

PATIENT ORGANIZATIONS' ACTIVITIES IN THE AFTERMATH OF THE EARTHQUAKES

Information Note
April, 2023

2023, April

This information note covers the summary of the earthquake disaster process evaluations of NGOs mostly composed of patients and caregivers* conducting patient-focused studies that act on the needs of patients and caregivers in the disaster area following earthquakes based on Kahramanmaraş Pazarcık and Elbistan on February 6, 2023.

This document includes patient organizations' processes for communication within the disaster zone, support mechanisms, constantly changing needs and suggestions for collaborations, how much we need in the process to a solidarity culture. It must also be considered that the needs of patient organizations and earthquakes and support mechanisms are varied and changed during the interviews. Therefore, this document contains the views that have been communicated so far.

We respect the existence of the 41 patient organizations** (associations, foundations, networks, federations) that we contacted, who sincerely share their ideas and opinions, who always express solidarity and never hold back from striving and struggling in this field, and we believe that we will find an inclusive common solution because we are a part of solidarity.

Social Innovation Center



* Terms of *Caregivers* used for patients' families and/or relatives

**This information note was prepared through interviews with 41 patient organizations (NGOs)

A. Last Condition for Earthquake

11 provinces (Adana, Adıyaman, Diyarbakir, Elazığ, Gaziantep, Hatay, Kahramanmaraş, Church, Malatya, Osmaniye, Şanlıurfa) were directly affected in earthquakes based on Kahramanmaras Pazarcık and Elbistan on February 06, 2023. It was explained that as of March 20th, death increased to 50,000 96 and the number of injured was 107,000 204*.

According to the press release issued on March 02 by the Ministry of Interior Disaster and Emergency Management (AFAD), the 332 tents of the city in the wise tent was established as 360,167 and the number of earthquakes in the tents is 1,440,668. The region stated that the infrastructure work and installation of 90,914 containers for the creation of 189 container cities was ongoing. The number of earthquakes living in container cities is 34,120. The total number of citizens who received housing services in the area affected by the earthquake is 1,593,808. In other cities, a total of 329,960 earthquake housing services are provided to affected by the disaster ** .

On March 15th, heavy rains that were effective in Adıyaman, Malatya and Şanlıurfa caused flooding, 20 people died in the flood, and tented cities were evacuated ***.

* AFAD President Yunus Sezer has provided an explanation. BBC News Turkish, “6 Şubat'taki depremlerde can kaybı 50 bin 96'ya yükseldi”, access: March 23, 2023,, <https://www.bbc.com/turkce/articles/c51kdv8d15jo>

** Ministry of Interior Disaster and Emergency Management (AFAD), “Kahramanmaraş Merkezli Yürütülen Çalışmalar Hakkında - Basın Bülteni - 37”,accessed: March 23, 2023, <https://www.afad.gov.tr/kahramanmaras-merkezli-yurutulen-calismalar-hakkinda--basin-bulteni--37>

*** BBC News Turkish, “ Şanlıurfa ve Adıyaman'da sel felaketi: Can kaybı 20'ye yükseldi”, access: March 23, 2023, <https://www.bbc.com/turkce/articles/c2j7kjj4r49o>

B. Early Days Following an Earthquake Crisis and Solutions

The earthquake affected roads, dents occurred in certain areas of roadways, and transportation was extremely difficult due to vehicle traffic. There have been difficulties communicating with the disaster zone, and healthy news could not be obtained in the early days due to the damage of GSM operators in the zone. As the hospitals were damaged, pharmacies have not yet opened and earthquakes are *no longer** able to access their existing medications, the patient and their caregivers urgently requested products such as the drugs, formulas, medical devices, and medical supplies that they use daily from** the patient organizations. Moreover, patient organizations started due diligence studies with the representative, volunteers, and members that they could reach in the region on February 6th morning.

After the first few days, the drugs started to be delivered to the region through official channels, but there were problems in delivering them to the patients. There has been a great challenge in providing drug and food support, especially for rare diseases and for those who have special nutrition. During this process, patient organizations went through hand-delivery of all support as they knew the needs of their patients/members well.

The crises experienced and how patient organizations deal with crises, the support provided in the region and the recommendations regarding the subject matter are detailed in this file.

