

# Out of sight

**Obstacles in accessing breast cancer screening and treatment for women in Northwest Syria (NWS)**

**COVER PHOTO**

IV drip containing medications for chemotherapy administered at SAMS-run Idlib oncology center.  
Photo: Syrian American Medical Society.

**Note on source of information**

The information presented in this brief was collected from October 2021 through 2022, and derived primarily from interviews with relevant stakeholders, through desk research, as well as from two surveys conducted inside Northwest Syria. Interviews with doctors and medical staff working in health facilities inside Syria supported by Relief International (RI) and Syrian American Medical Society (SAMS) through the cross-border mechanism, as well as interviews with Northwest Syria Health Cluster (NWS HC), Northwest Syria Sexual and Reproductive Health Technical Working Group (NWS SRH TWG) and UNFPA experts present the basis for this brief. Further reading to complement the information gathered through the interviews was used, with special focus on service mapping, reports on sexual and reproductive health, and other relevant literature produced by clusters and working groups.

Data related to breast cancer awareness and treatment was drawn from two household surveys using door to door sampling conducted in Northwest Syria by RI and SAMS during the months of April 2022 and July 2022 respectively. RI's awareness survey was conducted by community health workers who interviewed 396 women. Data related to SAMS patient survey was collected in October 2022 from 38 patients who had been diagnosed with breast cancer and started their treatment at SAMS's oncology centre in Idlib city. The final data analysis of results from the survey was provided by RI's Monitoring, Evaluation, Accountability and Learning (MEAL) department. To give a comprehensive overview over the most recent developments in access to breast cancer treatment, additional interviews were made with patients after the February 2023 earthquakes.

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# Context

Healthcare in Syria has been greatly affected by the protracted conflict; with **roughly 50% of Syria's health facilities destroyed, damaged or no longer functional** as a direct or indirect consequence of the conflict, the country's healthcare system was brought to its knees, severely **limiting access to basic medical services including cancer care**. This has been further exacerbated by the **"brain-drain" of specialised medical personnel** who continue to depart the country as a last-resort mean to provide for their families. As an example, **only 35 oncologists remain across Syria<sup>1</sup>**, resulting in **severe shortage of trained medical staff** that, coupled with lack of equipment, medication and organised healthcare systems, further erodes access to proper cancer care.

At the same time, poor living conditions and decaying quality of life have had a negative effect on public health in general, with an array of multi-faceted factors additionally aggravating the situation: increased exposure to carcinogenic toxins in the environment, including soil contamination with unexploded ordnance and chemical weapons, lack of proper solid waste management, fumes from burning garbage dumps, pollution of irrigation and drinking water systems and its mixing with untreated sewage – all disproportionately affect public health and wellbeing. Air pollution from the use of crude oil to generate electricity or heating during the harsh winter months, as well as the toxic substances emitted from the combustion in primitive oil refinery plants significantly raise the level of carcinogenic pollutants.<sup>2</sup>

Furthermore, **high levels of trauma and stress** compounded by multiple displacement, stress of adapting in a new hosting community and recurring shocks and threats of outbreaks of violence significantly **affect mental health and wellbeing** of Syrians and lead to adoption of negative coping mechanisms such as smoking and substance abuse and additionally **exacerbate exposure to certain types of cancer, especially lung-, throat-, kidney-, and breast cancer**.

On top of these, Syria's economic decline and devaluation of the Syrian pound make it difficult for an increased number of Syrians to **afford out-of-pocket money for the expensive cancer diagnosis and treatment**. Moreover, the **rising levels of poverty** also mean increased food insecurity and malnutrition – factors that create **micronutrient deficiencies and weaken the immune system**, inherently increasing the risk of cancer.

This paper takes a **closer look at existing gaps** in the health system to screen, test and treat breast cancer, obstacles that women are facing in accessing timely breast cancer medical interventions and the consequences it might have for their overall wellbeing, and contains a set of **recommendations** for different actors to address these gaps.

The paper further gives testimonies from patients encountering barriers in accessing oncology care after the earthquake that hit southern Turkey and Northwest Syria on February 6<sup>th</sup> 2023, so as to raise awareness about the **need to amplify efforts for enhanced cancer screening and care in NWS**.

<sup>1</sup> Sahloul E, Salem R, Alrez W. et al. Cancer care at times of crisis and war: The Syrian example. J Glob Oncol 2016; 3 (04) 338-345

<sup>2</sup> Investment in Cancer Prevention and Care for Forcibly Displaced Syrians Is an Urgent Priority: <https://ascopubs.org/doi/full/10.1200/GO.22.00382>



## Breast cancer care in Syria since the 2000s

### Cancer care before the conflict

Before the outbreak of the conflict in Syria, breast cancer care was mainly **provided through the public healthcare system**, with specialized breast cancer hospitals located in major cities providing a range of services for medical oncology management, including diagnostics, such as mammography, biopsy, and therapies, including surgery, chemotherapy, and radiotherapy. Breast cancer is **among the most common types of cancer in Syria** (and a leading type of cancer among women worldwide), and the country had a number of trained medical professionals, such as breast surgeons, oncologists and radiologists, who were able to offer comprehensive treatment and care to the patients. However, there were still **disparities in access to care, particularly in rural areas** where access to specialized clinics and hospitals was more limited. Additionally, breast cancer diagnosis

and treatment did not always measure up to international standards due to lack of advanced diagnostic tools and infrequent availability of specific drugs. Furthermore, **breast cancer awareness and education campaigns, as well as cancer screening were limited**, which may have led to a delay in diagnosis and treatment.

