NOVEL HEALTH CARE STRATEGIES FOR MELANOMA IN CHILDREN, ADOLESCENETS AND YOUNG ADULTS

Grant Agreement: 101096667

Report

The melanoma patient journey- a design thinking approach to capture deep insights from the European Melanoma Patient Community

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Executive Summary

This document presents key insights from workshops aimed at Mapping the Melanoma Patient Journey using design thinking principles to identify pain points and challenges from the patient's perspective.

Our investigation included two workshops on Melanoma Patient Pathways, resulting in Actionable insights and Recommendations to improve prevention, diagnosis, treatment, and palliative support for children, adolescents, and young adults (CAYA) affected by melanoma.

Contents

Acronyms & Abbreviations

Term	Description
AI	Artificial Intelligence
AMeR	Asociatia Melanom Romania
GPs	General Practitioner
CAYA	Children and Young Adults
CHM	Childhood Melanoma
CMN	Congenital melanocytic naevi
HCPs	Healthcare Professionals
ML	Machine Learning
MPNE	Melanoma Patient Network Europe
MTB	Molecular Tumour Boards
NCM	Neurocutaneous melanosis
PA	Patient Advocate
PE	Patient Expert
PAE	Patient Advocate Expert
RWE	Real World Evidence

Introduction

Motivation

Melanoma diagnosis significantly impacts the lives of patients and their families. At the same time, lack of access to proper melanoma care could add a considerable psychological burden. We have noted increased socio-economic pressure on patients on our forums, with increased out-of-pocket payments, and delayed access to diagnosis, treatment and support services in an overall environment of austerity and healthcare system pressures. However, what particular aspects of the patient's experiences and insights are critical from the patient's perspective is difficult to understand especially when discussing a complex system such as healthcare. Patient pathways or Journey Maps are design thinking methods to study the patient's own care experience and interactions with the entire care system. In our work within MELCAYA project, we have employed Patient Pathways to identify pain points and capture experiences and insights that could be transformed into actionable measures for other stakeholders and ultimately improve the patient's outcomes.

Background

A Historical Perspective on Melanoma

Over the past ten years, melanoma care dramatically improved once two classes of drugs target therapies and immune checkpoint inhibitors, changed the median survival in metastatic setting from 6- 9 months to 10 years [7]. Their use expanded from advanced stages to early melanoma and from common forms to rare types, such as childhood melanoma (CHM), uveal melanoma, and mucosal melanoma, all of which are characterised by highly unmet needs. Standardisations of melanoma-specific diagnostic procedures and improvements in radiologic surveillance have contributed to improved outcomes for melanoma patients [6]. Recent advances in AI and ML have demonstrated a high potential to improve early diagnosis and risk stratification of patients and populations at risk, potentially increasing their chances [3].

Still, more needs to be done to ensure optimal care for melanoma. More than half of patients die of melanoma, and survivors struggle with long-term toxicity, while prevention and timely accurate diagnosis are not widely accessible. Patients are part of healthcare systems differently organised, with different budgets and levels of expertise which drastically influence their outcomes and increase inequality in melanoma care across Europe.

Specific challenges for CAYA with melanoma

In this report, we refer to CAYA in the melanoma community as a group ranging in age from 0 to 39 years, while AYA include AYAs as those aged 15–39 years[8]. CAYA melanoma patients represent a heterogeneous group as defined not simply by their age but in terms of the challenges they face concerning access to appropriate cancer care, and short- and long-term health. Our experience in supporting children and adolescents with melanoma presents challenges both in helping patients achieving early and accurate diagnosis and securing access to effective therapies, that have already proven beneficial for adults. The existing inequities in adult melanoma care are even more pronounced in childhood melanoma due to its rarity, leading to substantial differences in expertise and quality of care across Europe [1]. Further, young adults, as the most productive segment of the population, have additional needs related to work, quality of life, family planning, and fertility preservation, leading to distinct risk-benefit considerations in their care decisions [4]. Although national healthcare systems claim to have programs and effective measures in place for these patient groups, it remains unclear whether the needs of patients are met. Thus, our involvement in MELCAYA focuses on examining the specific challenges melanoma patients face from the patient's perspective and contributing to solutions and policies that address their needs.

Communities and insights

Patients communities have organised online forums as early as the Internet developed, in our days, such cancer and melanoma communities are using well-moderated forum interactions daily for support, essential information and medical education, while the advancement in advocacy is the combination of online activities and face-to-face meetings. Is not surprising that years of exposure to the melanoma community make one sensitive to the patterns and the cyclicity of how some issues recur.

The spectacular change in research and clinical practice of the last ten years was quickly assimilated by patient communities who used forums not necessarily for sharing stories as commonly believed but to learn, raise questions and brainstorm solutions to their problems. Sharing insights into their particular situations was therefore not the primary need but came out naturally in the process of asking for help from communities and experiences were seen as sources of learning and progress.

A Design Thinking approach

Building on the culture of patient forums where narratives and collaborative problem-solving are prominent, we have looked further into design thinking methods to capture patient insights in a structured way. Design thinking is an iterative, that focuses on a collaboration between designers and users to bring innovative ideas to life based on how real users think, feel and behave [10]. The Patient Pathways Map, also known as the Patient Journey Map, preserves the natural expression and interactions seen in our online forums while offering a structured visual framework to gather diverse patient perspectives. We considereded this approach has the potential to captures needs, unexpected insights, and opportunities for improved solutions.

To create the right environment for developing Melanoma Pathways, we organized **a first face-to-face workshop** focused on understanding the specific challenges from the patient's perspective in Children, Adolescents, and Young Adults (CAYA) with melanoma.

