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Abstract	This report summarizes the findings of the desk and field research emerging from the analysis implemented in Italy, Spain and Poland. The research consisted in the implementation of two key activities (surveys and focus groups) aimed to identify the difficulties faced by RD patients in the participation to sports activities and competitions and share good practices on the topic. The findings of this joint report will constitute the basis for the implementation of the activities foreseen under WP3 (Organization and implementation of awareness raising campaign).
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The RoW Project

Research on rare diseases (RD) is scarce in most of the EU countries, while the lack of specific health policies for rare diseases translates into delayed diagnosis and difficult access to care.

This results in additional physical, psychological and intellectual impairments, inadequate or even harmful treatments and loss of confidence in the healthcare system, despite the fact that some rare diseases are compatible with a normal life if diagnosed on time and properly managed (Communication "Rare diseases: Europe's challenges"-2008).

Access to sport and leisure activities is even more ignored by most of EU countries: most of member states and the EU itself do not have a policy around RDs and sports.

According to most of the research activities on rare diseases, physical activity plays a pivotal role in patient care, combining both somatic and mental effects, aiming to increase quality of life. Individuals with RD frequently refrain from sports due to physical restrictions.

Nevertheless, patients undertaking physical activity, can develop elements of endurance, strength and social effects of "team play interactions" which are important to promote social participation and personal development for RD affected individuals. It is therefore fundamental to ensure participation to sports as a means for personal empowerment and social inclusion.

Only some decades ago, it seemed to be impossible for patients with RD to participate regularly in physical exercise. Due to an increasing opportunity of sufficient treatment options, things have changed now: not only it is possible for patients to undertake sports activities but also, they now claim to compete at the highest level, such as the Paralympics. Unfortunately, most of the RD are not considered disabilities preventing people from participating to the Paralympics.

The key to improving overall strategies for rare diseases is to ensure that they are recognised, so that all the other linked actions can follow appropriately. This is why RoW will undertake an awareness raising campaign on the topic, breaking the silence around RDs and show them under a new light, as people that can play sports, as well as and influencing policy makers in taking real measures to allow the full participation of people with RDs in sports activities and competitions.

In order to answer these needs, the general objective of the RoW is to promote equal access in sports activities (in particular cycling) and competitions for people and athletes affected by rare diseases, through the experimentation of the good practice "Rarity on wheels" in 3 different EU countries and through the exchange of good practices at European level.





The specific objectives of the RoW project will be:

- to identify the main problems and difficulties faced by athletes and patients affected by RDs in participating to sports activities;
- to promote the acquisition of knowledge, competences and skills among NGOs and sport managers, trainers and coaches on RDs and sport;
- to foster awareness raising on rare diseases, spreading knowledge on the topic through sport;
- influence policy makers to promote the definition of specific sports policies for RD patients and in particular for the recognition of their disabilities in Paralympic games.

Row addresses:

- Grassroots sport: by involving patients with RDs in sports activities and promoting the use of sport for the physical and psychological wellbeing of people affected by rare diseases (Health Enhancing Physical Activity)
- Professional sport: by involving athletes affected by rare diseases willing to access high level competitions such as Paralympics.

The RoW project will produce the following main tangible results:

1. Research (Surveys and Focus groups) on difficulties faced by RD patients in the participation to sports activities and competitions.
2. Implementation of awareness raising campaigns in partner countries.
3. Organisation of a awareness raising sports event in each partner country.
4. Elaboration of policy recommendations addressed to national and European policy makers and international sport organisations.





The research methodology

From April to June 2021, project partners carried out an initial research aimed to identify the difficulties faced by athletes and patients affected by RDs in participating to sports activities. The purpose of the initial research was to also to identify in each country needs and expectations, actions already undertaken in the field of rare diseases and sport (good practices) and the existing networks. To this end, a research framework has been designed by UPFLV based on the following steps:

Initial research Steps

The Survey

It aims at identifying the difficulties faced by athletes and patients affected by RDs in participating to sports activities. The survey will be carried out among RD patients and their families, caregivers, sports clubs, RD patients, disability associations and other relevant stakeholders working with selected target groups.

- Total number of respondents: 45
- Implementation period: April-May 2021

STEP
01

The Focus Group

In each project country a FG will be implemented aimed to identify the needs of RD patients in terms of autonomy and empowerment through sport. The FG will involve beneficiaries, family members, caregivers and potential stakeholders.