In 2009 in their annual overview of newly registered cancer patients, the hospital-based Syrian National Cancer Registry (SNCR) reported a total of 9213 male cancer patients and 8386 female cancer patients in Syria. Among women, **breast cancer was reported as the most prevalent type of cancer**, affecting 30% of all women diagnosed with cancer. Moreover, **cancer was ranked 3<sup>rd</sup> leading cause of mortality and 7<sup>th</sup> cause of morbidity/disability**.

### Cancer care during the conflict

In the current context of Northwest Syria's scattered healthcare system, **collecting information and data on cancer has become even more challenging**. Surveillance data collected in 2020 by the World Health Organisation's (WHO's) International Agency for Research on Cancer<sup>4</sup> revealed a total number 9243 male cancer patients and 11,716 female cancer patients for that year - a likely underestimate given poor access to diagnostics and histopathology (examination of biopsied samples) in many areas of the country. Breast cancer remained the most common type of cancer among women (37.5%)<sup>5</sup>, accounting for 20.09% of total cancer diagnoses among all registered cancer patients including both sexes. Based on the information from the 2020 survey, SAMS oncology committee<sup>6</sup> **estimated that there are between 2,000 and 3,000 new cancer diagnoses in NWS every year**.

are presently supported by non-governmental organisations (NGOs), who in turn depend on funding from external donors, whose priorities have been to cover the costs of primary and secondary healthcare. As **cancer treatment is generally considered tertiary healthcare**, it is currently **not funded by any donor in Syria**, leaving NGOs no other option but to fundraise independently and in an environment in which other emergencies continue to take priority. Furthermore, not only is the availability of health services related to cancer screening, testing and treatment in NWS limited due to lack of funding, but the few hospitals and health facilities offering such services are **scattered across the region**, forcing many women to **travel long distances in order to get a diagnosis or treatment**. In addition, the **quality of services varies from one health facility to another**, either due to lack of qualified medical staff, or to lack of medications, diagnostic equipment and/or qualified maintenance expertise.

The majority of health facilities in Northwest Syria

<sup>3</sup> Syrian health system profile, 2011

<sup>4</sup> IARC - WHO - Country fact sheet: Syrian Arab republic (2020): <https://canscreen5.iarc.fr/?page=countryfactsheetnew&q=SYR>

<sup>5</sup> Globocan 2020: <https://gco.iarc.fr/today/data/factsheets/populations/760-syrian-arab-republic-fact-sheets.pdf>

<sup>6</sup> Atassi, B. T., Gina, Mkhallalati, Hala; Debel, Jamil; Jemmo, Ayham; Khalil, Molham; Alrahal, Yahya; Almalki, Monzr; Hamadeh, Mufaddal; Tarakji, Ahmad; Abbara, Aula. (2022). Cancer Diagnoses during Active Conflict: Experience from a Cancer Program in Northwest Syria. *Avicenna Journal of Medicine*, 12(04), 157-161: <https://doi.org/10.1055/s-0042-1755331>

## Shifting priorities – levels of awareness about breast cancer

After 12 years of conflict and instability, **Syrian women and girls remain exposed to limited access to basic services** (including healthcare), lack of economic opportunities, risk from gender-based violence (GBV) and denial of basic rights. The number of female-headed households has increased exponentially over the past decade, putting women under additional risk from GBV and exploitation, and exposing young girls to early marriages as a means to resolve lack of income in the household. Particularly vulnerable are female-headed households living in displacement whose access to regular income is very limited and who live far away from (specialised) services. As public transportation is not available in Northwest Syria, finding means to pay for transportation to visit a healthcare facility exposes women to additional risks.

