

Collection of Good Practices of Patient Organisations' Cooperation with NGOs Representing Underserved and Vulnerable Groups

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1. Introduction

This collection summarises the good practices identified and collected during 2017 on the cooperation between patient organisations and non-governmental organisations (NGOs) representing underserved and vulnerable groups.

This collection of good practices follows EPF’s 2016 [Roadmap](#) towards the inclusion of vulnerable groups’ perspective within patients’ organisations. EPF has collected these best practices and carried out this exercise in order to demonstrate the current good practices that exist, to encourage and foster the scaling up and further development of such initiatives and to raise awareness of the importance of working together for universal health coverage for all.

The Treaty of Lisbon¹ mandates the Union with ensuring a high level of protection for human health in all EU policies. Similarly, strong, efficient and well-run health systems are a key cornerstone of universal health coverage. Access to healthcare is a basic human right² and one of the fundamental principles of European health systems, together with safety, quality, and equity³.

¹ <http://www.lisbon-treaty.org/wcm/the-lisbon-treaty/treaty-on-the-functioning-of-the-european-union-and-comments/part-3-union-policies-and-internal-actions/title-xiv-public-health/456-article-168.html>

² <http://www.un.org/en/universal-declaration-human-rights/>

³ <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2006:146:0001:0003:EN:PDF>

Yet, research provides evidence of the systematic failure of European health systems for many people currently living within the region, particularly people in situations of precarity, social isolation or vulnerability⁴. Persistent inequities undermine the EU's fundamental values and patients' rights, with an impact on social cohesion and economic growth.⁵

1.1 EPF's 2016 Roadmap towards inclusion of vulnerable groups' perspective within patients' organisations

In 2016, EPF together with a number of organisations representing underserved groups, vulnerable to health inequalities and/or discrimination, including undocumented migrants, LGBTI people, the Roma, homeless people and disabled people, developed a [Roadmap](#)⁶ towards the inclusion of vulnerable groups' perspective within patients' organisations.

This roadmap was developed as part of a reflection process on how patients' organisations can ensure they are inclusive and represent the views of all patients with chronic and long-term conditions. It defines actions that EPF needs to take in order to improve its inclusiveness and to establish meaningful cooperation with organisations representing groups that are vulnerable to health inequalities at EU level. It also provides our members with suggestions of possible actions they could integrate into their work, where relevant to them, in order to advocate for inclusiveness and universal access to high quality healthcare.

1.2 The importance of inclusive patient organisations

The aim of the roadmap for the inclusion of vulnerable groups' perspectives within patients' organisations is to raise awareness and foster reflection and action on inclusiveness in the patient movement, and to support patients' organisations' advocacy for the rights and specific needs of all patients in an inclusive way within the EU. It contains suggestions for actions to implement both for EPF and for patient organisations at European or national level.

Vulnerability is a cross cutting issue for patients with chronic and long-term conditions. Patients may be vulnerable due to the impact of their condition, and belonging to another vulnerable group may result in increased barriers to access quality healthcare that corresponds to their needs.

For this reason, proactive action is necessary in order to make the principle of inclusiveness a reality.

⁴ <https://www.doctorsoftheworld.org.uk/Handlers/Download.ashx?IDMF=7d8c2ef9-403a-402d-8571-e8cefbec8d00>

⁵ https://ec.europa.eu/health/sites/health/files/state/docs/health_glance_2016_rep_en.pdf;
https://www.eurofound.europa.eu/sites/default/files/ef_publication/field_ef_document/ef1442en.pdf;
https://ec.europa.eu/health/expert_panel/sites/expertpanel/files/015_access_healthservices_en.pdf

⁶ http://www.eu-patient.eu/globalassets/policy/anti-discrimination/roadmap-inclusiveness_final_december2016.pdf

1.3 Methodology for the collection of good practices

This collection of good practices was developed with the input of patient organisations and organisations representing underserved groups. The good practices were collected following numerous calls for such practices to the EPF membership and members of organisations representing underserved groups that EPF collaborates with on a regular basis.

1.4 What is the purpose of this collection of good practices?

In follow-up to EPF's 2016 Roadmap, EPF has collected good practices of patient organisations' cooperation with NGOs representing underserved groups.

Many patients' organisations are already developing activities in partnership with other associations or groups in order to promote inclusiveness and to advocate for universal health coverage. Sharing publications or information about these activities amongst the patient community is important to scale them up, encourage further action and foster more cooperation.

