LUXEMBOURG

First report
Interviews results

DIAGNOSIS ANNOUNCEMENT

LE GOUVERNEMENT
DU GRAND-DUCHÉ DE LUXEMBOURG
Ministère de la Santé
et de la Sécurité sociale
Direction de la santé

Institut National du Cancer

LUXEMBOURG INSTITUTE OF HEALTH

fhl
Fédération des hôpitaux luxembourgeois

Fondation Cancer
Info - Aide - Recherche

EUROPA DONNA
The European Breast Cancer Coalition

2024 - 2025

PATIENTE VERTRIEDUNG
ASBL

ARTSQUARE LAB

The diagnosis announcement project in Luxembourg

National Cancer Plan 2 | Axis 3

Plan National Cancer

The "Diagnostic Announcement" project is part of the National Cancer Plan 2 (PNC2) under Axis 3 – Rights, Information & Training for Patients, specifically linked to Action 3.4.1. This action focuses on implementing a structured process for delivering cancer diagnoses.

By aligning with PNC2, this project aims to improve the way cancer diagnoses are communicated, ensuring a patient-centered approach that respects the emotional and informational needs of patients and their carers, while also integrating the perspectives and needs of healthcare professionals.

PNC2.pdf

Project partners

Institut National du Cancer

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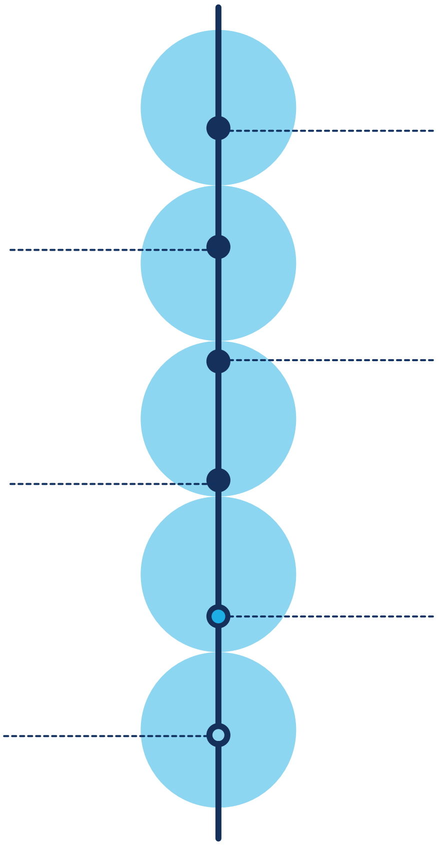
INTRODUCTION

The project objective

Announcing a cancer diagnosis is a crucial moment that requires sensitivity and care. This project aims to listen to patients, their carers, and healthcare professionals to understand their experiences and perspectives. By gathering real-life stories, we will identify key challenges and collaborate to find practical solutions that can improve the diagnosis announcement process in Luxembourg.

We will use the Design Thinking methodology. It is a human-centered approach to encourage collaboration among people who may not usually work together. This method emphasizes empathy and teamwork to deeply understand the needs of patients, carers, and health professionals. Through brainstorming, prototyping, and refining ideas, we aim to transform the way cancer diagnoses are delivered, making it more compassionate and supportive for patients and their loved ones.

The project timeline



Project definition

Afternoon of exchanges
March 2024

Patient and carers interviews
May - june 2024

Interviews with healthcare professionals
July 2024

Co-creation session
October 2024

First report
January 2025

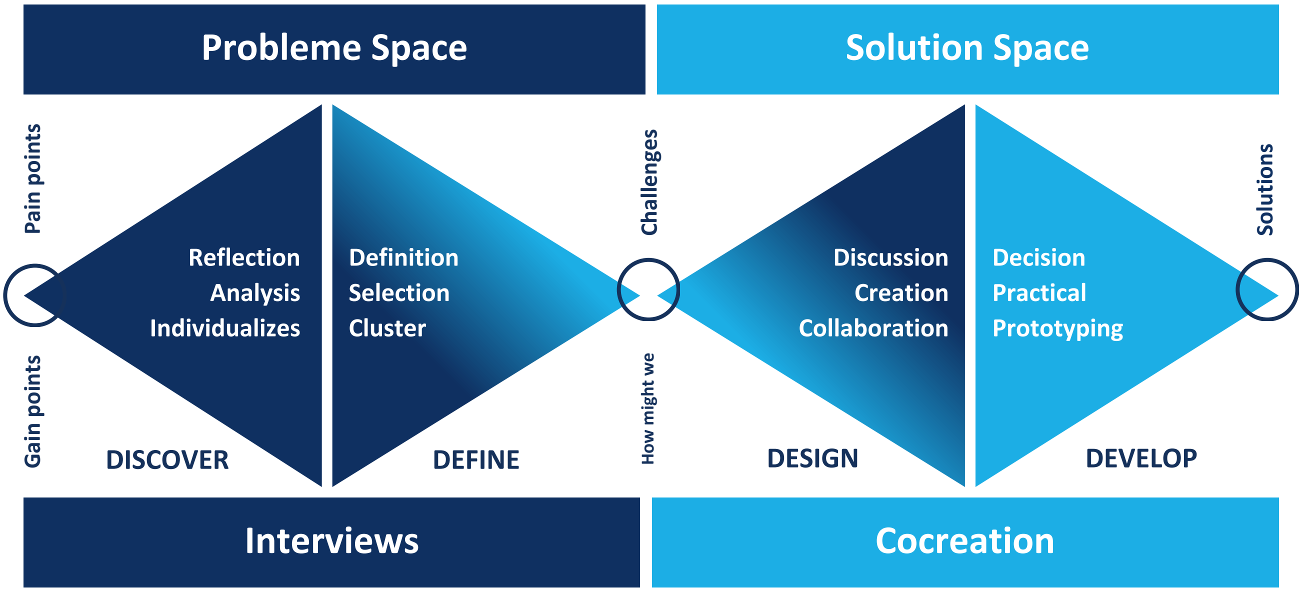
Second report
February 2025

Tool implementation

Methodology - Design thinking

Design Thinking is a problem-solving approach that focuses on people It encourages innovative thinking by combining creativity, collaboration, and a step-by-step process of testing and refining ideas. This method helps teams work together to develop practical and human-centered solutions. The process is organised into 5 main stages:

1. **Empathy**: Understand the needs and feelings of the people involved.
2. **Definition**: Clearly define the problem to be solved.
3. **Ideation**: Brainstorm and come up with new ideas.
4. **Prototyping**: Create simple versions of the solutions.
5. **Testing**: Check if the solutions work by getting feedback from users.



As part of the “Diagnosis Announcement” Project (PNC2 - Axe3), we use Design Thinking to:

- **Focus on patients and carers**: This method helps us understand their emotions, needs, and fears during the diagnosis announcement by taking an empathetic approach.
- **Include healthcare professionals**: It encourages teamwork to create practical solutions that fit their daily work.
- **Encourage new ideas:** Design Thinking helps find better ways to make diagnosis announcements less stressful, clearer, and more caring.
- **Test and improve solutions:** By trying out and adjusting ideas, we make sure they work well before using them widely.

In this context, **ArtSquare Lab** is our key partner for using this method in Luxembourg for this important project.

Report content

This report presents the results of **42 individual interviews** conducted between May and July 2024.

On March 20, 2024, we organised a national event to bring together cancer patients and carers to introduce our project and have open discussions. The goal was to share information about our work and collect useful feedback. More than 40 people attended the event. From this group, we interviewed 21 patients.

The goal of this project was to collect different experiences to improve how cancer diagnoses are shared and to find ways to make the process more supportive, clear, compassionate, and how it could be made less stressful.

By interviewing patients, their carers, and healthcare professionals, we wanted to better understand how the diagnosis announcement affects everyone involved, the challenges they face.

Participants

- **Patients**: We interviewed **21 patients** who received a cancer diagnosis between 2018 and 2024.
- **Carers**: We also wanted to include the perspectives of carers who were present during the diagnosis announcement. As a result, we interviewed **4 carers**.
- **Healthcare professionals:** Additionally, we spoke with **17 healthcare professionals** working in oncology to understand their views and experiences related to diagnosis communication.

42	21	4	17
Interviews	Patients	Carers	Health professional

Structure of each chapter

Each chapter in this report is organised to provide a systematic and in-depth exploration of the experiences gathered during the project.

- **Summary of Gains and Pains**

At the beginning of each chapter, boxes summarise the key "gains" (positive elements) and "pains" (challenges) identified. This summary provides a concise overview of the main findings for quick reference.

- **Analysis to offer deeper understanding**

Following the summary, each chapter presents a thorough analysis of the collected data.

- **Quotes from interviews**

To complement the analysis, direct quotes from interviews with patients, carers, and healthcare professionals are included. These quotes highlight personal perspectives, adding authenticity and emotional depth to the findings.

This structure ensures a clear and logical presentation of the results, facilitating both comprehension and application of the insights for improving the process of diagnosis announcement.

TOPICS

COMMUNICATION

01 Comprehensive diagnosis announcement

02 How diagnosis information is communicated

03 Finding the right balance : empathy and medical information

04 Understanding and adapting to patient's socio-cultural background

PATIENTS’ JOURNEY

05 Timely access to relevant and reliable info

06 Ensuring patients understanding and prepare for key milestones

07 Right support, right time for patients and carers

ORGANISATION

08 Defining the roles of patients and carers in the diagnosis journey

09 The right context: space and time for the diagnosis announcement

10 Structure for delivering a diagnosis

SUGGESTED IMPROVEMENTS

11 Improving the diagnosis annoucement experience

Comprehensive diagnosis announcement

The announcement of a cancer diagnosis is a deeply impactful moment, experienced differently by patients, carers, and healthcare professionals.

From the perspective of patients, this moment often brings overwhelming emotional shock, as they try to absorb life-changing information. Patients need clear, accessible communication that not only informs them but also provides reassurance and a sense of direction. When communication is unclear or incomplete, many patients turn elsewhere for answers, which can lead to confusion or misinformation.

Carers, while sometimes overlooked, play a vital role in this process. They act as a source of emotional support for patients and often help them process and retain the information shared by healthcare professionals. For carers, this can be a challenging task, as they navigate their own emotions while trying to be a pillar of strength for their loved ones.

Healthcare professionals face the complex task of delivering a diagnosis with sensitivity and precision. They must balance the need to convey essential medical information with the emotional and intellectual readiness of their patients.

To aid understanding, they often rely on tools such as simplified explanations, visual aids, and metaphors. Their goal is to ensure that patients and carers leave the conversation feeling informed and supported.

This chapter explores patients' feelings during the announcement of their diagnosis, carers' perspectives and examines the tools and strategies healthcare professionals use to ensure clear and compassionate communication.

#Metaphors
#Patient’s right
#Emotional support
#Reliable sources
#Carers’ roles
#Language clarity
#Capacity to understand
#Second diagnosis
#Access to documents
#Drawings
#Visuals

Patients speak out

Get clear and reliable information

Patients value clear communication, visual aids, simple drawings, and easy-to-understand language.

Patients stress the lack of reliable information.

Some patients seek a second opinion outside Luxembourg.

Many patients explained during the interviews that the moment of diagnosis is a shock, and they immediately need clear and simple information. They emphasized that visual aids, like simple drawings, and metaphors used by doctors are very helpful in understanding medical topics.

Patients also pointed out that simplified explanations should not be seen as trivial or oversimplified.

While patients need clear, straightforward information, they also want to feel that the complexity of their situation is respected. These simplified explanations should serve as a starting point for deeper discussions, where patients can ask questions and gain a better understanding. If this doesn't happen, patients often seek information elsewhere, such as on the internet, from doctors abroad, or by asking family and friends, which can lead to confusion.

“ Quotes ”

No, no one gave me... I didn't ask for any reference sites either. I looked it up myself. And when I saw it, it seemed a bit strange, but the site—I'm not sure what it was, I think it was 'www.cancer.ca'—and it was really well explained. It was factual, clear, and didn't have any dramatic stuff like 'there's a 50% survival rate' or things like that. It was really clear. Then I also asked the doctor some questions.

I understand the key terms, but not the entire diagnosis.

I could understand as the doctor explained things to us like we were children—about all types of cancers.

She immediately went into technical details. She took a paper and a pen and said, 'Here's where the tumor is, we'll do this. The plan is this. We'll start with this, and then that.' She explained everything by drawing and gave me the treatment plan.

Then I had to speak to a surgeon, who was fantastic. It was at the hospital, on the first day, at the end of the day. He explained everything to me very clearly and calmly... He made a drawing showing what was in my belly, what needed to be removed, and he clearly explained what tests needed to be done. After that, I could finally eat something, since I hadn't been able to eat for two days to keep my intestines clear. Then in the following days, I had an MRI, and I spoke again with the surgeon. He told me that the situation was good, the cancer was contained, nothing was found in other organs, and the surgery could be done with a good margin. He emphasized that it needed to be done quickly, no waiting for an extra month. I asked, 'Can I leave now? How do we proceed?' He said, 'Yes, the tests are fine, and you can go until we find an available date for the surgery.

Patients speak out

Insights on diagnosis communication

Patients feel more empowered when results and medical terms are clearly explained.

Not understanding reports creates stress and confusion.

Accessing the DSP platform provides early information, but clarity is often missing.

Patients need clear information about which documents or results they receive and who provides them.

Many patients explained that written documents, such as reports with test results, are often given to them in an unstructured way. Sometimes they receive them right after a specialised exam, other times through the DSP (Dossier de Soins partagé) platform. Not all doctors offer an explanation of these documents, which leads patients to try to interpret the data on their own, sometimes with the help of friends who are doctors or by searching online. This process often causes additional stress.

To avoid this, many patients stressed the importance of understanding the report with the help of a medical professional, especially the specialist, who can explain the results, their implications, and any further tests that may be needed to confirm or clarify the findings.

“ Quotes ”

Carcinoma, that already rang a bell, but then there were quite a few things we didn’t understand, like the word 'malignant.

Oh, for example, I got the scintigraphy results directly after the exam from the doctor who was there. He gave them to me. But for everything like the report and MRI, I only got those from the oncologist. So it’s always the doctor who performed the exam—whether it’s the oncologist or the gynecologist, like you mentioned.

I had the ultrasound, and he saw that something was wrong. He didn’t tell me anything directly, he just gave me the report. I asked for the report because often they don’t give it to you. I always ask the doctors for the reports because I have a history, I lost my mom to cancer, etc.

