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# "No one warned us about cancer": Understanding barriers and facilitators to accessing and utilizing cancer prevention services among Syrian refugees in Germany

Sara Bashir [a,b], Abdoul-Kawihi Issaka [c], Rihab Hadidi [d], Connie Hoe [b,e,*]

[a] Heidelberg Institute of Global Health, Heidelberg University, Heidelberg, Germany
[b] DKFZ Hector Cancer Institute at the University Medical Center Mannheim, Division of, Policy and Implementation Research for Cancer Prevention, Germany
[c] Department of Citizen Services, Public Safety and Order, City of Sachsenheim, Germany
[d] Liaison and public representative for the Syrian community in Sachsenheim, Germany
[e] Johns Hopkins Bloomberg School of Public Health, Johns Hopkins University, MD, United States

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ABSTRACT

*Background:* Cancer is a leading cause of death worldwide and in Germany. While the German healthcare system provides statutory health insurance (SHI) coverage for a range of cancer prevention services, structural inclusion does not translate to access and use of services. Syrian refugees constitute one of the largest refugee populations in Germany, yet little is known about their experiences with cancer prevention in Germany. This study explores the barriers and facilitators for accessing and utilizing cancer prevention services among Syrian refugees in Sachsenheim, Baden-Württemberg, Germany.

*Methods:* Semi-structured key-informant interviews were conducted with 25 participants in 2025 with Syrian refugees who a) have SHI, b) are aged 18 and above, and c) have been residing in Germany for 20 years or less. Data were analyzed deductively using Levesque's framework for healthcare access.

*Results:* Participants reported multiple barriers to access and use of cancer prevention services, including language difficulties, limited cancer literacy, insufficient outreach and multilingual cancer prevention material. Participants also described barriers and facilitators to healthcare access and use including long waiting times which was seen as indirectly influencing engagement with cancer prevention services. Facilitators included trust in the German healthcare system and healthcare providers, SHI coverage, Arabic-speaking doctors and translators, informal support networks. Participants recommended increasing knowledge about cancer prevention services, using multilingual and digital and in-person outreach, and leveraging the pivotal role family doctors.

*Conclusions:* Despite formal SHI coverage, access and utilization of cancer prevention services among Syrian refugees are shaped by structural, linguistic, and informational barriers which limit equitable engagement with preventive care.

*Policy summary:* Findings underscore the need for linguistically accessible cancer prevention materials that include information clearly outlining cancer symptoms, causes, screening test names, steps, locations, and cost and insurance coverage details. Professional interpreters should also be integrated into the healthcare system in Germany.

## 1. Background

In Germany, cancer is the second leading cause of death with around 500,000 newly diagnosed cases every year [5–7]. The Statutory Health Insurance (SHI) and substitutive Private Health Insurance (PHI) [8] provide coverage for cancer-preventive services [10,11]. Despite this, current literature shows that migrants tend to underutilize cancer screenings [12–16].

Refugees are a subgroup of migrants defined in Germany as displaced persons who are legal holders of a refugee protection status and have

* Corresponding author at: DKFZ Hector Cancer Institute at the University Medical Center Mannheim, Division of, Policy and Implementation Research for Cancer Prevention, Germany.
*E-mail address:* connie.hoe@dkfz-heidelberg.de (C. Hoe).

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their asylum procedure completed[1] [17]. As of 2023, 712, 000 Syrians were registered as refugees in Germany [18], making them the second largest group of refugees in Germany [19,20]. Despite this, research regarding their access and utilization of healthcare services in Germany is limited [21,22], with most focusing on access and utilization of mental health services and access to medications [23,24]. These studies show that language, structural issues and bureaucratic procedures and unmet mental health needs act as barriers, with limited focus on specific facilitators of access and use.

To the best of our knowledge, no study explored the barriers and facilitators to the access and utilization of cancer prevention services from the lens of refugee populations, particularly Syrian refugees, in Germany. This is important because designing equitable cancer prevention interventions requires incorporating the perspectives of those expected to use the services. Without understanding user experiences, services risk low uptake, resulting in inequitable access for refugee populations.

