

EMPATHY Project

Europe Meets Young Patients



Project Report

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Foreword

We are very pleased to present to you our report on the EMPATHY Project “Europe Meets Young Patients”, partially funded under the EU Youth in Action Programme of the European Commission. EMPATHY was the first project implemented in the framework of the European Patients’ Forum’s (EPF) Youth Strategy¹.

The EMPATHY project was implemented by a consortium led by the European Patients’ Forum, involving nine other patient organisations, which are either national coalitions of patient associations or pan-European disease-specific patient organisations.

The project idea was conceived and developed by the EPF Youth Group and the main activity consisted of a four-day Seminar which took place in Brussels from 8 to 11 July 2013.

EMPATHY aimed at promoting better recognition of the needs of young patients in EU decision-making. Through this Seminar 26 young people aged 15 to 25 with different chronic conditions from all across Europe had the opportunity to establish an active dialogue with EU-level policy makers, stakeholder groups and patient organisations and raise awareness of their needs and expectations in relation to EU-level policies that have an impact on them.

This report provides an overview of the themes discussed and summarises the main outcomes of the EMPATHY Seminar. At the end of this report are included two sets of recommendations developed out of the outcomes of the Seminar, the first one addressed to patient organisations and the second to other stakeholders and policy makers.

We hope that this report will provide you with an overview of the points discussed in the Seminar and that the conclusions will inspire future actions in relation to how to make EU-policies better aligned and more responsive to the needs and expectations of young people with chronic diseases.

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President of the EPF Youth Group

¹ <http://www.eu-patient.eu/About-EPF/The-Board/Youth-Strategy/>



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1. The rationale: why EMPATHY? What does ‘EMPATHY’ mean to young patients?

“The EMPATHY seminar was the opportunity to discuss and identify issues that young patients face regardless of their nationality or their condition. It also showed to older patient leaders and stakeholders what issues are truly affecting us as young patients”. (Andrew 23, Malta, Maltese Diabetes Association)

The project was conceived and designed by the members of the European Patients’ Forum (EPF) Youth Group as one of the key actions in implementing the EPF Youth Strategy adopted in 2011.

The EPF Youth Group

The EPF Youth Group is the backbone of the EPF Youth Strategy. The group is currently made up of 11 young patients aged between 15 and 25 years, with chronic conditions who have been nominated by EPF member organisations.

The Youth Group plays an important role in the implementation of the EPF Youth Strategy and was established to become the reference group through which needs and expectations of the young patient community are formulated and communicated to EPF and its members.

The rationale behind this project is that the needs and expectations of young patients are sometimes different than those of adult patients. Being a patient inevitably impacts on every aspect of a person’s life.

Having a chronic illness is difficult for everyone. For young people who are undergoing changes as part of their growth and development process, a chronic disease can be an enormous burden. A young person born or diagnosed with a chronic condition in their childhood or early adolescence is confronted with a set of additional challenges that have important repercussions on their growth and development and hence on their future adult life.

Critical stages in young people’s growth such as the transition from childhood to adolescence and from adolescence to early adulthood are experienced in a different way by people living with a chronic condition. In addition to ordinary learning processes all youngsters undergo, a young person with a chronic condition also needs to learn to become independent in managing their condition. This means that a young person with a chronic condition will need to learn and develop skills and knowledge that other young people will not.

Young people with chronic conditions enter and go through education as patients, meaning that they may have to miss classes from school and university because of the chronic condition and this may have a strong impact on their learning process as well as on their lives more generally. Due to their health condition, young patients often face discrimination at school and university. Accessing the labour market, especially in the current economic climate, is also a major issue specific to young patients.

Regarding the relationship between young patients and the health system, young patients believe that very little is known about their views and experiences; however, despite their youth they already have a wide experience of healthcare. Regardless the age, patients are “experts by experience”. Their perspective on chronic disease is unique: patients live with the condition every day, learn to manage it themselves with support from healthcare professionals, and in the case of young patients, from their parents as well. Despite their youth, young patients are experts in their condition and its impact on all areas of life, including education, the workplace and social interactions.



Over the last few years increasing attention has been paid to identifying ways to involve young patients in decisions relating to their health, as well as the health services they use more in general. However there are a number of issues remaining that are inappropriately addressed.

One of the challenges young people face and that is relevant to most teenagers and young adults with a chronic condition, is the transition from paediatric to adult care. There are also issues regarding the relationship between young patients and healthcare professionals and the role parents play in that context. Achieving balance between a young person's right to make autonomous decisions in relation to their health and their parents' responsibility for protection can be difficult. Inter-generational interaction needs to be further explored in this context in order to identify effective ways to move from determination by adults towards more self-determination by young people.

These are only some of the challenges young patients face in their everyday life that policy makers, institutions, and civil society organisations working in the health sector and beyond need to take into account when developing policies, programmes, or making decisions that might have an impact on young people. These are also issues that patient organisations themselves need to be able to address through the meaningful involvement of young patients.

So why is EMPATHY so important to us as young patients?

EMPATHY is a Greek word which refers to *"the capacity to recognise emotions that are being experienced by another person"*. There may not be a more appropriate word than this to describe what this project is ultimately about:

We, the young patients want policy makers and stakeholders, including patient organisations, to recognise the challenges we face in our everyday lives, become attuned to our needs, and integrate our perspective into policies that have an impact on our lives.

2. Objectives of the EMPATHY project

The purpose of the EMPATHY project was to organise a 4-day seminar where young patients with a chronic disease could establish an active dialogue with EU-level policy makers, stakeholder groups, and patient organisations centred on their specific needs and expectations as young patients. Through this project we therefore wanted to contribute to promoting a more holistic approach to addressing young patients' needs in EU decision-making processes.

EMPATHY also aimed to provide young patients with appropriate tools and avenues through which their specific needs and expectations towards EU policy makers and stakeholders could be put forward. Ultimately, this should lead to EU policies in the area of health, youth, education and employment that are more responsive to young patients' needs.