Patients speak out

Understanding patients’expectations

Timely Information builds trust

Breaking down information makes it easier to understand

Patients often expect a 360-degree overview right away

Many patients stressed the importance of receiving complete information about their condition, treatment, and next steps when meeting with a specialist or healthcare professional.

However, many expressed disappointment when they were not given all the results or information they expected. Patients noted that doctors often do not have all the test results at the time of the consultation and require them to wait for further tests.

“ Quotes ”

> *I said to the doctor, “Please tell me the truth, I don't want any surprises. Don't try to protect me—am I going to die?"*

> *Doctors tend to focus only on their own area of expertise and are often reluctant to discuss other fields.*

> *When I first found out I had cancer, the doctor mainly talked about the psychologist. She could see I was in shock, so she didn't give too much information right away. Later, the breast nurse stepped in and provided me with more details and continued support.*

Patients highlighted the need for clear communication about these steps to help manage their expectations, reduce stress, and prepare them for information coming from various sources at different stages, such as doctors, psychologists, and breast care nurses.

> *She told me that it’s not like before when cancer meant death. She said, 'I've had treatments. I have seven lines of treatment. If the first one doesn't work, there's the second, and then the third, and fourth. We’ll give you everything you need. Yes, it’s chronic and yes, it will come back, but we’ll keep you alive and in good conditions so you can live a normal life.*

> *Now that we're talking about it, I realise I didn't receive any detailed information at first. It didn't bother me at the time because I felt like I had the main information. I was told I had cancer, and now I had to face it.*

> *When explaining the process, she was very thoughtful. She didn't overwhelm me with everything all at once. She didn't tell me right away that I would lose my hair. Instead, she said, 'We're not there yet.' She knew I would lose my hair, but she preferred to take it step by step.*

Patients speak out

Understanding information during the diagnosis announcement

Patients create their own methods to retain information.

Patients rely on backup support to confirm the information they receive.

A strong shock can block patients from absorbing information.

Patients pointed out that their ability to understand the information provided by doctors during the diagnosis announcement is strongly influenced by their emotional state. The shock of receiving a serious diagnosis can be overwhelming, often triggering feelings of disbelief, fear, or confusion. These intense emotions can make it difficult for patients to focus on what is being said, as their minds are preoccupied with the gravity of the news. In this state, it becomes harder for them to process and retain important details, and they may find themselves unable to absorb crucial information about their condition, treatment options, or next steps.

As a result, many patients report feeling like they are not fully engaged in the conversation, unable to ask questions or seek clarification because their emotional reactions dominate their attention. This emotional barrier can lead to a sense of helplessness and uncertainty, making it challenging for patients to take in or remember the information they receive during the diagnosis announcement.

“ Quotes ”

My friend said, ‘You absolutely need to have someone with you because there’s too much information.’

Yes, I always carried something to take notes, and my husband also took notes.

I was really confused—I forgot a lot of information. For the next visit, I prepared questions.

My husband read all the flyers and told me what I had to read.

I was confused, numb, and didn't react until I left the hospital; I think the best thing was not to react.

I was a bit in shock, so it’s really helpful to always have someone with you. Maybe I only remembered 3 things from what he told me. But in my case, the information was fairly clear. The important thing is to have someone with you to make sure you don’t miss any details because you’re starting a new journey with a terminology you don’t know.

Carers speak out

The uncertainty of their role during the diagnosis announcement

Carers feel responsible for gathering information and understanding the diagnosis.

Carers feel left out when it comes to explanations about treatment and the impact on family life.

Carers are unclear about their role and responsibilities.

Carers explained that accompanying patients during the diagnosis is often a highly emotional experience, filled with shock and a sense of responsibility to provide immediate support. They feel compelled to react quickly and offer comfort to the patient.

However, many carers expressed that they are unsure about their specific role in this process. They often lack clear information on when and how they can be most helpful, and where their energy and efforts would be best directed.

“ Quotes ”

I would like to have more information on how I can support her, when I can help, and what I should do.

I would have appreciated being contacted with more details about the process, including side effects, and what I should do to support my wife. For example, if she vomits for two days, it would be helpful to know that it’s normal or when I should take her to the hospital.

I took notes, and after each appointment, we exchanged information.

My wife was just going through the emotions, completely paralysed.

I tried to stay as clear-headed as possible to understand what I, as an observer, could do. I accompanied my partner to ensure she could focus on her treatment and stay hopeful about recovery. It was important for me as a partner to stay supportive. She was sitting there, paralysed, as if the situation wasn't about her, just going through the emotions. I could see she wasn’t fully processing what was happening.

Health Professionals speak out

The challenges of delivering a diagnosis

Doctors need to quickly assess the patient’s knowledge, status, and education level.

Doctors must adapt the amount of information given to match the patient’s capacity to understand.

Doctors face high pressure to ensure that patients fully grasp the information.

Healthcare professionals pointed out that patients’ emotional shock can make it hard for them to process information during a diagnosis.

They stressed the need to consider the patient's emotional and intellectual ability to understand the information being shared. Factors like stress, knowledge, and education play a role in how much information doctors give during the first visit.

Doctors explained that they try to give enough key information so patients understand their condition but avoid overwhelming them. They often leave some details for the second visit. However, they noted that finding the right balance can be challenging. They emphasized that it’s important for patients to leave the consultation with a clear understanding of their situation, without feeling overloaded.

“ Quotes ”

And of course, you need to listen to what the patient wants to know. Bad news impacts patients differently. Some want to hear all of it, while others only want to know part of it—maybe 70%, 80%, or 90%. And families also play a role in how bad news is received.

Depending on who you have in front of you, you might increase their stress. So, I’m not sure if asking directly 'Tell me what you understood' would be helpful—it feels a bit too formal. But perhaps it would be interesting to get that feedback in a different way. It’s a challenge to figure out how to do this.

One of the biggest challenges is adapting to the personality of the person in front of you. That remains, I think, the biggest challenge.

The main challenge, I think, is the difference between what patients expect or want to know versus their level of education. Patient education is much more varied today.

Often, we send patients abroad, so they end up asking for information repeatedly. They don’t keep their records, and departments want to know everything again. So, when a patient returns months later with the same condition, we create a new file. If we had better connections between departments or if the systems were integrated, that could save time, but right now it’s very time-consuming.

Health Professionals speak out

Visual aids to improve communication

Simplifying medical terms makes communication clearer.

Visual aids help doctors clarify diagnoses for patients.

Doctors use creative techniques to explain diagnoses.

Diagnosis is difficult to understand because of complex medical terms.

Doctors stressed the importance of using visual aids to support verbal communication when delivering a diagnosis. Medical terms related to the disease, anatomy, or required exams often need further clarification, which can be provided through simplified language or drawings.

Some doctors have created their own techniques to tackle this challenge, ensuring that both they and the patients use the limited time during the diagnosis announcement effectively. These methods help patients better understand the information and ease the emotional impact of the situation.

“ Quotes ”

> ***I always make drawings. Patients leave with a drawing in hand, which is scanned into our file.***

> ***After announcing the diagnosis, I usually show them the histological report. It’s with this report that I explain the extent and aggressiveness of the tumor.***

> ***I draw in front of the patient and I also like to refer to numbers.***

> ***I show the mammogram, I take the example of the breast, I show the mammogram, I show the biopsy, I show all that, the scan that was done, everything that was done and I explain the histology, I put it all in context and then I explain what we have to do.***

> ***First, I simplify the vocabulary. It's normal because people don't have knowledge of biology or anatomy.***

Health Professionals speak out

Importance of clear communication in multilingual healthcare settings

Patients have the right to information in their own language.

Diagnosis is hard to understand without native language.

Many doctors and healthcare professionals highlight the challenges of delivering a diagnosis in a multilingual environment, such as Luxembourg, where patients may speak various languages. When commonly spoken languages like French, German, English, Luxembourgish, or Portuguese are used, communication typically poses no significant issues. However, when less common languages, such as Ukrainian or Chinese, are involved, clear communication can become more difficult. To address this, healthcare professionals often rely on professional translators, colleagues, and sometimes even the patient's family members for support.

Despite these efforts, professionals stress that delivering a cancer diagnosis is a pivotal moment that can significantly influence a patient's emotional reaction and attitude toward their treatment. Therefore, precision in communication is paramount. Misunderstandings resulting from poor translation or unclear explanations can jeopardize the patient’s comprehension and impact their decisions about next steps. Healthcare professionals recognize the importance of ensuring that the message is accurately conveyed during this crucial moment, underscoring the need for clear, empathetic communication.

“ Quotes ”

That doesn't mean everyone must speak all languages, but I believe that one should be able to hear that yes, a patient should be treated in their own language.

I feel like it's getting better in recent years. In the past, the doctor would provide the information as best as they could, and whether the patient understood or not didn't really matter. Now, it seems that doctors are actively looking for solutions. We have tools available, like a pocket translator service, that anyone can use.

HOW DIAGNOSIS INFORMATION IS COMMUNICATED

Clear and compassionate communication is essential during the diagnosis process for patients, carers, and healthcare professionals.

For patients, quality communication is a cornerstone of effective care. It not only saves time for patients and medical staff but also significantly reduces stress throughout the entire experience. It helps them understand their condition, feel supported, and manage their emotions, empowering them to make informed decisions and face their new reality with confidence.

For carers, clarity about their role allows them to support the patient without overstepping boundaries, which helps reduce their stress and strengthens their ability to provide meaningful help.

For healthcare professionals communicating a diagnosis goes beyond medical facts—it requires sensitivity to the patient's emotions and engaging both the patient and their carer effectively. Clear communication reduces misunderstandings and enhances the care experience, helping everyone feel informed and supported for better outcomes.

This chapter explores the impact of diagnosis communication through the perspectives of patients, carers, and healthcare professionals, highlighting strengths and areas for improvement.

#Body language

#Disorientation

#Fight mode #Relief #Hope

#Subject not object

#Stress triggers

#Moment of truth

#Capacity to understand

#Microsignals

#Fear #Anxiety #Stress

#Setting

#Shock #Panic

#Lack of navigation

Patients speak out

The need for trust, clarity and guidance

Receiving a diagnosis leaves patients feeling powerless

Patients worry about their future and security

Patients crave clear guidance and direction.

Receiving a diagnosis often leaves patients feeling overwhelmed with fear, helplessness, and panic. For many, the word "cancer" evokes thoughts of the end of life, making it hard to absorb information due to shock and strong emotions. Practical concerns about their family's future, their children, or daily responsibilities quickly follow, heightening their stress.

In these critical first moments, patients seek clear, straightforward information, guidance, and an understanding of what to expect next. They want to know their complete diagnosis, treatment options, and how their daily lives may be affected. Some patients hope to have all their questions answered during that first meeting, but this often leads to disappointment as the complexity of their situation requires ongoing conversations.

“ Quotes ”

If only someone could tell me what to do and how to do it. I needed direction.

When they tell you that you have cancer, your first thought is death.

My immediate question was: how much time do I have? What needs to be done?

They said they had so many patients to deal with.

The doctor ordered a scan after surgery, but they ended up doing it beforehand.

I think I went two weeks without sleeping—day or night.

I was completely lost.

You have no idea what’s coming next.

I instantly thought about my kids. What kind of life will they have? One is 3 years old, and the other is only 18 months.

Suddenly, it hits you—cancer usually means you won’t be able to work. How will I keep my business running?

I felt like I was doing the doctor’s job myself.

The two strongest feelings I had were fear and anxiety. They stayed with me for a long time.

I feel like being on an emotional rollercoaster

Patients speak out

The role of small signals in diagnosis communication

Timely, calm, and confident information builds trust.

A relaxed environment reduces stress.

Body language impacts stress levels.

The study showed that patients are very aware of how their diagnosis is communicated. They said that the doctor's attitude, the staff's behaviour, and the overall atmosphere can greatly affect their experience. These factors can either reassure them and give them hope, or make them feel overwhelmed and unable to process what's happening.

Patients shared that a calm, confident doctor helps them feel supported and secure. On the other hand, unclear or nervous communication can make them feel blocked or unwilling to accept the diagnosis. Clear, straightforward communication is especially important, as it provides guidance during a difficult time. Non-verbal cues, like body language, also play a big role in how patients respond and understand the situation.

“ Quotes ”

They did a scan, but the process was chaotic—no one seemed to know what to do.

The second doctor maybe didn't need to approach it that way. She focused more on making eye contact, communicating with me, and reassuring me. I wasn't the same person in both appointments, so each doctor adapted differently.

It felt like I was just seeing whoever was available that day. They never seemed to have much time.

The atmosphere was hectic, and no one seemed to have time. I felt the state of urgency.

I need a doctor who is calm and can explain things clearly.

I was crying, and he was nearly crying too. I thought to myself, he's too emotional to be delivering this kind of news.

I had no issues with empathy; my doctor was very gentle and kind.

Patients speak out

The importance of being seen as a person not a disease

Patients want to be seen as individuals with cancer, not just as cancer itself.

Patients need to be the drivers of their journey, not just passive participants.

Patients highlighted the importance of being treated as individuals, not just as a disease. When healthcare professionals recognize their unique experiences and perspectives, it empowers them and fosters a sense of hope.

This approach not only supports patients in coping with the initial diagnosis but also encourages them to be more engaged and proactive in their ongoing treatment.

“ Quotes ”

> *It was incredible. The way they work is amazing. It's like entering a different world. You don't feel like just a sick person.*

> *The problem was that the doctor didn't even look at me; he just looked his computer screen, making me feel invisible. It was unsettling because I was the one affected by this.*

> *From the start, it's important to consider the human side. Be a little empathetic if possible. I know it's not always easy to give a cancer diagnosis, especially when it's not clear if the person can be cured. It's more difficult when the prognosis is uncertain, and I understand that. But it should be done differently. For instance, my oncologist sat next to me, explained things, and said, 'I understand.' That kind of announcement, while tough to hear, makes you feel human and not just a number.*

Patients speak out

The diagnostic announcement, a moment of truth

The diagnosis journey starts at different times for each person, increasing stress.

Some patients try to make sense of incomplete information.

Medical staff and procedures can trigger stress related to a potential diagnosis.

Patients often talk about the initial diagnosis as the "Moment of Truth," when early signs from doctors or medical procedures indicate something serious.

These early clues can increase stress and lead patients to start looking for information on their own, marking the start of their journey.

Most of the time, these signs come through a phone call, a visit with a specialist, or hints from other medical staff, rather than directly from a doctor.

