

# EXPERIENCE REPORT

# Cancer patient ISSUE



# **INTRODUCTION**

n the "Experience Report -Oncologist issue", we focused on how to empower oncologists with human-centric services. Broad interest in the report inspired us to complete the picture with a view on the perspectives of cancer patients. Patient needs are becoming more complex and, in an ever-more digitized world, so is oncology itself.

In this report we again take a humancentered approach—this time to uncover the main pain points for cancer patients, particularly in the growing population of digital natives. Our combination of quantitative and qualitative research among more than 1200 patients from Europe and North America revealed four recurring challenges:

### Access to better information

Patients struggle to find personalized, understandable and reliable information. They want access to accurate input related to their personal cancer journeys. This includes a deeper understanding of symptoms, diagnostic and therapeutic options, and how to live with cancer.

### More involvement

Patients in our report describe a unidirectional relationship with their oncologists and want more involvement in their cancer journeys.

### **Increased holistic care**

Patients expect cancer care to take a holistic approach. Many participants want more mental health support and guidance on how to adapt their lifestyles to fight cancer.

### Reduced organizational hassle

Patients need more help with the dreary administrative, logistical, and domestic tasks of their journey.

This report goes beyond mere expectation matching. We identify opportunities that arise from evolving digital patient needs. Anticipating change is key to shaping solutions that support future healthcare services and embrace values like personalization, collaboration and diversity. Biopharma companies can use this intelligence to get ahead of the curve and significantly improve patient lives.



### Introduction

# **EDITORS**



Managing Director - Global Lead

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Cancer is a horrible disease. It affects all of us, through family or friends. Helping patients to survive extends beyond giving the best product, it entails managing their journey end to end to cope with this difficult situation. There is still a lot to improve.

Compared to our first oncology report, the Patient issue feels even more personal and connected to me. In order to not just confirm what we already know but also to attempt a glance into the future, we chose to shed light on the mindset of digitally savvy patients.

Focusing on NextGen ways and values is critical as our rapidly changing world forces humans and organizations to adapt and innovate at an unprecedented speed. Addressing the evolving needs and expectations of digital natives offers a new dimension of opportunities for biopharma companies to get ahead of the curve and significantly improve the lives of patients.



### Dr. André Dahinden

Managing Director - Global Co-Lead Precision Oncology CoE, Life Sciences at Accenture

The Patient issue offers a humancentred outlook on the future of oncology and can serve as a launch pad for change for biopharma companies.

We believe that better experienceand outcome design originates from a deeper understanding of patients' needs, which will extend beyond classic product- and business models.

Introduction

# **AUTHORS**



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Joel is a business designer who combines a multidisciplinary mindset with a passion for human-centered services and strategies. After starting his career in private banking, he gained extensive experience as a social entrepreneur in corporate sustainability and public health.



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As a service designer, Tanya is intent on understanding people's needs to design human-centered solutions that support them in their daily endeavors. She has experience in industries such as hospitality, insurance, and health care.



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# SUBJECT MATTER EXPERTS



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Christoph Loeffler is a managing director at Accenture Interactive and Fjord responsible for the Life Sciences industry. With over 22 years of experience in the industry, he has developed a great passion for human-centered research, business design and digital health.





at Accenture Interactive

As a business and experience design consultant, Hanspeter helps clients to develop holistic digital strategies and conceptualize new products and services. He has experience across various industries, with a core focus on life sciences and global pharma.



Sabrina Campagna Visual Designer at Fjord Milan

Sabrina is a multidisciplinary designer, passionate about branding. In her daily life, she mixes visual and service design to create beautiful, memorable experiences. Sabrina has a practical mindset, always looking at the big picture but expressing herself in the details.

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Dr. Sandra Dietschy-Künzle is the practice lead of Accenture's center of excellence for precision oncology and personalized healthcare. She has numerous life science publications to her credit. Sandra has more than 12 years' experience in the healthcare industry and in-depth oncology drug development expertise.



# **TABLE OF CONTENTS**

Introduction



Β. Pain points: patients' unmet needs and expectations

C. Areas of opportunity: turning challenges into opportunities

29 Themes

hassle

Theme 1: having a suspicion

Theme 2:

Theme 3: getting treatment

Theme 4: living with cancer



A glimpse of

the future

Patient experience

## **Recurring challenges**

Access to better information

More involvement

Increased holistic care

Reduced organizational

getting the diagnosis

58 What's next for biopharma companies?

60 Conclusion

# RESEARCH

We designed our methodology to be replicable across other fields. A powerful combination of quantitative and qualitative research, it was crafted to reveal important opportunities for biopharma companies.

# METHODOLOGY 1



# **OUR APPROACH**

# A. Mapping a patient journey: 1200 patients share their views

We surveyed 1200 patients in the US, the UK and Germany between the ages of 18 and 50. Our report included patients with all types of cancer who have identified their biggest challenges. More than 90 percent of them identified themselves as "digital natives" and answered questions about their end-to-end patient experience ranging from the discovery of first symptoms all the way to life after cancer treatment.

To go beyond statistics, we conducted detailed interviews with patients from each geographical area. Their responses added context to create a richer understanding of their unmet needs and expectations.

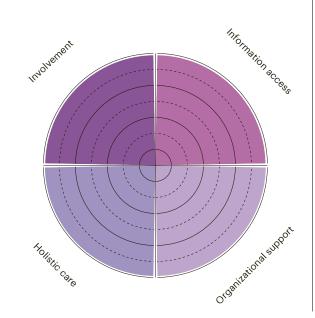
We organized our research findings as episodes and mapped these along a patient experience journey. Episodes describe distinct patient activities and are used to account for the fact that cancer journeys rarely progress in linear fashion. This allowed us to identify detailed implicit and explicit frustrations patients have while suffering from cancer.

# B. Pain points: patients' unmet needs and expectations

Even though patient journeys tend to be very heterogeneous, we nevertheless discovered that participants' pain points revolve around four recurring challenges:

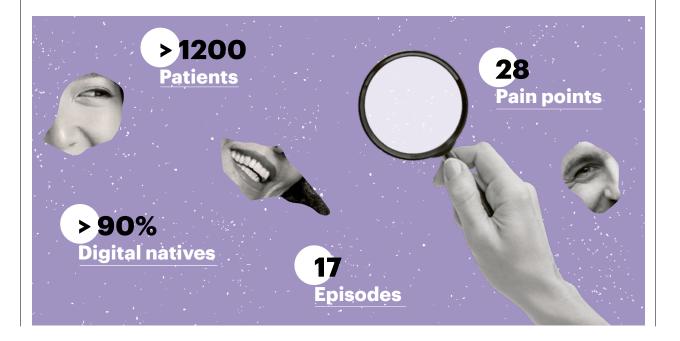
- Access to better information
- More involvement
- Increased holistic care
- Reduced organizational hassle

To compare the relative importance of each recurring challenge in different parts of the patient journey, we calculated the number of times they were mentioned in each theme. We have ranked them using a scale from 0 to 7 visualized using a spiderweb.



