

# Synthesis report on health needs and barriers to access cancer care prevention for the homeless population at system, provider, and individual levels.

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WP2: Participatory co-adaptation of the Health Navigators Model in the European context meeting the needs of organisations, professionals, and the homeless population.

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# LIST OF ACRONYMS

- H2020 Horizon 2020
- HNM Health Navigator Model
- N Nurse
- PCP Primary Care Physician
- PEH Person(s) Experiencing Homelessness
- PSY Psychologist
- SCP Specialist Care Physician
- SW Support Worker/ Social Worker (Psycho-Social Care Professional)
- WP Work Package





# **EXECUTIVE SUMMARY**

# **Background and objectives**

The CANCERLESS project aims to combine the principles of Patient Empowerment and the core features of Patient Navigator models to create a new framework known as the Health Navigator Model (HNM). This model is to be implemented with people experiencing homelessness across Europe to ensure that they are able to access cancer prevention in a timely manner.

This synthesis report forms part of Work Package 2 of the CANCERLESS project, the central aim of which is to better understand the health needs of people experiencing homelessness and the barriers they encounter in accessing primary and secondary cancer prevention services, and to use the evidence collected to adapt the HNM in a way that ensures it is appropriate and meaningful for the target population. Specifically, this report details the findings of an exploratory qualitative study conducted across four of the partner countries (Austria, Greece, Spain, and the U.K.) with people experiencing homelessness, both with and without direct experience of cancer, and relevant health and social care professionals. The findings reported will be used to inform pilot intervention that is to be implemented in the next stage of the project.

The overall objectives of this report are as follows:

- To explore and better understand the health needs of people experiencing homelessness.
- To explore and better understand the barriers and facilitators to healthcare for people experiencing homelessness, particularly in relation to accessing primary and secondary care prevention services.
- To better understand current practices and knowledge relating to cancer prevention among people experiencing homelessness and social and health care professionals.
- To identify specific factors that require consideration when improving cancer prevention for people experiencing homelessness.





# Methodology

In order to meet the above objectives, this study employed a cross-national qualitative design. Data were collected through semi-structured interviews (n=69) between August and October 2021 with people experiencing homelessness, both with and without direct experiences of cancer, and health and social care professionals. Data were thematically analysed in an inductive an iterative manner, and in accordance with the approach set out by Saldaña (2021). Partners in each of the four participating countries (Austria, Greece, Spain, and the U.K.) conducted and analysed the interviews which were then compiled into the current synthesis report.

# **Key findings**

Five overarching themes were developed through the process of analysis and are used to structure the findings from each country. These are as follows:

- Health needs of people experiencing homelessness
- Barriers to accessing healthcare
- Facilitators to accessing healthcare
- Experiences and understanding of cancer prevention and treatment
- Considerations for programme intervention

Across all settings, the general health of people experiencing homelessness was portrayed by participants as being very poor. Many of the homeless participants suffered with chronic physical health conditions, mental ill health, and substance-related disorders, and these were often described as being exacerbated by their housing circumstances and lifestyles. The widespread prevalence of self-neglect within the homeless population was explained both in terms of a limited understanding about how to properly care for themselves and also a tendency to focus on meeting more immediate needs rather than attending to long-term health.

Participants discussed an extensive range of barriers to healthcare which, taken together, suggest that mainstream healthcare services are ill-equipped to offer care to people experiencing homelessness and at times operate in a way that is entirely incompatible with the lifestyles and needs of this population. Particularly notable across





all settings was the presence of stigmatised attitudes towards people experiencing homelessness on the part of healthcare professionals, which were described as deterring homeless people from seeking the healthcare that they require. Problems around access to healthcare were also further compounded by a general lack of healthcare resources and staffing, an issue that has seemingly intensified through the COVID-19 pandemic.

The most consistent theme throughout the interviews with regards to facilitating access to healthcare was the pivotal role being played by the staff of social care organisations who work directly with the homeless population, and who regularly act as mediators in access to mainstream healthcare provision. When attending primary or secondary care services, homeless participants indicated that they were more likely to engage with healthcare professionals that they trusted and that communicated with them in a way that allowed them to understand and make decisions about their health. Participants also spoke positively about healthcare services that operated in familiar settings (for example, within social care organisations) and that were delivered in more flexible ways (for example, by using 'drop-in appointment systems) as these were seen to combat many of the barriers that exist to mainstream healthcare.

Participants' responses indicated that while cancer was a major source of concern and worry, people experiencing homelessness generally have a very limited level of knowledge and understanding around cancer symptoms and cancer prevention. Across all settings, specific programmes for cancer prevention for people experiencing homelessness were described as effectively non-existent, and very few homeless participants recalled being invited to a screening appointment. As a result, health professionals in some settings indicated that cancer in people experiencing homelessness was often missed in the early stages, and instead only picked up when the severity of symptoms intensified.

Overall, the findings presented here indicate that there is a high degree of overlap and consistency in the health needs of people experiencing homelessness, and in the barriers and facilitators that exist when accessing healthcare in the European context.





# **INTRODUCTION**

Existing research has consistently demonstrated that members of the homeless population are at an increased risk of experiencing poor health-related outcomes. Infectious diseases, mental health conditions and substance-related disorders are all over-represented among people experiencing homelessness (Fazel, Geddes & Kushel, 2014), while rates of premature mortality are significantly higher than in the general population with an average age of death of just forty-seven years old (Thomas, 2012). Critically in the context of this project, cancer-related mortality has been found to be twice as high compared to the general adult population in high-income countries (Asgary, 2018).

These poor health-related outcomes may be explained both by exposure to activities known to increase risk of poor health, and by the existence of barriers in accessing what are often highly complex and fragmented health and social care systems (Lebrun-Harris et al., 2013; Homeless Link, 2014). In particular, it has been found that people experiencing homelessness often present with symptoms that are missed by primary and secondary prevention strategies and are therefore over-reliant on acute healthcare settings such as emergency hospital departments (Field, Hudson, Hewett & Khan, 2019). Issues with access to appropriate healthcare for this population are also often compounded by lack of insurance, legal problems, risk of stigmatisation and experienced discrimination (Hwang et al., 2013; Lebrun-Harris et al., 2013). While it is essential that interventions are developed to prevent homelessness, there is also a pressing need for interventions to guarantee access to healthcare for those who are currently homeless.

'CANCERLESS: Cancer prevention and early detection among the homeless population in Europe: Co-adapting and implementing the health navigator model' is an EU Horizon 2020 project that aims to combine the principles of patient empowerment (WHO, 1998) and the core features of patient navigator models (American Medical Association, 2015) to create a new framework known as the Health Navigator Model (HNM). This model is to be implemented with people experiencing homelessness across Europe to ensure that they are able to access cancer prevention in a timely manner.





This synthesis report forms part of Work Package 2 of the CANCERLESS project. The central aim of this work package is to better understand the health needs of people experiencing homelessness and the barriers they encounter in accessing primary and secondary cancer prevention services, and to use the evidence collected to adapt the HNM in a way that ensures it is appropriate and meaningful for the target population. Specifically, this report details the findings of an exploratory qualitative study conducted across four of the partner countries (Austria, Greece, Spain, and the U.K.) with people experiencing homelessness, both with and without direct experience of cancer, and relevant health and social care professionals. The findings reported here will feed directly into other work packages and the pilot intervention that is to be implemented in next stage of the project.

# **Overall objectives of this report**

The overall objectives of this report, and that guided the collection of data, are as follows:

- To explore and better understand the health needs of people experiencing homelessness.
- To explore and better understand the barriers and facilitators to healthcare for people experiencing homelessness, particularly in relation to accessing primary and secondary care prevention services.
- To better understand current practices and knowledge relating to cancer prevention among people experiencing homelessness and social and health care professionals.
- To identify specific factors that require consideration when improving cancer prevention for people experiencing homelessness.

# **METHODOLOGY**

This study employed a qualitative research design, and followed the guidelines set out in Deliverable 2.3 of the CANCERLESS project. Data were collected through a series of semi-structured interviews with members of the homeless population, both with and without direct experience of cancer, and relevant health and social care professionals.





Interviews were conducted in field settings across four countries (Austria, Greece, Spain, and the U.K.) by a multidisciplinary team of researchers from a total of seven partner organisations between August and October 2021.

Adopting a qualitative design allowed us to conduct an in-depth exploration of the topic area whilst also ensuring that participants' perspectives, experiences, and language remained central through the analytical process and in the development of the key themes. The flexibility offered by a qualitative approach ensured that participants were granted a level of freedom and power to share what they felt to be most important or relevant, which is particularly important given that people experiencing homelessness are often highly marginalised. Moreover, given the sensitive nature of the topic in hand, the method chosen needed to allow for rapport-building between researcher and participant; indeed, it has been noted that the non-prescriptive nature of the qualitative interview format means participants are more likely to feel comfortable in disclosing personal experiences and opinions (Bryman, 2016).

# Data collection

Across all partner countries, participants were recruited with the assistance of relevant organisations (for example, accommodation providers, health services, advice services, day centres). Information was disseminated by study teams on the purpose and goals of the study to staff representatives who then assisted in making appropriate introductions between researchers and potential participants.

A total of **69 participants** took part in interviews across the four partner countries, with a sample breakdown as follows:

- 26 people experiencing homelessness with no direct experience of cancer
- 3 people experiencing homelessness who are living beyond cancer
- **6** people experiencing homelessness who are currently cancer patients / living with cancer
- **15** psycho-social care professionals (e.g., support workers, social workers, professionals working in cancer patient organisations)





• **19** health professionals (including nurses, primary care physicians, oncologists, and psychiatrists)

Interviews generally took place within the premises of the service/organisation with which the participant was associated (for example, a homeless day centre or health service) and were conducted in private or semi-private settings. Where necessary as a result of COVID-19 related restrictions, some interviews also took place remotely via videocall.

A set of question schedules were used to guide the interviews, and to encourage a level of consistency in the cross-national data collection. These were developed in consultation with practitioners from a homelessness organisation to ensure suitability of language and content. While specific schedules were designed for each of the participant groups, all covered the same broad topic areas:

- Perceived health needs of people experiencing homelessness.
- Barriers and facilitators to accessing and utilising healthcare services.
- Current knowledge and/or practices relating to cancer prevention.
- Direct experiences of cancer prevention and treatment (where relevant).
- Suggestions, priorities, and perceived challenges in improving cancer prevention and cancer care pathways.

# Data analysis and reporting of findings

All interviews were audio-recorded and transcribed verbatim in their respective languages, either manually or using appropriate software, before being internally checked for quality.

The completed transcripts were analysed according to the inductive thematic approach set out by Saldaña (2021), aided by either NVivo v12 or Atlas.ti v8. In the first stage of analysis, researchers worked through the data systematically attaching labels of a few words (codes) to capture meaning in the text. These codes were then reviewed and merged, first into tentative categories, and then into overarching themes, allowing the abundance of codes identified through the initial analysis to be condensed and synthesised. While the initial coding process was completed on a country-by-country





basis, partners from all countries met regularly to discuss the analysis of the data and the final themes were agreed upon collaboratively.

Five overarching themes were developed through the process of analysis and have been used to structure the findings from each of the partner countries. These closely mirror the topic areas of the question schedules as above:

- Health needs of people experiencing homelessness
- Barriers to accessing healthcare
- Facilitators to accessing healthcare
- Experiences and understanding of cancer prevention and treatment
- Considerations for programme intervention

## **Ethical considerations**

The Ethics Committee of the Medical University of Vienna approved the overall study, and each partner obtained additional approval from their designated ethical review board or institution before beginning data collection.

Prior to the start of the interviews, participants were supplied with an information leaflet about the study and given the opportunity to ask questions. In all cases, participants were reminded that participation was voluntary and that they did not need to answer any questions that made them feel uncomfortable. Full and informed consent was sought from and provided by all participants through a signed form and also verbally.