* Earthquake families whose homes are destroyed by earthquake or unable to enter their homes due to severe damage

**The NGOs mentioned in this document include only patient organizations.

C. In What Areas are Patient Organizations Supported After the Earthquake? / What was Done?

- **Drug support :** Until the pharmacies were established, drugs that must be used every day were delivered to the patients through patient organizations. During this process, drug support was provided in collaboration with the branch, association, representative, volunteer, university, healthcare professional that patient organizations contacted locally.
 - **Using Code 484 :** The application of the code 484, which was created to quickly meet the need for drugs in the disaster area, could not be solved for the procurement of the drugs of earthquakes going from the disaster area with another one, and the relevant issues were shared with patient organizations. During this process, it was witnessed that pharmacies in other provinces were not performing the procedure due to late knowledge of the process and/or other concerns in order to meet the needs of the patients whose residence is in the earthquake region. Patient organizations for the resolution of the problems experienced contacted the relevant patient and caregivers and they tried to implement the procedure. Some patient organizations have sent the relevant drug to the patient because the drug is provided urgently, and the pharmacist does not facilitate the process.
- **Transfer support:** Patient organizations were supported in the remote coordination of the patients in the transfer to other cities for the continuity of treatment processes of the patients in earthquake.

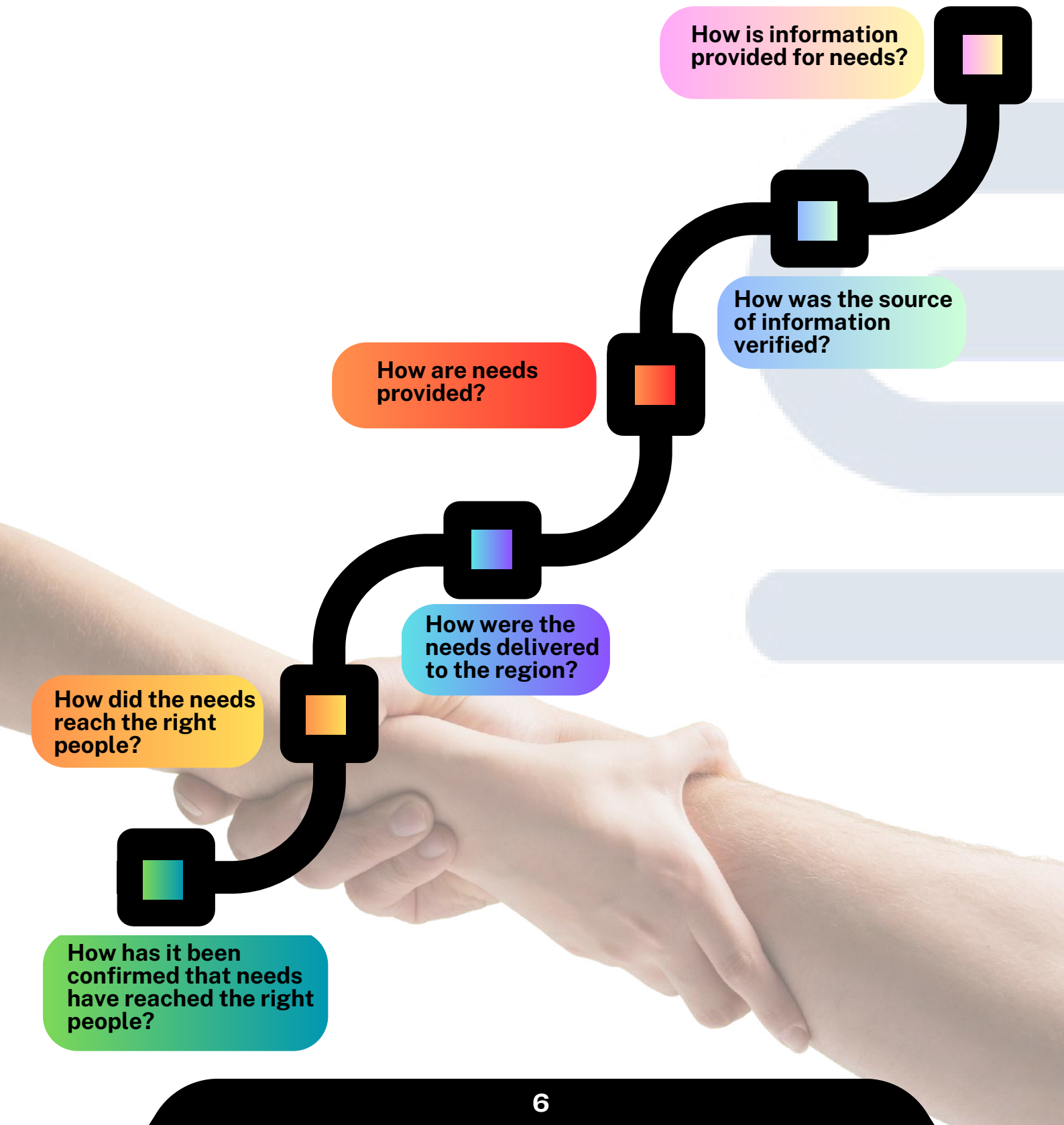
C. In What Areas are Patient Organizations Supported After the Earthquake? / What was Done?