EMPATHY had two short-term outcomes. As a result of this project we hoped to improve policy-makers' and stakeholders' awareness of young patients' opinions and needs, while also strengthening young patients' understanding of the dynamics of decision-making processes that have consequences on their lives, and learning how they can influence such processes through patient organisations.



3. The Consortium

The project consortium was entirely patient-based. Through its Youth Group, The European Patients' Forum was the leader of the project. Nine other patient organisations, which are either national coalitions of patient associations or pan-European disease-specific patient organisations, participated as associate partners.

The full list of partners was as follows:

- European Patients' Forum (EPF) – Project leader
- Estonian Multiple Sclerosis Society (EMSS)
- European Federation Crohn's & Ulcerative Colitis Associations (EFCCA)
- European Multiple Sclerosis Platform (EMSP)
- Federation of Polish Patients (FPP)
- International Diabetes Federation – Europe (IDF Europe)
- Lietuvos Asociacija "Gyvastis" (GYVASTIS)
- Malta Health Network (MHN)
- National Patients' Organisation - Bulgaria (NPO)
- Verenigde Ouderen en Patienten Organisaties (VSOP)

4. How was this project developed and implemented?

DEVELOPING THE IDEA

The project idea was developed by the EPF Youth Group at the 2011 Annual Meeting in Brussels. It aimed to address a fundamental aspect which stands at the very core of the EPF Youth Strategy; namely GOAL 2: "Promoting better recognition of young patient needs in EU policy-making".

The idea was further developed in the following months and a project application was eventually submitted in early 2012 under Priority 5.1 of the EU Youth in Action Programme "Meetings of young people and those responsible for youth policy". This action supports the implementation of structured dialogue between young people/youth organisations and decision-makers/experts in the youth field at local, regional, national or international level.

EMPATHY was successfully recommended for EU funding and the starting date was set for 1st August 2012.

PREPARING THE SEMINAR

To ensure relevance and promote ownership of the project, the activities, as well as the project's output and outcomes, young patients have been involved throughout from the very beginning. The EPF Youth Group with support from the EPF Secretariat and the other partnering organisations led the preparation of the EMPATHY Seminar, the core activity of this project.

During the ten months preceding the Seminar the EPF Youth Group Members further developed the programme and shaped the various activities. They conducted a stakeholder analysis with a view to

identifying relevant stakeholder and policy maker representatives to involve in the Seminar and helped project partners identify other young patients who might be interested in participating in the Seminar.

A list of external stakeholders and policy makers relevant to the topics dealt with in the EMPATHY Seminar was prepared by EPF drawing on the outcomes of a stakeholder analysis performed by the EPF Youth Group at the meeting held in Malta. The various European-level organisations and institutions were invited to attend the Seminar and some of them also contributed to the identification of policy themes to be included in the EMPATHY Seminar.

The recruitment of participant was conducted through a two-stage electronic application process launched in early 2013 according to a predefined set of eligibility criteria.

THE SEMINAR

DAY 1: WARMING UP AND GETTING ORGANISED

On the first day a welcoming session was organised aimed at introducing the EMPATHY Seminar. The participants were encouraged to get to know each other and to understand each others perspectives and expectations through games and a drawing competition whereby participants, who were split into four small groups, had to convey their understanding of EMPATHY through a drawing. During the session, roles and responsibilities for the various activities taking place in the following three days were agreed upon.



DAY 2: FOCUS ON HEALTHCARE

On the second morning, a session which focused on health issues involving young participants, senior patient leaders, and several stakeholder representatives and policy makers was organised. The purpose of this activity was to explore challenges young patients face in relation to healthcare services and discuss what could be done to address them.

Young patients performed a role play simulating a visit at an endocrinologist office after a young patient was diagnosed with Type 1 Diabetes. The role play involved a young person, two parents and the doctor. The purpose of this role play was to show that even in decisions relating to their own health, young patients are often not taken seriously by adults.



The role play was followed by two testimonials given by young participants, one focused on the relationship between young patients and health professionals and the second on the young patients perspective on the transition from paediatric to adult care. These topics were then discussed more in-depth within two parallel workshops. Outcomes of those workshops were then reported back and further discussed in the plenary.

In the afternoon a visit to the European Parliament was organised. The purpose of this activity was to provide young people with an overview of EU policy making process and the role of the European Parliament. The visit was hosted by MEP Rebecca Taylor whom young people had the opportunity to question.

Day 2 concluded with an “intercultural dinner”, in which the seminar participants had the opportunity to learn about European countries which were represented in the Seminar. Each person or group of people from the same country performed a 10 minute, creative presentation on their country. The participants then had an opportunity to sample local food and listen to traditional music from the represented countries.

DAY 3: FOCUS ON DISCRIMINATION AND THE EUROPEAN MEDICINE AGENCY

On the third morning a similar session to the previous day’s was held, this time focusing on the cross-cutting topic of discrimination. The purpose of this activity was to explore how young people can be discriminated against on grounds of their health condition at school, university, and in the labour market.

This session included two role plays performed by young patients. The first was a simulation of a job interview showing how a young person can be discriminated against on grounds of pre-existing medical condition or disability when accessing the labour market. The second was a simulation of an exam at school showing how lack of knowledge and awareness of a chronic condition can lead to discrimination and negatively affect a young patients’ performance at school.

The role play was followed by testimonials given by two young participants who agreed to share their stories about how they have been discriminated against because of their health condition. Role plays and testimonials were followed by policy discussions focused on how to address challenges young patients face in relation to discrimination.

This session was followed by an award ceremony for role play “Best Actor” and “Best Director”. Young participants could vote for the role play actors they liked the best as well as their favourite role play (each role play was “directed” by one young participant). The best actor and director were awarded the “EMPATHY Oscar”.



In the afternoon, a two-hour workshop run by a representative of the Paediatric Committee of the European Medicine Agency (EMA) was held to present the work of the EMA on activities relating to children and young people. The workshop was an opportunity for young people to shape and inform current activities that the Paediatric Committee of the EMA is involved in, in relation to the medicines that young people take. A short report on that session is provided in Chapter 6 of this report.