Quotes

The oncologist said, 'You need to come with someone because I'll be giving you a lot of information.

I now smile when I think of the ultrasound doctor's reaction when he said, 'Yes, there is something.' That's when the stress really started.

I asked, 'Can I come with someone even though it's Covid and visitors aren't allowed?' The doctor said, Yes, you must come with someone.' I already knew what that meant.

They did the biopsy and said the results would come in ten days, but the radiologist told me right away it was not good. We knew it was cancer, just not what type.

I remember it clearly. We were shopping at Delhaize when the phone rang. My wife looked at me and said, 'It's my gynecologist.' She answered, and the doctor said, 'You know why I'm calling. This is not good news, and we need to meet.' It was so surreal, standing there while everyone else went on with their normal lives. That was when our new chapter began.

Carers speak out

Putting the patient first

The need for patient-centered communication

Some carers shared that during the diagnosis announcement, they felt the doctor was focusing more on them than on the patient.

They stressed that it’s important to treat the patient as an individual, not just as a "case" or defined by their illness, right from the start. When the doctor treats the patient this way, it helps the patient feel more in control of their own journey with the illness.

Recognising the person, not just the diagnosis

For carers, this approach can also bring a sense of relief, as it shows that their loved one is being treated with respect and is more empowered to face the challenges ahead. It reassures the carer that the patient is being seen as a whole person, which can help both the patient and the carer feel more confident in managing the situation together.

“ Quotes ”

When we met the surgeon, my wife said, 'It was the only doctor who talked to me, not to you. She spoke directly to me.

Telling relatives instead of the patient can feel disrespectful.

Dr. X did a great job because she focused on my wife and explained everything to her. I could listen and then repeat the information to my wife later.

Carers speak out

Understanding their role and responsability

Carers feel responsible for gathering information.

They also advocate for the patient's needs and well-being.

Carers need clear details about treatment and its impact on family life.

Carers often underlines being the ones who receive diagnosis information from medical staff. They feel the need to take notes, remember details, ask questions, and sometimes learn more than the patient.

This responsibility is often not clearly explained, leaving carers with tasks they might not be ready for or comfortable with. While carers are vital in supporting the patient, their rights and ability to understand the situation should be clearly defined for both of them.

“ Quotes ”

Giving more information to family members than to the patient can feel disrespectful. We supported my wife as best as we could, and sometimes we needed to talk with the doctors in the hallway because it was important for her. I felt capable of handling it, but not all family members might be as thoughtful or capable. Some might mean well but cause more harm than good. The medical staff should consider how family members' involvement can impact the situation.

We felt listened to and heard. We probably asked some silly questions, but we never felt stupid. The medical staff treated us with respect and didn't look down on us. We were seen as patients in distress.

We go into fight mode and focus on ourselves. As a husband, I had to be strong for my wife, my kids, and our extended family. We were getting hit from all sides. It was a fight until the end—win, run away, or lose. But we had to push through for ourselves. It took courage. Nothing else mattered.

Health Professionals speak out

Adapting communication to the patient's understanding

Doctors feel responsible for delivering clear messages.

Health professionals recognize that there is no one-size-fits-all way to deliver a diagnosis. Some choose a direct and straightforward approach, while others prefer a more sensitive delivery that considers the emotional impact and context. This can include using a gentle tone, being close to the patient, and choosing the right time and place. The way information is shared is often adjusted based on the patient's or carer's emotional state and their ability to understand.

“ Quotes ”

> *Improving communication comes from practice and learning from trial and error, noticing reactions in the patient's or family's face. Unfortunately, we don't get much training in this.*

> *I feel I've improved my ability to read non-verbal signs, which helps me adjust my approach to suit each person. I aim to communicate in a way that fits them.*

Doctors adjust their communication based on the patient's ability to understand.

Many health professionals mention that experience teaches them to read non-verbal cues in the patient’s reaction, helping them know when to change their approach. Some believe that more training in communication skills could improve their ability to handle these conversations and ensure the patient truly understands and processes the information.

> *I've become more direct, especially when it comes to announcing metastases. Experience has taught me that falsely reassuring people doesn't help, so I prefer being straightforward.*

> *Medical diagnoses are cold and scientific, and they need to be. But it's important how the information is delivered—how it's framed and communicated in a way that suits the person.*

> *We go through a learning curve, especially at the beginning. Over time, we build confidence in our methods. It may not always be perfect, but with enough listening, you start to get immediate feedback from the patient. That’s why it’s important to engage with the patient, observe their reactions, and respond accordingly.*

FINDING THE RIGHT BALANCE: EMPATHY AND MEDICAL INFORMATION

The moment a diagnosis is announced marks a pivotal point in the patient's healthcare journey. It is a time when clear communication of medical facts is crucial, yet so is the demonstration of empathy.

For patients, receiving a diagnosis is not just about understanding medical terms, but also about knowing their condition and treatment options. This empowers them and helps them regain control. However, the emotional weight of such news can be overwhelming.

Carers, similarly value a combination of factual data to maintain hope and emotional connection to support the patient.

Empathy from **healthcare professionals** plays a vital role in providing reassurance and emotional support, helping patients navigate their path to recovery. Carers and family members, too, experience this journey and need both clear information and emotional support to remain hopeful and resilient.

The challenge for healthcare professionals is to balance clear medical explanations with the empathy needed to address emotional needs, fostering trust and open communication.

This chapter explores how the delicate balance between empathy and medical information is crucial in creating a supportive environment for patients and carers during the diagnostic phase. By prioritizing both the factual and emotional components of communication, healthcare providers can contribute to a process that is not only informative but also compassionate and understanding.

#Confidence
#Empathy
#Bad news
#Training
#Remain neutral
#Two-step-diagnosis
#Medical information
#Difficult conversation
#Hope
#Treatment options
#Communication skills
#Evidence-based Hope

Patients speak out

Importance of clear and evidence-based communication

Patients value receiving clear information.

Evidence-based information helps build trust.

Patients pointed out that their confidence during a diagnosis largely depended on receiving clear, detailed, and evidence-based information about their treatment options. They felt reassured when doctors explained not only the available choices but also the reasons behind each decision.

This transparency helped them understand their situation better and made them feel respected as active participants in their care. As a result, they were more empowered and developed stronger trust in their doctor, which gave them greater confidence in the next steps of their treatment.

“ Quotes ”

My oncologist told me, 'You have cancer, but it's very unlikely to be fatal. We can cure it.' I wish I had heard that at the time of diagnosis.

I have access to the latest treatment options here in Luxembourg.

I was reassured knowing that the breast cancer treatment protocol is standardized worldwide. There have been enough advancements to know what works and what doesn't, which gave me confidence.

She said, 'It's not like before when it was always a death sentence. I've had treatments—seven lines of them. If the first one doesn't work, there’s the second, then the third, and even the fourth. We will give you everything you need. Yes, it’s chronic, and it will come back, but we’ll keep you alive and in good condition, so you can live a normal life.

It was very important for me to know that action was being taken. My oncologist explained everything in detail—the treatment plan, including four rounds of intensive chemotherapy and twelve smaller ones over six months. It wasn’t easy, but it was more manageable.

Patients speak out

The importance of empathetic communication

Patients need reassurance and empathy.

Patients need timely information shared calmly and confidently to build trust.

Patients pointed out that one of the most important aspects of a diagnosis announcement is a balance between providing clear information about treatment options and showing genuine empathy for their concerns. They emphasized that simple reassurances, such as "it will be fine," are not comforting. What they need most is real empathy, which involves acknowledging their emotions and understanding the weight of the news they are receiving.

This means taking the time to listen to their fears, providing thoughtful responses, and showing patience as they process the difficult information. Such empathy helps patients feel supported and respected, making it easier for them to cope with the situation.

“ Quotes ”

The way my gynecologist communicated was perfect for me. He's very precise, which is why I chose him. He explained everything clearly and factually without getting overly emotional. It worked well for me.

What was really important to me was when she said, 'The prognosis is good.' It changed everything. She didn't say I would be cured or that everything would be fine, but just that the prognosis was good. From that moment, I felt a shift in my mindset, I stopped crying, and I was able to sleep again.

It would have made a difference if he had announced it in a more human way. I'm not the only one who feels this way; we talk about it in support groups, and certain doctors' names come up more often. Maybe more empathy would have helped. It felt very cold. Of course, you don't want to overdramatize it, but empathy would have been appreciated.

I simply asked the surgeon what I should tell my children, who were nearby at 8:30 in the morning. He gave me the right words to use. Then, seeing that I was a bit shaken, he showed empathy by placing his hand on my shoulder or arm and said, 'We will take good care of you.' I didn't need anything more at that moment.

Patients speak out

The need reassurance

Calm doctors help keep patients calm.

Trust is built on knowledge and understanding.

Patients pointed out that receiving clear and reassuring information during the diagnosis announcement is essential for their confidence and peace of mind. They emphasized the importance of doctors providing honest, detailed explanations about the diagnosis and treatment options, which helps them understand their situation better.

Patients also expressed that reassurance about their doctor's competence and expertise is vital, as it builds trust in the care they are receiving. Knowing that their doctor is knowledgeable and capable allows patients to feel more secure in their treatment decisions. This sense of trust and reassurance plays a critical role in making patients feel supported as they move forward in their healthcare journey.

" Quotes "

The doctor was helpful and professional, but not emotional.

They were professional; I wasn't expecting sympathy.

People are very anxious in that moment. If a medical professional shows their own anxiety, it can make the patient feel even worse.

If you already know what needs to be done and how to do it, the doctor's job is to guide me. That's what I expect from him.

Carers speak out

The need for empathy and clear information

Carers value the balance of empathy and medical information.

Carers value clear and concrete information.

Carers, like patients, emphasize the importance of a compassionate approach when it comes to communication during difficult times. For some carers, having clear, concrete information is crucial to maintaining hope.

This includes understanding statistics, the reasons behind treatment plans, and available options. For others, the most important aspect is empathy and building a genuine human connection between the doctor and the patient. Without this, carers feel frustrated and upset, sometimes leading them to seek care outside the country.

“Quotes”

She explained everything clearly, and the appointment lasted an hour.

She provided important information that gave us hope—concrete hope backed by research.

He asked us to leave multiple times. He lacked empathy, respect, and the ability to provide information.

He was very supportive and present with us. Just before removing the cast, he needed to apply gas, and you could immediately tell if there was empathy or not. You can feel it. This is something we really miss in Luxembourg—listening to the patient, informing them, and having open communication.

Health Professionals speak out

Clear information for better understanding

Providing patients with facts helps build their confidence.

The challenge for doctors: making sure patients understand.

Health professionals stress that delivering a complete and clear picture is essential when communicating a diagnosis. They focus on translating complex medical information into a message that patients can understand, using medical reports, statistics, and other relevant documents to back up their explanations.

Health professionals say that maintaining neutrality during these conversations is essential. It builds trust and ensures that patients receive the information they need without feeling additional anxiety.

Many doctors emphasize setting aside 30 to 45 minutes for these initial discussions, not just to make the announcement, but also to check that patients have understood the information. They have the impression that this approach strikes the right balance between detailed data and patient understanding, creating a sense of security and confidence in the care they will receive.

“ Quotes ”

Medically, we dedicate about 30 minutes to explain, revisit the images, go over what they have understood from our earlier discussions, and talk through their treatment plan with them.

After delivering the diagnosis, I usually show the patient the histological report. This report helps explain the size of the tumor and its level of aggression.

First and foremost, we are scientists, and part of reassuring patients involves explaining what is happening physically in their bodies so they can better understand the situation.

Health professionals should be allowed to communicate in a way that’s both suitable and precise, using language that respects the patient’s ability to understand. We’re not speaking to children; we’re addressing adults who are capable of thoughtful understanding when we communicate clearly.

Health Professionals speak out

The importance of communications training

Some healthcare professionals would like to receive training in communication skills.

Training to learn how to announce a diagnosis.

For some doctors, achieving the right balance between presenting scientific information and showing empathy is not always straightforward and requires thoughtful preparation. Many doctors gain this balance over time, learning through experience and direct patient interactions.

However, some health professionals highlight the need for structured training.

They suggest that integrating soft-skills training into medical education or offering continuous professional development focused on communication and empathy would greatly enhance contact with patient. This type of training can help doctors better connect with patients, making them feel understood and supported while still being informed with clear, evidence-based information.

“ Quotes ”

It's clear that proper training is essential, and this should start at universities and continue through internships. Our medical education is excellent and highly scientific, and that's important to maintain. However, we also need to work on communication skills. There has been progress, but more work is needed. Personally, I have benefited from ongoing training to improve in this area.

One area that needs more focus is communication. In my opinion, we should also prioritize training in this aspect. For example, in oncology, we now have students, but I'm not sure if their curriculum includes communication training.

I would definitely be interested in training on how to announce diagnoses because, in reality, this is something we learn on the job. During my initial training, I did not have access to any structured program.

UNDERSTANDING AND ADAPTING TO PATIENT’S SOCIO-CULTURAL BACKGROUNDS

The announcement of a diagnosis between two people: one with knowledge and the other in a vulnerable position.

This moment not only conveys crucial medical information but also serves as the starting point for building a relationship between the doctor and the patient.

Healthcare professionals must be prepared to recognize and consider patients’ socioeconomic, linguistic, and cultural backgrounds. These factors significantly shape how patients understand and interpret a diagnosis, influencing their emotional response, willingness to engage in treatment, and ability to cope with a challenging situation.

Cultural awareness plays a key role in this process.

It affects the communication style, how verbal and non-verbal cues are interpreted, and the dynamics of authority in the interaction. For example, a patient from a culture that highly respects authority might avoid asking important questions out of deference to the doctor. In contrast, a patient from a culture with more informal norms might ask many questions, expecting a collaborative dialogue.

This chapter explores the perspectives of patients and healthcare professionals on how socio-cultural factors shape diagnosis communication, highlighting challenges, opportunities, and strategies for more effective interactions.

#Socio-cultural

#Adaptation

#Intercultural

#Barriers

#Culture sensitivity

#Healthcare challenges

#Body language

#Nonverbal cues

#Patients context

#Expectations

#Various languages

Patients speak out

Personalised care matters

Patients value being seen as individuals with unique stories.

They appreciate when healthcare professionals recognise their background.

Patients stressed the importance of an approach that acknowledges their unique backgrounds and personal stories. They recognized the challenges within the healthcare system, such as limited resources and overburdened doctors. However, they emphasized how much they benefit from interactions with healthcare professionals who take the time to listen and show genuine care.