Data are stored securely in line with GDPR (2016) regulations, and all files are encrypted and stored on computers that require password access, with unnecessary duplicates avoided. All interviews were transcribed omitting identifiable details, and both interview transcripts and audio files were labelled using reference codes rather than names. The interview consent forms are stored securely and separately, linked to their respective transcripts via the anonymous reference code. Throughout the report, the use of quotations has been carefully considered to ensure they do not reveal an inappropriate level of detail about specific participants.





# **FINDINGS – AUSTRIA**

A total of 19 participants took part in interviews, with a sample comprising: eight people experiencing homelessness, one of whom was a current cancer patient, and another who was living beyond cancer; six health professionals, one of whom was an oncologist and the rest general practitioners; and five social support workers, one of whom had prior experience of homelessness. Participants were recruited through multiple homeless organisations located around Vienna. Further information about the sample characteristics is provided in Tables 1 and 2.

# Health needs of people experiencing homelessness

Participants generally perceived that the **circumstances faced by people experiencing homelessness** particularly affected their health and well-being. They described precarious or unstructured housing conditions, poor nutrition, and lack of sleep as factors that led to a weakened immune system and stark deterioration in health. Furthermore, participants felt that issues such as having to share housing facilities, having to constantly move around in extremes of temperature, insufficient food or often being on the street were damaging to their morale and sense of social belonging:

"There is nothing more threatening to one's existence than being homeless." (SW1\_AT)

As to the kind of **health problems faced by people experiencing homelessness** participants described chronic diseases such as diabetes and cancer, liver and lung diseases, open wounds and other skin problems, incontinence, dementia, hypertension, complex dental problems, and high-risk pregnancies. Participants from the health sector remarked that there were more cases of ear-nose-throat (ENT) tumours, colon, breast, and cervical cancers among those experiencing homelessness than in the general population.

Participants from the health and social care sectors stated that the majority of their clients suffered from extreme stress for multiple reasons leading to a range of untreated psychiatric diseases. Several participants who experienced homelessness themselves





described having mental conditions such as paranoid personality disorder, anxiety and bipolar disorders that often prevented them from seeking healthcare:

"Our biggest problem, health-wise, is certainly mental illness. Which is in the nature of things. Which is also often a reason for homelessness. That people are mentally ill and not treated. Not treated, not due to the fact that there is nothing, but that people are simply so ill that they cannot accept anything." (SW2\_AT)

Behavioural issues arising from these mental health problems were often claimed to be the result of addiction to alcohol and other substances. While several participants highlighted the difficulty in overcoming the vicious cycle of drug and alcohol dependency, some participants felt that there was a need for more cooperation from psychologists and psychotherapists to attend to the healthcare needs of homeless people wanting to get out of addictive behaviours:

"I had a check-up with the lung specialist, I should take a spray and reduce. Reduce. But how? I want to talk about whether there's a smoking therapy or something like that, or that I can at least reduce. A talk or something. I don't know, I want to find out if there is such a thing." (PEH5\_AT)

Some participants pointed out the **limited healthcare provision** available for homeless people with mental disorders, who were often denied care due to the lack of structural and staff resources. On the other hand, several participants highlighted the availability of specific homelessness healthcare centres and certain hospitals that accepted individuals who were homeless and/or uninsured. Most participants were aware of the availability of a mobile healthcare service, although even that was found to have limitations in capacity. Some participants mentioned the need for facilities offering a **continuum of care** due to the complexity of problems such as those faced by alcohol and drug addicts, but that little was done by society in terms of providing this:

"And one thing is clear ... the first thing that happens when we have to save, whether it is money or time, is that it hits the homeless or the addicts." (PCP3\_AT)





# **Barriers to accessing healthcare**

The main barrier identified by participants was the **absence of social and health insurance** among many people living in precarious housing situations. Participants from the health and social care sectors stressed that homeless people often presented with well-established health needs and needed immediate care but were delaying their attempts to access healthcare due to a lack of insurance, while those with insurance had poor knowledge of its importance. Some participants who experienced homelessness did realise that to have regular preventive checks or to be tied up with hospitals or specialists for further care, they needed health insurance.

"But the medicine, yes, from my health, of course I've got all that so far, except for the powders for diabetes, the difficulties I have with the foot and a full health check, I have to put all that off. The specialist I have to put off as well. I also have to put that off because I don't have insurance and it's actually kind of clear. Without insurance, privately, it doesn't work." (PEH3\_AT)

Some participants from the healthcare sector mentioned that while there were free services that were at times being utilised, there existed barriers at the systemic level that prevent all-round integrated care. They also addressed the high costs incurred by critical services such as hospital care and psychotherapy, which were not affordable for the uninsured and those with low income. It was further emphasised that medically underserved people who may contract preventable diseases affected societal health in general.

Subsequently, respondents across groups felt that there were **gaps in the framework of homelessness support** particularly for the uninsured, revealing a barrier between what homelessness services provide, and the reality of what is available to people experiencing homelessness. While some participants outlined the bureaucratic hurdles that needed to be overcome in order to register for services or documents, others emphasised the inability to connect uninsured homeless people to the regular health/social care system, making it unlikely for institutions to support their needs. It was mentioned that homeless people who worked unofficially and had no residency





rights were denied access to the labour market, making it impossible to secure insurance:

"There are so many free flats and the homeless live on the street. They always want to rent it out. They don't care whether homeless or not. They care about making more capital, making more money. Money is important. And that's why there are so many problems." (PEH6\_AT)

Most participants spoke about having to deal with **communication and cultural barriers** in accessing healthcare and explained that these were frustrating for both provider and client. In particular, it was noted that this affected understanding of health, healthcare provision and acceptance as well as compliance requirements. Participants from the health sector repeatedly stressed that enlisting cleaning staff or family members – especially underage children - to interpret medical issues was inadequate and unprofessional, likely leading to deficient care. Although some participants highlighted the availability of video interpreters in one homelessness healthcare facility, many stated that doctor visits were avoided because of language barriers.

"I think we are now increasingly looking after people with asylum status, some of whom do not speak German very well, and I think that will be the case more often in the future, so that will definitely be an issue." (SW3\_AT)

Though participants mentioned that health services were of good quality, they were consistent in highlighting the **inadequate ancillary support** needed to assure follow up treatment after hospitalisation or to comply with therapy or after care. Participants experiencing homelessness, however, disclosed that there was a broader set of problems at hand to consider, and healthcare or compliance was not necessarily relevant to their immediate concerns:

"Well, I'll tell you, when you're homeless, I don't think you look at it that much. At least that's how it was with me. When you're on the street, you look somewhere to scrounge up money so that you can buy a little something, that's it." (PEH5\_AT)

Healthcare and social staff participants further underscored the **low proportion of qualified staff**, and that there was an absence of nursing staff to provide medically knowledgeable care support to homeless people with precarious health conditions. Participants often specified the crucial need for dental care, but that it demanded high





'out of pocket' payments. Some participants also indicated that the healthcare concerns for the broader society were not necessarily the same for people experiencing homelessness, who worried more about more immediate needs (for example, access to food):

"In other words, homelessness is such a morbid process that if someone gets the best medical offer but is not supported in his existential threat, then all this effort of the best medicine is of no use." (PCP4\_AT)

Participants also highlighted the **stigma** faced by many people experiencing homelessness, and that there was a general view of that homeless people as socially unacceptable. Participants described incidences of homeless people being sent away from medical practices due to the way they presented and smelt, and that this experience meant individuals did not return or try seeking further healthcare for fear of disapproval. Participants across groups divulged that physical assaults, aggression and insults due to their living conditions, appearance, mental state, or addiction were endured, often resulting in their losing trust in non-homelessness healthcare settings:

"Many would probably say that a lot of it is self-inflicted or that people don't want to anyway and that the people are unpleasant and stink and stand out and can't keep to the social norms and therefore are not necessarily accepted." (SW3\_AT)

# Facilitators to accessing healthcare

Participants experiencing homelessness consistently highlighted the dedication of homelessness staff in providing **quality support and healthcare**. Participants revealed the commitment they ensured to enable their clients to cope with their everyday life. Some participants pointed out the extra support that was offered to those who were not entitled to benefits of homeless assistance such as warm clothing in winter. Most participants experiencing homelessness described that the care they received was sensitised and competent, and that one did not need to explain one's condition.

"Well, I mean, of course they were already specialised, and they didn't have any questions. So, they immediately addressed what the problem is. For example, without me pushing for it or thinking of doing a blood test, which revealed a vitamin deficiency. So, it wouldn't have even occurred to me to do that." (PEH7\_AT)





Participants who experienced homelessness were grateful for the **structural accessibility** to homelessness care. They mentioned that there were centres providing access to good nutrition, free medicines, healthcare, and essential information, as well as a place to meet others facing similar issues. They also described centres that provided a safe place to sleep in emergencies, and homes that were accessible for the vulnerable and sick. Participants across groups agreed that the acute care provision was good, and that healthcare could be accessed throughout the week without making appointments. They also mentioned the availability of a mobile healthcare service bus providing easily accessible care.

"I can only talk about myself....I got it here, from the P7, and then went to the new house. No, it was a good fit. I was also told there are buses for emergencies. So, I do believe that there is a lot of provision for acute cases." (PEH3\_AT)

# Experiences and understanding of cancer prevention and treatment

Among participants experiencing homelessness, most stated that they were not aware of specific cancer prevention programmes, except that mammography and pap smears were available for free for women. Some participants were aware of homeless people with cancer being provided treatment, and that additional cancer care such as radiation was partly provided by a local homelessness care facility. Two homeless participants who had experienced cancer highlighted that the **costs of treatment** were a significant issue for them:

"...they tried to get donations for my chemo. At first it was just a little bit of money and not enough for 5000€. And one man donated 5000€ for me, but he didn't tell his name. And immediately I could start chemotherapy." (PEH2\_AT)

"I do not know when it will be because right now, we are working only for therapeutic pocket money. It is not possible to collect 800€ for one night to stay in a hospital. I know that in the period of two years there have been a lot of changes. That is my trouble." (PEH8\_AT)





Although participants across groups recognised the seriousness of cancer among the homeless population, many participants from the social care sector and those who experienced homelessness felt that their own awareness of cancer prevention was limited. While some participants felt that **combining regular healthcare with cancer screening** was something to consider, healthcare professionals stressed that the regular health checks were not suitable for cancer prevention, and that there were no effective screening programmes in place for homeless people:

"I can also hardly imagine that the drop-in centre that treats a urinary tract infection can now do an oncological diagnosis. The problem is that this has to be followed up to some extent by the patient himself .... even for an all-round integrated person, it is difficult to keep all the appointments that are part of the diagnosis alone. And I imagine that is absolutely impossible in the homeless sector. There would have to be a real case manager for every single homeless person. But screening is also costly and not always useful, to be honest." (SCP1\_AT)

Other healthcare professionals further emphasised that cancer prevention is not about screening or early detection but providing access to exercise and wellness programmes such as strength training, yoga, nutrition counselling and stress prevention that could extend their life:

"In Austria it is difficult to actually live prevention with money and it is even more impossible to live prevention without money. And even in these early detection programmes, they are not prevention programmes, they are early detection programmes .... and the early detection programme actively targets people for whom early detection and potential early treatment saves costs compared to what happens if diagnosed and treated at a later stage. And there is actually no expression of human suffering in the whole equation...What actually makes sense under prevention, what works very well, is exclusively in the private sector. Namely, fitness studios with an extended range of services ... gyms that offer exercise programmes, that offer nutrition programmes, that offer stress prevention programmes, yoga classes and diet counselling." (PCP4\_AT)

Participants across groups particularly noted that cancer prevention is irrelevant if acute problems were not dealt with first. They recognised that financial problems had to be clarified at diagnosis, without which cancer was likely to spread by the time care was





assured. Incomplete treatment and follow up were often due to the lack of money and the lack of a secure job and housing:

"So, it's really a luxury to take care of preventive examinations and check-ups when you're still carrying acute problems around with you." (PEH7\_AT)

Participants from the health and social care sectors mentioned the need to **improve cancer care** offers for palliative care through trained staff, as well as to think about the entire continuum of care from diagnosis to the end of life. Some pointed out, for example, that care and treatment need to take into account the realities of the living conditions of people experiencing homelessness:

"Then sometimes examinations take place where the findings are inconclusive because the preparation doesn't work ... but do a laxative preparation for a colonoscopy while living on the street ... so there are things like that, you can give so many appointments and so many laxatives ... if you don't think about it, where do people do that? Then the investigation will not work." (PCP1\_AT)

## **Considerations for programme intervention**

Respondents across health and social care sectors felt that in order to work towards **low-threshold homeless care**, there needs to be specialists and staff who are willing to work with homeless people regardless of their physical or mental state. Some of these participants also indicated that a broader cooperation with existing services was essential and that more psychological support provision in the network was required. Participants suggested that people experiencing homelessness should be able to access affordable housing and healthcare, and that there should be greater clarity from social insurances on therapy coverage. A more **direct**, **consistent**, **and multilingual outreach** was also recommended by many participants to ensure greater awareness of available offers to homeless people:

"...for me the most burning point is that there should be health care for all, and we have to be serious about it. Not only on paper and in theory, but also in the actual design of the services. This means that the services have to be implemented in such a way that people can make use of them even if they have no one to take them by the hand and feed them." (PCP1\_AT)





Respondents also recognised the need for **raising awareness** among healthcare professionals and the homeless people themselves. Some participants stressed that in order for healthcare staff to understand the lives and contextual situations faced by a broad range of homeless people, they would need to be better informed of the facts on homelessness. Some participants mentioned that homeless peers are a resource that could provide motivation and contextual support. One particular participant experiencing homelessness stated the usefulness of specific information that homeless people should be aware of.

