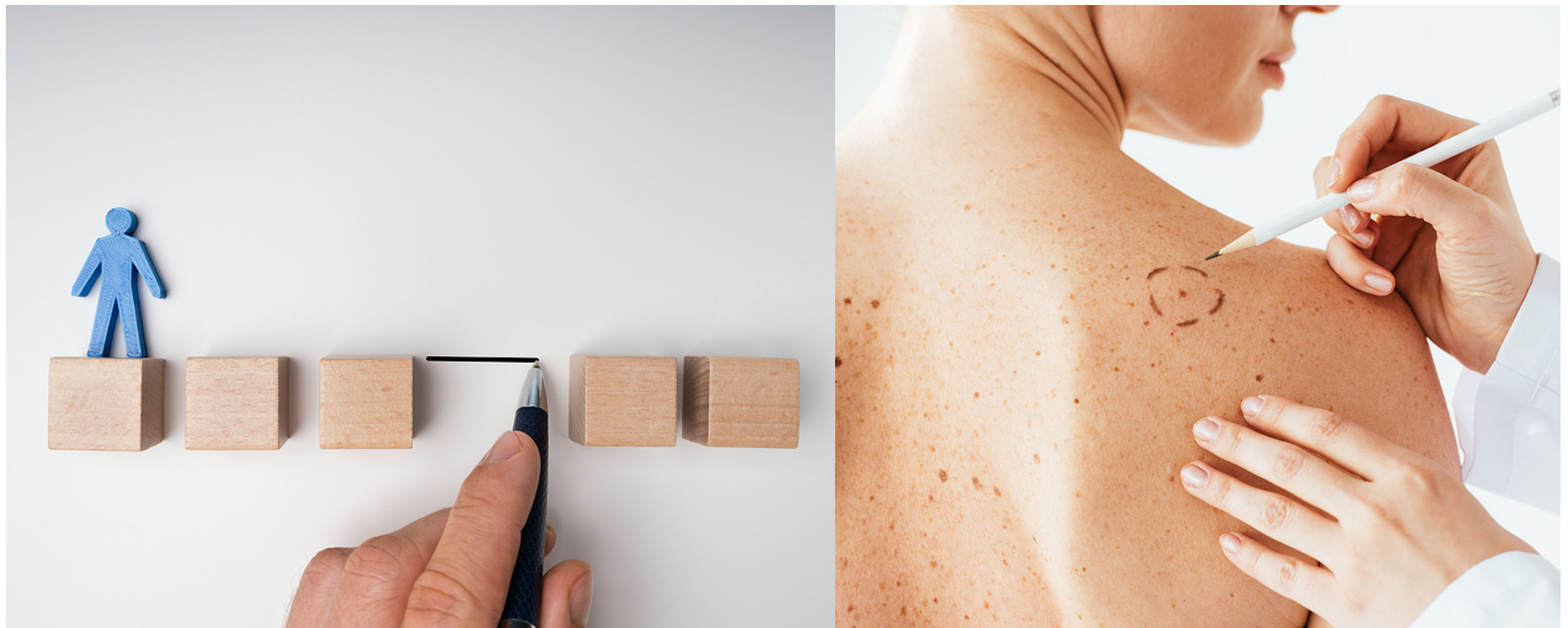


NEEDS EXAMINATION, EVALUATION AND DISSEMINATION (NEED): IDENTIFICATION OF UNMET HEALTH-RELATED NEEDS ASSOCIATED WITH MALIGNANT MELANOMA



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Acknowledgements:	We would like to thank Jef Adriaenssens (KCE), Jean-François Baurain (Cliniques Universitaires Saint Luc, UCL - Université catholique de Louvain), Nicolas Bouckaert (KCE), Diego Castanares-Zapatero (KCE), Wendy Christiaens (KCE), Marie Dauvin (KCE), Jens Detollenaere (KCE), Carl Devos (KCE), Evelyne Harkemanne (Cliniques Universitaires Saint Luc, UCL), Bart Neyns (UZ Brussel, VUB - Vrije Universiteit Brussel), Célia Primus-de Jong (KCE), Koen Van den Heede (KCE), Carine Van de Voorde (KCE) for their support during the study.
Reported interests KCE experts:	KCE is a federal institution funded by INAMI/RIZIV, by the Federal Public Service of Health, Food chain Safety and Environment, and by the Federal Public Service of Social Security. KCE's mission is to advise policymakers on decisions relating to health care and health insurance on the basis of scientific and objective research. It is expected to identify and shed light on the best possible solutions, in the context of an accessible, high-quality health care system with due regard for growing demand and budgetary constraints. KCE has no interest in companies (commercial or non-commercial, i.e. hospitals and universities), associations (e.g. professional associations, unions), individuals or organisations (e.g. lobby groups) that could be positively or negatively affected (financially or in any other way) by the implementation of the recommendations. All experts involved in the writing of the report or the peer-review process completed a declaration of interest form. Information on potential conflicts of interest is published in the colophon of this report. All members of the KCE Expert Team make yearly declarations of interest and further details of these are available upon request.
Reported interests external experts:	<p>All experts and stakeholders consulted within this report were selected because of their involvement in the topic of Unmet needs Melanoma. Therefore, by definition, each of them might have a certain degree of conflict of interest to the main topic of this report'.</p> <p>All members of Deloitte project team make yearly declarations of interest as further set out in the Engagement Letter between Deloitte Consulting & Advisory BV and KCE.</p>



Layout:

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Financially supported by Belspo

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Project number:

2022-03-HSR_Melanoma

Publication date:

9 September 2024 (2nd edition; 1st edition: 28 March 2024)

Domain:

Health Services Research (HSR)

MeSH:

Needs assessment, Surveys and Questionnaires, Qualitative Research, Melanoma

NLM Classification:

WI20

Language:

English

Format:

Adobe® PDF™ (A4)

Legal depot:

D/2024/10.273/06

ISSN:

2466-6459

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How to refer to this document?

Schönborn C, Léonard U, Van Goethem R, Dobbelaere J, Zhi Tan Y, Van Montfort T, Claerman R, De Jaeger M, De Pauw R, Kohn L, Levy M, Cleemput I, Maertens De Noordhout C. Needs Examination, Evaluation and Dissemination (NEED): Identification of unmet health-related needs associated with malignant melanoma. Health Services Research (HSR) Brussels: Belgian Health Care Knowledge Centre (KCE). 2024. KCE Reports 377C2. D/2024/10.273/06.



This document is available on the website of the Belgian Health Care Knowledge Centre.
<https://doi.org/10.57598/R377C2>



■ TABLE OF CONTENTS

LIST OF FIGURES	5
LIST OF TABLES.....	6
LIST OF ABBREVIATIONS	8
■ SCIENTIFIC REPORT.....	10
1 INTRODUCTION	10
2 DISEASE DESCRIPTION	11
2.1 EPIDEMIOLOGY	11
2.2 PATHOPHYSIOLOGY.....	15
2.3 MORTALITY	17
2.4 DIAGNOSIS	18
2.5 TREATMENT	19
2.1.1 Targeted therapy.....	20
2.1.2 Immune-based therapy	20
2.1.3 Other therapies	21
2.1.4 Follow-up.....	21
3 METHODS.....	22
3.1 ONLINE SURVEY	22
3.1.1 Data collection tool.....	22
3.1.2 Recruitment of participants	23
3.1.3 Quantitative data collection process	24
3.1.4 Quantitative data analysis.....	24
3.2 INDIVIDUAL INTERVIEWS	25
3.2.1 Selection of participants.....	25



3.2.2	Qualitative data collection tool	26
3.2.3	Qualitative data analysis	27
3.3	LITERATURE REVIEW	27
3.4	EXPERT OPINION	28
4	RESULTS – UNMET PATIENTS NEEDS	29
4.1	DESCRIPTION OF THE PARTICIPANTS	30
4.1.1	Surveyed participants.....	30
4.1.2	Interviewed participants	32
4.2	UNMET HEALTH NEEDS	33
4.2.1	Impact on general health-related quality of life	34
4.2.2	Impact on physical health	37
4.2.3	Impact on psychological health.....	42
4.2.4	Impact on autonomy.....	48
4.2.5	Impact on life expectancy	49
4.2.6	Other unmet health needs	50
4.3	UNMET HEALTHCARE NEEDS	50
4.3.1	Effectiveness of treatment	50
4.3.2	Burden of treatment	52
4.3.3	Quality of care	60
4.3.4	Accessibility of care.....	75
4.4	UNMET SOCIAL NEEDS	77
4.4.1	Impact on social life.....	77
4.4.2	Impact on education.....	81
4.4.3	Impact on work.....	81



4.4.4	Financial consequences	83
4.5	OTHER UNMET PATIENT NEEDS	85
5	RESULTS – UNMET SOCIETAL NEEDS	86
5.1	UNMET HEALTH NEEDS	86
5.1.1	Frequency	86
5.1.2	Transmissibility (contagiousness)	86
5.1.3	Antimicrobial resistance	86
5.1.4	Burden on informal caregivers	86
5.2	UNMET HEALTHCARE NEEDS	86
5.2.1	Value for money of standard care	86
5.2.2	Preventability	87
5.3	UNMET SOCIAL NEEDS	88
5.3.1	Productivity losses	88
5.3.2	Environmental impact of standard of care	88
6	RESULTS – UNMET FUTURE NEEDS	89
6.1	FUTURE HEALTH NEEDS	89
6.1.1	Burden of disease	89
6.2	FUTURE HEALTHCARE AND SOCIAL NEEDS	91
6.2.1	Economic burden	91
7	INEQUITIES	92
8	DISCUSSION	93
8.1	SUMMARY OF RESULTS	93
8.2	LIMITATIONS	95
8.2.1	Primary data collection	95



8.2.2	Secondary data collection	95
8.3	LESSONS LEARNED	96
8.4	ADDED VALUE OF THE STUDY	98
8.5	POTENTIAL SUGGESTIONS TO TACKLE UNMET NEEDS IN PATIENTS WITH MELANOMA	98
■	REFERENCES	100
■	APPENDICES	108
APPENDIX 1.	SUMMARY TABLES	108
APPENDIX 2.	ORIGINAL TESTIMONIALS	114
APPENDIX 3.	SURVEYS	129
APPENDIX 4.	INTERVIEW GUIDE	193
APPENDIX 5.	QUALITATIVE ANALYSIS CODES	204



LIST OF FIGURES

Figure 1 – Incident cases per 100 000 persons of melanoma of the skin 2004-2021 in Belgium, by sex	12
Figure 2 – Incidence of melanoma in Belgium in 2021, by age group	13
Figure 3 – Age-standardised incidence per 100 000 population of melanoma in EU-27 in 2020	14
Figure 4 – Death rate per 100 000 population in Belgium in 2019, by age-group, by sex	17
Figure 5 – Segmentation of candidates with melanoma for qualitative interviews	26
Figure 6 – Respondents participation flow diagram (melanoma)	29
Figure 7 – Type of melanoma reported (n=37)	31
Figure 8 – Stage of melanoma (n=37)	32
Figure 9– Number of comorbidities among participants with melanoma (n=37)	33
Figure 10 – Self-reported level of problems on each EQ-5D-5L dimension before the latest melanoma diagnosis and today	35
Figure 11 – Evolution in the dimension "pain/discomfort" of the EQ-5D-5L before latest melanoma diagnosis and today (n=37)	38
Figure 12 – Frequency of physical symptoms reported by respondents with melanoma (n=37) ¹	39
Figure 13 – Level of burden of the reported physical symptoms (n=37) ¹	41
Figure 14 – Evolution of the dimension "anxiety/depression" of the EQ-5D-5L before latest melanoma diagnosis and today (n=37)	43
Figure 15 – Frequency of psychological symptoms reported by respondents with melanoma (n=37) ¹	44
Figure 16 – Level of burden of the reported psychological symptoms (n=37) ¹	46
Figure 17 – Burden level of the six most frequently reported side-effects of melanoma (n=17) ¹	58
Figure 18 – Amount of explanations obtained from healthcare providers (n=37)	65
Figure 19 – Clarity of explanation provided about melanoma (n=36) ¹	68
Figure 20 – Involvement in choosing melanoma treatment (n=24) ¹	70
Figure 21 – Reported areas of unmet social support (n=37)	80



Figure 22 – Estimated relative change (in %) of melanoma incidence from 2020 to 2040 in the EU-27, using the baseline projected population90

LIST OF TABLES

Table 1 – Common types of pharmacological therapy for melanoma	20
Table 2 – Overview of contacted stakeholders for melanoma	24
Table 3 – Evaluation of treatment availability	28
Table 4 – Evaluation of treatment effectiveness.....	29
Table 5 – Distribution of participants within the online survey based on demographics (n=37)	30
Table 6 – Distribution of hospitalisation according to cancer stage (n=37)	32
Table 7 – Description of interview participants with melanoma (n=9)	33
Table 8 – EQ-5D-5L utility score before the latest melanoma diagnosis and today	34
Table 9 – Change in the self-reported level of problems on each EQ-5D-5L dimension before latest melanoma diagnosis and today (n=37)	36
Table 10 – Distribution of reported physical melanoma symptoms by level of burden (n=37).....	40
Table 11 – Change in the distribution of self-reported level of problems on the dimension “anxiety/depression” of the EQ-5D-5L before latest melanoma diagnosis and today (n=37)	42
Table 12 – Distribution of reported psychological melanoma symptoms by level of burden (n=37)	45
Table 13 – Change in the distribution of the dimension “autonomy” of the EQ-5D-5L before melanoma diagnosis and today (n=37)	49
Table 14 – Distribution of respondents per type of treatment received and melanoma stage (n=17) ¹	52
Table 15 – Distribution of respondents’ satisfaction levels with melanoma treatment, by treatment type (n=17) ¹	53
Table 16 – Distribution of respondents’ experienced burden of treatment for melanoma (n=17) ¹	54
Table 17 – Distribution of reasons for very or rather burdensome melanoma treatment (n=7)	54



Table 18 – Distribution of side-effects experienced due to melanoma treatment, by level of burden (n=16)	56
Table 19 – Distribution of melanoma healthcare utilisation by stage of cancer (n=37).....	60
Table 20 – Frequency, within the whole sample, of consulted medical specialists (n=35)	61
Table 21 – Respondents' level of satisfaction by type of healthcare provider (n=37)	62
Table 22 – Type of additional information sought (n=28).....	70
Table 23 – Distribution of participants by stage of cancer and time between first symptoms and decision to consult (n=37)	71
Table 24 – Distribution of participants by time between decision to consult and first consultation (n=37)	72
Table 25 – Distribution of participants by time between first consultation and melanoma diagnosis (n=37)	73
Table 26 – Melanoma stage distribution, by diagnosis and sex for the year 2020	73
Table 27 – Distribution of participants by time between melanoma diagnosis and first treatment (n=37)	75
Table 28 – Type of logistic activities that participants required assistance with (n=13)*	78
Table 29 – Distribution of the number of logistic activities that required assistance (n=13)	78
Table 30 – Work incapacity due to melanoma (n=29)	82
Table 31 – Financial impact due to melanoma (n=37)	83



LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
ALM	Acral Lentiginous Melanoma
AM	Acral Melanoma
BRAF	B-Raf Proto-Oncogene
CI	Confidence Interval
c-KIT	Receptor tyrosine kinase
CSD	Cumulative Solar Damage
CT	Computed Tomography
CTLA-4	Cytotoxic T-lymphocyte associated protein 4
DNA	Deoxyribonucleic acid
EC	Ethical Committee
EQ-5D-5L	EuroQoL 5 dimensions 5 levels questionnaire
GP	General Practitioners
HRQoL	Health-Related Quality of Life
IARC	International Agency for Research on Cancer
IQR	Interquartile Range
KCE	Health Care Knowledge Centre
LMM	Lentigo Maligna Melanoma
LUSS	Ligue des Usagers des Services de santé
MEK	Mitogen-activated protein kinase
MM	Mucosal Melanoma
MRI	Magnetic Resonance Imaging
NIH	National Cancer Institute
NM	Nodular Melanoma



NRAS	Neuroblastoma RAS viral oncogene homolog
PD-1	Programmed cell death protein 1
PD-L1	Programmed death-ligand 1
PET	Positron emission tomography
QoL	Quality Of Life
SD	Standard Deviation
SSM	Superficial Spreading
TNM	Tumour-Nodes-Metastases
UM	Uveal Melanoma
UVR	Ultraviolet Radiation
VAS	Visual Analogue Scale
VPP	Vlaams Patiëntenplatform
WHO	World Health Organisation
YLD	Years Lived With Disability
YLL	Years Of Life Lost



■ SCIENTIFIC REPORT

1 INTRODUCTION

The healthcare ecosystem is predominantly supply-driven, leading to a lack of innovation in financially less attractive health areas, inefficient use of public resources for healthcare, and unmet patient and societal needs. The NEED (Needs Examination, Evaluation, and Dissemination) assessment framework was developed with the aim of serving as a major tool for changing this situation and moving towards a more needs-oriented healthcare system. It allows to identify unmet health-related patient and societal needs in various diseases, highlighting gaps for intervention.

The ultimate goal of this report is to challenge the NEED framework, in order to assess whether it is effective to evaluate (through a standardised and transparent approach) the current and future unmet health-related needs of patients and of society associated with malignant melanoma. This is a crucial step that will enable the involvement of other national and international partners and the political support essential to NEED's sustainability.

To achieve this goal, the NEED assessment framework will be implemented in the Belgian context to answer the following research questions:

1. What are the current and future health-related unmet needs of patients and society related to malignant melanoma?
2. What are the current and future healthcare-related unmet needs of patients and society related malignant melanoma?
3. What are the current and future social unmet needs of patients and society related malignant melanoma?
4. Does the NEED assessment framework require certain adaptations to better assess health-related unmet needs?

The definitions of the various concepts related to unmet needs as well as the rationale and scope of the NEED approach can be consulted in the KCE report 348¹ and KCE report 377².



2 DISEASE DESCRIPTION

The aim of this chapter is to provide a brief overview of melanoma, also called malignant melanoma, by presenting a description of the disease, epidemiological data (incidence, risk factors, mortality rates), diagnostic methods, and available treatment.

Key points

- Melanoma is the 5th most common cancer in Belgium. Its incidence has been steadily increasing over the last decades and is expected to continue rising for another decade.
- Most melanomas are detected in people aged 51-60 years, which is younger than most solid tumours.
- Melanomas make up a heterogeneous disease entity, with significant implications for prevention, diagnosis, treatment, as well as prognosis.
- Around 95% of melanomas are diagnosed as primary tumours without any evidence of metastases.
- In Belgium today, the overall 5-year survival for melanoma is around 97% for women, and 94% for men.
- The main modifiable aetiological factor is high exposure to UV radiation, particularly during childhood, making this the main focus of prevention strategies.
- The mainstay of melanoma treatment is excision.
- Remarkable therapeutic progress has been made over the last decade as immune-based treatments have transformed the prognosis of advanced melanoma. However, high toxicity, resistance to treatment, and elevated costs represent major drawbacks.

Identifying patients with a high risk of recurrence remains an important challenge.

- Timely diagnosis is key to improving prognosis, but obstacles exist. Populations with lower socioeconomic status currently tend to present with later-stage disease at the time of diagnosis and display greater mortality.
- Rare types of melanoma, particularly present in individuals with highly pigmented skins, pose a diagnostic challenge and are associated with advanced stage at diagnosis and higher mortality.

2.1 Epidemiology

While melanoma accounts for only 8% of skin cancers in Belgium, it is responsible for the vast majority of skin cancer-related deaths.³

Skin cancers as a whole are the most common group of cancers in Belgium, representing around 40% of all cancers.³ For the year 2019, the Belgian Burden of Disease study estimated that melanoma was responsible for 8 364 Years of Life Lost (YLL), a measure of premature mortality that takes into account both the frequency of deaths and the age at which they occur.⁴ ⁵ Melanoma is the third most frequent type of skin cancer; the most common types being basal cell and squamous cell carcinomas, which progress slowly and metastasize rarely.^{6,7}

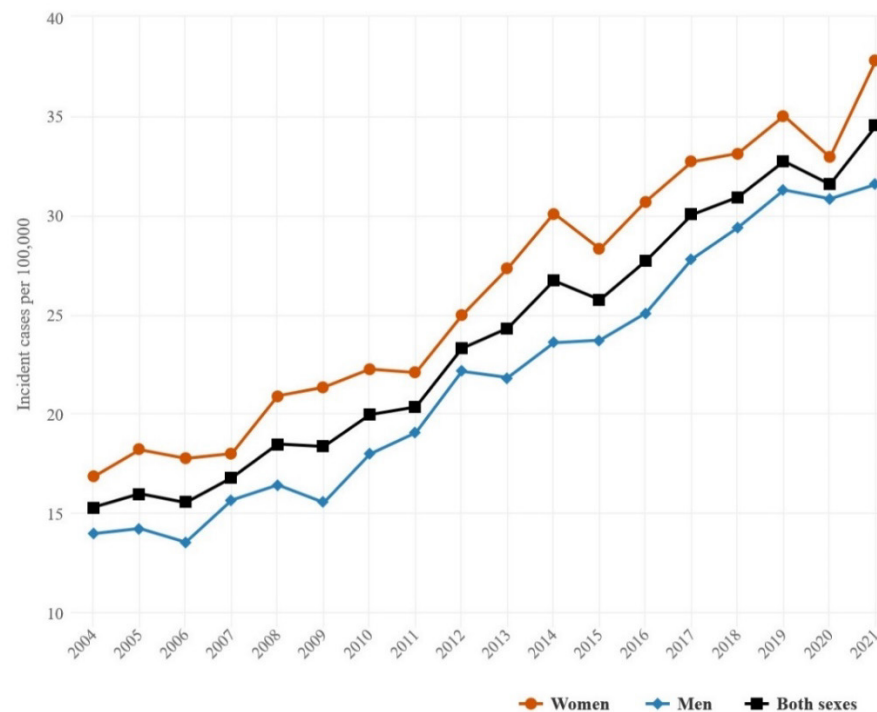
At the European level, it is estimated that in 2020 skin melanoma accounted for 4% of all new cancer diagnoses in EU-27 countries (all cancers, excluding non-melanoma skin cancers) and for 1.3% of all deaths due to cancer. This made it the sixth most frequently occurring cancer (after breast, colorectal, prostate, lung, and bladder cancers) and one of the 20 most frequent causes of cancer death at the EU-level.⁸



Incidence and prevalence

In Belgium, like in other European countries, the incidence of malignant melanoma has been steadily increasing over the last decades, particularly in individuals over 45 years of age.^{5, 8, 9} New diagnoses increased from 15 per 100 000 in 2004 to 31 per 100 000 in 2020 in Belgium (Figure 1).⁵

Figure 1 – Incident cases per 100 000 persons of melanoma of the skin 2004-2021 in Belgium, by sex



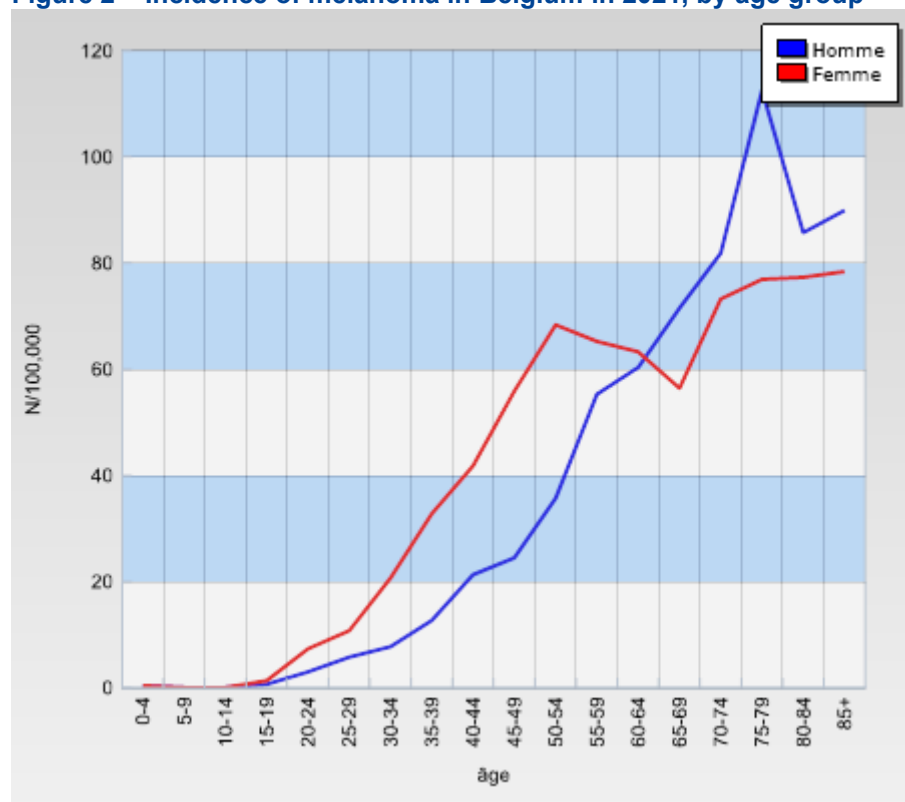
The data are age-standardised according to the Belgian population in the last observed year

Source: Sciensano, 2022⁵

The rising incidence of melanoma is thought to be mainly linked to increasing ultraviolet radiation (UVR) exposure and to population ageing.¹⁰ However, improvements in awareness and increasing screening practices facilitate more melanoma diagnoses, which might also play a minor role in the upward incidence trend.^{11, 12} Because of earlier detection, this increasing incidence mainly concerns an augmentation of thin and in situ lesions.¹²

In Belgium, melanoma represents the 4th most commonly diagnosed cancer in women, and the 6th in men, the lifetime risk of developing malignant melanoma being 1 in 74 for women, and 1 in 66 for men.¹³ In 2020, 3 618 people in the country were diagnosed with melanoma and, overall, there were an estimated 26 106 individuals who had a current or past melanoma.^{5, 14}

As opposed to many other cancers, diagnosis of melanoma often occurs in people aged less than 60 years (Figure 2). In Belgium, for instance, most malignant melanomas are detected in people aged 51-60 years, and the average age of onset is 59 years for women and 63 for men.^{8, 15} Because the incidence rates start to increase from 30 years of age, melanoma can be considered a tumour affecting young and middle-aged people, which is earlier than most solid tumours (e.g. breast, colon, lung, or prostate cancers).¹⁶ Indeed, it is the second most common cancer in people aged between 15 and 44 years.⁵

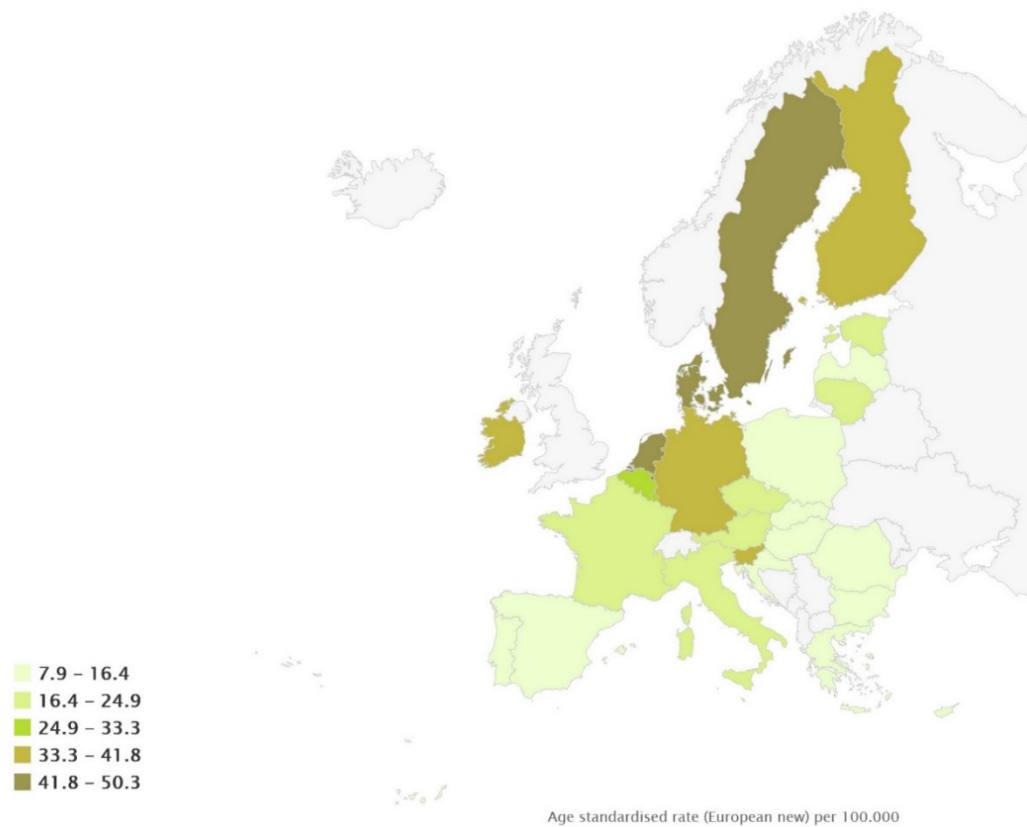
**Figure 2 – Incidence of melanoma in Belgium in 2021, by age group**

Source: Belgian Cancer Registry (available: <https://kankerregister.org/default.aspx?PageId=345>, last access: 22st January 2024)

While worldwide the incidence rates of melanoma vary by 100-fold, noticeable variation is also present within the European Union.^{17, 18} Belgium has a lower incidence than its northern neighbours (the Netherlands, Denmark and Sweden), but a higher incidence than southern and eastern European countries (e.g. Spain, Greece and Poland) (Figure 3).¹⁷



Figure 3 – Age-standardised incidence per 100 000 population of melanoma in EU-27 in 2020



Source: *European Cancer Information System*¹⁷



2.2 Pathophysiology

The vast majority (>90%) of melanomas occur in the skin and are therefore termed cutaneous melanoma. However, rarely, they can occur in the eyes (uveal melanoma), accounting for approximately 4% of melanomas, or in the mucous membranes (mucosal melanoma) in approximately 1% of cases.¹⁹ ²⁰ Cutaneous melanoma develops in melanocytes, the cells in the skin that produce and contain the melanin pigment which gives skin its colour. Melanocytes are found scattered throughout the skin or clustered into pigmented spots such as birthmarks or naevi (commonly called moles). Melanoma is the result of malignant transformation due to alterations in multiple genes within these melanocytes.²¹ Consequently, the melanocytes proliferate in an uncontrolled manner, typically causing a pigmented spot that grows or changes colour. The resulting malignant lesion can invade nearby tissues and can also metastasize to other parts of the body.²²