In light of this gap, the primary aim of this study is to identify the perceived barriers and facilitators that shape access and utilization of cancer prevention services among Syrian refugees in Germany.

## 2. Methods

A qualitative exploratory design was used, and data were collected using semi-structured in-depth interviews (IDIs). A public representative from the Syrian refugee community in Sachsenheim was involved in the entire research process including the design of the study and dissemination of results.

Ethical approval was received from the ethics committee at the medical faculty of the university of Heidelberg, under reference number S-119/2025. All study procedures followed the ethical guidelines established by the Ethics Committee at Heidelberg University Hospital. Written consent was obtained from each participant before data collection began.

## 3. Conceptual framework

The study was guided by the Levesque's framework for healthcare access [1]. It explains that barriers to access can occur due to system-level shortcomings and constraints linked to users' abilities to use services [1]. It has five supply-side dimensions: 1) Approachability; 2) Acceptability; 3) Availability and Accommodation; 4) Affordability; 5) Appropriateness and five demand-side dimensions 1) Ability to perceive; 2) Ability to seek; 3) Ability to reach; 4) Ability to pay; and 5) Ability to engage (Annex1).

## 4. Setting, sampling and data collection

This study was conducted in Sachsenheim in the state of Baden-Württemberg in Germany. Sachsenheim has a population of 18.5% with a migration background [25] which is similar to the overall percentage of people with a migration background in Germany 16.5%[2] [26,27]. Participants were purposively sampled with help from the city of Sachsenheim. The inclusion criteria were: Syrian refugees who have SHI, aged 18 and above, and have been residing in Germany for 20 years or less to ensure their relatiely recent experience with preventive services as first generation migrants. In Sachsenheim, 26.3% of the migrant group are Syrian refugees [25]. This is comparable to the overall concentration of Syrian migrants nationally who represent approximately 27% of all refugees in Germany, according to UNHCR [28].

Data collection took place between May 2025 and June 2025 via in person semi-structured in-depth interviews. A field guide was developed in English then translated to Arabic and piloted with Arabic-speakers. It included questions on participants' backgrounds, knowledge about cancer and cancer prevention services, perceived barriers and facilitators for accessing and utilizing these services, as well as their overall experience in accessing and utilizing healthcare services in Germany.

All interviews were conducted face-to-face and in Arabic in a private location. Each interview lasted between 30 and 90 min and participants were asked if they would agree to the interview being audio-recorded (24 participants agreed, and 1 did not agree). In the case where the participant did not agree, verbatim notes were taken throughout the interview. Those who completed the interview were provided with a 10-euro gift card as a small token of appreciation.

## 5. Data analysis

Participants' audio recordings were transcribed in Arabic verbatim and translated to English by SB, whose mother tongue is Arabic and speaks fluent English. The transcripts were transferred to MAXQDA (version 24.9.1) for analysis. Deductive coding was carried out following a codebook developed based on Levesque's framework for healthcare access [1].

A total of 25 participants took part in the study, with a mean age of 34.3 years (range 18–57) (Table 1).

### *5.1. Approachability and ability to perceive: lack of outreach, low cancer literacy and lack of awareness of where to go*

Few participants reported use of cancer screening services (IDIs 1, 2, 5, 10, 12, 13, 23, 24), such as breast and cervical cancer screenings (IDIs 1, 2, 5, 10, 12, 13, 24) and skin cancer screening (IDI 23) (Table 2).