Considering the above, the **majority of women in NWS avoid screening for breast cancer as a default**. One reason is **lack of awareness about the possibility of self-screening**, and the other is that, considering other hardships, screening for breast cancer, either at home or in a specialised facility, comes very **low on**

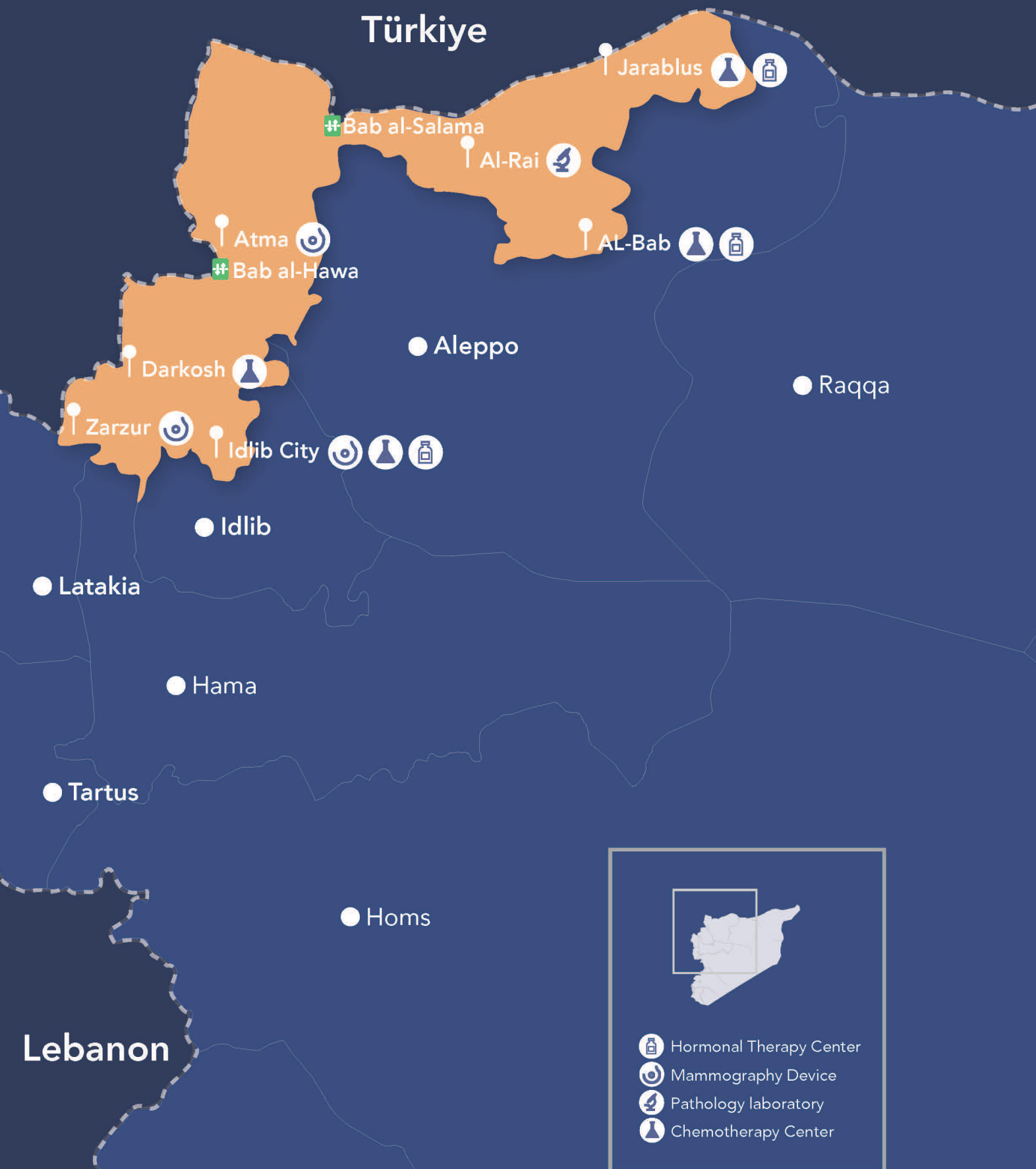
**the list of priorities**. Before the war in Syria, there was an acceptable level of understanding about cancer, early detection and importance to screen; many **women used to do regular self-checking at home** and then follow up with a doctor if they discover anything of concern. However, now, more than twelve years into the conflict, it's very **difficult for women to access healthcare and doctors**, especially to find **female doctors** considering the cultural sensitivities for many women to be examined by a male doctor.

In an April 2022 survey conducted by Relief International in Idlib and Aleppo governorates, roughly **half of interviewed women (49%) were not aware that they can do an initial self-examination** of their breasts to check for nodes. Furthermore, among the surveyed women, **65% did not know where to go for a mammography** screening should they need to. Less than half of women (**40%**) **said that they received awareness sessions on breast cancer or availability of specialised services**, making an early detection of breast cancer less likely.



Doctors and nurses in surgery at surgery at RI-run maternity ward at Nour hospital in Idlib. Photo: Mohamad Abdullah for Relief International.

# Breast Cancer Service Mapping in NW Syria



## From detection to treatment

For many women in Northwest Syria, **discovering a lump in a breast at home or during a health exam can be devastating**. It usually involves both additional expenditure for transportation, examinations, and further testing, and time-consuming travels between health facilities in order to find the necessary services. Generally, if a lump is discovered during self-screening, the woman would go to the nearest health facility for an initial exam by a general practitioner, who would then refer her either to a hospital or a private facility for a mammogram. Once the existence of a lump is confirmed through mammography, the same facility would conduct a biopsy, i.e. extract a sample from the lump that would then be sent to a laboratory for testing.