Around one third of melanomas have been estimated to arise from pre-existing benign naevi; however, the vast majority of naevi are stable and are more prone to regress than to progress to melanoma.²³⁻²⁵ In a 20-year-old individual, for instance, the lifetime risk of any selected mole transforming into melanoma by age 80 has been estimated to be approximately 1 in 11 000 for women and 1 in 3 000 for men.²⁶

Melanomas, from a clinical and pathological point of view, make up a heterogeneous disease entity (Box 1). The traditional McGovern-Clark classification has been revised by the more recent World Health Organisation (WHO) Classification of Skin Tumours (4th edition, 2018), which categorises melanomas on the basis of their genetic profile and ultraviolet (UV) association.^{27, 28} Melanomas that are related to sun exposure are the most frequent type and can be further classified into high and low histopathologic degree of cumulative solar damage (CSD). High-CSD melanomas include lentigo maligna and desmoplastic melanoma; whereas low-CSD are constituted by superficial spreading melanomas. Non UV-related melanomas include various rarer types such as Spitz melanomas, mucosal melanomas, and uveal melanomas among others. The relatively common nodular melanomas have distinctive clinicopathologic characteristics and are therefore now considered a separate melanoma

subtype.²⁸ It remains unclear why different modalities of exposure to UV radiation (e.g. chronic versus intermittent) induce different molecular damages and thus result in different melanoma types. For instance, chronic lifetime sun exposure, as seen in outdoor workers, is associated with specific DNA mutations characteristic of lentigo maligna melanoma, whereas intermittent exposure to UVR and sunburns at younger age are associated with other mutations leading to the development of superficial spreading melanoma.²⁹

Box 1 – Description of the main types of melanoma

- Superficial spreading (SSM) is the most common type of melanoma in Western countries and is associated with low to moderate prior sun exposure such as intermittent exposure on weekends or during holidays.^{28, 30} That is why this type of melanoma tends to occur on parts of the body exposed to the sun during these activities, such as the back in men and the legs in women. Superficial spreading melanoma typically grows outward (called radial growth) and spreads across the surface of the skin. However, it can also start to grow down into the skin (called vertical growth). Although initially essentially indistinguishable from a benign mole, it tends to gradually develop the distinctive “ABCDE” clinical characteristics (explained in section 2.4).
- **Nodular melanoma (NM)** is a raised growth that sticks out from the skin (polypoid). NMs grow and spread more quickly than other types of melanoma skin cancers, with a shorter window of opportunity for early diagnosis.^{28, 30, 31} They are thus the main contributor for thicker and fatal melanomas, hence constituting an important public health burden. Nodular melanoma is not as strongly linked to sun exposure as other melanomas, and typically occur on the face, chest, or back although they can also be found on areas of the skin that are usually not exposed to the sun. NM may mimic several benign lesions, which likely further contributes to diagnostic delay.
- **Lentigo maligna melanoma (LMM)** usually appears as a large, flat brown patch with an uneven border, and most often develops in older



people.^{32, 33} Lentigo maligna melanoma usually develops on skin areas that have been chronically exposed to the sun without protection, such as the face, ears and arms. Lentigo maligna is less aggressive than other forms as it exhibits a long radial growth pattern, and thus represents the most prevalent form of *in situ* melanoma.³³

- **Acral melanoma (AM) and acral lentiginous melanoma (ALM)** are cutaneous melanoma subtypes which exhibit their own clinical and genetic features.³⁴ They originate from the hairless skin of the palms, soles, or nail apparatus, and are not thought to be related to UVR exposure. Although they have similar absolute incidence rates across ethnic groups worldwide, they are the most common melanoma subtypes in people with pigmented skins, such as those of African, Asian, or Hispanic ancestries, who are less often affected by the sun-related melanomas.^{34, 35} Acral melanomas appear as asymmetric pigmented macules, ranging from light brown to black. AM and ALM are often hard to diagnose because of their particular anatomic locations. Acral melanomas have poor survival and account for a considerable share of melanoma-associated morbidity and mortality worldwide.^{35, 36}
- **Mucosal melanoma (MM)** is rare and develops on mucosal surfaces including the oral, nasal, anorectal, genitourinary, and vulvovaginal regions. MM has a worse prognosis compared with the more common cutaneous melanomas.^{37, 38} It is one of the most aggressive subtypes of melanoma, yet the biology of mucosal melanocytes as well as the risk factors and mutagens that contribute to the development of MM remain poorly understood. Furthermore, the occult anatomic locations in which it occurs and the lack of early presenting symptoms, make mucosal melanoma extremely difficult to diagnose at an early stage.³⁹ What is more, the tiny incidence and low patient survival rate are obstacles to carrying out sufficient randomised clinical trials, which results in a paucity of guidance for clinicians.³⁷
- **Uveal melanoma (UM)** is a rare type of melanoma that can develop in different parts of the eyes.⁴⁰ It mostly presents in middle-age and

is more common in lighter-eyed individuals. Most patients with uveal melanoma present with painless loss or distortion of vision, although some present with discoloration of the iris, or are asymptomatic and diagnosed on routine ophthalmic screening.⁴⁰ Compared to cutaneous melanomas, uveal melanoma differs in terms of risk factors, molecular changes, spread, and treatment approaches. It is associated with resistance to treatment and poor prognosis.⁴¹ Due to a lack of clinical trials, therapeutic management has long been extrapolated from the much more prevalent cutaneous melanoma; however, specific uveal melanoma trials are now increasingly carried out.

The development of melanoma involves a complex interaction between genetic, epigenetic, and environmental risk factors.⁴² Given that most melanomas are related to sun exposure, the main modifiable aetiological factor is considered to be high exposure to UV radiation (UVR), either because of increased exposure of the skin to the sun or because of the use of tanning devices.^{43, 44} It is especially the high intermittent exposure to UVR during childhood, and exposure leading to sunburn which bare the highest risks.¹⁶

In 2018, the International Agency for Research on Cancer (IARC) used the GLOBOCAN 2012 incident data and estimated the highest preventable melanoma burden in high-income countries. The data showed that, in Belgium, of new melanoma cases diagnosed that year, around 85-90% could be attributed to UVR exposure.⁴⁵

Certain individual characteristics increase the susceptibility of developing malignant lesions due to UVR exposure, namely fair hair, eye, and skin colours (Fitzpatrick phototype I-II), the tendency to freckle, the presence of a high number of naevi (particularly if atypical), obesity, and immunosuppression (such as in chronic lymphocytic leukaemia, or solid organ transplant recipients).^{43, 46-48} People with a genetic susceptibility, as evidenced by personal history or a family history of melanoma are also considered at higher risk.^{43, 49} Further suspected risk factors for melanoma are exposure to agricultural and manufacturing chemicals.⁵⁰ Box 2 summarises the main risk factors for melanoma development.

**Box 2 – Main risk factors for melanoma development****Environmental risk factors**

- Exposure to natural or artificial UV radiation
- Exposure to agricultural and manufacturing chemicals

Individual risk factors

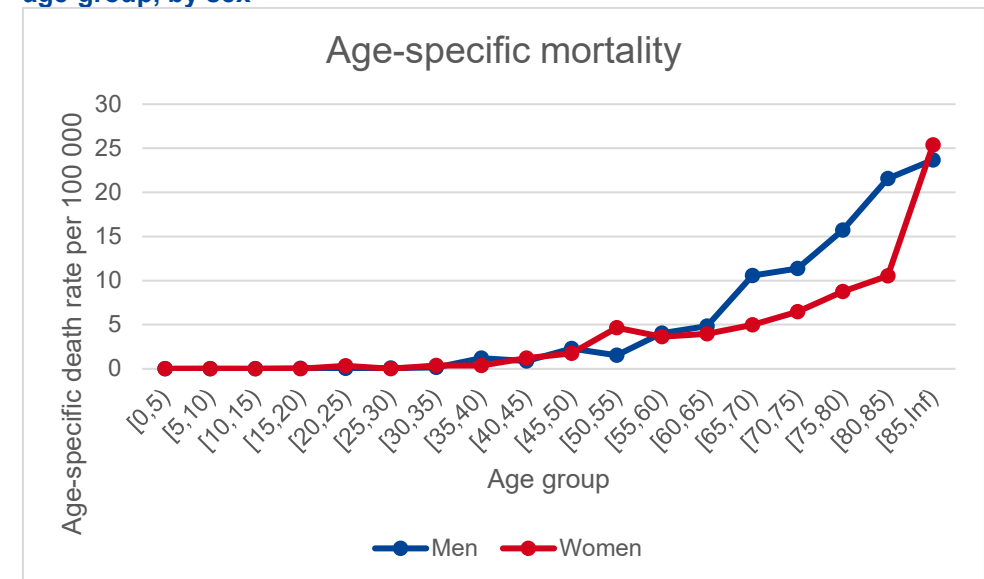
- Fair hair, eye, and skin
- Tendency to freckle or sunburn
- Presence of high number of naevi
- Obesity
- Immunosuppression
- Family history of melanoma

As will be described in more detail in section 7, social inequalities, lower socioeconomic status (SES) and skin pigmentation are risk factors for advanced stage at diagnosis and for increased melanoma mortality.^{43, 50-52}

2.3 Mortality

In Belgium today, the overall 5-year survival for melanoma is 97.3% (95% Confidence Interval (CI) 96.3, 98.2) for women, and 94.2% (95% CI 92.8, 95.5) for men and is strongly influenced by the age at diagnosis (Figure 4).¹⁵

Figure 4 – Death rate per 100 000 population in Belgium in 2019, by age-group, by sex



Source: Sciensano⁵³; Figure: KCE

Multiple factors contribute to the higher melanoma mortality among older patients, including variations in tumour characteristics and metastasis routes, lower host immune response, and possibly discrepancies in the application of care standards between older and younger patients.⁵⁴

Between 1955 and 1990 melanoma mortality rose steadily and even doubled in many fair-skinned populations.⁵⁵ Since then, mortality rates have levelled-off and even started declining in many European countries, particularly in younger age groups.⁵⁵⁻⁵⁷ The decline in mortality has been accompanied by a decrease in tumour thickness, which is likely the consequence of earlier detection of these cancerous lesions.⁵⁶

Research findings indicate that approximately 20% - 30% of melanoma patients experience a recurrence during the course of their illness.⁵⁸



Although advanced stages of disease at diagnosis bear the highest fatality, in terms of absolute frequency most melanoma deaths occur in patients who experienced a recurrence of disease that was early stage (stage I or stage II) when initially diagnosed.^{59, 60} Unfortunately, in these cases the recurrence of melanoma is often not detected until it has progressed to a symptomatic metastatic stage. Therefore, there is an urgent requirement for reliable prognostic tools that can accurately identify patients at high risk of recurrence and who would benefit from closer monitoring and adjuvant immunotherapy.⁶⁰

2.4 Diagnosis

Suspicious pigmented lesions are usually clinically analysed using the 'ABCDE' criteria and the 'ugly duckling' concept.⁶¹ The ABCDE criteria concern characteristic signs of cutaneous melanoma, and are used globally by physicians and the general population to detect early cancerous lesions.⁶² In this mnemonic, A stands for asymmetry, B for border irregularity, C for colour variability, D for diameter (usually >6mm), and E for evolution in terms of size, colour, texture, or other. This tool is simple and straightforward, having the advantage of easy public health messaging; however, it does not provide an exhaustive template for all melanoma types and characteristics, so relying on the ABCDE rule alone might result in missing early or featureless melanomas.⁶³ The idea of the "ugly duckling" can also be useful in detecting melanomas, as it is common for an individual's moles to have a similar appearance, while melanomas may look different from the typical mole pattern of that person.⁶⁴ Occasionally, melanomas do not present the characteristic diagnostic features (e.g. amelanotic or nodular melanoma), which represents a particular diagnostic challenge.

Today, it is recommended that dermoscopy routinely be used by dermatologists to magnify skin lesions with the use of a handheld instrument called a dermatoscope.^{65, 66} Contrary to what might be assumed, it is recommended that dermoscopy be used on all skin lesions, not just those that appear clinically suspicious. This is because it has the ability to detect

morphological asymmetry and specific dermoscopic features of melanoma at an early stage before they become visible to the naked eye.⁶⁶ Dermoscopy is a rapid way to improve diagnosis and reduce the number of unnecessary biopsies, with the benefits being particularly pronounced when the technique is used by well-trained and experienced dermatologists.^{24, 67} In Belgium, dermoscopy training is not mandatory.⁶⁸ While it has recently been incorporated into the training for dermatology residents, practitioners who specialised earlier might lack training in dermoscopy, which is integral for achieving optimal diagnostic outcomes.

Other diagnostic techniques that assess the evolution of lesions over time, such as total-body photography combined with sequential digital dermoscopy, have also been proven to enhance the early identification of malignant lesions and can be used in individuals at high risk of melanoma.^{66, 69} Further novel non-invasive techniques include reflectance confocal microscopy, which is now routinely used in university hospitals. Additionally, research is ongoing in the development of other techniques to enhance diagnostic accuracy in the clinical environment, such as machine-learning algorithms, trained on standard or dermoscopic images. These have shown promising results; however, their actual use in clinical practice still requires evaluation.^{66, 70}

Lesions considered suspicious must undergo a biopsy (ideally an excisional type) which is sent for histopathological testing. This, together with results from sentinel node biopsy and imaging when required, provides information for the tumour-nodes-metastases (TNM) staging, and include Breslow thickness, presence of ulceration, mitotic rate, presence of microsatellites, and clearance of surgical margins.⁶¹ In cases of unclear histological diagnosis, immunohistochemical staining can provide valuable information.⁶⁶ Melanoma should be classified according to the 8th version of the American Joint Committee on Cancer Manual, which is a compendium of the latest insights into the staging of adult cancers and serves as benchmark for classifying cancers, predicting prognosis, and, on this basis, determining the best treatment approaches.⁶⁶

Cutaneous melanoma can be classified as melanoma *in situ* if it remains limited to the epidermis, or as invasive when it infiltrates the dermis. The



invasive melanoma subtypes were traditionally divided into five primary clinicopathological subtypes, as described in the introduction: superficial spreading melanoma, lentigo maligna, acral, mucosal, and unclassifiable melanoma.²⁷ However, in the 8th version of the American Joint Committee on Cancer classification, these clinicopathological subtypes are no longer used.

If the melanoma has any concerning features (e.g. certain thickness), ultrasound of the loco-regional lymph nodes with fine needle aspiration, or sentinel lymph node biopsy should be carried out. These techniques rest on the principle that melanomas spread to the locoregional lymph nodes before metastasising to distant areas. Sentinel lymph node biopsies enable the determination of whether the cancer has spread to nearby lymph nodes, guiding treatment options and representing the most important indicator for staging and prognosis.

In Belgium, in the year 2020, around 95% of melanomas were diagnosed as primary tumours without any evidence of metastases.⁷¹ However, when there is suspicion of cancer having spread distally, imaging (e.g. ultrasound, CT, PET or MRI scans) is necessary. If metastatic disease is confirmed, patients must be followed-up by an oncologist and molecular analysis (principally for BRAF and NRAS mutations, and sometimes c-KIT) is done in order to guide treatment decisions. As further pharmacologically actionable oncogenic mutations are discovered and additional targeted treatments become accessible, the significance of multi-gene analysis in melanoma will likely grow in the future.

Box 3 – Simplified outline of cutaneous melanoma staging⁷²

Stage 0	Melanoma in situ
I	<1mm thickness, or 1-2mm without ulceration
II	>1mm with ulceration, or >2mm
III	Lymph node involvement
IV	Involvement of metastases

Source: adaptation of Gershenwald et al. 2017⁷²

2.5 Treatment

In Belgium, localised and intermediate lesions are generally treated by dermatologists, either in general hospitals or tertiary oncology centres, while advanced disease is managed by (dermato)oncologists.⁶⁸

The mainstay of melanoma treatment of any kind is excision, with the exception of the rare cases in which the site of the tumour makes it unresectable.

Surgical resection of melanoma with sufficient clear margins can sometimes be difficult for various reasons. Some melanoma lesions (e.g. lentigo maligna) can occur in cosmetically sensitive areas, particularly the head and neck, and at other times surgical margins might be equivocal. Furthermore, nerve involvement is possible and, if extensive, can make surgical excision technically challenging. When melanoma is unresectable, drug therapy and radiotherapy become the only available treatment options.

Beyond excision, the treatment of melanoma will depend on factors such as melanoma type, site, TNM staging, and specific characteristics (e.g. genetic mutations).⁷³ For localised lesions with low-risk of recurrence and which have been resected completely, a simple follow-up will be recommended. Because the risk of recurrence is highest during the first years after resection, the proposed follow-up is usually more regular in the beginning (e.g. every three months over three years, every six months thereafter).^{73, 74}

For more advanced disease or lesions with a high-risk of recurrence, additional interventions may be incorporated into the treatment. These can include lymph node dissection, immunotherapy, or targeted therapy. If metastases are found in the lymph node(s), a complete lymph node dissection in this area has been standard treatment until very recently. However, new trials have shown that depending on melanoma characteristics, survival is not always improved by complete dissection, whilst morbidity from this intervention is high.⁷⁵ Therefore, current practice is shifting towards reduced use of complete lymph node dissection.^{73, 76, 77} When technically feasible, metastasectomy is the initial treatment of choice for isolated distant metastases (e.g. in the brain, bone, lungs, skin) and for locoregional recurrences.⁷⁴ More generally, the management of advanced



melanoma is a continuously evolving field that has experienced remarkable advancements in the past decade, particularly with the development of immune-based therapies. These ground-breaking treatments have resulted in significant improvements in both survival rates and the quality of life for patients with advanced disease. Before these, the treatment of advanced melanoma mainly relied on post-excision chemotherapy and radiotherapy, with 5-year survival rates as low as 10%.⁷⁸⁻⁸⁰

2.1.1 Targeted therapy

Targeted therapy consists of drugs that target specific mutations, most commonly BRAF mutations, which are present in around 50% of melanoma.⁴⁶ Targeted therapy is used once these specific mutations have been confirmed and is employed in different situations. These include advanced disease (stage III or IV), early-stage melanomas that are considered at high-risk of spreading, or more rarely, in cases where tumours cannot be removed completely. Targeted therapy includes BRAF protein inhibitors or MEK protein inhibitors, which are often used in combination. These drugs can slow the growth of advanced tumours, sometimes even shrink them, or can be used to reduce the chance of recurrence.

Common **side effects** can include fever, fatigue, nausea, headache, skin thickening, rash, itching, sun sensitivity, joint pain, and hair loss. Less common but serious side effects can include heart rhythm abnormalities, liver problems, kidney failure, severe allergic reactions, squamous cell carcinoma, bleeding, severe skin reactions, and eye inflammation.⁸¹ Given the potential serious side effects caused by this type of therapy, it is crucial for patients to be closely monitored and to receive regular follow-up by healthcare professionals, in order to treat side effects promptly and to adapt therapy if necessary (Table 1).

Table 1 – Common types of pharmacological therapy for melanoma

Therapy type	Action	Examples	Drawbacks
Targeted therapy			
BRAF inhibitors	Block the BRAF and MEK proteins in the "OFF" position, halting the uncontrolled growth of cancer cells.	Dabrafenib Vémurafenib Encorafenib	Only effective for individuals with specific mutations.
MEK inhibitors		Cobimétinib Tramétinib Binimetinib	Potential serious side effects.
Immunotherapy			
CTLA-4 checkpoint inhibitors	Stimulate the body's immune system to find and kill melanoma cells.	Ipilimumab	Frequent immune-related side effects.
PD-1 checkpoint inhibitors		Nivolumab, Pembrolizumab	Frequent primary or secondary resistance.
PD-L1 checkpoint inhibitors			

2.1.2 Immune-based therapy

Immune-based therapies are another therapeutic option for advanced or unresectable melanoma, and can be used as monotherapy or in combination. Immune checkpoint inhibitors have transformed the treatment of advanced melanoma by restoring the natural anti-tumour activity of the immune system and stimulating specific T cells to eliminate cancer cells.^{79, 82} Indeed, cancer growth relies on various characteristics, including the ability to evade the immune system. Disruption of immune checkpoints enables cancer to achieve this evasion, and it is this mechanism which has formed the basis for immune-based therapeutic interventions. Particularly anti-CTLA4 and anti-PD-1 antibodies used together have significantly improved the management of advanced melanoma, with almost 50% of patients experiencing tumour regression and long-lasting control of the disease.⁷⁹



Given that immune checkpoint inhibitors stimulate the immune system in a non-specific manner, it is not surprising that they can lead to adverse effects resembling autoimmune diseases, particularly in combination therapy. These immune-related adverse events occur in up to 40% of treated patients and can impact various organ systems.^{60, 83, 84} Toxicity varies in severity, and can lead to discontinuation of treatment, or in some cases, even be life-threatening. The skin, colon, endocrine system, and liver are among the organs most commonly affected. These adverse events usually manifest early in treatment, and can often be managed by the administration of corticosteroids and other immunosuppressants. However, the latter come with their own set of risks and concerns have been raised about their potential impact on treatment efficacy.

Despite these overall advancements, approximately two-thirds of melanoma patients will experience disease progression after immune checkpoint inhibitor therapy, and half of those with advanced melanoma will succumb to the disease. At present, we are still lacking sufficiently sensitive and specific biomarkers of response to immune therapy (Table 1).⁷⁹

2.1.3 Other therapies

Previously, chemotherapy and radiotherapy were the primary treatment options for advanced disease, but their efficacy was limited. Given the development of more effective therapies, the use of chemotherapy and radiotherapy are now restricted to cases of inoperable metastatic disease or in cases of resistance to immunotherapy and targeted therapy.^{74, 75}

Radiotherapy is only used in specific situations such as unresectable lesions, palliative treatment in case of brain or bone metastases, or, rarely, as adjuvant treatment after resection.^{32, 74, 75}

Imiquimod is a topical immunomodulator, which has inflammatory and antitumor effects and can be used as topical treatment of certain unresectable types of in situ lesions such as lentigo maligna melanoma.³² However, it is not reimbursed nor approved by the European Medicines Agency (EMA) for this indication.

Finally, in recent years, it has become increasingly common for patients to participate in clinical trials involving new anti-cancer medications or approved medications for novel indications.

2.1.4 Follow-up

The management of disease that has spread typically requires the involvement of multidisciplinary teams comprising oncologists, dermatologists, surgeons, radiologists, pathologists, specialised nurses, and, when appropriate, psychologists and palliative care specialists. This allows to define individualised management plans that are most suitable for each patient. Additionally, regular monitoring and clinical examinations are usually necessary to promptly detect serious side effects or disease recurrence. While there is no consensus on optimal schedule, follow-up tends to be around every 3 to 6 months for the first 5 years, depending on the stage.⁷³ Some patients are best followed-up by specialised dermatologists, with surveillance of naevi by sequential digital dermoscopy or high-resolution pictures.⁸⁵ Additionally, patients should be taught to carry out self-exams of their skin to check for any new or changing lesions.

The increasingly early detection of melanomas and the new treatments have limited advanced disease and improved patient survival and quality of life. Despite these advances, melanoma remains a public health issue in Europe with noteworthy unmet needs, both from a patient perspective and from a wider societal perspective. This case-study will highlight these unmet needs.



3 METHODS

This section describes the methods used to identify unmet health-related needs of patients with malignant melanoma. An online survey as well as individual interviews with patients were performed. The methodological approach including the research protocol and the questionnaire, was submitted to and approved by the ethical committee of the 'Erasmus Hospital Brussels' (P2023/148/B4062023000088). The approval was valid from 27/04/2023 until 31/12/2023.

3.1 Online survey

3.1.1 Data collection tool

3.1.1.1 Development of the online questionnaire

Generic patient unmet needs questionnaire

The questionnaire used in the current study is based on the generic questionnaire developed and described in a previous KCE report.⁸⁶ Full methodological details of the development of this generic questionnaire can be found in the report. In summary, the questionnaire was developed to identify and assess different dimensions of patients' needs. For each dimension, the KCE research team listed the possible questions related to the dimensions of needs. The questionnaire was validated by a Delphi panel comprised of patient representatives from umbrella organisations of patient associations and sickness funds.

Adaptations made for malignant melanoma

The generic questionnaire was adapted to individuals with malignant melanoma by reformulating some questions (e.g. using "melanoma" instead of the generic term "your disease") and by adding questions that are specific for malignant melanoma (see Appendix 3). The additional questions were based on a pragmatic review of the epidemiology and pathophysiology of melanoma and the specific characteristics of the disease including symptoms, treatment options, adverse events, and relevant healthcare

professionals and services (see section 2). The questionnaire was reviewed by two external melanoma experts.

Translation and face-validity

The questionnaire was initially formulated in French and was translated to Dutch by KCE researchers. A comparison of the two language versions was carried out to ensure that both were identical in terms of structure and content. Subsequently, both versions were proofread by research team members.

Online version: Patient Survey

Once the versions were proofread by the research team, the questionnaires were uploaded onto an online platform (Qualtrics embedded in the KCE website). Five individuals from different age groups and with diverse backgrounds, none with a scientific background, participated in a pre-test of the survey to assess the clarity of the questions and the user-friendliness of the online version. The online questionnaire underwent minor adaptations based on their feedback. Finally, the research team pre-tested the online versions in both languages.

3.1.1.2 Final questionnaire

Study introduction and patient approval

The questionnaire started with an introduction to the study, describing the objectives, requirements for participation, and confidentiality policy. Respondents were asked to provide their informed consent before participation.



Questionnaire structure

The questionnaire consisted of 58 questions, organised around the following ten themes (disease-specific dimensions are flagged by means of an *):

- General information: demographic information, including self-identified gender, age, place of residence, level of education, employment status, and whether the respondents were answering for themselves or for another adult (as proxy).
- Disease*: disease-specific information including symptoms and their burden, and treatment. Questions on hospitalisation due to disease were also included. Respondents were asked about the type of melanoma they were diagnosed with, its stage, and the site(s) of lesion(s).
- Other illnesses: presence of comorbidities.
- General health status and health-related quality of life (HRQoL): the respondents' health status before the latest diagnosis of melanoma and today using the EQ-5D-5L^a as the HRQoL instrument. The EQ-5D-5L asks respondents to describe their health status on five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each item has five response categories, reflecting the level of problems experienced in each dimension (no problems, slight problems, moderate problems, severe problems, extreme problems). In addition, respondents are asked to score their health state before and after diagnosis on a visual analogue scale (VAS), ranging from 0 (worst imaginable health state) to 100 (best imaginable health state).
- Healthcare use and access to care: contact with healthcare services, such as delay between seeking a first appointment and first consultation, types of specialists consulted and satisfaction with them,

any forgone care due to access barriers. Quantity and clarity of information received about their disease.

- Treatment*: disease-specific treatment(s) received, level of satisfaction with this (these) treatment(s), burden of treatment, and side effects.
- Financial impact: financial impact of disease and its consequences.
- Social support: needed social support as a result of the disease.

A combination of pre-defined categories and open field responses

For most of the questions, respondents were given a choice of answers (often based on the literature) but were also given the opportunity to give additional responses in an open field.

For several questions, respondents were asked to indicate their level of satisfaction or level of burden on a Likert scale. Filter questions were sometimes used, which led to additional questions in the case of a positive response.

Invitation to participate in an in-depth interview

At the end of the questionnaire, participants were asked whether they would be willing to participate in an individual interview. Information of respondents who indicated their willingness were retained for shortlisting and, if suitable, contacted (see section 3.2.1).

^a <https://euroqol.org/eq-5d-instruments/eq-5d-5l-about/> (last access: 7 March 2024)



3.1.2 Recruitment of participants

Recruitment strategy

A multichannel recruitment strategy was used which included online information (KCE website, a press release, e-mails, and social networks) as well as posters and flyers in healthcare settings. A link was provided to the KCE website on which interested individuals could find further information and a Quick Response (QR) code to the survey and informed consent. A direct link to the online survey was also provided via the QR code on the recruitment materials. In addition, we asked sickness funds, the Dutch-speaking and French-speaking umbrella organisations of patient associations (VPP and LUSS), disease-specific and general patient organisations, hospitals, universities, and dermatologists to share and display the information regarding the call for participation.

Inclusion criteria

Respondents had to meet the following criteria to participate in the survey:

- Being 18 years of age or older;
- Diagnosed with melanoma by a doctor;
- Having been diagnosed with melanoma between two months and three years ago;
- Living in Belgium (main residence).

When responding on behalf of another adult (who met the inclusion criteria but was unable to respond), they had to respond as if the patient they represented would answer the questionnaire.

When the inclusion criteria were not met, the survey could not be accessed and individuals were provided with an explanation for their exclusion.

3.1.3 Quantitative data collection process

The questionnaire was launched on the 4th of May 2023 and ran until the 2nd of July 2023. Throughout the three-month period of data collection, the recruitment strategy was subject to continuous monitoring. When stakeholders participating in the dissemination of the call took no action, the project team recontacted the stakeholders with repeated instructions to solicit participation, thereby ensuring maximal awareness and opportunity for individuals to engage in the data collection initiative.

In total, communication was established with over 327 stakeholders (137 hospital sites, 39 associations, 6 sickness funds, 7 universities, 5 Facebook groups, and 133 dermatologists) via e-mail, and more than 330 posters were disseminated across the three regions in Belgium (Table 2).

Table 2 – Overview of contacted stakeholders for melanoma

Type of stakeholder	Melanoma-specific	Not melanoma specific	n
University		7	7
Sickness fund		6	6
Hospital site ¹			137
University		24	
Non-university		113	
Association	33	6	39
Social group	5		5
Dermatologist	133		133
Total			327

¹14 sites have been visited to deliver the materials; all other stakeholders received materials digitally or by post.



3.1.4 Quantitative data analysis

For all continuous variables, means $\pm$ standard deviations (SD) or medians with interquartile ranges (IQR) for normally and non-normally distributed data respectively were calculated. For all categorical variables, the associated percentages were calculated.

Health-related quality of life (HRQoL) utility scores were assigned to respondents' EQ-5D-5L health state descriptions, using the most recent Belgian value set.⁸⁷ The EQ-5D-5L utility values were collected for two time points: before and after the latest diagnosis of melanoma. A paired-sample t-test was conducted to determine whether there was a significant difference (mean Beta) between the mean utility scores before versus after the onset of the disease.

Some results were also analyzed by cancer stage (early stage vs. intermediate/advanced stage). Continuous variables were compared between the predefined subgroups using Student's t-test or Mann-Whitney U test depending on the distribution of the data, while chi-square test or Fisher's exact test were used to investigate differences in categorical variables.

The significance level was set at 0.05 for all statistical tests. All statistical analyses were performed using R version 4.3.0 (R Foundation for Statistical Computing, Vienna, Austria).

Open field responses were first analysed thematically and recoded into existing or newly defined categories when appropriate. If the response could be interpreted in different ways, the response was classified under 'Others'

to avoid misinterpretation. Open field answers in the online survey were also processed using the NVIVO® software.

