

# **A REPORT ON CANCER & DEPRESSION**

**THE PERSPECTIVES OF PATIENTS,  
INFORMAL CARERS AND CLINICIANS**



**European Cancer  
Patient Coalition**

## Acknowledgements

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# Table of Contents

Acknowledgements .....	2
Executive summary .....	5
Background to the project .....	12
Introduction .....	13
Objectives .....	14
Methods .....	15
Emerging and pre-defined themes from the workshops .....	16
Patient experiences and perspectives .....	17
A diagnosis of cancer .....	17
Telling friends, relatives and others .....	18
Having hope and psychological help .....	19
Impact of cancer .....	21
Strategies learnt and advice for others .....	23
Health professionals' views and perspectives .....	24
Early detection, screening uptake and navigating services .....	24
Improving engagement with healthcare .....	25
Treatment challenges and lack of joint working .....	27
Improving access and care .....	29
Discussion .....	32
Conclusions .....	33
Key areas for development .....	34
Recommendations .....	36
References .....	38









# Executive Summary

This project was formed as a joint initiative between GAMIAN-Europe and the European Cancer Patient Coalition (ECPC), and took place within the context of Europe's Beating Cancer Plan (2022).

The project's objectives were to:

- Raise awareness on the issue of depression as a cancer comorbidity
- Gather in-depth patient accounts on the issue of comorbidity
- Gather information from relevant stakeholders such as patients, clinicians, researchers and EU and national policymakers regarding the challenges of comorbidity
- Encourage dialogue between patients, clinicians and other stakeholders to be used as a basis for policy recommendations for EU and national policymakers.

This report details the findings of two workshops and a survey to seek the experiences of patients with comorbid cancer and depression and professionals working in the field.<sup>1</sup>

[1] A total of fifteen people attended the workshops (10 patients and five professionals). 41 people responded to the survey - 33 patients and eight informal carers.

# Patient themes

Patients provided valuable insights into their experiences of cancer and depression and their journey since their diagnoses. The key emerging and pre-defined themes from the workshop with patients and the survey included:

**Patient experiences and perspectives of cancer and depression** – The shock of receiving a cancer diagnosis was overwhelming and having to deal with the reactions from friends and family was challenging. Patients found people to be less sympathetic towards their depression, but more so towards their cancer diagnosis. Oncologists did not always take cancer symptoms seriously in patients with depression, which would be overlooked or overshadowed by their MH diagnosis.

**Hope and psychological help** – Patients described the importance of psychological support upon receiving a diagnosis of cancer. This was also reiterated by participating health professionals (HPs). Not all patients were keen to take up psychological support at first but found that they benefited from it when they did. This support also helped when dealing with the side effects of cancer treatment.

**Impact of cancer** – Managing both depression and cancer at the same time was formidable for patients and their families, but somehow they had to learn the best ways to keep going. Changes to their lives and daily routine were significant (e.g. by having to give up work). There were many practical problems to solve (e.g. managing appointments, and carrying out daily chores); all of which were compounded by treatment side effects and depression.

**Strategies learnt** – These included maintaining a sense of humour, taking up a hobby where possible, having psychotherapy and socialising with others who have had similar experiences.



# Health professional themes

Health professionals raised and discussed themes around the system of detecting and monitoring MH symptoms, and the difficulties for patients with cancer and depression to navigate multiple and complex healthcare services.

**Early detection and screening uptake and navigating services** – HPs noted how cancer symptoms in depressed patients are not only overshadowed by the latter diagnosis but that they may not have their cancer investigated or treated adequately. People with MH conditions may not engage in cancer screening programmes and this may prevent early detection. Navigating healthcare services is no easy feat, especially for those with comorbid conditions. A ‘pathway navigator’, a person to help guide patients with cancer through the diagnostic and treatment process is being piloted in Denmark to assist patients with this.

**Improving engagement with healthcare** – HPs described current initiatives and suggested several ways to improve engagement with healthcare services, including an app to monitor PH and MH symptoms, a liaison MH nurse working within cancer departments, regular screening for MH symptoms in cancer patients and improve public health campaigns to prevent and promote PH and MH.

**Treatment challenges and lack of joint working** – Patients with cancer and depression often have to move back and forth between primary and secondary healthcare services. Because of this, their case notes can be difficult for each department (MH and cancer) to view. This means patients have to repeat much of their history or update an oncologist about their MH which can be a challenge. There are numerous adverse drug interactions with cancer treatments that cancer professionals will usually be aware of. However, this becomes complicated by medication for a comorbid MH condition, which cancer professionals will know less about. Some cancer treatments and chemotherapy can also have a direct impact on patients’ MH, such as steroids and anti-hormonal drugs. HP’s access to other relevant specialists for advice and information about these issues can often be difficult in a ‘clunky’ healthcare system, where each department operates separately.



**Improving access and care** - Stigma plays an important role in how patients with severe MH conditions are perceived by generalist health services. This needs to be tackled head-on. Examples of good practice, such as a liaison MH nurse working within a cancer department, can make an enormous positive difference. Training healthcare professionals to manage comorbid conditions is a key solution. Cancer and MH services also need to be better integrated. This could start with a programme to reduce the likelihood of someone with cancer developing an MH problem throughout their diagnosis and treatment journey, by screening and monitoring for MH symptoms. Equally vital is social/peer support from third-sector organisations that can work more flexibly than healthcare services and offer other important services (e.g. signposting to other services, financial support, etc.). This is especially important for vulnerable and/or socially isolated patients. Informal carers also require essential support for their MH and PH. Prevention via improved public health campaigns is another important area for action to promote healthy lifestyles and mental well-being.