Participants showed low cancer literacy (IDIs 1, 2, 4, 6, 8, 9, 11, 13, 14, 15, 18, 20, 23), mentioning limited knowledge about cancer, including its causes and the prevention strategies available such as screenings and HPV vaccine. Others described misconceptions about cancer (IDIs 3, 4, 6, 10, 11, 12, 13, 14, 17, 18, 20, 22, 23), such as cancer being either 'male' or 'female,' with 'female' cancers being more aggressive (IDI 3), the non-hereditary nature of some cancers (IDIs 4, 12, 17, 18, 20, 23), that it causes hair loss (IDIs 6, 14), that most cancers cannot be detected early (IDI 10), or believing it can spread from person to person like an infection (22).

> *"I know that it [cancer] can come from things like sexual intercourse, sharing food, or even through breathing. You know"*
>
> ***IDI 22 Syrian Male* Refugee**

**Table 1**
Demographic characteristics of participants.

| Characteristic | N | % |
|---|---|---|
| **Gender** | | |
| Female | 10 | 40 |
| Male | 15 | 60 |
| **Age group** | | |
| Age group: 18–29 | 9 | 36 |
| Age group: 30–44 | 11 | 44 |
| Age group: 45–60 | 5 | 20 |
| **Years in Germany** | | |
| Years in Germany < 5 | 13 | 52 |
| Years in Germany 5–9 | 6 | 24 |
| Years in Germany < 10 | 19 | 76 |
| Years in Germany ≥ 10 | 6 | 24 |
| **Migrant generation** | | |
| First-generation migrant | 25 | 100 |
| Second-generation migrant | 0 | 0 |

[1] This definition is according to according to the German Federal Office of Migration and Refugees (BAMF), in accordance with the Geneva Refugee Convention.

[2] The total number of people with migration background in Germany is 14,061,640 according to Destatis, out of a population total of 84,746,132 in 2024, according to Destatis.

**Table 2**
Types of cancer screenings and number of eligible for screening and people who did the cancer screenings.

| Screening type | Eligible (total) | Eligible (females) | Eligible (males) | Completed screening (total) | Completed screening (females) | Completed screening (males) |
|---|---|---|---|---|---|---|
| Cervical | 9 | 9 | 0 | 6 | 6 | 0 |
| Breast | 7 | 7 | 0 | 6 | 6 | 0 |
| Skin | 10 | 6 | 4 | 1 | 0 | 1 |
| Prostate | 4 | 0 | 4 | 0 | 0 | 0 |
| Bowel | 1 | 0 | 1 | 0 | 0 | 0 |

* Eligibility criteria were defined based on national guidelines for cancer screening in Germany Gesundbund.de

Many participants reported never encountering any cancer-related outreach (IDIs 2, 3, 4, 6, 7, 8, 9, 11, 13, 14, 15, 16, 17, 18, 20, 21, 22) and emphasized that language could be a salient barrier to cancer prevention outreach (IDIs 6, 15, 13, 20, 25). For some, when presented with German cancer prevention educational material it was perceived as linguistically inaccessible and was rejected (IDIs 1–5, 8–13, 15–18, 20, 24, 25).

"If it's translated into Arabic, I could benefit from it. But currently, I wouldn't even go near it (laughs). Without a translator, I wouldn't benefit from it at all."

***IDI 18 Syrian Male***

Some participants demonstrated awareness of the link between smoking and cancer, however, they expressed their inability to quit, as they do not see the benefit of smoking cessation (IDIs 4, 6, 9, 13, 22, 24). For some individuals the long-term health risks did not motivate change (IDIs 6, 10, 13, 24).

### *5.2. Acceptability and ability to seek: gender and cultural norms, and motivation to seek cancer prevention services*

Some participants expressed fear and discomfort when speaking about cancer, (IDIs 12, 13, 14, 19, 21, 24). Many demonstrated mixed views on the impact of gender and cultural norms on the acceptability of cancer prevention services. Some did not view the doctor's gender as a barrier to screening if they did it or decided to do it (IDI 1, 2, 3, 6, 7, 8, 10, 12, 13, 15, 19, 22, 23, 24, 25). While for others, that was an important factor (IDIs 4, 5, 9, 14, 16, 17, 18, 20).