3.2 Individual interviews

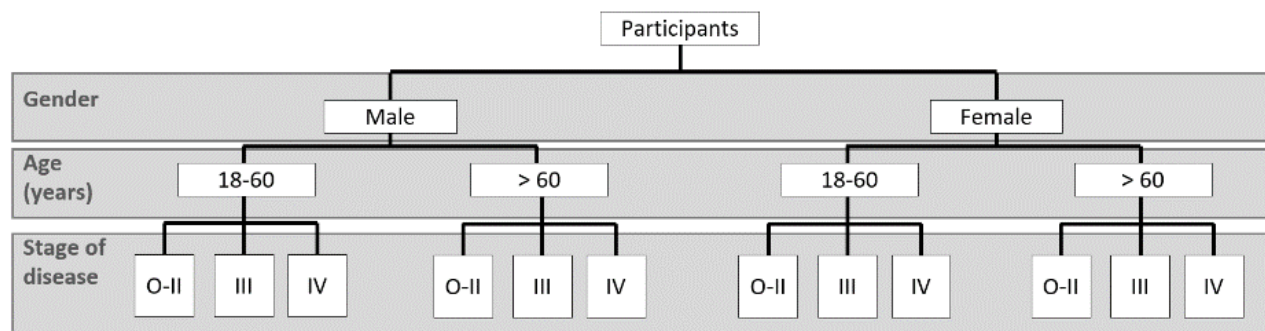
The guidance for the qualitative approach to identify patient needs has been developed in a previous KCE research project.⁸⁶ This approach was applied to melanoma to deepen our understanding of patients' perspectives on their unmet needs. The data collection was completed by a series of semi-structured individual interviews, developed in the context of KCE Report 348.⁸⁶ This methodology was first used in the KCE Report 344.⁸⁸

3.2.1 Selection of participants

Respondents participating in the online survey (see section 3.1 - Online survey) were offered the opportunity to participate in an individual interview. We aimed to conduct 20 individual interviews, with a distribution of 10 interviews in French and 10 in Dutch. To ensure a broad representation of respondent profiles, the researchers prioritised the recruitment of participants willing to participate in the interview from each language group, based on the following segmentation criteria:

- Gender: male and female;
- Age: 18-60 years and > 60 years;

Stage of disease: stage 0-II, stage III and stage IV (Figure 5)

**Figure 5 – Segmentation of candidates with melanoma for qualitative interviews**

In each segment of the population volunteering for the interview through the online survey, two participants were randomly selected, one for each language. In cases where there were insufficient candidates in a specific segment, additional candidates were contacted in adjacent categories.

3.2.1.1 Contact procedure

Participants selected to participate in the interviews received a phone call to confirm their willingness to participate and to set the date for the interview. Once they agreed, participants received the confirmation and informed consent form by e-mail. The e-mail included confirmation of practical details such as the scheduled time, date, and a direct link to access the meeting on Teams®. In a separate e-mail, they received the informed consent document as well as the information on how to sign it via Adobe® sign. Once signed by both parties (the participant and the researcher leading the interview), participants received another e-mail with a copy of the signed document.

If a selected candidate did not respond to three phone call attempts and e-mailing or refused to participate, another candidate within the same segment was randomly selected. Non-selected candidates were informed of their status via e-mail to ensure transparency and communication regarding the selection process.

3.2.2 Qualitative data collection tool

3.2.2.1 Development of the interview guide

Generic interview guide

The interview guide used in the current chapter is based on the generic tool developed in the context of KCE Report 348.¹ The topics covered during the interviews were derived from KCE Report 344.⁸⁸

Adaptations made for melanoma

Some parts of the generic interview guide were adapted to the disease-specific context, based on the main concerns reported by participants in the online survey and in the disease-specific literature review for melanoma.

Translation

The interview guide was initially developed in French and subsequently translated into Dutch by KCE researchers. A comparison of the two versions was carried out to ensure that both versions were identical in terms of structure and content. Subsequently, both versions were proofread by team members.



3.2.2.2 Final interview guide

The final interview guide is presented in the Appendix 2 original testimonials. The interview guide covers the following topics (disease-specific dimensions are identified by *):

- Symptoms*
- Impact of the disease*
- Patient journey leading to the diagnosis*
- Diagnosis and treatment*
- Encountered obstacles
- Information and support network
- Relationships with the medical profession
- Social and family relations

3.2.2.3 Data collection process

Participants were invited to take part in the interview via a secured teleconference. Although participants had the option to request an in-person interview if they preferred, all interviews were conducted online.

Interviews were conducted via Teams® in French by a native French-speaking researcher (RVG) and in Dutch by a native Dutch-speaking researcher (JD) in summer 2023. Both researchers had experience in public health and in leading semi-structured interviews. The interviews lasted approximately one hour each. Each interview was recorded and transcribed verbatim by the research team. To ensure confidentiality and privacy, all names of participants, institutions, and care providers were anonymised in the research.

3.2.3 Qualitative data analysis

A qualitative thematic analysis of the interview transcripts using NVIVO® software was performed, which structured the collected information and eased the analysis by the researchers (see appendix 4: qualitative analysis code).

The coding process for the French-speaking material, which includes transcripts of interviews and responses to open questions in the online survey, was conducted by one native-speaking researcher (RVG). Simultaneously, the Dutch-speaking material was coded by another native-speaking researcher (JD). These two researchers collaborated closely to develop a shared nodes tree, which served as the structural foundation for reporting the research results.

3.3 Literature review

Besides the primary data collection (patient survey and interviews) to assess patient-level unmet needs, secondary data collection was carried out to capture additional patient-level unmet needs (e.g. mortality data, disability weights, distribution of stages at diagnosis) which could not be captured by self-report, as well as societal and future unmet needs. This secondary data collection consisted in a pragmatic (non-systematic) review of the literature, which was conducted between March and December 2023. For each criterion included in the NEED assessment framework which was not assessed through the NEED survey, we searched for data in online databases, published scientific literature (through PubMed and Google Scholar), and/or in the grey literature (through Google). In PubMed, a restriction to systematic reviews and then to reviews was applied; if no reviews were identified the limitation was removed to yield primary studies. In PubMed, reference lists of relevant articles were screened, well as the PubMed tabs “similar articles” and “cited by”.

The melanoma disability weight was searched for in the Belgian Burden of Disease study (both on the Sciensano website and through published articles), and in the Global Burden of Disease study (through published articles).



The Years of Life Lost due to melanoma, its prevalence and incidence data were extracted from the online Belgian Burden of Disease study (Sciensano). Information on the distribution of stages at diagnosis, and age of onset were extracted from the Belgian Cancer Register. Information on the accessibility of specialist consultations (in terms of costs and waiting times) were gathered from the NIHDI (National Institute for Health and Disability Insurance) website and the Belgian Foundation against Cancer. The estimated future incidence of melanoma was searched in the published literature through PubMed and in the International Agency for Research on Cancer online database. Evidence on melanoma inequities were searched for in PubMed with the key words “social inequalities” or “inequities” or “Socioeconomic Factors”[Majr], and “melanoma”[Majr]. We report the inequalities only for the indicators for which we found evidence.

Information on the comorbidities associated with melanoma was searched for in scientific articles in PubMed using the key words “comorbidity”[MeSH Terms], and “melanoma”[Majr].

Evidence on the value for money of standard of care, productivity losses, and the future economic burden of melanoma were searched for in Google using the key words “economic burden” or “productivity losses” or “cost of illness” and “melanoma” and “Belgium”. Information on the environmental impact of standard of care for melanoma was searched in Google using the key words “environmental impact” and “melanoma” or “cancer care” or “anticancer drugs”.

We prioritised Belgian data and if none was available reported on other European studies.

3.4 Expert opinion

Two experts in melanoma (one dermatologist and one oncologist) were asked to rate the overall effectiveness and the availability in Belgium of treatment for melanoma. They were asked the following question: “*To what extent do you consider that the current treatment/management of melanoma is available and effective for the patient population?*”. For treatment availability they were asked to provide an estimation according to the description in Table 3.

Table 3 – Evaluation of treatment availability

Treatment availability	Description
Not available	Treatment(s) for the disease exist but none are available in Belgium (not authorised or not commercialised in Belgium)
Important availability problems	At least one key treatment for the disease is authorised and commercialised in Belgium, but other existing key treatments are not authorised/commercialised in Belgium, or treatment is commercialised but very expensive/not reimbursed
Some availability problems	Treatment is available for a majority of the population but too expensive for some, or there are some stock problems
No availability problems	Treatment is available for all patients without particular obstacles
There exists no treatment for the disease	For this disease there is currently no treatment anywhere
I don't know	

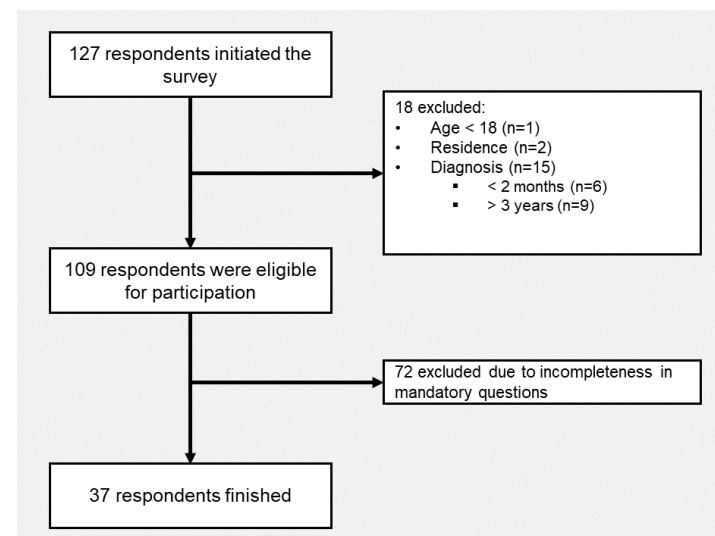
For treatment effectiveness they were asked to provide an estimation according to the description in Table 4.

**Table 4 – Evaluation of treatment effectiveness**

Treatment effectiveness	Description
Not effective	With current treatment the disease has a poor prognosis or the symptom burden remains very high
Somewhat effective	The current treatment is not curative or disease-modifying and important symptoms/impact on quality of life persist
Moderately effective	With current treatment the disease has a good prognosis (e.g. disease-modifying), but some symptoms or complications persist
Very effective	The current treatment is curative or disease-modifying and patients can achieve a very good quality of life without complications
Lacking evidence	There is lacking scientific evidence to make an overall evaluation of treatment effectiveness
I don't know	

4 RESULTS – UNMET PATIENTS NEEDS

Between May 4th 2023 and July 2nd 2023, 127 individuals initiated the survey for malignant melanoma. From this cohort, 18 participants did not meet the predefined inclusion criteria, resulting in a cohort size of 109 eligible respondents. Questionnaires without responses to all mandatory questions were deemed incomplete and hence excluded from the analysis (n=72). The final dataset included 37 respondents (Figure 6).

Figure 6 – Respondents participation flow diagram (melanoma)



4.1 Description of the participants

4.1.1 Surveyed participants

The sample consisted of 73% female participants. Geographically, Flanders emerged as the most represented region, encompassing 91.9% of respondents. Among the provinces, East-Flanders, Antwerp and Flemish Brabant stood out, with participation rates of 32.4%, 29.7%, and 16.2%, respectively. Linguistically, the Dutch-speaking population represented a majority, comprising 91.9% of the respondents. The study population was relatively young (mean age: 52.5 years), with more than half of survey respondents aged between 45 and 64 years (54%) and 27.0% between 24 and 44 years. The educational level of the participants reflected a substantial proportion with higher levels of education (64.9% with a Bachelor degree, Master degree or PhD). Furthermore, more than three quarters (78.4%) reported being engaged in paid employment before their diagnosis. In terms of survey administration, 2.7% completed the questionnaire on behalf of another person (Table 5).

Table 5 – Distribution of participants within the online survey based on demographics (n=37)

Variable	n (%)
All responses	37 (100.0)
Status of the respondent: completing the survey for	
<i>Yourself</i>	36 (97.3)
<i>Another adult</i>	1 (2.7)
Gender	
<i>Women</i>	27 (73.0)
<i>Men</i>	10 (27.0)
Language	
<i>Dutch</i>	34 (91.9)
<i>French</i>	3 (8.1)
Region	
<i>Flanders</i>	34 (91.9)

<i>Wallonia</i>	2 (5.4)
<i>Brussels</i>	1 (2.7)
Province	
<i>East Flanders</i>	12 (32.4)
<i>Antwerp</i>	11 (29.7)
<i>Flemish Brabant</i>	6 (16.2)
<i>West Flanders</i>	3 (8.1)
<i>Limburg</i>	2 (5.4)
<i>Luxembourg</i>	1 (2.7)
<i>Liege</i>	1 (2.7)
<i>Brussels</i>	1 (2.7)
<i>Walloon Brabant</i>	0
<i>Hainaut</i>	0
<i>Namur</i>	0
Age group (in years)	
<i>18-24</i>	0
<i>25-44</i>	10 (27.0)
<i>45-64</i>	20 (54.1)
<i>65-74</i>	5 (13.5)
<i>≥75</i>	2 (5.4)
Paid work before diagnosis	
<i>Yes</i>	29 (78.4)
Occupation before diagnosis	
<i>Employee</i>	19 (51.3)
<i>Self-employed</i>	6 (16.2)
<i>Retired</i>	4 (10.8)
<i>Labourer</i>	2 (5.4)
<i>Disabled</i>	0
<i>Unemployed</i>	1 (2.7)
<i>Others</i>	2 (5.4)
Occupation today	
<i>Employee</i>	19 (51.3)



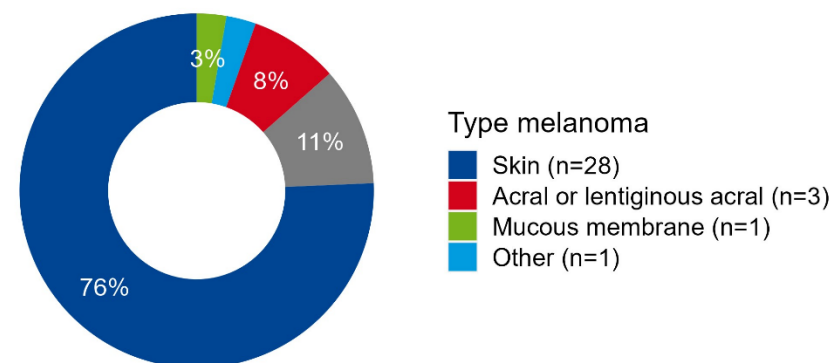
<i>Self-employed</i>	6 (16.2)
<i>Retired</i>	5 (13.5)
<i>Labourer</i>	2 (5.4)
<i>Disabled</i>	1 (2.7)
<i>Unemployed</i>	1 (2.7)
<i>Others</i>	3 (8.1)
Highest level of education	
<i>Lower level of education*</i>	10 (27.0)
<i>Higher level of education**</i>	24 (64.9)
<i>Other diploma</i>	3 (8.1)

* No diploma or primary education, Lower secondary education, Upper secondary education; **Bachelor's, master's, or doctoral degree

Three out of four participants had a melanoma of the skin.

Seventy-six percent of the respondents reported having melanoma that occurred on their skin. One in ten, 10.8%, indicated that they did not know the specific type and mentioned that the diagnosis had been made without the ability to determine the location or manifestation site (Figure 7).

Figure 7 – Type of melanoma reported (n=37)



More than half of participants (57%) were diagnosed with early-stage melanoma (stage 0, I, or II).

Almost one third (29.7%) of respondents reported their melanoma to be in an intermediate stage (stage III), while 13.5% mentioned their melanoma had progressed to an advanced stage at the time of diagnosis (stage IV, Figure 8).

Respondents with intermediate or advanced stages of melanoma exhibited a substantially higher rate of hospitalisation due to their condition (68.8%), in contrast to those with early-stage melanoma, for whom the hospitalisation rate was notably lower at 9.5% ($p < 0.001$, Table 6).



Figure 8 – Stage of melanoma (n=37)

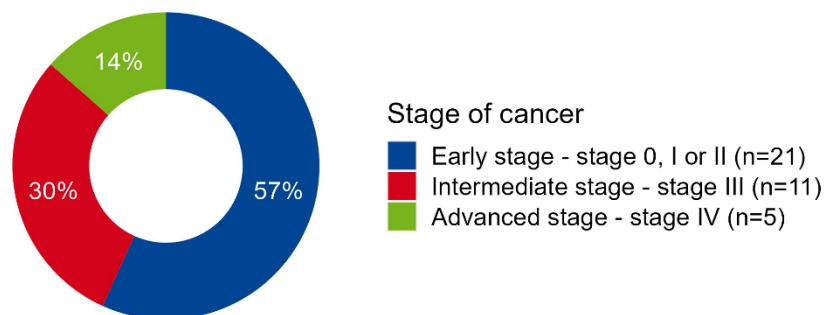


Table 6 – Distribution of hospitalisation according to cancer stage (n=37)

Hospitalisation due to disease	Early stage (n=21) n (%)	Intermediate & advanced stages (n=16) n (%)	p-value	Total n (%)
No	19 (90.5)	5 (31.2)	***	24 (64.9)
Yes	2 (9.5)	11 (68.8)	***	13 (35.1)

* Fisher's exact test, NS=Not significantly different, * p-value <0.05, ** p-value <0.01, *** p-value <0.001

4.1.2 Interviewed participants

Out of the 37 participants included in the study, 12 expressed their willingness to take part in an interview. Ultimately, nine of them responded favourably to our requests for interviews. Seven interviews in Dutch and two in French were organised. The majority of interviewed participants were female (Table 7).

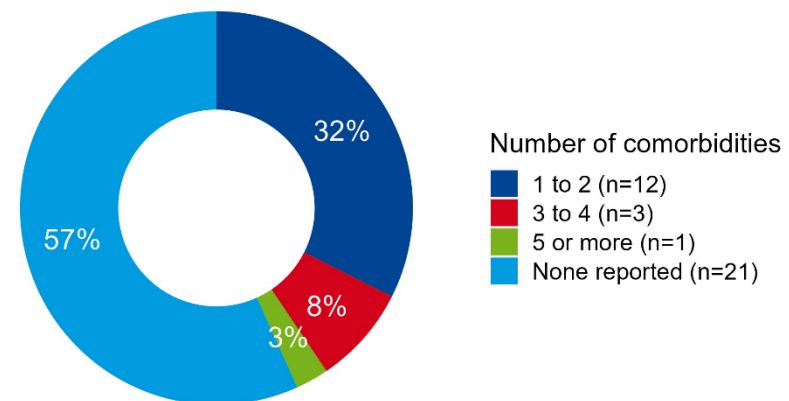

Table 7 – Description of interview participants with melanoma (n=9)

ID	Language	Gender	Age (years)	Time since diagnosis	Type of melanoma	Stage of disease
3N1	NL	M	40-49	2 to 3 years	Skin (cutaneous)	IV
12N1	NL	F	60-69	1 to 2 years	Skin (cutaneous)	IV
8N1	NL	F	50-59	1 to 2 years	Skin (cutaneous)	III
11N2	NL	F	60-69	2 to 6 months	Site not found	III
11N1	NL	F	70-79	2 to 6 months	Skin (cutaneous)	III
7N1	NL	F	50-59	2 to 6 months	Skin (cutaneous)	0-II
4N1	NL	M	60-69	2 to 6 months	Skin (cutaneous)	0-II
7F1	FR	F	40-49	6 months to 1 year	Skin (cutaneous)	0-II
10F1	FR	F	60-69	1 to 2 years	Skin (cutaneous)	0-II

FR: French-speaking; NL: Dutch-speaking; F: Female ; M: Male

Comorbidities

More than two in five participants (43%) reported having at least one comorbidity. Around 10% of participants reported having three or more comorbidities. The most frequently reported comorbidities were disorders of the musculoskeletal system (13.5%), respiratory disease (10.8%), skin disease (10.8%), and endocrine, nutritional, or metabolic diseases (10.8%).

Figure 9– Number of comorbidities among participants with melanoma (n=37)




4.2 Unmet health needs

4.1.1 Impact on general health-related quality of life

Based on the EQ-5D-5L utility scores, participants reported a significant decline in health-related quality of life (HRQoL) following the latest diagnosis of melanoma.

There was a statistically significant negative change in the utility scores reported, with the average score before the latest diagnosis decreasing from 0.93 (95% CI: 0.89; 0.98) to 0.81 (95% CI: 0.75; 0.87) at the time of the interview, resulting in an average beta (difference) of -0.12 (95% CI: -0.18; -0.04). Thus, based on Table 8 and the change in the EQ-5D-5L utility scores, there was a significant decline in HRQoL following the diagnosis of melanoma.

Table 8 – EQ-5D-5L utility score before the latest melanoma diagnosis and today

Variable	Mean	SD	95% CI	p-value

EQ-5D-5L before	0.93	0.14	0.89;0.98	
EQ-5D-5L today	0.81	0.18	0.75;0.87	
Beta ¹	-0.12	0.19	-0.18;-0.04	

*The EQ-5D-5L score ranges from -0.59 to 1, where 1 is the best possible health state. ¹Beta= EQ-5D-5L today- EQ-5D-5L before; new Belgian tariffs have been used to evaluate the individual scores obtained with EQ-5D-5L tool⁸⁷; ***Paired t-test total before-after: p<0.001; SD=Standard Deviation; CI=Confidence Interval*

A more granular analysis was conducted on each of five EQ-5D-5L dimensions to identify which ones show the greatest changes. For each dimension, the reported level of problems are illustrated in Table 8. Table 9 presents a summary, reporting the change over time in each of the dimensions.

The decrease in the overall EQ-5D-5L utility score was mostly driven by a shift from respondents with no problems before the diagnosis to having at least slight problems today across the five dimensions (Table 9). However, the magnitude of the change was largest for two dimensions: an additional 46.0% of respondents felt anxiety/depression today although they did not feel this way prior to diagnosis. Conversely, 32.4% of respondents felt pain/discomfort today although they did not have any problems prior to the latest diagnosis. The remaining dimensions, usual activities, mobility and self-care, were also affected, but to a lesser extent, with decreases of 27.0 percentage points, 18.9 percentage points and 13.5 percentage points respectively.

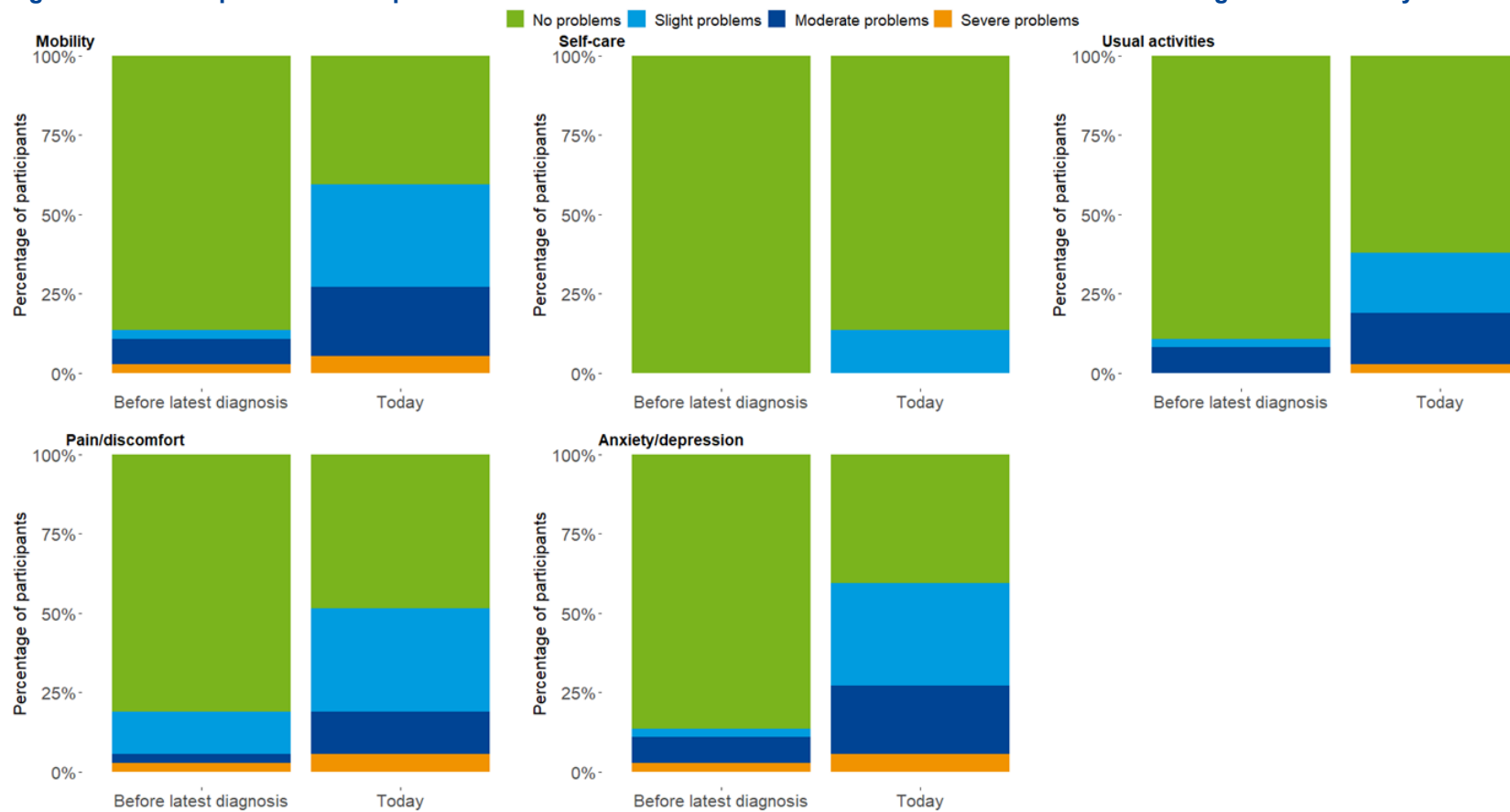
**Figure 10 – Self-reported level of problems on each EQ-5D-5L dimension before the latest melanoma diagnosis and today**

**Table 9 – Change in the self-reported level of problems on each EQ-5D-5L dimension before latest melanoma diagnosis and today (n=37)**

Level of problems	Today-Before (% points) Mobility	Today-Before (% points) Self-care	Today-Before (% points) Usual Activities	Today-Before (% points) Pain/discomfort	Today-Before (% points) Anxiety/depression
No problems	-18.9	-13.5	-27.0	-32.4	-46.0
Slight problems	+5.4	+13.5	+16.2	+18.9	+29.7
Moderate problems	+10.8	0	+8.1	+10.8	+13.5
Severe problems	+2.7	0	+2.7	+2.7	+2.7
Extreme problems	0	0	0	0	0

A significant difference in the change of EQ-5D-5L utility scores based on the stage of cancer.

When stratifying the EQ-5D-5L utility scores by cancer stage, the change in scores is most significant for respondents at an intermediate or advanced stage of cancer. For this group, the EQ-5D-5L utility score decreases from 0.94 (95% CI 0.86; 1.01) to 0.78 (95% CI 0.69; 0.86), which corresponds to a significant decrease in the HRQoL reported (p-value<0.01). While patients with early stage cancer also reported a decrease in their general HRQoL, this change was not statistically significant at the 5% significance level.

Table 8 – EQ-5D-5L stratified by cancer stage (n=37)

	Early stage (n=21)			Intermediate and advanced stage (n=16)		
	Mean (SD)	95% CI	p-value	Mean (SD)	95% CI	p-value
EQ-5D-5L			NS			**
Before	0.94 (0.11)	0.89; 0.99		0.94 (0.14)	0.86; 1.01	
Today	0.84 (0.19)	0.76; 0.93		0.78 (0.16)	0.69; 0.86	
Beta	0.10 (0.18)	0.01; 0.18		0.16 (0.18)	0.06; 0.26	

Paired t-test total before-today: NS = Not significant, * p-value <0.05, ** p-value <0.01, *** p-value <0.001



Associated comorbidities

The recent literature is providing increasing evidence for the association between autoimmune diseases and the development of different cancers.^{89, 90} As such, it appears that melanoma more frequently occurs in individuals with pre-existing autoimmune disease, while it also predisposes to the development of these diseases when treated with immune therapy.⁹¹ The exact link and causal pathway between these diseases still needs to be further clarified.

Years of life lived with disability (per case)

The Years Lived with Disability (YLDs), are a measure of the non-fatal disease burden calculated by multiplying the number of prevalent cases with a (severity-weighted) disability weight.^{5, 92} The YLDs can be calculated per case or per population.

For the year 2020, it was estimated that the melanoma YLDs per case were of 0.065.^{5, 92} This means that, on average, individuals with melanoma were estimated to experience a reduction of 6.5% in their general quality of life.

For the same year, the total prevalence-based YLDs in Belgium, when standardised for the Belgian population, were of 14.90 per 100 000 people.^{5, 92}

The disability weight used for these calculations stem from the 2013 Global Burden of Disease (GBD) study. The GBD study estimated disability weights through a method of paired comparisons for different stages of cancer taken as a whole.⁹³ These are therefore not specific to melanoma. The overall cancer disability weights were the following: diagnosis and primary treatment (0.288), controlled phase (0.049), metastatic disease (0.451), and terminal phase with medication (0.540). Using these disability weights has the advantage of comparability with disability weights for other conditions in the same population via the GBD study, but may not be exact for the estimation of melanoma-specific burden.

A Belgian study which published its results in 2014, calculated disability weights for each of the 10 melanoma stages both for treatment phase and remission phase. These DWs ranged from 0.127 (95% CI 0.098–0.156) for stage 0 in remission to 0.372 (95% CI 0.236–0.508) for stage IIIA under treatment.^{94, 95}

4.2.2 Impact on physical health

Approximately half of the respondents reported currently having pain or discomfort.

When analysing the pain and discomfort dimension of the EQ-5D-5L, it can be observed that while 81.0% of respondents reported they had no problems before the latest diagnosis, only 48.7% of respondents indicated no problems today. There was an increase in the number of participants that reported slight problems (+18.9 percentage points), moderate problems (+10.8 percentage points) and, to a lesser extent, extreme problems (+2.7 percentage points) (Table 9).