# Conclusions and recommendations

The two workshops and responses to the survey produced a myriad of interesting experiences, perspectives, themes and areas of action for **patients with cancer and depression**.

Participating patients **shared their experiences of being diagnosed, the impact on their close relatives and informal carers, and their treatment journey**. It is clear patients with cancer and depression are often underserved. Participating health professionals discussed the shortcomings of MH and generalist healthcare services and provided valuable suggestions for improving these.

Based on the workshops convened and the survey the following **recommendations** are suggested for improving healthcare for patients with comorbid cancer and depression, their informal carers and family:

## For MH and generalist healthcare services

- Offer and provide psychological support, hope and information to manage symptoms for all cancer patients
- Introduce 'pathway navigators' to support vulnerable patients with cancer and depression
- Better integrate healthcare services by creating multidisciplinary teams within cancer departments
- Ensure cancer health professionals receive adequate training to provide a more holistic approach to patients with comorbid cancer and depression
- Provide both PH and MH support for informal carers and family members to ensure their health and well-being are protected and monitored
- Connect patients and their informal carers to relevant third-sector organisations

## For governments

- Invest in cancer and MH services to ensure better support and monitoring are provided to patients with comorbid MH and PH conditions
- Introduce within training curriculums greater awareness of comorbid conditions, such as cancer and depression and how these can be treated more effectively and holistically
- Ensure continued support for third-sector organisations that provide invaluable support for comorbid patients and their informal carers/families
- Integrate PH and MH public health campaigns so that cancer can be detected sooner rather than later and to promote healthy lifestyles which can benefit MH and wellbeing

# Six key takeaways



## **Timely Access to Care**

There was unanimous agreement that people need timely access to psychological care throughout their cancer journey

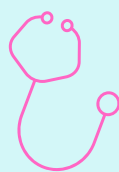
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## **Support Network is Key**

85% of those surveyed, spoke to either a professional or friends and family about their symptoms of cancer and depression

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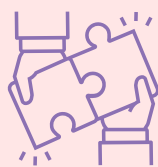


## **Screening Saves Lives**

Early and periodic screening for mental health problems in cancer patients throughout their treatment is vital

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## **Professional Collaboration**

Cancer and mental health professionals need to work together to improve support and treatment for those with cancer and depression



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## **Carers Need Guidance**

86% of informal carers from our survey said they received no advice from healthcare professionals but would have benefited from it.



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## **Depression is Stigmatised**

Cancer is given a lot more attention and sympathy than depression. This could be due to the stigma that surrounds depression and mental health in general

# Background to the project

In recognition of the growing concerns around physical and mental health comorbidities, particularly cancer and depression this project was formed as a joint initiative between GAMIAN-Europe and the European Cancer Patient Coalition (ECPC).

The project took place within the context of Europe's Beating Cancer Plan which aims to tackle the entire disease pathway through four main action areas: prevention; early detection, diagnosis and treatment; and quality of life of patients and survivors.<sup>1</sup> This plan also acknowledges the need to focus efforts on workforce training for better patient quality of life and well-being, by offering mental and psychosocial support. The impact on informal carers is also taken into account and this plan calls for better support to ensure their physical health (PH) and mental health (MH) needs are met.



# Introduction

## Patients with cancer who develop depression

The impact of cancer on a patient's MH can be formidable. Between 15% to 25% of cancer patients report having depression; a comorbidity often described as disabling.<sup>234</sup> There are many possible reasons why cancer patients develop symptoms of depression. These are wide-ranging and include the experience of loss or anticipated loss, uncontrolled pain, fatigue, metabolic abnormalities (e.g. anaemia, fever, vitamin B12 deficiency), sleep disruption due to treatments, medications and endocrine abnormalities.<sup>567</sup> A recent study also found unemployment to be another main predictor of psychiatric comorbidity for cancer patients discharged from hospitals.<sup>8</sup>

## Patients with depression who develop cancer

For those with an existing diagnosis of depression, cancer can be poorly treated or overlooked, where symptoms are overshadowed or misattributed as an expression of their existing MH condition. The reasons for this can include stigma and discrimination, which can have adverse consequences if cancer symptoms are diagnosed or treated late.<sup>9</sup> Patients with major depression have been found to have worse survival after a cancer diagnosis.<sup>10</sup>

## Making adjustments

Adjusting to the life changes that a diagnosis of cancer may bring can be difficult. The experience of shock, grief and sadness are normal reactions and need to be distinguished from symptoms of depression. But there is no doubt the risk of depression is higher for cancer patients than the general population.<sup>11</sup> Having major depression, alongside cancer can also impact negatively survival and cancer management.<sup>12 13</sup>

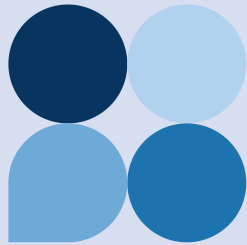
## Seeking and receiving psychological help

It is also known that only 20% of patients with comorbid cancer and depression and/or anxiety are recognised as having an MH condition and receive the right support. Many patients with cancer delay seeking psychological help which highlights the need for oncologists and MH professionals to ensure timely access to this care and treatment.<sup>13</sup>



# Objectives

Within this context this project sought to achieve four objectives:



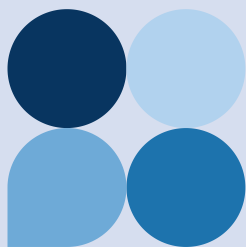
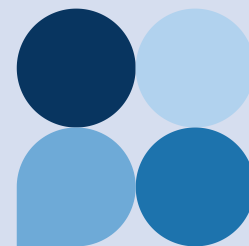
A) Raise awareness on the issue of depression as a cancer comorbidity.