# C. Areas of opportunity: turning challenges into opportunities

At the end of each theme, we identify areas of opportunity for biopharma companies based on patient challenges. The final chapter will dare a glance into the future and imagine the kind of service which could cater to the rising demand of digital natives.



# Terminology

**Episodes:** Key moments or activities of a patient journey.

**Pain Points:** Challenges and frustrations patients experience during episodes.

**Areas of Opportunity:** Turning pain points into problem statements and verbalizing solutions.

# RESEARCEL

In this chapter, we look at different stages of the patient experience journey and the main challenges patients may face. We also bridge the gap between challenges and opportunities and identify key areas where patient-centric service improvements are needed.



# We have identified 17 Episodes grouped into 4 Themes

# Theme 3 **GETTING THE TREATMENT**

This important part of the cancer journey is not just about

starting medical treatment. It is about deciding on the

best therapy given individual circumstances. The patient

needs to learn how to handle side effects and coordinate

care in the context of daily life-leisure time, work, sleep,

sport and diet-with therapy. Coping with all of that is

stressful and a big challenge.

Choosing a treatment plan and therapy

Episode 9

Episode 10

Episode 11

Episode 12

Episode 13

Coordinating the care

Starting and getting treatment

Participating in a clinical trial

Adapting personal life to side effects

# Theme 4



Episode 14 Having follow-up checks

Episode 15

Episode 16

Episode 17

# **PATIENT EXPERIENCE JOURNEY**

# Theme 1 **HAVING A SUSPICION**



This chapter of the journey is characterized by uncertainty about a final cancer diagnosis. First warning signs might unsettle the patient and trigger fear or denial. Searching for information online might additionally aggravate the situation. Waiting for appointments with doctors or specialists requires patience. Often the patient is overwhelmed by the situation.

**Episode 1a** Realizing first warning signs and investigating signals

Episode 1b Being diagnosed during a check-up

Episode 2 Having a first consultation with a general practitioner

Episode 3 Waiting between consultations

# Theme 2 **GETTING THE DIAGNOSIS**



Diagnostic tests might cause the patient to feel disempowered and uninvolved. A confirmed diagnosis is a key point in the patient journey. With an uncertain future ahead, it is now about coping emotionally with cancer, letting family and friends know, and accepting the situation. For most, it is overwhelming—and many feel isolated.

Episode 4 Undergoing diagnostic tests

Episode 5 Getting the diagnosis and coping with it

Episode 6 Adapting life to new circumstances

Episode 7 Telling family and friends about the diagnosis

Episode 8 Finding people with a similar story

# LIVING WITH CANCER

Even if patients are in remission or cured, the disease may still have far-reaching consequences. Some struggle with reintegration into their former lives, and with finding purpose in their journey. Others continue to live with side effects which may have an impact on their well-being. For most, continuous check-ups are a stark reminder of the formative experience they went through.

Sharing personal experience about cancer treatment

Moving on with life after having beaten cancer

Adapting professional life and financials to cancer

# RECURRING CHALLENGES

Our findings reveal that certain pain points are prevalent for most patients throughout their cancer journey. These recurring challenges are highlighted below.

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Research findings

"I only understood 'lymph gland cancer'. Everything else was too technical for me."

— Emmanuel

**RECURRING CHALLENGE 1** 

# ACCESS TO BETTER INFORMATION

"There was just no personalized information available online."

- Rachel

athering relevant information is a common theme for people with cancer. Whether before or after their diagnosis, those

affected tend to consult the World Wide Web first—only to feel overwhelmed by the volume of information, which is largely not based on evidence and often not applicable to the personal context. At the same time, our research suggests that many patients struggle to understand technical jargon and have difficulties in assessing how reliable the provided information is.

The resulting lack of personally relevant information increases uncertainty, fear, and confusion instead of alleviating them. Ideally, information should provide a sense of control and an ability to contribute to decision making alongside health care professionals (HCP). INFORMATION ACCESS

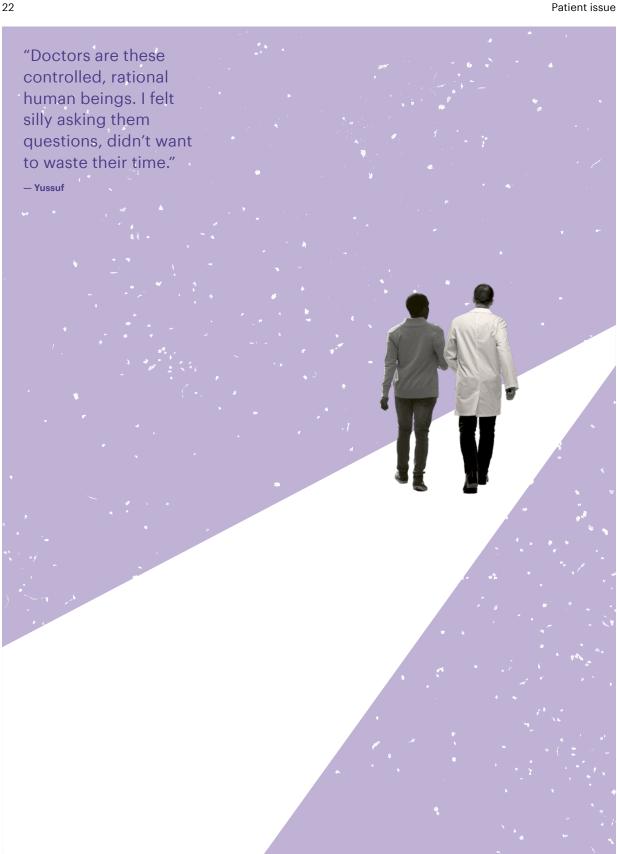




21

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**Research findings** 

# **RECURRING CHALLENGE 2**

# MORE INVOLVEMENT

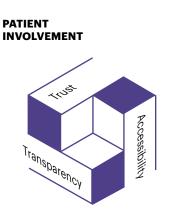
"The doctors treated me like a child, they didn't tell me anything." — Nora

ur report shows that HCPs are often perceived as unapproachable specialists who don't take questions and have limited time to talk to patients beyond what is absolutely necessary. This might leave patients hesitant to ask all the questions they have or challenge a proposed course of action. Consequently,

patients might feel excluded from decisions about their care.