Patients shared that when doctors, nurses, and case managers make an effort to connect with them on a personal level, it creates a feeling of being noticed and valued. This personalized attention helps them feel more confident in their care and more willing to engage in their treatment plans. For many, the human touch in healthcare is as vital as the medical care itself.

“ Quotes ”

She focused a lot on meeting my gaze, communicating with me, and reassuring me. But I wasn’t the same person during the two appointments, so each time, they adapted to me.

It's important to keep the patient in the dark as little as possible. How can I put this? Everyone reacts differently, but the time before the diagnosis and its announcement is just as important as the diagnosis itself. That’s when the emotional weight is the heaviest. You know something’s wrong. Maybe you’ve just come from a routine mammogram, a physical exam, a visit to the gynecologist, or a consultation with your doctor about another type of cancer.

Patients speak out

The impact of culture on communication

Patients know that their culture influences their understanding.

Patients emphasised that their understanding of a diagnosis is often shaped by the nonverbal cues given by medical professionals during conversations. These cues can be heavily influenced by cultural norms and expectations. However, patients may not always interpret these signals in the way they were intended. For example, formal language, limited eye contact, or a more reserved demeanor might be perceived as a sign of bad news, especially if patients come from cultures where communication is more open, involving touch, facial expressions, or other gestures of empathy and support.

“ Quotes ”

For example, when politicians visit another country, they have a team that helps them learn about the local culture. Their secretary gives them a briefing with important cultural points to know before they go.

Understanding cultures avoids misunderstanding.

Patients shared that when healthcare professionals don’t take cultural differences into account, it can lead to confusion and added stress. This can create a sense of uncertainty and anxiety, as patients might misread the situation or feel disconnected from the doctors. By considering and adapting to cultural context, medical professionals can ensure clearer communication, reduce misunderstandings, and create a more reassuring and supportive environment for patients.

A friend gave me the contact information for a psychologist in the Nantes area. He’s from Venezuela, so he understands Latin American culture well, but he also speaks other languages from the region. Being Venezuelan makes it easier for her to understand our values, emotions, and way of thinking. I’ve lived in several different countries, and I’ve noticed how the way people express themselves changes. I can tell the differences between how Swiss, German, French, Luxembourgish, Spanish, and Latino people communicate. Each culture is completely different.

Health Professionals speak out

Understanding the patient's situation

Consider the patient's social, professional, and family context.

Health professionals emphasize that getting to know a patient's background and situation is key to delivering a diagnosis in a way that fits the person's needs. However, this can be challenging. Doctors often use different approaches to learn about the patient's family life, work situation, and their ability to understand medical information.

Doctors tailor information to the patient's profile.

Doctors say that the tone and way they present the diagnosis are often shaped by this initial understanding. The insights gained from these early conversations help them communicate in a way that is thoughtful and appropriate for the patient's specific circumstances.

“ Quotes ”

> *Understanding the patient means having basic information about their life, which is crucial for how we approach them—whether they have a family, children, or a disabled relative at home.*

> *The process depends a bit on how prepared the patient is when they arrive. Many patients are referred by another doctor, so most are somewhat aware or fully aware of their diagnosis. Some might be in denial or hoping for a different outcome. Others might act as if they don't know anything at all.*

> *One of the biggest challenges is adapting to the personality of the patient in front of you. I believe it's the greatest challenge we face.*

> *I often ask, 'What do you think? What do you know? Tell me in your own words.' This helps me gauge what they understand and whether they want or are able to understand. I also look for any cognitive limits, language barriers, or signs of denial.*

> *We need to start by getting a sense of who the patient is and their level of understanding. Some people are easier to communicate with than others, so we must adapt our conversation to the person in front of us. It takes time to build that connection, but then we can be open and honest when delivering the news.*

Health Professionals speak out

The impact of cultural differences

A multicultural society calls for tailored communication with patients

Doctors pointed out that cultural differences add another layer of complexity to communication. These differences play a crucial role in shaping how patients perceive their diagnosis. Beyond speaking the same language, doctors need to understand the cultural nuances that influence how their message is received.

This includes recognizing how their tone of voice, body language, and eye contact may be interpreted by patients from different cultural backgrounds. In most cases, doctors rely on their years of experience to navigate these cultural differences effectively.

The challenge of intercultural communication

However, they noted that intercultural training could be valuable in enhancing their ability to connect with patients. Despite its potential benefits, this type of training was rarely mentioned by doctors during the interviews.

“ Quotes ”

In any case, I feel that I have improved my ability to pick up on non-verbal cues, which allows me to adapt my approach to different situations and tailor it specifically to the person. I believe it is adapted to the person.

This is a matter of generation and culture. In Luxembourg, there is a lot of diversity—it's not just Luxembourgers, but people from all backgrounds. And that is also a big challenge.

We currently have a Ukrainian patient, and it's very difficult. In this case, we have to rely on a family member for communication. For Syrians, there are generally translators, but it's still relatively rare. Usually, we find a nurse or one of our secretaries who speaks Portuguese. These people don't usually come alone. There are refugees—Syrian refugees or often those from Ethiopia. They typically come with someone from the shelter or an organization like Caritas. However, it's true that without intercultural communication, it becomes difficult, and it's not part of our daily routine.

When I fill in for other doctors, patients often tell me, 'Don't talk about that.' They don't want to know certain things or be asked why they're getting a specific treatment. This is often related to cultural and generational differences. In Luxembourg, there are people from many backgrounds, not just Luxembourgers, which makes communication challenging. Some languages have a tone that can come off as aggressive or too direct, even if that's not the intention. For example, Russian speech can seem reserved, while Spanish and Portuguese speech is more emotional, making it difficult to adapt.

TIMELY ACCESS TO RELEVANT AND RELIABLE INFO

Announcing a diagnosis should be seen as the start of an ongoing conversation, not just a single moment of bad news.

This approach allows **patients** to process the information step by step, ask questions, and feel more in control of their care, avoiding the overwhelming feeling that can come from a one-time announcement. It also helps **carers** understand the situation more clearly and support their loved ones through the process. To make the information easier to absorb, it's beneficial to break the announcement into several meetings, involving different **healthcare professionals** at each stage to ensure clarity and thorough understanding.

A crucial element of this process is ensuring that both patients and carers have a shared understanding of what to expect. Providing a clear overview or roadmap of the treatment helps anticipate future steps, reduce uncertainty and promote informed decision-making.

This not only builds trust in the healthcare team but also empowers patients and their carers to take an active role in the decision-making process. The result is better engagement, more informed choices, and a greater sense of control as they move forward.

This chapter highlights the importance of viewing the diagnosis announcement as an ongoing process, involving multiple stages and healthcare professionals. By breaking down the information and involving all parties, it helps build trust, prepares everyone for the next steps, and ensures that patients and carers feel more confident and supported throughout their journey.

#Dispatch
#Informed consent
#Support
#Structured information
#Teamwork
#Multi-step-diagnosis
#Trust
#Waiting time
#Information flow
#Crucial stage
#Shared-decision-making
#Collaboration

Patients speak out

The challenges of communicating medical information

Patients should be prepared for the unexpected.

Prepared patients handle uncertainty better.

Patients expect to get all information from their oncologist at once.

Patients have expressed the difficulties they face when different aspects of their diagnosis are not provided at the same time and when additional information comes from various sources, such as oncologists, specialists, case managers, breast nurses, psychologists, and dietitians.

Patients stressed that if they are not informed early on about this process and the need for information to be shared across different sources, it can lead to growing insecurity and frustration. This uncertainty often pushes patients to seek answers from unreliable online resources or to pursue second opinions and treatment options abroad.

Patients underlined the importance of being prepared for these different points of contact and understanding the gaps between them. Knowing what to expect and when to expect it can significantly reduce stress and avoid unnecessary actions, such as repeated phone calls and questions.

This feedback highlights the importance for health professionals to clearly communicate the process and timeline for sharing information. This approach helps decrease stress and reduces redundant actions, allowing patients and their carers to feel more confident and supported.

“ Quotes ”

I understand that my oncologist is very busy and doesn't have time to explain everything in detail. It would be helpful to have a resource that provides clear explanations. For example, a structured guide or decision tree with brief explanations at each step, like 'You are here because of XYZ.' Instead, I had to figure it all out by searching on YouTube.

Waiting for biopsy results is stressful. It’s important not to jump to conclusions, but the long wait for results is an issue that needs to be addressed and improved.

We need a medical professional to help us distinguish between what’s related to cancer and what isn’t. Sometimes, in moments of panic, we assume everything is connected to cancer, but that’s not always true. Having support to make these distinctions would be helpful medically and would ease patients’ minds. General practitioners aren’t experts in everything, so having clear guidance and information would make a difference.

The breast nurse was very helpful and provided all the information I needed, including flyers from the Cancer Foundation and Europa Donna. However, I never reached out to them except for help with a wig.

Patients speak out

The importance of mapping the care journey

Clear and structured information builds trust between patients and doctors.

Lack of clarity leaves patients confused and anxious.

Patients speak out about the importance of having a clear map of their care journey. They emphasize the need to understand who is involved in their care, what steps they need to take, and the decisions they will face along the way. When healthcare professionals provide this information clearly, patients feel more secure, confident, and better prepared to make informed decisions about their treatment. This clarity also helps foster a sense of collaboration with their healthcare professionals, building trust in the care process.

However, patients also point out that information comes from multiple sources, or what they refer to as the dispatch of information. They recognize that they won't receive all the details from a single healthcare professional but knowing where and from whom to expect information helps them manage their expectations. Without a clear map, patients often become confused and may search for answers from unreliable websites or seek second opinions, which can cause delays in their treatment and increase stress.

Patients highlight that providing a clear, structured overview of the care journey—detailing the sequence of information and key touchpoints—is crucial. This approach helps them feel more informed, reduces anxiety, and builds trust with their healthcare professionals. It ultimately empowers patients to feel more in control of their treatment, leading to better engagement and confidence as they move forward in their care.

“ Quotes ”

During the first appointment, it's mainly administrative—you book an appointment, pay your bill, and leave. Trust really starts to build during the consultation with the doctor, and it needs to be strengthened and maintained through ongoing interactions and support throughout the care journey.

Personally, I didn't search extensively for information about the different steps. My partner and I tried to keep track ourselves by making a list. I avoided looking things up online because, on the internet, it often feels like the worst-case scenario is the only one presented. I preferred to rely on the cancer experts instead.

Carers speak out

The need for a step-by-step approach

Information must be delivered in a step-by-step structured manner.

A step-by-step approach reduces frustration and misunderstandings

Carers stress that providing large amounts of information all at once can overwhelm patients, making it hard for them to process and retain critical details. They suggest that information should be divided into smaller, manageable portions and delivered step by step. This approach would not only reduce frustrations and misunderstandings but also give patients time to reflect and prepare additional questions for subsequent visits.

Carers also emphasize the importance of clearly distinguishing the stages of care and the roles of the different healthcare professionals involved, such as case managers, psychologists, and dietitians.

Understanding this network would help carers prioritize their own questions, saving less urgent ones for later and focusing on immediate concerns.

By having a clearer understanding of the process, carers feel they could remain calmer and more patient, offering valuable emotional support to the patients they care for. This structured approach would ultimately foster better communication and collaboration between all parties involved.

“ Quotes ”

Don't give all the information about the illness, treatment, and process at once. Instead, have several smaller, structured appointments.

I would have appreciated being contacted to explain the process in more detail and what would happen to my wife at each stage (side effects of treatment, how to respond, what I can do to support her). For example, it would have been helpful to know that if she vomits for two days, it’s normal, or when to go to the hospital with her.

Carers speak out

Timely and coordinated information

Ensure a more coordinated care process.

Carers emphasize that receiving information shouldn't rely on just one doctor. Instead, they highlight the importance of multiple touchpoints where information can be shared at appropriate times. This approach ensures that patients, carers, and doctors stay well-informed throughout the care journey.

Information should not rely on one doctor.

Carers report that when different professionals provide timely and relevant updates, it promotes better communication and a smoother flow of information. This allows everyone involved to dedicate the necessary time and attention to each stage, leading to a more coordinated and supportive care process.

“ Quotes ”

Having someone to ask questions about the current and future stages of the journey is very important.

Doctors need to take time to explain things clearly. Using simple, accessible explanations, even showing pictures, would help. When you leave the consultation, that's when the questions arise, and we need answers. It would help avoid having to search for answers on the internet.

There is a way to announce a diagnosis that involves providing clear information, reassurance, and preparing the patient for what's to come. What will happen next? What kind of psychological support is available? Some patients appreciate this, while others may not, and that's okay. It can also be helpful to share a list of support groups or organizations where patients can find peer support, which might be more suitable for some than a psychological consultation. Everyone is different, and it's important to offer options, so each patient can choose what makes them most comfortable. Patients often have many questions that are difficult or worrying, and not having answers can be hard to deal with.

Health professionals speak out

Importance of a staged diagnosis announcement

A step-by-step diagnosis gives patients time to think and prepare their questions.

A multi-step diagnosis allows doctors to provide complete information over time.

Health professionals emphasize that announcing a diagnosis should not be a single event but a gradual process. Delivering information in stages allows patients to absorb and process the news more effectively, mitigating the initial shock and emotional impact.

The first stage typically provides clear, essential facts about the diagnosis and outlines immediate next steps. This approach establishes a foundation of trust and clarity, helping patients feel informed and reducing their anxiety during a highly stressful time.

As the process unfolds, more detailed information is shared incrementally. Patients often require time to process initial news before engaging with discussions about treatment options, prognosis, or lifestyle changes. This measured delivery prevents information overload and supports emotional resilience.

A staged approach also addresses the psychological burden of waiting times. Breaking the information into manageable phases ensures that patients have opportunities to ask questions, seek clarification, and feel a sense of control, which health professionals note is vital for fostering trust and collaboration in treatment planning.

“ Quotes ”

I believe it’s important to immediately connect the diagnosis with the treatment and care plan.

So people at least feel something is wrong, they suspect it. That’s the first step. The precise diagnosis comes next, and often we don’t know it ourselves right away. We can say, ‘Here, we suspect a tumor, but we don’t know exactly which one.’ We have to wait for the results.

I think the process should probably happen in several steps, at least to give medical professionals time to fully understand the situation and provide the most complete answers.

Sometimes we need to wait 2-3 weeks for the histological results. It’s a difficult time. We cannot confirm the cancer stage or provide detailed information.