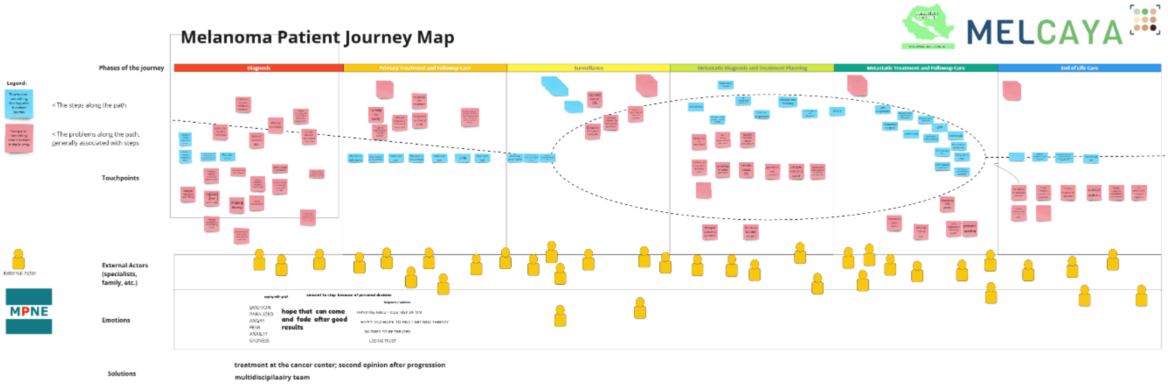
The **second workshop** focused on Advanced Melanoma but also served as an iteration of the previous findings. By revisiting insights from the CAYA-focused workshop and adding experiences of advanced melanoma patients, we aimed to build a complete perspective on melanoma patient pathways.

The status (patient or caregiver), the connection to melanoma, the country, and the level of advocacy and education (data not shown) were gathered to better understand the experiences and levels of patients proactivity. Each participant was categorised according to the classification previously developed by MPNE: patient or caregiver, patient advocate, and patient expert and patient advocate expert [9].

For both workshops, AMER used the MPNE Patient Journey template (Figure 1) in both printed and digital versions, a design thinking tool created by MPNE we previously tested for uveal melanoma [5].

Figure 1. MPNE Patient Journey Template

Figure 2. An example of a filled Patient Journey Map



MPNE Patient Journey map includes 6 phases: Diagnosis, Primary Treatment and Follow-up, Surveillance, Metastatic Diagnosis and Treatment Planning, Metastatic Treatment and Follow-Up Care and End-of-Life Care. Patients were invited to describe touch points as ‘’the steps they took along (in blue). Pain points (in red) signalised the problems along the path, generally associated with steps or something that is broken in the journey, example Figure 2. Maps included opportunities to describe the external actors (specialists, family, etc.) involved, emotions and proposed solutions.

The outcomes of this report will be further integrated into the context of WP7 objectives, particularly D7.2.

Workshops in detail

Photo Workshop 1, Berlin, March 22-24, 2024

Workshop 1- Understanding the challenges for CAYA

Berlin 22-24 March 2024

To study barriers to melanoma care in CAYA, AMER organized a three-day design thinking workshop during the 22- 24 March 2024, described here as workshop 1. https://www.mpneurope.org/melcaya-at-mpne

A total of 22 participants attended the Workshop 1, including 13 patients and caregivers who contributed to the Pathways, 3 moderators and 6 speakers.

Participants characteristics

Patients and caregivers (13) were organized into four working groups based on their condition: Group 1 – congenital melanocytic nevus (CMN), Group 2 – childhood melanoma (CHM), Group 3 – young adult melanoma, and Group 4 – adult melanoma, as shown in Table 1. Except for Group 1, all groups included participants from both Eastern and Western countries. The group consisting of organizers and moderators, did not complete the Patient Pathway Maps.

Table 1. Participants' profile and group allocation at the Design Thinking Worksop 1

No.	Participant	Link with melanoma	Advocacy	Country	Group
1	Patient	patient CMN	PA	Germany	**Group 1** CMN
	Caregiver	parent of a child with CMN	PA	Denmark	
3	Caregiver	Child melanoma *in situ*	NA	Romania	**Group 2** Childhood melanoma (0-15)
4	Caregiver	Child stage III	NA	Romania	
5	Caregiver	Child stage IV died	NA	Netherlands	
6	Caregiver	Nurse	PA	Spain	
9	Patient	stage I	PA	Romania	**Group 3** Young adults (15-39)
8	Patient	stage I	NA	Romania	
7	Patient	stage III	PA	Netherlands	
11	Patient	stage III	PA	Germany	**Group 4** Adult melanoma (39+)
10	Patient	stage IV	PA	Netherlands	
12	Patient	stage IV	PA	Sweden	
13	Caregiver	stage IV	PA	Poland	
14	Caregiver	stage IV	PAE	Sweden	Organisers Moderators
15	Caregiver	stage IV	PAE	Netherlands/Ro	
16	Patient	rare melanoma (ocular)	PE	Netherlands	

*P patient, C caregiver, PA patient advocate, PAE patient advocate expert, PE patient expert, NA- no or minimal advocacy involvement; *organisers and moderation activities, the group was only supervising.*

Participants were residents of the Netherlands (5), Romania (4), Sweden (2), Poland (1), Germany (2), Denmark (1), and Spain (1). Experiences varied, as individuals had histories as patients and patient advocates in more than one country. The majority were patient advocates with differing levels of advocacy, while several had little to no experience or minimal involvement in patient advocacy. The work resulted in four Melanoma Pathway Maps, allowing participants to describe the particular steps along their path and associated problems, the external actors involved, and the emotions of patients and families. Subsequently, participants transferred the maps to the Miro Board for further iteration.

https://miro.com/app/board/uXjVL6ihG9o=/

RESULTS

Below, we outlined the pain points encountered along the patient journey associated with each phase as shared by patients and their families. Results are reported by Group (1, 2, 3, 4) and by journey phase: (1) Diagnosis, (2) Primary Treatment and Follow-Up, (3) Surveillance, (4) Metastatic Diagnosis, (5) Treatment Planning, Metastatic Treatment, and Follow-Up Care, and (6) End-of-Life Care.

