When Russia invaded Ukraine on February 24, consultant clinical oncologist Mohammed Hojouj put out a call for help: “Cancers do not stop growing because there is a war. But cancer patients stop being seen as a priority.” The story he told in *Cancerworld* in early April was about an acute shortage of almost every essential cancer drug.

That was then. Checking back with him today, more than 120 days into the war, the situation on the drugs access front seems to have improved somewhat. Cancer drugs are now reaching Ukraine, and Hojouj is no longer advising his patients to leave the country to seek treatment abroad. “But the country is still in a war situation,” he says, and Ukrainian cancer patients – those who stayed in the country, those who fled abroad, and those left and then returned – still face many barriers to getting the care that they need.

At the start of the conflict the primary focus was on locating patients and families who were fleeing the country, and helping them find access to the support and cancer care they need. The response then and now from the cancer community – and particularly from Europe’s highly networked patient advocacy groups – will have made a huge difference to this vulnerable population in their time of need.

But as that initial mass movement across borders subsided, the ongoing crisis is highlighting the need to upgrade cancer care capacity in Ukraine as well as in some of the surrounding countries now hosting refugees,

Richard Sullivan, Director of the Institute of Cancer Policy and Co-Director of the Centre for Conflict & Health Research, at King’s College London, points out that Ukrainians have been living with war for nearly a decade, since the conflict in Donetsk and Lugansk stardted in 2014. “This has a really degrading effect on society,” says Sullivan, who is also an advisor to the WHO on non-communicable diseases, and co-chairs the ECO–ASCO Special Network on the Impact of the War in Ukraine on Cancer. He points out that the level of disease – both of cancer and associated comorbidities – had already been rising in Ukraine before the latest invasion.

Between 12,000 and 13,000 new cancer cases were diagnosed each month prior to February 24, he points out. It’s a “complicated, big country” – territorially the largest in Europe – with wide variations in levels of economic development. Even prior to the war, access to cancer centres was often difficult, and reforms had been underway to reduce the out-of-pocket expenditure of patients. “And then February 24 happens, and the world falls in.”

A wholly changed treatment landscape

Patients remaining in Ukraine after the invasion faced a wholly changed treatment and care landscape, says Sullivan. While surgical oncology treatment is still available, patients faced a limited supply of drugs. “Already before February 24, some clinics had shortages in drugs. And right now, the biggest issue is accessing oral chemotherapy drugs, as there have been intermittent stock-outs of essential drugs,” says Sullivan. Breast cancer patients, for example, had to cross the border to access treatment. At the same time, Ukraine is surrounded by countries where essential drugs are also in relatively tight supply. “There has been a problem in distributing enough of these drugs. But we have very cloudy intelligence on this.”

Radiotherapy, heavily reliant on cobalt-60 machines, is also disrupted by the conflict. According to an analysis by Sullivan and colleagues, published in May, radiotherapy capacity in Kyiv and the western part of Ukraine, at the time, was sufficient to manage and provide therapy to internally displaced cancer patients. In addition to concerns about degradation of infrastructure in a chronic conflict, Sullivan points out that cobalt-60 sources are already degrading and old, and should be

replaced with newer sources, as cobalt-60 is a security issue in a conflict.

> “New hubs and referral plans are now in place, so they are able to cope better. But still, there are many challenges”

In Ukraine, patients face out-of-pocket expenditure for many newer cancer treatments. Newer generation targeted drugs as well as immune-oncological treatments are paid for by patients. “As the war bites, fewer people are able to afford these drugs.” At the same time, in a country that used to be a major area for trials, nearly all trials are closed, shutting down one avenue of treatment.

By June, Ukraine had got over the initial shock of the invasion. “New hubs and referral plans are now in place, so they are able to cope better. But still, there are many challenges. And it is basic cancer care being delivered now – things like CART are not possible.”

Sullivan is impressed also by how colleagues in Western Ukraine are dealing with the conflict. “Western cancer centres in Ukraine are having to absorb more patients, work longer hours, and often don’t know how patients have been treated previously. Ukrainian cancer colleagues are stepping up incredibly well to dealing with this incredibly difficult situation.”