Motivation to seek preventive cancer services among many participants was largely contingent upon the presence or development of cancer-related symptoms (IDIs 3, 12, 15, 16, 17, 18, 25) or sufficient awareness of the disease and the available preventive care services (IDIs 1, 2, 6, 7, 8, 17, 19, 20, 21, 23, 24).

*"As I said, you only go to the doctor if you're in pain and you wait for hours. But for cancer preventive services, no one really cares."*

***IDI 1 Syrian Female* Refugee**

### *5.3. Availability and ability to reach: appointment system as a barrier and social support as facilitator for reaching care*

Within the health system, long waiting times are viewed as a significant barrier to accessing preventive services and were viewed as "misaligned" with the logic of prevention and early detection (IDIs 7, 13 15).

*"… They [the doctors] tell you to take an appointment that is in two or three weeks. I could have already worsened or died …. Cancer is dangerous, and for example, leukemia is one of the most dangerous cancers, and if it spreads in the blood that's a disaster, and the doctor must give treatment from the beginning so that he can overcome the illness. But if the appointment is delayed, the disease might spread"*

***IDI 15 Syrian Male* Refugee**

Participants highlight that social support from friends and family facilitates access to healthcare services by having someone who speaks German at their doctor visits to translate, especially for those still learning the language (IDIs 4, 5, 9, 10, 12, 14, 18, 19, 20, 22, 23, 24, 25).

### *5.4. Affordability and ability to pay: SHI as facilitator, direct and indirect costs as barriers to access and use of care*

Participants reported being members of SHI plans and were willing to go and undergo screening when services were provided (IDIs 1, 3, 4, 5, 6, 7, 8, 9, 14, 19, 21, 23, 24, 25).

However, some participants reported that direct out-of-pocket payments were sometimes incurred in mammograms and HPV vaccines (IDIs 1, 2, 5, 13, 19). They mentioned that the cost of the HPV vaccine if taken outside of the recommended age was too high. This discouraged uptake among adults:

"She [participant's daughter] can get it [HPV vaccination] now, but it's expensive. *Before 18, it's free, but now it has to be paid out of pocket"*

***IDI 5 Syrian Female* Refugee**

Indirect costs, particularly the time lost due to travelling to appointments locations, often showcased as caregiving roles and working hours, might impede the use of cancer prevention services, as it is more difficult to prioritize preventive care, even when technically free (IDIs 10, 16, 24).

*"We once had a pediatric appointment in the morning during work hours. It was inconvenient, I had to take time off work and pull the children out of school. Timing is not flexible. Honestly, this is a real issue. And it's not just me, many young people, including my cousins and even Germans, face this. But for migrants especially, it's an even greater burden."*

***IDI 15 Syrian Male Refugee***

### *5.5. Appropriateness and ability to engage: engagement in cancer screenings, interpersonal dynamics and language as a barrier in clinical encounters*

Some female participants described engaging in gynecological screenings, often requested by themselves, due to perceived risk after childbirth, awareness of family risk, or prescribed by their doctor (IDIs 1, 5, 7, 10, 12, 13, 24).

Participants frequently mentioned that language is a serious barrier to access and use of healthcare services in general healthcare settings and iterated that this might also affect access and use of cancer prevention services (IDIs 1, 2, 4, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 22, 24, 25).

*"The first and biggest obstacle is language."*

***IDI 2 Syrian Female* Refugee**

For some, this communication barrier was partially mitigated either by relying on informal means of translation such as the translator on the phone, or by choosing Arabic-speaking doctors as their family doctors (IDIs 1, 2, 3, 4, 5, 7, 10, 12, 15, 25).

Most participants mention positive and respectful encounters that reinforced their trust in the German healthcare system and in their doctors (IDIs 1, 2, 3, 4, 6,10, 12, 15, 17, 19).