Group 1- CMN Patient Pathway

Diagnosis

- Problems with diagnoses: *’’It’s extremely frustrating that healthcare professionals make unprofessional guesses about whether it’s a nevus or suggest other possibilities that are not well-founded’’*
- Lack of support and sufficient insight in the disease: *After childbirth, many parents panic if the staff cannot provide credible information, leading them to rely on Google*
- Unprepared healthcare professionals: *’’It’s extremely difficult for parents to find a specialist knowledgeable about CMN (e.g. highly skilled surgeons for large CMNs). When they are also in shock, the additional burden of finding a qualified practitioner on their own is unreasonable’’, ‘’Fear that a "normal" headache could be a symptom’’*
- Old or no guidelines in most countries
- Newborn screening is NOT available for CMN
- Psychological support is necessary in this phase but not always available

Surveillance

- Problems accessing annual preventive body screenings
- Stress: high visibility of CMN serves as a constant reminder
- The need for a holistic approach in monitoring: ‘’*CMN requires tracking size, number, and colour through thorough screening. It should also include measuring head circumference, assessing motor and linguistic development, and providing general advice and information.’’*
- Confusion about International Classification: *it’s important that CMN is registered under the correct ICD diagnosis code so patients can be identified for research or new guidelines regarding surveillance and check-ups.*

Primary Treatment and Follow-up Care

- Incorrect treatments (e.g., dermabrasion and laser therapy) *''make it harder to identify melanoma''*
- No treatments and clinical trials available for NCM
- The need for individualized treatments for each case, such as MEK inhibitors
- Side effects management is poor: *many treatments lead to complications*
- Long waiting times for removal/surgery
- Difficult access to highly skilled surgeons usually involving cross- border access
- Surgery seems not sufficient *''Removing the CMN does not reduce melanoma risk''*

Group 2 - Children Melanoma Pathway

The challenges families perceived in the childhood melanoma pathway (CHM) are presented below:

Diagnosis

- Families often identify suspicious moles indicating some gaps in paediatric dermatological checks
- Children experience delays in referral to specialists e.g. *children should not wait in line for consult*
- Families experienced histopathological and staging inaccuracy e.g. *from in situ melanoma to ''not malign'', from melanoma III A to melanoma III B*
- Genetic testing is not suggested in earlier phases e.g. family demanded *''genetic testing with professional recommendations''*
- Families received no personalized information about relapse risks or predisposition to other cancers
- There is a tendency to blame patients *''Blame: doctors blame patients''*

Primary Treatment & Follow-Up Care

- Families struggled to find a knowledgeable specialist, as expertise in paediatric melanoma is scarce, often searching melanoma centres and treatment options on their own e.g. *''Paediatric oncologists totally unprepared- still treating melanoma patients'', [we were] finding a patient organisation for the best responses.''*
- Families pushed for genetic tests *e.g. ''we demanded a BRAF test from the pediatric oncologist''*
- There was no access to treatment or clinical trials for children; paediatric oncologists seemed unable to provide treatment solutions forcing families to seek second opinions or search on their own e.g. *[we] obtain a recommendation from another oncologist and we buy treatment, treatment not suggested by medics but by Patient Association*, [we find] *no clinical trials for children*)

Surveillance and Follow-Up

There was no established follow-up for childhood melanoma e.g. ''*scans are left to the family to take care of'', ''no standard follow-up'', ''look and listen to the patient and schedule based on that, in case of signals seen by patients or parents- scan! ''*

- Symptoms were often dismissed, leading to missed opportunities for early intervention
- Follow-up scans were considered unnecessary and families receive false reassurance e.g. ''*nothing is wrong''*
- There was a lack of (appropriate) psychosocial support for parents and children e.g. ''*real needs are not covered''*

Metastatic Diagnosis & Treatment Planning

- Treatment information came from patient organizations rather than medical professionals e.g. *treatment not mentioned by medics but by Patient Association*
- Families switched several medics and hospitals in their search for better care, e.g. *we asked for second opinions, we changed hospital*
- Parents bear the financial burden of securing effective treatments, e.g. *we bought our treatment*

Metastatic Treatment and Follow-Up

- Lack of coordinated, interdisciplinary care between specialists (e.g. ''*dermatologists, surgeons, oncologists, psychotherapists''*)
- Lack of clinical trials or access research programs for children, e.g. *no clinical trials dedicated to children*;
- No access to immunotherapies and targeted treatments for children, e.g. *we bought our treatment*
- No clear treatment protocols: e.g. *oncologist did not assume the decision to continue/stop the treatment*

End of Life

- Palliative care missed *real needs* (age- appropriate), both medically and psychologically
- Psychological and social support was insufficient for parents and children e.g. ''*[we needed] psychological support from the start*, *be aware of the Pygmalion effect''*
- In some countries, palliative care was absent, forcing families to find their own solutions
- Parents experienced deep guilt and grief in the context of a lack of closure and support.
- The impact on siblings and school colleagues was underestimated and left to the parents to take care
- There was a high need for justice after a child's death, implying parents wanted to make the healthcare accountable (not shown on pathway, but shared)

Group 3- Young Adults Melanoma Pathway

The challenges Young Adults perceived along melanoma pathway are presented below:

Diagnosis

- GPs lacked knowledge of melanoma, leading to delays in referrals.
- Skilled dermatologists were rare, making diagnosis difficult
- Local biopsies needed to be redone due to poor-quality procedures.
- Delays in care due to reimbursement issues, with crucial tests scheduled too late.
- No psychological support was offered at the time of diagnosis.
- Social media plays a dual role—helpful for learning but also a source of misinformation and pressure.

Primary Treatment and Follow-Up

- Guidelines were outdated or not implemented consistently
- Surgeons may not be up-to-date with the latest melanoma treatment advancements
- Quality care was mostly available in large cities
- No multidisciplinary team coordination, leading to fragmented care
- Treatment choices depended on hospital resources, not necessarily on best practices
- Lack of shared decision-making: patients felt excluded from treatment choices
- Patients were unsure about first-line treatment, which adjuvant therapy to choose or if clinical trials are the best options
- No genetic testing was available for early-stage patients, limiting a personalized approach
- Time was wasted moving from doctor to doctor, delaying effective treatment.
- Lack of consideration for long-term life planning, such as fertility and family planning
- Doctors rarely discussed clinical trials

Surveillance- monitoring

- Follow-up plans often did not align with clinical guidelines.
- Knowledge existed but in silos, leading to inconsistencies in follow-up schemes

Metastatic Diagnosis and Treatment Planning

- Physicians did not take physical complaints seriously, leading to missed or delayed diagnoses
- Scan reports with concerned signals were ignored, delaying metastatic diagnosis