The EMA workshop was followed by a training session on communication specifically designed to prepare young participants for the activity envisaged for the day after, i.e. the press conference simulations. The purpose of this training was to provide young people with practical knowledge on how to ask questions in a press conference setting, as well as how to develop communication material tailored to specific audiences, e.g. journalists, and convey messages to the public.

DAY 4: PRESS CONFERENCE SIMULATIONS

Two press conference simulations were held on day four of the seminar, one with senior patient leaders and another with representatives of external stakeholders and policy makers. The purpose of this activity was to question experienced patient leaders, stakeholders, and policy makers on how they intended to use the outcomes of the EMPATHY Seminar in their own work.



The two press conference simulations were live-tweeted with the #EMPATHY hashtag. Two young participants were in charge of the live tweet under the supervision of the EPF Communications Officer. The two press conference simulations proved particularly useful in informing the drafting of recommendations addressed to patient organisations, policy makers and other

stakeholders.

A preparatory session was held in the morning to prepare questions to be raised during the press conference simulations. A small group of people were in charge of drafting a press release with the support of the EPF Communications Officer. The press release was then sent out to thousands of contacts, including European and national journalists.

After the press conferences a presentation of the Youth in Action Programme by EACEA representatives was held, after which EMPATHY certificates were awarded to all participants.

FOLLOW-UP PHASE

The follow-up phase included four sets of activities: production project resources (project report and recommendations), evaluation, dissemination and the development of a project sustainability plan meant to ensure proper exploitation of project results.

The EPF Youth Group held an EMPATHY-dedicated session at the 3rd Annual Meeting of the Youth Group in September 2013 in Bulgaria to review the outcomes of the seminar and agree on the final draft recommendations for patient organisations, stakeholders and policy makers. These were then circulated to all participants for final remarks and endorsement.

At this meeting the Youth Group also developed a sustainability strategy meant to take the outcomes of the EMPATHY project forward, as part of the implementation of the EPF Youth Strategy.



5. Growing-up with a chronic disease: young patients tell us their experience

The EMPATHY Seminar was centred on two major themes: the relationship between young patients and the healthcare system and the cross-cutting theme of discrimination.

The second day of the seminar was dedicated to exploring the first topic, while the third day looked more closely at how young people can be discriminated against in society as a result of their chronic disease.

YOUNG PATIENTS AND HEALTHCARE SYSTEMS

Having a chronic illness is a challenge for everyone. However, for young people who are undergoing changes as part of their growth and development process, a chronic disease can be an enormous burden that poses specific challenges in relation to treatments, medications, and healthcare services. In addition to this is the psycho-social implications arising from the disease (these will be discussed further in the report).

To illustrate the specific challenges a chronic disease can pose to a young person we would like to quote the story of a young participant with diabetes.

"Finding time to control my condition is a key issue, it's a lot to do and keep track of. Not only the self-care, trying to get a stable blood sugar level day and night so that the mind will function "normal", trying to learn more to improve it, but also finding time for doctor appointments (doctor, nurse and nutritionist), going to the pharmacy etc., when at the same time you are trying to have a normal life. The general knowledge of the condition in society is barely existing giving a lot of misunderstandings, preconceptions in the daily life, meaning that you always have to work against a constant repugnance. The condition don't always follow a routine, so when you got a day based on routines it can be hard to get a understanding when you might have a rough time and need to deviate from that. It can be at work, when you study (exams and lectures), etc. Getting the best care and equipment for your condition is often hard due to the economic situations/limits. It's impossible to be at your best if you can't take part of the best care there is. Every day is like a challenge because I want to prove that people with chronic conditions can live the same life, like everyone else".

Another participant with transplanted kidneys reported the following: *"My challenges are like most of the people with transplanted kidneys - medicine that needs to be taken throughout my entire lifetime, a very challenging situation when you want to study or work abroad because of constant need to visit your own doctor for tests and medicine".*

Despite increasing attention being paid to identifying possible ways to better involve young people in decisions concerning their health, the opinion of young patients' is that very little is still known about their views and experiences on those issues.

EMPATHY confirmed that despite their youth, young people who grow up with a chronic disease already have extensive experience of the healthcare services they use. Failing to involve them therefore means we are missing out on the opportunity to gather valuable evidence that could inform how best to shape healthcare services to meet the need of young people.

RELATIONSHIP WITH HEALTHCARE PROFESSIONALS AND THE ROLE OF PARENTS

A major issue raised by young patients is their relationship with healthcare professionals and the role parents play in that context. Young patients, especially those who are very young, highlighted



the lack of direct communication between themselves and health professionals. Indeed, the intermediary role of parents very often alters that relationship and young people do not always have the chance to express their concerns directly. Moreover, parents' attitude may sometimes be overprotective or not supportive of youngsters' meaningful participation in decisions relating to their health, which creates another barrier for young people in terms of becoming involved. Too often, parents' views are sought as proxies for their children, even when they are in their late adolescence. There nevertheless seems to be growing awareness of the need to listen to children and young people themselves. Parents who have been very involved in their teen's care for many years may find it difficult to let go of their role as primary caregiver.

A good relationship between young patients, parents and health professionals is of course possible. It relies on the ability of the health professional to play the role of a 'bridge' between parents and young people. It also depends on the parents' ability to involve their children in decisions relating to their health, encourage their self-determination, and support them in becoming independent in coping with the disease. One challenge is that at the moment there is no clear pattern that would suggest that roles are defined for young patients, parents, doctors, and nurses.

A negative response from some doctors in the aftermath of a diagnosis has been reported by some young patients. One person reported her disappointment with the doctors negativity concerning her chronic condition during appointments. She had not been diagnosed for long, but hearing comments about how she must be finding it hard, worrying, and asking if she is wondering why she is the one with that specific health problem and not someone else is concerning. *"I am just beginning to manage and accept the way that things have turned out to be, I don't want to hear about things that might happen in the future yet. I just want reassurance that if I can control it then I should be okay in the future"*, she said.