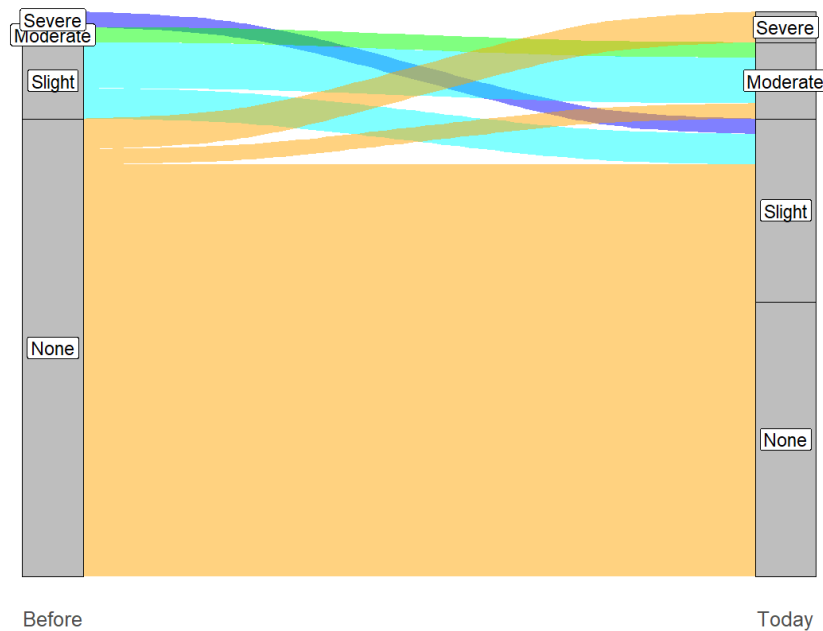
Table 9 – Change in the distribution of the dimension “pain/discomfort” of the EQ-5D-5L before latest melanoma diagnosis and today (n=37)

Level of problems	Before diagnosis (%)	Today (%)	Delta (% points)
No problems	81.1	48.7	-32.4
Slight problems	13.5	32.4	+18.9
Moderate problems	2.7	13.5	+10.8
Severe problems	2.7	5.4	+2.7
Extreme problems	0	0	+0

The flows of changes in the distribution of self-reported pain or discomfort can be observed in Figure 11.

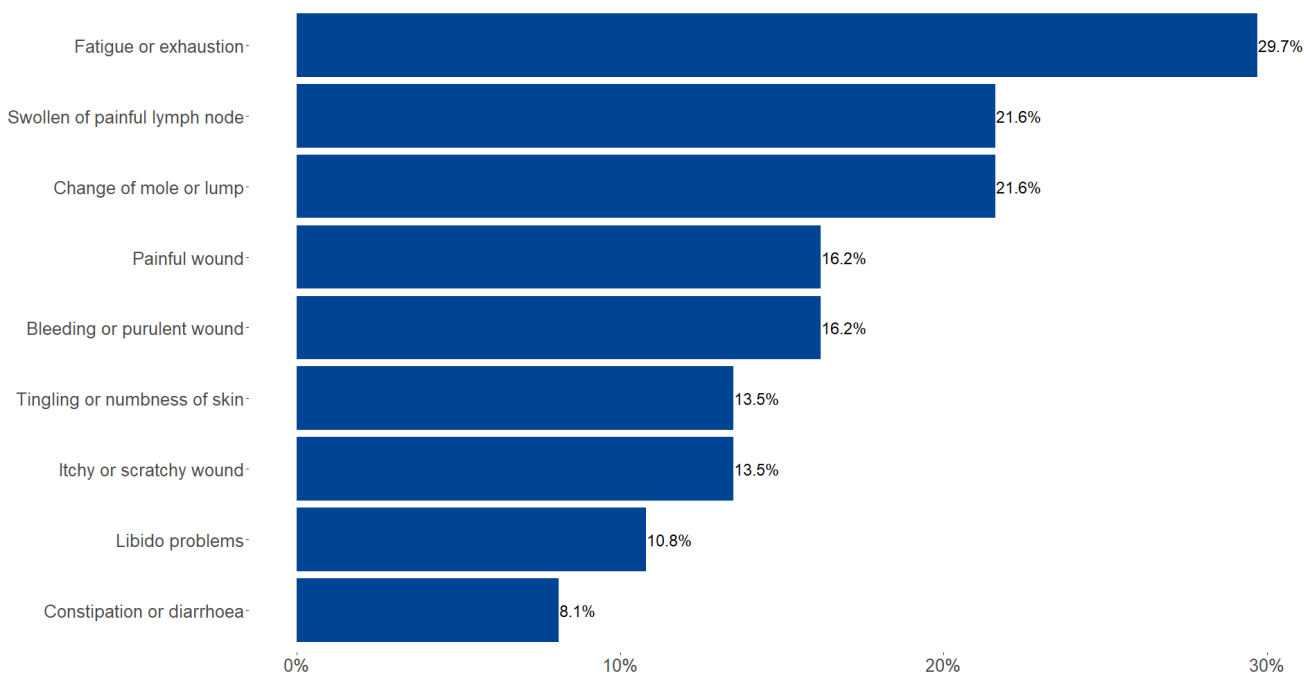


Figure 11 – Evolution in the dimension "pain/discomfort" of the EQ-5D-5L before latest melanoma diagnosis and today (n=37)



Fatigue, the most common physical symptom, was experienced by one third of respondents.

Participants were asked to indicate which physical symptoms they experienced in relation to melanoma. As indicated in Figure 12 and in Table 10, almost 30% (29.8%) of respondents indicated feeling fatigue or exhaustion, 21.6% indicated a change of mole or lump, and an equal number of participants indicated swelling of a painful lymph node.

**Figure 12 – Frequency of physical symptoms reported by respondents with melanoma (n=37)¹**

¹Only physical symptoms reported by at least 3 participants are displayed in the figure. Other symptoms reported are: stomach ache (n=2), shortness of breath or difficulty breathing (n=2), nausea or vomiting (n=2), loss of appetite (n=2), bone pain (n=1), weight loss (n=1), joint pain (n=1), fever (n=1), vision problems (n=1), muscle weakness (n=1), speech problems (n=1), voice problems (n=1), swelling or oedema (n=1).

In addition, participants were also asked to indicate the level of burden associated with each of the symptoms reported (Table 10 and Figure 13). Out of the 37 participants, 9 reported having at least one physical symptom that was very burdensome. The symptoms that were always considered as very burdensome by those experiencing them, were bone pain, joint pain, speech and voice problems and weight loss. However, each of these symptoms were only experienced by one person.

Among the most frequently reported symptoms (>10% of participants), those that were most commonly considered rather or very burdensome were painful wound, fatigue or exhaustion, and swollen or painful lymph node.

Among participants reporting fatigue or exhaustion, the most frequently reported symptom in the survey, 81.9% considered this symptom to be rather or very burdensome.

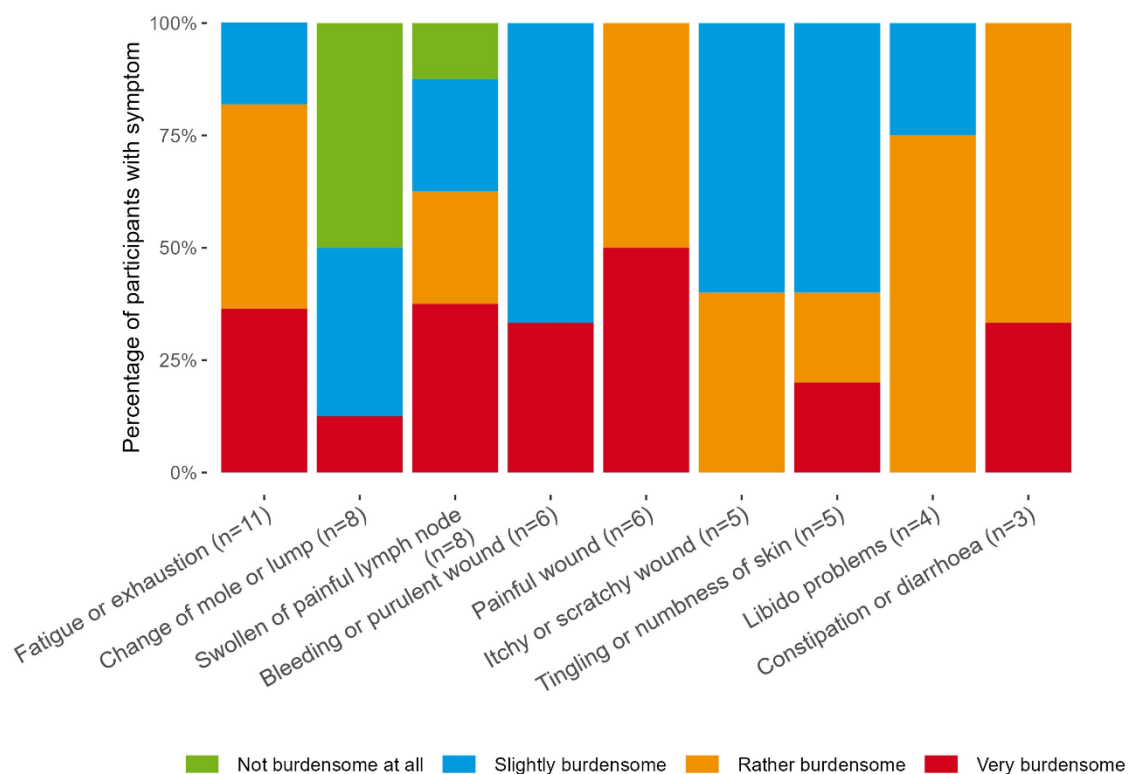
**Table 10 – Distribution of reported physical melanoma symptoms by level of burden (n=37)**

Physical symptoms	Symptom frequency n (%)	Reported burden n (%)			
		Not at all burdensome	Slightly burdensome	Rather burdensome	Very burdensome
Fatigue or exhaustion	11 (29.7)	0	2 (18.2)	5 (45.5)	4 (36.4)
Change of mole or lump	8 (21.6)	4 (50.0)	3 (37.5)	0	1 (12.5)
Swollen of painful lymph node	8 (21.6)	1 (12.5)	2 (25.0)	2 (25.0)	3 (37.5)
Bleeding or purulent wound	6 (16.2)	0	4 (66.7)	0	2 (33.3)
Painful wound	6 (16.2)	0	0	3 (50.0)	3 (50.0)
Itchy or scratchy wound	5 (13.5)	0	3 (60.0)	2 (40.0)	0
Tingling or numbness of skin	5 (13.5)	0	3 (60.0)	1 (20.0)	1 (20.0)
Libido problems	4 (10.8)	0	1 (25.0)	3 (75.0)	0
Constipation or diarrhoea	3 (8.1)	0	0	2 (66.7)	1 (33.3)
Shortness of breath or difficulty breathing	2 (5.4)	0	1 (50.0)	1 (50.0)	0
Stomach ache	2 (5.4)	0	0	1 (50.0)	1 (50.0)
Nausea or vomiting	2 (5.4)	0	0	2 (100.0)	0
Loss of appetite	2 (5.4)	0	1 (50.0)	0	1 (50.0)
Vision problems	1 (2.7)	0	0	1 (100.0)	0
Weight loss	1 (2.7)	0	0	0	1 (100.0)
Swelling or oedema	1 (2.7)	0	0	1 (100.0)	0
Bone pain	1 (2.7)	0	0	0	1 (100.0)
Joint pain	1 (2.7)	0	0	0	1 (100.0)
Muscle weakness	1 (2.7)	0	0	1 (100.0)	0
Speech problems	1 (2.7)	0	0	0	1 (100.0)



Voice problems	1 (2.7)	0	0	0	1 (100.0)
Fever	1 (2.7)	0	0	1 (100.0)	0

Figure 13 – Level of burden of the reported physical symptoms (n=37)¹



¹The graph is ordered by frequency (leftmost highest frequency). Only physical symptoms reported by at least three participants are displayed in the figure. Other symptoms reported are: stomach ache (n=2), shortness of breath or difficulty breathing (n=2), nausea or vomiting (n=2), loss of appetite (n=2), bone pain (n=1), weight loss (n=1), joint pain (n=1), fever (n=1), vision problems (n=1), muscle weakness (n=1), speech problems (n=1), voice problems (n=1), swelling or oedema (n=1).



During the interviews, participants reported that their energy levels were fluctuating, sometimes unpredictably, taking a toll on their ability to commit to activities and to be relied upon. This sometimes limited their social interactions. They reported being particularly exhausted during periods of intense follow-up (e.g. investigations, or awaiting results).

"Now I think that the melanoma itself took energy during the first two months, two, three months. But that in itself is no longer the case. I already had a history. So I think it's more than the breast cancer. I also had CVS, so yes, it's an "and-and-and" story. But I can't say that the melanoma itself is now taking energy, it consumes energy during the moments when you have to undergo tests and wait for results and such. But yes, after that, it actually went pretty well." (7N1) [1]

"That has of course had an impact when I was operated on. Both... Well, it still has an impact, because I used to... Now football is on hold for a while, but it will start again. I used to go to the canteen on Mondays and Wednesdays, in the evenings during training, to keep the canteen open. But I can't do that anymore. I don't do that anymore, because one day it might be possible, the other not. But people have to be able to count on you. I will see in the future whether I can take that up again, or one day a week. But in the evening, probably also because of that cortisol, from around six o'clock, half past six, my battery is empty, I'll put it that way, and then I'm really... Because I'm not sitting still during the day, you know." (12N1) [2]

4.2.3 Impact on psychological health

At the time of survey data collection, around 60% of participants suffered from anxiety or depression

While only 13.5% of respondents suffered from at least slight anxiety or depression before their last melanoma diagnosis, 59.4% of respondents indicated suffering from anxiety or depression at the time of survey completion (Table 11). At the moment of the survey, 32.4% of participants indicated having slight problems (2.7% before diagnosis), 21.6% having moderate problems (8.1% before diagnosis) and 5.4% having severe problems (2.7% before diagnosis).

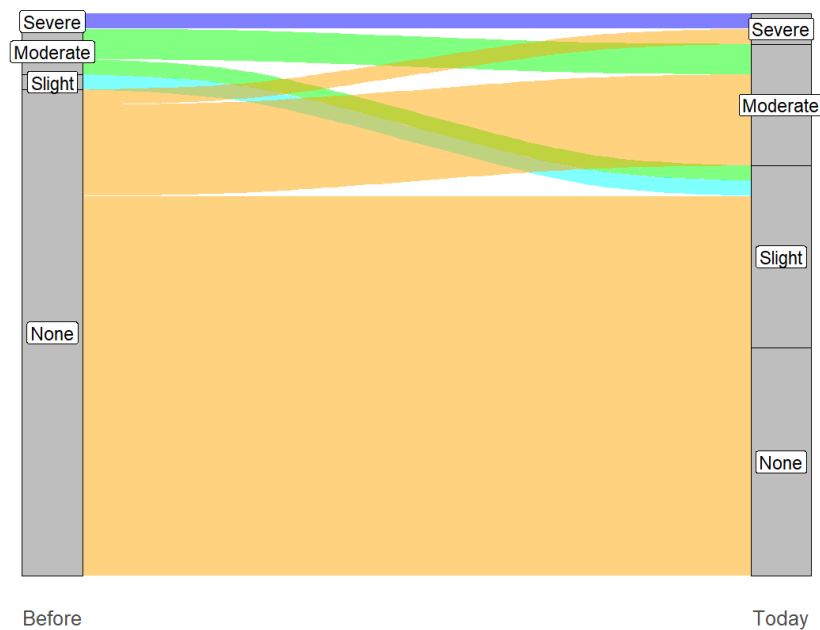
Table 11 – Change in the distribution of self-reported level of problems on the dimension “anxiety/depression” of the EQ-5D-5L before latest melanoma diagnosis and today (n=37)

Level of problems	Before diagnosis (%)	Today (%)	Delta (% points)
No problems	86.5	40.5	-45.9
Slight problems	2.7	32.4	+29.7
Moderate problems	8.1	21.6	+13.5
Severe problems	2.7	5.4	+2.7
Extreme problems	0	0	+0

The flows of changes in the distribution of self-reported anxiety or depression can be observed from Figure 14.

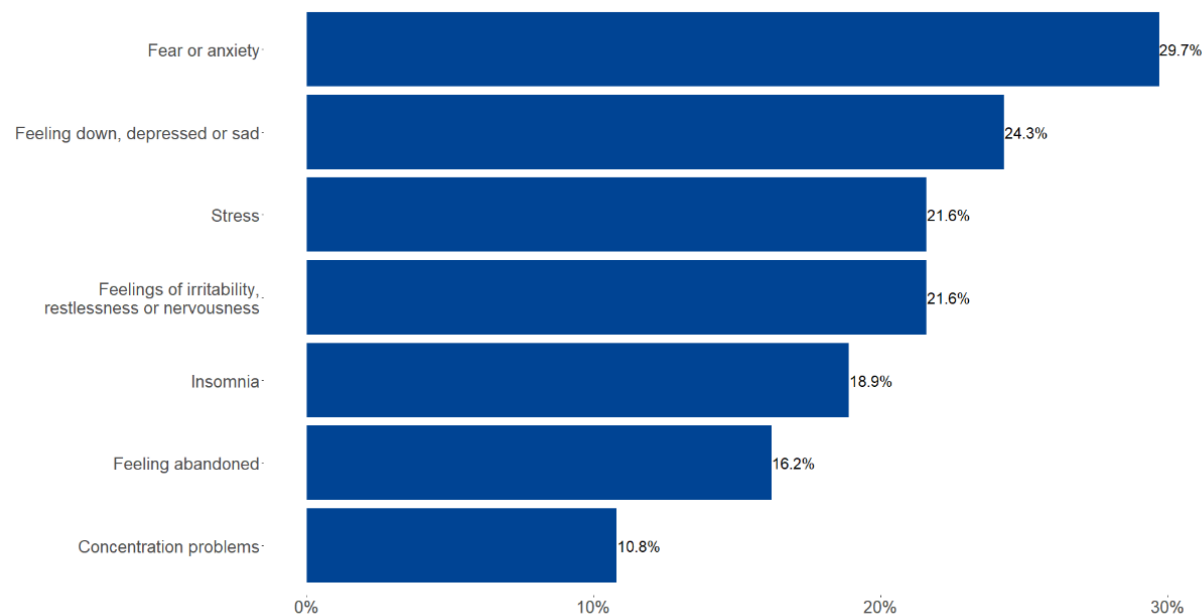


Figure 14 – Evolution of the dimension "anxiety/depression" of the EQ-5D-5L before latest melanoma diagnosis and today (n=37)



One in two survey participants (48.6%) reported suffering from at least one psychological symptom. The most common psychological symptoms were fear or anxiety (29.7%), and feeling down, depressed or sad (24.3%; Figure 15).

Other frequently reported symptoms included feelings of irritability, restlessness, or nervousness (21.6%), and stress (21.6%).

**Figure 15 – Frequency of psychological symptoms reported by respondents with melanoma (n=37)¹**

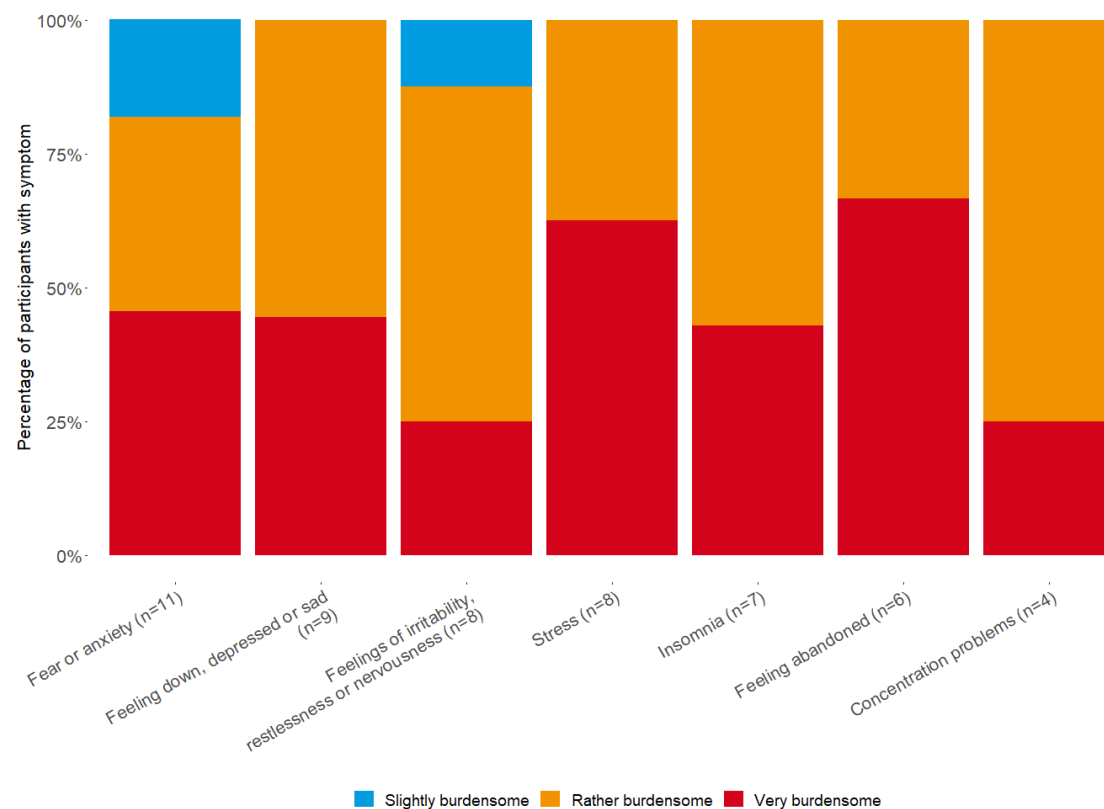
¹Only psychological symptoms reported by at least 3 participants are displayed in the figure. Other symptoms reported are: mood swings (n=2), anger or aggressiveness (n=2) and difficulty or loss of memory (n=1).

Additionally, ten patients (27%) reported that at least one of the psychological symptoms they experienced was very burdensome (Table 12).

Among the psychological symptoms experienced by at least 10% of survey participants, the ones most frequently considered as very burdensome were feeling abandoned, and stress. The ones most frequently considered as rather or very burdensome were feeling down, depressed or sad, stress, insomnia, feeling abandoned, and concentration problems.

**Table 12 – Distribution of reported psychological melanoma symptoms by level of burden (n=37)**

	Symptom Frequency n (% of all respondents)	Reported burden n (% of respondents reporting the symptom)			
		Not at all burdensome	Slightly burdensome	Rather burdensome	Very burdensome
Fear or anxiety	11 (29.7)	0	2 (18.2)	4 (36.4)	5 (45.5)
Feeling down, depressed or sad	9 (24.3)	0	0	5 (55.6)	4 (44.4)
Feelings of irritability, restlessness, or	8 (21.6)	0	1 (12.5)	5 (62.5)	2 (25.0)
Stress	8 (21.6)	0	0	3 (37.5)	5 (62.5)
Insomnia	7 (18.9)	0	0	4 (57.1)	3 (42.9)
Feeling abandoned	6 (16.2)	0	0	2 (33.3)	4 (66.7)
Concentration problems	4 (10.8)	0	0	3 (75.0)	1 (25.0)
Anger or aggressiveness	2 (5.4)	0	0	1 (50.0)	1 (50.0)
Mood swings	2 (5.4)	0	0	1 (50.0)	1 (50.0)
Difficulty or loss of memory	1 (2.7)	0	0	0	1 (100.0)

**Figure 16 – Level of burden of the reported psychological symptoms (n=37)¹**

¹The graph is ordered by frequency (leftmost highest frequency). Only psychological symptoms reported by at least 3 participants are displayed in the figure. Other symptoms reported are: mood swings (n=2), anger or aggressiveness (n=2) and difficulty or loss of memory (n=1).



Having cancer appeared as a shock to many participants.

The notion of urgency associated with the diagnostic process, led to significant stress for one respondent. For instance, the swift referral to a university hospital had a psychological impact on the participant, prompting awareness that a serious diagnosis was under consideration.

"And he sends you to a hospital... a big university hospital, [name of the hospital], well, it's okay and you know that it's a very big university hospital, so that also induces stress because you think, 'well if they send me there it's because...'"" (10F1) [3]

The interviews showed that the terms "cancer" and "melanoma" provoked anxiety. The fact that patients were followed up in oncology departments was also perceived by patients as a shock, as it made them aware of the severity of the disease.

"Yes, that's a blow to the head when you hear that. Because you know first of all: cancer, that's already something. The word cancer. Then melanoma, you know, that's really something serious. All cancer is serious, but yeah. [...] Oh yeah, psychologically, just the word cancer is something. They say there is a life, before and after cancer, and that's true. And I mean purely psychologically." (12N1) [4]

"But we're in the oncology department, so it's really with everything. With all the patients who are on chemotherapy, etcetera. So that's also in addition... well it's even more... it's confronting." (7F1) [5]

Melanoma generated fear of reoccurrence and of death.

Respondents highlighted their concerns about how long they would live and the consequences on their loved ones if they died. They expressed the fact that it was difficult not to think about these aspects.

"So, between each patient, well I only thought about one thing, I thought about the hospital, and then I thought especially... especially about the children, and things like that [...] We're busy with the patient so we don't

think about it, but we get in the car and there it is, 'if something happens to me, what will happen to my children'... etcetera. So that was it. All the time, all the time." (7F1) [6]

"Because I am sick, but if I die, my wife will be left behind. So psychologically, that also hits deep." (3N1) [7]

Another psychological impact noted by the interviewed participants was the fear of recurrence of the disease. Even when melanoma was treated, patients remained in constant fear that another one would develop. The metastatic aspect of the disease also added to the psychological burden of melanoma.

"That my life now completely changes, even if the therapy stops. Yes, I still have to go to the dermatologist every few months. And you will always be afraid that there is a spot... Yes, I have that now too. So I am diligent in the shower, and I see a spot that I thought, 'that wasn't there before'." (4N1) [8]

Some participants expressed the psychological consequences as a change in character, which also negatively affected their relatives.

Some participants noticed a change in their temperament, becoming more easily stressed and irritable, which had consequences on their relationships.

"But it's harder. A problem that is small is now magnified. I also notice that I become more nervous. And that's not my character, because normally when there is a problem I have to stay calm." (4N1) [9]

Patients felt abandoned with their illness

During the interview, feelings of loneliness and abandonment were expressed, compared on occasion as being imprisoned.

"We are very fragile when we arrive at the hospital. [...] Well, I felt very fragile when I entered the room alone, since the lady dropped me off at the entrance, I entered that room at 9am and I burst into tears. [...] I felt



abandoned, totally abandoned and... that's it. It's like being taken to prison." (10F1) [10]

The importance of hope for new therapies

Participants interviewed testified to their fear of exhausting all possible treatments and finding themselves in an incurable situation. In their eyes, it was important to maintain hope in other therapies.

"I think that's very important, for people who are, so to speak, out of treatment. Or that they can have access to possible therapies that may still be hopeful. I think that... Because I think that if you get that word; that you are out of treatment, it's a serious blow. And I think that in some ways I would still try to find something that might still work." (12N1) [11]

Participants adopted coping mechanisms to deal with the psychological impact of the disease.

To limit the psychological impact of melanoma, participants adopted coping mechanisms, such as trying to put things in perspective, relaxing, and engaging in activities to stay distracted, or adapting their environment.

"[...] now we have installed a pergola, telling me that now if I want to go, I go outside. It's not me who will change my habits to go eat or things like that. If I want to go in the sun, no, I don't go in the sun, but if I want to go outside I can go outside. So I go thinking, here, it's me who will have the upper hand. I put greenery in the garden, just like that. To have shaded areas, things like that. So yeah, psychologically like that, telling myself 'no, I'm not going to let myself be beaten'." (7F1) [12]

Patients experienced difficulties finding the right coping mechanisms to address the psychological aspects of melanoma.

"The only thing I will do now when I go to [name of the hospital] next time is indeed, on advice from a psychologist or psychiatrist, to talk, because I try to process it myself and I notice that it doesn't always really work, because you stay in a kind of vicious cycle, because I always say, every time I go to [name of the hospital], 'why am I doing

this, why am I doing this?' And eventually I should stop with that and say, 'okay, I'm doing it'. And not ask the question every time, because then it also comes back to me differently. So that doubt always, that eternal doubt. So that is one of the priorities now, yes." (4N1) [13]

Despite these challenges, participants did not always feel the need for psychological support.

"No, I didn't feel the need. Then I had family who were there. People who were... who are in the medical field. So, it's also easier. But yes, I can understand that someone will have... should have... need that additional psychological support. I also had a car accident. So yeah, psychological follow-up would have been good for a lot of people." (7F1) [14]

The psychological impact of the disease over the long term was also highlighted by interviewees. For example, the fact that they could no longer donate blood was perceived as if the disease never really ended.

"After how long can I donate my plasma again?" So I was transferred directly to the doctor. The doctor tells me... well I ask the question directly and the doctor tells me "yes, well it's over." There is no... You can no longer donate your plasma." So again we think the disease is over, but in the end it's not over, it will never be over since we can no longer donate blood for life." (7F1) [15]

4.2.4 Impact on autonomy

Individuals diagnosed with melanoma faced different levels of challenges across various dimensions of autonomy, including mobility, self-care, and usual activities.

The largest change in score occurred for usual activities, for which 10 respondents (27.0%) indicated that they had no problems before diagnosis but faced at least slight problems at the time of the survey. A change was also observed with regards to the mobility indicator, for which 18.9% of the respondents who indicated that they had no problems before diagnosis, reported at least slight problems today. Modest change occurred on the self-



care indicator for which all participants indicated not encountering any issues prior to diagnosis but five of them (13.5%) reported having developed slight problems in their ability to self-care (Table 13).

Table 13 – Change in the distribution of the dimension “autonomy” of the EQ-5D-5L before melanoma diagnosis and today (n=37)

Level of problems	Mobility			Self-care			Usual activities		
	Before	After	Difference (percentage points)	Before	After	Difference (percentage points)	Before	After	Difference (percentage points)
No problems	86.5%	67.6%	-18.9%	100.0%	86.5%	-13.5%	89.2%	62.2%	-27.0%
Slight problems	10.8%	16.2%	5.4%	0.0%	13.5%	13.5%	2.7%	18.9%	16.2%
Moderate problems	2.7%	13.5%	10.8%	0.0%	0.0%	0.0%	8.1%	16.2%	8.1%
Severe problems	0.0%	2.7%	2.7%	0.0%	0.0%	0.0%	0.0%	2.7%	2.7%
Extreme problems	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%

A better insight into what it meant to lose mobility for some individuals was gathered during the interviews. For example, someone could no longer ride a bicycle, because of the pain of sitting on a saddle. For another person, losing their mobility meant having to use a walking stick to get around.

"Yes. My body can't handle that mass anymore. With the mobility scooter it's better now. I sit and now I always bring my walking stick with me. Because yes, if we're somewhere and I have to go pee, I have to take my walking stick. For all the places you don't know. At home, I can walk around here and there. That's different. Then fortunately I don't need my walking stick yet." (11N1) [16]

4.2.5 Impact on life expectancy

In 2019, the Years of Life Lost (rate) for Belgium (adjusted for the Belgian population in the last observed year) were estimated at 73.109 per 100 000 inhabitants (95% CI 69.443 – 77.624).⁵³

Inequalities in melanoma mortality according to ethnic group have been reported and are further described in section 7.