Metastatic Treatment & Follow-Up

- No standardization of second and third-line treatments, leading to variability in care.
- Side effects of treatments were underestimated, impacting patients' well-being.
- Quality of life (QoL) was not considered in clinical decision-making.
- Clinical trial options were not routinely discussed, limiting access to innovative therapies
- Delayed scans to monitor treatment progress led to delays in metastatic diagnosis.
- For some- no option for re-challenging melanoma treatment after toxicity or relapse, limiting treatment options

End-of-Life Care

- Minimal or no structured palliative care was available, leaving patients unsupported

Group 4- Adult Melanoma Pathway

The challenges Melanoma Adults perceived along melanoma pathway:

Diagnosis

- diagnostic approaches were inconsistent across hospitals: patients experienced different pathways depending on where they seek care *"Surgeons and dermatologists don't always follow the latest guidelines or not every hospital uses the latest guidelines or consensus documents''*
- Patients delay seeing a doctor due to fear, underestimation of symptoms, or long wait times *"transfer from GP to dermatology had a waiting list of 6 weeks''*
- *Few skilled dermatologists*: patients face misdiagnosis or incorrect initial treatment.
- Biopsy and histopathology issues
  - *shave biopsies that compromise diagnosis.*
  - *external pathology labs may lead to errors, requiring second opinions*.
- Referral issues
  - delay in transfer from GP to dermatology (e.g. *6-week waiting lists*).
  - confusion *about which specialist to see, depending on melanoma location (e.g., dermatologist vs. head and neck surgeon).*
- Lack of patient support after diagnosis: *no guidance after receiving bad news.*
- Family burden: *melanoma becomes the centre of life, creating guilt and changing family dynamics*

Primary Treatment and Follow-Up: gaps in care

- Surgical errors- *wrong excisions lead to additional procedures*.
- Limited treatment access
  - No immediate availability of standard treatments.
  - No access to clinical trials.
- Emotional, logistical, and financial help was missing.- patients and families coped alone.
- *Side effect management* waspoor- patients struggled with side effects without being helped in time.

Surveillance

- Inconsistent use of imaging and guidelines- some hospitals followed outdated protocols *''Follow-up schemes do not align with standard guidelines''*
- Lack of information about scans- patients are unaware of what scans they need or why '' *"I had no information on what scans were indicated and their purpose''*
- No structured follow-up information- patients don't know what to expect post-treatment.

Metastatic Diagnosis & Treatment Planning

- Adverse event management is poor- side effects are not handled properly *When I needed urgent help, I had trouble finding the right contact"*
- Lack of multidisciplinary teams - no communication between specialists, leading to mismanagement, '*Multidisciplinary teams do not exist!''*
- There were errors in diagnosis and treatment choices, incorrect staging or missed metastases.
- No rehabilitation plans or guidance for recovery.
- Access to treatment was limited in the latest phases
    - No referrals to specialists when needed.
    - *No cross-border treatment access*.
    - *Price negotiations delay drug availability*.
- Financial burden was high in the latest pahses - medical costs strain patients and families.
- No integrative approach: *Everything focuses on melanoma only*- other health issues or long-term impacts were overlooked.

Metastatic Treatment and Follow-Up Care

- Emergency care was not helpful- melanoma patients struggle to get urgent medical help.
- Patients were left without alternative options after two treatment lines failure
- There were treatment delay due to cost-related negotiation
- Genetic testing took time and money, limiting personalized treatment options.
- Follow up plans were inconsistent, leading to missed recurrences.
- Burden on families increased in advanced stages: *''Disease becomes the centre of my family life – it changed dynamics in the family, [I have] feelings of guilt.''*

End-of-Life Care:

- Families experienced isolation with the end of life care: home hospice care was inaccessible, patients struggled, pain management was poor in eastern European countries
- caregivers could not work, and costs and responsibilities overwhelmed families (heavy social and economic burden)
- Lack of emotional closure and despair when no more treatment options
- Some families were restricted to visit patients in the hospital and end of life setting
- "*Theatre playing roles*" *No psycho-oncological support*'' notes indicated a lack of real support

Figure 3. Adult Melanoma Pathway

Workshop 2- Special focus on advanced disease

Berlin December 6, 2024

Photo Workshop 2- Berlin, December 6, 2024

The session took place during MPNEhubs gathering https://www.mpneurope.org/mpnehubs2024 and involved 23 melanoma patients and caregivers (including 4 ocular melanoma patients) from Cyprus, Finland, France, Germany, Hungary, Ireland, Latvia, the Netherlands, Romania, Poland, and the UK (Table 2).

Participants were affected by cutaneous and ocular melanoma, with 8 diagnosed at a young age (young adults) and 15 in adulthood. For practical purposes, participants were divided into six tables combining different stages of the disease. After completing the maps participants transferred the result on Miro for further reference and iteration https://miro.com/app/board/uXjVL6hmU3s=/ Here we report on the pathways for advanced cutaneous melanoma, designated as Group 5.

Table 2. Participants in the iteration Session, Workshop 2

No.	Participant	Link with melanoma	Advocacy level	Country
1	Patient	Stage I	PAE	Latvia
2	Patient	Stage I	PAE	Finland
3	Patient	Stage I	PA	UK
4	Patient	Stage I	PA	Romania
5	Patient	Stage I	PA	Germany
6	Patient	Stage II	PA	Cyprus
7	Patient	Stage III	PA	Netherlands
8	Patient	Stage III	PA	Germany
9	Patient	Stage III	PA	Hungary
10	Patient	Stage IV	PA	Ireland
11	Patient	Stage IV	NA	UK
12	Patient	Stage IV	NA	UK
13	Patient	Stage IV	PA	Netherlands
14	Patient	Stage IV	PA	Netherlands
15	Patient	Stage IV	PA	Sweden
16	Caregiver	Stage IV	PA	Poland
17	Caregiver	Stage IV	PA	Netherlands
18	Caregiver	Stage IV	PAE	Sweden
19	Caregiver	Stage IV	PAE	Netherlands/Romania
20	Caregiver	Stage IV	PAE	France
21	Caregiver	Stage IV	PAE	Romania
22	Caregiver	-	PA	Poland
23	Caregiver	-	PA	UK

*PA patient advocate, PAE patient advocate expert, PE patient expert, NA- no or minimal advocacy involvement; *organisers and moderation activities, the group was only supervising, green colour rows- Young Adults (15-39), light orange Adults (39+).*

RESULTS

Below, we outlined the pain points encountered along the journey associated with each phase as shared by patients and their families. Similarly with workshop 1, the input of Group 5 is reported by journey phase: (1) Diagnosis, (2) Primary Treatment and Follow-Up, (3) Surveillance, (4) Metastatic Diagnosis, (5) Treatment Planning, Metastatic Treatment, and Follow-Up Care, and (6) End-of-Life Care. After completing the journey on physical maps, participants uploaded the information to the Miro board (e.g. Figure 4).