Relating to:

- The importance of early intervention for identifying and treating depression in cancer patients (cancer-associated or pre-existing)
- The specificities of symptom display in cancer patients (as opposed to non-cancer patients)

B) Gather in-depth patient accounts on the issue of comorbidity, with an emphasis on:

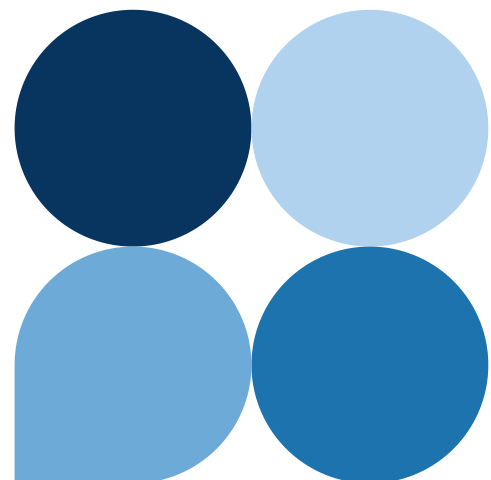
- Negative experiences of care for patients suffering from both cancer and depression as well as the views of caregivers
- Success life stories of people who managed and dealt with comorbidity



C) Gather information from relevant stakeholders such as patients, clinicians, researchers and EU and national policymakers regarding the challenges of comorbidity, focusing particularly on:

- The obstacles to the detection and diagnosis of depression in cancer patients, and cancer in depressed patients
- The risk factors associated with developing depression in cancer patients
- The main barriers to accessing adequate treatment for depression in people with cancer

D) Encourage dialogue between patients, clinicians and other stakeholders to be used as a basis for policy recommendations for EU and national policymakers.



# Methods

To address objectives (B) (C) and (D) two workshops were convened to gather accounts from both patients with cancer and depression and clinicians supporting those with this comorbidity. A topic guide including questions and areas for discussion for patients and carers was developed to cover diagnosis, impact on daily life, treatment, and recommendations. A separate topic guide was developed for health professionals to include diagnosis, improving engagement with services, current practices, key challenges and ways to improve care for patients with cancer and depression.

Patient members were invited to participate in these workshops from across GAMIAN-Europe and the ECPC spanning several European countries. Informal carers were invited through the European Federation of Associations of Families of People with Mental Illness (EUFAMI). Clinicians were invited through known contacts and word of mouth.

A survey was also conducted to gather additional views and experiences from wider networks (via social media) and members. A questionnaire for the survey was developed using questions broadly based on the patients' and carers' workshop topic guide.

## Workshop participants and survey respondents

Ten patients from three European countries (Croatia, Greece and the UK) participated in the first workshop - seven were female and three were male.

Five professionals attended the second workshop. These included professionals from Denmark (HP1, female); a Consultant Nurse in Child and Adolescent Mental Health and visiting professor at the University of South Wales (HP2, male); a Mental Health Consultant for Aferiad Recovery (HP3, female); a Research Fellow at the University of Cardiff working on cancer screening prevention and early diagnosis (HP4, female); and a pharmacist working within a Community Mental Health Team (HP5, male).

A total of 41 survey responses were received; 33 from patients and eight from informal carers.

# Emerging and pre-defined themes from the workshops

Emerging and pre-defined themes drawn from the two workshops and surveys with patients, informal carers and professionals are included below.

## Patient experiences and perspectives

Patients provided valuable insights into their experiences of cancer and depression and their journey since their diagnoses.

### ► A diagnosis of cancer

How cancer was identified in participating patients varied, and for some came as a major shock.

A diagnosis of cancer was overwhelming for most participating patients, which for some led to their experience of depression. One female patient described how intense her shock was given she was relatively young, a personal trainer who took regular exercise and ate a healthy diet. She was diagnosed with lung cancer and had to educate herself about this disease through internet searches.

Similarly, another female patient talked about how devastating her cancer diagnosis was. Given her cancer affects 70% of her bones her doctors have told her not to do any physical activities, including walking. She has found this extremely difficult, especially as she was so active previously.

Another female patient found it difficult to convince doctors that something was wrong. She described experiencing pain for many years, but was made to *'feel that I had hysteria'*. (Female, P4). For her, being diagnosed with cancer was a relief as it confirmed her suspicions.

A male patient talked about how complicated it was for him to be diagnosed with cancer, which took a long time. He had first been diagnosed with depression several years before. It took several visits to different doctors to receive his cancer diagnosis, by which time his cancer had advanced. This patient was in no doubt his cancer symptoms were overshadowed by his diagnosis of depression and knew he had to do something.