Key points

- The onset of melanoma was associated with a decrease in quality of life among survey respondents, from an average EQ-5D-5L utility score of 0.93 before diagnosis to an average score of 0.81 after diagnosis
- While 81% of respondents indicated that they did not have pain or discomfort problems before diagnosis, the percentage fell to 49% at the time of the survey
- Almost 30% of the respondents reported suffering from fatigue or exhaustion, which was qualified as rather or very burdensome by 82% of them
- While 87% of respondents indicated that they did not have anxiety or depression problems before diagnosis, the percentage fell to 40.5% at the time of the survey
- The fear of melanoma recurrence and the fear of death were common aspects of anxiety
- Living with a melanoma imposed limitations on individuals' daily lives, due to aspects such as exhaustion or sun avoidance
- The onset of melanoma was associated with a 27% percentage point increase in problems carrying out usual activities, which were predominantly considered as slight problems (rather than moderate, severe, or extreme)

4.2.6 Other unmet health needs

Interview respondents highlighted a need for maintaining hope through research and further treatment options. Patients wished for more large-scale clinical studies (including at EU level). Patients reported the importance for them not to feel that the end of the field of treatment possibilities was reached. Maintaining hope for a cure was a decisive factor in their day-to-day fight against the disease.

4.3 Unmet healthcare needs

4.3.1 Effectiveness of treatment

According to a qualitative study carried out recently in the Netherlands, melanoma patients face difficulties with cancer symptoms, treatment side effects, and how these symptoms affect their physical and emotional well-being both during and after treatment.⁹⁶

Despite the remarkable therapeutic progress, current therapies are not a cure for many patients with metastatic melanoma. This can be attributed to the genetic heterogeneity of melanoma: the ~50% of patients whose tumours lack a BRAF mutation cannot benefit from targeted therapy, and patients with rare melanoma subtypes (e.g. uveal, acral, mucosal) face major therapeutic challenges. Indeed, their melanoma locations not only make them more difficult to diagnose, but also make them more difficult to resect. Furthermore, there is a paucity of clinical trials, there are no targeted treatment options for rare types of melanoma, and immunotherapies demonstrate reduced efficacy in these patient populations compared to those with cutaneous melanoma.^{37, 97, 98} The treatment of subungual melanoma, for instance, remains controversial: for a long time, treatment relied on digital amputation, but more recently less aggressive surgery options have been studied, albeit data quality remains weak and randomised controlled trials insufficient.³⁶



Moreover, many melanoma patients are inherently resistant to immune-based therapies (primary resistance), or become resistant following an initial response (acquired resistance).^{97, 98} As described in the “treatment” section above, immune checkpoint inhibitors frequently lead to adverse effects resembling autoimmune diseases, with varying degrees of toxicity. This can result in discontinuation of treatment, and in some cases, be life-threatening.

Two experts in melanoma (one dermatologist and one oncologist) were asked to rate the overall effectiveness of treatment for melanoma. They considered overall treatment to be moderately effective for advanced melanoma and very effective for early stage melanoma. They highlighted an important treatment effectiveness gap in cases of metastatic ocular melanoma.

During the interviews, some participants expressed doubts about the effectiveness of treatments, and therefore, about their usefulness. They found it particularly difficult to understand the usefulness of treatment aiming to prevent recurrences.

"Now we are in the phase where we are actually trying to frame the side effects of immunotherapy, but for me every time I go to the oncology day center, it's still something like what am I doing here? Because it's not proven, not even in the literature, that the therapy they are giving me now is not standard, but what is standard of course... So I'm always still in doubt about what they can do... I look at it like this, if you don't have a headache, do you take headache pills? And if there are no tumors, what does that immunotherapy actually do in my body?" (4N1) [17]

Treatment research gaps

Studies show that the majority of fatalities resulting from melanoma happen in individuals who were first diagnosed with early stage melanoma and subsequently had a recurrence. Recurring melanoma is often not detected until it has already spread or metastasized. Thus, **further research is needed to accurately predict which patients would benefit from more aggressive treatment** despite their low stage of melanoma. Recently, for instance, a method based on artificial intelligence was developed which

identified certain key characteristics that predicted a higher risk of relapse, but this method still necessitates validation and evaluation for routine use.⁶⁰ Also, research is needed to **identify sufficiently accurate biomarkers of response to immune therapy**.⁷⁹

Secondary Prevention and research gaps

The literature shows that early detection of skin cancer greatly reduces both short- and long-term morbidity and mortality.

Further research is needed concerning the effectiveness and best practices of counselling adults about self-skin examination.⁹⁹ Studies are also lacking concerning screening strategies to detect hard-to-diagnose cancerous lesions such as nodular melanoma.³¹ Moreover, although some studies have explored the option of malignant melanoma screening in the general population, there is currently insufficient evidence to either support or refute this approach.¹⁰⁰

The need for more early detection campaigns was expressed by interview participants. Suggestions included the organisation of “melanoma days”, where people could go directly to a doctor for screening. The idea of mobilising dermatology students to increase the accessibility of early detection was also put forward.

"I don't know if it already exists, a bit like the campaigns where you can go directly to the doctor, where they have a melanoma day. That's a day for everyone, we inspect everyone's skin. So maybe that? [...] Putting dermatology students, asking them too. Under the supervision of a professor, or whatever. [...] To do... yes, a national screening." (7F1) [18]

"Prevention. A campaign around that. Ensuring that there can be good identification on time. Early detection." (11N2) [19]

Others expressed the need for innovation in terms of techniques or devices capable of better detecting early melanoma.



"But I think that if something can still happen in the medical world, then I think that early detection is actually important. Because I'm already going to the dermatologist every year now and yet we missed it. So, I wonder if there are no other possibilities or methods or devices that can detect it better." (11N2) [20]

4.3.2 Burden of treatment

4.3.2.1 Description of treatment use and satisfaction

Surgery and immunotherapy were the most frequently used treatments in survey participants.

Overall, slightly less than 50% of respondents reported that they were receiving or had received treatment for melanoma. This figure differed a lot depending on melanoma stage: 28.6% of those with localised disease at diagnosis reported having had treatment compared with 68.8% of those with more advanced disease at diagnosis. The treatments most frequently reported by the respondents included surgical removal of melanoma (82.4%), immunotherapy (76.5%) and surgical removal of lymph nodes (47.1%; Table 14). Respondents diagnosed with intermediate or advanced melanoma often underwent various types of treatments.

Table 14 – Distribution of respondents per type of treatment received and melanoma stage (n=17)¹

Treatments	Early stage (0-II)	Intermediate (III) + advanced (IV)	Total
	n=6 n (%)	n=11 n (%)	n (%)
Surgical removal of melanoma	6 (100.0)	8 (72.7)	14 (82.4)
Immunotherapy	4 (66.7)	9 (81.8)	13 (76.5)
Surgical removal of lymph nodes	2 (33.3)	6 (54.5)	8 (47.1)
Physiotherapy	1 (16.7)	3 (27.3)	4 (23.5)
Radiotherapy	0	3 (27.3)	3 (17.6)
Prescription drug	0	3 (27.3)	3 (17.6)
Targeted therapy	0	1 (9.1)	1 (5.9)
Other²	0	1 (9.1)	1 (5.9)

¹20 respondents did not indicate any treatment received for melanoma ; ² Other = participation in clinical trial



The unexpectedly low proportion of individuals reporting having received treatment for their disease is likely an unreliable figure. In fact, during interviews with six individuals who had initially reported not receiving any treatment, four of them disclosed that they had undergone a (brief) surgical intervention to remove the melanoma. The other two also mentioned receiving immunotherapy.

Patients with more than one melanoma received multiple lines of therapy such as chemotherapy, surgery, radiation therapy, and immunotherapy.

"I still have chemo, chemo, I don't know. Yeah, I don't know all that well. So wait, they did surgery first, then they removed the lymph node, then removed a piece of lung. If you tell it all like that, then there's still radiotherapy in between, then a piece of lung removed, then immunotherapy and now targeted therapy. So I think I've had everything that's currently on the market." (3N1) [21]

Patients' satisfaction with treatment

For all treatments, the large majority of participants expressed being very satisfied or satisfied with the treatment they received. However, when it came to radiotherapy, this result could be nuanced: two out of three participants indicated that they were "Rather satisfied" and one was "Rather unsatisfied" (Table 15).

Table 15 – Distribution of respondents' satisfaction levels with melanoma treatment, by treatment type (n=17)¹

	Very satisfied n (%)	Rather satisfied n (%)	Rather unsatisfied n (%)	Very unsatisfied n (%)
Surgical removal of melanoma	12 (85.7)	2 (14.3)	0	0
Immunotherapy	6 (46.2)	6 (46.2)	0	1 (7.7)
Surgical removal of lymph nodes	4 (50.0)	4 (50.0)	0	0
Physiotherapy	4 (100.0)	0	0	0
Radiotherapy	0	2 (66.7)	1 (33.3)	0
Prescription drug	3 (100.0)	0	0	0
Targeted therapy	1 (100.0)	0	0	0

¹20 respondents did not indicate any treatment received for melanoma



From the interviews, it appeared that participants trusted their oncologist to make the appropriate treatment decision. Making sense of all the different treatment possibilities and balancing risks and benefits was very difficult for patients, hence they trusted their oncologist to make the decision.

"That was determined by an oncologist, I had to fully trust the oncologist on that. Because there are of course many different products. There are also, because you prefer to look it up, like... With me it was [name of treatment] that I received. But there are also, I see that sometimes they combine with two different medications. So yeah, that's purely trusting a doctor. Because with the type of cancer I have, she found that to be the best treatment." (12N1) [22]

Alternative medicines were also used to address psychological effects of the disease.

Alongside conventional treatments, some patients also turned to alternative medicines such as osteopathy and acupuncture to address the psychological and stress-related consequences of the disease.

"Osteopathy and acupuncture, when you talk about dry needling and acupuncture, mainly also stress-related complaints, can be treated with those. Ultimately, you have a lot... You are constantly under stress and you start to get complaints. So those are treated... I also go to an osteopath and he cracks everything out well. That helps, I have found. What I have come to know a little more lately is just care massages and such." (3N1) [23]

Despite the high satisfaction with treatment, 41% of respondents who declared having had treatment reported that it was rather or very burdensome.

Six participants (35.3%) under treatment indicated that the treatment received was somewhat burdensome, whereas four (23.5%) reported it not to be burdensome at all (Table 16).

Table 16 – Distribution of respondents' experienced burden of treatment for melanoma (n=17)¹

Symptoms	Total n (%)
Very burdensome	1 (5.9)
Rather burdensome	6 (35.3)
Somewhat burdensome	6 (35.3)
Not burdensome at all	4 (23.5)

¹20 respondents did not indicate any treatment received for melanoma

Different reasons were provided by the seven respondents that described their treatment as burdensome. The most common reason was the side-effects, which was reported by six of the seven participants. Furthermore, four respondents indicated that the burden was due to the treatment compelling them to consistently contend with their illness. Additional reasons for burdensome treatments for melanoma are listed in Table 17.

Table 17 – Distribution of reasons for very or rather burdensome melanoma treatment (n=7)

Symptoms	Total n (%)
Side-effects	6 (85.7)
It forces me to constantly deal with my illness/treatment	4 (57.1)
I have been on the treatment(s) for a long time	2 (28.6)
It demands a very strict life discipline	1 (14.3)
Other ¹	1 (14.3)

¹ Other: having to avoid sun exposure



Time-consuming treatments

The treatments were described by the patients interviewed as being particularly time-consuming. Certain treatments actually required going to the hospital at regular intervals (e.g. every 3 weeks) and required spending the entire day at the hospital, with the travel time sometimes also being significant.

"No, from the moment I actually went to the oncologist, on the first day, he said, we're going to put you on sick leave, because you're going to have a lot on your mind, you're going to have a lot of appointments in the hospital, and emotionally, he said, it's better that you're on sick leave. So he actually put me on full-time sick leave right away, and that's still the case now." (11N2) [24]

"That's a day trip. I see it as a day trip. It's five, six hours, because it's in [city]. That's an hour and a half that you still lie on that bed." (8N1) [25]

The invisibility of treatment effectiveness generated stress

An important element related to the treatment that emerged from the patient interviews was the invisible nature of melanoma during treatment. This invisibility generated a feeling of uncertainty, and follow-up consultations were moments of anxiety in the phase of (possible) disease progression.

"It's only when it, when it gets worse and it spreads of course, then it can suddenly go fast of course. [...] So then you're really confronted with it, but the first time, when you think okay it's gone, it's gone, then you get over it pretty quickly, it's not like with another look, if it's in an organ or something, but that's inside you, that's a totally different feeling than when it's on your skin and they cut it away and it's gone." (3N1) [26]

"Next week I have to have a PET scan on Monday, and then the consultation on Wednesday. Those are very stressful moments. I feel that again. That last week, that it's building up again, the stress of that scan." (11N2) [27]

4.3.2.2 Description of side-effects of treatment

Fatigue was the most-reported side-effect, with more than half of respondents suffering from it.

Among the 17 survey respondents who reported to have received treatment for melanoma, 16 reported suffering from side-effects (94.1%). The most reported side-effects were fatigue or exhaustion (56.2%), skin problems (37.5%), constipation and/or diarrhoea (31.2%), and joint pain or arthritis (25.0%; Table 18).

**Table 18 – Distribution of side-effects experienced due to melanoma treatment, by level of burden (n=16)**

Side-effects	Side-effect frequency n (% of respondents reporting side-effects)	Reported burden n (% of respondents reporting the specific side effect)			
		Not burdensome at all	Slightly burdensome	Rather burdensome	Very burdensome
Fatigue or exhaustion	9 (56.2)	0	2 (22.2)	2 (22.2)	5 (55.6)
Skin problems	6 (37.5)	0	3 (50.0)	2 (33.3)	1 (16.7)
Constipation and/or diarrhoea	5 (31.2)	0	0	3 (60.0)	2 (40.0)
Joint pain or arthritis	4 (25.0)	0	0	1 (25.0)	3 (75.0)
Nausea and/or vomiting	3 (18.8)	0	0	2 (66.7)	1 (33.3)
Liver problems	2 (12.5)	0	0	0	2 (100.0)
Heart problems	2 (12.5)	0	0	1 (50.0)	1 (50.0)
Eye problems	2 (12.5)	0	1 (50.0)	0	1 (50.0)
Headache	1 (6.2)	0	0	0	1 (100.0)
Loss of appetite	1 (6.2)	0	0	0	1 (100.0)
Hypertension	1 (6.2)	0	1 (100.0)	0	0
Lung problems	1 (6.2)	0	0	0	1 (100.0)
Kidney problems	1 (6.2)	0	1 (100.0)	0	0
Allergic reactions	1 (6.2)	0	1 (100.0)	0	0
Other ¹	6 (37.5)	0	2 (33.3)	2 (33.3)	2 (33.3)

¹ Other: hyperthyroidism, lymphoedema, pain at injection site, pancreatitis, sleep problems, eye irritation, hypophyseal problem.



These side-effects were further contextualised by respondents during the interviews. In addition to fatigue and joint problems, nausea and inflammation of the hypophysis due to immunotherapy were mentioned.

"I say it, the most symptoms that I have the most trouble with are nausea, spontaneous nausea, painful joints. Yes, poor sleep, that's the biggest problem for me, and for everyone actually, poor sleep." (4N1) [28]

"They are very serious for me, the side effects. In the sense that I got hypophysitis from the immunotherapy. My pituitary gland no longer works, not in that area. I don't have diabetes, or not yet. And that's why I have to take cortisol. Every cortisol. And that is of course, yes, not easy to get the right dosage and so on. In other words: fatigue." (12N1) [29]

The side-effects mentioned by respondents included post-surgical complications, such as scars, inflammation, infection and healing, and even allergies from the use of bandages.

"That was after the radiation actually, then the doctor actually, yes there was actually an inflammation, there was an open wound under my armpit and it got infected and then again, I had the beginning of sepsis, so my lymph nodes and things were all inflamed." (3N1) [30]

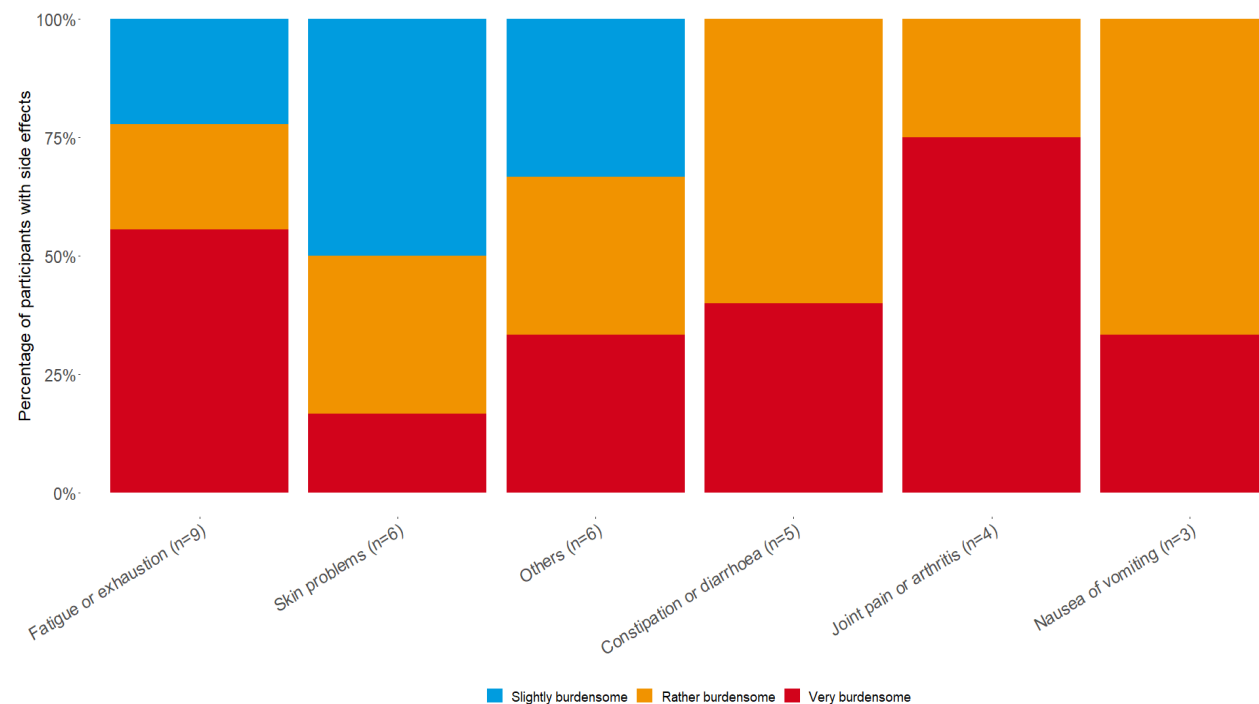
"Moments of high stress like when I realized I had to change my dressings and didn't have a solution. And then on my first outing, after a few days I thought 'well, I'll go for a little walk in town, it'll do me good', and when I came back, I had an allergy to the dressings here." (10F1) [31]

Other side-effects were also reported, such as sleep disorders for which they required medication support to maintain adequate sleep.

"It's not a sleeping pill, but a sleep aid. That's half a tablet. But I think it's psychological when I do that. But my average sleep pattern is six hours. That also has a bit to do with age. But I did notice what happened when I didn't take that pill, then I woke up at night and started hyperventilating actually. I'm not used to that, I'm a very good sleeper before that therapy." (4N1) [32]

4.3.2.3 Experienced burden of side-effects

Among the most frequently reported side-effects in the survey, fatigue or exhaustion was identified as the most burdensome by respondents: more than 78% of participants who experienced this side-effect expressed it was "rather" or "very" burdensome. Participants experiencing the most commonly reported side-effects usually reported them as very or rather burdensome (Figure 17). Conversely, participants never reported the burden of the side-effects to be "Not at all burdensome".

**Figure 17 – Burden level of the six most frequently reported side-effects of melanoma (n=17)¹**

¹The graph is ordered by symptom frequency (leftmost highest frequency). Only side-effects reported by at least three participants are displayed in the figure. Other reported side-effects were: liver problems (n=2), heart problems (n=2), eye problems (n=1) and hypertension (n=1).

**Surgery side-effects had long-term implications for patients.**

Surgery sometimes impacted mobility and the way respondents dressed, for example. More support to overcome these constraints would have been appreciated by respondents.

"And the fact that there was a tumor in the lymph node, that in itself and now the immunotherapy, that doesn't really affect my daily life that much. But the surgery does. That also has a huge impact on my mobility. And yeah, I don't really feel well supported in that regard. I was bedridden when I came out of the hospital. Which I actually didn't expect." (11N2) [33]

"Yes, if you have to drill a hole, so to speak, you can't make it look nice on the surface. How do I experience that? At first, I actually... for a moment, I thought 'wow, what is this? Do I have to wear long pants all the time?' No, not really. I walk around with it exposed. Then I wear shorts once and then it's less noticeable. But you always see the deep one, because I have to say... Really. I can't wear tight pants anymore. I had to get rid of all my long pants. So... Surgically, he said: 'Look [name], you're going to have to learn to live with that. One leg will always be thicker than the other.'" (11N1) [34]

One participant described the aesthetic side-effects of a surgical intervention which caused a distress for which he/she sought psychological support.

"Because in my first surgery, it went out from under the big pit. My shark bite, as I call it. Then I... I went to the psychologist three times." (11N1) [35]

Treatments' side-effects limited patients in engaging in meaningful activities. Due to their weakened state, interviewed participants reported being sometimes, unable to engage in any physical activity.

"I also had no idea what to do with my time. I was just lying there, I could hardly do anything physically, but my mind wasn't still. And then I can assure you, everyone says, oh, you can watch Netflix series, so fun.

No, it's not fun. For starters, it gets boring after a while, just watching TV all the time [...] So yeah, it was really difficult to find something, to find a meaningful activity." (11N2) [36]

Fear of side-effects from certain treatments pushed patients to refuse treatment.

During interviews, there was talk of refusing a PET scan for fear of radioactive effects on other organs. Other participants refused pain treatments because they wished to limit their consumption of drugs and felt they could handle the pain.

"I should also be back under the PET scan by now. [...] Why did I say 'no'? I feel my own body and I'm still recovering. And that PET scan, I don't have to tell you, that's two hours of a lot of radioactive stuff. Somewhere that may not be good for my other organs, or I don't know what, especially for those kidneys. Because where does it accumulate? In the kidneys. So I just refused it, because I felt like I couldn't handle it." (11N1) [37]

"[Did you have to undergo treatment beyond the surgery?] No. [And did you take medication after the surgery?] No. [Maybe painkillers?] Ah yes, it was written on the sheet so I took a little bit in the first few days but very little because I try to avoid it." (10F1) [38]



4.3.3 Quality of care

4.3.3.1 Experience with the organisation of care

Medical specialists, dermatologists in particular and general practitioners, were the most consulted healthcare professionals.

Despite a wide variety of consulted healthcare professionals, specialists and general practitioners were seen by almost all respondents (97.3% and 70.3%, respectively). As expected, individuals with intermediate or advanced stages of melanoma cancer consulted more healthcare professionals than individuals with an early stage cancer at diagnosis (Table 19).

Table 19 – Distribution of melanoma healthcare utilisation by stage of cancer (n=37)

	Early stage (0- II) (n=21) n (%)	Intermediate (III) & Advanced (IV) stages (n=16) n (%)	Total n (%)
Specialist ¹	21 (100.0)	15 (93.8)	36 (97.3)
General practitioner	14 (66.7)	12 (75.0)	26 (70.3)
Coordinating nurse for oncology care	3 (14.3)	10 (62.5)	13 (35.1)
Nurse consulting in hospital	2 (9.5)	8 (50.0)	10 (27.0)
Psychologist	1 (4.8)	8 (50.0)	9 (24.3)
Physiotherapist	2 (9.5)	6 (37.5)	8 (21.6)
Home nurse	1 (4.8)	6 (37.5)	7 (18.9)
Radiotherapy technician	2 (9.5)	3 (18.8)	5 (13.5)
Dietitian	1 (4.8)	4 (25.0)	5 (13.5)
Social worker	1 (4.8)	3 (18.8)	4 (10.8)
Emergency services	0	3 (18.8)	3 (8.1)
Speech therapist	1 (4.8)	0	1 (2.7)
Other ²	1 (4.8)	0	1 (2.7)

¹ See Table 20 for information on medical specialists. ² Other: geneticist



Among the 36 participants who reported having consulted a medical specialist, the majority consulted a dermatologist (91.9%), closely followed by a surgeon (70.3%) and an oncologist (67.6%). Finally, approximately one third of survey respondents had consulted a radiation oncologist (Table 20).

Table 20 – Frequency, within the whole sample, of consulted medical specialists (n=35)

Specialist	n (%)
Dermatologist	34 (91.9)
Surgeon	26 (70.3)
Oncologist	25 (67.6)
Radiation oncologist	10 (27.0)
Other ¹	3 (8.6)

¹ Other: gynaecologist, gastroenterologist, ophthalmologist, endocrinologist, geneticist

Respondents generally expressed high levels of satisfaction with the various healthcare providers they consulted (Table 21). This observation is particularly true for the services provided by oncologists, for which 23 individuals (92.0%) reported that they were very satisfied.

**Table 21 – Respondents' level of satisfaction by type of healthcare provider (n=37)**

	Very satisfied	Rather satisfied	Rather unsatisfied	Very unsatisfied
	n (%)	n (%)	n (%)	n (%)
Specialist	28 (80.0)	6 (17.1)	1 (2.9)	0
Dermatologist	24 (72.7)	7 (21.2)	2 (6.1)	0
Surgeon	16 (61.5)	9 (34.6)	0	1 (3.8)
Oncologist	23 (92.0)	2 (8.0)	0	0
Radiation oncologist	8 (80.0)	2 (20.0)	0	0
Other	2 (50.0)	2 (50.0)	0	0
General practitioner	20 (76.9)	6 (23.1)	0	0
Coordinating nurse for oncology care	10 (76.9)	2 (15.4)	1 (7.7)	0
Nurse on consultation in hospital	8 (80.0)	2 (20.0)	0	0
Psychologist	7 (77.8)	2 (22.2)	0	0
Physiotherapist	7 (87.5)	1 (12.5)	0	0
Home nurse	5 (71.4)	2 (28.6)	0	0
Radiotherapeutic technician	5 (100.0)	0	0	0
Dietitian	2 (40.0)	2 (40.0)	1 (20.0)	0
Social worker	4 (100.0)	0	0	0
Emergency services	3 (100.0)	0	0	0
Speech therapist	1 (100.0)	0	0	0
Other¹	2 (40.0)	2 (40.0)	1 (20.0)	0

¹ Five participants entered "Other". Based on the descriptions provided by respondents, three answers were recoded and two were kept as "Other". However, such recoding could not be performed for the level of satisfaction.

Expressed need for a better multidisciplinary approach

During the interviews, participants described the challenges associated with having to consult several specialists (e.g. dermatologist, ophthalmologist, gynaecologist). This took up much of their time and complicated their patient journeys.

"And it does take some time, I call it every two weeks, on Thursday for a consultation and on Friday to get a baxter. Yeah, that takes time. And eventually you have something like, yeah. Because then you have to go to the dermatologist every few months, I think three months. And then

to the eye doctor, because a melanoma can also be in that eye. A dermatologist can't see that. And then you also have to go to the gynecologist, because you'll also have melanomas there. And so you keep busy with a lot of tests." (11N2) [39]

The multidisciplinary and complex nature of care was sometimes accompanied by a lack of communication between specialists and generated a feeling of frustration by the patient, who had the impression of being continually transported from one point to another.



"And yeah, I don't really feel well supported in that regard. It starts with the story that you actually need an oncologist because you have cancer. But he doesn't operate. He sends you to the surgeon who is specialized. He just sends you to surgery. And then in surgery, the story begins of which doctor will operate on you. I was first with one surgeon, but he had something like, I'm actually not specialized in that area. So then you end up with another surgeon. I often used a metaphor of them playing a relay race with me and I'm the stick. I was already with a surgeon who passed me on to the oncologist. The oncologist did his job. He gives me back to the surgeon. And I never really felt like there was communication there." (11N2) [40]

On the contrary, some patients shared the experiences of dermatology and oncology departments that were seamlessly integrated, so that it was difficult for them to discern which department they were in. Participants appreciated this holistic approach.

"The waiting rooms are next to each other so... someone who's not paying attention feels like they're at the dermatologist's office. Yeah, and it also allows for a global treatment, you don't have to worry about where you're going, it was taken care of at the hospital level, and I imagine the scheduling, all of that was done automatically." (7F1) [41]

Sub-optimal organisation of follow-up

Follow-up represented an important part of patients' experience with the organisation of care. Some interviewees expressed frustration with certain aspects of follow-up that were not considered optimal. Interviewed participants disliked having to chase results because they were important for them. For example, having to call the hospital although the hospital was supposed to call back, or the lack of proactivity of healthcare professionals when it came to administrative aspects (e.g. medical certificates).

"So I kept my phone always near me while teaching, telling myself 'well, she'll call me', I'm telling you it was on Tuesday. End of the week, still no news. On Monday, since I still hadn't heard anything, I called [name of the hospital], and then they told me 'oh but the secretary was on

vacation, she's coming back tomorrow'." (10F1) [42]

A lack of care continuity was also reported by some. Patients expected healthcare professionals to meet their commitments and ensure continuity of care via a fellow healthcare professional when they were unable to do so themselves.

"To remove the stitches, he sent me to my general practitioner about ten days later, I went to my general practitioner who removed the stitches, and who was supposed to receive the results... well, according to what we had calculated: a few days later. And so the general practitioner, who is overwhelmed, told me, 'you send me a text message on Friday at 10am and I'll answer you right away'. [...] never got a response from my general practitioner." (10F1) [43]

In addition to their disease, patients also had to cope with a heavy administrative burden.

The administrative burden associated with the organisation of care was highlighted during interviews. This encompassed, for instance, the numerous controls required by the doctor of the sickness fund, even after the diagnosis had been officially established. Additionally, there was mention of the substantial paperwork that needed completion, despite the potential for information exchange among the various stakeholders involved. Respondents expressed the sentiment that they shouldn't always be the intermediary in all these procedures.

"More integrated care, those control doctors need to be there and there needs to be some control and such, but in the case of cancer, if you go to an oncologist who says you have cancer and that you have to stay home for a certain time or for a longer time, what's the point of going to a control doctor again and having all the problems again and all that, that you have to fill out a paper every month to say I'm still sick and all that. That can be done in a different way and doesn't necessarily have to go through the patient in that way, I think that's also important, that you can say okay if a doctor writes you sick, that it is simply passed on to the health insurance without having to fill out a paper again, bring it



to the hospital or that you, and then those dates have to match again and I know what else, how many papers I had to submit again because there was a difference, that one was from Friday and then one was from Monday and that's not allowed because it has to run from Saturday and I know, little things." (3N1) [44]

Interviewed participants also referred to a diary that they needed to keep to document symptoms. The resulting administrative burden on patients sometimes negatively impacted the quality of the recorded data because they did not see the relevance of keeping such a diary.