Group 5. Advanced Melanoma Pathway

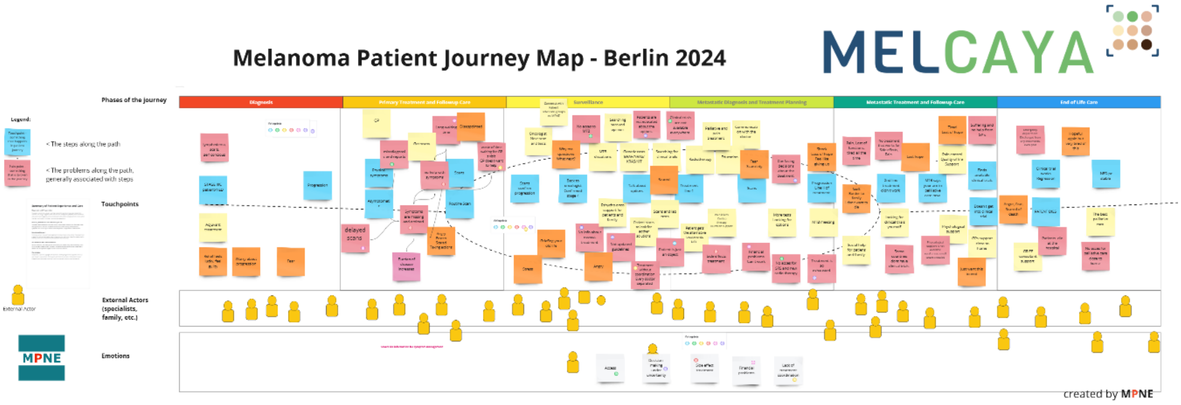


Figure 4. Advanced Melanoma Pathway

Diagnosis

- There were long waiting times for GP appointments, diagnostic tests, BRAF status, and imaging.
- Misdiagnoses, incomplete reports, and GPs dismissing symptoms caused frustration.
- It was difficult to access personal medical information on time
- There was a need for second opinions due to misdiagnoses or being insecure
- Some patients missed biomarkers to guide risk and treatment decisions
- Patients were concerned about leaving children behind/ facing a life-threatening illness
- Associated feelings: denial, shock, sadness, fear, anger.

Primary Treatment and Follow-Up

- There were delays in referrals to oncology, treatment planning, and side effects management
- Doctors were too busy to explain plans in detail
- "Doctor knows best" culture left patients feeling not informed and uninvolved
- Lack of access to personal medical data made it difficult for patients to understand their own condition
- Patients feared disease progression and side effects but reluctance to report symptoms
- Associated feelings: disappointment, anger, fear, and lack of trust.

Surveillance

- Patients needed referrals for scans, blood tests, and genetic testing, sometimes having to fight for them.
- Waiting for test results, uncertainty about staging results and disease progression
- There was no clear treatment planning—patients were unsure of what’s next
- Transition between specialists (e.g. gynaecology to dermatology) was slow
- Doctors showed little empathy and failed to explain test results or next steps
- There were limited treatment options for some patients and long-term side effects
- Associated feelings: shock, anger, grief, fear of scans ("scanxiety"), stress, denial.

Metastatic Diagnosis and Treatment Planning

- Patients researched their treatment options and clinical trials
- There was also limited access to advanced radiotherapy techniques (SRS)
- Patients and families struggled to access and understand their own data.
- There was no access to molecular tumour boards for treatment discussions
- Care seemed uncoordinated, and doctors worked in silos
- Financial burden worsened, patients and families struggled to work.
- Pain, loss of function, and exhaustion increases as the disease progressed.
- Patients felt like "just an object" in the system, rather than an individual.
- No psycho-oncology and social support for both patients and families.
- Mistrust- patients do not always share information with clinicians
- *Waiting to see if accepted into clinical trials*- stressful as time is limited
- Associated feelings: frustration, loss of hope, feeling like a burden, dehumanization, guilt

Metastatic Treatment and Follow-Up

- Patients searched for alternative treatments and clinical trials on their own
- Some countries lacked access to clinical trials entirely, limiting hope
- There was high interest but limited access to next-generation sequencing.
- Lack of GP support for symptom and pain management.
- No effective treatments for side effects and pain- patients were suffering
- Progression after multiple treatment lines with no further options
- Patients self-funded or went private due to limited public healthcare options
- Work and insurance complications led to financial instability
- Emotional burden worsened as treatment options become exhausted
- Some clinicians did not consider patient concerns
- Uncertainty while *waiting to be unblinded from trials* added further stress
- Associated feelings: exhaustion, hopelessness, frustration, financial burden, feeling abandoned.

End-of-Life Care

- Patients were often discharged from care, even for pain management.
- Palliative care and home hospice were not accessible in some areas.
- Some patients experienced temporary disease regression, leading to short-term hope
- There was stress and worry over being a burden on family, guilt, and fear of dying
- Grief support was not provided for families after the loss (mostly in Eastern European countries)
- Associated feelings: hopelessness, exhaustion, guilt, fear, emotional distress.

Joint analysis

Joint analyses incorporate findings from all melanoma maps, with Groups 1-5 categorized based on recurring themes that form the core patient complaints. Additionally, we highlighted pathway-specific challenges and opportunities for interventions based on patients' contributions.