The first role play exemplified the issues concerning healthcare professionals' negativity and overprotective parents. Young people wanted to show that health professionals need to adopt a more empathic approach to address young people's concerns, as they are the people who are expected to motivate the young person and help them realise their potential. They should arouse feelings of helplessness, low self-worth or depression about the health condition they have been diagnosed with.

The point was made that when a young person is diagnosed with a chronic condition it can be very worrying for them as they try to determine how they will cope with the disease in the future. Mentoring could help young people cope with the condition. They could learn from another patient's experience, potentially from someone who has achieved their dream or a person with the same condition and similar age to them. Currently, locating mentors is difficult, but the potential benefit one could see from mentoring should not be underestimated. It could help to keep someone motivated to achieve their dream and keep them believing that everything is still possible.

TRANSITION FROM PAEDIATRIC TO ADULT CARE

This situation is further amplified during the transition from childhood to adult care. Young patients must be able to rely on the emotional and practical support of their family and healthcare provider during this critical transition phase.

Transition can be quite daunting for both the young patient and parents as it means a new clinic and location and new doctors and nurses who often know little about the young person and are sometimes ill-equipped with the skillset required to accompany the young person and their family throughout the transition.



There is a demonstrated need for a more systematic approach to transition preparation for young chronic patients. Health professionals need to explicitly define their roles in preparing patients for transition. Special focus should be given to consistent, thorough and comprehensive patient education, mitigation and redefinition of the parent's role in the young adult's care, and agreement among health professionals to ensure that these goals are achieved.

DISCRIMINATION

Discrimination on grounds of health condition was dealt with as a cross-cutting theme in the EMPATHY Seminar. The issue has long been debated within the EPF Youth Group and, although any person with a chronic disease can be discriminated against, young chronic patients represent a group that is particularly vulnerable. All young patients who participated in the EMPATHY Seminar felt they had faced discrimination as a result of their chronic disease.

The protections currently afforded to chronically ill patients in Europe are thin and somewhat vague, and differ from one country to the next.

Several actions have been taken by the European Union to combat discrimination. Article 19 of the TFEU provides the legal basis to take action to combat discrimination on six grounds (sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.). The Charter of Fundamental Rights of the European Union prohibits discrimination on these six grounds and nationality (article 21).

Under the existing EC legal framework, discrimination is prohibited:

- on the grounds of religion or belief, disability, age, and sexual orientation in the field of employment
- on the ground of gender, in the field of employment, access to supply good and services
- on the ground of race/ethnicity, in the fields of employment, social protection (including social security and healthcare); social advantages, education and access to and supply of goods and other services which are available to public, including housing.

This framework could apply to patients with chronic diseases, providing they are considered to be within the definition of disability. The UN definition² is less restrictive than a medical definition. In most advanced interpretations, patients with chronic diseases are included in the "long term physical" category. The European Court of Justice has ruled that sickness is not disability.³

As a result of this, patients are not always protected by anti-discrimination legislation. It will likely depend on their disease, e.g. whether associated to disability, whether physically visible or not, as well as the definition used by their Member State's law. These vary from very restrictive definitions in which only a group of "truly disabled people" (according to definitions of social security law) is protected, to definitions where they can be included if they prove they have an "impairment" which is considered to have a substantial impact on their life, to yet a broader definition (used in Ireland) in which they can always be included.

² "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

³ For Further information on definitions of disability in the European Union:
[Lawson, A. and Waddington, L., "Disability and non-discrimination law in the European Union: An analysis of disability discrimination within and beyond the employment field." European Network of Legal Experts in non-discrimination field, July 2009.](#), pp 15-23



The debate revolving around “disability versus chronic illness”, that is currently being held in a number of Member States is not relevant as anti-discrimination law also protects patients from discrimination on the grounds of health status. Accordingly, there is no need to prove that patients fall within the scope of disability definitions.

Discrimination can happen in many areas. Young representatives identified three sectors where they face discriminatory behaviours: education, access to employment and access to treatments.

DISCRIMINATION IN EDUCATION

An area where chronic disease may lead to discrimination is education. Youngsters involved in the EMPATHY project highlighted the fact that there is very little knowledge and awareness of chronic conditions in the education system, which often results in young patients being discriminated against at school and university. Discrimination in education has a major impact on young patients’ performance at school with implications on their ability to find a job afterwards.

Discrimination in education may take the form of less favourable treatment of a person with chronic disease or disability, which the school cannot justify, or failure to make necessary adjustments to ensure the young person is not at a substantial disadvantage, compared with other students. Several examples were brought to the attention of stakeholders and policy makers during the EMPATHY Seminar.

Young patients reported that one of the main challenges they face as young persons with a chronic condition is school. Some highlighted the challenges associated with them having to regularly miss classes due to hospital appointments or because of feeling ill. Others highlighted challenges they face in trying to not be distinguished from their peers, but at the same time not having the same amount of time to spend on studying and preparing for exams.

Preparing for exams becomes an issue if the person feels very sick, but problems can also arise during the exams. One person reported the challenge of taking exams in an examination hall with many other students and teachers who do not understand the condition or mistake it for something else. Some schools for instance do not allow students to test their glucose levels in class because they think the meter sounds like a mobile phone. Likewise, a patient with Crohn’s disease may need to use the toilet several times during the exam without warning due to sudden attacks of pain. In the Seminar, a specific role play was designed to illustrate this situation involving patients with different chronic conditions during an exam.

Involvement in extra-curricular activities can also be a challenge for a young person with a chronic disease. In order not to become further isolated a young patient wants to be involved in these activities but this may sometimes prove difficult if the activity does not suit the person, or the young person is simply unable to make it a regular commitment alongside attending hospital appointments, blood tests, and other medical appointments which are inevitably scheduled after school when extra-curricular activities take place to avoid disruption in the school day. Sometimes a compromise can be made, but it is often not possible to find a solution and that leads to disappointment and frustration.