On Ukraine’s cancer care frontline

The organisational and logistical improvements reported by Sullivan are translating into better care at hospitals like the Central Hospital in Dnipro where Mohammed Hojouj works as a consultant oncologist. “5-fluorouracil was the only thing we had: 500mg for each patient,” says Hojouj, referring back to the situation he previously reported having faced in March and April. “Now, we have drugs and the opportunity to give them in combinations. It is still limited, but what I have in my hands, like cisplatin, carboplatin, gives some options.” Uncertainty remains, however. “These are the drugs I have for one month, one and a half months. We don’t know what we will have then.”

Targeted therapy and immunotherapy have become unavailable, he adds. “Those are a dream for us now.” And, in a system that relies strongly on clinical trials, the halting of trial activity has taken a heavy toll. “Some sponsors have supplied some drugs for humanitarian reasons, but all trials have stopped.”

Another challenge he mentions is simply getting to the hospital. As petrol is in limited supply, Hojouj walks or bikes to the clinic, where he then sometimes stays for several days. Many of the out-patients have to rely on volunteers to be able to come for chemotherapy. And continued attacks mean that some patients have no option at all. “Patients from Zaporizhzhia, which is an hour away from Dnipro, have called me to say that they can’t come for treatment, as the route to Dnipro is not safe.”

For men aged between 18 and 60, who in many cases cannot leave Ukraine, access to cancer care has become impossible in some cases. “Many men who were recently diagnosed or would have been in early stages of treatment are going to the frontline to fight,” says Hojouj.

Despite this, and despite the numbers who have left for other countries, Hojouj currently finds himself caring for even more patients, as many fled from regions in eastern Ukraine to the centrally located Dnipro. “We have about 120% the number of patients that we cared for before the war – more patients, and fewer personnel, as some doctors also left the country with their families. But we

are not stopping. We do our best here."

Ukrainian patients abroad

Getting a clear picture of what is happening with cancer patients who have fled their homes is extremely difficult, says Sullivan. An estimated 12 to 13 million people are internally displaced within Ukraine, and about 5 million refugees are moving across the border. "It is very hard to tell where refugees are ending up," he says.

More certain is the reality that many neighbouring countries are not well placed to offer fleeing cancer patients the treatment and care they need. "Moldova was over capacity even before the war started, they simply have no capacity to treat more patients," says Sullivan. Hungary and Romania are in the yellow zone, "because most [refugee] patients are not staying in these countries". Only Poland is still green, says Sullivan, indicating that it is currently still able to absorb more patients.

Hojouj reckons that about 30% of his patients have left Ukraine. He is in contact with patients who have reached Poland, Germany, France, Czechia, Austria and other countries – and he is also in contact with their treatment teams. "In the beginning, some patients didn't have medical records, and I was contacted, as there was no time to start extensive examinations again. Now, we make tumour board decisions together. The doctors acknowledge our knowledge and support, and patients are comfortable that we are in contact with each other," he says.

At a high level, managing the flow of patients has been very complicated, says Sullivan. The "huge dynamic of patients" made centralised operation and planning very difficult. He is impressed at the way many patient advocacy organisations have stepped up to use existing networks and create new ones, to provide their respective patient communities with the support they need.

"There was an impressive grassroots movement to help patients access treatment outside Ukraine, or help them to access treatments within Ukraine, in centres outside the immediate conflict zone. Patient organisations have been remarkably adaptable to help patients access care," he says.

Coalition for Ukrainian lymphoma patients

A great example of the sort of work being done comes from the Lymphoma Coalition – a worldwide network of patient organisations, operating in over 50 countries to support patients with lymphoma. "We were already working with one organisation for lymphoma patients in Ukraine, as well as with the Ukrainian Haematology Association", says Natacha Bolaños, Head of Membership and Alliances at the Lymphoma Coalition. When the conflict started, Bolaños got in contact to ask what support they needed. "I had a conversation with the President of Ukrainian Haematology Association, Irina Kryachoc, and the first thing she asked for was to help her ensure patients can continue treatment – and whether we were prepared to move patients abroad to carry on receiving treatment and care."