Recurrent themes

Results of both workshops (Groups 1-5) highlighted several recurring themes that were consistent across each melanoma group, namely: 1. Expertise issues, 2. Access barriers, 3. Research barriers, 4. System barriers: 5. Attitudes and behaviours 6. Emotional, social and financial burden 7. Patient agency. We have resumed the issues as follows:

Expertise Issues

- HCPs were insufficiently prepared to recognise melanoma, treat and support melanoma patients and families, most affected were CHM and advanced melanoma patients.
- Insufficient knowledge about tracking CMN development, risk factors, and optimal management strategies.
- Real needs were not fulfilled in psychological, palliative and end- of life care
- Lack of up-to-date guidelines and standardized treatment protocols

Access Barriers

- Poor access to clinical trials, precision oncology and treatments, especially for children, CNM, NCM patients and advanced melanoma

- Limited access to psychological, palliative and end- of life care for all Groups (1-5)
- Poor follow-up care and inconsistent monitoring led to late detection of progression (all groups)
- Limited availability of experts: long wait times for specialist referrals and diagnostic procedures forcing families to travel or seek out multiple consultations.

System Barriers

- Lack of interdisciplinary coordination and collaboration leads to gaps in care, requiring families to switch hospitals for adequate treatment and manage independently.
- There were obvious out of pocket costs in melanoma care across Europe
- Fragmented healthcare pathways with inconsistent policies, for example no clear transition process from paediatric to adult care, leaving gaps in treatment or monitoring

Emotional, Social, & Financial Burden

- Treatment costs, particularly for cross-border care and systemic (off-label) therapies created a significant financial burden
- Patients experienced significant distress due to lack of credible information and miscommunication from healthcare providers.
- There was isolation at the end of life and lack of medical care and lack of closure
- Parents experienced stress to find the right specialists for their child's condition.
- The highly visible nature of CMN contributes to stress and anxiety in patients.
- There is little emotional support for families, siblings and school colleagues after a child dies

Agency & Advocacy

- Patients and families asked for screening, searched for treatment options and advocated for their own care.
- Parents engaged with patient organizations to obtain information and solutions
- Families pushed for healthcare accountability and justice
- Patients were seeking systemic changes following misdiagnoses or treatment delays or inaccessibility.

Pathway-Specific Challenges

Childhood Melanoma (CHM) was affected more about:

- ➢ Lack of expertise leading to misdiagnoses and delays in treatment initiation.
- ➢ Lack of risk stratification tools to improve follow-up and treatment approach
- ➢ A very fragmented and uncoordinated care
- ➢ Poor follow-up and false reassurances
- ➢ No treatment choices: lack of research programs, clinical trials for paediatric patients
- ➢ No integration of paediatric melanoma care Melanoma specialized centres for coordinated management

Young Adults with Melanoma were affected more about:

- ➢ A slow diagnosis due to GP inexperience with melanoma symptoms
- ➢ Geographical and socio-economical level differences – lack of equity
- ➢ Delayed access to dermatologists and oncology specialists that affected their chances (early intervention and treatment)
- ➢ They were more likely to get chances in clinical trials (higher mobility, no language barriers) but they lacked discussion about clinical trials and research-based treatment options.

- Fertility and long-term quality-of-life considerations were overlooked in decision and treatment planning in this group view
- They were more likely to complain about poor symptoms managements and no structured palliative care
- They appeared less likely to dedicate time to finding solutions, likely due to career, hobbies, and family commitments - evidenced by their journey map containing the fewest suggestions for improvement.

Adult Melanoma Patients experiences:

- They have in place innovative standard therapies, but were affected by Inconsistent diagnostic approaches and lack of adherence to up-to-date treatment guidelines.
- They lost time and opportunities because poor coordination between specialists, even solutions were existing, requiring patients to navigate care independently
- They experienced waiting times for referrals and specialist consultations
- Lack of rehabilitation plans following surgery or advanced treatment was reported
- High financial burden due to treatment costs, travel expenses, and out-of-pocket medication fees.

Advanced Melanoma challenges were related to:

- Limited access to next-generation sequencing and precision oncology approaches.
- Systemic delays in imaging lead to late-stage diagnoses and treatment delays
- Lack of accessibility to clinical trials due to eligibility criteria: too sick, to many treatments behind, too old or too young
- Poor coordination between oncologists, dermatologists, and radiologists and other specialities involved in treatments, monitoring and side effect management
- Lack of transparency and argumentation in treatment plans led to patient lack of trust and distress.
- Palliative was introduced too late, with inadequate support for symptom management.
- Isolation at the end of life and lack of medical care

Needs and opportunities for interventions

CMN

- ✓ Medical education on CMN and NCM for general practitioners, dermatologists, surgeons, midwives, and paediatric oncologists
- ✓ Clinical guidelines for CMN and NCM diagnosis and treatment
- ✓ Research and treatment solutions for NCM and melanoma cases
- ✓ Newborn screening programs for CMN in hospitals.
- ✓ Support to help families finding the right care.
- ✓ Support and insurance coverage for CMN and NCM cross-border care

- ✓ Advocacy for newborn screening policies to allow early diagnosis.
- ✓ Routine annual body screenings to monitor CMN changes.
- ✓ Standardized ICD coding for CMN to facilitate research and policy development.
- ✓ Development of non-invasive surveillance tools for monitoring CMN changes.

Children

- ✓ Research and precision oncology for risk stratification and treatment strategies
- ✓ Explore the integration of paediatric melanoma in melanoma centres: access to specific expertise for diagnosis, follow-up and treatment
- ✓ Collecting RWE to secure access/reimbursement to off-label therapies
- ✓ How to develop fast-track access for children to prevent delays in CHM care
- ✓ Optimal follow-up: frequent scans and brain MRIs for early diagnosis and early treatment
- ✓ Early psychosocial and palliative support for families, responding to their ''real needs''
- ✓ Specialised training for HCPs to improve expertise in paediatric melanoma
- ✓ Exploring the role of patient organization in educating and guiding families

Young Adults

- ✓ AI-assisted diagnosis to solve delays and access to dermatologists/specific expertise
- ✓ Access to clinical trials, quality clinical research for improved treatment solutions
- ✓ Advocacy for updated guidelines and standardization
- ✓ Better follow-up and early intervention for metastatic disease
- ✓ Integrated palliative care with QoL considerations