Often, organizational silos prevent different specialists from sharing a patient's data effectively with one another. This places an additional burden (mediating between specialists or getting a second opinion) on the patient.





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**Research findings** 

"The diagnosis was a brutal meltdown. I was so afraid of dying and just needed somebody to talk to and show empathy."

- Rachel

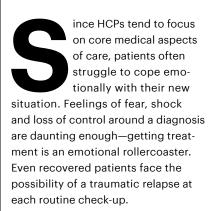


**RECURRING CHALLENGE 3** 

# INCREASED HOLISTIC CARE

"I would have needed somebody to take me by the hand and tell me how to lead in my life in terms of exercise, nutrition and sleep."

— Ralf



Many patients are eager to take steps to improve their own well-being. Yet they are often left alone in learning how to adapt their lifestyles, eat more nutritious food or develop an adequate exercise routine. Giving patients access to more holistic care enables empowerment and increased well-being.







**Research findings** 

### **RECURRING CHALLENGE 4**

# REDUCED **ORGANIZA-**TIONAL HASSLE

– Paul

ureaucratic challenges tend to get overlooked in the patient journey. From the first consultation to routine checkups,

patients have to engage with different HCPs, clinics and doctors, as well as health insurance and other third parties. It is not unusual for patient files to be paper-based, making the process of getting a second opinion or sharing information with their care ecosystem difficult and inefficient.

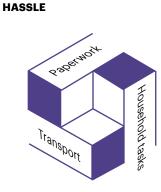
At the same time, patients need to deal with the logistical burden of receiving cancer care and managing their households. While transport to and from healthcare facilities must be organized, daily duties such as house cleaning, food purchases and laundry don't go away.

Minimizing this three-dimensional hassle could considerably reduce patients' emotional and physical stress.



# "My boyfriend was central in helping me to clean the apartment and buy stuff. Without him, I don't know what I would have done during chemo."

ORGANIZATIONAL



# THEMES

In this section, we dive deeper into each phase of the patient journey to uncover detailed pain points and opportunities for human-centered services.

Having a suspicion



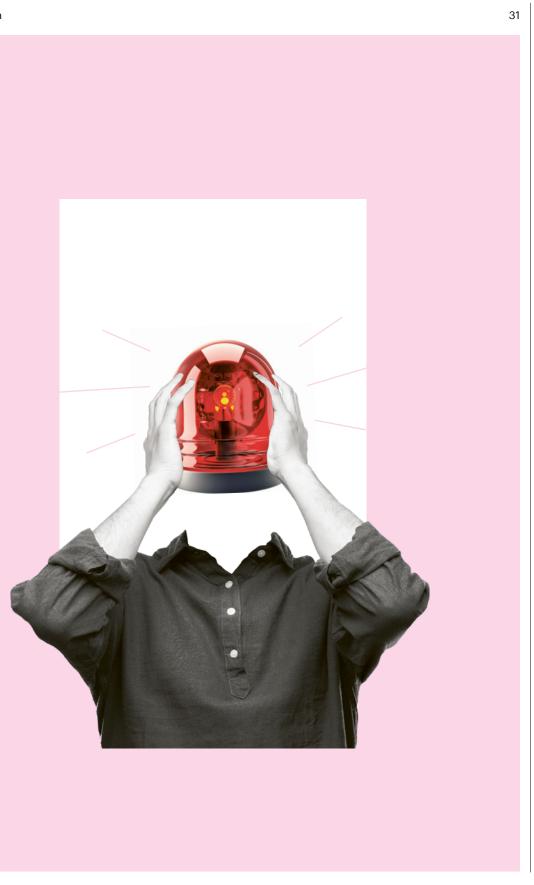
The patient's path from noticing first symptoms to consulting an oncologist.

# **EPISODES**

Episode 1a: spotting the first warning signs and investigating signals Patients notice the first symptom(s) and suspect that something might be wrong. Some tend to ignore these signals as long as possible before taking action. Others plunge into the Internet in search of more information and guidance.

# Episode 1b: being diagnosed during a check-up

Not every diagnosis is a result of a suspicion. Tumors are often detected coincidentally during routine checkups or during the treatment of unrelated symptoms with a specialist.



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PAIN-

"I was frustrated about myself; I wish I would have gotten checked out earlier. But the thought of having cancer at 26 just hadn't really crossed my mind." — Max

## **Episode 2: having a first** consultation with a general practitioner

A general practitioner (GP) or family doctor is normally the first point of contact for patients who notice initial warning signs. The GP's role is crucial: interpret the first signs correctly and initiate further steps in a timely manner while helping the patient deal with fear and uncertainty.

## Episode 3: waiting between consultations

Several factors (like different health-care systems or the initial GP assessment) affect the waiting period for a specialist consultation. In many cases, there is already a significant likelihood of a positive cancer diagnosis, but no certainty until tests are conducted. Some patients suppress thoughts of cancer; others investigate every detail about the implications of a positive diagnosis.

>30% were overwhelmed by the number of sources of information when trying to find out more about their symptoms.<sup>(1)</sup>

# Every 3rd found it time consuming to find the

information they were looking for when faced with symptoms. <sup>(2)</sup>

"When you start to search for information online, you're already dead anyways."

POINTS

## Pain point: dealing with uncertainty

The suspicion of cancer creates great fear and uncertainty. Seeking information about one's symptoms is a common coping mechanism but often increases feelings of anxiety and confusion. Even talking to family and friends may be less useful than anticipated if contradicting opinions and recommendations are forthcoming. In the worst-case scenario, patients could even take the wrong course of action-like procrastinating about seeking care—and lose precious time before consulting a specialist.

## Pain point: losing time between consultations

A GP consultation often results in a specialist referral at some point. This intermediate step may create the risk of unnecessarily losing time to get a reliable diagnosis from the relevant HCP.

### Pain point : insufficient awareness of own exposure

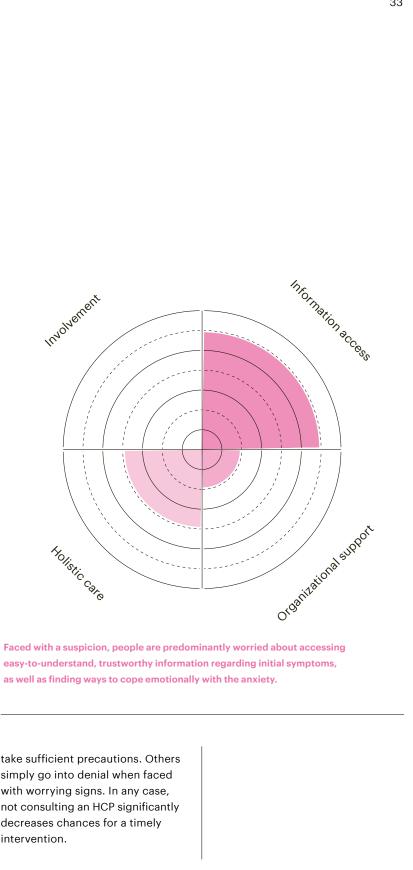
Young people are often particularly unaware of cancer as a potential risk factor for their health and therefore lack the urge to get a check-up. Even individuals who are aware of hereditary risk factors might not

Involvement <sup>ri</sup>olistic care

as well as finding ways to cope emotionally with the anxiety.

take sufficient precautions. Others simply go into denial when faced with worrying signs. In any case, not consulting an HCP significantly decreases chances for a timely intervention.