- **Medical Device / Medical Supplies / Disabled Toilet / Wheelchair / Mask / Hygiene Set (All Women) support:** Patient organizations were sent to the area of the products they had on the morning of February 6th and the requests for medical devices, medical supplies, disabled toilets and wheelchairs were met for the patients and their caregivers who they contacted from the area. Patient organizations sent masks to protect people in the area from the danger of aspects*, and hygiene set deployments took place to share with all women, not just patients.
- **Nutrition / Food Supplement (Special diet food and food):** Only for people who were fed with special dietary foods, patient organizations learned the need from the area and handed it over.
- **Financial Support:** Patient organizations learned the need from the field and contacted patient advocates and provided financial support to patients & caregivers for medical devices and medical supplies needed.
- **Patient Follow-up / Physician support:** Physicians who specialize in the relevant disease in the new province established for the continuity of treatment processes of patients with earthquake in other provinces have been provided with referrals.
- **Shelter service support:** Patient organizations have also communicated with the relevant institutions and platforms to ensure that the caregivers who are sick in earthquake receive housing services and they have supported the families (patient & caregivers) in following the process.

* For detailed news, see <https://www.cumhuriyet.com.tr/saglik/prof-dr-ergor-deprem-bolgesinde-asbest-tehlikesi-geri-planda-kaliyor-2056935>

D. How did Patient Organizations Manage the Process? / How did Patient Organizations Support?

Patient organizations have faced many crises and come up with rapid solutions to provide support for the needs of patients and their caregivers. This section will include the steps for patient organizations to carry out the process with regards to how the support is delivered to the right people.



D. How did Patient Organizations Manage the Process? / How did Patient Organizations Support?

How is information provided for needs?

Communication was disrupted in the disaster zone, and healthy communication could not occur both over the phone and the internet. Communication took days to recover. Communication could be established in certain and restricted areas of the disaster zone. All patient organizations, without exception, made calls to patients and their caregivers in the region via social media tools and indicated that they were ready for support in the relevant areas. However, in the early days, some patient organizations specifically considered reaching out to patients via social media as a “fruit effort” due to the difficulty in accessing the internet in the region. There are also patient organizations in the process that communicate via social media and communicate support to those patients whose needs have been determined. Internet use and mobilization to use the internet vary depending on the circumstances of the patient and his/her caregivers. In particular, elderly patients have been limited in this regard.

Communication between *Patient Organization – Patient* in the process.

- **Performing calls from head office:** Patient organizations, which are the current communication database comprised of patients and their caregivers, contacted those who lived in the disaster zone by phone and conducted the necessary support studies regarding their needs.
- **Branch/Representation/Regional Volunteerism (Patient advocates, physicians):** Patients and caregivers have been reached through patient organizations affiliated with the roofing organization if the NGO’s branch, representative offices, volunteers, or roofing organization is located in that region.
- **Patient and caregivers’ access to patient organizations:** Earthquakes have reached patient organizations with their needs on social media.

D. How did Patient Organizations Manage the Process? / How did Patient Organizations Support?

During this process, patient organizations that progressed with the contact details of the patients and their caregivers learned the need directly and ensured that the right assistance was provided to the right people. In particular, patient organizations have played an important role in getting people to the right support at the right time for patients who need personalized medicine, formula, food use groups, special dietary formulas, continuous use of medications, and medical device support.

Moreover, patient organizations stayed in contact with patients and supported them with guidance in both their absence of their medications and inability to remember which medication they used in the panic.

How was the source of information verified?