To ensure equal access to education, young patients suggested that rules be adopted to meet the specific needs of young people with chronic diseases. These needs are numerous, for example the need to miss courses because of treatments, special requirements to be able to sit exams due to a health condition, etc. Teachers and examiners may sometimes be the involuntary cause of discrimination as ‘standard’ rules do not fit all. Schools and universities are expected to make ‘reasonable adjustments’ to meet the needs of students with chronic diseases. They should therefore be aware of the broad range of needs of students with different chronic diseases. Patient



organisations should play a key role in terms of raising awareness of the disease and helping schools and universities make the necessary adjustments to meet the specific needs of students with chronic diseases.

DISCRIMINATION IN EMPLOYMENT

Discrimination in employment is also a major challenge for young people with a chronic disease. For many patients with a chronic disease finding a job or even an internship proves very difficult.

Generally, employers are not eager to employ someone with a physical handicap or a chronic disease. The situation is amplified by the current unfavourable economic situation characterised by raising unemployment and increased competition in the labour market.

Discrimination often appears during job seeking. Young patients soon learn that a selection process may not be based simply on meritocracy and professional skills. Employers sometimes fear that chronic conditions might undermine their employee's performance. Employers need to be trained and learn that a chronic disease does not necessarily affect the quality of work.

Secondly, employers have to make sure that a person with a disability or chronic disease can actually perform the tasks. This may mean for example, modified equipment or flexible working hours will be required.

STIGMA AND PERCEPTION OF YOUNG PATIENTS

This report classifies discrimination in broader terms to also encompass issues such as stigmatisation and perception of the disease by society. EMPATHY confirmed that those who are stigmatised often experience discrimination in some fashion. Stigma happens when others devalue a person or a group of people because they are associated with a certain disease, behaviour or practice. Stigma increases the vulnerability of young people with chronic diseases by affecting their ability to fully enjoy their rights as citizens in their daily lives.

The social aspect of a chronic condition is a key issue for a young person with a chronic disease. Stigmatisation is a major challenge faced by young patients. People tend to pity young people with chronic conditions and this represents one of the biggest challenges young patients face. Some participants reported that on numerous occasions they have had to tell people about their disease and they instinctively respond with comments such as "Oh, you poor thing" or "Ohhh, that's terrible". *"Such comments do upset me", a young patient said. "I think that this is an issue faced by many individuals with chronic conditions as they are constantly pitied, babied or made to feel bad about themselves because of their condition", she concluded.*

"One of the issues I'm dealing with every day is that I have to take my pills at a specific hour twice a day in the morning and in the evening. It can be difficult sometimes when I'm with my friends or at school because I have to hide to avoid their questions", another young patient said.

"It is also unfair when an adult is insensitive and speaks to you about your condition in front of people who may not know about it or say that you can't do something because you have a chronic disease", another young patients argued.

Another young patient shared his story: *"to be honest, being a haemophilic patient changed my entire life. I don't need to mention that I haven't played football or any other sport when I was a kid, although, in those times, that really affected me. Also people are mean (mostly without realising) excluding those who have health problems, like blood disorders or articulation difficulties. When I was a kid, I faced this kind of problems. I would like to say that it never affected me, psychologically speaking. but the truth is, and it is universal, every restriction from what a kid would to, being a kid,*

affects him in future, making him more careful and, at some point, making him more pessimistic about being in a group and taking part like anybody else”.

“The social aspect of a chronic condition is difficult as a young person because due to the illness I cannot meet up with my friends much out of school and I am often absent at school”. A final, general issue for a young person with a chronic condition is definitely self-administering medicine and taking medicine when away from home, such as at a sleepover (which I tend to avoid due to the difficulties of taking medicine and the timings) and on residential school trips, when again it can be difficult to talk to a teacher about it when you feel uncomfortable about speaking about your condition with anyone and as teachers (from my experience) seem to put all chronic or hidden conditions together as one rather than treating it individually”, another young patient said.

“Most of the time other people treat me as a person that cannot do anything, and I always try to explain them that I can do everything like everybody else, but the lack of knowledge is a very severe obstacle”, another young patient concluded.

OTHER EXAMPLES OF DISCRIMINATION ON GROUNDS OF CHRONIC DISEASE

Apart from education and employment a young patient with a chronic disease can be discriminated against in other ways. Applying for loans, for example, when one has a chronic condition often leads to getting less favourable terms than others. Finally young patients face discrimination in access to treatments. They may experience difficulties in accessing treatment while travelling abroad for studies, for instance.

“During my third year in school I had to go abroad for half a year. I chose to go to Helsinki, Finland for this period and discovered how difficult it is to get all the arrangements in place to get my medication there locally. First of all there were privacy restrictions which meant I had to do everything via the hospital pharmacy, which had no experience in the matter themselves. This led to bad solutions and many problems with getting medication locally. In the end I barely managed to get my medication in time. I think this is a good example of a challenge that any person with a chronic condition could face. Wanting to do something, but not having the expertise yourself to set things up so that you can do it safely or having trouble finding the right address to solve the problem”, one young patient told us.

Another area that was discussed is sport. Sport is very important, especially for people with a chronic condition. It contributes to a healthy way of life and reinforces self-esteem. *“With my experience at the sport association of my municipality I can say that the complexity of regulations for sport is horrible. In my country (the Netherlands) regulation for sport equipment adjustment is regulated on the municipal level. This creates a situation where people that live in different municipalities get treated very differently and this is sometimes a reason why people stop doing sport, or not start doing so at all. Also again finding out what exactly the regulations are can be very difficult”, one patient said.*

“Due to my chronic disease I had to give up doing sport to focus more on non-sporting activities because sports which I did enjoy are not able to accommodate for my condition which can be unpredictably better or worse”, one young patient argued.

6. EMA gathers the views of young patients

The [European Medicines Agency](#) (EMA) was invited to contribute to the EMPATHY Seminar in a session devoted to collecting views on new EMA initiatives which are targeted towards young people. The exchanges were very fruitful for the EMA which demonstrates the importance of involving young patients in the design of tools that are addressed to them.