If the sample returns positive for cancer, a course of treatment is decided upon, depending on the size of the mass and the cell count. Most of the hospitals in Northwest Syria have the capacity to perform resective and exploratory

surgeries – i.e. biopsy the mass for testing depending on size, or extract it as a course of treatment. However, **any advanced treatment** – and especially the second course of treatment through radiotherapy – **requires a referral to hospitals outside of Syria**.

In the survey conducted by SAMS among patients received at the Idlib oncology department before the earthquake, 29 patients (76%) who underwent surgery were referred to Turkey for radiotherapy after their post-surgery round of chemotherapy, while the remaining 9 (24%) did not require additional therapy and could therefore remain inside Syria. Referrals were essential mainly because **many of the cancer patients come for screening and get their diagnosis late**, when their cancer had already metastasized (spread to other organs) and their treatment cycle requires radiotherapy.

The **time between a doctor's referral letter**



Umm Ahmad, a breast cancer patient from Idlib, currently waiting for resumption of referrals to Turkey after February earthquakes to continue with her treatment. Photo: Syrian American Medical Society.



*I was referred by the doctor at the oncology center here [In Idlib] to receive radiotherapy in Turkey. I had started but I still had a few sessions to go; my next appointment was planned on February 6<sup>th</sup>, the day of the earthquake. I was already there in Turkey, it was Gods' will that I survived: the hotel where me and other cancer patients were lodged was destroyed, many patients died. I came out of the rubble without anything, I lost all my belongings, including my official documents. I only had thin layered prayer gown on me (and it was freezing). It was so hard. I decided to go back to Idlib to wait until things become better because the situation was very difficult.*

*Now I can't go back, also there is no treatment here, I can't go to other parts of Syria either because first of all there are no roads, second I would be so scared to do so. What should I do, should we die slowly? I know other patients who are also in much critical situation. We look to you, the United Nations and NGOs, to find a solution for us, be it to treat us here, or to send us elsewhere for treatment.*  
Umm Ahmad, Idlib

to the actual treatment in Turkey takes a minimum of one month and can extend to up to six months, which would worsen the cancer stage during that time. The process involves requesting permissions for travel from both local and Turkish authorities, finding an available hospital in Turkey where the treatment would take place, a date when treatment would be available for the patient, and then arranging all practicalities for the actual transfer.

When the patients referred to Turkey were asked if they had challenges regarding the referral, 7 patients (18%) responded that they did, 5 complained about the lengthy bureaucratic process, one patient mentioned financial difficulties, and one patient the inability to bring a companion. Indeed, since the establishment of Covid-19 cross-border travel restrictions, breast cancer patients, and cancer patients in general, are not allowed to bring a companion into Turkey, having to go through the treatment without adequate emotional and psychological support. All surveyed patients expressed a varying degree of concern about managing childcare and separation from children during their absence, exacerbating levels of stress.

Recurring shocks, such as the earthquake that

affected southern Turkey and NWS has however, impacted the capacity to receive cancer patients in Antakia/Hatay. Unfortunately many Syrian breast cancer patients who were in Turkey perished in the earthquake while waiting for treatment. Women like Um Ahmad – a breast cancer patient from Idlib city who was in Turkey for treatment when the first earthquake hit – vividly remembers how the events unfolded as the ground started shaking. She was one of the few cancer patients in Antakia/Hatay to survive the earthquake but has not been able to continue her treatment since she returned to Syria, as treatment referrals to Turkey have yet to resume since February 2023.

With all the shortfalls of the process, referral of patients for treatment outside of Syria's borders remains the only viable option that continues to save lives of many cancer patients. Without serious overhaul of the existing approach to cancer care inside Syria, there is currently no alternative to the referral process.

## Scarcity of screening equipment and technical staff

Ultrasound and radiography diagnostic services are provided by five health facilities in Northern Aleppo governorate and nine facilities in Idlib governorate<sup>7</sup>. During 2022, patients in Northwest Syria had access to seven computed tomography (CT) scanners and only one magnetic resonance imaging (MRI) machine<sup>8</sup>. As for mammography, NWS has four mammograms, largely available in NGO-funded health facilities and not always concurrently functional due to maintenance issues. Screening is generally very expensive, and even where possibilities for screening do exist, there is an acute lack of radiologists and technicians – medical staff with expertise to run the equipment, to read the screening results or to produce a quality health report that doctors could use to tailor the treatment. The majority of patients have to resort to visiting privately-run facilities to get a complete CT scan, which then translates into an exponentially increased cost. At 15 USD per scan, breast cancer screening becomes a luxury that the vast majority of women in NWS cannot afford.