When patient organizations learned about the needs directly from patients, they were able to act quickly without wasting time for the accuracy of the information source. Patient organizations have contacted patients and their caregivers via phone numbers - social media accounts to learn about the accuracy of shared needs from social media groups and social media channels. They have also communicated to confirm the news through networks where patient organizations representatives are located. The issue patient organizations faced when confirming needs was mostly duplicative news, and old-dated news. Remaining in circulation and resharing without confirming needs shared on social media channels has resulted in patient organizations spending time on need confirmations.

D. How did Patient Organizations Manage the Process? / How did Patient Organizations Support?

● *How are needs provided?*

Some patient organizations went to support the area on the morning of February 6th without contacting the patients living in the area and their caregivers to deliver medical supplies / medical devices that may be needed (patient organizations that quickly send existing resources to the area). Some of the patient organizations who learn about the needs started by making purchases from the cities where they are located, while others bought products from the nearest medical stores in the region. Patient organizations that are provided with drug support, on the other hand, collected the spare drugs of the patients living in other regions at the relevant site and sent them to the site.

Patient organizations who learned the need from the area contacted the private sector about the issue and forwarded the donated food, materials to the patients.

Donations received from patient organizations that are in contact with international patient organizations and are members of international networks were sent as financial support to meet the needs of the patients.

● *How were the needs delivered to the region?*

Patient organizations getting their needs to the region has been one of the areas where patient organizations are developing solutions to crises.

- **Pickup Trucks:** Patient organizations have reached the space with pickup trucks to quickly communicate needs from their region.
- **Trailers:** With the learning of the needs, it has been forwarded to the support area with both private and municipal trailers. Patient organizations have provided logistical support.

D. How did Patient Organizations Manage the Process? / How did Patient Organizations Support?

- **Vans:** Vehicles are blocked from entering the area after the State of Emergency announcement. Patient organizations that traveled by vans to meet the needs of the patients received letters from doctors to provide access to cities.
- **Ambulance – Cargo Aircraft:** Patient organizations that send the needs to the area by renting ambulances and cargo planes so that the needs do not get caught in the roadblock.
- **Submitting Medical Supplies with Healthcare Professionals:** Some patient organizations have communicated needs to the earthquake area with the support of healthcare professionals.
- **Purchases from nearby cities – delivered to address:** Patient organizations that contacted medical stores in provinces near the earthquake area, which is both a quick solution to meet the need and an important example in terms of delivery to the addresses of the patients, made purchases (medical materials, medical device, wheelchair, disabled toilet) and have ensured that patients are sent to their address (Some patient organizations have preferred them because they think that patient caregivers are faster to take gradually after purchases).

How did the needs reach the right people?

Drug and medical supplies support sent to the disaster area has much greater sensitivity than shipping food, clothing, etc. Patient organizations have experienced crises in delivering the needs sent to the region to the right people. Unfortunately, some patient organizations have heard that the material sent to the region, food support has not reached the patients. Therefore, patient organizations have taken care in the follow-up of the supports.

D. How did Patient Organizations Manage the Process? / How did Patient Organizations Support?

Each patient organization support to the region has been made in different ways. If patient organization is a volunteer, member, branch or collaborating member of the patient organizations in the region, the support received through the trailers in the region was received by the relevant individuals and handed over to the patients.

Some patient organizations have informed patients that the relevant support can be provided from these centers by determining the patient organizations they collaborate with and university hospitals as sites. People have increasingly provided their needs.

Patient organizations who made purchases from nearby cities and sent medical supplies to the address also ensured that the needs were delivered to the right people.

Especially rare disease patient organizations have handed over the needs of the patients (with vans, ambulances).

How has it been confirmed that needs have reached the right people?

Patient organizations have emphasized the importance of moving forward with confirmation in this process. If the representatives of the patient organizations did not go to the area, if they were progressed with the subjects from the region, they confirmed whether the need was fulfilled or not by calling the caregivers on earthquake.

Additionally, photos were requested from the companies that sent medical supplies.

E. What Solidarity and Collaboration Did Patient Organizations Conduct When Managing the Process?

Advancing NGOs with solidarity networks and collaborations, they have stated that they are not alone, and they are acting together to work on their potential much more. As well as networks that have been moving together for years, networks that were established quickly after the earthquake and that acted together after the earthquake even though they worked in different areas have also formed. The Unobstructed Disaster Platform is just one example of a network of patient organizations coming together for a common purpose after an earthquake. Additionally, support has been provided to networks established for humanitarian aid.

It has determined the mobility of the patient organizations, the contact of the patient organizations, organization practices in other cities, voluntary-member relations and of course the financial opportunities of the patient organizations. NGOs who are part of international networks in the process contacted quickly and stated that they also received support from their external stakeholders.