"It should be cheap, it should be informative. If you can put it in brochures or information leaflets, it would be cheap. By the way, I also do prevention. I inform other homeless people what to look out for, especially when they are homeless in winter. What the dangers are and what problems they can get into as far as health is concerned." (PEH7\_AT)

Finally, some participants highlighted that care providers should not be too intrusive when approaching homeless individuals but should rather give them more time and information about the issues they were dealing with. Further strategies proposed by respondents involved having homeless people engage in meaningful activities as well as providing **incentives** that were of benefit to them, such as nutritious food packages or public transport tickets so as to motivate participation and inclusion in informational events and continued care services.

"So, you have to come up with a little reward system, I think. It doesn't have to be an insane amount of money, but a small reward system. Two beers or something. You know what I mean? Now, this may be medical bullshit when I tell you this. But if you want to keep them in line, you have to come up with something." (PCP5\_AT)





ID	Location	Age	Gender identity	Ethnicity	Housing circumstances (ETHOS typology)	Existing health conditions
PEH1_ AT	Vienna, Austria	40	Male	Iraqi	8.1. Temporarily with family / friends	Several burns, stress
PEH2_ AT	Vienna, Austria	50	Female	Georgian	8.1. Temporarily with family / friends	Occasional headache
PEH3_ AT	Vienna, Austria	56	Male	Austrian	2.1. Night shelter	Diabetes, leg pain
PEH4_ AT	Vienna, Austria	29	Male	Arabic	8.1. Temporarily with family / friends	Good health
PEH5_ AT	Vienna, Austria	47	Male	Serbian	7.2. Supported accommodation for formerly homeless people	Respiratory/lung problems, smoker
PEH6_ AT	Vienna, Austria	42	Male	Bangladeshi	8.2. No legal (sub)tenancy	Hip pain, smoker
PEH7_ AT	Vienna, Austria	55	Male	Austrian	11.3. Temporary structure	Good health
PEH8_ AT	Vienna, Austria	54	Female	Slovakian	11.3. Temporary structure	Cervical carcinoma

Table 1. Austria Participant Information – People Experiencing Homelessness





ID	Location	Job role
SW1_AT	Vienna, Austria	Social worker
SW2_AT	Vienna, Austria	Social worker
SW3_AT	Vienna, Austria	Social worker
SW4_AT	Vienna, Austria	Social worker
SW5_AT	Vienna, Austria	Support worker
PCP1_AT	Vienna, Austria	General practitioner
PCP2_AT	Vienna, Austria	General practitioner
PCP3_AT	Vienna, Austria	General practitioner
PCP4_AT	Vienna, Austria	General practitioner
PCP5_AT	Vienna, Austria	General practitioner
SCP1_AT	Vienna, Austria	Oncologist

Table 2. Austria Participant Information – Health and Social Care Professionals





# **FINDINGS – GREECE**

A total of 18 participants from Greece were interviewed, with a sample comprising: 10 participants with current or prior experience of homelessness, including one participant currently living with cancer and one participant living beyond cancer; five health professionals including two psychologists, one nurse, one oncologist and one primary care physician; and three social care professionals including one sociologist, one social worker and one member of a patients' cancer association. Further demographic details of the participant sample are provided in Tables 3 and 4.

# Health needs of people experiencing homelessness

It was evident from participants' responses that homelessness is highly multifaceted, and the **health needs of the homeless population are often varied**, and often interwoven with other forms of vulnerability and social exclusion:

"The homeless person without legal documents in the country is different, and the homeless Greek injecting drug user is different. With different, not so much needs, but very different access to the health system."(PSY1\_GR)

"The homeless population is a population that has rather mixed characteristics ... that is, there are some homeless people, homeless people due to economic reasons, there are some homeless people as a result of the use of drugs, dependent homeless people, there are some homeless people of severe mental illness ... they have very ... different health needs." (PSY2\_GR).

In terms of physical health, participants indicated **that hygiene levels among people experiencing homelessness were very poor**, and that this often contributed towards physical ill health. For those living on the street, access to drinking water as well as to clean water for personal hygiene and for washing clothes was limited, and **dermatological issues** were described as common:

"I go to the fountain and wash my hands or face. When I wash my face in the fountain, what exactly is being placed on the skin?" (PEH2\_GR)





"Because of homelessness, what we've noticed is that there are more dermatological problems because they don't have an easy access to bath, to clean themselves, to wash their clothes." (SW1\_GR)

It was also mentioned that people experiencing homelessness may face **orthopaedic problems** due to the strain of carrying their belongings. This was seen to be particularly common among older homeless persons:

"Or for orthopaedic issues that are commonly experienced by the homeless service recipients we see on the street work. Because of their age. When we talk about the homeless population, we are talking about a very large 50- to 80-year-old population." (SW3\_GR)

Many professionals also cited **the poor eating habits of the homeless population**, and the negative impact of diet on physical health. They point out that the lack of access to: (a) healthy food, (b) specific food that they might need for their health condition, and (c) proper number of meals per day. Specifically, it is emphasised that people experiencing homelessness struggle to follow a specific diet based on their health needs as their meals are not consistent, while finding food of good quality is difficult:

"Their eating habits on the street are basically whatever they can get their hands on. So, let's say a diabetic, a heart patient or a cholesterol sufferer. You know homeless and skinny doesn't mean they can't have cholesterol. It's possible that he may not have access to food that is beneficial to his condition."(PSY1\_GR)

"In principle, he is not well nourished. It's about the hygiene issue, the nutrition issue. When someone doesn't eat consistently, he may not eat for two days, this causes some other kind of problems in his digestive system too." (SW3\_GR)

Similarly, it was explained that in many cases people experiencing homelessness **struggle to take prescribed medications** due to their living conditions (e.g., lack of access to a fridge). This issue was often described as being compounded by professionals who are not aware of the realities of living on the street:

"I was going to have a test to look at the pacemaker and he asked me to do a test and that's when I found out I have a blood sugar of 2.35. They gave me some medication which had to be in the fridge. Very basic. And I had to stop them ... You





see, it was an insulin substitute and that needed to be refrigerated. When you don't necessarily have it, you stop it. So now I'm on the pills ... You can't keep the drug out of the fridge. Basic problem." (PEH5\_GR)

Finally, and from the perspective of health and social care professionals, people experiencing homelessness often showed little regard for and neglected their health, and are instead **focused on meeting more immediate needs** (for example, accessing shelter):

"Look, the fact that they stay on the street has of course frustrated them, discouraged them from many issues, you see they are more distanced from society itself." (SW3\_GR)

# **Barriers to accessing healthcare**

One of the main barriers to accessing the healthcare system identified by participants was that many people experiencing homelessness do not have a full understanding of their rights, or where and whom they may approach to access help and support. Crucial barriers are identified through the interviews are: (a) **a lack of knowledge** concerning cancer because prevention policies are weak, which also leads to lack of health-protective behaviours, (b) a **lack of immediate and timely access** to the health care system when someone experiences symptoms, and (c) **a lack of understanding of health problems** and their consequences:

"That is to say, even what he is entitled to, he does not know in order to claim it. So, what is it? Knowledge is power. That is, to let people from below know that by doing preventive exams, we will be here to help you do them, so that they can work, otherwise just wishful thinking, it doesn't work." (SW2\_GR)

"Prevention is a big gamble because homeless people cannot be easily linked to prevention, and this is a problem for both the homeless and the state." (SCP1\_GR)

"It's not easy. And it's not easy for the simple reason. You approach him. He believes in you and follows you. How can he get treatment when he has no shelter or money? After all, cancer drugs after so many years and so many discoveries, the price hasn't gone down." (PEH7\_GR)





A significant issue raised by participants was **the lack of legal documents and/or insurance** among people experiencing homelessness and particularly migrant populations, which automatically leads to the inability to access the healthcare system. Even where access to healthcare was available, homeless patients were often unable to cover the high cost of medicines:

"A big problem is that those who are immigrants do not have papers, because those who have a social security number are at least entitled to health care in the public system." (SW2\_GR)

"I don't know how to put it but it's very difficult. It doesn't help my health. For example, when I was in the park one time, I had a seizure, and I couldn't go to the hospital because I didn't have an AMKA number (social security number) ... people came and took me to the hospital, but they wouldn't admit me." (PEH4\_GR).

"I say I have the social security number ... 'No, bring me your health book'. As soon as they see you're uninsured, they say 'no, we're not looking at you'. And I had an appointment, but [they said] 'I'm not gonna do anything to you because you don't have insurance'." (PEH4\_GR)

Linked to this, several participants emphasized the difficulties **in keeping documents and medication safe**. Participants explained that medication and documents are frequently stolen, meaning vital medical information is lost:

"You're on the road. Where do you keep the medicine? It's no secret, people who live on the street often lose their stuff, have it stolen. ..... There is a technical issue, could each hospital have storage areas?" (SW3\_GR)

"You've got your papers on you, for your homelessness, the necessary welfare documents, and suddenly you get robbed. And you lose everything. A lot of times you have your medication, and they take that away too." (PEH6\_GR)

Participants also highlighted issues relating to **time delays in booking healthcare appointments**, an issue which has escalated during the COVID-19 pandemic causing serious disruptions been really threatening during the COVID-19 pandemic which can have a serious impact on a patients' situation:





"That is to say, it is unthinkable, especially at this time, that someone is to be operated on and the operations are not done because the clinics have changed to covid. And I said that this, the state mechanism will pay for it much more dearly when that patient knocks on the hospital door with an advanced cancer." (SW2\_GR)

"Many months go by that my condition remains the same. I am not being seen. And when the time comes to do the fourth test, because I feel that my condition is getting worse, I will be told to do the other three tests all over again." (PEH3\_GR)

The **poor mental health of people experiencing homelessness**, compounded by their experiences on the street, was also seen to create a barrier for engaging with healthcare. Indeed, it was suggested that when living on the streets, homeless people were more likely to 'accept' their poor health rather than take steps to improve it:

"Once you're exposed to the elements, whether rain, sun, cold ... willingly or unwillingly, you accept it." (PEH5\_GR)

Another problem noted by participants was **language barriers** among homeless asylum seekers, refugees, and migrants, which was often described as leading to miscommunication and misunderstanding. Interpreters at public hospitals were described as almost "non-existent" and in the few cases that translation was provided in public hospitals, only specific languages were available:

"As with language, we now have many refugees, immigrants. For refugees, sometimes Farsi, Arabic I will find. There are also immigrants who speak other languages. Romanian, Polish. They are not immigrants, they are in the EU some of these countries, they don't have access because of language." (SW3\_GR)

Across the interviews, a major barrier to accessing healthcare services mentioned were the **poor attitudes** of health professionals towards people experiencing homelessness. It was noted, for example, that many people experiencing homelessness were refused the attention of treatment from services because of their appearance and/or smell. The expectation of a dismissive reaction by health services often deterred homeless participants from attending appointments, who emphasised the importance of their **dignity**:





"When I have to go to an appointment at the IKA (service that offers free medical appointments), is it a bathing day? Am I okay? I'm not, I get on a bus because I can't walk long distances anymore and all of a sudden, I have a two-metre gap where I'm standing, and I pretend I don't understand, and people pretend they don't understand." (PEH2\_GR)

"The truth is, when you're out there, you don't live decently. Just the disparaging look that other people give you is enough and if you have pride, it is even worse of a feeling." (PEH5\_GR)

In addition, participants explained that on many occasions people experiencing homelessness are refused access to health services unless **accompanied by someone else**. As a result, staff of relevant organisations often need to attend appointments with their beneficiaries in order to achieve an outcome:

"The other barrier was often the difficulties that different health structures might bring in saying he's on his own we can't care for him, he needs to have an assistant ... the facilities often times would take issue because he is dirty, and somebody has to take care of him. There were difficulties ... I saw a general ignorance." (PCP1\_GR)

## Facilitators to accessing healthcare

Participants consistently explained that **mediation by social care organisations** (NGOs working with homeless people) is crucial in being able to access healthcare, both in terms of facilitating the booking of appointments for mainstream services (e.g., public hospitals), but also through the provision of medical services in the organisations themselves:

"[Name of organisation] has helped me a lot. They mediated between me and the hospital and ensured that the doctor in charge of my case would call me whenever I needed a check-up." (PEH6\_GR)

In particular, participants emphasised the importance of the **positive and trusting relationships** that are built over time between people experiencing homelessness and social care professionals:





"There was this social worker ... I kept her, only her, I sent away all the others who came. She came and found me at my spot, but instead of canned food or bread or food she left a thermometer, painkillers and Niflamol for my teeth. She listened to me. It was not about what she gave me, but that she listened to me. She said, 'If I can't make it today, I'll come tomorrow with the food route'. She didn't show up, like she said she wouldn't, but the next day she came in her own car." (PEH2\_GR)

"I think the best way is to create a relationship of trust with these people. We can accomplish this through our continuous presence either in the streets or at our offices, as much as we can." (N1\_GR)

Homeless participants also explained that **being accompanied to healthcare services**, and supporting them both psychologically and practically, was highly beneficial and was seen to ensure the best possible outcome in terms of diagnosis and treatment. Notably, for people experiencing homelessness who do not speak the national language, the need of translators/cultural mediators was emphasised:

"Even if the appointment has been booked, it's still a process of getting there, feeling up to it etc. And they know this here, I have said it to them, "guys, inject me with a dose of confidence!" ... If my spirits are up when I go, I'll talk more. So, both me and the doctor will gain from this. The more they know, the more they'll understand and will be more likely to offer me the right treatment." (PEH2\_GR)

"They should be accompanied when going for check-ups. It lifts their spirits." (PEH6\_GR)

The importance of **appropriate and informal lines of communication** to deliver information around healthcare was also emphasised. For example, it was felt that having **conversations with other people experiencing homelessness** was particularly beneficial since they tend to use the same language ('slang') and are more likely to trust someone with whom they have a shared experience:

"Someone who has lived like this knows how a homeless person feels. Not that you are not capable of understanding, but you haven't experienced it. So, you can't know what kind of steps you need to take and when." (PEH7\_GR)





"Our best practice was exactly this, having a person who belongs or used to belong to these groups. This way, we could approach people more easily. It is fundamental for them to feel that a person is like them, understands them, or "speaks their language", their slang. This makes communicating with them much easier." (N1\_GR)

Social care workers emphasised the importance of **flexibility** and suggested that in order to encourage their homeless clients to attend a check-up or be examined by primary care physician, they **avoid fixed appointments** and instead operate in a way that allows people experiencing homelessness to present themselves at any time and receive an on-the-spot appointment:

"I don't book them appointments, I just tell them, 'Come, you know where the medical offices are, come and a doctor will see you'. And when they do, we try to see them immediately, we have notified the doctors. If I book them an appointment, I might lose them, they might not show up." (SW3\_GR)

Finally, a facilitator mostly mentioned by homeless participants was the forming of a positive and trusting relationship with the doctor providing treatment. One participant, a cancer patient, described his appreciation towards his doctor and how he communicated directly with him regarding upcoming appointments and treatment issues. In doing so, he felt that the doctor cared about his wellbeing and was trying to offer him the best treatment possible within the healthcare system:

"[the Doctor] has helped me a lot. They mediated between me and the public hospital. And the doctor in charge of my case calls me whenever it's time for my check-up." (PEH6\_GR)

# Experiences and understanding of cancer prevention and treatment

Participants felt there was an overall **lack of cancer prevention activities** taking place with the homeless population, and did not know of any relevant campaigns or activities:





"No, I have never been informed about cancer prevention. I don't know how to prevent it. If I get checked up, then I might be able to see if I have it or not." (PEH1\_GR)

"Look, I haven't seen that many campaigns, I am not aware of something like this taking place for homeless people. Overall, there are actions for breast cancer prevention, now and then, but as far as this specific population group is concerned, I haven't noticed anything regarding cancer." (SW1\_GR)

Responses indicated there is an **overall lack of knowledge** of cancer prevention and symptoms among people experiencing homelessness, and where participants did share their understanding, this was generally relatively vague and based on personal experiences, or internet searches:

"No, I am not aware of anything about cancer prevention, I'm not even informed on its symptoms." (PEH4\_GR)

"Look, overall, they say prevention saves lives. Apart from that, I have no general knowledge on the topic because I never bothered, or it did not concern me until now. It is good to be aware of these things. It is even harder if you don't have access to any of this. I just think information is the most important thing from start to finish." (PEH5\_GR)

"No, no I have never been informed by someone about cancer prevention. I get my information from Google. They have some articles there and I sit and read them. Not just about cancer, about other things as well." (PEH2\_GR)

Participants explained that **preventive check-ups for cancer do not constitute a priority** for people experiencing homelessness, when compared with meeting other more immediate needs such as accessing accommodation, food, work, and clothing. It was also emphasised that people experiencing homelessness may not prioritise preventive examinations or even attend appointments following cancer diagnosis due to their poor mental health, particularly when living on the street:

"When you can't even afford a bagel, you can't get tested for cancer or for any other disease. When you have nothing to eat, do you think you go to get medical check-ups?" (PEH7\_GR)





"If a person lives in the street and doesn't have access to basic things, obvious things like toilet facilities, water, security, I doubt they will bother with preventive medicine." (PSY1\_GR)

"If a homeless person remains helpless and unsupported for over a month, they then start to feel depressed. Depression means apathy, closing ourselves up." (PEH7\_GR)

From the perspective of health professionals, the lack of preventative care meant that **cancer diagnosis often occurred by chance and when cancer was already advanced**, and was only detected because of a specific intervention performed by specialist healthcare organisations and specialists who work with people experiencing homelessness:

"Usually, diagnosis is circumstantial. For instance, if I want to wash my clothes and take a shower, I will go to the day centre, where the social worker will tell me: 'you know, we have a doctor here, if you need anything'. And I'll think about how I've recently been vomiting or something like that. I'll go see the doctor, a general practitioner who provides primary care services. If a person has been coughing incessantly for a while, has turned yellow or whatever, the doctor will start with a referral for further examination to a hospital or to a person specialising in lab work etc. So, at this stage, this is how a diagnosis takes place." (PSY1\_GR)

"We rarely see mobile health units or teams in the street, offering cancer-related services. ... The patient needs to go to a medical centre, a medical office, somewhere to gradually put them in line. Which is why it is usually too late when we find out these people have cancer, or some form of cancer." (SW2\_GR)

"So, by the time a homeless woman gets an indication that she has breast cancer, it must have already spread, because, as you know, it does not cause pain. This is why prevention is essential when it comes to cancer." (SCP1\_GR)

In the delivery of cancer treatment, participants emphasised the need for additional **psychological/moral support** for homeless patients from health and social care professionals, (this was one of the most consistent themes concerning health care needs of those experiencing cancer). In addition, it seems very important ensuring





patients have access to **safe housing and facilities where they can manage their treatment** (e.g., access to fridge to store medicine, running water):

"Usually, people who have cancer also need psychological support. It depends on where it (the cancer) has hit you." (PEH6\_GR)

"When entering a treatment cycle, we need something more, we need to have transport, because this is not always provided by the support system. In addition to transport, it is necessary to have a person, a healthcare professional who can check up on the progress of the treatment cycle. A person undergoing these treatments, these chemotherapies, definitely needs to be monitored at home too, because the treatments cause various symptoms, due to the medication. So, there is need for someone to later monitor these people, a medical scientist, to check up on them, to see if they are okay; to see what's going on, what they have been given." (N1\_GR)

"Because cancer alone is a tough journey with painful treatment. You can't undergo chemotherapy and be homeless, searching for a place to spend the night. This is why we, from the homeless shelter, try to find beds at least for people in treatment. The issue is that we don't always succeed. There are many cases where people have nowhere to stay and most times these are lonely people without a family." (SW2\_GR)

On this issue, one healthcare professional recalled a specific case where they felt the positive outcome for the homeless cancer patient was directly associated with the presence of a **strong support network of professionals and particularly peers** (other people experiencing homelessness):

"Yes, I can think of a homeless patient with cancer. Her treatment was successful and now she is in a very good condition. She had the support and care of the community she belongs to, during the process of cancer diagnosis and treatment." (PSY2\_GR)

Professionals also provided examples where **additional support and resources were already being provided to homeless patients.** In one public hospital, homeless patients undergoing cancer treatment are offered the option of staying at the hospital during their therapy. In addition, homelessness organisations often work as mediators to ensure that homeless patients transition directly into accommodation post-treatment.





"We at the public hospital have the option of admitting homeless patients, until they complete their treatment, and their critical days are behind them. We can keep them for 8 days in order to ensure that anything that could occur outside will occur inside, in a controlled environment. This is a success story however, because in other cases, these people might not be able to get any kind of treatment." (SCP1\_GR)

# Considerations for programme intervention

All participants responded positively to the aims of the CANCERLESS programme and felt the intervention to be necessary given the lack of cancer prevention among the homeless population at present. Many made suggestions of how we can ensure the effectiveness of the intervention as described below.

Participants suggested involving a **multi-disciplinary team** consisting of a combination of health professionals, psycho-social care professionals and peers (e.g., people with lived experience). It was generally felt that communication between professionals and people experiencing homelessness should be **long-term**, **direct**, **and frequent** to ensure continued engagement, and that the same professionals should be involved over the full span of the intervention in order to develop trusting relationships:

"I think the best thing is, to create that relationship of trust with these people, is our constant presence [...], the consistency that we can have, whether in the doctor's office or on the street, and approach them with the kindness that you approach everyone."(N1\_GR)

In terms of the content of the intervention, several participants suggested that the intervention should focus on **education and information sharing** around (a) the need to prevent cancer, and (b) how to identify possible cancer symptoms. As homeless people often do not know where to access information or help concerning disease prevention, it was also felt that a central aspect of the intervention should be **signposting to relevant services**. On this point, it was explained that using simple language to explain key information and providing accessible/translated materials would help to ensure engagement.

Several participants felt strongly that access to preventative examinations needs to be guaranteed. To facilitate this, it was felt that examinations could be conducted either in




the clinics of homelessness organisations, or in partnership with public hospitals/health centres. However, in order to achieve this sort of direct linkage to hospitals, it was recognised that strong and structured **collaboration** would be needed between health and social care services.