1.5 How can this collection of good practices be used?

This collection of good practices is intended for patient organisations to firstly take inspiration from these good practices in order to increase such collaboration and secondly identify and tackle barriers to such collaboration.

This collection of best practices is also intended for policy makers and aims to illustrate the importance of inter-sectoral action for health, sustainable investment in and a holistic approach to social and health services.

2. Good practices

2.1 Norway – Health Centre for Undocumented Migrants

Helsesenteret for papirløse migranter (HPM)

<https://kirkensbymisjon.no/about-us/>

Undocumented migrants in Norway have only the right to emergency health care. HPM is a health centre for undocumented migrants which run and financed by Oslo Church City Mission, a non-governmental organisation, and the Norwegian Red Cross. The organization's mission is to uncover violations and injustice, provide help, comfort, presence and relieve suffering, and to identify and counteract the causes of injustice. The centre provides free primary health care.

Patients in need of specialised care are referred to public hospitals even if they are not entitled to such care. In situations where the hospital refuses the referral, all patients have the right to make a complaint. The health centre helps patients that have been refused care to make their complaint to

the County Governor. This process is complicated. To get an answer, a follow up is needed and it takes a lot of time.

In this respect, the Health centre works in cooperation with the **Patient and User Ombudsman**. The Ombudsman has agreed to follow up the cases from undocumented patients until a favourable or unfavourable decision. As many cases end up with an unfavourable decision this may seem wasted work however the centre believes this to be important work in order to raise awareness, combating discrimination in Norway.

The health centre for undocumented migrants has four main objectives:

1. Provide health care and health information to undocumented migrants.
2. Contribute to undocumented migrants receiving health care in the ordinary health care system.
3. Documenting and communicating issues concerning undocumented migrants' health.
4. Become redundant and shut down as soon as access to health care becomes universal.

The health centre is based on volunteerism with a small staff facilitating and organizing the activities.

2.2 Spain – Access to Healthcare for Homeless People with Disabilities

<https://raisfundacion.org/derecho-salud>

Homeless people with disabilities or homeless people recovering from illness are subject to specific vulnerabilities. RAIS Fundación, a non-profit, independent, social initiative entity works towards raising awareness to public institutions and other organisations of challenges faced by homeless people in accessing healthcare and recovering from ill-health.

The health system is currently designed for people who have a home where they can recover and take care of themselves. When you live on the street it is very difficult to follow treatments and medical care. The effects of living without the protection and security of a home have devastating effects on people's health. RAIS Fundación is tackling this forgotten emergency through several initiatives and activities.

Concerning **homelessness and disability**, RAIS Fundación carried out a study in collaboration with **Fundación ONCE**, a non-governmental organisation that works towards social inclusion of people with disabilities (2012-2013). The purpose of this study was to analyse the situation and vulnerabilities of homeless people with disabilities and recovering from ill-health.

The results of the study indicated that:

- The incidence of disability is 5 times higher amongst people in a homeless situation than for the general population (22,9% vs 4,7%).
- Only half of the people in a situation of homelessness have an official recognition of the disability, which hinders access to the protection network.
- Disability has a direct impact on social exclusion processes.

- Professionals working in protection networks acknowledge that services are not adapted for the support of people with disabilities in a homeless situation.
- 86% of homeless people with disabilities do not access specific services for disability.
- Coordination and collaboration between homeless and disability networks is urgently needed.

In light with these data, RAIS Fundación are going to undertake a new study in 2017-2018, with the design and piloting of specific services.

2.3 Spain – ‘Housing First’ - Right to Housing for Homeless People recovering from ill-health

<https://raisfundacion.org/derecho-vivienda>

Housing First is a way of working that has radically changed the way we intervene with homelessness. The results with this model in countries such as the United States, Canada and Finland are evidence that it is possible to end chronic homelessness in our cities.

Habitat is the RAIS Fundación programme which is based on the Housing First methodology that is being developed in Spain with very positive results both in the lives of people and in the economic efficiency of the program. The success in its implementation is 100%.

In 2010 RAIS Fundación identified that the resources needed to provide **homeless people in a situation of convalescence or recovery from ill-health or treatment** with an appropriate place to recover were simply not available and such provisions were not present in public services.