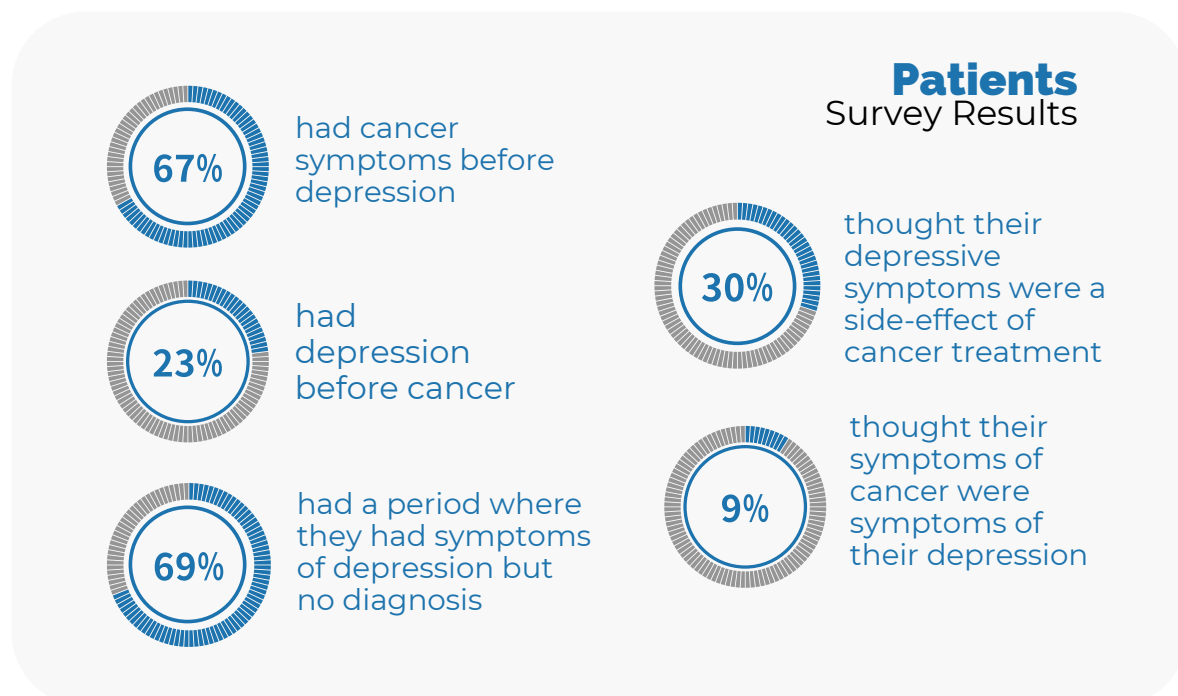


*'I had to lie to have a mole removed. I was shocked at the result of the biopsy which showed I had cancer. I wasn't prepared for this diagnosis.'* (Male, P2)

He was also told he had a 50/50 chance of survival, which made him angry; knowing his 'cancer journey' would have been shorter if he did not have a previous diagnosis of depression.

A young female patient had a different experience, despite a previous diagnosis of depression. She explained that her main symptom of cancer, feeling very tired, was taken seriously, although she dismissed this initially because of having COVID-19.

Two female patients described having a diagnosis of cancer on two separate occasions, within a period of several years. One of whom was in the middle of receiving chemotherapy for her second cancer and was due to have an operation in two days following this workshop. She showed tremendous courage and was grateful for the support she received from her husband and health professionals (Female, P10). Everyone was visibly moved by her experience.



## ► Telling friends, relatives and others

Communicating a diagnosis to the family was not easy. Patients found relatives and close friends often responded badly. As one female patient described:

*'There was no positive way to tell people about her cancer diagnosis.'* (Female, P1)

This, in itself, presented further difficulties for patients who would also be trying to cope with their inner turmoil of emotions about their cancer diagnosis. Patients were conscious of the impact on family members, especially their spouses and children.

A female participant described how her husband first reacted when she told him about her diagnosis. He then swiftly began clearing out the fridge of any unhealthy food or drink. Another explained:

*'It's tempting to hide that you have the disease just to not have to explain it. But awareness should also be changed.'* (Female, P1)

It was clear patients found it difficult to tell their loved ones about their cancer diagnosis, often having to reassure them if they thought the worse. Interestingly, the reactions from relatives, friends and others differed between the two conditions. Participants explained how people were more sympathetic when hearing about a diagnosis of cancer, but less so about their diagnosis of depression. One female patient described how medical staff had little sympathy for her depression but did for her cancer. She this was also the same when she posted about it on social media.

## Patients

### Survey Results

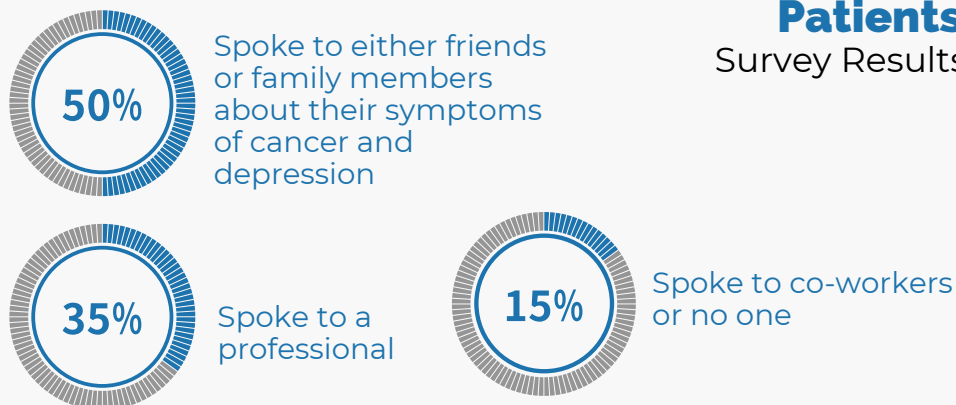
When asked how respondents found people's attitudes towards their diagnosis of cancer compared to their diagnosis of depression, the following themes came up:

- Depression is less understood by people relative to cancer
- People are more sympathetic towards cancer than depression

Two female patients described very negative reactions from relatives which were very stressful. One described how abusive her father was. Another explained how her brother became angry with her when she became tired, blaming it on her weight. As she explained, *'tough love doesn't work for me'*, (FP4) and support from a cancer organisation gave her the understanding she needed. Especially, when it came to hearing about the experiences of others.

## Patients

### Survey Results



## ► Having hope and psychological help

Doctors can be negative or unclear about a patient's chances of surviving cancer. Patients talked about the need for health professionals to offer hope on receiving a cancer diagnosis. One female patient offered an alternative and thoughtful view.

*'I wanted to know what would happen to my life but I wasn't ready to hear the answers with depression and cancer at the same time.'* (Female, P5)

The offer of psychological support was an important theme and almost all participant patients agreed that access to this soon after receiving a diagnosis of cancer was essential. Not all patients were offered this by their oncologists, but as a female patient stated, *'psychological support should come from day one!'* (Female, P4)

Another female patient explained that it was the doctor that prescribed her pain medication and suggested she receive talking therapy. She was wary of this.

*'I didn't like the idea of this [psychotherapy] at first, but it helped a lot with my problems.'* (Female, P5)

Another female patient took up the offer of psychotherapy straight away to help manage her shock and the changes cancer brought to her life.

Not everyone was able to receive psychotherapy. Access in some European countries can be very limited and the wait list long (up to a year). Some doctors do not wish to refer patients for psychological help and instead suggest they see a Chaplain. Psychological support is generally offered whilst receiving palliative care. Psychological support was also seen as a good way to help deal with the side effects of cancer treatment.

One male patient felt it was a bad practice not to offer psychotherapy to all cancer patients and their informal carers. Although he decided not to take up any psychological support and tried to deal with his emotions by himself, he recognised how this took a heavy toll on his wife and family. He later regretted this decision and understood that:

*'It would have been better to have someone to talk to [a psychotherapist] instead, either alone or together with close family'.* (Male, P9)



Talking to someone, other than family and friends about having cancer was seen as crucial. This was especially so as one female patient described, *'sometimes people are not equipped to help others.'* (Female, P8) She found it annoying when people would tell her what to do and instead asked people to just listen.

Some patients received support from third-sector cancer organisations. This was an important way to access support and to speak to someone who understood their experience. Peer support from such organisations was another important source of help.



## ► Impact of cancer

Many patients detailed the big changes to their daily living and life generally following a cancer diagnosis. Some had more severe cancer than others and each patient participant was at a different stage of their treatment and recovery journey.

A female patient who had depression first and cancer sometime later described having to slow down and be kind to herself concerning both conditions.

*'I had to learn how to deal with myself and to get going again.'* (Female, P3)

All patients acknowledged the impact on family members, some of whom had to assume the role of informal carers. A female patient described how difficult her husband/carer found the changes they had to make. Not only did he look after her but also had to take on all her usual responsibilities (the shopping, childcare, taking out the dog, etc.).

## Informal carers

### Survey Results



They were providing care for their parents. The rest were cared for either by their spouse, friends or children



Informal carers said they received no support. Those that did received psychological and social support



Received no advice from healthcare professionals on how to provide care for their loved one



The main challenge for them was to properly understand their needs



Would have liked to have more information about how to care for or the specific condition before they started giving care and support

**The advice informal carers would give to someone who is a carer included:**

- The power of just listening
- Honesty and empathy
- Educate yourself on the condition or disease

Some patients had to stop working and with this came financial difficulties, adding to already mounting emotional strains. There were practical problems to solve too. Attending appointments for cancer treatment proved challenging for one male patient who lived 20 miles from the hospital. He described cancer as, *'having turned my life upside down'* (Male, P2). The practical help he received from his carer was invaluable and without it would have negatively impacted his ability to recover.

## Patients

### Survey Results

**When asked how having both cancer and depression impacted day-to-day life, the following themes were described:**

- Large levels of anxiety
- Being constricted physically as well as psychologically
- Life became extremely difficult with the combined side effects of cancer compounded by the hopelessness of depression
- Social and personal life is drastically impacted (e.g. not wanting to go out or see people or do any social or solo activities)

## ► Strategies learnt and advice for others

Patients had some very helpful suggestions and advice for people who experience both cancer and depression. One female patient stated the importance of seeking help quickly when a person identifies a possible symptom of cancer (e.g. a lump). *'Take courage and go.'* (Female, P7)

Another female patient explained how stigma can get in the way of seeking help for depression. For her, psychotherapy was so important in coping with what can be a long and difficult journey when coupled with cancer.