Furthermore, lack of technical staff to repair a mammogram when the equipment fails renders for decreased access to available screening capacities. The imported machines get tested and prepared in Turkey, however once they cross the border into

Syria, the technical support is not available anymore. Should a machine fail, it is likely that the equipment will remain out of operation for an extended period of time until a qualified personnel and/or spare parts are found to fix it. A new, good quality mammography machine costs more than 100.000 USD, while the basic one amounts to about 50.000 USD. The more expensive mammograms also have the possibility to do biopsy, however without a public health system in place, and in the light of shrinking humanitarian funding for Syria, most hospitals acquire machines with basic features. Oncology doctors at SAMS also mentioned the need for bone-scanning devices that would enhance possibilities for earlier cancer detection and can be purchased at a much lower cost.

Simple mitigating measures could be put in place to facilitate increased awareness on more frequent self-checks as preventive measures; for example, initiating a close collaboration with gynaecologists and midwives to, as a minimum, frequently provide relevant information to women to do self-examinations. The next step would be to rigorously advocate for increased funding to establish facilities that would have technical equipment, technical capacities and possibilities to offer breast cancer screening for free, for every woman, on a regular basis.



A radiologist reading the results of a mammography scan. Photo: Syrian American Medical Society.

<sup>7</sup> Northwest Syria Sexual and Reproductive Health Technical Working Group (NWS SRH TWG): Breast cancer service mapping in NW Syria, June 2021.

<sup>8</sup> Health Resources Availability Monitoring System (HeRAMS). First Quarter, 2022 Report. Turkey Health Cluster for Northwest of Syria: <https://www.humanitarianresponse.info/en/operations/stima/document/turkey-health-cluster-herams-q4-report-2022>



## Scarcity of laboratories for pathology of biopsy samples

Biopsy is a simple diagnostical procedure that entails extraction of a sample of the mass from the breast and sending the sample for pathological examination. **Free of charge pathology testing of samples is currently available only at one pathology laboratory** at Al-Rai hospital in Northern Aleppo. At Al-Rai, pathology is done in partnership between the Turkish ministry of health and SAMS; the lab receives specimens from hospitals in NWS and provides pathology diagnosis for free. A recent study<sup>10</sup> showed that this lab has analysed a total of 1,654 specimens in the period between January to December 2020, with samples coming from eight public and private hospitals in the local area including the cities of Azaz, Albab, Jarablus, Marea, and Al-Rai. The lab diagnosed cancer in 397 (24%) of these samples, breast cancer represented 20.2% of the overall cancer cases, almost all diagnosed cases (79 out of 80) among women.

There are **two private laboratories** where in-house pathology can be independently conducted. The two available labs are both **located in Idlib governorate**, and the majority of samples from the Idlib governorate come for analysis to these two labs. Although there are labs in Afrin, the expertise level is not the same; the doctors there either consult the doctors in Idlib, or send the samples to the government-controlled areas.

Among the key reasons for this is the **high cost of specific laboratory equipment and medical materials for testing** – something that the majority of pathologists cannot afford. The existing solution includes relevant hospitals having to contract private pathology laboratories and pay for testing of individual samples separately. The caveat is that most **hospitals have to pay for such testing from their own budgets**, as no donor allows for such costing to be budgeted to the grants provided for NGOs. A very small number of hospitals that do have funding for lab work can only afford **sample testing for a limited number of patients per month**. On very rare occasions, wealthier patients who have connections in Turkey send their samples for testing there and cover the cost of both sample transportation and testing themselves.

The **general laboratory testing** during the treatment course (routine blood count and differential, blood chemistry, coagulation factors, etc.) is however **not usually supported by NGOs**, it would therefore require patients to go to private laboratories, with a fee that could vary from 20 to 100 USD per test, depending on whether the doctor has requested to perform also some additional tumour marker tests or not, making the **testing unaffordable for many in an area where 97% of the population lives below the poverty line**.



Medical professional performing a blood test at RI-run Nour hospital in Idlib. Photo: Mohamad Abdullah for Relief International.

<sup>10</sup> Atassi, B. T., Gina, Mikhallalati, Hala; Debel, Jamil; Jemmo, Ayham; Khalil, Molham; Alrahal, Yahya; Almalki, Monzr; Hamadeh, Mufaddal; Tarakji, Ahmad; Abbara, Aula. (2022). Cancer Diagnoses during Active Conflict: Experience from a Cancer Program in Northwest Syria. *Avicenna Journal of Medicine*, 12(04), 157–161. <https://doi.org/10.1055/s-0042-1755331>

## Diagnosed, but where to get treatment?



A nurse checking on the progress of chemotherapy at the SAMS-run Idlib oncology center. Photo: Syrian American Medical Society.

