pain
Other

22) At what age were you diagnosed by a medical doctor with this condition?
(A list of numbers from 0-35+)

23) At what age did you discover your first symptoms?
(A list of numbers from 0-35+)

24) Do you have access to a rheumatologist to treat your condition?
<Always, Very often, Sometimes, Never>

SOCIAL LIFE & SUPPORT

25) Does your condition limit your social life?
<Always, Very often, Sometimes, Never>

26) What are the main barriers for your social life? **Please tick the appropriate boxes.**
Fatigue
Pain
No interest in social activities
Friends fail to understand my needs
Lack of accessible public places
Lack of public transportation
Other, please specify.

27) Who assists you when you need it?
Friends <Always, Very often, Sometimes, Never, Not applicable>
Parents <Always, Very often, Sometimes, Never, Not applicable>
Siblings <Always, Very often, Sometimes, Never, Not applicable>
Partner <Always, Very often, Sometimes, Never, Not applicable>
Health professionals <Always, Very often, Sometimes, Never, Not applicable>

28) Does your condition have a negative impact on your mental health?

<Always, Very often, Sometimes, Never>

29) Do you need psychological support?

<Always, Very often, Sometimes, Never>

30) Do you have the possibility to get psychological support?

<Always, Very often, Sometimes, Never>

31) Do you talk about your condition with others?

<Always, Very often, Sometimes, Never>

32) When do you not talk about your condition? **Please tick the appropriate boxes.**

In school

At work

With a new partner

With friends

With family

With a stranger

At a job interview

Other

33) Do you feel that you would be disadvantaged if people knew about your condition?

<Always, Very often, Sometimes, Never>

34) Please rate the following statements

I feel satisfied with my life <Always, Very often, Sometimes, Never>

I feel that I can achieve important goals in my life <Always, Very often, Sometimes, Never>

I feel that I have control over my own life <Always, Very often, Sometimes, Never>

I feel optimistic about my future <Always, Very often, Sometimes, Never>

INTIMACY

35) Does your condition interfere with your sexual life?

<Always, Very often, Sometimes, Never, Not applicable>

36) What interferes with your sexual activity or satisfaction? **Please tick the appropriate boxes.**

Fatigue

Pain or discomfort in my body

Feeling that my body is less attractive

Lack of sexual interest or desire

Medication

Lack of communication with partner

Immobility

Other Please specify...

37) Would you like to receive information regarding how to deal with sexual issues?

<Yes, No>

ORGANISATIONS

38) Have you been involved in any activity organised by a patient group or patient organisation?

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<Yes, No>

39) Would you like to receive information from your national organisation?

<Yes, No>

"If you would like some more information, please fill in your email address. Your responses to this survey will still remain completely anonymous, and cannot be linked to your email address. We will forward your email to your local organisation".

Thank you for filling out this survey! For more information visit XXXX or www.eular.org