*"I trust the healthcare system in Germany,*

***IDI 11 Syrian Male Refugee***

### 5.6. Participants' recommendations

Many participants recommended in-person outreach and stressed the role the municipality can play in organizing such events (IDI 1, 5, 13, 16, 23), as well as digital outreach (IDIs 3, 6, 10, 11, 12, 15, 16, 17, 18, 19, 22, 23, 24, 25). Furthermore, many emphasized the central role of the family doctor as both a facilitator of access and the first point of contact when it came to cancer prevention inquiries (IDIs 5, 9, 14, 18, 19, 21, 23, 24).

*"Maybe I won't think to go, but if the doctor advises me, I will go."*

***IDI 5 Syrian Female* Refugee**

Participants recommended provision of information on the causes and symptoms of cancer, procedures, timing, and purpose of specific screenings, cost/insurance coverage (IDIs 3, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25).

## 6. Discussion

This study showed that language, limited cancer literacy, insufficient outreach and multilingual health material, and long waiting times served as barriers to accessing and utilizing cancer prevention services. On the other hand, trust in the German healthcare system and in healthcare providers, SHI, presence of Arabic-speaking doctors and translators, informal social support networks served as facilitators.

Language appeared to be the biggest barrier experienced by Syrian refugees in their clinical encounters. This finding is consistent with M. Green [29] who also reported that language was the main barrier facing refugees in accessing quality healthcare in Germany and with Mangrio, E., and Sjögren Forss [30] who emphasized the role of language barriers in effective communication with healthcare professionals across Europe. This study showed that Syrian refugees seek either Arabic-speaking doctors or rely on translation tools or informal interpreters, such as acquaintances, friends, family members, or volunteers from the municipality to mitigate this language barrier. However, such tools might raise concerns about the private and ethical patient-doctor encounters. Furthermore, miscommunication because of language proficiency and/or inability to adequately explain one's health conditions might lead to misdiagnosis and inappropriate treatment. Reliance on informal interpreters might discourage health-seeking, because going to the doctor might be dependent on the availability of someone who translates [30]. A key policy recommendation is that Germany should integrate professional interpreters into the healthcare systems.

This study highlighted the need to enhance cancer literacy among Syrian refugees. This reflects the importance of developing linguistically accessible cancer prevention educational materials that include information on cancer, its symptoms and its causes as well as information clearly outlining cancer screening test names, steps, locations, cost and insurance coverage details. This information could be delivered through family doctors, community organizations, or digital tools. These can be considered as pragmatic solutions that support the suggestions of Kikhia et al [31]. on the provision of customized information on the German healthcare system and the establishment of a health-literacy supporting environment for Syrian women in Germany. A hybrid outreach model, integrating both digital platforms and in-person communication could function as an effective, culturally sensitive awareness raising approach.

Perceived financial barriers further complicated access. Some participants reported out-of-pocket payments for mammograms or HPV vaccine impeded uptake. Although these expenses sometimes undermined engagement, it is important to note that awareness should be raised about the clinical risks of over-screening and non-required vaccinations**.** Tests like mammography and echo are not universally recommended at all ages or frequencies, and vaccines outside of the recommended age range in some cases may have more risks that may outweigh the benefits**.** For example, the current recommendations by STIKO are that HPV vaccination should be administered for children between the ages of 9 and 14, with catch-up vaccination possible up to age 17 however, is not routinely advised unless in high-risk groups, due to lower efficacy and a lack of potential for reduced benefit-risk ratios [32] Similarly, over screening has been associated with harms including increased numbers of false positives, overdiagnosis, and psychological distress attributed to the unpleasant screening process [33]. Thus, public health communication and outreach should also offer balanced education about appropriate use based on evidence-based guidelines.

In this study, most participants who accessed cancer prevention services were women. This is consistent with evidence from Germany and globally showing that women generally make greater use of preventive health services than men [34–36]. This may reflect the need for cancer prevention services that adequately engage men.