Getting comprehensive information about available services for breast cancer is a cumbersome exercise. The NWS Health Cluster led by the World Health Organisation conducts service-mapping on a quarterly basis, however **hospitals frequently declare that specific services are provided, while in reality they only partially exist**. For example, some NGO-run hospitals declare availability of chemotherapy in their premises, however donor-funded projects do not include these medications in their standard kits for health. Instead, medical staff who can administer chemotherapy under the supervision of a doctor are available, but **only if the patients themselves purchase the medications privately**. Specific NGO-funded hospitals are mentioned as service providers in different stages of breast cancer screening and treatment cycle, while **only one partner in NWS provides comprehensive services**.

The majority of hospitals in NWS have surgical teams who can perform the surgical part of the treatment, however the more advanced stages of

cancer that require radiotherapy need a referral to Turkey, as **possibilities to receive radiotherapy treatment currently do not exist in NWS**. This is partly due to the fact that acquisition of equipment or medications for such therapy is either difficult, too expensive, or not even possible.

In addition, most of the breast cancer treatment medications and equipment are expensive or are a **part of secondary or tertiary healthcare**, and as such not funded by the donors; this is **valid for both chemo-, and hormonal therapy**. When it comes to equipment, no specific restrictions are imposed on the import of goods, however some equipment is very expensive and not a funding priority for donors. An example of this is that the **average cost for providing chemo and hormonal therapy for a single breast cancer patient could go up to more than 5000\$** using generic medications, which is still considered expensive and difficult to procure. This complicates the treatment significantly and puts patients' lives at further risk.





A breast cancer patient being administered chemotherapy by a nurse at the SAMS-run Idlib oncology center. Photo: Syrian American Medical Society.



## Treatment options and availability

Available treatment options inside Northwest Syria are limited to **surgery, hormonal treatment, and chemotherapy**. As mentioned above, **radiation- or radiotherapy** – a specialised treatment that uses high doses of radiation to kill cancer cells and shrink tumours **is unavailable in NWS**. Radiotherapy equipment, besides being very expensive, also **requires constant calibration and maintenance**, as well as specific safety and protective measures. More importantly, **trained radio-oncologists and skilled technicians** who would be needed to operate such equipment have long left the country, and consequently skilled experts to train new generations **are currently not available inside NWS**. As previously indicated, patients who need radiotherapy used to be referred to Turkey – a process that was fully halted post-February 2023 earthquakes.

Surgical treatment for breast cancer i.e. **mastectomy is provided for free by multiple NGOs** (including five hospitals run by Relief International in Binnish, Harem, and Darkoush, Ein El-Bayda, and Daret Azza), and three hospitals run by SAMS (Idlib central hospital,

Bab Al-Hawa hospital, and Afrin Al-Shifaa hospital).

**Hormonal therapy and chemotherapy are provided in only three centres:** one in Idlib province (Idlib oncology center, established in November 2018), and two in Northern Aleppo (at Al-Bab national hospital, and at Jarablus PHC). These centres are operated by SAMS **with support from the Syrian diaspora** who provide for the majority of funding, trainings, and resources, with contributions from NGOs such as Direct Relief in the United States.<sup>11</sup> The cost of treatment differs depending on the diagnosis and treatment protocol, which in turn is based on cancer stage as identified through diagnostic tests. On average, medications for breast cancer for each patient in Syria with the currently purchased medications **cost between 250 USD –1500 USD per treatment cycle**.

Data from the second half of 2022 shows that a total of 11,461 oncology consultations were provided in NWS, and 2,827 doses of chemotherapeutic agents were administered free of charge (~ 60 % of total administrated doses).

#	Idlib center	Jarablus center	Al-Bab center	Total
Total number of consultations	8178	1485	1798	11461
Consultations for the first time	1231	323	438	1992
The number of newly diagnosed patients	778	54	175	1007
Breast cancer	167	14	40	221
Hodgkin's and non-Hodgkin's lymphoma	38	5	13	56
Colorectal tumour	78	4	8	90
Testicular tumour (Added in May)	8	0	6	14
Ovarian tumours (Added in May)	17	0	5	22
Other tumours	470	4	3	477
The number of examinations for healthy blood diseases	2981	27	100	3108
The total number of drug doses administered intravenously	3912	683	387	4982
Supported doses	2084	218	525	2827
Unsupported doses	1828	114	335	2277

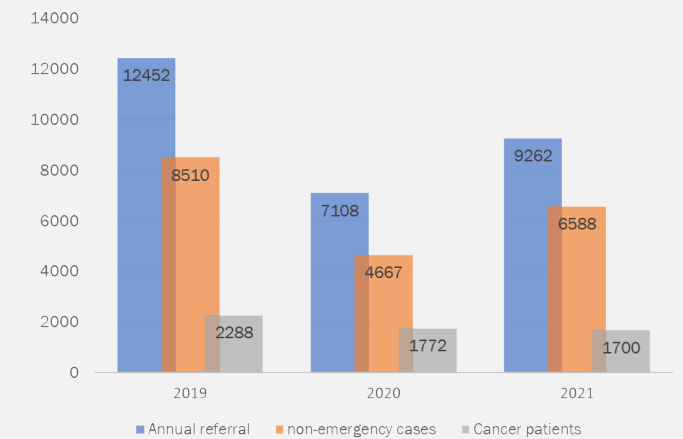
Cancer care services provided on a monthly basis by SAMS' three centers in Northwest Syria in the second half of 2022.