- Total number of participants: 30
- Implementation period: April-May 2021

STEP
02

The Report

Data from the individual national focus groups will be collected and processed together with survey results in the initial research report. The Report will:

- summarize the findings of the research activities about the difficulties faced by athletes and patients affected by RDs in participating to sports activities/competitions
- collect and share good practices on the topic.

Implementation period: June 2021

STEP
03





The results collected at the national level are now being systematized in this report that will serve as a transnational guidance tool for the next task. UFPLV is responsible for the analysis and systematization of the national results in the consolidated report.

Such a research approach permits to get a better understanding of the main target groups' needs in relation to the participation in sport activities, but it also contributes to:

- involve the target group and key stakeholders at an early stage of the project's implementation as a strategic factor for the sustainability of the project;

- make the target groups aware of the project's objectives and activities.

Data from the individual national focus groups have been collected and processed together with survey results in the initial research report. UFPLV is responsible for the comparative analysis of all the collected data and the related production of this final report in M6 (June 2021), which represents the first milestone of the project and it will be available on the [project webpage](#).





Surveys

UFPLV, with the support of all project partners, designed an online survey to be carried out among RD patients and their families, caregivers, sports clubs, RD patients and disability associations and other relevant stakeholders working with selected target groups.

The aim of the survey was twofold. Firstly, to collect information about the difficulties faced by athletes and patients affected by RDs in participating to sports activities and competitions. The survey also aimed at collecting and sharing good practices on the topic.

Each partner was asked to circulate the survey through relevant national stakeholders and collect a minimum number of surveys (15/country).

A total number of 60 participants took the RoW Surveys.

Country	Number of participants	Profile of participants
Italy	29	<ul style="list-style-type: none">• RD patients• Family members of a person with RD• Caregivers• Sport club
Spain	16	<ul style="list-style-type: none">• RD patients• Family member of a person with RD• Caregivers• Sport clubs• Disability Association
Poland	15	<ul style="list-style-type: none">• RD patients• Family member of a person with RD• Caregivers• Sport clubs• Disability Association• Other





Italy

Most respondents (93%) have never taken part in a sport activity/event involving people with RD (Q1.3). However, they all claimed that sport activities can be a great opportunity for encouraging social inclusion and raising awareness about disability and RDs.

According to the respondents (Q1.5), sport events involving people with rare disease and their families are crucial in terms of:

- enhancement of social inclusion and relationship (*"encourage friendship among patients and families"*);
- raising awareness on RDs;
- empowerment and well-being (*"accepting your limitations and going beyond your own limits due to disease", "motivation and resilience", "light-hearted moments"*).

On the other side, a few respondents also highlighted some critical issues linked to the participation of RD patients in sport activities, pointing out that "sport accentuates physical differences" and this could lead to frustration.

Regarding the question (Q1.7) the issues to consider when organizing a sport activity addressed to people with rare disease and their families, respondents underlined the relevance of:

- a. Medical and emotional aspects of the persons involved (*"Organizers should pay particular attention to all RD patients' needs and create a socially positive and fully inclusive environment for people with RD and their families"*);
- b. Safety, Medical services and equipment (*"Toilets, ambulances", "Mobility barriers"*);
- c. Involvement of RD patients in the organization of the sport activity to get more information about their needs/potential risks/possible adaptations in order to design that are accessible for them (*"I would take into account the difficulties of the patients and select the activities that are accessible for all of them", "I would try to know the specific needs of the participants according to their disease" , "both the psychological and the physical aspects must be considered", "it is important to identify the suitable sport activity and involve everyone because sport brings people together"*).

When asking about the knowledge of any other activities implemented at local, national or European level aimed to promote social inclusion and raising awareness (about disability, RD etc.) through sport (Q1.8),





participants were able to identify only a few activities implemented at local and national level:

- [Insuperabili](#): a national project implemented by Insuperabili Onlus and Reset Academy. Through football, the project aims to ensure the growth and social inclusion of children with disabilities.
- [La rarità su due ruote](#): a national sport project developed by UFPLV to promote equal access in sports activities (with a focus on cycling).

Spain

Most respondents (62,5%) have never participated in a sport activity involving people with RD (Q1.3). According to the respondents (Q1.5), such sport events could play a key role in:

- increasing RD patients' motivation and well-being ("*These events are necessary to give this people mood and strong to fight against the illness*", "*we normalize their situation, transforming their rare disease in common disease, with normal support of medical institutions*", "*good sense of community and dedication*");
- personal and social development ("*sport is one of the best tool for integration, solidarity and personal growth*");
- encouraging social inclusion;
- increasing visibility and raising awareness on RDs;
- increasing the opportunity for fundraising.