Adults

- ➢ Improve diagnosis and risk stratification- *research*
- ➢ Ensure continuity of treatments- advocacy
- ➢ Access to melanoma research and clinical trials at home/country – advocacy and *lobby*
- ➢ Re-organization of care based on patient needs – *research*
- ➢ Cross-border access to clinical trials – *legislation*
- ➢ Psychological and social interventions tailored to needs- *research*

Advanced Melanoma

- ➢ Biomarker research to improve staging and treatment planning.
- ➢ Research on next-generation sequencing (NGS) and precision oncology.
- ➢ Prediction tools for side effects and research on side effect management and symptom reporting.
- ➢ Biomarkers for treatment response and disease progression
- ➢ Rethink the follow-up schemes, adapt to the new melanoma context- build RWE evidence
- ➢ Better sharing of patient data between medical centres to ensure continuity of care.
- ➢ Faster access to test results and personal medical data.
- ➢ Better referral pathways to avoid unnecessary delays.

- Increased access to psycho-oncology and social support for families.
- Palliative care and better pain management that are integrated earlier in care.
- A "treatment partner" to support and educate or a patient app to help explain the medical journey and improve decision-making.

Actionable insights and recommendations

As shown, results of both workshops (Groups 1-5) highlighted several recurring themes that were consistent across each melanoma group, namely: **1. Expertise issues, 2. Access barriers, 3. Research barriers, 4. System barriers: 5. Attitudes and behaviours 6. Emotional, social and financial burden 7. Patient agency.** For each of these we have extracted below several patient advocacy recommendations to be further translated in policy recommendations.

Expertise issues

All patient groups involved in the design thinking workshops experienced **gaps in melanoma expertise**, leading to misdiagnosis, delays, and inconsistent treatment decisions. CHM patients reported the most severe gaps in diagnostic expertise with a lack of melanoma education among GPs, dermatologists, pathologists, and pediatric oncologists (e.g., *"GPs lack awareness of melanoma," "Pediatric oncologists are unprepared"*). Young adults and adults also faced misdiagnosis, outdated knowledge, and inconsistent care, particularly outside cancer centres. However, adults generally did not encounter the extreme expertise gaps seen in childhood melanoma and adolescents. Advanced melanoma patients had a high need for precision oncology expertise and access to centres with clinical trials. They were also more vulnerable to inconsistent expertise among oncologists and pain-management specialists particularly after exhausting first- and second-line treatments.

Recommendations:

- Support healthcare professionals managing Melanoma and Rare Melanomas for training and education
- Support up-to-date guidelines to improve diagnostic accuracy, risk stratification, follow-up and treatment sequences
- Improve skills on Pain and Side Effects management in Eastern European countries
- Implement assessments for healthcare professionals' communication skills and mental well-being

Access barriers

Access barriers are the most prominent issue across all melanoma patient groups, impacting every stage of the patient journey, from diagnosis to end-of-life care. Limited access directly affects survival, family life, work, and the emotional well-being of both patients and caregivers. Access difficulties seemed linked with a lack of expertise, delayed diagnosis, a shortage of clinical trials, reimbursement delays, and restricted eligibility for treatments and precision oncology. Additionally, access is limited by the absence of personalized approaches, inadequate early risk stratification, and the lack of functional Molecular and Multidisciplinary Tumor Boards, with patients reporting that these are often unavailable *("MTBs do not exist")*. The access situation seems worse in rural, suburban areas and eastern European countries (e.g. Latvia, Hungary, Poland, Romania) but the barriers exists elsewhere.

System Barriers

For adults and young adults, system issues such as lack of coordination in melanoma care, hospital resources, lack of guidelines, delays in approval and drug price negotiations seems to affect profoundly all patients, while for melanoma children and adolescents effective treatments simply are missing. Families noted there are no pediatric melanoma guidelines and the access to systemic therapies hangs entirely on **(*off-label*) drugs,** an area not clearly regulated. A striking similarity in stories for accessing accurate diagnosis and effective drugs exists in childhood melanoma irrespective of the region (e.g. Netherlands vs Romania)., but magnitude might not be the same. For all groups- children, adolescents, young adults and adults **cross-border diagnosis and treatment is often blocked** even in the home country options are limited or there are no specialized melanoma centres.

Recommendations:

- Timely diagnosis, risk stratification and treatment: establish clear patient pathways
- Widely reimbursement of AI- related screening and diagnostic devices
- Improve and speed up the drug approvals and price negotiations schemes
- Access to extended molecular testing for all patients in need
- Revise the *off label* use at national level and facilitate fast reimbursement, while collecting data
- Support timely cross-border treatment in specialised centres and clinical trials
- Consistently integrate fertility, work and quality-of-life in recommendations
- Revise Multidisciplinary Tumor Boards functioning and establish clear protocols for their use, criteria for when they should be convened and the decision-making process. Patients should receive a report detailing the MTB discussion, recommendations and participating specialists.
- Build an infrastructure linked to specialized melanoma centers through satellite hospitals in rural, suburban, and Eastern European regions to facilitate learning and consultation.
- Improve access to personal medical data so patients make informed decisions
- Tumour specific patient organizations needs visibilities in healthcare facilities.

Opportunities for research

- Implement precision oncology programs, to offer options for those without options
- Diversify local options for patients via pragmatic clinical research
- Develop better tools to predict treatment response and side effects to improve patient selection
- Access and compassionate use programs need to be open for all European patients
- We need flexible schemes for reimbursement based on RWE and patient centric clinical research
- Is there a mismatch between palliative and psychosocial care and patients' needs?
- What we can do to identify and decrease the risk of melanoma in CNM patients?

The **lack of coordinated melanoma care and continuity** appeared as a major pain point in all patient pathways. Patients experienced 'treatment without coordination', not sufficient explanations or contradictory recommendations in the process of diagnosis, melanoma treatment and side effect management. Especially in the Eastern European countries, resolving the toxicity induced was left on the emergency units where knowledge about the latest treatments in melanoma is missing. The follow-up and surveillance were elsewhere considered inappropriate for high risk patients. Inappropriate frequency of scans and healthcare professionals not taking patients' symptoms seriously led to late detection of metastases, suffering and premature death.