<sup>10</sup> Meyers T. Bringing cancer care to a conflict zone. Direct Relief. Accessed July 21, 2022 at: <https://www.directrelief.org/2019/07/cancer-care-syria/>

## What happens with patients who complete the surgical and chemotherapy? How do referrals work? Is there follow-up?

Cancer patients would be referred to Turkey based on a decision from their treating doctor if they are eligible for referral, and after obtaining their consent to do so. For example, when a patient is diagnosed with cancer and needs additional radiotherapy, the **doctor proceeds to seek a referral to Turkey for treatment**. The patient would receive a medical report, including mammography and biopsy results, surgery post-op report, a report on administrated chemotherapy doses (when applicable), which she then submits to the medical office in Bab al-Hawa. A panel of experts convene to assess individual medical reports and advises on go/no go for a referral to Turkey. If approved, the **process to acquire relevant permissions to cross the border** and additional coordination with medical facilities in Turkey commences. Generally speaking, cancer patients whose treatment course is not particularly urgent could end up waiting for a final decision about the referral for weeks. **Breast cancer specifically is not considered a priority**, and patients wait for a month and longer. In emergency cases, the process goes quicker.

In 2021, 9,282 people were referred to Turkey for medical care, 1700 of whom were cancer



Annual referrals of patients from NWS to Turkey between 2019 and 2021.

patients. This represents a **26% decline in total number of referrals** in comparison with 2019 following the Covid-19 pandemic travel restrictions. The trend has **still not returned to its pre-pandemic levels**, mainly due to the increased financial burden on the Turkish economy and the Turkish health system. Furthermore, **after the February 2023 earthquakes, the referral of cancer patients was completely suspended**, and patients are starting to understand the grave consequences should they not be able to resume their radiotherapy as soon as possible.



“ I am a breast cancer patient. I was receiving further cancer treatment in Turkey, I am terrified about the news that the referrals are closed now.. I can't afford to pay for the doses if they are not supported in charity hospitals. We would need either need to get the treatment here [ in NWS], or be brought back to Turkey. Aya - a patient living in Atmeh camp

Aya, a breast cancer patient attending to her two daughters inside her tent at Atmeh IDP camp. Photo: Syrian American Medical Society.





A nurse checking on a patient undergoing chemotherapy. Photo: Syrian American Medical Society.

## Follow-up

Post-treatment follow-up with a doctor to assess the effectiveness of the treatment is **essential if patients are to be fully cancer-free**. This is best done **three months after the treatment** so that an initial assessment can be conducted, and then **six months after** to order a new mammography scan that would determine if the cancer is still present. Many **patients in Syria fail to follow these instructions**, with **key reasons being affordability**, but also fear from finding out that the cancer might have returned.

In 2022 SAMS conducted a survey to further examine the patients' attitude and behaviours towards post-treatment follow-up. In a small survey of patients, 19 (50%) had completed their treatment course, 10 (26%) were still in treatment, while 9 patients (24%) had dropped out of treatment altogether. **Women who received treatment in Turkey largely don't return to their doctors to check on their post-treatment health status** (29% of all patients surveyed by SAMS) citing both travel costs and complicated process to re-acquire relevant permissions to

enter Turkey. For patients treated inside Syria, the frequency of follow-up appointments usually corresponds to the length of the treatment and how the patient had responded to it. There is a **higher likelihood that a patient treated inside Syria will return to their doctor for a follow-up**, as was also confirmed by SAMS survey results. All patients who were receiving treatment inside Syria confirmed that they plan to follow up with their doctors. However, although the majority of surveyed patients who completed their treatment in Syria did return for follow-up appointments, 89% also confirmed knowing other cancer patients who did not.

This further confirms that **efforts and resources must be invested in establishing post-treatment care systems** that would keep a record of a patient's health and treatment history, and have automated notifications in place when the time would come for a follow-up examination. This would give a **possibility for medical staff to reach out to patients directly and offer options for further care**.



Waiting room at SAMS-run Idlib oncology center. Photo: Syrian American Medical Society.



# Recommendations

## For donors

- **Expand funding for specialized and tertiary healthcare** (especially after the earthquakes, as it is expected that the referral function would be impeded or decreased to Turkey in the upcoming period), in order to **foster establishment of infrastructure inside Syria** that would increase availability of breast cancer screening and treatment, by establishing a comprehensive cancer radiotherapy center in NWS that includes a medical linear accelerator (LINAC), advanced laboratory diagnostics and cancer markers, as well as an advanced imagery equipment (Pet-Scan, bone-scan, and MRI).
- **Frequently revise the list of medications that NGOs are allowed to procure** in order to enhance availability of medications for chemotherapy and laboratory testing, palliative treatment and pain management drugs to improve a patient's quality of life.
- **Increase funding for medical education/in-service training of (especially female) health staff and medical practitioners** - especially for specialised disciplines such as oncology, radiology, pathology and gynaecology, as well as of medical technicians **to build competence and abilities within Syria** that would enable enhanced access to comprehensive breast cancer services.