The number one thing to keep in mind is to inform this population what cancer is. The point is to get them into the process of thinking, that when I see something strange in my body, I have to go to the doctor. So, in developing a model, first you inform them and then you find the way to connect them with health services." (SW3\_GR)

Participants also felt that it was important to offer a **holistic approach**, by supporting homeless patients not only at the point of prevention but also during ongoing treatment, and by **considering the individual support needs and cultural background** of each person and working with them in an appropriate way:

"Homeless people do not have a supportive environment. So yes, the model definitely has to fit into that somehow. In the sense of proving further support during cancer treatment. If we need to enter a cycle of therapies, transportation to and from the hospital need to be ensured. Then, there must be a health professional, who can control what happens after the treatment. A follow-up is needed after the patient return back home." (SW1\_GR)

Finally, it was explained that work would need to be done to ensure a more flexible healthcare system, whereby homeless patients are able to avoid unnecessary **bureaucratic barriers** (e.g., lack of legal documentation) and where there is flexibility in terms of appointment times and locations.





ID	Location	Age	Gender identity	Ethnicity/ Country of origin	Housing circumstances (ETHOS typology)	Existing health conditions
PEH1_ GR	Athens, Greece	56	Male	Pakistani	11.2 Non- conventional building / 13.1 Highest national norm of overcrowding	Hepatitis C, Psoriasis, cirrhosis of the liver, ophthalmological and orthopaedic problems
PEH2_ GR	Athens, Greece	56	Male	Greek	1.1 Public space or external space	Regurgitation, gastritis, gallstones in the gallbladder
PEH3_ GR	Athens, Greece	32	Female	Congolese (DRC)	11.2 Non- conventional building	Menstrual cycle abnormalities, uterine cancer under investigation
PEH4_ GR	Athens, Greece	49	Female	Congolese (DRC)	8.1 Temporarily with family/friends	Cardiac Blood Pressure, gastritis
PEH5_ GR	Piraeus, Greece	61	Male	Greek	1.1 Public space or external space	Diabetes, Cardiological issues
PEH6_ GR	Piraeus, Greece	58	Male	Greek	3.2 Temporary accommodation	Current cancer patient (skin cancer)
PEH7_ GR	Athens, Greece	71	Female	Greek	3.2 Temporary accommodation	Asthma





PEH8_ GR	Piraeus, Greece	62	Female	Finnish	11.2 Non- conventional building	Current cancer patient (oesophageal cancer); recovered from anal cancer, problem in the spinal column
PEH9_ GR	Athens, Greece	57	Male	Iranian	1.1 Public space or external space	Mental health issues (Depression)
PEH10 _GR	Athens, Greece	60	Male	Greek	3.1 Homeless hostel	Healthy

Table 3. Greece Participant Information – People Experiencing Homelessness

ID	Location	Job role
PSY1_GR	Athens, Greece	Psychiatrist for children and adolescents
SW1_GR	Athens, Greece	Sociologist
N1_GR	Athens, Greece	Nurse
SW2_GR	Athens, Greece	Patients' Organization Professional
PSY2_GR	Athens, Greece	Psychiatrist
SW3_GR	Athens, Greece	Social Worker
SCP1_GR	Athens, Greece	Oncologist
PCP1_GR	Athens, Greece	Primary Care Practitioner

Table 4. Greece Participant Information – Health and Social Care Professionals





## **FINDINGS – SPAIN**

A total of 17 participants participated in the interviews, with a sample comprised of: eleven people with experience of homelessness, including three current cancer patients with an active oncological diagnosis cancer and one person living beyond cancer, and six health and social care professionals including two social workers, two primary care physicians and two nurses. All homeless participants and social care professionals were recruited through a single homelessness organisation, of which they were either clients or direct employees, while health professionals were recruited directly through relevant healthcare providers. Tables 5 and 6 provide further detail of the participant sample.

## Health needs of people experiencing homelessness

The overall health of the people experiencing homelessness was generally described as poor, with a high prevalence of varied support and treatment needs, both in relation to their physical and mental health. People who participated described how homelessness both leads to new health issues, and also how it magnifies existing problems.

Regarding physical health, participants indicated that there was an increased risk of developing poor health as a consequence of their living conditions. Some of the main health problems that participants specified, for example, were linked to the impact of having inadequate food, poor levels of hygiene and a lack of place to sleep:

"It has happened to me, for example when I got sick I had very deep wounds with pus and other things, and I did not go to the hospital to heal because having to go there and return to where you are living was very complicated." (PEH1\_ES)

"Homelessness has a very strong, very strong impact and not only at physical level to be able to take care of yourself, to be able to take care of your diet." (PEH2\_ES)

"It's very hard not to have a place to live ... People who live on the street can catch a lot more diseases, you know, due to not having good health, due to not having a clean home." (PEH3\_ES)





Health and support workers consistently referenced the high prevalence of cardiovascular and liver diseases and other chronic conditions, again relating these to lack of hygiene and adequate nutrition:

"People who have problems with alcohol and heart diseases usually come here to the centre. There are a lot of liver diseases, poorly controlled diabetes and associated problems such as amputations and vision loss." (PEH5\_ES)

"The street or, in this case, being homeless generates that any type of disease you have can become chronic and that is very hard. You can be cold, catch a simple pneumonia and make it chronic ... you will always have health problems." (SW1\_ES)

"I think there's no way to have health if you don't have a home and can't access to your minimum basic needs that are nutrition, hygiene ... Right now, that we have a pandemic ... so, the health of these people has to be forcibly deteriorated." (PCP1\_ES)

"In the neighbourhood where I work there are many cardiovascular diseases, oncological ... and these patients differ a little from other diseases or imported infections that they may have or sometimes we see some drugs problem in a patient." (PCP2\_ES)

With regards to mental ill health, participants noted a wide variety of conditions as being common in the homeless population. Generally, mental health conditions were described as developing because of the poor living circumstances associated with homelessness (for example, depression, acute loneliness, and social isolation) and were often also interwoven with harmful substance use and addictive disorders.

"I think it is very important that a person has balance in his life, if you have your house with your comforts in comparison to a person who lives on the street ... People who are homeless can more easily end up in alcoholism or drug addiction than people who have a home" (PEH7\_ES)

"With mental health then ... many of the patients are schizophrenic. Homeless people use drugs like heroin, marijuana, cocaine." (PCP1\_ES)

"The first need they have from the point of view of health I would say is mental health due to two things, either because it is the mental health problem that has





made them be on the street, or because the fact of being on the street is a situation that is reached after going through many phases of uncertainty and poverty." (PCP2\_ES)

From the perspective of health and social care workers, this meant that many of their homeless clients required additional levels of emotional support:

"Homeless people fundamentally need a lot of emotional support ... they are people who are very lonely and very deteriorated because they have no way to take care of themselves ... when they are sick with cancer, I think the situation is aggravated because classic treatments produce many side effects and even if a person who has support and means finds it difficult to manage this" (N1\_ES)

In terms of health management, participants indicated that there was a tendency to **neglect health needs** due to the prioritisation of their more immediate needs (for example, accessing food, finding a place to spend the night). This tendency to overlook health translated into an overall lack of self-care:

"The priorities of a person living in a house can be taking care of themselves, going to the doctor ... but when you are living on the street your priority is to eat something and not having your belongings stolen, if you are not on the street, you don't know it, but I think that's the main thing." (PEH3\_ES)

"Being healthy is not a priority for people living on the street and that should also be part of the study ... the priority for homeless people is the home, not health." (PEH6\_ES)

"Homeless people worry about their health when they are already very sick and have to go to the hospital, but normally they worry more about drugs, food ... their priorities are very different from the rest of the people who are inside the system." (N2\_ES)

#### **Barriers to accessing healthcare**

Both homeless participants and health and social care professionals described how one of the biggest issues in accessing medical care is the presence of **social stigma**. Lack of access to adequate hygiene, for example, was often described as causing







embarrassment that prevented people experiencing homelessness from attending health services for fear that they would be judged based on their appearance or treated as less deserving members of society. The prevalence of stigmatised attitudes among health professionals was described as heavily dissuading people experiencing homeless people to attend services when needed:

"The hospital is going to see you, you are going to smell, you are not suitable, and you are embarrassed ... you feel ashamed to look like this when you have to be taken care of." (PEH9\_ES)

"The main barrier is unfortunately created by us, the people who are homeless, because it is very shameful to say that I have no home." (PEH11\_ES)

"On the two occasions in which I have treated them, they came in embarrassed, they tried to come as clean as possible, without attracting attention, they were hesitant and had the feeling that no one knew the situation in which they found themselves." (PCP2\_ES)

Another barrier that participants mentioned related to a **general lack of healthcare resources**, which has been further exacerbated by the impact of the COVID-19 pandemic on the healthcare system. Participants repeatedly spoke about the waiting times they faced in attempting to confirm appointments and in generally accessing the services they needed:

"Now I'm waiting for them to call me for a surgery, for a surgery on my chest but with the COVID things they have not called me, I have done all the tests for the operation, but they have not called me yet." (PEH5\_ES)

"So, this day 21, already at the age of 50, I have been waiting for two years in order the Community of Madrid to invite me to have a mammogram, because they no longer do it for the healthcare system, but it is carried by the Community of Madrid, from the age of 50 ... I don't know if it is going to be delays because of COVID but I have received the letter." (PEH7\_ES)

"For example ... a few days ago I was going up the wall, I was hysterical, I was arguing and fighting with everyone over little things, okay? Then I called my doctor and told him, and he told me that he was going to send me to the psychologist, and





they give me the appointment for the psychologist on December 23 and we are at the beginning of September ... it is absurd the time distance between the moment you have the problem and when they attend to you." (PEH10\_ES)

The **lack of flexibility** within healthcare systems was also evident in the **practical barriers** that participants experienced when trying to access healthcare services. This included, for example, being refused access based on a lack of appropriate documentation (health card) and fixed address (evidence of residency):

"If you don't have a registration of residency, you can't have a doctor, that's what I've been told in the healthcare centres." (PEH11\_ES)

"I think it is very important to ensure that the person has a health card or give it or ... the medical document you need to be able to access the medicines and treatments prescribed before leaving the hospital, which is not always done." (N2\_ES)

"The fact of not having an address on their health card makes it impossible for them to access preventive programs or cancer detection and when they finally come for something more serious you do not stop to do prevention ... I try to work with them when I see them, so the health card does not mean a problem for them." (PCP1\_ES)

Alongside difficulties in registering, participants also reported that they often missed notifications or appointment reminders due to a lack of mobile phone:

"Many times, it happens that they say to send the information to the mobile and you do not have a mobile or we send the letter to your house, and you do not have a house, you are on the street." (PEH8\_ES)

The fragmented nature of services was also identified as a key barrier to accessing health care in a timely manner. The need to attend various appointments or resources located in different settings and centres in order to receive care was considered incompatible with the chaotic lifestyles of the homeless. As a result, health and support professionals highlighted the **difficulty in maintaining homeless people's engagement with the health system**, and the difficulties they faced in following up with patients and encouraging patients to keep to scheduled appointments:







"We as family doctors are used to a quota of patients at the time of follow-up, and a homeless person is seen as "uncomfortable" for us, I have to say in this way because we will not be able to have a follow-up and there may be difficulties in the coordination with social workers, first because not always in a healthcare centre there is one, or because you have to refer him to a place and you don't know if that person is going to attend for any reason." (PCP2\_ES)

"The main issue is the lack of follow-up; this affects two points. One, chronic diseases that need a continuous monitoring and if you do not have a home, you do not have access to something as simple as for example a prescription and that these people, if they do not have a home, disappear from the system and no one is aware of them. And the other issue is that we take longer to diagnose things, because these people don't come when they are directly unwell, but always endure more." (N2\_ES)

#### Facilitators to accessing healthcare

Although the majority of the homeless participants' experiences of accessing health services were challenging and at times described in negative terms, several also highlighted positive instances whereby **health professionals had helped them to participate more actively** in their health care:

"In communication, they have been very clear with me from the beginning, they care about telling me everything I have, everything that happens to me and truthfully ... I don't have any problem with that." (PEH3\_ES)

"The doctors and social workers informed me of everything... yes, exactly and a very direct attention ... they came to visit me every day in the room, the nurses who took care of me worked very hard." (PEH6\_ES)

"For me, all was very positive both with the doctors and the nurses ... they informed me of everything I needed, anything I needed, and they explained all the tests that ... they were doing to me." (PEH10\_ES)





As these extracts indicate, homeless participants emphasised the importance of information being shared with them in a way that was clear to understand, suggesting the value of using **appropriate and tailored forms of communication**.