Health professionals speak out

Clear roles and team collaboration

Effective coordination between specialists enhances the care process.

Poor collaboration between specialists can lead to confusion and frustration for patients.

Healthcare professionals speak out about the importance of effective communication and coordination during the diagnosis and care process. They highlight the need for collaboration among a network of professionals, including specialists, GPs, nurses, and other key figures, each playing a distinct role in patient care. This coordinated approach ensures that information flows smoothly and that all involved understand their responsibilities.

For this system to work effectively, patients and carers must be informed about the roles of different healthcare professionals from the outset. When patients and families are aware of whom to approach for specific concerns or support, it reduces confusion and fosters trust.

Understanding who is responsible for what at each stage helps patients feel more secure, supported, and empowered as they navigate their care journey. It also allows healthcare professionals to focus on delivering the most effective treatment, knowing that all roles are clear and well-understood.

This shared clarity not only enhances coordination but also creates a supportive environment, improving outcomes for patients and their families. By making sure everyone knows their role and who to turn to for specific needs, the care process becomes smoother and more efficient, ultimately leading to better patient engagement and trust in the healthcare system.

“ Quotes ”

Sometimes we review what has already been discussed. My secretaries are also briefed and call each patient the morning after their cancer diagnosis discussion to check if they have understood everything.

Breast care nurses can also answer questions —they are part of the team and the process.

The oncologist doesn’t directly call the psychologist. First, the oncologist contacts the case manager to schedule the treatment, and then the psychologist gets involved.

That’s why we have case managers who are part of the team and often follow up with the patient. They handle practical, everyday questions and anything related to social support.

ENSURING PATIENTS UNDERSTANDING AND PREPARE FOR KEY MILESTONES

Empowering Patients with Clear Roadmaps: navigating Tests, Appointments, and Milestones Effectively

Patients and **carers** often see the announcement of a diagnosis as an ongoing process rather than a one-time event. They highlight the need for a clear roadmap to help them navigate different stages of their journey, including tests, appointments, and other milestones. Such a plan could help them anticipate waiting periods and make use of the time effectively. Patients and carers suggested various formats for this roadmap, such as paper documents, journals, folders, or digital tools.

Health professionals, however, have some concerns about creating standardized maps for individual use. They emphasize that any roadmap would need to be highly adaptable to reflect the unique and changing nature of each patient's situation.

This chapter explores the perspectives of patients, carers, and health professionals on how to best support patients through the diagnostic process and the potential benefits of providing a flexible, comprehensive roadmap.

#Resilience

#Fight Mood

#Protagonist

#Clear Next Steps

#Teamwork doctor-patient

#Written summary

#Waiting time

#Roadmap

#Anticipation

#Navigation

Patients speak out

Navigating the diagnosis journey

Patients need support to navigate the process.

A roadmap helps patients manage challenges.

Patients feel uncertain when doctors don't provide guidance.

Patients often describe the experience of receiving fragmented information during the diagnosis process as confusing and overwhelming. They highlight the need for a comprehensive plan that clearly outlines the next steps in their journey. A visual roadmap that lays out the main stages, including expected waiting times, would be especially helpful in allowing patients to anticipate what comes next and feel more in control of the process.

Quotes

He contacted the oncologist, who was a colleague of mine, and made an appointment for the following Tuesday. This was on a Friday, and by Tuesday, I was at the hospital for a liver biopsy. He took care of everything.

A roadmap would be very helpful, and with current technology, we can make it available to everyone.

It's comforting to have a piece of paper to hold onto after the diagnosis, especially during a crisis when you don't know what to do.

They took care of everything – the tests, the follow-up – and then gave me a roadmap with my upcoming appointments. I didn't even have to arrange it myself. They provided everything.

Patients value the support provided by doctors and case managers who assist in organizing the initial stages of their journey. This structured approach helps create a sense of stability during an uncertain time. Evidence of this importance is reflected in the fact that many patients, even months or years after their diagnosis, can recall specific details such as the date, day, and name of the first examination they were referred to. This shows how impactful clear guidance and organization are for patients as they navigate their diagnosis and treatment path.

A written report of the diagnosis would be helpful.

It was just taking it one day at a time, getting through each day and seeing what would come next.

I know she went to the hospital herself to make my appointments and speed up the process. That support was very important and reassuring for me.

Right now, everything feels disconnected. There is some coordination through the case manager, but it's still very fragmented. I wonder if patients should be given an overview of their journey and what to expect. I was given some information, and it was explained to me.

I had an action plan, and what helped was that my gynecologist, who diagnosed me, already scheduled an appointment with the surgeon. This made me feel prepared for what was coming. She also explained about the committee and other details.

Patients speak out

The role of information and active involvement

Informed patients become stronger in the face of challenges.

Patients build the ability to respond effectively.

Without a clear framework, patients may struggle to find motivation.

Patients highlighted that having clear and equal access to information about their journey, starting from the moment of diagnosis, helps them feel more in control and involved in their care.

Knowing what to expect at each stage and understanding the time between them can make them feel stronger and more prepared to face challenges.

This knowledge also gives them the chance to take emotional breaks and be ready for new information, encouraging them to take an active role.

However, being in control of their journey isn't always easy. Many patients said that not having enough information, feeling afraid to ask questions, or struggling to understand the details often leads to a sense of helplessness and a lack of empowerment.

“ Quotes ”

It took me two weeks to accept it, and then I switched to a fighting mindset.

They took care of everything – the tests, the follow-up – and then gave me a roadmap with my upcoming appointments. I didn't even have to arrange it myself. They provided everything.

Due to past experiences where I didn't always have good interactions with some professionals and saw their lack of expertise, I learned to find information myself and verify what I was told to find the best solutions. This time was different, though. It was one of the first times I fully trusted a professional based on their reputation and others' feedback. I never questioned their decisions, which was very important. Accepting the treatment plan as my own and trusting the process was essential.

Carers speak out

Navigating the challenges of the diagnosis journey

A clear roadmap makes navigating challenges easier.

Carers struggle to support patients without knowing the next steps.

Carers highlight the immense responsibility they bear during the announcement of a diagnosis, balancing the emotional task of reassuring the patient with the practical need to help them prepare for the next stages of their journey.

Many underline the value of having a clear roadmap, even if flexible, to guide both patients and carers through the process.

They emphasize that such guidance can transform waiting times into opportunities for preparation, such as formulating questions for the next steps, rather than managing anxiety or searching for answers online.

Additionally, carers point out their own need for support, noting that when they feel informed and reassured, they are better equipped to provide the necessary care and stability for their loved ones.

“ Quotes ”

Of course, we needed a few days to process the information.

When we had questions, they were answered, but we didn't have many at that moment. The situation was overwhelming, and so much happened that day that we didn't have the chance to ask many questions.

It would be helpful to have step-by-step explanations of what will happen next.

It takes time to present options and make decisions.

I'm not sure... well, maybe it would be helpful to read something afterwards, but as a partner, I prefer having a person explain everything—what is happening and what comes next—rather than just reading brochures.

Health Professionals speak out

Preparing patient for treatment milestones

Creating a roadmap is helpful for patients and carers.

Health professionals highlight the need for a clear treatment framework, with key milestones like treatment phases, follow-ups, and recovery expectations, to help patients and carers prepare mentally. However, treatment plans must be flexible to adapt to changes in the patient’s condition, therapy response, or unforeseen complications, making rigid schedules problematic.

“ Quotes ”

So, this is the most important collection for the patient and for the family. And then you can see usually the patient doesn't relax, but if the bad news is connected to some kind of « parcours » than the patient usually- not always- is able to at least digest some some some of his diagnosis. Not everything. That's not possible.

It's a journey because not all the data arrives at the same stage. And the diagnosis is “Yes, we have breast cancer.” But what do you do with breast cancer? So what are the next steps? So it's something to work on.

Creating roadmap is a challenge for the doctors.

While a general roadmap offers reassurance, it must acknowledge the uniqueness of each patient's journey. Patients should understand the key milestones, but also know adjustments may be necessary. This approach ensures patients are informed yet adaptable, without feeling overwhelmed by rigid timelines.

Open communication about potential changes helps manage expectations, reduce anxiety, and keep everyone focused on effective care. By balancing structure with flexibility, healthcare professionals provide the support patients need while remaining responsive to evolving needs.

Sometimes, patients ask for a roadmap, such as what will happen in six months or whether their chemotherapy will be on July 2nd or July 7th. It’s difficult to plan that far ahead. Some patients ask for it, but we have to explain that it’s not possible because there can be unexpected changes, like not feeling well, needing a break from chemotherapy, or adjustments based on the progression of the disease.

Right support, right time for patients and carers

Navigating the cancer journey presents significant challenges for patients, carers, and health professionals.

Each group plays a vital role in the process and has unique needs and expectations, making effective collaboration and timely support essential.

Patients often face emotional distress, practical difficulties, and an overwhelming amount of information. While they primarily turn to oncologists for guidance, their journey also relies on a network of professionals like case managers, psychologists, nutritionists, and social workers. Many also seek peer support outside the healthcare system to find human connections and shared experiences.

Families and carers play a critical role in supporting patients but often lack the tools and timely assistance they need to navigate emotional, administrative, and practical challenges. Accessing the right resources at the right time is crucial for their well-being and their ability to provide effective care.

Health professionals are central to coordinating care, ensuring patients and carers receive tailored support, including psychological assistance, administrative help, and connections to reliable information. Clear communication between healthcare providers (e.g., oncologists and GPs) is essential to streamline the process and prevent confusion or wasted effort.

This chapter looks at the challenges faced by patients, their families and healthcare professionals. It highlights the gaps in current support and proposes solutions to ensure that the right support is provided at the right time.

#Information Flow

#Patient Organisations

#Carers Support

#Timely Support

#Peer-to-peer Support

#Psychological Support

#Trusted Resources

#Guidance

Patients speak out

Seeking peer-to-peer support

Patients seek connection with peers.

When faced with a cancer diagnosis, many patients instinctively seek connection with others who have experienced a similar journey. They underline the importance of peer-to-peer support as a way to share experiences, gain emotional strength, and feel less isolated. This is why patient associations and support groups dedicated to specific types of cancer play such a critical role.

Patients also emphasize the value of being guided toward trustworthy sources of information and assistance.

Patients value being referred to trustworthy sources by healthcare professionals.

Often, healthcare professionals refer them directly to reliable organisations such as Fondation Cancer, Europa Donna, or Think Pink, which provide not only practical resources but also a sense of community and understanding.

These connections, whether through healthcare professionals or self-initiated outreach, are seen as vital steps in helping patients navigate the initial shock and ongoing challenges of their diagnosis with greater confidence and clarity.

“ Quotes ”

I went to Europa Donna because I was completely lost. It was helpful because the president gave me some advice on how to manage the treatment journey and access support services. These services weren’t centralized in Luxembourg at the time, but they might be now.

An addition of a social worker or psychologist, you have a patient partner who you can share the rest of your story with. You don’t talk about emotions or financial issues with them, but they help you manage your feelings, fears, and doubts and gain confidence in your treatment and involvement.

I got back in touch with the Cancer Foundation and the psychologist. I was still in contact with them, but we only spoke every couple of months just to check in, as there are always questions.

I just thought, ‘Okay, now it's your turn,’ without thinking about the end of my life. 6 out of 100 people get prostate cancer, but not all of them talk about it. It’s a bit of a taboo, especially because it’s linked to sexuality.

Europa Donna explained what services were available in hospitals and outside them, including support care. What I missed the most, even if I didn’t realize it at first, was talking with others in a similar situation. It was hard to find people of my age with similar experiences. Most of the people I met were older, which I couldn’t relate to.

I reached out to Think Pink Luxembourg, which focuses on cancer support. That same day, they dropped off their guide to living with cancer in Luxembourg and sent weekly check-in messages asking how I was doing and if I needed anything. But that was the only support I received. I didn't contact the Cancer Foundation or Europa Donna because their website wasn’t in English.

Patients speak out

The need for psychological support

Patients need timely psychological support.

Without psychological support, patients felt overwhelmed and powerless.

Patients highlight that psychological support at the time of diagnosis is crucial for coping with the emotional impact. Many patients felt a sense of relief and gratitude when they received timely support from their oncologist, which helped them manage the stress and uncertainty that comes with a cancer diagnosis. However, some patients mentioned that they were unsure about when to expect this support or what kind of help would be provided, which sometimes led to confusion or anxiety.

For those who did not receive psychological support, the experience was notably harder. They spoke of feeling overwhelmed, stressed, and powerless without the guidance they needed. This feedback emphasizes the importance of ensuring that patients receive clear communication and timely emotional care to help them navigate the early stages of their diagnosis more confidently and with greater support.

“ Quotes ”

Psychological support? Forget it. Nothing at all. It was just 'thank you, goodbye,' and that was it.

I think that as soon as the radiologist sees that it's something serious, they should immediately call the psychologist without asking, 'Do you want me to call a psychologist?' They should just ensure support is in place because I was alone and had to drive myself there.

I found great benefit in the psychological support offered by the Fondation Cancer. It was something I continued to use, and I believe it’s very important.

When he mentioned the psychologist, no one told me anything about any foundation or support. But in hospital, the psychological support was excellent. The psychologist would always visit me, and she even saw my children. My husband didn’t need it because he’s a sophrologist and does a lot of things to help himself.

Patients speak out

The importance of a dedicated contact person

A dedicated contact person guides patients and provides timely information.

Without this help, patients can feel overwhelmed and alone.

Patients consistently highlighted the positive impact of having a dedicated contact person, such as a case manager or breast nurse, during their diagnosis. They stressed that this support was essential for guiding them through the process, ensuring they received the right information when needed. This dedicated contact also provided crucial ‘ad hoc’ support during moments of high stress or panic, especially when their main oncologist was unavailable.

Patients shared that knowing there was someone they could reach out to for immediate assistance made them feel more secure, supported, and less alone during difficult times. This kind of care helped them navigate their journey more confidently and with greater peace of mind.

“ Quotes ”

I needed someone to help me after my appointment.

Having one person to manage things, like appointment reminders and transport, would have been a big help.

I missed having someone to check in with, like a case manager, alongside the doctor

A case manager or nurse who helps prepare the patient for the fast-paced process, including unexpected appointments, and ensures they are ready with necessary notes and information.

I’m not sure if there are enough staff for case managers, but having someone to track appointments and answer questions would be useful.

There should have been a contact person, not a doctor, to guide me through the process.

Carers speak out

The importance of punctual psychological support

Carers valued punctual psychological support.