## For coordinating agencies

- **Create and frequently revise the minimum service package** for (breast cancer) services and **put in place treatment protocols** that would be adopted by all health actors and standardised in all health facilities inside Syria for a more comprehensive and unison service delivery.
- **Develop and frequently update standard packages for capacity enhancement** of medical professionals who specialise on cancer service delivery, and ensure frequent refresher trainings.
- Put in place a **universal unified information management system for all health facilities** to enhance patient tracking, easier referrals and follow-up, better case management, and access to supporting services.
- Frequently **update the annual service mapping** and ensure that the availability of services corresponds with reported health facilities. This would be achieved by conducting **regular spot-checks**, especially for services related to non-communicable diseases with complicated treatment.

## For coordinating agencies (continued)

- Enhance **collaboration with the government of Turkey to reactivate and improve the referral process**, especially after the earthquakes. Until an alternative solution is available to treat the patients in NWS, lives of many cancer patients are depending on having access to cancer care in Turkey. Actively engage with the Turkish government in order to: **simplify and shorten the process to obtain cross-border permit** for cancer patients; **allow for family members to accompany patients** for the entire duration of treatment in Turkey; **establish a tracking system** and referral network for patients treated in Turkey; **share information** on treatment outcomes and follow-up.
- **Advocate and support fundraising efforts for breast cancer diagnosis and treatment** including facilitation of procurement and supply of cancer treatment medications and medical devices.
- **Increase repatriation to third party countries for breast cancer patients** who are unable to seek the treatment in NWS or in Turkey after the earthquake, especially for mothers or female led families with their children.

## For health-implementing NGOs

- Enhance efforts to **raise awareness about breast cancer** and kick off a breast cancer screening campaign across NWS.
- **Create safe spaces** that would:
  - a) Train health workers, community health workers, and others to always **remind women and mention the importance of self-checking** as part of their routine contact with women.
  - b) Offer **psychosocial support for patients diagnosed with cancer** in order to provide more comprehensive care;
  - c) Provide **child care support for mothers receiving breast cancer treatment in Turkey**, especially for female-headed households.
- Provide **accurate data on the actual extent of cancer-related services** offered in individual health facilities, so that the health cluster service mapping is accurate, up to date and reflective of geographical distribution, so that both patients and other health actors can have a **better overview of service availability, offer better quality healthcare**, and ensure that gaps are filled/ alternative options provided where services are not available or are out of reach for patients.





Doctors and nurses prepping for surgery at RI-run Nour hospital in Idlib. Photo: Mohamad Abdullah for Relief International.

*Relief International (RI) is a non-profit organization working in 16 countries to relieve poverty, ensure well-being and advance dignity. We specialize in fragile settings, responding to natural disasters, humanitarian crises and chronic poverty.*

*RI has been implementing integrated health, nutrition, protection and institutional water, sanitation and hygiene (WASH) programming in Syria since 2012. Leveraging on a decade of experience in delivering lifesaving humanitarian response in Syria, RI has become one of key health actors, engaging directly with communities to best identify and respond to their needs. By offering primary and secondary healthcare services to Syrians through 50 health facilities, RI annually delivers healthcare to over 1 million people across northern Syria. RI-supported health facilities provide lifesaving primary and secondary health care services, including nutrition. Using health as an entry point, RI is also able to address disclosures of GBV incidents, and safely refer survivors to its specialized protection services, which include case management, emergency financial support for survivors and individuals at risk, a wide range of PSS services, etc. delivered through ten women and girls' safe spaces and mobile protection units. Through the gained community acceptance in complex security contexts, RI has not only been able to reach most vulnerable Syrians in areas where no other actors operate, but also to successfully integrate services and maximize the use of available resources on the ground.*



*The Syrian American Medical Society (SAMS) was founded in 1998 as a professional society to provide networking and educational opportunities to medical professionals of Syrian descent across the United States. The charitable arm of SAMS, SAMS Foundation, was launched in 2007. With the eruption of the conflict in Syria, SAMS Foundation has become one of the most active medical relief organizations working on the front lines of crisis relief in Syria, neighboring countries, and beyond. SAMS's Mission is dedicated to delivering life-saving services, revitalizing health systems during crisis, and promoting medical education via a network of humanitarians in Syria, the US, and beyond.*



*SAMS's Vision is to strengthen the future of Syria's healthcare, delivering dignified medical relief where needed, fortified by a dedicated medical community.*