The society compiled an initial list of more than 250 patients who needed to be transferred out of Ukraine, which was divided into high, medium and low risk. At the same time, the Lymphoma Coalition put out "a massive call" to its member organisations and partners in Europe, "including the registries, hospitals and reference centre, the European Lymphoma Institute, scientific societies, key opinion leaders – everyone with whom we had worked with before. We took all our network and connections and used them," said Bolaños.

One thing they hadn't expected, she says, is how little support they were able to get from the official aid agencies. "We contacted organisations specialising in humanitarian aid about connecting them with critically ill patients who would need transfer and medicines. We thought they'd help, but in

war times their priority is public health, not non-communicable diseases." The Lymphoma Coalition also identified and connected with other organisations working on evacuating people fleeing the war zone to ask for help with patient evacuations. "We were lucky enough to get Helping to Leave on board," said Bolaños.

> "Many needed bone-marrow transplantation. For these patients, delaying treatment by just a few weeks can be fatal"

Around 80 patients on the first list were classed as high risk, based on the aggressiveness of their disease. "Many needed bone-marrow transplantation. For these patients, delaying treatment by just a few weeks makes the difference between treatment success and death," Bolaños emphasises. "Once Kyiv, the only city in Ukraine equipped with specialist units performing bone-marrow transplantations, was attacked, bone-marrow transplantations were completely disrupted in Ukraine."

With Polish partners indicating that their country had no spare capacity to care for more patients, other countries took in the first patients within days. "Fondazione Italiana Linfomi offered to organise the management of the first high-priority patients, and matched patients with hospitals with appropriate experience and capacity." Getting patients to their assigned treatment location was a challenge, says Bolaños. Each group of patients travelled with family members and/or their caregivers, plus two people able to offer medical assistance if required. Regional organisations are taking care of accommodation, food and other needs of patients with lymphoma and leukaemia arriving from Ukraine.

More than 120 days into the war, the Lymphoma Coalition is continuing to monitor capacity in Ukrainian hospitals and to update lists of hospitals in other countries that are ready to admit Ukrainian patients. "Evacuations are continuing. At the beginning, those who left were in a critical condition, their paramount need was to continue treatment. Chronic patients didn't want to leave at the beginning, but now some have entered aggressive phases of their disease. Or, as the situation keeps changing, their doctors have convinced them to seek care abroad now." What is clear, says Bolaños, is that all the patients want to return to Ukraine.

SAFER Ukraine and the unicorn for paediatric cancer patients

Organisations working in the childhood cancer field were among the quickest to react following the invasion. "They already had operations hubs and intelligence within Ukraine," notes Sullivan, "They moved very quickly to evacuate childhood cancer patients, as they require complicated long-term care that cannot be interrupted. Here, the operations were perfectly well managed."

Pragmatism and a will to adjust to the situation were behind the success in helping children with cancer from Ukraine, says Anita Kienesberger, Chair of Childhood Cancers International Europe (CCI Europe) the pan-European organisation for paediatric cancer patients. The advocacy organisation partnered with the SAFER Ukraine project run by St Jude's Global Alliance, an international organisation committed to improving children's access to care for cancer and other catastrophic diseases. "In the first three weeks, the challenge was to evacuate children. This was done in pilots: one way was attempted, if it was better – this was adopted. If not, the process was further changed. This is how the ideal process was reached: evacuating children from Ukraine to Poland, and then transferring them on from Poland to other European or North American countries."

Tabletochki collected the child's medical records, translated them into English, and sent them to SAFER Ukraine

The coordinating centre in Ukraine was the Tabletochki Foundation – a Ukrainian paediatric cancer patient organisation and member of CCI Europe. The process, dubbed "St Jude's Path", started with the patient's family or clinician getting in contact. Tabletochki then collected the child's medical records, translated them into English, and sent them to SAFER Ukraine. Patients and their families were then transported to Poland from a safe and central departure point in Ukraine, often via Lviv and the Western Ukrainian Specialised Children's Medical Centre.