- Ralf



Having a suspicion

# **AREAS OF OPPORTUNITY**

"It would be very helpful to be able to type in your specific cancer history and get individual recommendations back about how you should adapt your lifestyle."

- Paul

# Lower the barriers to preventative check-ups

Cancer is typically subject to a paradox: people are aware of the general risk of cancer but tend to underplay the risk for themselves. "It can't happen to me," is a frequent misconception in younger generations. More accessible prevention and more accurate risk assessments need to be a priority.

What if people received automatic invitations for preventative cancer screening (like those sent by some dentists), depending on personal data, family history and location? They would be freed from the administrative and emotional hurdle of organizing checkups.

**Imagine** a service that calculates personal cancer risk scores. AI and smart algorithms could use scientific and biological data (like genetics, behavior and age) to assess risk and automatically book an appointment with the appropriate specialist as necessary.

# Warning signs? Enable appropriate patient guidance

Detecting potential cancer symptoms can be worrying. Before the Internet the first point of reference was the trusted GP. These days, people consult WebMD or their favorite search engine. Appropriate filtration can reduce patient stress and speed up the journey to the right care.

What if getting the right, relevant information were straightforward? People would avoid the anxiety and confusion caused by unreliable sources and conflicting information.

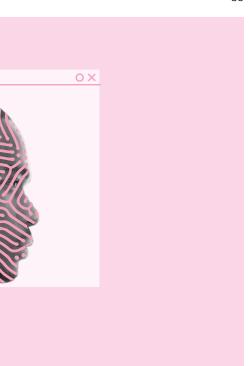
Imagine universal access to a service where people could document their symptoms and get an evidence-based risk assessment running on embedded AI and real-world data. They would have the option to automatically be referred to relevant specialists who would have access to their data.

Nearly half of respondents found

it difficult to find information about initial symptoms.<sup>(3)</sup>

# **OUR** PERSPECTIVE

Digitalization will enable a more customized patient experience. Increasingly personalized data will improve patient insight and enable them to proactively manage their cancer journeys-whether it be getting preventative care or finding the right oncologist. On the other hand, oncologists will be able to use an increasing range of channels and formats to drive personalization forward.



35

"First, I was shocked, then scared, then angry. The most important thing was to reach acceptance to be able to take the next steps."

— Ralf

Patient support during the stressful period between testing and diagnosis is critical.



"Waiting after the diagnosis was really hard because nobody told me what I can do to fight this thing myself. I just had to wait until surgery for 3 months."

- Rachel

THEME 2:

36

# **EPISODES**

# **Episode 4: undergoing** diagnostic tests

After the first consultation with a specialist (depending on the type of cancer) patients must undergo different diagnostic tests. The tests localize a tumor, define its stage of advancement and level of malignancy, and results determine the urgency of treatment options. The interval between diagnostic tests and final diagnosis varies from a couple of days to several weeks.

# **Episode 5: getting the** diagnosis and coping with it

Patient responses to diagnosis depend on their personalities. Some feel the need to proactively seek information and take preventative measures (e.g., adapt their lifestyle or diet), or consult professional help (e.g., psychologists). Others go into denial and avoid the subject altogether. Most are overwhelmed.

# **Episode 6: adapting life** to new circumstances

When embarking on a new life with cancer, patients start to think about different treatment options, logistics and how to adapt their professional and personal lives.





# **Episode 7: telling family and** friends about the diagnosis

38

When the patient informs family and friends, some will have questions and offer advice while others will be devastated and need emotional support themselves. Often, patients do not want to become a burden to loved ones even though they need support.

# **Episode 8: finding people** with a similar story

Patients search online or in their treatment circles for people in a similar situation. They share experiences and give each other advice and hope. Usually, patients prefer to meet other patients with the same cancer type and stage of advancement, as higher degrees of similarity increase the ability to empathize and offer relevant advice.

# PAIN-POINTS

# Pain point: going through a new experience

Unlike the GP, the oncologist is usually a stranger to the patient. The consultation itself might take place in an unfamiliar environment, be subject to time restrictions, and focused on purely medical aspects, not emotional ones. In addition, testing itself might be a new and painful experience, which also increases anxiety.

# Pain point: disinvolvement in diagnostic test choice

Many patients are not involved in choosing which diagnostic tests will be conducted. They may feel uninformed about the big picture and only know the next step. This causes discontent and decreases one's sense of agency in the process.

**More than** 

would have liked to be more

diagnostic tests to run.<sup>(4)</sup>

involved in the decision about which

did not choose their oncologist. (5)

half

56%

# Pain point: no ownership of their own files

Records and test results are usually kept by care providers. Patients may be excluded from ownership of their own data, which can complicate the process of getting a second opinion.

# Pain point: receiving the bad news

Even though a cancer diagnosis creates fears of death, diagnostic test results and follow-up consultation dates are often communicated with little empathy (e.g., over the phone without warning). Being caught offguard, resulting feelings of shock, helplessness and anger may add avoidable emotional hardship.

# Pain point: coping with the bad news

In overcoming the initial shock and accepting their cancer journeys, patients must generally pass through different emotional stages. Friends and family are often unable to help, and HCPs tend to focus on medical advice. These realities can make coping with cancer one of the loneliest experiences of a patient's life. However, acceptance is the starting point for the healing process.

# Pain point: one-sided care

Following acceptance, patients often want to regain some agency and control. The care they receive from HCPs is often limited to medical aspects, so it is left to patients to adapt their lives in terms of nutrition, exercise and recreational patterns, which leaves many to feel overwhelmed.

# Pain point: fear of telling family and friends

Sharing the bad news with loved ones is one of the toughest tasks of the journey. Patients may not want to burden their friends and family or prefer to be treated normally. Some struggle to receive the kind of empathetic support they deeply desire. As a result, a patient's social circle often gets smaller during treatment.