This study highlighted the central role of family doctors in facilitating access to cancer prevention. Many indicated that they would only consider undergoing cancer screening upon recommendation or referral by their family doctor. Kikhia et al. [31] describe the reliance of Syrian women on Arabic-speaking doctors for general care, but they do not explore the unique role of general practitioners to structured cancer prevention efforts**.** This study adds the novel contribution by showing that family doctors do not only act as linguistic or cultural barriers in healthcare, but also as potential triggers for seeking cancer preventive care.

## 7. Limitations of the study

This study was conducted in a single geographic location, which may limit the transferability of the findings to other contexts. Additionally, including the perspectives of migrant healthcare workers could have strengthened the study by enabling triangulation of perspectives.

## 8. Conclusion

Findings highlight the need for linguistically accessible cancer prevention materials. Additionally, professional interpreters should be structurally included within primary healthcare. Future research on cancer prevention among refugee populations is needed to inform the development of tailored interventions that directly respond to the barriers and leverage the facilitators and recommendations identified.

## Author contribution statement

CH and SB conceived the study. SB conducted the interviews, with support from AI and RH, and performed the analysis. SB drafted the manuscript with conceptual and editorial input from CH, AI, and RH. CH provided overall guidance and supervision. All authors reviewed and approved the final version of the manuscript.

## CRediT authorship contribution statement

**Rihab Hadidi:** Data curation, Validation, Writing – review & editing. **Connie Hoe:** Conceptualization, Methodology, Supervision, Writing – review & editing. **Sara Bashir:** Conceptualization, Data curation, Formal analysis, Writing – original draft. **Abdoul-Kawihi Issaka:** Data curation, Validation, Writing – review & editing.

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## Declaration of Generative AI and AI-assisted technologies in the writing process

During the preparation of this work, the authors used Grammarly and ChatGPT to proof-read the manuscript with the prompt: "Identify any grammatical errors and/or any typos, repeated words and unclear sentences and/or words". After using this tool/service, the authors reviewed and edited the content as needed and take(s) full responsibility for the content of the published article.

## Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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## Annexes

**Annex 1**

Table provides a summary of the definitions of each dimension and their use in the scope of this research

| Dimension | Definition | Use of dimension in this research |
|---|---|---|
| Approachability | Transparency, outreach, information screening | When participants do (not) know about available general health and cancer prevention services for example: when people say, "I did not know this existed" or "nobody explained this to me." |
| Acceptability | Aspects such as: professional, values, norms, culture or gender that influence uptake, use and access to services. | When participants mention that sociocultural aspects might affect access and/or use of health/cancer prevention services |
| Availability | Geographical location, accommodation, hours of opening, appointments, and mechanisms that influence the use and access to services. | When participants mention that distance, transport, hospital opening hours, or waiting times as barriers. |
| Affordability | Direct and indirect opportunity costs associated with accessing and using services | When participants mention financial and temporal resources needed to access a service (cost, insurance issues, or loss of income, missed work hours) |
| Appropriateness | Technical, interpersonal, quality, adequacy, coordination and continuity | When participants mention the fit between the patient's needs and the offered health/ cancer prevention services |
| Ability To Perceive | Health literacy, beliefs, trust and expectations about services | When participants mention their knowledge, beliefs on cancer, and their trust in and expectations from the available cancer prevention services |
| Ability To Seek | Personal, social values, culture, gender, autonomy Intent to seek services. | When people describe the process of finding where and how to get screened, how they learned (will learn) about health/cancer prevention services. |
| Ability To Reach | Living environments, transport, mobility, social support | When participants mention transport availability, distance and social support that helps them reach, use, and access health/cancer prevention services. |
| Ability To Pay | Income, assets, social capital, health insurance | When people mention that use of health/cancer prevention services is hindered or enabled by financial barriers |
| Ability To Engage | Empowerment, information adherence, and caregiver support | When participants reflect on how well they understand information related to cancer prevention, and how confident they feel in participating in health/cancer prevention services, and how they are supported (e.g., through caregiver support) and to follow through with recommendations. |

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