In Poland, a reception centre – the Unicorn Marian Wilemski Clinic – was set up in a former hotel in Bocheniec, about 270 km west of the border with Ukraine. While children needing immediate care were taken direct to hospital, all others stayed with their families in the Unicorn Clinic, while working out where their care could be continued. The goal was to transfer patients to other hospitals within 48 to 72 hours, wherever possible.

As of July, 29 countries have taken in several hundred paediatric patients from Ukraine in more than 200 clinics. The Unicorn Clinic is continuing to operate, says Kienesberger, as it is expected to be needed over the coming months and possibly years – especially as children still in Ukraine are newly diagnosed with cancer.

"As a paediatric cancer community, we received high visibility, acceptance and respect for this action," says Kienesberger. "But we have to accept that Europe doesn't have the lead here: St. Jude's Global is in the driver's seat." As she points out, the St. Jude's Global Alliance had already been active in Ukraine before the invasion, and knew the structures and contact persons in the country. "As the war broke out, the question arose: should the children be treated where they are, or do we get them out of the country? After the decision was made to evacuate them, they proceeded step by step towards this goal."

One of the first steps was getting European partners on board, including CCI Europe and its member organisations, says Kienesberger "Our role as patient organisations, on the international and national levels, was to see who arrives in the country, who accompanies them – or who will join later – welcome them and organise everything they needed, especially accommodation. And to ensure that a regional organisation will take care of the family."

"The crisis made problems apparent that were already present"

Speed and efficiency of the evacuation process was made possible by strictly hierarchical structures, Kienesberger acknowledges. "but we would have liked more communication, in particular regarding a country's capability to take care of the assigned children." She worries that some children were sent to very small centres that don't meet the criteria of centres of excellence in terms of the number of paediatric cancer patients treated per year, or the necessary infrastructure and expert staff to provide paediatric oncological treatments. "The crisis made problems apparent that were already present," she says.

Overall, she feels the collaboration, which included St. Jude's Global Alliance, CCI Europe, Tabletochki, the European Society of Paediatric Oncology and others, was fundamental for the

operation's success, and brought the community closer together.

A chain of trust for melanoma patients

Violeta Astratinei, President of Melanom Romania, a member organisation of Melanoma Patient Network Europe agrees that collaboration has been essential. One of the first actions they took in support of members of their community in Ukraine was to get together with other members of WECAN – the umbrella group of European cancer patient advocacy organisations – to talk through strategies and options.

"We had a crisis chat on Telegram, and exchanged information through a shared MURAL board. For me it was obvious: if you don't collaborate, you are going to be crushed under the pressure of helping so many people." Patient organisations worked together efficiently and paid attention to solutions that could scale. "When a melanoma patient contacted an organisation covering a different disease, they asked us to take over and refer them to the right care. And of course, vice versa."

> We contacted people and organisations we have worked with and trust. You cannot move fast and safe if you don't use the appropriate network

MPNE did not organise evacuations of patients, but it helped patients access melanoma-specific care once they had crossed the border. "Of course, we had to make sure that the organisations we referred patients to could be trusted. So we solved challenges with a chain of trust: We contacted people and organisations we have worked with and trust, and asked them who they trust. You cannot move fast and safe if you don't use the appropriate network."

Melanom Romania worked with its European partners as well as with national NGOs at the Romanian–Ukrainian border to direct patients towards the right care. "One tool first developed by both the Romanian organisation and MPNE was the use of Google forms in Ukrainian to ask patients, in a standardised way, for the most relevant information with a focus on melanoma care. "We needed to ask the right questions in order to help them faster."