*'Humour was important too. As another female patient put it, 'Milk, bread and therapy!'* (Female, P5)

### Patients

#### Survey Results

The things patients said helped them to manage their cancer and depression included:

- Seeing a psychologist
- Taking up activities or hobbies, such as gardening
- Being with family members and pets
- Medication and psychotherapy
- Socialising with others going through the same experience



## Health professionals' views and perspectives

### ► Early detection, screening uptake & navigating services

Health professionals (HP) noted some of the challenges of diagnosing cancer in patients with an existing MH condition, especially if severe. As described by one patient with depression (P2) cancer symptoms can be dismissed or overshadowed by health professionals. This further extends to other problems as one HP explained:

*'[Patients with mental health conditions] may not be as investigated, diagnosed or treated for physical health problems as vigorously compared to those without. So that's definitely an existing problem.'* (HP5, male)

The same HP also outlined the difficulties of patients with an MH condition engaging with screening programmes generally, which he felt was contributing to the shorter life expectancy for those with MHCs, who die considerably younger compared to the general population.

This was confirmed by another HP (HP3) who oversees a screening programme within their organisation (Adferiad, Recovery), for women of varying ages. A GP will come to the unit to provide screening services but patients are reluctant to attend. This HP also described a situation in which a woman with bipolar disorder developed breast cancer at a young age, but because of her psychological state at the time struggled to believe she had found a lump and delayed seeking help.

HPs discussed some of the main issues with specific screening programmes which are often too focused on one particular disease and not good at screening for others.

*'From an mental health perspective, lots of people with serious mental health conditions don't go to their General Practitioner, especially men.'* (HP2)

Another HP explained how diagnosing cancer is quite complex as it requires further investigation. It is very likely a person with depression will feel hugely overwhelmed and scared if they are told they may have cancer which needs more tests.



The existing healthcare system is also set up so that if you are offered an appointment to see a consultant you are required to respond in a short period. You are also expected to be able to read letters and comprehend what you have to do, which can be complicated for some. If a patient is experiencing low mood, or other MH symptoms and is socially isolated they could easily miss the deadline for responding or not have anyone to help them. As a result, the system can automatically classify a person who does not respond in time as 'DNA' or does not attend appointments.

Navigating the healthcare system as a patient, therefore, especially someone with comorbid cancer and depression can be challenging. In recognition of this, some hospitals in the UK have introduced 'pathway navigators' to help guide patients with cancer through the diagnostic and treatment process.

## ► Improving engagement with healthcare

HPs suggested what could be done to improve engagement with screening and accessing healthcare for someone with cancer and depression. They also described different initiatives being piloted in their respective countries.

One included the possibility of expanding cancer screening so that multiple physical health checks or 'cross-over' screening could be carried out in one go, via primary care, using more innovative communication approaches. One example is being tested in Denmark which includes a new symptom monitoring app.

This type of app could help people better engage with health services, but recognised that it could also create a social equity problem, in that many patients might not have the technology or know how to use the app. However, there is also the option for patients to complete a questionnaire about their MH and PH every few months which essentially does the same thing as the app.

Another HP described a liaison MH nurse who works within a cancer team. This MH nurse has referred patients struggling with their MH and will also help patients with issues concerning their diagnosis, appointments and treatment.

An HP made an important observation about the two different populations referred to in this discussion and the importance of distinguishing between the two and their access to psychotherapy or lack of.

*“We have a population with a diagnosis of cancer who develop mental health problems because of their diagnosis of cancer, and can’t access psychological support because not much of it is out there.”*

*“You have those with identifiable mental health problems who have difficulty getting a diagnosis of cancer because of their mental health problems, who will have difficulty accessing psychological interventions for either their mental health or cancer diagnosis.” (HP2)*

The same HP explained that screening and diagnosis are paramount for both populations.

*“We need to enable the people doing the diagnosis of cancer to be able to work in both cancer and mental health domains.” (HP2)*

Another way to improve many of these issues is to ramp up public health promotions/ campaigns and to provide age-specific home tests to get people to think about their PH earlier/ in advance.



## ► Treatment challenges and lack of joint working

Because patients move back and forth between primary and secondary healthcare services for each condition their case notes do not follow them across cancer and MH services. Because of this, any issues flagged up by either service are not seen by the other. This means their comorbid cancer and MH is not seen early on which presents another challenge.

*'[The system in Denmark makes] the patient 'fall back' all the time and they have to fight to be heard to let doctors know their other issues. Patients have to be their own coordinators and that's a very big problem if you don't have the resources [and know how].'* (HP1)

Another HP noticed in his work, as a pharmacist how oncologists make decisions about treatment for patients with MH.

*'Clinicians and oncologists will make slightly different decisions for patients with mental health problems which is not based on evidence. They don't always use first-line cancer a treatment because of concerns about how that might affect a person's medication for their mental health condition. But they don't always check out these ideas.'* (HP5)

There are numerous drug interactions with cancer treatment and cancer professionals will have a medication list to understand these, and so avoid harmful drug combinations. This however becomes complicated by medication for a comorbid MH condition.

*'They [cancer health professionals] seem to think that meds for mental health are inferior and don't try to find the right medicine to combine the two. The patient has to find out what to do to manage their mental and physical health.'* (HP1)

Some cancer treatments and chemotherapy have a direct impact on patients' MH. For example, steroids which are commonly prescribed can lead to depression and even episodes of psychosis. Also, anti-hormonal treatments for breast and prostate cancer, which need to be taken for 5-10 years, can result in a low mood. It is important therefore that cancer health professionals prescribing these, check on the patients' MH status and contact MH specialists if necessary.