"But I don't find that annoying, but I think sometimes the process, the assistants come to me with questions, while I enter a diary every day via the Nexus app health, so I have to enter a diary every day, where I report the symptoms, and there is too much time between that. [...] Both psychologically and symptomatically. For our patients, they have a diary, where I have to say, nausea, fatigue, psychological stress, temperature, I just put something in there, because I'm not going to take my temperature every time, but I do that daily." (4N1) [45]

Interviewees wished to have a more supportive healthcare system and professionals.

During interviews, a lack of humanity from healthcare professionals was sometimes noted. This was attributed to doctors' lack of time and to a certain dehumanisation of hospitals.

"Here I just told him that I still had pain... Every time I ate, I had pain, just behind the scar, and then he cut me. And he said to me, 'no'." (10F1) [46]

Situations where respondents did not feel taken seriously – especially by primary care professionals – were also reported.

"Mainly the feeling that you're not being listened to and that you're not being taken seriously. That was the main reason we just decided okay we're going to another general practitioner in the future." (3N1) [47]

One interviewee highlighted the need for better emotional sensitivity by consulting nurses. According to the participant, appropriate training in psychosocial support could reduce the need for a psychologist in the future.

"What I missed is the attention from nursing to the patient who is somewhat emotional. If they pay more attention to that, then they don't need psychologists. So that's important, more attention to the psychosocial aspect in the training and work of nurses. I think that means they also need better processes in the department, so that people can do that. It's usually not their personal attitude, but the fact that there is no space or no attention for it in the department itself." (11N2) [48]

It was also emphasised during the interviews that appropriate mental support was required and was expected to go beyond being friendly and kind. One interviewee wished that healthcare professionals would ask questions about his or her specific case, not merely questions of convenience.

"But if you say, listen, one or two people who come to say hello on a good day, but don't talk about oncology, but talk about the person themselves, because I always get the same question, how do you feel? Yes, what should I say? Then I say, yes, I feel good, but I don't feel good. Well, I don't think that's a stupid question, but if you have to hear it 20 times, no, there are other things where you would say, listen, I make it something psychological different." (4N1) [49]

The need for **better care coordination** was brought up, compelled by the lack of availability of general practitioners.

"I know that in terms of social follow-up, it doesn't work. Social workers are overwhelmed with all the situations, etcetera, but otherwise yes, it's true that ideally, a coordinator... that's it. I know it should be the general practitioner, but he no longer has the time. General practitioners, they are all [...] overwhelmed. They don't have time to play the role of a social worker who follows Mrs. X file well, who has to go there, who has to call there, who has to do that." (10F1) [50]



The need for freedom of choice as to where to receive treatment was also expressed. Being able to receive treatment in different settings would thus require better information exchange and shared clinical records across institutions and healthcare professionals.

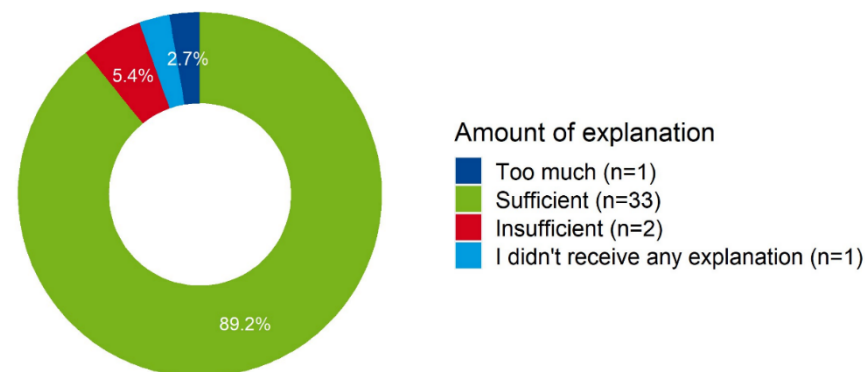
"I think the general problem that can be addressed is certainly the choice of hospital. Where you have surgery doesn't matter. But I chose [name university hospital] because we knew there were good specialists there. But that's where it stops. And then they shouldn't say, if something happens, it has to be open. That just has to be open, because then they say okay, you're a patient, but you can get your immunotherapy from XYZ. I don't know if there's profit being made on that, but that won't be the case. But for me, it would be different if they said 'that's not a problem', we'll contact everyone, because I see that in that app too. All the results I learn from the hospital or from my heart specialists, the cardiologist, that also comes in that app. So they can all look at that. So I think that would be one of the main points, not just for me, but for many patients, that there is a kind of freedom of choice."
(4N1) [51]

4.3.3.2 Quantity of information received

According to survey participants, healthcare professionals mostly provided sufficient explanations

Healthcare professionals were generally effective in providing sufficient explanations, as reported by 89.2% of the respondents and only 5.4% of respondents rated the amount of explanation received as insufficient (Figure 18).

Figure 18 – Amount of explanations obtained from healthcare providers (n=37)



The interviews highlighted a need for more information about the surgery and its impact on patients.

Among the information deemed insufficient by patients, information relating to surgical interventions was singled out (technique used, need for plastic surgery, healing, impact on patient mobility, post-surgery, etc.)

"And there, yes, I didn't know of course, what was going to happen, can it be stitched up like that? They didn't know that themselves yet. Does it need plastic surgery? Does a piece of skin need to be transplanted? Because it was a relatively large cancerous growth. So I had actually gone there with the intention of hearing something about it. [...] I didn't get an answer right away, but then eventually, I think I had to make a new appointment, a regular consultation. And then, yes, it was discussed a little more, what we had discussed earlier and he said: "Look, we'll see at the time of the operation what can and can't be done."
(12N1) [52]



"As for the post-operative period, so when I came on Thursday, I also had to go to the registration, where they explained to me... not enough things, and in any case... absolutely nothing about what was post-operative... and they didn't ask me any questions." [...] "The surgeon didn't tell me at all during the consultation, that after such an intervention I had no idea, there are so many weeks of recovery." [...] "No one asked me after the operation if I had someone near me to watch over me, to help me, to uh... and they didn't explain to me that I would need a nurse to change the dressings. They hadn't told me anything." (10F1) [53]

The quality of information was reported as being as important as the quantity of information received

Besides surgical interventions, other types of important information were perceived as insufficient particularly because patients received contradictory information. For example, practical information about the treatment, the research progress, or the life expectancy depending on the stage of the disease .

"Yes, about the treatment, about the progress in melanoma research, how to support melanoma research, if there are also things... Life expectancy in relation to the stage, because we see a lot of things, uh... that are contradictory too." (7F1) [54]

"So yes, it's a bit of searching for information. I have now understood from the doctor that they are working on an interactive brochure or something, about melanoma. But I don't know exactly how or where that fits together. Where you can specifically search for information. Okay, where is the treatment? What stage are you in? What treatment are you going to get?" (3N1) [55]

Various participants wished to proactively receive information instead of searching for it on their own.

Patients sometimes felt alone in their situation (especially when people lived alone) and appreciated receiving information directly from healthcare professionals rather than having to proactively request information. In the

absence of information from healthcare professionals, participants said they turned to the internet for additional information and to learn from experiences of other patients.

"I also do it by doing research on the internet like that. Because I don't get the information from him... He said "yes, you have to protect yourself" but that's it. Here, I have different associations, or on Youtube, there are also people who talk about melanoma, and who say "here, every three hours" they put on sunscreen; SPF 50. Things like that. Yes, but yes. Internet, a little bit of Youtube because there are experiences. Sharing experiences. But as for my training, well I go to Pubmed: I know where to look for relevant information. I don't go directly... well I don't go to Google, and I don't search like that. So I have no idea where it stands in relation to that, whether good information is being given or not. I don't pay attention." (7F1)[56]

Interviewees highlighted the importance of open communication channels with doctors.

In general, respondents appreciated the availability of communication with doctors for any questions. The suggestion of having a telephone number for inquiries was raised, and some respondents received such contact information, including that of an onco-coach, to address their questions.

"They always asked me, you know... "do you have any more questions?" But at the time we don't really have any questions. [...] It's true that they always asked me "do you have any more questions?", etcetera... but not if you have any questions, you can call a number or... No, he didn't have that. So it might be good to have something official available for... something like that." (7F1) [57]

"I was given a piece of paper. I also saw that lady. What they call an onco-coach. Who you could call if there was something. And I thought once, I'm getting a rash here, but it turned out to be nothing. And then I called and the lady told me, do this or do that or... Well, yeah. And then I never had anything else. I never had to call again." (8N1) [58]

**Sub-optimal communication methods were sometimes used to communicate the diagnosis to the patient.**

Given that the disease was frightening, the announcement of it by the medical profession was perceived as all the more important. During the interviews, participants highlighted sub-optimal situations where the doctor held a negative discourse, did not dare to announce the diagnosis (or to use the words “cancer” or “melanoma” explicitly) to the patient or even announced the diagnosis by mail or via an online portal, which left the patient alone in front of the announcement.

"But I had to be there within ten days to have the stitches removed. Okay. But who didn't call? That was my dermatologist. And I knew there was trouble. Because I knew her too well, we were so close. That she would tell me everything and now she didn't call. So okay, I went to her to have the stitches removed. "[Name], come on!" And I said straight to her: "No good news, I guess?" 'No,' she says, 'I didn't dare call you.'" (11N1) [59]

"What I reproach a little bit [...] is that she never used the word, you know. She said "well, that has to be removed, you have to make an appointment with the surgeon, you call the surgeon tomorrow." And she had put "spot on the abdomen," something like that. Uh... "colored spot" [...] Yes, maybe, to be more explicit because I could have continued to say to myself "well, it's not serious, I won't make an appointment right away." Maybe use the word, and explain it clearly." (10F1) [60]

"From that clinical biologist, you just get a letter, a thing like yes, it's melanoma and uh, then you have to go to the dermatologist, you have to wait a few more weeks, to the dermatologist to then see okay how will it be treated further." (3N1) [61]

The positive experiences reported were those where the doctor took the time to explain the diagnosis to the patient in a calm and transparent manner, and where patients had the opportunity to ask questions. Showing compassion was important to patients.

"Actually, I have to say that the doctor, the plastic surgeon, was very correct. [...] No, in a... Yes, a calm way of speaking. I could ask questions, he answered correctly." (11N1) [62]

"Really very good. So good that at the time I was so shocked that I told him... I left saying "oh well, thank you because I imagined it would be worse than that"! Whereas, in dermatology, it wouldn't have been worse than that after all." (7F1) [63]

Taking the time to discuss the disease with patients was an important satisfaction criterion.

The information received from healthcare professionals was particularly appreciated. Just like with the diagnosis, interviewed participants appreciated that doctors took the time to explain, and that they were available and open to questions, even when asked by family members.

"But I also have to say, my oncologist also provided the necessary information. Not only to me, but also to my wife, my children. I think my parents called him once. And he took the time every time to explain it, okay, that's it. Here we are now. These are the treatment options." (3N1) [64]

Conversely, a bad experience was described as a situation where the doctor did not take the time to answer the patient's questions.

"Yes. But with my GP, I really felt like I didn't have time there. But for nothing. Then I have to make two, three appointments, because he didn't have time for all my questions. So yeah, I'm definitely not going there anymore." (8N1) [65]

The international scientific literature reports of healthcare professionals tending to inform patients of ethnic minorities with more pigmented skins less about the risks of UV exposure and about the importance of self-examination. These inequities are further described in section 7.

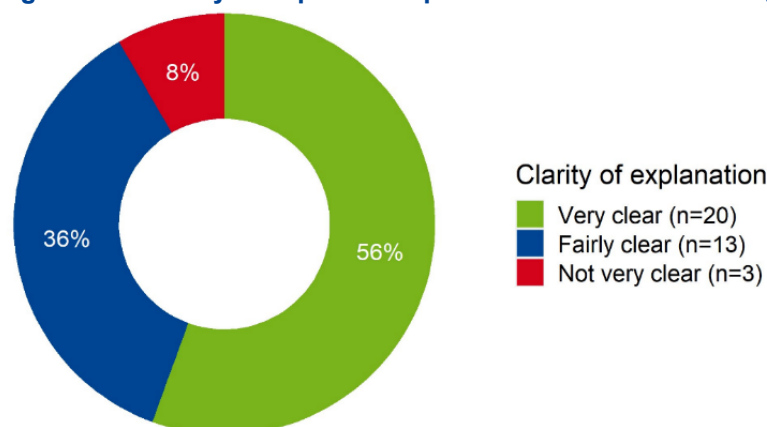


4.3.3.3 Clarity of information received

The majority of survey respondents perceived the provided explanation as clear.

Thirty-three of the 36 respondents (91.7%) who received explanations found it to be very or fairly clear, while 8.3% reported that it was not very clear. No one answered “not clear at all” (Figure 19).

Figure 19 – Clarity of explanation provided about melanoma (n=36)¹



¹ One participant indicated they did not receive any information

Interviewees expressed a need for clear and understandable information.

The testimonials below illustrate the difficulty for respondents to understand scientific statements. Participants in the interviews stressed the importance of a clear explanation from the doctor, which sometimes involved repeating important points and checking to ensure that the patient understood them correctly.

"And then he explained everything to me, in detail, and with the words...

uh, the scientific words, and luckily I had a piece of paper and a pen, all the words that I didn't understand at all what he was saying, at the same time he explained a little bit anyway, but there were things that I didn't understand, which allowed me to go and look on the internet and understand it well at my leisure." (10F1) [66]

"The right level of information, I actually don't find that. For example, the last time I was with him, we really went over everything step by step. Because, I know that, I tell my students that when they deliver bad news, you know that patients only hear half of it. Either they hear it wrong, or they don't remember it. But I always thought, well, that won't happen to me, because I'm trained for it, when it comes down to it. But that's not true, it happens to me too. So yeah, the last time I really went over everything with an oncologist, what did I understand well, did I not understand that well. And then he explains it again. I tell him that, but let me say it in my own words first. And then confirm or correct it." (11N2) [67]

Beyond the information provided by healthcare professionals, interviewees also reported that it was difficult to find information that was useful and pitched at the right level for them.

There were reports of information at two extremes: oversimplified information gathered from the internet which tended to be oversimplistic, and other information from scientific articles which proved difficult for “ordinary” patients to understand.

"If you look up information, you find two things. Either very simple information, really super simple, that everyone can understand, where things are presented so black and white that you're actually not getting anything out of it, because it's not really about you. Plus, you don't want to recognize yourself in it, because it usually concerns bad prognosis, good prognosis. So that's not good. Well, that's how it is, what's on the Kom op tegen Kanker website, I'm not getting anything out of it. But the other things you search for, the scientific articles, are actually so specific to oncologists, and I'm not an oncologist, so they're too complicated for



me and I don't understand enough of them. And even then, you still don't know if you fall into that research population or not. So no, I actually don't find the right information that can help me." (11N2) [68]

Respondents also seemed to require communication reflecting the right level of concern and being taken seriously by their healthcare professionals. They also appreciated messages that were balanced, so not underestimating the potential severity of disease but also not causing unnecessary anxiety.

"I just said, 'so, are you going to have an appointment with the dermatologist?' and he [other patient] said, 'yes, but the doctor told me it's not urgent anyway, and you don't die from melanoma anymore.' So that was also hard. Also hard to hear, well for me, for the patient... I don't know how things like that are possible." (7F1) [69]

"He [the doctor] told me, 'no, in principle there's no problem; it must be nothing at all, a little wart or something like that, but just to be safe we'll remove it.' That's it. And so he removed it. I didn't worry about it more than that." (7F1) [70]

Participants wished to have tailored communication that took their preferences into account. This was also perceived as building trust and leading to patient satisfaction.

"Actually, I have to say that the doctor, the plastic surgeon, was very correct. [...] Yes, a calm way of speaking. I could ask questions, he answered correctly. Meanwhile, he hasn't been calling me "madam" for a long time, because now it's: "[Name], come on over" "Come on, because yes, you're already a customer from 2019." I have a relationship of trust with him." (11N1) [71]

"And then he really didn't want to put me in that oncology program, but then he wanted to send me to my personal trainer or to a BOV coach. And then I had to plead so hard and say, I want to go to that rehabilitation program, because I feel like I need it." (11N2) [72]

Imbalance in the information available to French- and Dutch-speaking patients

During the interviews, a notable difference emerged in terms of information available to Dutch-speaking and French-speaking patients. Where "Melanoompunt", a proactive support group for patients with melanoma, was an important source of information and support in Flanders, there was no equivalent organisation for French-speakers. A general lack of reliable information in Belgium about melanoma was reported, resulting in the need to search websites from other countries (e.g. United States, Netherlands).

"In Flanders, there is the 'Melanoompunt', the first day I was at [name Flemish hospital], I was still in the hospital when the Melanoompunt called me, saying 'here we are now organizing...', it was two weeks later, 'we are organizing the annual meeting, with all patients who have had melanomas, and so you are also part of the melanoma family', you know." (7F1) [73]

"So, there you go. And in Belgium, there's not too much. We don't have too much information. I had to go to websites more, but again, Dutch etcetera. And I also looked at American websites like Mayo Clinic. Here, we don't have access to information that is verifiable." (7F1) [74]

The additional information searched by patients included treatment options, disease progression, and disease prognosis

Out of the 28 survey participants that sought additional information, the vast majority of them (75.0%) requested information on the different treatment options that were available for melanoma (Table 22). In addition, 12 respondents (42.9%) looked for information on clinical studies related to patients' treatment. Study participants also sought information on the evolution of their health status (60.7%) and more generally on their condition (57.1%).



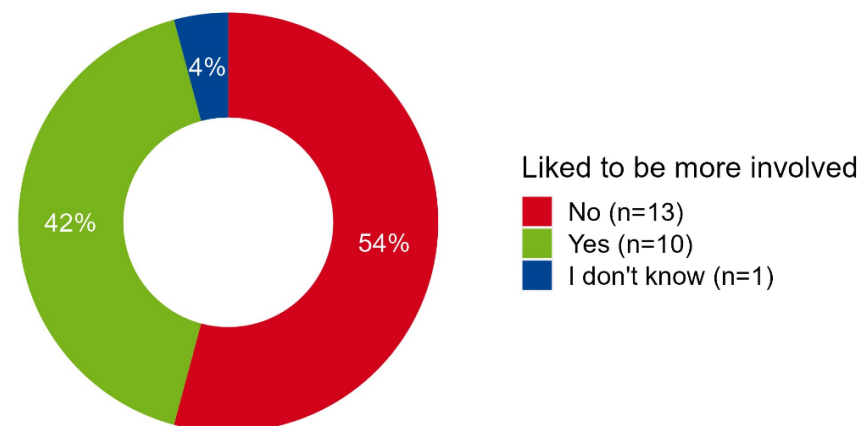
Table 22 – Type of additional information sought (n=28)

Additional explanation	n (%)
Treatment options	21 (75.0)
Evolution of state of health	17 (60.7)
Condition	16 (57.1)
Clinical studies related patient's treatment	12 (42.9)
Access to own data	8 (28.6)
Patient associations	8 (28.6)
Establishing the condition or diagnosis	7 (25.0)
Accompaniment, psychological support, coaching	6 (21.4)
Costs of treatment and own expenses (not reimbursed by health insurance)	4 (14.3)
Places where treatment is possible	4 (14.3)
Therapeutic education	4 (14.3)
Support available	2 (7.1)
The return home and possible arrangements (or alternative accommodation)	1 (3.6)

4.3.3.4 Involvement in treatment choice

One third of participants wished to be more involved in the treatment decisions

Around one third (35.1%) of respondents indicated that they did not wish to be more involved in the decision and a similar proportion indicated that it was not applicable to their situation. Nevertheless, ten participants (27.0%) wished to have been more involved in the decisions regarding their treatment.

Figure 20 – Involvement in choosing melanoma treatment (n=24)¹

¹13 participants indicated that this question was "Not applicable" to their situation.

Treatment options were sometimes perceived as limited and rigid by interviewees

The participants interviewed highlighted the difficulty of being more involved in decisions relating to their treatment. Indeed, they noted that treatments were relatively locked down and that there was little room for choice, even for doctors.

"Yes, of course, that is discussed to some extent. On the other hand, a doctor is also limited in the possibilities. I can only say, from the mutualities and such, there are only a limited number of possibilities to take. And if you meet those conditions, then you can take that therapy. And I mean, that treatment path is also fixed. A doctor doesn't have so much... He does have a number of choices and I can... But there aren't that many choices with melanoma, of course. To say, we're going to do something completely different now." (3N1) [75]



Sometimes patients preferred not to be too much involved in the decisions because they did not feel qualified to make such a choice. Asking the patient to choose amongst the options occasionally left the patient with the impression that the doctor was not knowledgeable on the subject, leading to lack of trust.

"And then the surgeon said to me at one of the consultations, yes, what would we do? Would we dare to remove that drain once? And then I thought, I'm not an experiment, either you know it and you remove it, or you don't. It's a statement, people should pay more attention to that. I got the feeling that I was allowed to decide for myself whether we were going to dare to do that or not. And I think that was a way of speaking from that person, but actually I didn't find that appropriate. That didn't really give me confidence, I have to say." (11N2) [76]

4.3.3.5 Diagnostic delay

Time between first symptoms and decision to consult

Patients with early stage cancer waited longer to consult a healthcare professional after symptom detection than patients with intermediate or advanced cancer.

Approximately 50% of survey respondents indicated that they consulted within the three months after their first symptoms. However, a clear difference in patterns could be noticed when looking at the stage of cancer. The majority of respondents with early stage melanoma (66.7%) indicated that they waited more than three months between the first symptoms and their decision to consult. This proportion was only 18.8% for the group of respondents with intermediate or advanced melanoma (Table 23).

Table 23 – Distribution of participants by stage of cancer and time between first symptoms and decision to consult (n=37)

	Early stage (0-II) n=21 n (%)	Intermediate (III) + advanced (IV) n=16 n (%)	Total n (%)
Time between first symptoms and decision to consult (aggregated)			**
Less than 3 months	6 (28.6)	13 (81.2)	19 (51.4)
More than 3 months	14 (66.7)	3 (18.8)	17 (45.9)
I don't know	1 (4.8)	0	3 (8.1)

* Fisher's exact test, NS=Not significant, * p-value <0.05, ** p-value <0.01, *** p-value <0.001



The decision to consult was driven by the emergence of other symptoms, advice from relatives, or awareness campaigns.

From the interviews it transpired that the decision to seek consultation was often influenced by the emergence or persistence of certain symptoms, or by the advice and experiences of others. Interviewees explained, for example, that an itching mole was a trigger for the decision to consult. The development of other symptoms such as swollen lymph nodes or the concurrence of atrial fibrillation were also cited. The decision to consult a doctor was sometimes also encouraged by family members, or stimulated by testimonials from people who had had melanoma, which made patients aware of the importance of having their skin checked by a doctor. Awareness campaigns also encouraged patients to consult.

"It's clear that the spot was really a textbook case, it looked very much like what you see on posters, and at the same time I thought 'no' well, there you go, so I really went into denial, and it's because... Well, a year ago this spot started to ooze, to itch very strongly, that... that's when I thought... then I showed it to my son, who said 'mom, that's not good', and I decided to go to the dermatologist at that time." (10F1) [77]

"Actually, my brother was the reason. A few years ago he had a melanoma and it was surgically removed and that was it. There was no treatment, no follow-up or anything like that. [...] Another reason was also because my sister-in-law died of a melanoma. That made the urgency even greater." (11N2) [78]

It appeared from the interviews that some respondents had not been aware of their individual risk of melanoma and did not take appropriate preventive measures.

"I didn't think about it. When I was 19, I had a complete check-up of all my beauty marks because I have a lot of beauty marks. So I had a complete check-up at the hospital at that time. But since then, I was followed by dermatologists at the time for beauty marks that I also had removed. But for no reason, unsightly beauty marks that I had removed, but I never felt the need to say 'here I have to regularly see my

dermatologist because I'm at risk'. I never had that notion of risk in mind." (7F1) [79]

Time between decision to consult and first consultation

Once the decision to consult a healthcare professional was taken, four in five saw one within a week.

Once the decision to consult was taken, 40.5% respondents indicated that they successfully had a consultation in less than a week, whereas almost 30% after more than a month (Table 24).

Table 24 – Distribution of participants by time between decision to consult and first consultation (n=37)

	n (%)
Less than 1 week	15 (40.5)
1 week to 1 month	8 (21.6)
1 to 3 months	4 (10.8)
More than 3 months	7 (18.9)
I don't know	3 (8.1)

Although the quantitative results showed a fairly rapid turnaround time for appointments, the individual interviews with respondents provided some nuances. For example, it was reported that an appointment had been exchanged with a relative in order to avoid having to wait six months. Another respondent benefited from a cancelled appointment from another patient, which allowed for an earlier consultation. Moreover, it was mentioned that appointments were cancelled because of the COVID pandemic.

"Now it's a battle to get an appointment. [...] So there you go, also a bit complicated and I had a great stroke of luck, which is that my husband had an appointment two days later for himself, with the dermatologist. While I hadn't thought of it, it was him who said 'oh I have an appointment in two days...' and we exchanged because my appointment was six months later." (7F1) [80]



"Before the lockdown, and so I had an appointment with the dermatologist just before the lockdown, early 2020. I don't even remember if she had told me to go to the surgeon or not. Or I had another appointment with her, but since all appointments were cancelled. So, it fell through." (10F1) [81]

Respondents also indicated that an appointment or investigation was conducted earlier than scheduled after insisting on healthcare professionals.

"But my wife was of course angry with those dermatologists, because they didn't see that it was a malignant tumor. But then I say, is my wife in, how she did it, I don't know, then in less than a month I was able to do all the tests. Because it's not so easy in the hospital to arrange a PET scan, even an MRI, there are waiting times. But very coincidentally, she also came to a post where people cancel, then you are called and she makes an appointment." (4N1) [82]

Time between first consultation and diagnosis

More than 90% of diagnoses occurred within a timeframe of two months from the first appointment.

Almost half of the participants were diagnosed less than two weeks after consultation (48.6%), and 43.2% between two weeks and two months. Some cases (8.1%) took longer than two months (Table 25).

Table 25 – Distribution of participants by time between first consultation and melanoma diagnosis (n=37)

	n (%)
Less than 2 weeks	18 (48.6)
2 weeks to 2 months	16 (43.2)
2 months to 1 year	2 (5.4)
More than 1 year	1 (2.7)

A diagnostic challenge identified through the international literature concerns the **accuracy of diagnosing rare types of melanoma**.¹⁰¹ This includes atypical morphologies (e.g. amelanotic melanoma) and concealed

locations (e.g. mucosal and uveal melanoma), significantly impacting early detection and leading to advanced disease at diagnosis, and consequently, poor outcomes. Rare melanoma variants can mimic inflammatory conditions and other less severe skin neoplasms, leading to diagnostic challenges even for the most experienced dermatologists.¹⁰²

The **stage of cancer at the time of diagnosis** can be an indirect indicator of diagnostic delay through a combination of factors such as patient awareness and behaviour and access to healthcare. It can be useful in comparisons across countries and across cancer types to identify the reasons behind particularly advanced stages at diagnosis. The Belgian Cancer Registry shows the following distribution of melanoma stage at diagnosis, by sex, for the year 2020 (Table 26).¹⁵

Table 26 – Melanoma stage distribution, by diagnosis and sex for the year 2020

	Stage I	Stage II	Stage III	Stage IV	Stage X	Stage NA	Total
Males	1,193 (72.0)	248 (15.0)	116 (7.0)	39 (2.4)	13 (0.8)	47 (2.8)	1,656 (100.0)
Females	1,554 (79.2)	226 (11.5)	112 (5.7)	28 (1.4)	12 (0.6)	30 (1.5)	1,962 (100)

Staging according to the TNM 8th edition. Combined TNM stage: compilation of pathological (pTNM) and clinical (cTNM) stage. pTNM prevails over cTNM, except when cTNM stage is IV. Stage X: diagnoses with an unknown stage. Stage NA: diagnoses with a histological diagnosis where no stage can be evaluated (Not Applicable).

The scientific literature consistently describes patients with more pigmented skins presenting with more advanced stages at diagnosis. These inequalities have been further described in Section 0.



In order to overcome the reduced accessibility of dermatological consultations and to reduce referrals for benign lesions, a promising strategy that's gaining attention involves training of GPs in the screening of melanoma, which has shown to increase their effectiveness of triaging skin lesions.^{103, 104, 105}

Difficulties to identify melanoma at first sight

Although a majority of respondents benefitted from a quick diagnosis, for 8% this took multiple months. Some interviewed participants testified that it was not always easy to identify the melanoma. In fact, in various cases melanomas were mistaken for benign pathologies (e.g. wart, hernia, regular mole), so a correct diagnosis was missed, despite annual check-ups. In one case, the primary lesion was never detected despite annual checks and the respondent only got diagnosed when the cancer had spread. These diagnostic delays can have serious consequences for the patients, giving the cancer time to grow and spread, and delaying the initiation of treatment.

"No, it wasn't diagnosed through annual check-ups, because nothing was ever found. It's actually because I had a symptom, because I had the swollen lymph node. And it turned out to be the result of a melanoma that had once been there." [...] "So that means that with that metastasis in the lymph node, which was in the lymph node, I was actually already in stage 3, while a melanoma had never been seen. So all those years no melanoma was found. We looked for it, given my brother's story, but no melanoma was found." (11N2) [83]

"I had a tumor on my left elbow and it was checked by dermatologists. And in September 2022, I went to the dermatologist and it was actually a benign, harmless tumor. And after Covid, I thought, I'm going to have it removed. Then I went to the plastic surgeon, but he said he was going to take a biopsy anyway. And it turned out not to be benign and a malignant melanoma. So that was of course scary, because I go to the dermatologist annually. So, in my opinion, you can't call it a medical mistake, but a medical misinterpretation, which of course has serious consequences for me." (4N1) [84]

The need for more (widespread) effective tools/technologies to detect melanoma was also highlighted by interviewees.

"But I think that if something can still happen in the medical world, then I think that early detection is actually important. [...] Because I want to say now, when I see how a dermatologist examines me, yes, I understand that they can miss that." (11N2) [85]

The fact that the initial diagnosis was missed created distrust by the patient for subsequent diagnoses. The fear of missing something important persisted.