During sometime, RAIS Fundación was looking for solutions, and in 2012 they launched a **service to care for homeless people in convalescence or in accompaniment of a terminal illness**. The programme was unknown, and a lot of effort and work was needed to raise awareness of this programme within Social Work Departments in Hospitals and explaining them the service. These departments identified the necessity and soon recognized the usefulness of the service in addition to the other existing public resources. Sometime after, the service, which started out as a programme led by RAIS Fundación was integrated as a public service in Madrid.

The main aim of the programme, apart from health care itself, is to achieve the empowerment of people in relation with their own health care both in their daily life and in relation with social and health institutions.

Highlighted findings include:

- During the stay, there was an improvement in all the areas in which the service provides support: health, citizenship and participation, relationships, personal development, functioning and dependence, access to basic goods, leisure and free time, training and labour.
- The service resulted in an increase in primary care visits and use of ambulances (in comparison to the 6 months preceding the stay), but it also resulted in a decrease in days spent in hospitals and

use of emergency services giving as a final result an average saving of 24,357.30 € per person for the health system.

RAIS Fundación concluded that the programme, which is a bridge between health and social systems, helps homeless people to improve their skills and particularly in relation with health. Due to its usefulness and effectiveness, the programme should be replicated in other regions to benefit both homeless people and public services through savings.

Regarding the convalescence programme in Madrid, RAIS Fundación collaborates with most of the public hospitals in Madrid (around 40). The programme has also now been launched in Murcia, where RAIS Fundación have contacted all the public hospitals and at this moment in time collaborates with 30% of them.

2.4 Germany - Accessibility of Patient Information Leaflets for the Blind and Visually Impaired

www.patientenInfo-service.de

Every available drug, sold to patients has to include a patient information leaflet. Even for a seeing person these are sometimes hard to read. In 2005, German legislation ruled, following EU-guidelines, that the patient leaflet has to be provided in a format legible by blind and partially sighted people.

Since then the German Association for the Blind and Visually Impaired (DBSV - Deutscher Blinden- und Sehbehindertenverband e. V.) has been in exchange with the German Ministry of Health and the associations of pharmaceutical Industries in Germany, amongst others, to not only ensure that the requirements are met by those responsible, but also to provide counseling regarding suitable formats for a productive implementation.

Thus, the internet version of “Die Rote Liste”, a compilation listing most available drugs in Germany, also became a repository for **patient information leaflets in different formats**, providing access to that vital information to visually impaired people. Formats provided up to now are accessible in HTML, PDF in normal and enlarged print and Daisy audio format. The work is still ongoing, but a big step has been taken already.

3. Conclusions

As indicated above, many good practices of cooperation between patient organisations and organisations representing underserved groups are ongoing.

Nevertheless, we have identified that such reported cooperation is limited. In this respect, we have listed the possible reasons for the lack of reported cooperation and collaboration to date and made some recommendations.

- Currently, health and social sectors work predominantly in silos. This may result in damageable competition for resources for example and therefore reduced cooperation.
- Similarly, this siloed approach may limit interaction between patient organisations, predominantly working within the health sector silo, and organisations representing underserved and vulnerable groups predominantly working within the social sector silo or other.
- Additionally, programmes funded by social systems can see savings for health systems for example. As these systems currently work in silos, results of these investments are not directly identified. This can cause budgetary tension.
- Weak, scattered and unstable funding for such organisations (patient organisations and organisations representing underserved groups alike) is also a significant barrier to long-term collaboration.

For these reasons:

- Implementing inter-sectoral action for health, meaning collaboration between the health sector and other sectors, such as social, labour, economic and environmental sectors to eliminate inconsistencies, damageable competition and address policies and actions affecting health outcomes undertaken by sectors outside the health sector is of utmost importance.
- EPF promotes a holistic and integrated care approach to health and social services' structure at the system, financing and service delivery levels to enable patient groups including vulnerable groups to collaborate more systematically on health issues.

Health is defined according to the World Health Organisation as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity". However, Europe currently lacks inter-sectoral action and collaboration for health, and a systematic health in all policies approach.

Identifying and eliminating the above-mentioned barriers to such cooperation is important in order to promote further collaboration between patient organisations and organisations representing underserved and vulnerable groups.

In coming years, EPF will continue to implement the actions proposed within EPF's roadmap towards the inclusion of vulnerable groups' perspective within patients' organisations. Furthermore, we will also continue to encourage our members to develop such cooperation and to share their actions, addressing rights and needs of vulnerable or underserved groups in order to share ideas for activities and good practices. To this end, EPF will develop a progress report in 2019.



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