# Experiences and understanding of cancer prevention and treatment

Participants characterised their **understanding of cancer as very limited** and indicated that this knowledge was usually based on personal experiences, or experiences of family members or other users of the centre where they were located. Many of the patients felt unable to identify cancer symptoms and had only some understanding about how to prevent cancer. Indeed, participants generally referred to the symptoms that are most clearly visible and that perhaps most widely recognised in society (for example, weight loss and hair loss):

"Besides the depression, hair loss and weight loss, I don't know any other symptoms that people who have cancer can suffer." (PEH6\_ES)

"I've seen that more or less some symptoms that people start to lose much weight and other symptoms that people have and that more or less can be observed and detected like hair loss." (PEH8\_ES)

When asked about cancer prevention strategies that they were aware of, homeless participants tended to focus on changes related to their diet. For example, the reduction of foods considered carcinogenic was repeatedly described as a key strategy in preventing cancer. A smaller number of participants also referred to the role of self-examination (for example, checking for lumps) and attending regular healthcare appointments as methods for cancer prevention. However, overall, participants again emphasised that their knowledge was limited:

"Preventing cancer, I do not know this ... it depends on the studies, there are foods that you cannot eat, but I have nothing to say ... I know that there are foods that are carcinogenic, but I do not have a clarity to tell you which ones are, and which ones are not, I know that there are studies saying that some foods can cause cancer." (PEH2\_ES)





"Preventing it, I wouldn't know, I wouldn't. I do know that there are some foods that are more carcinogenic than others ... Now I have learned because of my heart disease, these are the industrial products that are bad for your health and can increase your risk of cancer." (PEH3\_ES)

"I know how to prevent it, my sister found out from her husband because he squeezed a little in her breasts and she complained in one area but not in another, then his husband told her that she would have to go to the doctor to have a breast check and as a result of that they detected it." (PEH8\_ES)

"I believe that food also has a great influence ... excess of alcohol, excess of spicy food and excess of fats, I think that this accentuates the possibility of having cancer a lot." (PEH10\_ES)

With regard to seeking help for cancer symptoms, most of the homeless participants indicated that they would be most likely to attend their healthcare centre and speak directly to their primary care physician so that they could later refer them to specialist clinicians if necessary:

"I would go to the primary care centre, I would go directly to my family doctor, unless it is something very serious or they could not attend to me because any reason, then I would go to the emergency department, but it would have to be something very specific." (PEH2\_ES)

"First of all, I think my first step would be to go to my usual family doctor. Then I would also tell my sister who is the only one I have left from family, tell her, but ... I would go directly to the primary care physician, and he would already advise me or tell me where I have to go." (PEH7\_ES)

From the perspective of the health and social care professionals, cancer prevention activities or programmes tailored to the homeless population are currently non-existent. None of the professionals interviewed (social workers, primary care practitioners and nurses) were aware of cancer-related initiatives with people experiencing homelessness:

"As far as I know, no. I mean, with the patients I work, I do not know any cancer prevention programs and if a person who lives on the street is identified and has





cancer, it is because we have insisted and insisted ... no one has contacted us about any cancer treatment program." (PCP1\_ES)

"No, and I've been thinking about this for a while these days as a result of having read this program that you are doing." (N2\_ES)

In line with this, the vast number of homeless participants indicated that they had never been invited to attend any sort of cancer-related screening or appointment:

"No, not specifically for cancer, no one has told me anything. I haven't received anything." (PEH4\_ES)

No, no, never. I've never received an appointment to see if I have cancer or not. When I went to the doctor, I was not informed that there are cancer tests neither." (PEH8\_ES)

No, never, that's one of the things that I ... no offense, I understand that they are very behind." (PEH10\_ES)

#### **Considerations for programme intervention**

When asked to comment specifically on the implementation of the CANCERLESS Health Navigator programme, participants highlighted a number of different factors to consider. Early detection of cancer was seen to be difficult to achieve due to the chaotic lifestyles of people experiencing homelessness and a general lack of knowledge about symptoms, as noted above:

"Both for homeless people and people with home, I think there's a lack of early detection ... because I have worried then every six months I do a blood test, but every six months or every year we should ensure that all people ... because there are people ... no offense, there are a lot of ignorance." (PEH1\_ES)

"Well, some people are not aware ... so it's very difficult to treat to everyone as in the same boat ... because there are some people who are not aware, they live on the street, but they don't know what is happening ... they are living in that way without thinking and I see that is very difficult." (PEH6\_ES)





As a result, a key point raised by participants was the importance of **raising awareness** through education, and the role of information sharing as a strategy to engage and empower homeless people. Indeed, many homeless participants explained that they would appreciate access to this information, and that this would be an appropriate starting point to engage people with cancer-related care:

"The teaching, because unfortunately ... cancer is still quite a taboo, cancer is not talked about openly ... Many people don't know they have it and think it may be cured." (PEH3\_`eS)

"Information is the key, the most important thing ... I think that is fundamental and more in cancer disease, we are not talking about a flu or other small things." (PEH7\_ES)

Another of the recurring suggestions across the interviews was the need to have **more professionals engaged with and accessible to the homeless population**. Several homeless participants felt, for example, that the programme would benefit from the expertise and involvement of professionals such as psychologists, doctors, and social workers. They explained that being able to access and take advice from these professionals would encourage them to engage with cancer prevention:

"Well, as I've told you ... the help of a psychologist, a social worker, as they are the reference points to help us." (PEH4\_ES)

"It would be nice to have professionals like a psychologist and a doctor who can talk to them and convince them until they agree and do the tests." (PEH9\_ES)

Finally, in discussing the some of the potential obstacles that may be encountered during the intervention of the CANCERLESS Health Navigator programme, health and social care professionals placed particular emphasis on the difficulties associated with **developing consistent communication channels** with people experiencing homelessness and keeping them continually engaged with mainstream healthcare services. They therefore felt there to be a need for a specific and tailored pathway for cancer prevention and treatment:

"Well, I would say that communication is the most important challenge here ... It is the fact of being on the street, trying to approach these people on the street trying







to know or determine what is happening to them, their pathology ... this is complicated and it is very complex because on the street there are many people who do not want to communicate, they just want you to feed them and leave them alone and go away ... then the key and important concept is the communication with the homeless people." (PEH5\_ES)

"The problem is that I don't know if it can be carried out within the current healthcare system, but what is clear is that we need to create a special pathway for this group of people, not with the intention to discriminate them, but to facilitate... Because these patients can have thousands of things at the healthcare centres and hospitals, and if we want them to participate in preventive activities, in this case, related to cancer then we need them to be within the health system." (PCP1\_ES)

"It's probably necessary to create a special pathway because otherwise we will lose these people in the usual healthcare pathway. Or work to facilitate their access to healthcare. This happened during the pandemic, when registries and medical records were opened to patients who were not registered for various reasons." (PCP2\_ES)





ID	Location	Age	Gender identity	Ethnicity	Housing circumstances (ETHOS typology)	Existing health conditions
PEH1_ ES	Madrid, Spain	65	Male	Spanish	3.1. Homeless hostel	Living with cancer - active oncological diagnosis. He has an inguinal hernia and vision problems in his right eye. Former alcoholic and former smoker
PEH2_ ES	Madrid, Spain	56	Male	Spanish	3.1. Homeless hostel	Wheelchair-bound; leg orthosis, diabetic foot.
PEH3_ ES	Madrid, Spain	51	Male	Spanish	3.1. Homeless hostel	Recovered from COVID19; leg pain.
PEH4_ ES	Madrid, Spain	51	Male	Spanish	3.1. Homeless hostel	Severe heart disease, heart surgery, chronic high cholesterol.
PEH5_ ES	Madrid, Spain	50	Female	Bolivian	3.1. Homeless hostel	Living beyond cancer (colon); diabetes.
PEH6_ ES	Madrid, Spain	52	Female	Spanish	3.1. Homeless hostel	Recovering from a fractured tibia and fibula; hypertension; historical substance addiction – currently in relapse.
PEH7_ ES	Madrid, Spain	59	Male	Spanish	3.1. Homeless hostel	Reduced mobility; chronic pain.





PEH8_ ES	Madrid, Spain	49	Female	Moroccan	3.1. Homeless hostel	Living with cancer (breast) - active oncological diagnosis; hypertension, high cholesterol.
PEH9_ ES	Madrid, Spain	61	Male	Senegale se	3.1. Homeless hostel	In recovery from COVID19; respiratory difficulties; high blood pressure.
PEH10 _ES	Madrid, Spain	49	Female	Uruguaya n	3.1. Homeless hostel	On crutches. Thyroid condition; reduced mobility; spinal problems; fibromyalgia.
PEH11 _ES	Madrid, Spain	48	Female	Spanish	3.1. Homeless hostel	Bone metastases; asthma.

Table 5. Spain Participant Information – People Experiencing Homelessness

ID	Location	Job role
SW1_ES	Madrid (Spain)	Social Worker
SW2_ES	Madrid (Spain)	Social Worker
N1_ES	Madrid (Spain)	Nurse
N2_ES	Madrid (Spain)	Nurse
PCP1_ES	Madrid (Spain)	Primary Care Physician
PCP2_ES	Madrid (Spain)	Primary Care Physician

Table 6. Spain Participant Information – Health and social care professionals





# **FINDINGS – UNITED KINGDOM**

A total of 15 participants took part in interviews, with a sample comprising: six people with experience of homelessness, one of whom was a current cancer patient; four health professionals; and five social care professionals (support workers), one of whom also had prior experience of homelessness. The majority of participants were recruited through a single homelessness advice and accommodation service located in the East of England, with a small number of the health professionals recruited through existing professional networks. Further demographic information of the participants is provided in Tables 7 and 8.

### Health needs of people experiencing homelessness

The overall health of people experiencing homelessness was generally described as being very poor, with a **high prevalence of support and treatment needs**, both in relation to physical and mental ill health and also substance and alcohol addiction. Participants repeatedly described how the experience of homelessness had resulted in the development of new health issues, and also exacerbated and intensified pre-existing conditions.