"I had a lot of appointments with the dermatologist afterwards, I had lots of beauty marks that he said 'no, it's not at risk', but since I had that experience at the beginning that said 'it's not at risk'... I didn't have much confidence anymore, so in the end we still did it, so I think in total I had 8 or 9 beauty marks removed." (7F1) [86]

Uncertainty on the diagnosis as source of stress for the patient

The time in between the initial suspicion of melanoma and the exact diagnosis was reported as a very stressful period for interviewees, particularly when they had to wait for multiple weeks before getting surgery or scans. Not knowing and having to live with uncertainty about the diagnosis also had a psychological impact on patients. It was difficult for them to accept this uncertainty, and they expressed frustration with medical technologies that they felt should be more advanced and more precise.

"Yes, we have to move on, so it's actually a combination of circumstances and even during the examination at [name of the hospital], they didn't even know if it was a primary melanoma or a metastasis, so for me it's really a difficult case, because I'm of the belief that technology should be further along, so actually even in the final report there is still doubt in this situation, but I think that can happen in the medical world, but my brain doesn't understand it." (4N1) [87]



"I don't think they've ever seen anything on my scans. I think they do my scans to see if there are any metastases somewhere. They've never seen anything on my scans. And even now on my previous MRI, they didn't see anything either. [...] So my melanoma was 2.4 mm or something like that. That was already stage 3B. And then they say, yes, but I could be wrong now. In a PET scan or an MRI, they can see something from 5 mm. And then I think, if they just see it, then they're good. Because that's where I have fear." (8N1) [88]

Time between diagnosis and first treatment

A large majority began initial treatment shortly after diagnosis

Close to 90% of respondents received their first treatment within one month after diagnosis of melanoma. About a third of respondents (27%) received a first treatment in less than one week after diagnosis. For four respondents (10.8%), the treatment was received after more than one month (Table 27).

Table 27 – Distribution of participants by time between melanoma diagnosis and first treatment (n=37)

	n (%)
Less than 1 week	10 (27.0)
1 to 2 weeks	11 (29.7)
2 weeks to 1 month	12 (32.4)
More than 1 month	4 (10.8)
I don't know	0

However, patients sometimes expressed frustration that the melanoma was not directly removed. Additional examinations (e.g. biopsies) sometimes had to be carried out after diagnosis, to determine the best treatment.

"And then, what I found more annoying, was that a biopsy was still taken. And not immediately removed, because the doctor said it's better to first take a biopsy, because then you can also see what kind of cancer it is and what treatment would be best. I followed that too, then the biopsy was taken. But then between the biopsy, the biopsy was a melanoma of a certain type, an aggressive type. And then the intention

was to surgically remove it." (12N1) [89]

4.3.4 Accessibility of care

4.3.4.1 Treatment availability

Two experts in melanoma (one dermatologist and one oncologist) were asked to rate the availability of melanoma treatment in Belgium. They considered that there are some availability problems, that is that "treatment is available for a majority of the population but too expensive for some, or that there are some stock problems".

Inequalities across EU countries in terms of access to metastatic melanoma treatment are described in Section 0 .

4.3.4.2 Foregone care

The literature shows that while early recognition of disease is presently the main factor for a more favourable prognosis, there are various obstacles to timely diagnosis.⁵⁶ The Belgian Foundation against Cancer stated in 2019 that according to a survey, around half the individuals who had noticed the first symptoms of melanoma waited between 3 and 6 months for a doctor's appointment.¹⁰⁶ Today, waiting times for dermatological consultations in Belgium have possibly increased even further, particularly in rural areas (personal communication by expert). Additionally, while the baseline price for a routine dermatological consultation with a conventioned specialist is not particularly high (33€-38€ of out-of-pocket expenses in 2022), the vast majority of dermatologists claim a higher price.¹⁰⁷ Indeed, in 2018, data from the Inter-Mutual Agency showed that dermatologists were the specialty with the smallest proportion of conventioned practitioners (11%).¹⁰⁸

The vast majority of survey respondents (n=35) indicated that they received care when needed. The two respondents who did not receive care when needed highlighted three main reasons: transportation problems, very long waiting times, and lack of information.



A lack of dermatologists limiting access to care.

According to some of the interviewed participants, the lack of dermatologists was an important barrier to timely access to care, causing excessively long waiting times and complicating their care journeys.

"It was just almost impossible to get into a practice nearby. I think that's mainly an issue on all health levels. That's not just dermatologists. That's a big issue. Accessibility to a dermatologist. But all the good dermatologists in the area have a patient stop." (7N1) [90]

Obtaining an appointment at a convenient time slot was also cited by participants as a barrier to care (e.g. a teacher who was unable to make an appointment outside of teaching hours and who had difficulty finding a slot during the holidays). This could lead to consultations being postponed, which could be detrimental.

"When we call for an appointment, we are given dates, but there are days when you have classes, so you say 'well no, I'm not going to be absent'. First of all, because it's not covered, we're not covered for medical appointments, we can't be absent for medical appointments. And so we give up, we postpone all the time, we give up because we know that it's not going to fit in the schedule." (10F1) [91]

Access to care was sometimes hindered by transportation issues.

During the individual interviews, some reported that relying on other people was considered essential in providing transport solutions in certain circumstances.

"So I live alone. So I've already had to manage in an emergency, luckily the local grocer told me 'there are services to take you to the hospital'. On the other hand, for the return, I had still found a friend, I had called a friend, without knowing exactly the time of the return and so I had someone just to take me back home. So in the end, I managed all by myself; I found someone in the neighborhood - thank you Facebook - who came to get me." (10F1) [92]

Participants reported barriers in terms of geographical access to care. Some interviewed participants would have liked to choose where to be treated so as to avoid the drive to a university hospital that was farther away from their place of residence.

"I also think that in this case, immunotherapy should be available to the patient in whichever hospital they want to do it, I think that's very important, that we don't have to go to [city], so that should be much better coordinated." (4N1) [93]

Some interviewees felt that **psychological support was not readily accessible**, both because of insufficient availability, and because of insufficient fee reimbursement. Furthermore, patients wished that psychological support would be more proactively encouraged by healthcare professionals.

"And on a mental level, yes... we all know that access to care for psychologists is very difficult. So access to care for psychologists should be made more accessible. But yes, that's a problem, not just for cancer patients. Even people with mental problems have difficulty accessing it, so I think that's important." (12N1) [94]

"So there, too, I think there is now an intervention of a certain number of psychological sessions, but that can certainly be expanded. And maybe more attention can be paid to that. Okay, that's there if... because a nurse, an oncologist doesn't have the time to have all those conversations. But in my case, I wasn't referred to it. And I don't think that happens much yet. But I actually don't know. It's more on my own initiative. And because I have already experienced the usefulness of it in the past, I have now used it again." (7N1) [95]

On the contrary, positive experiences meeting patients' psychological support needs were also reported.



"So then I had a hard time with that, but I have to be very honest, we were very well guided psychologically at our hospital. I say we too, my wife too, we could go directly to the psychologists, we talked together, we had separate sessions and things, it was never actually made into a problem and all that." (3N1) [96]

Key points

- Early detection of melanoma is crucial in determining its prognosis. Awareness about suspicious lesions and access to early diagnosis by a healthcare professional is therefore paramount. In our survey, half the participants waited more than 3 months before taking the decision to seek medical advice for their symptoms.
- One in four survey participants had to wait for more than a month between the moment they decided to seek consultation and their first appointment
- For 50% of respondents, it took more than two weeks between the first consultation and the diagnosis.
- Overall treatment can be considered moderately effective for advanced melanoma and very effective for early stage melanoma
- Fatigue was the most frequently reported treatment side-effect acknowledged by 56% of survey participants undergoing treatment, with half of them deeming it highly burdensome. The most burdensome treatment side effect, albeit encountered by only a quarter of respondents undergoing treatment (four in total), was arthritis or joint pain.
- Interview participants highlighted the need for a better multidisciplinary approach as well as a greater availability of healthcare professionals for rapid appointments.

- Respondents were satisfied both with the quantity and the clarity of explanations provided by healthcare professionals. Interviewees would welcome more proactive information sharing and more patient-friendly, yet accurate, information on the internet. A contact person or telephone number to reach out to with questions was also considered to be lacking by some.
- More than one in three survey participants wished to be more involved in their treatment decisions.
- While more than 95% of respondents indicated that they received care when needed, transportation issues, lack of information and very long waiting times were reported as hurdles to access care.

4.4 Unmet social needs

4.4.1 Impact on social life

Melanoma requires changes in lifestyle that have an impact on patients' social life and usual activities.

Required change in habits, such as activities exposing patients to the sun, sometimes led to frustration.

"The effects are that I loved going in the sun. My summer was really punctuated by my sun exposure on my little terrace, even if since 2020 I was... It was always before 11am and after 4pm but so that programmed my little days, I read in the sun in the morning etcetera and I got tanned, so since the operation I haven't exposed myself to the sun as much, so that hasn't been easy in terms of daily life because, as I said, I loved it." (10F1) [97]

Fear of exposure to the sun was perceived as an important restriction in daily activities, and led some participants to become less sociable, and more inclined to stay indoors. The lack of social activities was also attributed to a



lack of energy, which led people to refuse certain social activities (in the evenings, for example).

"It was really beautiful every day [...] and so I practically didn't even go out. Because even though you can wear a hat, sunglasses and total screen, I was a bit disgusted so I didn't leave the house, I practically didn't leave the house, so that is indeed an effect of the melanoma, it has made me a bit unsociable." (10F1) [98]

Moreover, fluctuating energy levels were reported to impact upon patients' willingness to participate in social activities, limiting their social interactions.

Support and assistance is required by a minority of respondents.

About 35% of participants (n=13) reported that they needed (or had needed) assistance with routine logistic activities due to melanoma. This assistance was mainly required for household tasks, meals, and personal hygiene (Table 28).

Table 28 – Type of logistic activities that participants required assistance with (n=13)*

Type of activity	n (%)
Household	12 (9.2)
Meals	11 (84.6)
Travel	9 (69.2)
Personal hygiene	6 (46.2)
Dressing	5 (38.5)
Childcare	1 (7.7)

* Multiple responses were possible

Whereas 23% of those requiring assistance did so for only one or two activities, most needed assistance for three or more of these activities (Table 29).

Table 29 – Distribution of the number of logistic activities that required assistance (n=13)

Number of activities	n (%)
1	1 (7.7)
2	2 (15.4)
3	4 (30.7)
4	3 (23.1)
5	3 (23.1)

Assistance mainly provided by relatives

According to the survey responses, when assistance was needed, this was provided by informal caregivers and family members in the vast majority of cases. Only rarely were patients assisted by a healthcare professional. In the quote below, an interviewer describes the support received by a friend.

"Usually I take medication to be a bit calmer, which is not recommended for driving. Then there is a friend who is present at all appointments and procedures, who is quite often at home, or we try to coordinate appointments when she is at home, and she almost always accompanies me. It's a luxury that I have her to take with me every time." (7N1) [99]

Despite needing support, some patients did not want to be transparent about their illness in order to avoid being labelled as a 'cancer patient' and receiving pity.

"I didn't think everyone had to know. And I certainly don't want compassion. I don't want pity compassion. I know how I am myself when I hear someone has cancer. That's really... So I think no, I don't want to be looked at like that my whole life either." (8N1) [100]

When respondents could no longer benefit from the help of relatives, they found themselves having to manage these aspects on their own.

"And then since my mother had passed away in February, and I had all



the estate boxes, I know I had a box with a lot of things in it, so someone came to the house, looked and we found everything we needed to change the dressings. I did that myself. So, I managed that all by myself." (10F1) [101]

Assistance by a third party was sometimes required for different kinds of tasks, including wound care (e.g. changing dressings, disinfecting a wound), daily tasks (e.g. preparing meals or going to the toilet), and day-to-day psychological support.

Respondents also indicated that sickness funds' interventions were sometimes conditional on the completion of administrative procedures. However, these procedures were perceived by participants as being complex or irrelevant, or as being difficult to follow because they sometimes required input from third parties over which they had no control (e.g. their doctor).

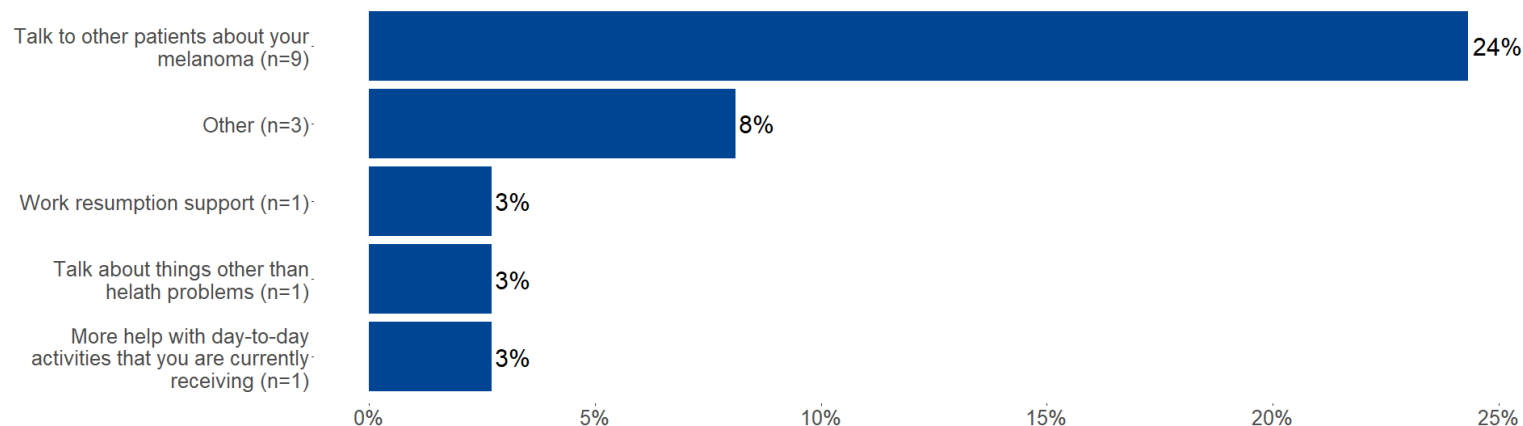
"But you have to do that every time. So you are always confronted with it, while I think: they know I have cancer now anyway, because you also get a thing via email, yes, you have cancer. So they are not afraid to talk about cancer, but you have to add it every time. If you forget to attach it, then you have nothing, so to speak." (12N1) [102]

"That's a bit of survival, but the biggest stress doesn't come so much from the disease, but from all the paperwork that comes with it and in the health insurance, you have to fill in those forms. And if you forget to fill in that form confidentially, then the doctor fills it in wrong and then you get the letters and then it becomes a lot of hassle." (3N1) [103]

"The first time I didn't have enough points. A second time after that I did, but the doctor has to have that paper, and it depends more or less on the doctor whether they give enough points for the reimbursement. I find that a bit, well. So it's not my fault, it's the doctors' fault." (11N1) [104]

Unmet social support needs

In the patient needs survey, we asked participants if there were any kinds of social support they did not receive but wished they had received. Twenty four participants (64.9%) responded that there was no additional support they wished they had received. The most commonly reported area for unreceived support was the lack of opportunities to talk to other patients about their melanoma, experienced by around a quarter of survey participants (Figure 21).

**Figure 21 – Reported areas of unmet social support (n=37)****The need for a care coordinator, case manager, or buddy was expressed.**

Participants expressed a need for a dedicated reference person to guide them throughout their journeys, helping with various tasks such as communicating with healthcare services, handling administrative procedures, and navigating both healthcare and social services. They also identified this role as a crucial source of emotional support. A comparison was drawn to the clinical pathway in breast cancer, which was perceived as clearer and more supported.

"That there is a care coordinator or a case manager or that you have a personal coach who can guide you through all phases and not so much emotionally. Although I think you shouldn't split that up into different functions. I think you should have an oncocoach who can do everything. Someone who can follow up on the administrative side for you and, that

can't be too much work, but someone who can do that. But who can also provide some emotional support. And then I think that will be more effective. I think a psychologist is more in the second line. And is not necessary for everyone. But such a coach who walks alongside you, who holds the baton for you. I think that would be ideal for me. Who also takes care of transfer, first line, second line, contact, GP if necessary." (11N2) [105]

"But of course, I don't know how the trajectory goes with someone who is in an advanced stage and who needs more surgery and who needs post-treatment, such as chemo. I suspect that they will also come into a trajectory with accompanying... I'm not sure. But with breast cancer, for example, there was a very clear conversation about what you can expect, what we offer you, what we do to make care easier and all those things." (7N1) [106]



Patient groups as a source of information and support for some.

Patient groups were perceived by some as opportunities to share their experiences and felt that this mitigated the impact of the disease. However, not all interviewed participants felt this way.

"Yes, it was nice. The whole family was there. But we know that they are all people [...] who have melanoma and so, it actually helps to destress. We say to ourselves, 'well, these are normal people after all'. [...] So there you go. And then we were able to talk to quite a few people, super nice of course. And who all have this perspective of sharing their experience. To take the drama out of the situation a bit." (7F1) [107]

Some participants reported that patient associations were useful sources of information (e.g. Facebook pages, videos), allowing them to share experiences and organise meaningful activities.

"Although I haven't used it much yet, in the future, and if I have time, in the sense that I am not on sick leave, I will definitely still participate. There have already been many speakers. They do put that on their Facebook and then you can see those videos. There have already been many speakers, such as from the Netherlands." (12N1) [108]

"No, that's just for reading. I didn't even know that [name patient organization] existed. I saw a note about it in the hospital and then I went there. And then you can only join if you are seriously involved with melanoma. But yes, I see that they do come together. In July they went to Puyenbroek for a day, last year it was Pairi Daiza." (8N1) [109]

However, involvement in a patient group was also perceived as emotionally challenging. Indeed, it was common for deaths to be announced in these groups or for people to report relapse years later, when they thought they were definitively cured.

"Absolutely, and I'm on that Facebook group and a lot of people are not on there. And every month or so, at least once, someone dies and someone puts it on there that that person has passed away. And then you're back on the ground again. But yes, I always think, it won't happen to me again, but you never know." (8N1) [110]

"That has, in my opinion, positive and negative... can have consequences. In the sense that you see people who have been cancer-free for five years, for example. You see people who have been cancer-free... I mean, with melanoma. Who were cancer-free for three, four years and then relapsed. Who now have cancer again, but still with treatment. The negative is, of course, when there are deaths. Then you say, well, look, they didn't survive." (12N1) [111]

4.4.2 Impact on education

No information found in the literature.

4.4.3 Impact on work

Most working individuals affected by malignant melanoma did not experience any work incapacity (73.3%).

Among the eight individuals who had experienced work incapacity due to melanoma, two participants went back to work as before, three went back to work but less than before, whereas three didn't return to work at all (Table 30).

**Table 30 – Work incapacity due to melanoma (n=29)**

	Early stage (0-II)	Intermediate (III) + advanced (IV)	Total
	n(%)	n(%)	n (%)
Paid work before diagnosis			30 (100.0)
<i>No incapacity</i>	15 (88.2)	7 (53.8)	22 (73.3)
<i>Incapacity</i>	2 (11.8)	6 (46.2)	8 (26.7)
Return to work after incapacity			
<i>Return to work, as before</i>	0	2 (33.3)	2 (25.0)
<i>Return to work, less than before</i>	2 (100.0)	1 (16.7)	3 (37.5)
<i>No return to work because of health state</i>	0	3 (50.0)	3 (37.5)

Both the time needed for treatment administration and the subsequent side-effects impacted respondents' ability to work.

Treatment quickly followed the diagnosis of the disease, and respondents had little time to adjust their working hours. Absences sometimes had a major impact on the continuity of their work (e.g. for teachers).

"So, well, my colleagues reacted very well, I found replacements very quickly, so I spent Wednesday afternoon with my replacements explaining everything to them. So that they could take over from Thursday and ensure the end of the year, you know." (10F1) [112]

Combining work with coping with the disease proved difficult. Participants reported difficulties with focusing on work, particularly due to fatigue and concentrating issues, but also because of the multiplicity of medical appointments and the emotional burden that the disease represented.

"The advantage of my job, of course, is that I can work 99% from home, I work a lot remotely, but it's getting harder. A problem that used to be a problem before is now a big problem with the same mindset. I have to make an effort not to say 'I quit, yes'." (4N1) [113]

"That's mainly due to fatigue and concentration problems. If I have a whole day, I have an office job, but when I come home in the evening, I'm just naturally dead tired." (3N1) [114]

Others did not change their working patterns because they felt they had to remain available by virtue of their profession (healthcare professional in this case).

"Just on the day of the operation. They told me not to lift anything, etc., well, that wasn't possible. Because of the lymph nodes that were removed in the groin, not lifting people; not making any movements, going down and all that, wasn't possible, so I worked the next day. Maybe I would have taken a break for that. Here it's not about being independent, it's simply the fact that there are people who are... who are dependent on me." (7F1) [115]

Flexibility in relation to work appeared to depend on the type of job. Certain sectors (e.g. the public sector) seemed to be more conducive to flexible working.

"Yes, I work for an intermunicipal company, so that's already something more flexible than a private company. And I have a good department



head and all, so that's never been a concern. Yes, more from myself, I won't be able to do that full-time, which I don't really have to. But I've always been understood. Yes, I can't do that. But you can also indicate which days or how or what. The check-ups often fall on the days I work, that's not a problem either. So, they are fully on board with the story and just always happy that I'm back." (7N1) [116]

Some participants reduced their working time while being treated.

Returning to work part-time after treatment was not always the patient's direct choice, but rather a result of their weakened health state.

"I currently work with, I always forget the name, I work three and a half days a week and one and a half days I'm still on sick leave. Definitely progressive work resumption, for three years now during treatment. That's mainly due to fatigue and concentration problems. If I have a whole day, I have an office job, but when I come home in the evening, I'm just naturally dead tired. [...] So I really need that time to recover a bit and do things." (3N1) [117]

Given their melanoma's health burden (e.g. fatigue), some patients said they had anticipated their retirement to try and enjoy life while they still could.

"Because, you know, I think it's better to enjoy life and anyway... I could see that I was too tired, that I wouldn't have been able to handle it, and rather than managing it poorly, it's better to retire. I was already eligible for retirement for more than two years anyway." (10F1) [118]

4.4.4 Financial consequences

Two in five respondents reported experiencing a financial impact directly linked to their illness.

When patients perceived a financial impact, this was mostly linked to the loss or lack of income (61.5%) and medical expenses (46.2%).

Table 31 – Financial impact due to melanoma (n=37)

	n (%)
Did not suffer a financial impact	22 (59.5)
Don't know	2 (5.4)
Suffered a financial impact	13 (35.1)
Type of financial impact (n=13)	
Loss or lack of income ¹	8 (61.5)
Medical expenses ¹	6 (46.2)
Loss of employment or unemployment ¹	1 (7.7)
Other ¹	1 (7.7)

¹Type of financial impact reported by those who suffered a financial impact (n=13)

²Other: "Weigering schuldsaldo verzekering"

Reducing working time due to illness inevitably had a financial impact on the participants that did reduce their working time. Interviewed respondents that were unable to work and received a work incapacity benefits testified that they received replacement income from the sickness fund, which was lower than their salary.

"Yes, it's always a third less that you have at the end of the month anyway. So you have to take that into account. I immediately fall back on full-time sick leave." (7N1) [119]

As shown in the table above, the majority of the participants did not perceive significant financial consequences because of their illness. During interviews, the level of reimbursement (via sickness funds and hospitalisation insurances) was praised by respondents.



"That is fully reimbursed. I am happy about that. I think I take about 15,000 euros worth of pills per month. So that is fully reimbursed. So that is... So I have absolutely no problems with that. Actually, I don't have any consultation fees. But if I just go to the day hospital, the costs are also reimbursed through the hospitalization insurance. So, in essence, I have little financial impact there." (3N1) [120]

4.4.4.1 Out-of-pocket healthcare costs

One in six survey participants suffered a financial impact that was linked to medical expenses.

Six participants in the survey (16.2%) indicated that, due to melanoma, they suffered a financial impact linked to medical expenses. The increase in healthcare expenses was either directly linked to consultations, both medical and non-reimbursed paramedical consultations such as with an osteopath, or due to the purchase of medical material (e.g. crutches) or the frequent purchase of sunscreen.

"For example, for my hip operation, I had to purchase a shower chair, a raised toilet, and I still needed crutches. I mean to say that this also brings extra costs because it is actually seen as a separate illness." (12N1) [121]

"If you have another condition, medication, you get reimbursed. But actually, our medication now is sunscreen. Or in my head, it is related to that. But as far as I know, you don't get much or anything back for that. That is actually your daily medication." (7N1) [122]

Some participants questioned the necessity of paying for a consultation when simply picking up medication and the cost of multidisciplinary oncology meetings, especially when certain healthcare providers listed could not be present.

"And then two consultations. Because when you go to get your baxter, you also have to pay for a consultation with the oncologists. If I'm not mistaken. Even if she's not there. And what I also find very striking is

the MOC meeting. The multidisciplinary oncological meeting. It shows who is present. But also who can request reimbursement. And with which nomenclature number. So if, for example, there is a general practitioner there, while they are never there. Then I think that's something you can save on." (11N2) [123]

4.4.4.2 Non-healthcare costs

Even if it did not initially appear as a significant cost, regular hospital parking expenses contributed to an overall increase in costs. Participants deemed it unfair to incur expenses due to the necessity of spending hours in the day hospital, a situation not of their choosing. Additionally, they highlighted the unequal treatment compared to other pathologies, for which parking was free in certain hospitals.

"Yes, parking, I think... I think they should make a separate parking lot for that day center, because it's six euros every time. And I actually think that's too much for... It's not like I'm visiting, but I can't help it that they take such a long time... Sometimes I have to sit in that chair or on the bed for three hours. That's not a mortal sin, but I think 6 euros is too much for actually being such a patient, a cancer patient. [...] That's not our choice, so they call it a social rate, but I don't think 6 euros is a social rate." (4N1) [124]

The significant costs (and lack of reimbursement by health insurances) of supportive or "well-being" services (e.g. massages, pedicures, home arrangements such as stairlift) was flagged by interview participants, who valued these services to mitigate the burden of treatment side effects and of melanoma's impact on mental health.



Key points

- Around one third of the participants reported needing assistance with routine logistic activities due to melanoma.
- When assistance was needed, relatives and other informal carers were the main providers of support to patients.
- Working ability was reduced in survey participants with intermediate or advanced disease, with only 2 out of 8 individuals having interrupted work returning to work as before. The reasons mainly included disease symptoms and treatment side-effects.
- The majority of the respondents did not report a financial impact due to melanoma. One third reported a direct financial impact, primarily attributed to income loss (62% of respondents reporting a financial impact) and medical expenses (46% of respondents reporting a financial impact).

4.5 Other unmet patient needs

Some unmet patient needs that were highlighted during interviews are not covered by the NEED framework and are therefore reported below.

The **need for more innovation** was mentioned in different contexts during the interviews. For example, the idea of an application to better plan in-patient room visits by different care professionals during hospitalisation to better manage expectations.

"I was thinking, if they could make something like public transport, where you have an app that shows you when the nursing staff is coming, or where they are, so you can estimate whether it will take fifteen minutes or half an hour, but at least you can take that into account and go to the toilet comfortably." (11N2) [125]

The need for research is particularly acute for melanoma patients. The need for larger-scale research on a European scale has been expressed.

"But certain hospitals that are specialized, for example in Melanoma, will also organize themselves more specifically for those studies and may therefore have more results, more participants, those studies may be more reliable... In other words, I think, with Europe, that would also be good, that they can also collaborate on a European level. As they eventually did for Covid." (12N1) [126]

Finally, improved availability of disabled spaces and more prompt allocation of parking rights for disabled spaces were emphasised.

"We once received a fine because we were parked in the disabled parking lot. 160 euros. I had a drain in the wound for a long time. And it started to leak. So we rushed to the hospital. We parked in the disabled parking lot, quickly went into the hospital. When my husband came back, the police were writing a ticket. 160 euro fine." (11N2) [127]

"No, because my husband drives with me because there are too few, and that's everywhere, parking spaces for the disabled. So I don't even think about driving alone, because the parking spaces are usually taken. As far as I'm concerned, everyone can drive a mansion, I don't care. I've never been jealous and I never will be, but then the disabled parking spaces are taken or they're still waiting in the car for their, for whom? For someone who's in the clinic...? And my husband and I agreed, 'if he drives with me, and he doesn't want to come upstairs, then drop me off at the entrance and go park somewhere else.' So that people who really need that space can use it." (11N1) [128]



5 RESULTS – UNMET SOCIETAL NEEDS

5.1 Unmet health needs

5.1.1 Frequency

In 2020, the age-standardised incidence of melanoma in Belgium was of 31 per 100 000 and the prevalence of 26 106 individuals.⁵

5.1.2 Transmissibility (contagiousness)

Not relevant.

5.1.3 Antimicrobial resistance

Not relevant.

5.1.4 Burden on informal caregivers

Participants reported adverse psychological consequences affecting their relatives and their relationships with them.

Interviewed participants, as described in section 4.1.1, explained that the impact of melanoma on the patient's social life was not limited only to their own life. Testimonies showed significant impacts on spouses and other family members. Furthermore, the burden on family members was sometimes considered secondary because of the priority attributed to the cancer patient.

"My wife, she deals with it in her own way, but of course, I make myself a priority, while that's not correct. A bit selfish. But I do have cancer. So you have to be able to put that all into perspective, but it does have an impact on our relationship." (4N1) [129]

A systematic review of studies carried out across the globe uncovered significant unmet needs from the perspective of **informal caregivers** of patients with advanced cancer. These needs include psychological aspects

(particularly managing concerns about cancer recurring and addressing fears about deterioration), health system and informational needs (concerning the patient's prognosis, physical requirements and financial support), as well as needs related to patient care and support (such as obtaining sufficient pain control, and coordination and continuity of care).¹⁰⁹

Key points

- **In 2020, the age-standardised incidence of melanoma in Belgium was of 31 per 100 000 and the prevalence was of 26 106 individuals**
- **Informal caregivers, particularly family members, experience a psychological burden due to concerns about disease progression, adverse psychological and physical impacts on their affected relative and increased responsibility and logistic demands.**

5.2 Unmet healthcare needs

5.2.1 Value for money of standard care

No information on the value for money of standard of care could be found in the literature. Value for money assessment requires information about the expenditures and outcomes. With respect to the expenditures, no cost estimates were found for Belgium. However, based on extrapolations from other countries, a study which modelled the cost-of-illness for melanoma skin cancer in all EU member states based on 2012 data, estimated that the direct costs in Belgium based on the GDP were €9.8 million in total and €5 050 per patient.¹¹⁰ When these estimates were based on the healthcare expenditures in Belgium, the national direct costs were €10.2 million and costs per patient were €5 270. These direct costs might be underestimated because since the publication of this paper, new expensive treatment options have been approved in Europe. A more recent study reported that direct costs of melanoma skin cancer in 2014 in Belgium were €40.1 million,



of which 37.9 million were costs borne by the healthcare payer and €2.2 million were costs borne by the patient.¹¹¹

5.2.2 Preventability

Primary prevention

Current preventive strategies mainly consist in promoting sun protection practices and closely monitoring individuals who exhibit high-risk characteristics.²⁶

Primary preventive strategies include disseminating awareness of the risks associated with intentional exposure to UVR (both natural and artificial) and providing information on skin-protective behaviours, including checking the UV index to determine necessary precautionary measures.^{36, 44, 112} Given the significantly increased risk associated with childhood sun exposure, it is important that primary preventive strategies also target parents and adolescents.¹¹³

Continuous efforts are required for these preventive strategies, especially to counteract the aesthetic norms and fashionable ideals that foster a positive perception of tanned skin. These influences have disproportionately affected women, particularly adolescent girls.¹⁶ Underlining the necessity of these strategies, a survey conducted on behalf of the Foundation against Cancer in 2021 uncovered inadequate protective practices among individuals in Belgium, notably during outdoor leisure activities. Out of the 1000 surveyed participants, 79% of adults and 43% of children suffered a sunburn that year, and only one quarter of adults routinely took the UV index into account.¹¹⁴

A modelling study that analysed the cost-effectiveness and the budget impact of primary prevention of skin cancer in Belgium concluded that over the next 50 years, implementing both an awareness-raising campaign and an outright prohibition on sunbed use would result in an increase in quality-adjusted life-years and financial savings.¹¹¹ They estimated that investing one euro in the campaign would yield long-term savings of €3.6 for the healthcare payer.