Carers mentioned that punctual psychological support for themselves and their families could be a highly beneficial part of the services offered. However, not all carers had access to this support, even though they all emphasized how valuable it would have been. They explained that their constant state of alertness and readiness to support others often led them to overlook their own needs.

Not all carers had access to it.

When doctors offered psychological support or provided a list of available psychologists through support organizations, it was seen as extremely helpful. Carers also pointed out that psychological support for children is essential but must be tailored to their specific needs and provided at the right time.

“ Quotes ”

We saw a psychologist who explained what would happen next and was there if we needed them. It was reassuring, though I’m not sure of all the details of the process.

The Fondation Cancer should offer more support for carers, like simple check-ins or listening services. Even a small gesture of support can mean a lot.

Psychological help wasn’t really offered to me. I only saw a psychologist because my wife requested it.

Once it was offered, we agreed right away. We met with different therapists, and even when the main therapist was away, the replacements were familiar with our case and continued the support.

I was in 'fight mode' to support my loved ones. It felt like I was getting hit from all sides and couldn’t stop to think or care for myself. I had to stay strong for everyone else, even if that meant ignoring my own needs.

Psychological support for families is needed. The way a diagnosis is shared matters—it should include clear information, reassurance, and preparation for what comes next. Some carers appreciate psychological support, while others prefer different options, like support groups. It’s important to give everyone choices that fit their needs and comfort levels, as unanswered questions can be difficult for both patients and carers.

The psychologist at the hospital was kind, but it wasn’t enough for my kids. The way the information was shared wasn’t designed for children, and we received no guidance on how to talk to them about difficult topics. I had to handle it myself.

Health professionals speak out

The importance of reliable information

Doctors guide patients to trusted resources.

Reduce patient and carer stress by preventing searches in unreliable sources.

Health professionals emphasize the crucial role they play in guiding patients to trustworthy sources of information. Doctors highlighted that directing patients to local support organisations, credible online resources, and accurate printed materials is essential.

This guidance helps prevent patients from resorting to potentially harmful or misleading internet searches and ensures that they receive the most reliable and helpful information available. By providing this support, health professionals can empower patients to make informed decisions and reduce stress and confusion during challenging times.

“ Quotes ”

I encourage the patient to go home and check reliable sites, like books or trusted online resources. I tell them to avoid blogs or any site that could lead them astray.

I also provide them with information, explaining that it’s better than looking online and finding strange forums with stories. I have a printed page with scientific links from major European, American, and Canadian medical societies.

I give them flyers, which we have in three languages. It’s a lot of material, but the flyer is the simplest. People often pass them along to others.

We now have a binder at the HRS with information about their illness, what to expect, side effects of chemotherapy, immunotherapy, radiotherapy, and useful contact numbers, like taxi services for transport. I also include the recent brochure from the Cancer Foundation.

Health professionals speak out

Enhancing collaboration and support

Doctors need teamwork for better care.

Better communication between oncologists and GPs is key.

Healthcare professionals stress the importance of a team approach to diagnosis. Nurses and case managers play a key role in helping patients manage their emotions and providing essential information. This support is particularly valuable when communication between the oncologist and the general practitioner could be further strengthened, to guarantee patients a reliable and continuous source of information.

leaving patients without a single, reliable source of information.

Improved sharing of reports between oncologists and GPs can save time for oncologists by allowing GPs to address patient questions and concerns that they are equipped to handle.

“ Quotes ”

The issue is that GPs are not always aware of the patient’s full situation. We have our multidisciplinary meetings and send them a report, but it’s not always enough.

We give the patient a copy of the report, which they can take to their GP. Unfortunately, radiology rarely sends the reports to the GP, even if requested. And we don’t send our chemotherapy notes, as it would become unmanageable with paperwork.

I remind patients that if they have further questions, they should contact my desk. We’re always available to meet again if needed. I also tell them I’ll send a report to their GP, so they can discuss it with them if they wish. It’s important to keep communication channels open.

Case managers play a big role in supporting patients, especially with practical and social questions about daily life. They often take over after the initial consultation and help manage patients’ needs.

We sometimes revisit topics we discussed earlier. My secretaries are trained to follow up and call patients the day after an initial cancer diagnosis to check if they understood everything properly.

In my opinion, there should be more collaboration with family doctors, similar to how it’s done in England or Scandinavian countries, where their role is more structured. However, this depends on the individual doctors—some are willing to work closely with oncologists, while others find it difficult or prefer not to.

Health professionals speak out

Psychological support for patients and carers

Patients and carers should decide the right time for psychological support.

There is no standard process for providing psychological support.

Health professionals stress the importance of psychological support for patients and their families during the diagnosis process, although there is no standardized approach for when or how this support is offered. While many hospitals have psychologists available, the integration of these services can vary.

Doctors usually involve case managers to plan treatment, and psychologists are brought in as needed. This approach ensures support is offered without being forced on patients. It was mentioned that having a psychologist present during the initial diagnosis might not be helpful and could even be counterproductive.

Support should be offered in a way that allows patients to choose when they need it.

Patients are informed about available psychological resources, and social workers, to help them access support. Health professionals also ensure that carers and family members, including children, are considered and offered psychological assistance when needed, even though these services are not standardized. Overall, while psychological support is seen as vital, it is provided based on the patient's needs.

“ Quotes ”

The oncologist does not directly call the psychologist. First, the oncologist contacts the case manager to plan the treatment, and then the psychologist gets involved.

If we need to announce a diagnosis, there are resources available, such as a social worker, case manager, or psycho-oncologist. We always ask if they need psychological support or help, including for children.

I don’t think it would be helpful to have a psychologist in the same room. It could even be counterproductive. People need to feel free to reach out for psychological support when they’re ready, without being forced.

DEFINING THE ROLES OF PATIENTS AND CARERS IN THE DIAGNOSIS JOURNEY

The announcement of a diagnosis is a pivotal moment that influences whether **patients** perceive themselves as active participants or passive observers in their healthcare journey. This perception is shaped by multiple factors, including their relationship with the doctor, communication with other health professionals, clarity of their current situation, and understanding of the resources at their disposal. The pace at which the situation evolves—whether rapidly or gradually—also impacts both patients and carers, determining the extent of their engagement.

Carers often serve as vital partners in this process, balancing emotional support and practical involvement. Their role depends heavily on the guidance and communication they receive from medical staff, as well as their ability to navigate complex healthcare systems.

Health professionals play a crucial role in framing patients and carers as active collaborators in the treatment process. However, they face challenges such as ensuring informed consent and managing the complexities that family involvement can bring. This requires a personalized and adaptive approach to meet the unique needs of each patient and their carers.

This introduction sets the stage for a deeper exploration of how these roles are defined and interconnected, shaping the journey from diagnosis onward.

#Regaining control

#Decision-making

#Support

#Responsiveness

#Actors

#Informed-decision

#Responsibility

#Protagonist

#Empowerment

#Responsibility

Patients speak out

Ownership and active participation in care

Patients want to be a protagonist of their journey.

Empowered patients feel more engaged in their care.

Poor communication make it hard for patients to manage their treatment

The patients underline the importance of being recognised as active contributors in their treatment journey. They emphasize that feeling empowered to participate meaningfully in decisions about their care fosters a sense of ownership over their health. Patients note that this involvement allows them to navigate their situation with greater confidence and purpose.

However, the ability to respond effectively to their circumstances is not something they can achieve alone. Patients stress that they rely on health professionals to provide clear communication, guidance, and support. This includes not only explaining options and consequences but also ensuring patients understand their role in the process.

Some patients expressed that being encouraged to take “responsibility” for their health decisions requires health professionals to approach their care collaboratively, offering reassurance and clarity during difficult times. This sense of shared responsibility can help them feel better equipped to handle the choices and uncertainties ahead.

This feedback underscores the necessity of building a partnership between patients and health professionals, where patients are actively supported in their role as key decision-makers in their treatment.

“ Quotes ”

I knew I had to keep my thoughts positive. And what do you find online? Mostly negative things. I didn’t want that, so I stayed focused on the positive and kept connected to it. That was my job. I trusted the specialists to handle the rest.

They need to understand the patient’s knowledge and adapt their explanations accordingly. Decisions should involve the patient—not just telling them what to do, but how to do it.

Why did I hesitate so much? The key was trust. I think it was because of past experiences with professionals who lacked expertise, which made me rely on myself to find information and ensure it was accurate. This time, for the first time, I trusted the professional completely based on others' feedback. I never questioned decision, and that trust was crucial. Trust isn’t just about the doctors but also the people around them. The medical office staff needs to be patient and empathetic; otherwise, things can fall apart. Scheduling and contact should be smooth, as the patient should always be at the center of it.

It’s about empowering the patient in their journey, making them an active participant who can manage as best they can, but with support to help them do so.

Patients speak out

The importance of being involved and informed

Patients should be seen as co-decision makers.

Feeling not recognised by doctors pushes patients to seek outside support.

Patients underline the need to be taken seriously by health professionals and to be well-informed and considered equal partners in the decision-making process. With access to a wide range of information, many patients now come to appointments prepared and do not see healthcare providers as their only source of knowledge. As a result, they increasingly expect meaningful dialogue and interaction, rather than simply being given facts that keep them in a passive role.

“ Quotes ”

When I spoke to the urologist, I learned that my case was more serious than just observation, as I clearly had cancer. The urologist suggested radiotherapy instead of surgery, and since I wasn't fully informed, I trusted his quick decision.

Finally, someone took the time to sit with me, and I had a conversation with the anesthesiologist. My surgeon called to say he couldn't see me before surgery due to his busy schedule but wanted to make sure I could ask questions. I also spoke with nurses about what to expect after surgery and how to take care of myself.

He said, 'I need to discuss everything with you,' but I replied, 'No, you don't. I have a nurse in the family who's been through this.' He insisted, 'You're making my job easier, but I think we should go over all the options.' But I wasn't interested in options; I knew which one I wanted.

Take patients seriously. I had to see three different doctors before finally getting a colonoscopy prescription. That experience still makes me angry, and I work hard not to let that anger take over because the outcome was what it was. But I felt like I had to almost beg to get the care I needed.

I made it clear from the start that I'm very logical and need detailed information to process things. I told everyone at the hospital, 'I want to know everything, no hidden information.' The nurses were amazing—beyond my expectations, showing true human care. You feel very vulnerable in the whole journey from the diagnostics until the recovery comes.

Patients speak out

Taking control of their journey

Support from others helps patients stay proactive.

Waiting for decisions can make patients feel powerless.

The patients emphasize that support from their surroundings is crucial in maintaining an active role in managing their illness. Many express a desire to take initiative instead of passively waiting for decisions to be made on their behalf.

They seek out the resources they need to stay proactive, such as involving carers in a specific, supportive role, reaching out to healthcare professionals, and even trying to influence the timing of scheduled exams. This approach allows them to feel more in control of their treatment journey and empowers them to navigate their disease more effectively.

“ Quotes ”

It was comforting to know he was there, had answers to my questions, and that everything was taken care of. All I had to do was deal with my cancer and later, my amputation.

Luckily, my friend stepped in and took charge, making all the appointments for me. But that’s not usually how it goes. I was fortunate to have someone who acted as my guardian angelslavall.

I was a bit in shock, so it’s helpful to have someone there with you. I only retained a few things from what was said, but it was clear enough for me. It’s important to have support, especially to avoid missing any information, as we’re starting down a path we don’t know and using unfamiliar medical terms.

Carers speak out

Supporting patient through their healthcare journey

Carers bridge gaps, offering emotional support.

Carers underline the important, complementary role they play in supporting patients throughout their treatment. In moments of uncertainty or when communication from healthcare providers is unclear, carers often step in to assist by seeking additional information, clarifying details, and ensuring that the patient’s voice is heard.

“ Quotes ”

> ***You can support someone to a point, but in the end, the patient must take ownership of their journey.***

> ***During a critical moment, we had the full care team present: the head of the department, a surgeon, a psychologist, and a nurse. This collective support made a big difference.***

> ***Sometimes, doctors shared more with me than with my wife. While I understood it was important for her, it felt disrespectful not to address her directly. Still, I did my best to support her and ensure she wasn’t overwhelmed.***

> ***At the beginning, I accompanied my wife to her oncology appointments to ensure all our questions were addressed. The doctor rightly prioritized her as the patient. We prepared our questions in advance, discussed our concerns, and made sure everything was covered. This approach was very important for us.***

Carers often fill in when communication is unclear or insufficient.

Carers act as partners in the process, helping patients understand complex medical information, sharing updates, and facilitating communication between the patient and medical professionals. Their involvement can also help patients explore available options and stay organized, such as managing appointments or gathering second opinions when needed.

By providing both emotional and practical support, carers contribute to creating a more cohesive and patient-centered care experience.

> ***After the biopsy results, we discussed treatment options, including a potential amputation. The doctor handled it with empathy, understanding, and respect, which made us feel heard and valued, even when we asked basic questions. We were treated with dignity as patients in distress.***

> ***We were in fight mode. I had to be the psychological support for my wife, children, and extended family, all while facing challenges from every direction. You have no choice but to summon courage and face the fight head-on.***

> ***One evening, after getting the diagnosis, we met the surgeon. My wife was overwhelmed and broke down. The surgeon, unfortunately, directed all her communication to me and ignored my wife. It lacked empathy and left us both with a negative impression.***

Health professionals speak out

The challenge of informed consent

Health professionals value informed consent and aim to support patients.

Patients may struggle with decision-making due to lack of knowledge and emotional distress.

Health professionals recognise the importance of obtaining informed consent from patients before proceeding with treatment. However, they also acknowledge that not all patients are in the best position to make fully informed decisions.

Factors such as limited medical knowledge, emotional distress, and difficulty understanding complex information can impact a patient's ability to process and make decisions effectively. This highlights the need for healthcare providers to support patients in a way that helps them feel empowered and informed, while also ensuring they are not overwhelmed during critical moments.

“ Quotes ”

Informed consent. I was in Namur for an ethics training session, and we were told that informed consent doesn't really exist. Because the one who is truly informed is the doctor, the oncologist, and never the patient. The patient is often a layperson with no medical knowledge.

It's a significant challenge to understand the patient's mindset. This situation is stressful for them because they are facing something they don't want to deal with, and it can't be predicted. There is a great deal of uncertainty: it can go very well or very badly. And even if a patient seems to accept, they can be surprised the first time they face reality and say they never agreed. Sometimes, informed consent appears to have been given, but it's important to have notes to be certain.