EMA came to the EMPATHY seminar with the willingness to involve young patients in the development of their [Paediatric Committee](#) (PDCO) project. The objective was to consult the opinions of children and young people on matters related to medicines and clinical trials.



The presentation and discussions focused on two tools developed by the EMA/PDCO: a draft informative video and a questionnaire. The video showed the Committee's activities and young patients had the opportunity to comment on it to help the Agency to further develop it. It emerged from the discussions that the video was considered too heavy and too complex. The group advised the Agency on how to make the layout more 'friendly' and less formal to capture the attention of a young audience.

The Committee's questionnaire about medicine use and clinical trials also came under the young people's review. They directly pointed out the need to split the current form in two different ones for clarity.

The debates provided useful feedback for EMA. The participants were happy to take part in this consultation and highlighted the importance of such early dialogues to ensure that EMA efforts are adapted to patients.

"The EMPATHY seminar was the ideal scene for such consultation as the audience was very diverse both in terms of nationalities and diseases. The young patients were particularly vocal in expressing their thoughts on what works and what doesn't. They were clearly interested in our work, it is very important for us to interact with them", said **Elin Haf Davies, European Medicines Agency**

Both EMA's representative and the youth group agreed on the need for a continuous dialogue in this type of project.

7. EMPATHY from the perspective of the participants

This section of the report provides an overview of the feedback received by the participants.

THE POINT OF VIEW OF YOUNG PATIENTS

Razvan Barbuta, 20, Romania, Romanian Haemophilic Association

Thanks to the EMPATHY seminar I understood how EU institutions can help people with chronic diseases. The seminar had a major impact on me, it gave me the possibility to learn more about myself and how I can have a more positive attitude towards problems.

I also learnt more about discrimination and how we can face it. We can help people understand what are our needs and how discriminatory practices can affect us. I now know better how I should express my concerns to my healthcare professionals. I should constantly keep in touch with them because they play an important role, not only helping me to manage my health issues, but also to forge my personality. I was happy to see that we can also be involved in decisions, such as when we met and discussed with the European Medicines Agency representative. I felt my opinion really counts.



As a member of Romanian Haemophilia Association, I will try to use what I learnt to explain to other patients that there is no mountain too high when you have dedicated people around you, and I will try to improve their perspective on the future. They will realise that they are not alone in life and that the health obstacles are easier to overcome with the help of the right people. Last but not least, I felt something special during the meeting and I will use this for myself to move ahead.

Urška Perc, 21, Slovenia, Slovenian Diabetes Association

The EMPATHY seminar was for me a really inspiring experience. I was surrounded by motivated young patients, who want to make a difference for all of us in Europe as well as in their country. I will use the ideas we discussed for our association in Slovenia. I realised that we should never take 'no' for an answer and be persistent to always try to find solutions to move forward.

So far I have attended a few such international meetings, but this was the first one where several diseases were represented. We discovered that after all our problems are similar. Together we are stronger and if we can build empathy with our healthcare professionals and other stakeholders, I think we are on a good way to overcome many of our problems.

Andrew Zammitt McKeon, 23, Malta, Maltese Diabetes Association



The EMPATHY seminar was the opportunity to discuss and identify issues that young patients face regardless of their nationality or their condition. It also showed to older patient leaders and stakeholders what issues are truly affecting us as young patients.

The seminar was interesting and allowed us to express our views among us but also with decision-makers such as MEP Rebecca Taylor. The main benefits that I personally gained from this seminar were to really talk with other participants, both the younger and the older ones, and share our views.

I was surprised to see how similar the issues we face are regardless of our age, condition, situation or nationality. Issues such as discrimination, lack of understanding and the general lack of young patient's voice on a national, international and European level were highlighted repeatedly. I believe

that these issues were also noted by the stakeholders attending the seminar and that they will start to consider young patients as real partners in health related discussions.

With this experience I wish to help other young patients to deal with their issues and to make our voices heard.

Page Nyame-Satterthwaite, 17, United Kingdom, National Children’s Bureau

The EMPATHY seminar was a fantastic experience. Over the four days I learnt a lot about communication, healthcare across Europe and the similar challenges young people with chronic conditions face across the EU.

The seminar was an interesting, informative and insightful experience. From the activities I have learnt how to become a better young patient advocate and how to convey my message clearly. Information about rights for patients with chronic conditions at European level is especially useful as I am interested in travelling and studying abroad.

My favourite activity was the visit to the European Parliament. This included a tour of the European Parliament buildings in Brussels and the chance to speak with MEP Rebecca Taylor. It was an excellent opportunity to be able to voice the concerns of young patients at EU level and we gained a unique insight into the work of the European Parliament.



The range of activities from role plays to the press conferences made the seminar engaging throughout. I hope to use what I have learnt from this seminar in the UK in several ways, for example as a member of my region’s hospital youth council I aim to highlight the more comprehensive approaches to transition in other countries, which should be used as inspiration to improve the current UK system. It has also encouraged me to become more involved with patient associations in my own country and at European level in order to be a more active patient advocate like many of the other participants.

In short I learnt so much, laughed so much and look forward to using knowledge gained from this experience to help other young patients.

EMPATHY FROM THE PATIENT LEADERS’ PERSPECTIVE

Experienced patient leaders attending the EMPATHY Seminar brought their wisdom and guidance to the young audience.

Katrin Rütel, Estonian Multiple Sclerosis Society

My overall impression of the seminar is very good, both in terms of contents and organisation.

I found particularly interesting the exchange of experiences with other patients and learn how they cope with their condition. I learnt a lot from discussions on discrimination, especially when employment is concerned.





I am developing a project on the same issue so it is essential to hear about others' experience.

The presentation on how to put together a press release as well as communicate with media is also something needed in every single organisation.

The EMPATHY seminar equipped me with the necessary skills to involve our young members in the EMSS activities.