Some of the respondents also underlined some critical issues linked to the participation of people with RDs in sport events:

- lack of RD awareness prevents people from practising sport ("*sometimes due to the lack of awareness of the condition people might not find the need to get involve*")
- lack of systematic cooperation between the organizers and public authorities.

When asked about the issues to consider when organizing a sport activity addressed to people with RDs and their families (Q1.7), respondents identified the following:

- a. getting more information about RD patients' needs/potential risks/possible adaptations to design that are accessible for them through:
 - 1.study on the specific RD ("*study and adjust the activity to the people thar suffer these illnesses*", "*adequate sports activity to the physical ability of the sick*").





2. The direct involvement of the RD patients (*"I would try to involve them from the beginning. Make interviews with them about their daily life so people that are going to participate at the event know well the cause they are helping. I would tell them details about what we are organizing in aid of them so they can become ambassadors of the event. I would invite them to attend the event"*).

- b. Creating systematic opportunities for inclusion (*"Try to achieve the highest level of integration and comfort for those affected they have to feel supported but un an inclusive way", " full integration of rare disease patients to normalize their situation in order to integrate them", "That it was an event that served all people without distinction", "involve as many people as possible outside the disease"*).
- c. Maximizing the visibility of the event (*"Announcing, reach out to as many people as possible"*).

Most of respondents are not aware of any activities aimed to promote social inclusion and raising awareness (about disability, rare diseases etc.) through sport (Q1.8). The only activities mentioned by the respondents are:

- [Asdent](#) is a Spanish non-profit association created in 2011 to raise awareness about Dent disease. To this end, Eva Giand David Muñoz, Nacho's parents, founded the association with the aim of promoting awareness of the disease suffered by their son and to raise donations to cover the costs involved in the research. Eva participated in many bicycle races, such as the 'Morocco On Bike by Iguña 2020' MTB competition.
- [Special Olympics](#): global movement committed to create a new world of inclusion and community, where every single person is accepted and welcomed, regardless of ability or disability.





Poland

Large number of respondents (73,3%) took part in Paragedon - Festival of Sport for People with Disability organised in Kielce (Q1.3). Results showed that the interest of respondents towards sport activities is quite high, as pointed out by one of the respondents: *"I am a mother of a little girl, so I have no experience on that. But I hope to be involved in sports activities in the future as I can't imagine the life of my daughter without sport"*.

In relation to the strengths of a sport event involving people with RD and their families (Q1.5) participants highlighted the following issues:

- promotion of social inclusion (*"great opportunity for integration," "integration of people with rare disease"*);
- promotion of healthy lifestyle;
- opportunity for aggregation (*"such sports competitions are a good way to meet and socialize"*, *"It is very good for social integration. Each year we invite family members of people with disabilities with whom we work. We cook together, organise a bonfire, eat together and sing together. It is a great chance to meet and socialize"*);
- raising awareness on RDs (*"promotion of knowledge about rare diseases"*).

Respondents also reported some critical issues involved in the participation of RD patients in sport activities, namely the lack of interest and knowledge about RDs (*"There are some rare diseases which don't prevent participation in sports events so they participate fully"*, *"my rare disease doesn't disable me from taking part in sports activities"*; *"people may be at different levels of sports skills, so the risk of no real competition is high"*, *"people fully skilled cannot feel the sense of achievement"*).

In relation to the issues to consider when organizing a sport activity addressed to people with RDs and their families (Q1.7), respondents pointed out some key aspects:

- a. Involving families (*"More responsibility given to family members so that they feel more involved in the process"*);
- b. Knowledge and awareness about the RDs involved (*"Very deep and thorough research on the sports abilities of the participants and their needs"*, *"Deep analyses of what needs people with rare diseases have"*, *"I would ask about the needs of potential participants"*, *"I would check what kind of rare disease the participants are in order to prepare it well"*, *"I would like to know what exactly the rare disease is and how it stops the patient to practice sport, if the patients have any limitations"*, *"I would like to have a training provided by somebody who is more experienced than me"*);
- c. creating opportunities for bringing people together (*"I would treat it as a tool to socialise not to practise sport"*).