Another challenge, which is even more complicated, is dealing with patients in denial. It becomes difficult to know what to do, especially when important decisions need to be made. Even though we strive for transparency and we are no longer in the paternalistic approach of 30 or 40 years ago, we must be realistic: even with informed consent, the doctor always influences the patient. It may seem like the patient has total freedom of choice, but if I tell you that there is a high probability that the proposed option increases the chances of recovery and we discuss it together, it complicates things. For patients in denial, they want everything to be managed in their favor, but it's challenging, especially when family members are nearby. This is the greatest challenge: staying impartial.

Health professionals speak out

Involving family and carers while remaining patient-focused

Involving carers can empower patients and clarify next steps.

Health professionals recognize that involving carers and families in the treatment process can help empower patients and reinforce their understanding of what comes next.

Ensuring patients' perspectives are prioritized, even when families are proactive.

However, some doctors point out that the focus should stay on the patient, particularly when family members have trouble finding their role as supporters. This can happen because of language barriers, cultural differences, or difficulty coping with the situation.

“ Quotes ”

> *I always make sure to deliver bad news to the patient directly, never just to the family. It's always a joint conversation, but I must remember that the family's needs are different from the patient's, and I am the patient's doctor, not the family's.*

> *Sometimes, family members can be the biggest challenge, not the patient herself. The husband, a friend, or a partner who is present can be overwhelming. A patient might be strong and composed, while the person accompanying her is acting inappropriately. Sometimes it's the opposite, with calm family members and the patient becoming completely distressed by the diagnosis.*

> *For me, the most important aspect is not the office or the consultation, but the direct exchange between the doctors, the patient, and their family in a calm and respectful environment. It should be an equal exchange. I have worked in the United States and have seen consultations where the doctor sits directly next to the patient, without a table between them. This is preferable as it fosters an equal conversation, especially when the patient is lying in bed. Giving a diagnosis to a patient who is in bed is problematic because it creates an imbalance: the patient is already vulnerable, and the caregiver is in a position of power. This makes it difficult to have an open conversation about treatment and consent. Of course, there are exceptions, such as in emergencies or when an unexpected diagnosis is discovered, but ideally, a consultation outside the hospital is better. For example, I decided not to visit a patient who was hospitalized last week, choosing instead to wait until they were ready to be discharged to see them here. In my opinion, that's the best solution.*

09

ORGANISATION

THE RIGHT CONTEXT: SPACE AND TIME FOR THE DIAGNOSIS ANNOUNCEMENT

The setting and timing of a diagnosis announcement are critical factors that can significantly influence the experience for patients, carers, and health professionals.

For **patients**, a calm and supportive environment helps reduce anxiety and enables them to process sensitive information with greater clarity. Face-to-face interactions are particularly valued, as they offer a sense of security and stability, helping patients and their **carers** navigate the emotional challenges of a diagnosis. Carers often highlight the importance of these moments in gaining a clear understanding of the situation and providing essential support.

For **health professionals**, carefully planning the space and time for delivering a diagnosis is vital to ensure effective and empathetic communication. A thoughtful approach not only fosters better comprehension but also strengthens trust and relationships between the medical team and the patient.

This chapter explores how these factors - space, time, and interaction - impact the delivery and reception of a diagnosis, highlighting perspectives from all three groups.

#Essential points

#Quality Time

#Room Atmosphere

#People Present

#Diagnosis Space

#Human connections

#After announcement

#Powerless

#Limited Attention

#Privacy

#Phone Announcement

Patients speak out

The impact of diagnosis announcements

After a diagnosis announcement, time for reflection is important.

Announcing a diagnosis over the phone increases anxiety.

Patients shared varied experiences regarding how their diagnosis was communicated, with significant differences in emotional impact and overall perception.

Some patients who received their diagnosis by phone expressed disappointment and noted the stress associated with this method. They highlighted feeling shocked and alone, grappling with the uncertainty of what the future would hold. The phone call left them with a sense of isolation, as they struggled to process the news without the immediate support of in-person interaction.

However, not all responses were negative. One patient shared a unique perspective, stating that the telephone diagnosis allowed him to release his emotions in a way he felt he could not do in front of a doctor. This reaction underscores how individual needs and preferences can shape how patients cope with difficult news.

These insights from patients emphasize the importance of considering the method and context of delivering a diagnosis to provide support and foster a sense of security during such challenging moments.

“ Quotes ”

When the results came back, she called me on a Friday night and said, ‘Hello dear, your results are in and they’re not good… It could even be harder, you know. If I was at home and needed to cry, it would be easier to do it in the comfort of my own space rather than in front of professionals. You’re used to seeing people break down and things like that.

It was a bit unusual because I received the announcement over the phone, which I imagine isn’t normal. But I can’t imagine it being done any other way because that’s how they did it.

I go to bed early, so I was already in bed when she called me at around nine-thirty. How was it? Oh, it’s terrible. It’s just... It’s like, no—‘there’s a tumour.’ Ok, a tumour, but not the C-word, you know…

Patients speak out

The atmosphere and aftermath of diagnosis announcement

A personal space to process the diagnosis would help patients manage their emotions.

Leaving the consultation and driving home was stressful and overwhelming for patients.

A tense environment increases stress.

Patients often recall the atmosphere during the diagnosis announcement as a significant part of their experience. They noted how the behavior of medical staff—whether tense or calm—set the tone for the encounter. The room's decor, color scheme, and lighting were also mentioned as factors that influenced their emotional response and perception of the moment.

Several patients suggested that having a personal space to process the news would have been beneficial. While such a space was not available, many patients emphasized that it would have allowed them to take a moment to collect their thoughts and manage their emotions before moving on to practical matters.

Leaving the consultation after a diagnosis announcement was often described as difficult. Patients mentioned the added stress of having to pay the bill and walk through the waiting area filled with other patients, which made the experience even more challenging. They also pointed out the difficulty of returning to their car and driving back home after such an emotional moment, with many feeling overwhelmed by the sudden need to transition from the intensity of the announcement to the practical act of leaving the clinic. Some patients expressed confusion and frustration about having to pay for a consultation that involved delivering a diagnosis, feeling that this financial obligation added an unnecessary burden to an already emotional situation.

“Quotes”

They were all very serious.

It was a small, dark office at the doctor's.

Patients speak out

The atmosphere and aftermath of diagnosis announcement

If you could sit in a cozy room, that would make a difference - a room where you could have a cup of coffee, or a waiting area with a better atmosphere. That would already help.

The atmosphere was busy, with no one having time, and there was a sense of urgency in the air.

The staff was very professional, even under time pressure.

The doctor received us in a tiny, horrible room in the emergency department. It felt like a prefab, very cramped and uncomfortable.

When fears start to come up, if they could offer a room where you can go with someone you trust, for example, that would be helpful.

That moment is something I will never forget. The doctor - how he walked, how he looked. He was very somber, very anxious. It was not a good experience. I needed someone to be calm, but instead, there was a lot of anxiety in the room.

I cried when he told me, but when he started talking about the technical details, it helped me focus because I'm someone who likes numbers and facts. It distracted me from the emotional part a bit. But when I was outside on the sidewalk alone, I thought, 'What do I do now?'

But when I went into the same room for my fourth biopsy in three years, everything was different. The nurse who usually took care of me wasn't there, and I noticed how serious everyone was. The nurse held my hand and said, 'Don't worry, don't worry.' I hadn't worried until that moment. Then I thought, 'Yes, I'm in trouble now.' I knew right then that this was different - it was next level.

At the hospital, there was a small room with just the doctor and his assistant. I was told that normally, the colonoscopy is done while sedated, but I needed to stay an extra hour. When I woke up, they said I had to stay because the doctor needed to speak with me. I thought something must be wrong.

Carers speak out

The importance of how a diagnosis is delivered

Being there during the diagnosis allows carers to help the patient cope emotionally.

Carers, like patients, stress the importance of receiving a diagnosis in person rather than over the phone. They highlight that an in-person announcement allows them to be there for the patient, providing emotional support and comfort during a difficult moment. This presence helps the patient feel supported and less alone as they process the news.

A phone diagnosis increases distress and leaves carers feeling powerless.

When a diagnosis is given over the phone, carers feel it intensifies the patient's trauma and leaves them in an overwhelming and helpless situation. The phone call feels impersonal and abrupt, making it difficult for carers to fully grasp the situation and offer the support the patient needs. This can create a sense of emotional distance and make it harder for carers to help the patient cope and move forward.

“ Quotes ”

But then, I remember, on the same day, we meet in the school, she's back from the exam. I couldn't go with her for these pictures. I said okay, it wasn't good. From that day until the diagnosis, she died every day. I always say, we die every day and the family dies together every day until they see the extent of this disease, because they say, it's not good, we have to check.

And then we went shopping together, and I remember it clearly. We were at Delhaize when the phone rang. My wife looked at me and said, 'This is my gynecologist.' She answered the phone, and the doctor said, 'You know why I'm calling. It's not good news, and we need to meet in person.' It was such a moment… We were standing there in Delhaize, surrounded by people going about their normal lives, while ours would never be the same again. That's when the new chapter began.

Health professionals speak out

The challenge of diagnosis announcement

Announcing a diagnosis in a non-appropriate space adds stress for patients and doctors.

Health professionals in hospitals often point out the difficulties of announcing a diagnosis in an inappropriate setting. They stress that the lack of a dedicated, comfortable space adds stress for both patients and doctors, as difficult news is delivered in a formal office environment.

“ Quotes ”

The ideal situation would be to have a place that is truly calm.

It’s essential to have a dedicated place for discussing personal and sensitive matters

It’s not ideal because, unfortunately, we still see situations where patients receive diagnoses in a room shared with a neighbor.

We have an issue with easy access to a neutral consultation room that allows for a proper exchange. However, we interpret exams in interpretation rooms, and since COVID, some stations have been relocated to our offices. But picture my office: I’m sitting at my desk, surrounded by a wall of screens, and behind them is the patient. So, we are not in an ideal setting... And if I move the screens aside, I can no longer work.

Accessing patient records during the conversation can interfere with the human connection.

Doctors also highlight the challenge of balancing empathy with providing detailed information during these conversations. The need to use digital devices and access patient records during the discussion can disrupt the human connection needed in these moments. This makes it harder to create a supportive and compassionate environment for the patient.

The room, the setting. Yes, the room. That’s the issue in hospitals. We have offices, but they are often mobile, shared spaces.

When we are called to see someone, we need to quickly find an available room...

I believe case managers also sometimes need a space in the hospital where they can meet with patients. A space other than the ambulatory chemotherapy room, where patients are often in a shared space with a lot of traffic and little privacy. The same applies to psychologists, and so on.

Diagnostic announcements can be made in our office, and that’s what we do. But case managers sometimes need a space to see patients privately, away from the ambulatory chemotherapy room, which is shared, has a lot of movement, and doesn’t offer much privacy. The same goes for psychologists, etc.

Health professionals speak out

Time constraints in diagnosis announcements

Doctors must tailor appointment times to each patient.

Preparing files and treatment discussions take time.

Doctors face time constraints as the next patient is always waiting.

Doctors underline that announcing a cancer diagnosis typically requires 45 to 60 minutes, which needs to be carefully scheduled to avoid interruptions. However, these appointments often extend beyond the planned time when paperwork or further explanations are necessary.

Health professionals emphasize the importance of dedicating sufficient time for these conversations to ensure patients receive the support they need. However, due to busy schedules filled with multiple consultations, this can be difficult to manage.

Doctors note that while 45 minutes is generally the minimum needed for a first diagnostic consultation, time constraints and a high patient load often lead to delays.

Additionally, doctors point out that managing paperwork and planning discussions can be very time-consuming. Preparing patient files and discussions related to treatment planning or follow-ups, such as for chemotherapy, can take up to 45 minutes to an hour.

These factors highlight the challenges health professionals face in balancing thorough, compassionate care with busy schedules and administrative demands.

“ Quotes ”

When it's cancer and a diagnostic announcement, I think it’s hard to go below half an hour.

We need at least half an hour to explain things, show images again, discuss what they understood from previous information, and talk about their treatment plan.

Health professionals speak out

Time constraints in diagnosis announcements

Overall, I say 45 minutes. For me, a first consultation for a diagnosis announcement should be at least 45 minutes.

Sometimes we also discover many surprises, so it takes at least three-quarters of an hour to prepare the file.

Sometimes, it's the opposite. People who are trying to stay calm while the patient is completely overwhelmed by the diagnosis. We need to adapt and adjust during that hour-long discussion. I usually say an hour, but it can be 45 minutes or even 90 minutes.

The ideal time would be an hour, but I often take an hour outside my regular consultations. Today, I haven't had any consultations and saw two patients before meeting you. It's my only day without consultations, because otherwise, I can't manage.

Even chemotherapy often requires 30 to 45 minutes of discussion, planning, and paperwork, which can be very time-consuming.

I think it's around 40 minutes. But the issue is that in pulmonary medicine, we handle thoracic oncology. Oncologists have a specialized oncology unit for diagnostic announcements that we don't have. It takes a lot of time, and we're often running late, that's just how it is.

Normally, we bring patients into this cozy office, and for me, there is a strong principle: we need to take the necessary time. So, a consultation for announcing a cancer diagnosis takes about an hour. These patients are always the last in a consultation with an open end because otherwise, we are constrained by time, and it is impossible, at least for me. People leave here fully informed.

Health professionals speak out

Balancing time for diagnosis

Dedicated time slots are essential for clear, empathetic diagnosis announcements.

Doctors adapt the time to the capacity of patients.

Health professionals agree that announcing a diagnosis requires careful planning and adequate time to ensure patients fully understand the information.

While it is generally recommended that initial consultations last between 45 to 60 minutes to cover all necessary details, some doctors suggest a different approach. They propose that the first meeting could be limited to around 30 minutes to avoid overwhelming the patient, taking into account their limited capacity to absorb information at the beginning of the process. A follow-up consultation can then be scheduled to provide additional details, answer questions, and discuss next steps, allowing the patient to process the information at a more manageable pace.

This strategy aims to strike a balance between thorough communication and patient well-being, ensuring that the patient feels informed and supported without feeling rushed or overwhelmed.

“ Quotes ”

Even when we want to communicate the key points, in my opinion, the patient listens for two or three minutes, and then it’s over. We go over the details later. We even say, if you want to come back or have questions, you can come back.