Hanna Milczarek, Forum of Polish Patients

I came to Brussels for this meeting as a Senior Patient Leader. I came with mixed feelings:

*Number one: am I not too 'senior' to my younger colleagues, who are only between 15-25 years old?
Number two: would they accept my leadership and what would they understand by 'leadership'? I was afraid, that they could perceive me as an older aunt who came to control them and patronize....but I was totally wrong, they warmly welcomed me and broke the ice with a lot of questions!*

The meeting with the MP Rebecca Taylor from Committee on the Environment, Public Health and Food Safety was the best example that young patients are not afraid to ask very important and difficult questions.

The meeting with EMA representative was an excellent example to show that no one in the health sector should decide about patients' needs without consulting the patients themselves. The simulation of the press conference was also a much needed exercise!!!!

The main learning outcome to me was the opening of a new opportunity window - establishing a platform of common dialogue between decision-makers and young patients being backed by patient organisations.

I would like to organise a very similar event for a group of young patients from different organisations combined with the visit to Polish Parliament and Ministry of Health. The pattern is there, the problems, issues -very similar to those discussed in Brussels. I just cannot wait to make it happen in Poland.

EMPATHY FROM THE POINT OF VIEW OF MEDICINE AND PHARMACY STUDENTS

Olga Rostkowska, European Medical Students Association

It has been a great honour to be part of such an event where the microphone was in the hands of those whose voice is sometimes not heard. Young patients kindly explained to us their daily challenges, fears, doubts and expectations.

For undergraduate health-care professionals who EMSA represents, that was a great 4-day lesson on the professional but also the personal side. Working hand in hand with young patients as equal partners is the best way to focus our efforts to better serve their needs. Putting together, around an equal table, the ones who deliver therapy and those who experience it should become a standard in developing modern approach to medicine.



Karolina Paciorek and Ljiljana Lukic, European Medical Students Association (EMSA)

Thanks to the EMPATHY seminar, we have been able to actively participate in discussions about young patients' rights and problems in EU member states.

We recommend more communication between all stakeholders, policy makers, health professionals and young patients as well as patients groups. Only this way we can provide the best health care and human approach to children and young people. It has been an intense experience and will serve us in our future.

Guilherme Monteiro Ferrera, European Pharmaceutical Students Associations (EPSA)

By participating in the EMPATHY seminar I got the impression that the will of younger patients to share their views and concerns is guaranteed by their active involvement in different local and national patients' advocate groups.

Patients are an important voice whenever healthcare is concerned and the training of young advocates for the greater good of our healthcare systems is one of the greater assets of this project().

From my point of view, the seminar provided not only a platform for sharing experiences but also some tools for these young patients to become better advocates for their causes.

THE POINT OF VIEW OF EXTERNAL STAKEHOLDERS

Jurate Svarcaite, Pharmaceutical Group of the European Union (PGEU)

My overall experience of the EMPATHY seminar was excellent. Stories and experiences of young and often vulnerable patients were overwhelming and enlightening. It was great to listen to their real problems and feelings and think together about possible solutions. It helped me to understand how different the needs and expectations of this group of patients are and I will certainly use this experience in my job to inform future policies of PGEU. We within the pharmacists' community can certainly do more for and together with young adults who are born or diagnosed with chronic conditions.

Camille Bulot, Assembly of European Regions (AER)

Health is a burning topic in Europe. Stakeholders often meet at a table to discuss solutions addressed to patients. They discuss the policies to adopt, the tools to implement, the services to provide, the priority areas for researchers... The only problem is: the patient is missing at that table!

The EMPATHY Seminar filled in a gap by connecting these stakeholders to the person they work for, by putting patients really at the centre. Regional politicians have a lot to learn from these young patients.

The EMPATHY Seminar raised a lot of interesting questions: who is responsible for including and empowering the patient? How to ease the difficult transition between paediatric care and the "adult environment"?

Young patients sent a strong message to European stakeholders: "Chronic diseases are not a barrier to employment, leisure, education. It is the society's role to comprehend that they have to do a little more for everyone to feel better".



AER has always been convinced that patients need to be at the centre: we will keep conveying the message in the regions.

Annex I: List of recommendations for patient organisations on how to involve young patients

The young patients who participated in the EMPATHY project have agreed on the following set of recommendations geared towards patient organisations:

Involving young people means investing in the future of your organisation

Involving young patients is paramount to the sustainability of any patient organisation. Involving young patients means that you are preparing the new generation of patient leaders. As such, it is an investment in the future of the organisation. Involve young patients and make them feel part of the organisation. Give them the opportunity to use their creativity to help you achieve your goals.

Be open to change

Successful patient organisations are those that are able to change and adapt. Involving young people in an organisation means bringing in new enthusiasm, new ideas, and change. If you want to actively involve young patients in your organisation you therefore do not have to be afraid of change. The real challenge is how to manage that change and getting the balance right between the need to make the organisation more responsive to young patients' needs and expectations while protecting "the core spirit" of the organisation.

Adopt a youth friendly approach

To be successful at involving young patients, patient organisations have to look critically at their own image and adopt a youth-friendly approach in their daily practice and activities. This includes, among others, communicating in a language which can be understood by youngsters and exploiting the opportunities presented by new information and communication technology. Use social media as communication platform, but do pay attention to the needs of those who do not want to use or share certain information on social media.

To be able to effectively reach youngsters, it is crucial to adapt communication strategies to the needs of young people. Patient organisations need to be more open to their work with youngsters, be more creative and welcome youth volunteers.

Find your own recipe to involve young people

There is no one single recipe for involving young patients in patient organisation and motivating them to participate. Each organisation must find its own way to "market" itself to be more attractive to young patients.

Develop a youth strategy in your organisation

Be very clear about what you want to achieve for and with young patients. To that end it is recommended to develop a Youth Strategy defining the objectives you want to achieve through young patient involvement.

In developing the Youth Strategy make sure that:

- Do not develop a youth strategy without young people!