The majority of respondents is not aware of any sport activities to encourage social inclusion and raising awareness (about disability, RD etc.) (Q1.8). The only sport activities - implemented at local level – mentioned by the respondents are:

- [the Festival of Physical Activity of People with Disabilities](#): Projekt Świątokrzyskie is organising annually the Festival of Physical Activity of People with Disabilities. The Festival took place on September 13-14 2019 and was attended by 500 sportsmen with disabilities from Poland;
- [Boccia Events and competitions](#): organised by Andrzej Janowski, former sportsman who underwent an accident and is now on a wheelchair;
- [Amp Futbol Kielce](#) : the Association Megamocni from Kielce organises football tournaments for people with disabilities.





Focus groups

The second and last stage for the implementation of the initial research in partner countries consisted in the organization and conduction of one focus group in each project country. Between May and June 2021, project partners from Italy, Spain and Poland implemented one national focus group aimed to identify the needs of RD patients in terms of autonomy and empowerment through sport and will involve beneficiaries, family members, caregivers and potential stakeholders in order to obtain complete information.

Focus group research is a qualitative research method/data collection technique that seeks to gather information that are beyond the scope of quantitative research. Focus groups consisted in a small group of selected participants that were stimulated with open-ended questions. This research method is particularly useful when the interaction between participants can enrich the topic and the co-construction of the discourse is useful for the research objectives.

A total number of 28 participants joined in the RoW national Focus Groups.

Country	Number of participants	Profile of participants
Italy	9	<ul style="list-style-type: none">• Athlete affected by RD• Board members of sport clubs for people with disabilities• President of Paralympic Committee• Family members of kids with RD• Sport Journalist• Social worker• Members of association for sport and social inclusion, RD patients/disable people
Spain	9	<ul style="list-style-type: none">• Athletes affected by RD• Disable people• Family members of people with RD
Poland	10	<ul style="list-style-type: none">• RD patients• Family members of people with RD• Members of sport associations





Italy

The focus group was organized online on the 25.05.2021.

A total number of 9 participants joined the event.

Participants unanimously affirmed that sport plays a relevant role for social inclusion, since it:

- gives the possibility of improving physical and mental benefits,
- develops skills one does not believe to have.

In addition, while practising sport, people with and without disability play on the same level. Participants pointed out that everyone should be aware of the possibilities that sport gives and consider sport as a platform for social issues. Respondents mentioned a few initiatives carried out at local and European level aimed to raise awareness about RDs/disability through sport, with a special focus on some initiatives aimed to foster social inclusion of vulnerable people:

- [Lucky Friends](#): Italian association promoting sport for and with vulnerable people
- [Resport - European sports network for rehabilitation of persons with disabilities](#): Erasmus+ funded project aimed to support the development of a new set of sport rehabilitation activities which provided a comprehensive approach to rehabilitation of persons with disabilities through adapted sports activities.

According to the participants, the major challenges faced by people with RD sport activities are linked to the issues mentioned below:

- real life proposes excellence examples that put disable people in a disadvantaged position;
- clubs and trainers do not want to take the responsibility (lack of legislation);
- finding facilities and clubs/associations/gyms willing to welcome vulnerable people;
- lack of preparation of coaches/trainers to face the situation and support vulnerable people;
- Pietism that marginalize even more vulnerable people.

With regards to the development of social and personal skills, according to the participants, the most important skills people with RD could develop while practicing sports are:

- Well-being
- Communication





- Collaboration
- Growth mindset
- Managing to learn.

Participants agreed that some key aspects should be considered in the organization of a sport event/competition involving people with rare disease, with a special focus on the following issues:

- Recognition of rare diseases at the Paralympic level
- Preparation of educators and coaches
- Adequate facilities
- Screening at regional level to link doctors and sports directors
- Identify more suitable sports depending on the pathology (creation of a grid)
- Having staff and tools to support frail people (guides for the blind, tools, technology).

Spain

The focus group was held online on the 16.06.2021.

Participants pointed out that sports can play a key role breaking down barriers and building bridges where boundaries usually exist and be crucial to create a feeling of inclusion.

The interviewees claimed that there is still much to be done to ensure the full social inclusion of people with disability/RD. In that regard, promoting sport for all is a key issue.

This is the most important aspect that should be considered in the organization of a sport event/competition involving people with rare disease.

Participants highlighted the relevance of sport activities in the development of both social and personal skills. They believe that the most important skills people with RD could develop while practising sports are:

- Self-regulation
- Autonomy
- Empathy
- Collaboration.

Poland

The focus group took place face to face on the 15.06.2021.

All the 9 participants underlined the fact that sport is the best tool for social inclusion, as it integrates, gives thousands of options to work with people with disabilities and vulnerabilities.