There are also patient organizations that are quickly located in the earthquake area with the support they receive from the private sector or that support their patients spread across a wide range of points in Turkey with temporary migration.

Under the Public Relations heading, there were different examples where public institutions both supported and requested support. Containers were created with patient organizations for the nutrition and treatment of patients. However, it was observed that patients did not benefit from this service as much as expected due to factors such as logistics and security. In another dimension of public and NGO solidarity, some public institutions made requests to patient organizations for the needs of patients. Especially in the first few days, patient organizations reported that local government officials in the area and officials from social assistance units called patient organizations and requested support.

F. Recommendations for Support for Patients and Their Caregivers in Earthquake?

Above, the current situation has been photographed, including what happened in the region. Unfortunately, some of the services that must be provided in the early days are still on the agenda as a need, even though days have passed. Patient organizations stated that they continue to learn the current needs through the subjects, members, patients and caregivers who live in the region, the collaborators and institutions. Support recommendations for these needs are shared below.

- The housing needs of patients can be evaluated and met in terms of their disease
- Providing support to infants and adults who require special care within the scope of their requirements
- Providing hygiene environment in the disaster area (patient toilet, toilet, shower, laundry) and sending hygiene materials (sending scabies, lice medicines to prevent epidemics) and sustainability of water use in the region
- Ability to create private spaces if hospitals in the disaster zone need to be strengthened
- Elimination of access problems to medicines used especially in the field of rare diseases and ultra-rare diseases (There are current problems in accessing critical medicines both in and outside the disaster area)
- Opening physical therapy and rehabilitation centers in disaster area
- Payment for medical devices (For those individuals who lose their medical device in disaster, the relevant device must be paid by the Social Security Institution once more)
- Raising mobile scan trailers to avoid omissions in the region, especially in areas where early diagnosis such as cancer saves lives (Not postponing Mammography and controls)
- Initiation of regular psycho-support processes with specialist psychologists in both trauma and chronic diseases

F. Recommendations for Support for Patients and Their Caregivers in Earthquake?

- To ensure that patients do not experience treatment rejection and that their treatment continues;
 - Conduct patient awareness and awareness
 - Establishment of support points for patients migrating to different cities or who can no longer continue the treatment process with their doctor so that they can reach the right expert in their treatment
- Strengthening health capacity to rebuild patient-physician relationship
- Providing logistical support in cooperation with district municipalities. With the cooperation of the Ministry and the municipality, allocating municipal vehicles to meet the needs of patients in that region

G. Recommendations for Patient Organizations to Sustain Support

- **Dissemination - Database:**

Patient organizations have emphasized the importance of proliferation and capacity strengthening processes as an NGO in this process. In the region, patient organizations who are volunteers, members and representatives learned about individual-based needs with confirmation and were able to carry out a healthy but highly lavish support. On the other hand, the support of patient organizations who do not have contact in the region has been limited individually. Therefore, it is recommended that NGOs be organized by identifying branch, representative, field volunteers in different cities and regions. In addition, the importance of patient organizations constantly updating the database has once again become apparent. It is recommended that **patient databases** are created in accordance with the scope of the Protection of Personal Data and Privacy Policy and disaster situation in collaboration with the Ministry.

G. Recommendations for Patient Organizations to Sustain Support

- **Financial Support:**

They emphasized that existing support must continue to ensure that patient organizations can maintain their assets and contact more patients. In general, patient organizations have used all their resources in this process to address the needs of the patients in earthquake. Patient organizations have been shown to need more financial support to sustain their assets and incur spending on a need basis. It is therefore recommended that **special joint projects, grants, funds** be developed.

- **Disaster Crisis Plan & Disaster Platform:**

It has been emphasized that disaster recovery coordination is needed for patients under the Ministry of Health or/and Ministry of Interior Disaster and Emergency Management (AFAD). It is recommended to create a **Disaster Crisis Plan** for patient organizations that includes inclusion (physicians' support is also highlighted), the public, civil society, and industry.

It is recommended to strengthen cooperation channels with networks of different patient organizations and to establish a **common patient organizations disaster platform**.

In particular, the agenda that all patient organizations contacted to evaluate the process underlined for the future and expressed at every opportunity: **the need to determine road maps with meaningful coordination specific to disasters and the need for patient organizations to come together and create a Disaster Crisis Plan.**

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