# Pain point: identifying relevant information

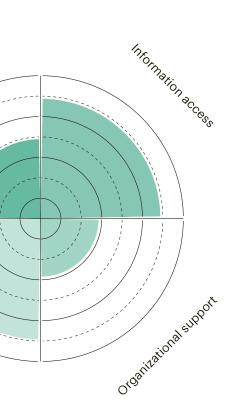
Being informed is a vital dimension of regaining agency and control. Yet, patients often struggle with finding relevant information or with Involvement Holistic Care

After the diagnosis, patients may seek different ways to empower themselves and adapt their lifestyle to fight the cancer. While HCP consultations intensify, patient involvement in decision-making and accessing personalized information become a central concern. Bureaucratic and logistical issues also increase.

assessing the trustworthiness of the source. The Internet is the most accessible source of information, but also the most generic or fearinducing. Online searches may add unnecessary confusion and lead people taking the wrong course of action.

# Pain point: understanding information

Even information from a trusted source might be difficult to understand due to technical jargon. A lack of understanding may exclude patients from decision making at the start of the treatment process and cause them to lose agency.



# Pain point: organizational hassle

A cancer diagnosis means mountains of new paperwork from insurance providers, HCPs, and/or government agencies. These administrative tasks are an often-overlooked patient burden during a turbulent time.

# Pain point: waiting for treatment

Patients must often wait for weeks or even months before treatment begins. During this period, a lack of updates from the HCP might increase anxiety and prevent them from making lifestyle changes to support their recovery.

# AREAS OF OPPORTUNITY

# Help patients to deal with one of the most difficult times of their lives

Coping with the emotional roller coaster is a key challenge of any patient's cancer journey. The time it takes patients to overcome the initial shock and accept their situations could be significantly shortened so that appropriate treatment can begin sooner.

What if patients were automatically offered digitally enabled personalized psychological support when receiving their diagnosis? Such support would provide patients with simple, individualized ways to cope with emotions, include their social circles in their journeys and connect with other patients facing the same type of cancer, or professional counselors.

**Imagine** a living, personalized support system, meeting the individual emotional patient needs and complementing medical treatment. Such a system would relieve HCPs of the counseling burden and patients would be empowered through empathetic guidance. Empower patients to find relevant and understandable information and give them easy advice on how to adapt

When faced with a potentially life-threatening illness, it is a core human urge to learn as much as possible about one's invisible enemy and what can be done to beat it. But randomly browsing the Internet often turns into a boomerang, as cancer is a highly individualized experience and specific, trustworthy information is hard to find. If guided to appropriate sources of information, patients' emotional hardship could be reduced through accessible self-empowerment.

What if patients knew where to search and had access to relevant and trustworthy information right after their diagnosis? Embedded AI could assist patients to find personalized information on their specific cancer type, the most promising treatment options and effective self-management strategies. Instead of being solely dependent on HCPs, patients would increase their selfcare capacities and could involve themselves in key treatment decisions.

**Imagine** a patient received access to a digital platform detailing their diagnosis, with the latest updates on their specific cancer type— along with understandable, personalized advice and exercises to increase psychological and physical fitness. While this should not replace any action from the HCP, it could

**44%** would have wanted more thorough and transparent communication from their oncologists about the diagnostic tests. <sup>(6)</sup>

Give patients ownership of data Patients often lack ownership of their record and test results. In many cases, the data is r

Patients often lack ownership of their records and test results. In many cases, the data is not even digitally available. Patient data sharing could be much faster, more convenient and open up new opportunities to connect with specialists and services.

**What if** a patient had full control over their file and were able to conveniently share it with any HCP of their choice? This would give patients

complement the cancer journey and make it more holistic and transparent.

Imagine sharing up-to-

**Imagine** sharing up-to-date patient records with different stakeholders in a matter of seconds to get a second opinion, coordinate care and ongoing checkups or be considered for a clinical trial. Beyond this, patients could volunteer data for research once recovered.

more control to consider different options and choose the most suitable way forward.

"Cancer is a hyper-individual experience. But what every patient has in common is fear and a desire to live a healthy life."

— Andrea



# **OUR PERSPECTIVE**

Future patients will have different expectations of the cancer treatment journey. HCPs should be open to a future where patient management will be complemented with services from other providers, initiated by the patient. Patients will be able to take advantage of services outside of their core treatment plan, like microservices from a vast ecosystem of smaller providers. These will offer care for different aspects of patients' lives and disrupt today's often one-sided relationship between HCPs and patients.





Getting treatment

Whatever treatment plan is chosen, it has far-reaching implications on many aspects of a patient's life.

# **EPISODES**

scheduled by the treating physician, some patients might consider special or complementary treatment options.

# Episode 11: starting and getting treatment

Starting treatment is another moment of high uncertainty in the patient journey. Before the first appointmentbe it surgery, radiation-, or drug therapy-patients can only guess how they will respond to their treament and what side effects will occur. In addition, treatment commonly takes place in an unfamiliar environment among strangers.

# Episode 12: adapting personal life to side effects

For many patients, life changes drastically during treatment. Almost all patients experience side effects, even though the kind and severity are individual and can change during treatment. Patients need to adapt their routines and behaviors to the new reality.

**Episode 9: choosing a** treatment plan and therapy

Physicians choose treatment plans and assess whether therapy makes sense. Patients are involved in this step to varying degrees and might also seek second opinions at this stage. If patients are diagnosed with advanced-stage cancer, time becomes a central factor and options might be limited.

# **Episode 10: coordinating** care

In addition to treatment decisions, logistics and transportation must be organized. Depending on the therapy, it might take place on an outpatient basis, but sometimes an inpatient stay might be necessary. Even if the default treatment is organized and

# Nearly

would have liked to be more involved in their overall treatment plan decisionmaking process. (7)

64%

were overwhelmed and unable to get involved in the decision-making process.<sup>(8)</sup>

# **Episode 13: participating in** clinical trials

For patients facing an unfavorable outlook for recovery, experimental drugs provide a glimmer of hope. However, access to unapproved drugs is usually dependent on physician initiatives and is associated with additional uncertainty and administrative hurdles.

# PAIN-POINTS

### Pain point: getting a second opinion

The difficulty of finding appropriate channels to get a second opinion may make patients dependent on their HCP's sole judgment. This results in a loss of agency and prevents other options from being considered.

## Pain point: disinvolvement in treatment plan choices

Patients are often too overwhelmed to find relevant information or lack the confidence to get inin choosing their treatment plans. This fosters an imbalanced HCP relationship and prevents alternative courses of action from being considered. Often, the interval between diagnosis and treatment is short, which increases overall pressure and leaves patients completely dependent on the HCP.

### Pain point: other lifechanging aspects are not sufficiently considered

When choosing a treatment, patients may not be fully informed about its life-changing implications. Treatments may affect mental and physical capabilities. As beating cancer clinically often is the primary focus of HCPs, it is up to patients to manage the other factors.