Having patients carry their health records is an important means by which to provide a timely exchange of key health information. Another builds on having trained MH professionals working in cancer teams. A multidisciplinary team working within a cancer diagnosis and treatment service, which includes a pharmacist would overcome many issues relating to comorbidity of cancer and depression and adverse drug interactions.

*'We've helped people on clozapine for schizophrenia to have chemotherapy which previously was seen as impossible. We've managed it by working together as clinicians from different parts of the healthcare sector.'* (HP5)

Another key problem with interdisciplinary working is that many health and MH professionals do not know each other.

*'If I want to liaise with a gastroenterologist I wouldn't know who they are and they don't know who I am. I have to liaise with the GP to do this but it would be easier if could talk directly with each and work things out.'* (HP5)

This is largely due to how health trusts and services operate separately. In Wales, these are combined but in other health systems, such as Denmark and France these are separated. There are also the different 'languages' that each speciality speaks, which act as another barrier to joint and holistic working.



## ► Improving access and care

Participating HPs listed several ideas and potential actions that could improve access and the health care patients with cancer and depression could and should receive. These include areas concerning stigma and MH, training for generalist health professionals, and integrated cancer and MH services.

Stigma plays an important role in how patients with severe MH conditions are perceived by generalist health services. While there has been work around parity of esteem, to give equal weight to both mental and physical health, there continue to be challenges around access to generalist health services for those with severe MH conditions.

*'There's a lot of stigma for those with serious mental health problems, especially for those with bipolar disorder, psychosis, and serious depression who struggle with accessing healthcare services.'* (HP3)

This needs to be tackled head-on. Examples of good practice described above, such as a liaison MH nurse working within a cancer department, can make an enormous difference.

Training for healthcare professionals to manage comorbid conditions is a key solution. As one HP described, 'this goes right back to basic training at degree level' (HP). Very little is included in generalist training concerning MH, and vice versa.

One HP mentioned they are involved in setting the curriculum for medical students and noted how the elements of the training are kept separate.

*'Here's physical health, here's mental health. We should integrate these better.'* (HP4)

Cancer and MH services also need to be better integrated. This could start with a programme to reduce the likelihood of someone with cancer developing an MH problem throughout their diagnosis and treatment journey. This could include screening and monitoring for MH symptoms using standardised questionnaires, such as the PHQ9 or a simple picture of a thermometer / barometer asking, 'how are you feeling today?' It would be easier to refer cancer patients with an existing comorbid MH condition or developing symptoms if MH professionals are integrated within cancer services.

Certain MH questions may be difficult for generalist health professionals to ask (e.g. around suicidal ideation) which MH professionals are specifically trained for, and so important to bear in mind.

*'Asking about suicidal thoughts linked to their depression is quite a difficult thing to do, or people find it difficult. MH professionals don't. It's how to react to that which is also important.'* (HP3)

Part of integrating services includes looking at the interface with third-sector organisations, which are more agile than the NHS given they work within different parameters.

*'If we joined up the services with the cancer charities, like MacMillan who are very active with services, with Adferiad Recovery or Mind, [for example], they may be able to offer psychological therapy quicker.'* (HP2)

This non-traditional access to psychological therapy and routes of support would be something of vital importance for patients with cancer and depression - especially as the average waiting time for psychological support is between 6-12 months.

Equally vital, is social support which again third-sector organisations can deliver and can include peer support. This is important for targeting patients who may be socially isolated. Informal carers also require essential support for their MH and PH. Financial support is another key area with the cost of living crisis.

Prevention is another important area for action. This can also include prevention messages around healthy eating and lifestyles and the promotion of MH and well-being.

*'It's about primary prevention strategies for me and tackling depression and cancer upstream. This means going back to prevention messages to promote healthy lifestyles.'* (HP5)



# Discussion

The shock of receiving a cancer diagnosis cannot be underestimated for some. The offer of psychological support at this stage of a cancer patient's journey and beyond is essential. Having an existing MH condition, especially if severe, complicates the process of both diagnosing and treating cancer.

Participating health professionals discussed the shortcomings of MH and generalist healthcare services and provided a multitude of suggestions for improving these.

Stigma appears prevalent amongst generalist healthcare professionals, in which symptoms of cancer can be overshadowed by a patient's MH condition. There is much work to be done to tackle this head-on and improve engagement with screening, access to services and treatment for those with an MH condition who later develop cancer.

Picking up MH problems in cancer patients is another vital area in need of further development and expansion. Screening for MH problems and access to psychological support is absolutely vital for those with this comorbidity.

Cancer and depression can be overwhelming for a person to manage at the same time. This is further compounded by MH and cancer services being ill-equipped to help in timely and efficient ways. These services operate separately, with little or no cross- or collaborative working. Integrating these services, with trained MH professionals working in cancer departments and vice versa, underpinned by primary care presents an important way forward for this group. A pathway navigator can help coordinate comorbid patients through multiple and complex health services which they will need to access, something vulnerable patients will find challenging.



# Conclusions

The two workshops and responses to the survey produced a myriad of interesting experiences, perspectives, themes and areas of action for patients with cancer and depression.

Participating patients shared their experiences of being diagnosed, the impact on their close relatives and informal carers, and their treatment journey. It is clear patients with cancer and depression are often underserved. Participating health professionals discussed the shortcomings of MH and generalist healthcare services and provided valuable suggestions for improving these.