Regarding other activities implemented at local and national level aimed to promote social inclusion and raising awareness (about disability, rare





diseases etc.) through sport, participants mentioned “Paragedon”, an initiative organized by Projekt Świętokrzyskie that has involved around 800 participants with disabilities. According to the respondents, the lack of clear rules is the main challenge faced by people with RD sport activities, preventing them from being fully involved.

With regards to the development of social and personal skills, according to the participants, the most important skills people with RD could develop while practicing sports are:

- Autonomy
- Flexibility
- Communication
- Growth mindset.

Respondents pointed out some crucial issues to take into account in the organization of a sport event/competition involving people with RD, in particular:

- setting clear rules
- identifying categories.





Cross-country results

A comparative analysis was conducted to gain a more nuanced understanding of similarities and differences across partner countries in the following key issues:

- needs of RD patients in terms of autonomy and empowerment through sport,
- difficulties faced by RD patients in the participation to sports activities,
- good practices implemented at local, national and/or European level in the field of rare diseases and sport.

The analysis of the results emerging from the surveys and the national focus groups have shown a large agreement from the participants (RD patients, family members, caregivers, sport clubs and any other potential stakeholders) on the role of *sport as a driver of active social inclusion* and also fundamental for the physical and *social development* of people with RD. The findings of this research show not only that sport is seen as unique in its ability to break down barriers but also genuine interest in *promoting equal access in sports activities* and competitions for people and athletes affected by rare diseases.

The research highlights the *scarce* and sometimes even *missing knowledge of any activities aimed to encourage social inclusion through sport*. In fact, as clearly underlined, there seems to be a lack in the general knowledge of any activities implemented at national, and above all at European level aimed to encourage social inclusion and raising awareness (about disability, RD etc.). To this end, a particular attention should be paid to the *dissemination and valorisation* of the RoW project results.

Besides highlighting the *need for breaking the barriers to participation in sports*, respondents recommend some *key aspects* to consider in the organization of a sport event involving people with rare disease:

1. Getting detailed information about *people with RD' needs/potential risks/possible adaptations in order to design that are accessible for them*. This is a key element that ensures that patient suffering from RD to have access to sports. The lack of understanding and awareness of the specific rare disease deeply affect people with RD's participation in sports and physical activities.





In addition, RD patients often experience issues in accessing sports due to *lack of appropriate equipment/facilities and trained coaches*.

With the purpose of overcoming barriers to participation in sports and ensure full access to sport, two key issues seem particularly relevant:

- a. *study on the specific RD*: not all RD patients are the same. Rare diseases are indeed characterized by a wide diversity of symptoms and signs that vary not only from disease to disease but also from patient-to-patient suffering from the same rare disease¹. So, the direct involvement of the RD community in the organization of the sport is key to getting more information about the specific rare disease(s) and designing sport activities that are accessible for the person with RD.
- b. *creating systematic opportunities for inclusion by organizing sport events involving people with RD*: this plays a pivotal role in raising public awareness of the RD community and making it more visible across Europe.

As shown below, the comparative analysis results reveal that there are *differences* across partners countries related to the skills that people with RD could develop while practicing sports:



¹ [What is a rare disease?](#)





Conclusion

The results emerging from the surveys and the national focus groups represent a solid basis for *identifying the needs* of the main target groups in relation to the participation in sport activities.

The comparative analysis has found strong consensus on the role of sport as a driving force for:

- promoting people with rare diseases' cognitive, social and emotional *development*;
- encouraging *social inclusion* of people with RD.

The comparative analysis results also highlight some *crucial obstacles* (e.g. lack of preparation of coaches to support people with RD shortage of facilities and clubs/associations willing to welcome people with RD; lack of accessible facilities, health and safety) to sport participation.

As already pointed out, our research shows the *scarce and sometimes even missing knowledge of any activities* - implemented at national, and above all at European level- aimed to encourage social inclusion and raising awareness about rare diseases. Nevertheless, the analysis of the results shows how in the three partner countries involved the need for ensuring people with RD better access to sport is a *priority*.

Hence, the implementation of awareness raising campaigns in partner countries, the organisation of awareness raising sports events (WP3) and the elaboration of policy recommendations (WP4) represent not only an innovative approach but also needed tools for supporting social inclusion and equal opportunities in sport and enhancing the participation in sport, physical activity and health enhancing activities in people with RD. The implementation of the three project results mentioned above is key to developing *a real movement on sport for rare diseases across Europe* and facilitating the creation of a *standard methodology* aimed to promote the connection between people with RD with local sport options.