Involvement is a key feature of Theme 3, as patients want to co-determine the course of their treatment. At the same time, the treatment's organizational aspects become more predominant. Staying informed and getting holistic care remain relevant during this crucial phase.

# Pain point: managing logistical challenges

While frequent trips to the clinic/ hospital might be necessary to get the treatment, patients are often physically or mentally unable to undertake these trips themselves. The same is true for daily tasks such as buying food, cleaning or washing clothes. The resulting effort adds another logistical burden to the patient.

# **More than** everv 4<sup>th</sup> respondent experienced transportation

difficulties during treatment.<sup>(9)</sup>

Pain point: dealing with physical pain and impediment Cancer treatment is highly individua-

lized and is usually a hybrid of surgery, drug- and/or radiotherapy. Whatever the treatment entails, many patients experience unexpected side effects and physical impediments, which pose a serious obstacle to leading a normal private and professional life.

### Pain point: personal isolation

Patients undergoing cancer therapy are often socially isolated, as the therapy often results in uncomfortable changes like hair loss, sweating, edemas and significant associated embarrassment. The changes also leave patients tired and less willing to engage in social encounters. Many lack the energy to continue as normal during this phase and place their focus on conserving energy.

### Pain point: not finding a clinical trial

Many patients will be unable to participate in clinical trials. The reasons are complex, but often include administrative barriers or an HCP's lack of time or willingness to review available trials.

# **For 91%**

the possibility of joining a clinical trial never came up. (10)

Nearly 60% of patients are significantly impaired by side effects. (11)

What if information about life-changing decisions like cancer treatment plans were easy to understand and instilled confidence about the right choice? Accessible, understandable and personalized information would increase patient empowerment and awareness of treatment options while reducing the time, energy and emotional hardship of trying to get informed.

# **AREAS OF OPPORTUNITY**

# **Provide patients with under**standable information about their options

A lack of ability, energy or desire to dig through complex information frequently makes patients rely solely on the HCP's opinion. Providing patients with understandable information about their cancer type and the trade-offs of different treatment options could re-balance the HCPpatient relationship and empower patients to discuss alternative treatment options more confidently.

Imagine AI-driven, curated content based on global scientific evidence and patient-specific data comparing personalized treatment options. The content would enable HCPs and patients to jointly assess available therapeutic options, even in a community-practice setting.

### Getting treatment

"I want to have my data centrally available so that I can grant access to whoever I want in an easy fashion."

— Nora



# OUR PERSPECTIVE

It is currently a challenge for patients to share their own health data and coordinate their treatment across different services providers. Giving patients ownership of their own data and the freedom to share it with relevant healthcare professionals and services has the potential to improve patient empowerment and outcomes significantly. Besides this, new delivery models, decentralized care options and emerging microservices will allow a disentanglement of a patient's location from eligibility for certain treatment options such as clinical trials.

# Support patients in day-to-day tasks while they focus on recovery

The fight against cancer requires great physical and mental strength. For many, this means they have less time and energy to complete everyday tasks such as preparing food, doing the dishes, or cleaning their homes. Supporting patients with their daily chores would reduce their physical burden, free up precious time, and allow patients to focus on their healing process.

What if patients had automatic access to support in daily tasks as part of their treatment? The support would consider individual needs and requirements, allowing patients to complement already existing arrangements with their loved ones and get easy access to help if they are alone.

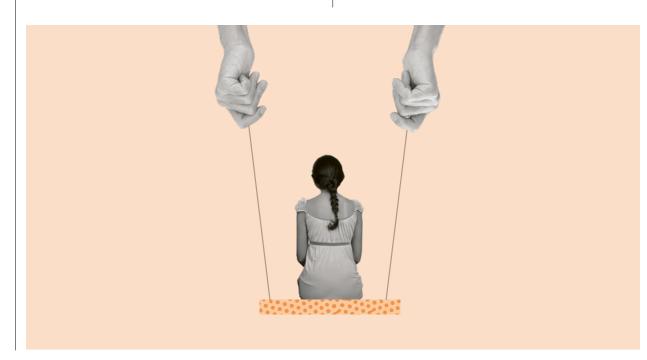
**Imagine** the platform economy offering services tailored to cancer patients (such as transportation, grocery shopping, or childcare) embedded in their current ecosystems.

# Empowering patients to deal with side effects

Most patients experience side effects during treatment. While the type and severity vary from case to case, the occurrence of side effects usually decreases a patient's energy level and has implications on their mental and physical wellbeing. Helping patients to manage side effects could not only increase the efficacy of treatments but also the overall patient experience.

What if patients didn't have to wait for an HCP consultation to assess and treat side effects? Side effects could be monitored remotely, and patients receive useful inputs from a digital device on how to deal with physical or mental discomfort. Reducing the number of HCP calls and hospital visits would generate more comfort, reduce logistical and administrative hassle and decrease patients' anxiety levels.

**Imagine** a digital service where you could easily capture side effects and get personalized notifications on appropriate steps to take in alignment with your oncologist.



# Heddlife after Balanse Shedding light on life after treatment. THEME 4

# 96%

believe that digital solutions would help them in continuing to live a healthy life. <sup>(12)</sup>

# **79%**

say that an app or digital tool could help them in managing anxiety of cancer returning. <sup>(13)</sup>

# **EPISODES**

# Episode 14: follow-up consultations

After completing cancer treatment, regular follow-up consultations are needed. Patients need transport to and from checkups and must integrate these follow-up visits into their daily routine – often parallel to a full-time day job.

# Episode 15: sharing personal experiences of cancer treatment

For many patients, it is important to learn about the experiences of others and give advice around the topic. These connections are usually established through social media channels, cancer forums, as well as support groups associated with the medical or treatment facilities.

## Episode 16: moving on with life after having beaten cancer

Living with or having beaten cancer is a transformative experience, and makes people reflect on life. While some continue their newly formed habits with great discipline, others are more eager to have their life before cancer back. Whatever the case, most patients want to return to some degree of normalcy, accepting the fact that cancer has been an important part of their lives without wanting to keep a constant focus on it.

### **Episode 17: adapting** professional life and finances to cancer

As preventive measures and regular check-ups continue to incur costs, living with cancer may pose a significant and ongoing financial burden. While insurance systems vary across countries, financial considerations continue to preoccupy former patients and impact their decisions going forward. In this context, negotiating terms and conditions of work with current or new employers in line with their new reality and limitations is key to returning to regular life.

# "Since the end of therapy, I want to acknowledge that I suffered from cancer, but I don't want to talk about it all the time anymore."