- Set up a group for young people who are interested in becoming patient advocates and encourage diversity
- Be very clear about criteria for and what your organisation can offer to young people
- Be very clear regarding the age-range for the youth group: it should not be too broad and age range should be defined out of the challenges you have to address from a young patient perspective
- Give young people ownership of the development of the youth strategy. Guide them, coach them but do not influence them.
- Make sure they themselves are able to identify problems and explore how they can contribute to solving them through the organisation
- Make the strategy ambitious, but is achievable!

Make sure your values are shared by young people

It is important that not only do young patients understand very clearly what the values, mission and goals of the organisation are, but also that those are shared by young people and that the contribution young people can make to the organisation is fundamental to achieving them.

Listen to young people: do not assume you know what a young patient wants

Listen to and then give young people a voice in your patient organisation. If you want to involve young people, you need to learn about their lives and how their lives are affected in all the different aspects. Do not be paternalistic and never pretend you know already what young people want or how they think.

Empower young people

Involving young patients in patient organisations is an effective way to empower them. Involvement, however, will not be successful if young patients do not feel the ownership of the process. Do not regard youngsters as “peripheral”, but work to create an environment where the young could develop their voices and policies, without paternalism, to express their creativity, and to fight for their rights.

Ensure the active involvement of young patients in your organisations’ events such as the general assembly, conferences, and workshops with active participation of youth and youth-led sessions.

Promote self-determination of young patients

In empowering young patients, parental involvement is key. Young people do want their parents to be involved, but in the right way. The challenge is, however, to get the balance right between young patient’s autonomy (autonomous decisions) and protection. Inter-generational interaction needs also to be further explored. Patient organisations should explore how to move from determination by adults towards more self-determination by young people.

Learn from other patient organisations

Look at benefits of involving youngsters by learning from the experience of other patient organisations that have been successful at doing so.

Give young people clear roles and responsibilities

Give young people concrete roles and responsibilities within the organisation. Make them responsible, give them incentives and rewards and always ensure their work is valued by and valuable to the organisation.

Be faster and realistic



Young people expect things to happen much faster. Do not promise things if you cannot implement them.

Create an environment that overrides stigma

Stigma is indeed an issue for many young patients; in some disease areas more than others. The only way to convince young people to overcome that barrier is to offer an environment where they can feel protected, and feel they can realise their ambitions.

Establish cooperation with key institutions

Patient organisations should establish cooperation with schools and universities in order to raise awareness of the specific needs of young people with chronic conditions and encourage them to adopt specific measures to accommodate the needs of students with chronic diseases.

Cooperate with youth organisations

Patient organisations should try to promote themselves proactively to outsiders. Particularly, patient organisations should establish continuous dialogue and relationships with youth associations and try to identify common interests, mutual benefits and areas for cooperation.

There are barriers between young patients and the society. Cooperation between patient organisations and youth associations should focus on finding solutions to overcome these barriers. Patient organisations and youth associations could work together for example on non-formal education programmes and activities focused not only on disease, but also on other aspects which are relevant to young patients, such as education, access to employment and services and leisure.

Annex II List of recommendations for policy makers and stakeholders on how to integrate a young patient perspective in their work

The young patients who participated in the EMPATHY project have therefore agreed on the following set of recommendations geared towards policy makers:

Young patients as active part of civil society

Young patients want their view to be taken into account. They are not just a patient or young person. Policy makers should consider their requests both in the debates and in decision making processes.

Empower young patients to self-management

Self-management is an important step to becoming empowered patients. Young patients can be capable and reliable patients, able to manage their health conditions. Empowerment is achievable through education and easy access to information about diseases. Policy makers may introduce in all public services (schools, hospitals etc.) educational tools to learn about health conditions.

Changing perceptions of young patients

Often health professionals, parents and the larger public think young patients need to be over protected, patronized. On the contrary, young patients have their own view on their health condition. Having learned from their experience they should be considered as “resourceful persons”.



Health professionals should take into account their point of view and consider them as an asset in the management of their health condition.

Adapting Healthcare professionals' skillset for them to be able to better interact with young people and provide all necessary support

Young patients need more dedicated time with their health professionals.

Regular and adapted communication would help increase both mutual understanding and trust. To this end, health professionals may need specific professional trainings.

Better coordination between doctors, patients and other health professionals

Good coordination and transfer of information is particularly important for young patients.

Good coordination may positively affect the delicate phase of transition from childhood to adult care. When transition is not well managed, it has negative psychological side effects on young patients, with consequent lack of trust in health professionals. This aspect requires major attention because lack of management in transition to adult care may result in lack of assistance and care for young adults with chronic conditions.

Policies and initiatives tailored on the needs of young patients

Access to healthcare and healthcare services should present characteristics tailored on the specific needs of young patients. A specific policy that guarantees access to healthcare should apply to young people with chronic conditions. More than patients they are students. Nowadays being a student in Europe means having access to educational systems in different EU countries through mobility programmes such as Erasmus. For the moment, no legal framework provides young patients with equal and timely access to healthcare across EU countries. Lack of legislative framework may result in reduced mobility in Europe and fewer opportunities for young patients.

Educate educators

Childhood and adolescence are a delicate phase of a person's life.

Young patients face at the same time the uncertainties typical of childhood and adolescence and the psychological fragility caused by their condition. Therefore educators need to learn how to cope both with the psychological difficulties both with practical needs of students with chronic conditions.

Educate employers

Access to employment opportunities is a challenging experience, especially in time of crisis. Employers need to learn that young people with chronic conditions can be an important asset to their organization.

Remove barriers

Rules that act as barriers should be removed both from the educational system and employment market. Because of their specific conditions young patients face the side effects of standardization and rigid administrative systems in their daily life. Rigidity should be replaced with adaptability and flexibility in order to let young patients have equal chances.

Recognise "chronic condition" as a ground for discrimination

Chronic conditions should be recognized as grounds for discrimination at the same level as disabilities. Most of the time chronic conditions are not visible and this makes it more difficult to prove discriminatory behaviors.



Policy makers should set up a legislative framework that protects patients and promotes equal chances.

This legal framework on patients' rights should be easily accessible and understandable to the wider public.

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