When we tell them they have cancer, it becomes... I don’t think talking for more than half an hour is helpful, especially at the beginning when the diagnosis is announced. Studies show that after hearing the word cancer, they only remember about one-third of what we say. So, we need to make sure they understand the main, important points.

Yes, that’s why we can’t provide too much information to someone who just found out they have cancer. We don’t talk for more than 30 minutes because they won’t retain it. Long explanations are pointless; it’s always the same questions. So, we handle it like this and schedule these discussions at the end of the day to allow for an open-ended conversation.

10

STRUCTURE FOR DELIVERING A DIAGNOSIS

The announcement of a diagnosis is rarely delivered according to a standardized approach.

Each doctor typically follows their own methods, shaped by personal experience and individual practice. Health professionals often describe the diagnosis process as consisting of several stages, allowing the patient time to process the emotional impact, receive updated information, understand their options, and plan the next steps. This approach is sometimes referred to as a "multi-step diagnosis." However, these stages require effective communication skills, which are not always adequately addressed in medical training programs.

For **patients** and **carers**, the experience of receiving a diagnosis is often emotionally overwhelming, which can make it challenging to follow or recognize the structured steps described by health professionals. They emphasize the importance of empathy and clear communication, as well as having information broken down into manageable pieces. These elements can help them better understand their situation and navigate the next steps in their care journey.

Health professionals face the challenge of delivering diagnoses in a way that balances the need for accuracy, clarity, and empathy. While many practitioners aim to follow a structured and patient-centered approach, variations in training and practice mean that this is not always consistent.

This chapter explores the perspectives of patients, carers, and health professionals on the process of announcing a diagnosis. It examines the challenges faced, the importance of clear communication, and the benefits of a more structured and empathetic approach to improving the experience for all involved.

#Key Information

#Multiple-step Diagnosis

#Clear Communication

#Process Structure

#Understandable

#Training

#Necessary support

#Diagnosis process

Patients speak out

The importance of structured communication

Clear, structured communication helps patients feel supported.

Poor communication leaves patients feeling overwhelmed.

In moments of uncertainty and potentially life-changing news, patients emphasize the importance of having a clear framework to help them feel less overwhelmed and more grounded. They point out that when health professionals deliver structured diagnosis announcements, it can provide essential guidance and support. This structured approach helps patients understand the complexity of their situation and face it with the help of their carers, families, and the healthcare team.

Patients stress that communication adapted to their ability to understand makes a significant difference in how in control they feel. When information is shared clearly and understandable, patients are better able to process it, feel supported, and engage actively in their treatment and decision-making.

“ Quotes ”

During the diagnosis announcement, my gynecologist was very precise, which is why I chose him. His way of communicating was perfect for me—clear and straightforward. He explained everything factually, without getting overly emotional. He just told me what I had.

Psychological support from experts can be helpful during this time. It’s important for doctors to mention that such support is available. Many people don’t know this option exists and miss out. Including this information in the diagnosis announcement process could be helpful for patients.

It’s important to minimize the time a patient spends in uncertainty. Everyone reacts differently, but the period before the diagnosis and its announcement is as crucial as the diagnosis itself. The emotional stress starts before you even get the results. You know something is wrong. Whether it’s after a mammogram, an exam, or a visit to the doctor, you can feel that something isn’t right. This waiting period can be full of anxiety, and the mind tends to overthink and imagine the worst. It’s important to stay calm, especially when there’s no support from family or loved ones nearby. Managing emotions well is crucial to avoid falling twice —once due to the stress of waiting, and again when the diagnosis is confirmed

Carers speak out

Supporting patients during the diagnosis announcement

Carers need structured communication to better support patients.

Providing all information at once is overwhelming for patients and not helpful.

Carers highlight the complex role they play during the diagnosis announcement. They are tasked with providing emotional support while also absorbing as much information as possible to respond effectively to their loved one's health situation. Carers are acutely aware that presenting all the information at once can be overwhelming for patients and is not a suitable approach.

They emphasize the importance of breaking down the information into smaller, manageable pieces delivered over time. This structured and step-by-step approach allows them to better process the news and provide the necessary support to both the patient and themselves during such a critical time.

“ Quotes ”

They don't need a script, but they should show more empathy when speaking.

Everything should be explained: the announcement, the oncologist discussing the treatments, the nurse going over what will happen, and reassurance that they will be there to take care of you if anything goes wrong. But all of this happened in one day.

Receiving bad news could be done differently. When you find something, you do the biopsy – waiting for results takes too long, which is not good. The way the news is given is very important, as it's a shock and not good for the patient or their carer. Now that I know I have cancer, a triple negative... and more. It would have been better if the announcement had been made with more empathy, saying, 'We will take care of you. Don't worry too much; we know how to handle this and will support you. Now, it's all about you.' I would have preferred it this way instead of just a phone call. It's always bad news, but this change could make a difference.

Health professionals speak out

Key elements on the diagnosis process

Providing facts helps patients build confidence.

Inconsistent approach can cause confusion.

Health professionals, especially oncologists, highlighted key elements in the diagnosis announcement process that can help meet patients' needs and help them adjust to their new situation:

- Providing empathy and understanding for the patient's individual situation.
- Sharing reliable, fact-based information, which may also include messages of hope.
- Discussing future steps and treatment options, and allowing patients to have choices.
- Encouraging patient confidence in participating in decision-making.

Doctors may approach these aspects in different orders. Some prefer a multi-step process, allowing time between appointments for patients to absorb information and for doctors to gather results from various tests.

“ Quotes ”

There's a lot to plan. I think we need to give people a lot more guidance on their journey, especially as people have a lot of questions. They come with a lot of stuff that they read on the Internet, things that can be good and things that can be terribly bad. But you have to integrate things. The pitfall is the speed at which it happens, and you've already asked this in your questions, i.e. the patient comes, you need a set time and you need to structure it.

A diagnosis can be announced once, but the treatment plan should be discussed in multiple steps.

On one side, taking the time to explain and allowing them time to process and ask questions is crucial. On the other side, there is the urgency to start the treatment sequence.

We take about half an hour to explain the situation medically, review the images, check what they understood from the previous discussion, and discuss their care plan with them.

The first consultation, the diagnostic announcement, is crucial for the patient’s well-being. It sets the tone for how they are listened to, understood, and supported. For me, this is essential.

I prefer to see the patient alone — it helps build trust. I also address sensitive topics like children and fertility with women.

I told them, ‘I don’t want a decision today. Tomorrow morning, I’ll come back, and you’ll tell me what you want or don’t want.

A multiple-step approach may be necessary, even just to allow time to fully understand the situation and provide the most comprehensive answers.

Health professionals speak out

The need for communication training

Communication training is important for doctors.

Medical education often lacks adequate training in this area

As a result of interviews, health professionals emphasized the importance of proper training in interpersonal skills for doctors. This includes training in communication techniques, providing feedback, and active listening.

Many doctors noted that such training is not always part of medical education or is offered only in limited amounts of time. This gap in training can impact their ability to effectively connect with patients and address their needs, especially during difficult moments like a diagnosis announcement.

“ Quotes ”

Personally, I would welcome training on how to announce a diagnosis because it is something we learn on the job. During my initial training, I never received structured education in this area.

Another improvement that is difficult to implement in Luxembourg is training doctors on how to announce a diagnosis. I don’t think they are properly trained for this, and the relational aspect is still somewhat underestimated in medical education.

Communication is one of the areas where people need more time to develop their skills. In my opinion, we should also focus on training, as I am not sure if oncology students receive communication training in their curriculum.

IMPROVING THE DIAGNOSIS ANNOUCEMENT EXPERIENCE

The following suggestions were proposed by patients, carers, and health professionals during interviews, focusing on improving the diagnosis announcement process.

This chapter highlights key ideas to make the diagnosis delivery more structured, supportive, and empathetic, ensuring that **patients** and their **carers** feel well-informed and prepared for the journey ahead.

Health professionals also emphasized the importance of refining this process, as they believe it would enhance patient care, reduce stress, and foster a stronger, trust-based relationship between medical teams and patients.

1. Roadmap for Patients and Carers

Patients recommended developing a tool to outline the diagnosis announcement process, covering all stages, not just treatment. This roadmap would help them understand what to expect, increasing confidence and emotional readiness for the steps ahead. Possible formats include visual maps, PDF guides, or digital apps.

Carers highlighted that such a roadmap would support them in providing clearer and more effective assistance. It would reduce uncertainty during waiting periods, enabling them to offer better emotional and practical support.

Health professionals agreed that a visual roadmap would improve communication between patients and medical teams. It would help manage expectations, streamline interactions, and ensure that patients receive consistent and thorough information.

However, while a general roadmap is reassuring, healthcare professionals were keen to point out that it must absolutely take into account the uniqueness of each patient's journey. Patients need to understand the milestones, but also know that adjustments may be necessary. This approach allows patients to be informed yet able to adapt, without feeling overwhelmed by rigid timetables.

2. Support materials to remember the information

Patients suggested creating materials like journals, organizers, or notebooks to help process and manage the large amounts of information received during and after the diagnosis.

This could include sections for notes, questions and important contact information. This would help patients stay organized and reduce stress.

IMPROVING THE DIAGNOSIS ANNOUCEMENT EXPERIENCE

3. Training in communication

Patients highlighted the need to train healthcare professionals beyond medical knowledge, to include interpersonal skills such as active listening, empathy and body language. This would allow health professionals to deliver diagnoses with a balance of medical accuracy and compassion.

Many healthcare professionals have recognized the value of this type of training, pointing out that, although medical skills are at the heart of training, interpersonal skills are essential for accompanying patients through difficult conversations. Improving communication would help to strengthen the relationship between patients and doctors, get patients more involved in their care and ensure a better understanding of the next steps.

4. A comfortable space for diagnosis announcement

Patients, carers, and health professionals all highlighted the need for comfortable environments when delivering difficult news.

Some patients described the ideal space as a calm, private area, akin to an astronaut's capsule or a dedicated "chill-out" room. Such spaces would give patients the opportunity to take a moment to process the news on their own or discuss it with carers and support staff. Ensuring a peaceful, private setting helps create trust and emotional safety during challenging conversations.

Carers pointed out that a comfortable space would benefit both them and the patient, allowing them to process the news together without feeling rushed.

Health professionals agreed that a well-designed, private space would facilitate better communication, allowing them to deliver difficult news and address patient questions and emotions in a supportive environment.

IMPROVING THE DIAGNOSIS ANNOUCEMENT EXPERIENCE

5. Personal support or case manager

Patients who had a case manager or breast nurse to guide them through the diagnosis process found it invaluable. These contact persons provided both practical support, such as organizing appointments, and emotional assistance, which helped patients feel more secure and less alone during their journey.

Oncologists noted that having a dedicated support person for patients can make a significant difference, easing the burden on medical staff and ensuring patients have consistent guidance and support.

Carers of patients without a case manager expressed the need for a primary contact person who could help navigate the process, answer questions, and offer continuous support, contributing to a more comprehensive care experience.

6. Improved communication between health professionals

Patients noted that better communication among their GP, specialists, and oncologists would improve the continuity of care. Standardized procedures could help synchronize information, reduce stress, and prevent repeated tests.

Health professionals supported this view, agreeing that better communication would streamline patient experiences, reduce confusion, and ensure all care team members are aligned. Standardized protocols would enhance efficiency and resource management within the healthcare system.

7. Reliable information on available support

Patients highlighted the frustration of having to search for reliable information on available support services, often leading to confusion and stress. They emphasized the need for healthcare providers to proactively share systematic, trustworthy information about support resources such as cancer foundations, patient associations, and peer support groups.

Healthcare professionals have recognized that it is essential to provide patients with reliable, comprehensive information about their illness and the support services available. This helps them feel informed and responsible, while reducing the need to seek answers from unreliable sources. They stressed that facilitating access to verified information would prevent misinformation and empower patients to make informed decisions about their care and support.

CONCLUSION

Analysis of interviews and key challenges for improving diagnosis announcement

We conducted interviews with patients, carers, and healthcare professionals to identify the positive aspects (gains) and negative aspects (pain points) in the diagnosis announcement process. These insights were organised into categories to highlight areas that need improvement.

From the analysis, we identified three main areas for improvement:

1. Communication: This focuses on how the diagnosis is announced and how patients and carers understand the information. Clear and empathetic communication is essential for helping them grasp the diagnosis and its implications.

2. Patient Journey: This involves understanding the steps in the patient's care, how they are sequenced, and where to find the right information. Clarifying this can reduce anxiety and help patients make informed decisions.

3. Organisation: This refers to how the announcement process is structured, including timing, space, and the roles of each person involved. A well-organized process can reduce confusion and make it easier for everyone to follow.

Based on these areas, we developed "How Might We" (HMW) questions to encourage participants to think about possible solutions. These questions were discussed during the co-creation workshop in October, where patients, carers, and healthcare professionals worked together to find solutions.

The challenges were selected because they are important to all three groups, ensuring that the solutions benefit everyone involved in the diagnosis announcement process. The goal is to create practical and effective solutions that improve the overall experience.

Next Report: Co-Creation Workshop Results

In the next report, we will present the results of the co-creation workshop held in October. At this workshop, participants discussed challenges and suggested solutions to improve the diagnosis announcement process. The second report will highlight the main ideas retained and the next steps to implement these solutions.

CONCLUSION

How might we questions

01 How Might We conceive the diagnosis announcement to be understandable for everyone?

02 How Might We provide patients with relevant information throughout the diagnosis process?

03 How might we ensure that the information given by healthcare professionals is heard and integrated by the patient?

04 How might we provide support to patients and their families at the right time?

05 How might we design a diagnosis announcement that balances empathy with medical information?

06 How might we structure the diagnostic process to prepare patients for the next steps, while making waiting times tolerable?

07 How might we help healthcare professionals identify patients' socio-cultural differences and integrate them into their communication?

08 How might we clarify the roles of patients and caregivers in the process of diagnosis announcement?

09 How might we ensure that the diagnosis is announced in a comfortable setting to minimize patient stress?

10 How might we define an effective diagnosis announcement and improve the process?

LUXEMBOURG

Report summary

The "Diagnostic Announcement" project, as a part of the National Cancer Plan 2 (PNC2) under Axis 3 – Rights, Information & Training for Patients, aims to enhance the experience of patients and their carers during one of the most critical moments of the care pathway: the announcement of a cancer diagnosis. It seeks to ensure that this announcement is delivered in a compassionate, clear, and supportive manner, respecting the emotional and informational needs of patients while fostering trust between patients and healthcare professionals.

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