- Ezrah

# PAIN-POINTS

## Pain point: struggling to return to normalcy

Having been immersed in treatments and surrounded by HCPs, the disease becomes a central part of patients' lives. After recovery people want to move on but reminders of cancer that happen in daily life (during a conversation, for example) can cause trauma to resurface.



### Pain point: issues with reintegration

Reintegration into regular life is often daunting, as people need to get reacquainted with peers who may not know how to handle the situation and show empathy. This may leave former patients isolated and cause them to withdraw from social life.

### Pain point: not knowing what to do with their life

For others, the journey causes them to reconsider their life choices. While they know they do not want to go back, they may have no idea what they want to do with the rest of their lives. Being left without support at this critical junction, many end up depressed.

# Pain point: dealing with lasting side effects

While cancer may be defeated, many continue to live with serious pain, deteriorating mental capacity (like decreased concentration), or other lasting effects from their treatment. They may not be able to perform all the professional and personal activities they used to and need time to learn to live with their limitations.

### Pain point: managing the financial burden

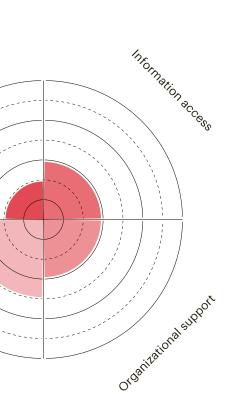
Patients may struggle with the ongoing financial burden of cancer. This not only pertains to direct costs, such as regular check-ups and medication, but may also include indirect costs such as transport or preventative measures (like nutritious food or gym membership). While, depending on

Involvement holistic care

Once treatment ends, holistic care remains important to cope emotionally and engage in preventative measures. Routine check-ups continue to take place, which is why involvement and organizational aspects are still relevant.

the country, insurance will cover some of the total cost, the significant overall financial burden of cancer is often overlooked. For those left unemployed due to lasting impediments, this may pose a life-threatening problem.

Almost every 4<sup>th</sup> patient struggles with unforeseen financial costs. (14)



# Pain point: the possibility of relapse

Regular check-ups and being faced with the possibility of cancer returning can be a traumatic experience, as the fear of death resurfaces.

# Pain point: finding the right place to share and process their story

Looking for people with the cancer type and stage to share personal experiences can be challenging, given the individual nature of cancer journeys. Even though former patients often feel the urge to share their experiences and lend purpose to their struggle, they are unable to find appropriate channels or platforms to do so.

# AREAS OF OPPORTUNITY

# Enable patients to live in their new normal

Even after treatment, a cancer journey remains a highly individualized experience. While cancer may be defeated, many continue to live with side effects. These can have lasting physical and psychological impacts. For many of those healed, there is the ongoing fear of relapse. The central role cancer plays in a patient's life makes it hard to move on. Some patients need ongoing care in their transition from treatment back to normal life.

**What if** support for former patients continued beyond their treatment and addressed new concerns and questions which arise? Holistic care could extend beyond healing and enhance patients' wellbeing, giving them a chance to flourish in their new lives.

**Imagine** patients and their loved ones had access to ongoing support on how to manage their physical, social, and emotional health and wellness. This could include digital solutions offering dietary advice or mentoring sessions, which help patients transition to the new normal, without constantly reminding them of their journey.

# Give patients a platform to connect with those who share the same experience

Many former patients express the need to help others who have experienced the same disease. However, given the individuality of a cancer journey, finding people with the same story might be difficult. Former patients could be guided in connecting with current ones, which would help both sides emotionally and increase mutual chances for growth and healing.

What if former patients could use their experience to guide others in their quest for recovery? Healing would be a democratized, collaborative effort with former patients receiving a sense of purpose and current patients being inspired by those who have had a similar journey.

**Imagine** a global service that automatically connected people affected by the same cancer type, based on matching needs, giving them an opportunity to chat and easily share their stories and best practices. There could even be a career path to becoming a certified cancer counselor. >60% of patients wish to share information with other patients. <sup>(15)</sup>

Patient issue

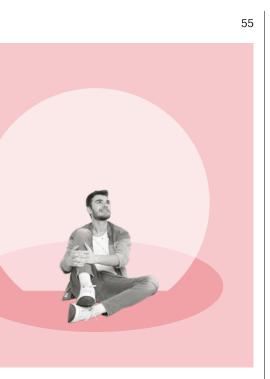
Living with cancer

"I'm not the same person as before, I worry a lot more and realize that I am quite vulnerable."

- Rachel

# OUR PERSPECTIVE

At the end of their treatment patients are often unprepared to lose the support system they had during their treatment. Routine check-ups that patients must continuously undergo are often linked with a buildup of fear and anxiety. Subtle, passive monitoring systems could reassure former patients that they will automatically be notified should an early intervention be needed, rather than constantly being preoccupied with a possible relapse. Patients can then focus on reintegration and building their new routine. It is important for former patients to have access to an ongoing support system at their own discretion. Beyond this, what if cancer became the start of a new professional calling?



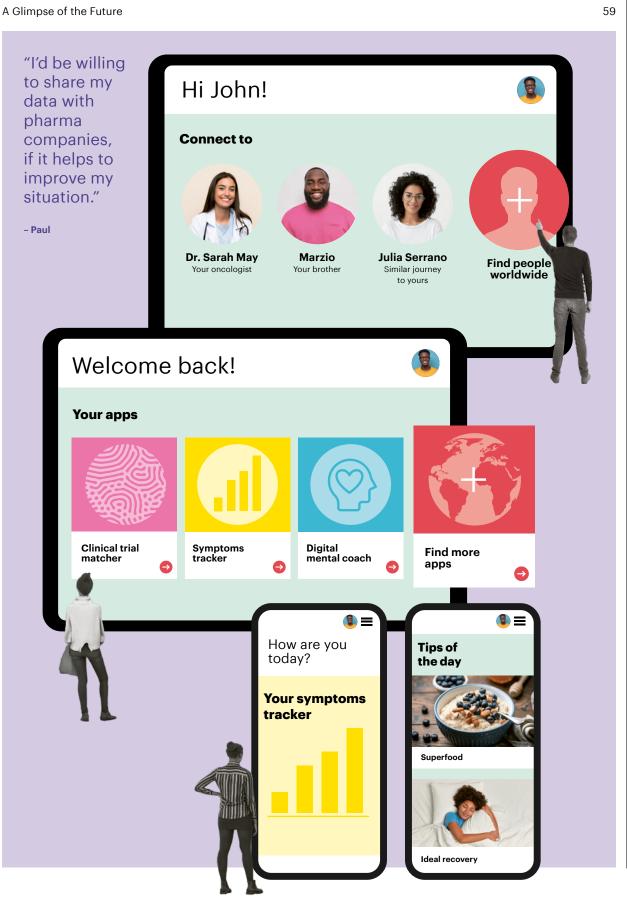
# A GLIMPSE OF THE

# FUTURE



to share my data with pharma companies, if it helps to improve my situation."