With regard to physical health, participants referenced an extremely wide variety of conditions. From the perspective of health workers, respiratory and cardiovascular illnesses, as well as infectious diseases such as Hepatitis C were particularly over-represented within the homeless population:

"Respiratory issues, vascular issues, trench foot issues ... that's the majority of the people that I see ... A lot of bacterial endocarditis ... and a lot of bacterial neuropathy, from sleeping rough. Things like Hepatitis C, a lot of people have." (N1\_UK)

With regard to mental health, most of the participants who had experience of homelessness reported that they had multiple co-occurring diagnoses. Anxiety, depression, and personality disorders were all noted as being extremely common:





"Mental health, that's huge. People who are homeless, or even people who aren't necessarily homeless, but who come in for support, they have mental health needs, anxiety, depression, PTSD, paranoia." (SW5\_UK)

The prevalence of **harmful substance use and addictive disorders** within the homeless population was also explained to have significant impacts on health and wellbeing:

"If they're injecting, ulcerated legs do come up quite a lot, and they can get infected if they don't go to the doctor. Yeah, addiction, alcoholism, mixing their prescribed medication with alcohol, that's a big thing." (SW2\_UK)

Notably, the physical side-effects of substance use were specifically described as having the potential to mask the symptoms of serious health conditions:

"I wonder whether sometimes they're just 'this is how I feel everyday', and can they actually identify whether 'is it a side effect or an effect of the substance that I'm using, or is it health issue'?" (SW5\_UK)

In terms of the management of health, participants consistently indicated there to be a tendency for **self-neglect** among people experiencing homelessness. This was explained in terms of both a limited understanding of how to care for themselves, but also a tendency to focus on more immediate needs (for example, accessing accommodation, food, or substances):

"I have missed appointments, buried my head in the sand, and with no stability, just wasn't in the mood to address things." (PEH6\_UK)

"Because they are faced with so many other problems in their life, sometimes they don't even realise that there is a problem or even if they do, they don't really realise the need to address that." (PCP1\_UK)

"I think a lot of it comes around the way they're living, they're not learning those skills to take care of themselves. So, they'll have things like skin conditions, UTIs and issues that are brought on by not eating properly." (SW5\_UK)

"They [health issues] are usually left until things have got a lot worse ... So, when we do see chest infections, they are well-established, and when we see wounds, they are well-established, and when we see people with drug and alcohol issues, their addictive behaviours are well-established." (N1\_UK)





#### Barriers to accessing healthcare

The **support needs of people experiencing homelessness** were recognised as a key barrier in access to healthcare. Several participants mentioned they lacked confidence when attending mainstream services, which they described as "overwhelming" and "scary", and subsequently struggled to communicate their needs to professionals:

"I'm not really an outspoken or like a confident person who could be like 'I've got this, I want it sorted now'." (PEH2\_UK)

"Sometimes I've thought ... are they understanding me? Sometimes I've got nervous, my mind goes blank, I get really confused ... it's just really stressful." (PEH4\_UK)

"[I was] frightened to ask for help with anything." (PEH6\_UK)

Several of the support workers also mentioned that the prevalence of **erratic and challenging behaviours** amongst their clients made engagement with mainstream healthcare services extremely difficult, particularly in terms of setting and keeping to appointments:

"Sticking to appointments can be an issue, they turn up when they want to, and with regards to temperament ... it can be quite challenging." (SW1\_UK)

The majority of participants felt that people experiencing homelessness were treated very poorly in comparison to the general public, and **stigmatised and judgemental attitudes** on the part of healthcare professionals were a common source of frustration:

"It was just like a stigma, like you're homeless and it's your own fault. That's what I felt like they thought." (PEH3\_UK)

"They look at them and don't think that they deserve the same treatment as the rest of us." (SW5\_UK)

In particular, it was reported that healthcare professionals often made assumptions regarding the health needs of people experiencing homelessness, specifically in terms presumed substance abuse. The potential that symptoms of serious health conditions were being disregarded by healthcare professionals was raised as a specific concern:





"It's a real second-class citizen system for homeless people ... There's an expectation that the patient is usually more needy and drug seeking. So, every presentation usually comes back to a behaviour or addiction illness as the diagnosis, rather than pursuing it." (N1\_UK)

This prevalence of stigmatised attitudes on the part of healthcare professionals was described as being a major deterrent for accessing mainstream healthcare services, with previous negative experiences often serving to dissuade people experiencing homelessness from seeking care:

"They feel like they're going to be judged and not get the same service that 'joe public' would get ... and that puts them off from going and seeking help." (SW1\_UK)

"They say 'oh they just judge me and then what's the point, they don't help me because I take drugs so what's the point, they don't help me because I'm homeless so what's the point?" (N3\_UK)

The **fragmented and inflexible nature of services** was identified as a key barrier to accessing healthcare. The need, for example, to attend multiple appointments and locations in order to receive treatment was viewed as incompatible with the chaotic lifestyles of people experiences homelessness. As such, there was very little by way of continuity in care:

"Taking bloods doesn't happen in local practices anymore, so if a person presents with symptoms, they'd be given a form and told to go somewhere else ... and that's done, their engagement is then finished, 'cos there will be something much more important to do." (N1\_UK)

"Let's say I've seen somebody with a chronic cough that a support worker identified and has brought the patient to me ... I have examined the patient and I think there might be something going on and I start the process of investigation, maybe ask for a chest x-ray or some blood tests and ask them to come back. But after that initial visit, they never come back. So even if we are identifying them ... they have been lost to follow up." (PCP1\_UK)

Mainstream healthcare services were seen as having an extremely **low level of tolerance** towards missed appointments and other forms of 'non-standard' behaviour (for





example, use of particular language). In some cases, this had resulted in patients being excluded from services or facing an extended wait for care:

"Rather than saying 'I've been waiting two hours', they say 'I've been waiting two fucking hours' and that's then classed as verbal aggression and then they're removed for the sake of a little bit of street vernacular." (N1\_UK)

"They miss the call, and they get put to the back of the queue and they have to start the whole process again. Some people have severe mental health issues and drug addiction, and when the phone rings, they forget about it you know." (SW2\_UK)

The lack of flexibility in current healthcare systems was also apparent in the **practical** and **bureaucratic barriers** participants had experienced in attempting to accessing services. This included examples of being turned away by doctor's surgeries due to a lack of identification, struggling to make appointments without use of phone or email, and facing difficulties in retrieving prescription medicines without a fixed address.

"So, when I was street homeless, when I did try and get into a doctor's, they said I needed some sort of identification ... the doctors wouldn't do anything about it because got no form of ID. That's one of the struggles that I had." (PEH2\_UK)

Finally, participants consistently mentioned an **overall lack of healthcare resources** in the local area, and that this had been exacerbated further by the COVID-19 pandemic. Participants regularly spoke of the difficulties they faced in making appointments, and the long waiting lists for referral into services:

"You ring the doctors and you're like 21st in the call queue, trying to get a bloody appointment is just unreal." (PEH5\_UK)

"I'm still waiting, I've actually been referred a couple times now, recently just a couple weeks ago, I've been referred to see a specialist, but just haven't heard one thing back from them. No letters, no phone calls." (PEH1\_UK)

On this point, the lack of mental health and substance-related services was noted as being particularly problematic. Indeed, several support workers explained that without being able to access to this sort of intensive/emergency provision, encouraging their clients to engage with preventative care would be near impossible:





"There's hardly anything for mental health about in town at the moment. For people who need care, people who need to be somewhere, stay somewhere residential, there's nowhere. There used to be units and places that people could get that help." (SW4\_UK)

#### Facilitators to accessing healthcare

While experiences with healthcare professionals were generally described in negative terms, a small number of participants described how having a **positive relationship with a specific healthcare professional** had facilitated their engagement into regular healthcare. One participant explained that he felt confident in managing his health because of the trusted relationship he had built with a doctor at his local surgery:

"He always rings me back because he knows that I struggle. I would always speak to [name of doctor] ... He listens to everything that I say ... he always makes time for me, always. Doesn't matter how busy he is, he always makes time for me." (PEH3\_UK)

This need for **familiarity and continuity** was a consistent theme within the interviews, with participants regularly explaining that they preferred to receive care and support in settings and with professionals known to them, and who they felt that they could trust. A specialist nurse attended the service where interviews were conducted at least once weekly, and this in particular was valued by participants:

"Having it somewhere like this, knowing there's someone there in the back of my mind, so if I did have a worry, rather than being pressured to actually going to a hospital or to a doctor, I could go there." (PEH2\_UK)

"The service was there, and they offer it to you ... you don't have to go looking." (PEH5\_UK)

"I think me being at [name of service] and building a rapport with everyone who comes through the door and having a familiar face, friendly face, I think that helps ... because they do come to me for anything, even if they've split up with a partner, they'll come and like it's a shoulder to cry on, someone to talk to, someone that's not going to be judgmental, and someone that will just listen to them." (N2\_UK)





Receiving **encouragement and reassurance from trusted professionals** was also noted as a way to ensure engagement with healthcare. Several support workers explained that their clients were more likely to attend mainstream services if they themselves facilitated this:

"I've found if you go with them, if you agree to meet them or for them to come here to the centre, and we go from here to that appointment, that tends to happen then, it's just that little bit of a nudge that they need sometimes ... We've got one young lady, she's terrified of the doctor, and she just wants you there, she'll say, 'please hold my hand' and then she'll talk to the doctor because you're with her ... I know how to talk to them to encourage them to tell the doctor the symptoms." (SW5\_UK)

"At [name of homelessness organisation], the staff being so down to earth made me want to address my issues and problems." (PEH6\_UK)

Several participants also emphasised the value of adopting a more **personalised approach to care** in order to meet the needs of people experiencing homelessness. For example, one nurse explained how he tailored his language, appearance, and style of care to ensure engagement with homeless patients:

"I have no problem throwing the odd swear word into my dialogue with my patient if it's appropriate. When I talk to drug and alcohol users, I always use the street terminology ... and I dress like this for a reason, I think uniforms are a barrier ... if I'm wearing a uniform people won't engage." (N1\_UK)

# Experiences and understanding of cancer prevention and treatment

Health professionals aside, almost all participants characterised their knowledge and **understanding of cancer as very limited** and generally based only on the personal experiences of family or friends. Many participants expressed concern that they would not be able to identify symptoms either in themselves or others:

"I don't think I would have a clue how to spot the symptoms. There's no wrong or right way that we've been taught, and we need to be aware, but none of us have got that knowledge of it." (PEH5\_UK)





"I wouldn't say I am any more qualified or in the know than your average person, really. I haven't had any training or anything, although I have had personal experiences." (SW4\_UK)

When asked about where they would seek help if they identified a possible symptom of cancer, almost all participants indicated that a local doctor would be the first place they would attend. However, given the prevalence of long waiting times, a smaller number of participants also noted that they would also consider attending the Emergency Department at hospital. From the health worker perspective, however, **cancer was not being identified at the primary care level**, and was more commonly diagnosed when homeless patients were already in hospital or by alternative healthcare provision (e.g., drug specialist care):

"I think they came [to our department] from another hospital transfer, so maybe via A&E. And I think things can get to the point where they have to present at A&E." (N3\_UK)

"There's a lot of people who have those issues, but they're picked up very quickly, very well via drug services, who refer into hospitals" (N1\_UK)

From the perspective of the healthcare professionals, **tailored cancer prevention activities** (for example, screening) among the homeless population were described as being effectively non-existent:

"Interviewer: How would you characterise current approaches to cancer prevention for people who are homeless?