The most important question turned out to be "Where are you at the moment?", says Astratinei, as the volatile situation meant that patients were frequently on the move. "We kept in constant contact with patients in transit via WhatsApp or Telegram " Using a standardised algorithm, they also enquired about basic requirements – how many persons were travelling, what were their housing, transport and food needs – as well as informations about their disease, such as melanoma type, stage, and the last treatment received. Patients on targeted therapy were the highest priority. "We know targeted therapy stops working almost the moment a patient stops taking it, so for patients with metastases under control with targeted therapy, stopping these pills means disease progression and death, unfortunately. So these patients were our priority, and we also checked their drug supply at first contact."

Once Ukrainian patients had reached Romania, they were entitled to the same medical treatments as Romanian patients. "But at the same time, this means that Ukrainian patients faced the same difficulties and disadvantages that Romanian patients face, including scans and therapies that are not always available for melanoma patients," says Astratinei. While patients were initially welcomed, more recently hospitals have started putting demands that are making it harder to access care, she

adds.

One such barrier is a new requirement for translators to be present during each hospital visit. “We already translate the most important medical records or advise patients to do so, if they can. And we communicate through translation software. But how can we provide a translator for each patient?” Astratinei asks. “Even if a medic is willing to take care of a patient, the patient can’t be received without a translator. For me, things are being invented in order to limit the access of Ukrainian patients to the healthcare system.”

> “Accepting drug donations was a big responsibility and concern, but one can’t just let people die”

Existing problems in the Romanian healthcare system, such as a lack of digitalisation, fragmented cancer care, and poor communication are complicating matters. The advocacy group ended up accepting drugs donated by patients to ensure Ukrainian patients were able to stay on treatment for the month – or even two months – it took to access the drug through the medical system. “And we’re talking about patients at risk of brain metastases.” Accepting drug donations was a big responsibility and concern, says Astratinei, “but one can’t just let people die.”

In the end it came down to knowing the right physician and the right clinic, says Astratinei: “I must recognise that some cancer centres dealt better and faster with Ukrainian patients than others. This was observed elsewhere in Europe. Personal contacts and trust sometimes counted more than the measures announced by local authorities.”

Some patients who contacted MPNE wanted to stay in Ukraine, and the organisation did its best to support them. An oncologist in Lviv was a contact point, and some companies continued to supply drugs. “But it was our frustration that we couldn’t follow patients who chose to stay in their own country.” Astratinei mentions the case of a patient with stage IV melanoma who contacted her. “We told her where she could receive treatment in Ukraine and to come back to us if she encountered any problems. But we did not hear from her again and don’t know what happened. She could not even access her dossier as her oncologist had left and the clinic was closed.”

Astratinei is proud of the help they have been able to provide for Ukrainian patients, but says organisations working on the ground lack the capacity to deal with problems of this scale and need more support. She also feels that, while patient organisations can provide networking and points of contact, they cannot be expected to shoulder main responsibility for providing support to patients fleeing the war. We want to see more concrete actions from authorities at a national and European level,” she says.

What next?

As the war drags on, it seems that patients are increasingly opting to stay, says Hojouj. “They have their kids here, their families, their homes. And we have some drugs to treat them.” Several of his patients who originally fled abroad have now returned to Ukraine. “People outside the country support them, and the doctors there are doing their best. But it is hard, and people prefer to stay home in their own country.”

Reconstruction is something that should be a focus already now, says Sullivan. “The war put a spotlight on those things that have been a problem so far, like radiotherapy and supply issues.” But

building the human resources capacity – as staff face burn-out or are leaving the country themselves – is the hardest and the highest priority. “This will be more fragile the longer war lasts. Living under constant threat day in, day out, takes its toll. So human resourcing will be the biggest issue.”

While Hojouj previously recommended his patients to leave the country, he no longer does so. “Now, I don’t have the right to recommend this anymore, because we have options. I tell my patients to keep taking their medications, and wish for them to stay alive. We now have drugs and I will do my best.” While his appeal to keep supplying oncology drugs to Ukraine still holds, Hojouj has just one wish. “Stop the war – and everything would be sorted.”