# WHAT'S NEXT FOR **BIOPHARMA COMPANIES?**

Our report has created a rich understanding of patients' main challenges and identified several areas of opportunity for biopharma companies. With these findings in mind, we looked at possible future patient solutions—with a specific focus on the emerging group of digital native patients.

Digitalization has not only accelerated innovation cycles but has also emphasized the need to re-imagine the business. Shareholder value is not the sole measure anymore, and digitalization can help companies to transform their core businesses more sustainably.

With digital natives coming of age, we can expect significant changes in the current patient journey. Growing up within a digital and more service-oriented ecosystem, tomorrow's patients form part of the most educated generation in history. We should prepare for a healthcare future that reflects next-generation needs.

They will expect clear, concise and personalized information presented to them through the channels they choose. Next generation patients will demand seamless experiences across all channels, tailored to their individual needs and empowering them to become involved in their own care. Being used to navigating a complex system of digital social interactivity, they are collaborative, eager to voice their opinions and embrace diversity.

# 88%

would use a digital platform to enter personal information, monitor health status and share data with specialists. (16)

Digital empowerment will allow patients to engage

their HCPs in open discussions and mutual decisionmaking instead of silent acceptance. As in other industries, digitalization will spark democratization and equity in healthcare.

Integrative consumer-driven platforms are likely to become a norm in medicine in general and in oncology specifically. Customizable forums and personalized content unify and filter the oncology ecosystem and create a space for patients, HCPs and other service providers to interact. This not only allows patients to get in touch with a worldwide community, but also to choose from a holistic set of relevant services at different stages of their journey.

For biopharma companies, future opportunities will arise from participating in such platforms. Integrating their offerings into such ecosystems and delivering high-quality services will help them to become patients' preferred choice. While we may not know the specific formats of the digital technology that will arise in the future, we can predict with 100% certainty that they will come. The challenge is to anticipate and interpret these inevitable changes.

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Conclusion

# **CONCLUSION**

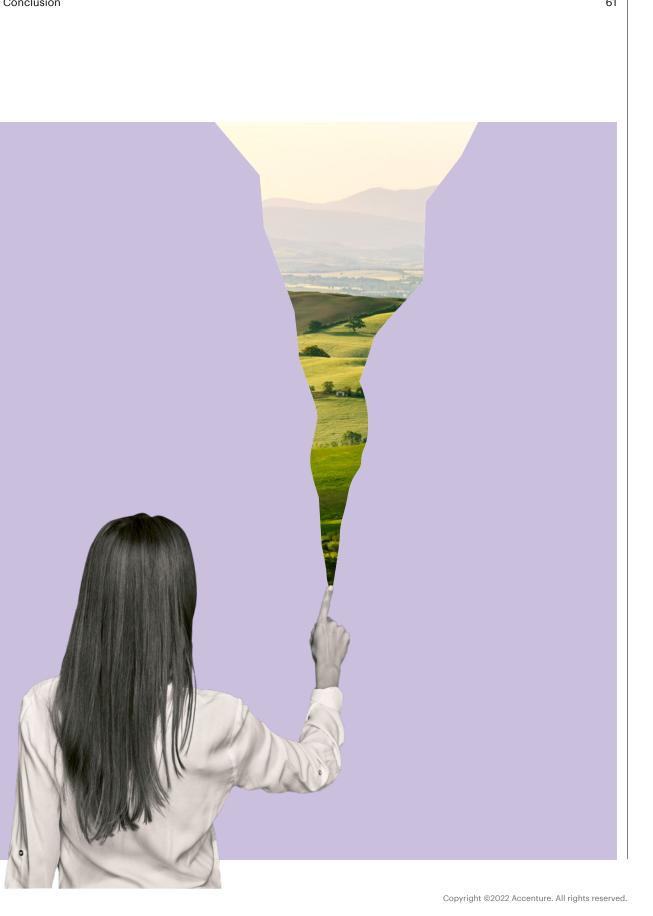
here is great potential to improve the experience journey of cancer patients. However, it is crucial that future services are human-centric and take a more holistic perspective of the well-being of patients.

The "Experience Report - Cancer patient issue" identified four recurring challenges (access to better information, more patient involvement, increased holistic care, reduced organizational hassle), which patients commonly face in their journeys. Given a future composed of digital natives, it is imperative that health care interventions and services align with patients' evolving demands. New offerings centered on personalized information and holistic care will empower tomorrow's patients to take ownership of their journeys and strive for better health outcomes.

This report can serve as a launch pad for change. In reality, transformation projects can have different ambition levels and time horizons. At Accenture, we improve established oncology services iteratively, and support ambitious strategic bets. Most importantly, we believe that better experience and outcome design comes from a deeper understanding of patients' needs.

«I just hope for more interdisciplinarity in oncology."

- Andrea



# **ABOUT US**

### About Accenture Life Science

Accenture's Life Sciences group is committed to helping our clients make a meaningful impact on patients' lives by combining new science with leading edge technology to revolutionize how medical treatments are discovered. developed, and delivered to people around the world. We provide end-to-end business services as well as individual strategy, consulting, digital, technology and operations projects around the globe in all strategic and functional areas- with a strong focus on R&D, Sales & Marketing, Patient Services, and the Supply Chain. We have decades of experiences working with the world's most successful companies to innovate and improve their performance across the entire Life Sciences value chain. Accenture's Life Sciences group connects more than 15,000 skilled professionals in over 50 countries who are personally committed to helping our clients achieve their business objectives and deliver better health and economic outcomes.

# About Fjord

Fjord, part of Accenture Interactive, is a design and innovation consultancy that reimagines people's relationships with the digital and physical world around them. We use the power of design to create services people love. By combining a human-centered approach with robust methodology, we work with some of the world's leading businesses to make complex systems simple and elegant. Founded in 2001, Fjord has a diverse team of 1,200 design and innovation experts in 38 studios, including Atlanta, Auckland, Austin, Barcelona, Berlin, Bogotá, Buenos Aires, Canberra, Chicago, Copenhagen, Costa Rica, Dubai, Dublin, Helsinki, Johannesburg, Lima, Lisbon, London, Los Angeles, Madrid, Medellin, Melbourne, Mexico City, Milan, New York, Oslo, Paris, San Francisco, Santiago, São Paulo, Seattle, Singapore, Stockholm, Sydney, Tokyo, Toronto, Washington, D.C. and Zurich. Learn more, follow us @fjord and visit www.fjordnet.com

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