Participant: I would say it's completely ignored." (N1\_UK)

Indeed, almost none of the homeless participants could recall being invited to or attending a cancer-related appointment or screening. One participant, a female, did speak specifically about attending a cancer screening after identifying a potential symptom. However, she described how a lack of follow-up by health professionals after the appointment had left her feeling worried:

"I had to go for a screening myself because I had a lump in the middle of my chest, I've still got it now, but they don't know what it is [Interviewer: So, do you know what





happens next?], no, I'm just basically you know left in the lurch at the moment." (PEH5\_UK)

This perceived **lack of care** was also apparent in the account of the one participant who was a current cancer patient. He explained, for example, how he had received very limited support at the point of cancer diagnosis:

"At the hospital, the doctor came in, he was very rude ... halfway through the conversation his phone rang, and he never returned." (PEH6\_UK)

Finally, and in terms of direct experiences of cancer treatment, a clinical nurse specialising in oncology explained how the **lifestyles of people experiencing homelessness** made delivering often very intrusive treatment extremely challenging. As above, this related specifically to difficulties in maintaining appointments but also a lack of secure accommodation to recover from treatment and store medication. Subsequently, she explained that outcomes among people experiencing homelessness were at times less positive than in the general population:

"The ability to be able to cope with, you know, the treatment that we were proposing for them is always quite difficult because it involves multiple trips to hospital, attending various appointments and a lot of people in that situation are not used to having such order ... having cancer treatment is often very regimented ... how they live their lives is not conducive to the kind of care we want to provide and there's often not much room to be flexible around that really ... and the medication that we give to them also has to be safely put somewhere, especially 'cos some of these drugs can be dangerous in other people's hands, so that's definitely been a consideration in terms of what we can give." (N3\_UK)

#### **Considerations for programme intervention**

When asked specifically to comment on the implementation of CANCERLESS' Health Navigator programme, participants agreed that the success of the programme would rely on the intervention being delivered by the '**right' sort of professionals**, who are able to establish positive and trusting relationships with people experiencing homelessness:





"It's quite a complex case of patients and I think you've got to have the right kind of attitude and personality to work with them." (N2\_UK)

"The first obstacle is the professionals you employ because it does take a different kind of person to work with this client group." (N1\_UK)

Participants generally felt that **professionals already engaged with and knowledgeable about the homeless population** (for example, community nurses and/or support workers) would be best equipped to deliver the programme, or that specialist training on the issues surrounding homelessness would be required:

"When we think about cancer treatment, it's mainly secondary care and tertiary care. ... But not necessarily they're the best people who would have the best knowledge about what is going on, on the ground. So, if you have to find somebody to facilitate, figure out someone who's close to the ground level. You know a community nurse or somebody who knows the community well." (PCP1\_UK)

"Having the language, having a knowledge not particularly of services, but of what makes people tick, how they got to where they are, having some mental health understanding, and understanding their own limitations. So, when people have got post-traumatic stress, knowing there is a special clinician to unpack that, it's not me. I think a knowledge of the lifestyle, so a knowledge of the soup kitchen, knowledge of drugs, paraphernalia, knowledge of how you use drugs, knowledge of drinking habits, knowledge of alcohol abuse, respiratory knowledge, gastrointestinal knowledge." (N1\_UK)

Notably, several participants also specifically highlighted the value of **involving those with lived experience** in programme delivery, based on their ability to better connect with and understand the lives of people experiencing homelessness :

"It's knowing someone has been down the same avenue. I hear it from clients all the time, and it was my thinking as well: 'What do you know? You've not been there, you don't know what it feels like'. So, when it comes from someone who has been there, it just means more." (SW1\_UK)

In order to meet the needs of the population, it was also suggested that any intervention would need to be **proactive** in its approach, and 'reach out' to and encourage





engagement from people experiencing homelessness. It was also felt by several participants that the intervention would need to be **longitudinal**, both to allow trusting relationships to develop and to remedy the fragmented nature of mainstream healthcare systems:

"If somebody told me [to attend a screening], if somebody prompted me to do it I would, but I would need prompting." (PEH3\_UK)

"It's perseverance, they have to trust us ... And then if you put in an intervention and follow it through, the take up of intervention is more likely to be successful rather than 'oh, here is something, take it and I don't want to know you ever again' ... If I'm telling you, it is important today, and again next Monday, and again the following Monday, things are likely to stick." (PCP1\_UK)

"Making sure, if we don't think they're going to contact us that we do more of the contacting of them. I mean, we normally give people a number to call if there's any problems, but certainly with those more vulnerable patients, we reach out much more." (N3\_UK)

The **suitability of the setting** was also described as being an important factor for consideration. Along the same lines as the above, participants emphasised that a programme delivered in familiar and trusted space would be most appropriate:

"They treat this place like a second home, or it is like home 'cos they haven't got home a lot of them ... There's a certain amount of trust for this place and we tend to have more success in getting people involved in things like that if it's somewhere around here." (SW4\_UK)

"Work with [name of local homeless organisation] ... have a mobile screening bus outside their facilities. Have leaflets and support at [name of local homeless organisation] ... I think providing support via them would be incredibly beneficial to patients and homeless and vulnerable people." (PEH6\_UK)

In delivering the intervention, several of the participants emphasised that the CANCERLESS programme should begin from a point of **improving awareness and providing education**, both to people experiencing homelessness and those that work





directly with them. On this point, the importance of using accessible language to deliver key information was again emphasised:

"You need to be putting information out. We do all read the stuff that gets put out on the tables and stuff. So, if the information is there, the people then come, the people will then be more willing to go and get that sorted." (PEH5\_UK)

"Educate them and show them ... Then you're giving them information to give them control over their own bodies, and to, we all know if you give somebody just that little bit of power back, self-empowerment and it starts to grow." (SW5\_UK)

"Providing information so that they can digest that in whatever way works for them, be that written, or you know verbally, and I guess there's language needs as well because obviously not everybody speaks or understands English." (N3\_UK)

Finally, and when asked about potential obstacles that the programme may face at the point of implementation, the majority of health and social care professionals raised concerns around **resource and staff availability**, given that most services are already extremely overstretched. Indeed, it was felt that the programme may meet some resistance in this sense, particularly from primary care providers:

"Time and money ... so for example, if you are asking a nurse to come out of a practice to be with somebody from time to time, that void needs to be filled up ... every aspect of healthcare when you look at it, it's quite stretched ... How are you going to backfill?" (PCP1\_UK)





ID	Location	Age	Gender identity	Ethnicity	Housing circumstances (ETHOS typology)	Existing health conditions
PEH1_ UK	East of England	25	Male	British	7.2. Supported accommodation for formerly homeless people	Epilepsy
PEH2 _UK	East of England	34	Male	British	7.2. Supported accommodation for formerly homeless people	None reported
PEH3 _UK	East of England	42	Male	British	3.1. Homeless hostel	Multiple mental health conditions
PEH4 _UK	East of England	45	Female	British	Own tenancy (formerly 3.1. Homeless hostel)	Multiple mental health conditions
PEH5 _UK	East of England	42	Female	British	8.1. Living with family/friends	Emphysema, kidney issues, chronic pain.
PEH6 _UK	East of England	39	Male	British	7.2. Supported accommodation for formerly homeless people	Current cancer patient (lung)

Table 7. UK Participant Information – People Experiencing Homelessness





ID	Location	Job role
N1_UK	East of England	Nurse – Vulnerable populations
N2_UK	East of England	Nurse – Vulnerable populations
N3_UK	East of England	Nurse – Oncology/ Haematology
PCP1_UK	East of England	Primary Care Physician
SW1_UK	East of England	Support Worker (Prior experience of homelessness)
SW2_UK	East of England	Support Worker
SW3_UK	East of England	Support Worker
SW4_UK	East of England	Support Worker
SW5_UK	East of England	Support Worker

Table 8. UK Participant Information – Health and Social Care Professionals





# DISCUSSION

This report has synthesised the findings of a qualitative study conducted across four partner countries (Austria, Greece, Spain, and the U.K.) to explore the health needs of people experiencing homelessness and the barriers they encounter in accessing primary and secondary cancer prevention services. Particular attention was also placed on gathering participants' input with regards to various factors that should be considered in the design and implementation of CANCERLESS' Health Navigator Model.

The overarching findings of this report and a series of recommendations are provided below, followed by a brief evaluation of the strengths and limitations of this study.

## Summary of key findings

Overall, the findings presented here indicate that there is a high degree of overlap and consistency in the health needs of people experiencing homelessness, and in the barriers and facilitators that exist when accessing healthcare in the European context.

Across all settings, and reflecting the existing literature, the general health of people experiencing homelessness was portrayed by participants as being very poor. Many of the homeless participants suffered with chronic physical health conditions, mental ill health, and substance related disorders, and these were often described as being exacerbated by their housing circumstances and lifestyles. The widespread prevalence of self-neglect within the homeless population was explained both in terms of a limited understanding about how to properly care for themselves and also a tendency to focus on meeting more immediate needs rather than attending to long-term health.

The extensive range of barriers to healthcare that participants discussed suggests that mainstream healthcare services are, overall, ill-equipped to offer care to people experiencing homelessness and at times operate in a way that is entirely incompatible with the lifestyles and needs of this population. Particularly notable across all settings was the presence of stigmatised attitudes towards people experiencing homelessness on the part of healthcare professionals, which were described as deterring homeless people from seeking the healthcare that they require. Problems around access to





healthcare were also further compounded by a general lack of healthcare resources and staffing, an issue that has seemingly intensified through the COVID-19 pandemic.

The most consistent theme throughout the interviews with regards to facilitating access to healthcare was the pivotal role being played by the staff of social care organisations who work directly with the homeless population, and who regularly act as mediators in access to mainstream healthcare provision. When attending primary or secondary care services, homeless participants indicated that they were more likely to engage with healthcare professionals that they trusted and that communicated with them in a way that allowed them to understand and make decisions about their health. Participants also spoke positively about healthcare services that operated in familiar settings (for example, within social care organisations) and that were delivered in more flexible ways (for example, by using 'drop-in appointment systems) as these were seen to combat many of the barriers that exist to mainstream healthcare.

Participants' responses indicated that while cancer was a major source of concern and worry, people experiencing homelessness generally have a very limited level of knowledge and understanding around cancer symptoms and cancer prevention. Across all settings, programmes, and activities for cancer prevention for people experiencing homelessness were described as effectively non-existent, and very few homeless participants recalled being invited to a screening appointment. As a result, health professionals in some settings indicated that cancer in people experiencing homelessness was often missed in the early stages, and instead only picked up when the severity of symptoms intensified.

#### **Recommendations for implementation of the HNM**

The key recommendations drawn from this report to be considered in the design and implementation of the Health Navigator Model are as follows:

 The programme should make use of trusted professionals (e.g., psychosocial care staff, support workers) and, where possible, be delivered in familiar settings that people experiencing homelessness already have access to (hostels, day centres).





- A proactive approach should be taken to engage with people experiencing homelessness, and additional encouragement and prompting of individual users may be required. The use of outreach services for this purpose may be beneficial.
- The programme should be **longitudinal** (delivered over a substantive period of time) in order to combat the fragmented nature of healthcare systems, and to allow for the building of trusting relationships.
- The programme should adopt a **flexible and person-centered approach that responds to individual needs.** For instance, it may be necessary to offer 'dropin' appointment systems and use varying channels of communication.
- The limited knowledge of cancer among people experiencing homelessness suggests there is a need to initiate engagement from a point of education and awareness building.
- Training in health literacy and self-care should be provided among people experiencing homelessness to empower them to manage their own health and be able to identify relevant symptoms.
- Any communication around cancer (either written or verbal) should be delivered using accessible and simple language, and with translation available.
- At local levels, focus must be placed on building relationships with and between health and social care providers, to allow for a co-ordinated pathway of care to be implemented. This could involve employing multidisciplinary teams to deliver the intervention. Strategies for incentivising involvement may also be required given the overall lack of resources reported.
- When involving mainstream healthcare providers in programme delivery, there may be a need to address the social stigma that surrounds homelessness by providing education to professionals about the lifestyles and needs of people experiencing homelessness.







#### **Strengths and limitations**

The exploratory qualitative design is a clear strength of this study as it allowed us to conduct a thorough investigation of the perceptions, experiences, and priorities of our participants. Working inductively also allowed us to remain open to unexpected lines of inquiry, which was particularly appropriate given that the topic area is currently underresearched. The systematic approach to analysis, along with the involvement of multiple researchers, also ensure the confirmability and credibility of the findings presented (Korstjens & Moser, 2018).

This study includes a substantive and highly varied sample comprising both individuals with lived experience of homelessness and cancer, as well as a range of relevant professionals. However, it is noted that in relying on voluntary and professional organisations to recruit participants, the experiences and needs of the 'hidden' homeless population who are not engaged with services (for example, non-visible rough sleepers, sofa surfers, those residing in private hostels) may not fully represented in this report. Sampling was also focused predominantly in urban areas and large cities meaning and therefore does not include the experiences of more rural homeless populations. Moreover, the number of health professionals specialised in oncology included in the sample was relatively limited. As such, ensuring the inclusion of this perspective will be a priority in the next stages of the development of the Health Navigator Model.

Finally, it is important to recognise that the diversity in national healthcare systems and in homelessness service provision may mean that the findings presented here are not indicative of what is happening in other contexts. That being said, the commonality and consistency in the themes identified across the partner countries, as noted above, does suggest that this data has a high degree of transferability beyond the specific settings where data was collected.





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