# Key areas for development

Participating patients and health professionals were unanimous regarding the importance of timely access to psychological support throughout a person's cancer journey. Not all cancer patients are agreeable to receiving psychological support at first, but it should always be available when they change their minds.

Patients also felt that cancer health professionals need to offer hope about their cancer prognosis and provide information about what they can do to help manage their symptoms and the side effects of their treatment.

Participating patients and HPs recognised the need to support informal carers and family members' physical and MH, who may find their additional responsibilities challenging and emotionally stressful.

Both participating patients and HPs valued the support third-sector organisations can offer patients with cancer and depression. These organisations provide information, people with similar experiences to talk to (e.g. peer support), and social and other support to help manage the negative impact of cancer on patients' lives.

For participating HPs, screening for MH problems in cancer patients early on and throughout their treatment was considered vital.

MH training for cancer health professionals is an important tool for tackling stigma and ensuring MH is screened effectively in cancer patients.

Integrated working by, for example, having a liaison MH nurse operating within cancer services enables timely referrals to MH support. This would provide a more holistic approach. The implementation of pathway navigators, people who help guide patients with cancer and depression through the healthcare system, to assist vulnerable or socially isolated comorbid patients with appointments and/or to advocate on their behalf was considered another important area for development.

Another important advancement, suggested by HPs is the creation of multidisciplinary teams that include a pharmacist. This helps to avoid, for example, harmful drug interactions with cancer and MH treatment combinations.



From a public health perspective, HPs felt there was a need for PH prevention and promotion campaigns to ensure prevention and early detection of cancer symptoms, which can also help those with depression and other MH conditions.

HPs also identified the need to explore better communication approaches, for example, by using technology to connect more effectively with patients, for example, to monitor their symptoms (both cancer and MH) over certain periods of time; offering alternative approaches to those who are unable to use technology.

The experiences and perspectives shared by all participants were both valuable and insightful. Each offered solutions which provide an important way forward for patients with comorbid cancer depression, and indeed patients with other PH and MH comorbidities.



# Recommendations

Based on the workshops convened and the survey the following recommendations are suggested for improving healthcare for patients with comorbid cancer and depression, their informal carers and family:

## For MH and generalist healthcare services to:

- 01 Offer and provide psychological support, hope and information to manage symptoms for all cancer patients; starting from the time of diagnosis and continuing throughout their treatment journey.
- 02 Introduce 'pathway navigators' to support vulnerable patients with cancer and depression to help steer them through multiple and complex healthcare services and to advocate on their behalf when needed.
- 03 Better integrate healthcare services by creating multidisciplinary teams within cancer departments that comprise MH professionals (e.g. clinical psychologist and/or MH nurse) and a pharmacist. This will ensure timely screening and monitoring of MH symptoms and appropriate/effective treatment combinations for cancer and depression/other MH conditions.
- 04 Ensure cancer health professionals receive adequate training to provide a more holistic approach to patients with comorbid cancer and depression, which should include patients with lived experience of MH problems to help reduce stigmatising stereotypes and their negative effects of these.
- 05 Provide both PH and MH support for informal carers and family members to ensure their health and well-being are protected and monitored.
- 06 Connect patients and their informal carers to relevant third-sector organisations that can provide valuable social and other support to help improve their day-to-day lives.



## For Governments to:

07

Invest in cancer and MH services to ensure better support and monitoring are provided to patients with comorbid MH and PH conditions, including digital technology and suitable alternatives to improve communication with patients/informal carers during their treatment journey.

08

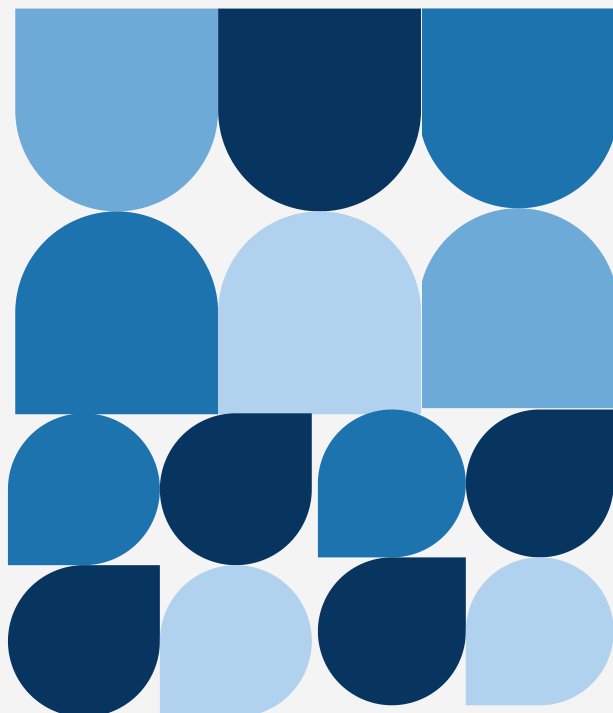
Introduce within training curriculums greater awareness of comorbid conditions, such as cancer and depression, and how these can be treated more effectively and holistically.

09

Ensure continued support for third-sector organisations that provide invaluable support for comorbid patients and their informal carers/families.

10

Integrate PH and MH public health campaigns so that cancer can be detected sooner rather than later and to promote healthy lifestyles which can benefit MH and wellbeing.



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Don't go it alone. It can be tough to have cancer and depression. There is help available ask health providers for mental health support.