The emotional burden might be linked with economic burden for families/society left behind looking for justice and closure. The sudden shift between active treatments and end-of-life care was criticised as not always a clear line could be drawn between them (e.g patients sent to end-of-life care while still wanting to receive treatments or vice versa).

Recommendations:

- Improve the efficient use of hospitals resources and coordination in melanoma care
- Align Follow-up schemes to modern medicine for timely detection of progression and early treatment
- Integrate children and adolescents melanoma care in specialized melanoma centers for tumour specific management (paediatric oncology seems a far too large umbrella for that)
- Consider a dedicated service for side effects management of cancer patients
- Make palliative and psychological care part of routine for patient and families
- Support patient decisions with evidence and explain (e.g choices between treatments, stop/start treatment, follow-up)
- Ensure patients' right to know by providing information on all available options, including those not offered at the treating hospital, available at other facilities, abroad, or not covered by reimbursement.

Opportunity for research

- Consider cost for society of inappropriate measures for early detection and treatment in terms of psychological and economic burden for society /families left behind

Research barriers: Poor integration of research into clinical practice

While children lack clinical research, melanoma research for young adults and adults is not sufficiently translated in clinical practice, leading to underutilisation of research funds and capabilities. Patients noticed there is no risk stratification for childhood melanoma, and children are missing genetic tests that could bring prognosis information or guide treatment choice. Although several countries have precision oncology trials in place, CAYA and adult patients seem unable to access such potential lifesaving programs. Young adults and adults are often not informed about clinical trials or consider their eligibility conditions unrealistic *''Need to be well enough to wait for trial to start''* or they are ineligible due to prior exposure to similar treatments.

Recommendations:

- Research results need to be used as early as possible for the benefit of patients
- Advocate for patient centric clinical research that fulfil both present and future patients needs
- We need research programs—both academic and private— that offer solutions for better follow-up strategies, faster and less invasive diagnostics, and innovative therapies.
- Patients and tumor-specific patient organizations should be present in the research funding decisions

Emotional, social and financial burdens

A recurring complain regarded the **lack of appropriate palliative and psychosocial care** failing to cover the ''real needs''. Why patients find palliative and psychosocial care not corresponding to their real needs is not completely clear and warrant further investigation to ensure that provided support is effective.

In particular, we noticed that emotional and financial burden could be a reason *not* to seek care. Often, patients delay medical help due to denial, fear, mental exhaustion or financial difficulties (''Denial, no -pushing for treatment, ''tired not knowing how much I have left and just wanting to die'', ''Having to go private or self-fund''). The struggle with the disease itself and on top, healthcare system issues, the ''changes in family dynamics'' or work patterns due to melanoma seem to lead to significant emotional burden, with feelings of fear, separation, anger, shock, loss of hope, guilt for ''leaving the family and children behind and generally 'feeling dehumanized'', '' like an object''.

Recommendations:

- refine psychological support and palliative care interventions to align with current patient needs and advancements in modern medicine
- Understand the impact of healthcare barriers on patients and families and the emotional and financial burden they caused in patient communities beyond melanoma itself.
- patients need access to high-quality melanoma care irrespective of their salary or economical level of their country

Attitudes and behaviours - Defensive medicine, the *doctor knows best* and *blame* culture

Patients in the CNM pathway, families of children with melanoma, and advanced melanoma patients who had exhausted standard treatment experienced attitudes resembling defensive medicine. They described concerning situations of under-treatment, such as healthcare providers not recommending necessary scans, treatment-guiding genetic tests, or potentially life-saving therapies. This phenomenon was particularly noted in high-risk groups where evidence was limited. In all cases, patients perceived these decisions as being driven more by a desire to avoid clinical liability and melanoma care costs rather than prioritizing patient needs.

"The doctor knows best" attitude or medical paternalism, was a common complaint, particularly among patients in advanced stages (Groups 2-5). Patients reported not being involved in decision and not receiving explanations for medical choices (why certain things are done in a certain way). This often led them and their families to seek multiple second opinions or frequently change physicians. While paternalism is widely discussed in older medical literature, its persistence in modern medicine remains surprising. Even more concerning is the culture of blame, which can drive patients away from evidence-based medicine toward pseudoscientific alternatives, decision that can ultimately cost their lives.

Recommendations:

- Patients and physicians would benefit from decision-making and evidence-based dialogue
- Replace the attitude of blame with one that encourages learning, support patients with scientific and medical resources
- Strengthen efforts to bring science closer to patients and families to increase the use of evidence-based interventions and reduce the risk of pseudoscientific alternatives.

Patient agency- Proactive behaviour and patient need for agency.

Despite challenges, we have noted the motivation of patients and families to continuously seek solutions and look for better care. For example, parents switch hospitals and doctors for better treatment, particularly as the disease progresses (e.g. ‘’pushing for treatment, 'looking for clinical trials yourself, ‘’moving to another country" and searching opportunities to contact new specialists and for education. All groups (1-5) seemed motivated to research their own treatment options and understand their data. In this effort patients are looking for ways to inform and educate themselves.

It is important to acknowledge the need for families and patients to gain control over their disease management and to provide proper support, as this can foster agency while also preventing patients to fall for pseudoscientific interventions.

When supported, agency enhances patients' ability to translate their needs into proposals for further solutions, such as improved staging and risk stratification, optimized follow-up protocols, the development of biomarkers for melanoma progression, tools to predict treatment response and side effects, data sharing between cancer centres, and expanded access to NGS and precision oncology.

We also detected calls for action and patient control, e.g. better patient-centric care policies, education for HCPs and clear guidelines, and digital tools (e.g. medical journey app) to navigate independently in the system, help track treatments and improve coordination between specialities**.** Overall, the results reflect high proactivity, most probably linked with most patients and caregivers participants in the design thinking workshops being active in advocacy at the national and European levels.

Recommendations:

- ➢ Support patient agency to strengthen their ability to manage their disease while preventing pseudoscience-based decisions.
- ➢ Leverage the knowledge and motivation of patients, families and patients' advocates to create healthcare strategies that match patient needs.

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