Because of the very low lifetime risk of a single selected naevus progressing to melanoma, the general excision of benign naevi is not recommended as a prevention strategy. Furthermore, individuals with a high number of naevi are at higher risk of developing melanomas not only within the naevi but also in parts of their skin not associated with naevi. Therefore wholesale excision of naevi as a strategy to prevent melanoma may not only have limited effect but may also provide a false sense of security.²⁸

During our interviews, participants also highlighted the importance of melanoma prevention to them. Some more specifically discussed their sense of responsibility towards future generations and the importance of raising awareness among young people and children.

"I also expect that more attention should be paid to it in Belgium. In my case, it was atypical, I didn't have any spots, I didn't go in the sun, so I was very unlucky. I asked a dermatologist, the oncological dermatologist, who said no, it comes from the sun, the melanoma comes from the sun." (4N1) [130]

"Simply prevention to inform future generations. It's us who have to pay attention to the little ones. [...] We talk more and more about melanoma, right. [...] But we still see children outside without protection, running around on the beach naked and... it's four o'clock." (7F1) [131]

"Yes, that's with my children and grandchildren. But even my granddaughter, when she puts a foot outside, grandma, first put on sunscreen. So I don't know, she's four years old. I think they even sang a song about it in class. I think it's really important to teach them from a young age." (8N1) [132]



Key points

- **The estimated direct costs of melanoma skin cancer in 2014 in Belgium were elevated (€40.1 million)**
- **Primary prevention through UV protection strategies is estimated to be a cost-effective and viable strategy**

5.3 Unmet social needs

5.3.1 Productivity losses

A study which modelled cost-of-illness for melanoma skin cancer in all EU member states based on 2012 data, reported that the annual total indirect costs or productivity losses in Belgium were €59.4 million, including €4.7 million due to morbidity and €54.7 million due to premature mortality. The annual indirect costs per patient were €30 662, including €2 414 due to morbidity and €28 248 due to premature mortality.¹¹⁰ Another study estimated that the productivity losses due to melanoma skin cancer in Belgium in 2014 amounted to €29.3 million, with €12.8 million attributed to men and €16.5 attributed to women.¹¹¹

No data were found regarding productivity losses of informal carers of individuals with melanoma.

5.3.2 Environmental impact of standard of care

Although the carbon footprint of cancer care has not yet been quantified, the use of chemotherapy and radiotherapy and the frequency of patients' hospital visits are likely to have an impact on the environment.¹¹⁵ Cytostatic drugs are among the most toxic chemicals produced and are the only pharmaceutical products classified as "hazardous" under the Waste Framework Directive of the European Commission.¹¹⁶ One study highlighted that anticancer drugs (also known as chemotherapy drugs or antineoplastic drugs) were present in wastewater and natural environments and that most of these drugs could be persistent in these environments. Anticancer drugs

may impact aquatic organisms (e.g. algae and fish) and promote changes in soil and water microbial communities, potentially altering the functioning of the ecosystem.¹¹⁷ Nevertheless, it is important to note that, over the past decade, the use of chemotherapy for melanoma has drastically decreased.

Key points

- **The estimated productivity losses due to melanoma in Belgium are estimated to be between €29.3 million and €59.4 million, with most of the losses due to premature mortality**
- **Data is lacking concerning the environmental impact of melanoma care. However, it is known that the use of chemotherapy drugs permeates into wastewater and natural environments with, at best, adverse impacts on the environment.**



6 RESULTS – UNMET FUTURE NEEDS

6.1 Future health needs

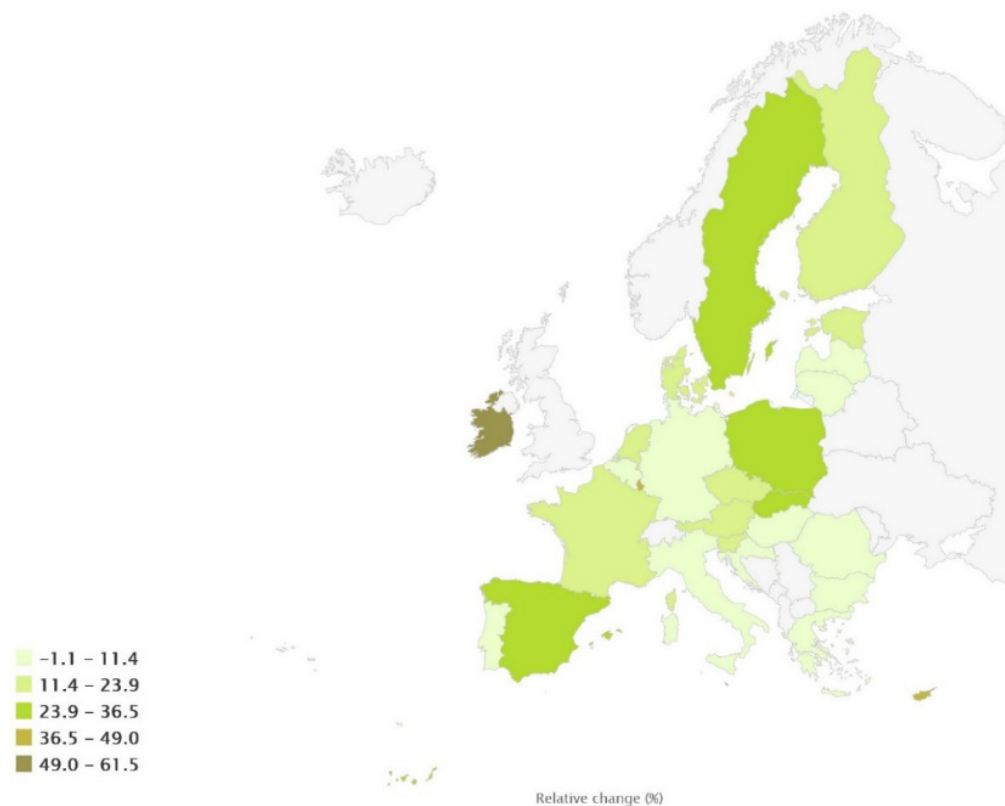
6.1.1 *Burden of disease*

Over the next decade, cutaneous melanoma incidence is predicted to increase due to population growth and population ageing, together with the cohort effect of high childhood sun-exposure in individuals born in the mid-1900s.^{12, 55, 118, 119} In Belgium, the incidence of melanoma skin cancer is estimated to increase by 11.3% by 2040, which is somewhat lower than the 13.7% EU27-average (Figure 22), and the new annual cases are expected to increase from 3 372 in 2020 to 3 847 in 2040.¹²⁰

Beyond these factors, the future incidence of melanoma will also depend on behaviours related to UVR exposure. Currently, intentional exposure to UVR are common practice, driven by daily activities, fashion, and the positive perception of tanned skin, particularly for women.¹²¹ These trends are partly offset by a greater awareness of the risks associated with sun exposure, leading to more widespread use of sun protection and avoiding sun exposure during the most dangerous times of the day.¹¹ However, as discussed above, these protective behaviours and the uptake of screening are more prominent among wealthier individuals, leaving populations with lower socioeconomic status more at risk. The incidence of non-UVR related melanoma on the other hand is stable and is not predicted to change drastically.¹²²



Figure 22 – Estimated relative change (in %) of melanoma incidence from 2020 to 2040 in the EU-27, using the baseline projected population



Source: *European Cancer Information System*¹²⁰



6.2 Future healthcare and social needs

6.2.1 Economic burden

Although most melanomas are picked up at early stages, the treatment aimed at preventing cancer progression remains financially and emotionally burdensome for patients and costly for societies.¹² It is estimated that in Belgium the number of patients requiring care following a diagnosis of skin cancer will increase by 77% by 2030.³ Costs will also continue to rise due to the growing incidence of skin cancer and the development of new (and expensive) medications for melanoma treatment. This situation calls both for prevention measures to reduce the number of patients, for the effective management of diagnoses, as well as for the possible healthcare reorganisation in the fight against skin cancer.³

One study estimated that the future total cumulative costs of melanoma skin cancer in Belgium for the period 2014-2034 will be of €3.2 billion, including €1.9 billion healthcare payer's costs, €341.8 million patient's costs and €931.1 million productivity losses. In addition, total cumulative costs over a period of 50 years (2014-2064) were estimated at €8.1 billion, including €5.2 billion healthcare payer's costs, €993.6 million patient's costs and €1.9 billion productivity losses.¹¹¹

Key points

- In Belgium, the incidence of melanoma skin cancer is estimated to increase by 11.3% by 2040, due to population growth, population ageing, and the cohort effect of high UV sun exposure during childhood of individuals born before the widespread use of sunscreens.
- Future incidence of melanoma will also depend on population behaviours related to UVR exposure, including the use (and regulation) of tanning devices.

- The incidence of non-UVR related melanoma on the other hand is stable and is not predicted to change drastically.
- Protective behaviours and the uptake of screening are more prominent among wealthier individuals, leaving populations with lower socioeconomic status more at risk.
- Costs associated with melanoma care will continue to rise due to the growing incidence of melanoma and the development of new (and expensive) treatments.
- In Belgium, the total cumulative costs over a period of 50 years (2014-2064) were estimated by one study at €8.1 billion, including €5.2 billion healthcare payer's costs, €993.6 million patient's costs and €1.9 billion productivity losses.



7 INEQUITIES

From a societal perspective, melanoma entails (somewhat concealed) inequalities in terms of the burden of disease. Melanoma incidence tends to be highest among groups with **higher socioeconomic levels**,^{43, 50, 51} which might be attributed to their historic proneness to travelling to sun-exposed areas on holidays.¹²³ Because sun exposure is likely linked to cohort effects, the association with socioeconomic status might change in the future with higher educated populations today being more likely to have benefitted from public health campaigns on melanoma prevention and to afford adequate sun protection, thus possibly experiencing lower incidence (when adjusting for other risk factors) in the future. For instance, tertiary-level educated patients have been found to be more likely to use sunscreen on a daily basis.⁵⁰

Despite this predisposition of groups with higher socioeconomic levels to increased incidence, individuals from **lower socioeconomic backgrounds** tend to present with more advanced-stage melanoma and experience higher mortality rates.^{50, 51, 124} A population-based cohort study found that, in Belgium, individuals with a primary level of education or less had almost twice the chances (adjusted OR 1.91, 95%CI 1.45-2.51) of being diagnosed with an advanced stage of melanoma compared with individuals who had a higher level of education.⁵¹ The study also found that, in women, lower housing quality was associated with a higher risk (adjusted OR 1.88, 95%CI 1.44-2.46) of advanced-stage melanoma at diagnosis.⁵¹ This inequality can potentially be attributed to delayed diagnosis. A study conducted in the United States that surveyed newly diagnosed patients discovered that those with lower levels of education tended to have a lower perception of their risk for melanoma.¹²⁵ Additionally, physicians were found to be less likely to advise melanoma screening and detection to patients with lower education levels, and these patients were also less likely to inform their physician if they noticed changes in a mole. While analogous patterns could also apply to European countries, evidence is still lacking.

These findings emphasise significant concerns regarding the adequate awareness of melanoma risks, the adoption of effective protective behaviours, the affordability of sunscreens, the implementation of self-

screening practices, and the barriers to healthcare access among these populations.

While malignant melanoma is much rarer in **people with highly pigmented skins** compared with fair-skinned people, the former experience a higher mortality burden, with increased morbidity and case-fatality as evidenced by the overall more advanced stage at diagnosis and lower 5-year survival rates.^{52, 126} Lacking awareness and education both among the general public and among healthcare professionals about the potential of melanoma in populations with highly pigmented skins is one likely explanatory mechanism.^{127, 128} For instance, higher rates of melanoma misdiagnosis were observed in primary care in the UK for black patients compared to white patients.¹²⁹

More generally, the research and practice of dermatology have predominantly been based on individuals with fair skin types, inadvertently influencing the quality of care provided to people of colour.¹³⁰

According to a recent systematic review, UV exposure might not play a significant role in the development of melanoma in individuals with highly pigmented skin.¹³¹ However, the authors highlighted that the available evidence supporting this claim was of moderate to low quality, and additional research would be necessary to gain a more thorough understanding of this relationship. Nonetheless, the site of melanoma occurrence in people of colour supports the lack of association with sunlight, as melanomas are commonly found in sun-protected locations, such as acral, subungual, and mucosal surfaces. This recognised **gap in knowledge** highlights the need to further identify and stratify risk factors for melanoma in these populations.

Furthermore, the prompt diagnosis and adequate treatment of rarer types of melanoma (e.g. acral melanoma), which often affect these populations, remain a significant challenge.

Another dimension of inequality concerns the fact that at EU-level, significant discrepancies exist across countries in terms of access to metastatic melanoma treatment. It has been estimated that, each year, more than 5 000 patients with metastatic melanoma do not have access to recommended first-line innovative treatments.⁶⁸



8 DISCUSSION

8.1 Summary of results

The integration of both primary and secondary data facilitated an understanding of the prevailing unmet needs among individuals affected by melanoma. The online survey provided insights into the experiences and perceived unmet needs of 37 individuals affected by melanoma in Belgium, with around half having localised disease and half having more advanced melanoma, meaning that the unmet needs of individuals with more advanced disease were over-represented compared to the general melanoma patient population. Most of the respondents were aged between 25 and 64 years of age. Additionally, in-depth interviews with nine volunteering survey participants enriched our comprehension of the reasons behind patient unmet needs and shed light on the diverse impacts of their disease on their lives. This information was complemented by a literature review on specific criteria within the NEED framework and consultation with clinical experts in melanoma.

Overall, we observed significant disparities in unmet needs based on the stage of melanoma. Low-risk localised disease is generally associated with a lower burden compared to advanced disease, encompassing health-related quality of life, burdensome physical and psychological symptoms, treatment burden, and healthcare implications.

It is important to point out that some aspects of melanoma's impact on patients and society (e.g. overall survival since the development of newer drugs for advanced disease, significant reimbursement of healthcare costs) were not overly adverse, and that the quality of care appeared good or satisfactory in various respects (e.g. access to care when needed, quantity of information received). The study nevertheless uncovered several needs that remain unmet, which we will summarise below.

Unmet patient health needs

One of the most significant impacts on patients stems from the progressive nature of the disease and its potential fatality, reducing life expectancy and implying severely burdensome physical symptoms in advanced stages and significant psychological symptoms regardless of stage, due to the fear of progression and the fear of death.

Anxiety, low mood, and fatigue seem to be the most prevalent and most burdensome symptoms affecting individuals with melanoma, with important consequences on usual, professional, and social activities.

Unmet patient healthcare needs

Early detection of melanoma is crucial in determining its prognosis. Awareness about suspicious lesions and access to early diagnosis by a healthcare professional is therefore paramount. In our survey, half the participants waited more than 3 months before taking the decision to seek medical advice for their symptoms, which revealed a lack of awareness of personal risk of developing melanoma. According to patients, awareness about the dangers of direct exposition to the sun could be particularly improved among young people and parents of young children.

Significant unmet healthcare needs are related to the diagnosis of disease. There is a need for better diagnostic tools, particularly for faster progressing atypical skin lesions and for non-cutaneous melanoma. Limited access to screening by dermatologists due to long waiting times and high costs is another area that warrants improvement.

While treatment effectiveness for advanced melanoma has increased drastically over the last decade, there is still a great potential for improvement, particularly for non-cutaneous melanoma, and for individuals that cannot benefit from targeted treatment or develop resistance to immunotherapy. Significant unmet needs also persist in terms of treatment burden in advanced disease, particularly in terms of side effects.



Concerning patient journeys, interviewees expressed the need for better access to integrated care, including occasional follow-up by a multidisciplinary team and the opportunity to contact their healthcare professionals for questions.

Both the quantity and clarity of information received were considered sufficient by the large majority of survey participants. However, some interviewees expressed a desire for more easily understandable information from both healthcare professionals and online sources. Notably, French-speaking patients faced a lack of reference organisations that could offer accurate and patient-friendly information about melanoma.

When it came to accessibility, the need to access specialist doctors within reasonable timeframes was pointed out by interviewees, and reflected in the fact that one in four survey participants waited more than one month between the decision to consult and their first appointment. Some participants also viewed distance to specialised care as an access barrier. Moreover, access to psychological care was perceived as limited by lacking availability and significant costs.

Unmet patient social needs

One third of the survey participants reported needing assistance with routine daily activities due to their illness, which was mostly provided by relatives. Approximately a quarter of survey participants expressed a need to discuss their melanoma with other patients but were unable to do so. This emerged as the most frequently reported area of unmet social need.

The working ability of individuals with intermediate or advanced melanoma was reduced. The reasons mainly included disease symptoms and treatment side-effects.

The majority of the respondents did not report a financial impact due to melanoma. Forty percent reported a direct financial impact, primarily attributed to income loss and to medical expenses (e.g. for medical consultations, complementary medicine, or medical devices).

The administrative complexities of healthcare and particularly sickness funds were highlighted, and a need for administrative simplification and for a coordinating person or buddy was expressed to assist with these tasks.

Unmet societal needs

Informal caregivers of melanoma patients are the main providers of assistance, which takes a toll on their psychological and general wellbeing. Further research is needed to quantify these impacts.

The estimated costs due to melanoma are elevated (estimated at €40.1 million in Belgium in 2014) and likely rising with the development of new expensive treatments. The productivity losses associated with melanoma in Belgium were estimated to be between €29.3 million and €59.4 million.

Research and evidence is needed to describe and quantify the impact of melanoma healthcare on the environment (and eventually on population health). For instance, it is known that chemotherapy drugs regularly permeate into wastewater and natural environments with, adverse impacts on the environment.

Future needs

In Belgium, the incidence of melanoma is estimated to increase by 11.3% by 2040, due to population growth, population ageing, and the cohort effect of high UV sun exposure during childhood of individuals born before the widespread use of sunscreens. Future incidence will also depend on current and future behaviours related to UVR exposure, including the use of tanning devices. The incidence of non-UVR related melanoma on the other hand is stable and is not predicted to change drastically.

Currently, protective behaviours and the uptake of screening are more prominent among wealthier individuals, leaving populations with lower socioeconomic status more at risk. This may have an impact on future inequities.

The costs associated with melanoma care will likely continue to rise.



8.2 Limitations

Various aspects should be considered when interpreting the findings.

8.2.1 Primary data collection

Firstly, the generalisability of the survey results is significantly limited by the low number of respondents. The limited interest in the survey by individuals who have been cured, coupled with a relatively low prevalence of individuals with a recent melanoma diagnosis, likely contributed to the low number of responses. More specifically, we chose to exclude individuals diagnosed more than three years ago to minimise recall bias and capture the most up-to-date unmet needs. However, this decision resulted in the exclusion of individuals with 'older' early-stage diagnoses that were most likely cured through excision alone, constituting the majority of melanoma cases. Therefore, individuals with advanced melanoma were overrepresented in our sample. Consequently, the identified unmet needs more prominently reflect the (more significant) unmet needs of patients with advanced melanoma. Stratifying results by cancer stage was thus an important strategy to mitigate this bias. The low sample size also prevented us from doing more advanced statistical analyses and adjusting for confounders, and increased the impact of outliers.

Furthermore, another limitation was the use of an *online* survey as the primary data collection method. While online surveys offer convenience and accessibility for most, they come with inherent barriers for participation. Technological knowledge, access to an appropriate device and internet connection may have excluded particularly vulnerable populations, which was reflected in the average high level of education (64.9% with a Bachelor degree, Master degree or PhD). The survey results may therefore underrepresent the unmet needs of the most socioeconomically disadvantaged populations.

Many respondents (72 out of 109 eligible) initiated the survey but subsequently closed it, which limited the sample size and may have introduced selection bias in the sample. Unfortunately, we do not have any information about the reasons behind this in order to assess whether respondents differed from those who ended the survey before completion,

but we suspect that the length of the questionnaire may have contributed to this.

Another limitation relies in the fact that we only asked participants what their stage of melanoma was at diagnosis. While this provided a measure of diagnostic delay, it does not necessarily correspond to the current disease stage at the moment of the survey, which limits the interpretation of certain items (e.g. EQ5D evolution stratified by melanoma stage). Adding a question on current disease stage in future NEED surveys on cancer or other progressive diseases would be useful.

As mentioned in Section 4.3.1, the unexpectedly low proportion of individuals reporting having received treatment for their disease is likely an unreliable figure. Indeed, during interviews, some individuals who initially reported not receiving any treatment revealed that they had undergone a surgical intervention, with or without subsequent immunotherapy. We suspect that the term 'treatment' in the questionnaire item may have been misinterpreted by some, particularly those who had not received any medicinal treatment (i.e., excision only). This is reinforced by the fact that the majority of respondents who claimed not to have received treatment had localised disease. To address potential misinterpretations, we intend to review and refine this questionnaire item for future surveys, possibly by including an explanation of what is meant by 'treatment'.

8.2.2 Secondary data collection

Each criterion of the framework should ideally be measured by providing up-to-date, and high-quality evidence, which should be identified through systematic reviews for comprehensiveness. Because we did not have the time and resources to carry out systematic reviews, we gathered the data through pragmatic searches for each criterion of relevant databases and websites. We may have therefore missed other important sources of evidence or included low-quality evidence.

Finally, due to the tight time schedule, we were only able to consult two experts (one dermatologist and one oncologist) for the criteria measured through expert opinion. Ideally, a larger sample of experts should be consulted.



8.3 Lessons learned

Gathering data for all framework criteria related to melanoma yielded important insights and valuable lessons.

Survey development

Regarding the survey development, we aimed to use the EQ-5D-5L tool and integrate it into a survey platform ("Qualtrics"). The survey was incorporated on the platform in two languages (Dutch and French). Implementing changes to the survey simultaneously in two different languages presented challenges due to the platform's limited customisation options. Consequently, we had to rely on JavaScript to implement the necessary modifications, which made the incorporation on the survey platform more difficult and time-consuming. Such potential delays should be taken into account in the planning of future surveys.

Furthermore, throughout the study (mainly through patient interviews and stakeholder consultations) we identified additional potential unmet needs, that could be incorporated into an updated version of the questionnaire. This case study also enabled us to enhance the clarity and coherence of certain survey questions and answer options.

Recruitment

The recruitment phase of the study presented several noteworthy challenges.

One of the main challenges in terms of accurately measuring unmet needs through a survey is obtaining a sample that is sufficiently large and representative of the population with the disease. This is crucial to provide accurate estimates of how frequent those unmet needs are, and is also crucial to make meaningful comparisons between diseases. Furthermore, an adequate sample size is necessary to make relevant statistical analyses (e.g. stratification, calculation of associations). Various reasons likely led to the reduced sample size in our survey.

Firstly, engaging patient organisations and specialists in patient recruitment proved difficult due to their limited involvement during the questionnaire

development stage, which hindered the ability to leverage their networks effectively. Involving patient organisations and specialists from the beginning might therefore help to increase recruitment.

Timing emerged as a critical factor, as stakeholders had a limited windows of opportunity to fully engage with the study and distribute it within their respective networks. Allowing for a longer recruitment period for more individuals affected by the disease to get informed about the study and to find the time to respond would almost certainly have helped to increase the survey sample size.

Furthermore, the initial inclusion criteria were strict, excluding participants under the age of 18 years, a decision that was questioned by specialists. We are aware that the study of unmet needs must include children, yet, before being able to do so, some of the methodologies will need to be slightly adapted. However, only one potential participant was excluded on this basis. Furthermore, results from the survey revealed that the time since the last diagnosis for melanoma was too narrow, excluding a significant portion of the cohort. To address these issues and increase the participation rate, stakeholder outreach was expanded to include general practitioners, private dermatologists, and general organisations. Additionally, the deadline for participation was extended by one month, and small flyers were developed to promote awareness and engagement. Widening the inclusion criteria should therefore be an important consideration for future NEED surveys.

It is important to note that the survey was exclusively conducted online, inevitably excluding particularly vulnerable populations, which was reflected in the average high level of education. The educational level of the participants reflected a substantial proportion with higher levels of education (64.9% with a Bachelor degree, Master degree or PhD). A combination of dissemination strategies and outreach to include vulnerable populations would therefore be ideal. Concerning vulnerable populations, such as migrants, it would be important that future surveys be available in other commonly spoken languages by recent immigrants (e.g., English or Arabic).

Another challenge is including individuals at the margins of healthcare, who likely have specific (or higher) unmet needs. Yet, because the recruitment



was partly done through healthcare (e.g. posters in waiting rooms) there is a great chance that they got excluded.

Ensuring a sufficient representation of the unmet needs of individuals with rare types of melanoma also seems essential. In our survey, only three individuals with acral or lentiginous melanoma, and one with mucosal melanoma were included, limiting the generalisability of results for this subpopulation. Oversampling individuals with rare types and stratifying results by melanoma type might be an appropriate approach.

Another unforeseen hurdle was encountered when hospitals required ethical committee approvals specific to their institutions (in addition to the general approval of the ethical committee for the project) which had not been initially anticipated.

Dealing with complexity

One of the challenges in accurately measuring unmet needs for a disease lies in obtaining a comprehensive snapshot that encompasses the entire range of diversity in disease characteristics and synthesizes this intricate complexity. Most diseases exhibit heterogeneity and dynamism, making it challenging to summarise unmet needs, especially considering varying stages, subtypes, and fluctuating symptoms, particularly in chronic diseases. For instance, providing an overarching estimate of treatment burden or effectiveness becomes complex when patients undergo multiple treatments simultaneously, with treatment regimens changing over time.

In the context of chronic diseases, an additional challenge emerges concerning temporality. The relevance of measuring past unmet needs, such as changes in quality of life, treatment burden, and diagnostic needs, poses a dilemma. In our survey, we evaluate the quality of life before the onset of the disease and at present, seek a unified measure of treatment burden and of diagnostic needs. However, some of these events might have occurred decades ago. Determining the relevance of past unmet needs in the present remains a crucial consideration.

Another critical complexity revolves around multimorbidity. While comparing the burden of disease and other unmet needs across different diseases, it is

essential to acknowledge that some diseases are frequently associated with others sharing common pathophysiology, and significantly impacting individuals' lives. Accounting for this additional burden is necessary but proves challenging to quantify.

Interviews

In the interview phase of the study, a challenge was encountered related to the limited number of participants available to cover all predefined domains adequately. To address this limitation, participants from adjacent groups were included as replacements.

Literature reviews

While we conducted the exercise of collecting data for all framework criteria across various diseases, we encountered difficulties when summarising our findings for each criterion. Firstly, many indicators had multiple sources of evidence, and to ensure comprehensiveness, a systematic review would be required to incorporate them all. Secondly, the quality of evidence, as determined by systems like GRADE, should also be considered, a step we have yet to undertake. Additionally, we observed that results from different databases or studies were sometimes non-comparable due to variations in methodologies, definitions, and measurement units. Thirdly, while there were multiple sources of evidence for some criteria, others had none. Addressing missing data for certain criteria when comparing unmet needs across different diseases poses a challenge.

Generally, it proved more challenging to find data for societal needs criteria (e.g., financial and environmental impacts). The literature on the environmental impact of the standard of care for specific health conditions is in its early stages, with measurement methods still under development. Therefore, data for indicators related to the "environmental impact of the standard of care" are expected to become available in the near future.

Lastly, in instances where national data were unavailable for an indicator, data from other European countries were sometimes used as a proxy, therefore combining data sources.



While we were able to describe in detail various unmet needs related to melanoma, both from the patient and societal perspectives, we do not yet have a specific method that allows us to evaluate the importance of these unmet needs and through the use of specific thresholds categorise them, for instance, as 'high,' 'moderate,' and 'low.' This aspect will be developed in our future work.

8.4 Added value of the study

The added value of this study lies in different aspects.

First and foremost, it **tests the applicability of the NEED assessment framework**, complementing our previous work carried out on long COVID in 2021.⁸⁸ The primary data collection, including participant recruitment and the responses gathered, served as a crucial test of the feasibility and acceptability of the method. Overall, the findings were positive; however, this pilot study provided valuable insights, helping us to identify certain types of unmet needs (particularly through the qualitative interviews and stakeholder consultations) that were not initially included in the patient survey. These findings will be integrated into future assessments. Furthermore, the pilot study allowed us to refine some survey questions and answer options for better clarity and coherence. In addition, the pursuit of evidence beyond the primary data collection aimed to provide data for criteria related to patient unmet needs that cannot be measured at the individual level (e.g., mortality) and criteria related to the broader societal impact of the disease. This first-time attempt proved feasible, albeit challenging and resource-intensive (see section 8.2).

By integrating various sources of evidence—such as existing literature, the evaluation of patient unmet needs through a specifically developed survey and qualitative study, and expert opinions—we believe that the current **framework comprehensively measures a broad spectrum of unmet needs** associated with melanoma at both the patient and societal levels. The evidence collected through this and other case studies will feed into the creation of a NEED database containing information on unmet patient and societal needs for different health conditions, that will allow highlighting the most pressing needs for each condition and will allow

making comparisons across different diseases. This study therefore represents an important milestone in the creation of such a database.

Furthermore, this study can help policy-makers, healthcare stakeholders, researchers, and industries in targeting actions related to melanoma towards identified unmet patient and societal needs.

8.5 Potential suggestions to tackle unmet needs in patients with melanoma

Compiling and describing the unmet needs associated with melanoma can guide the development of relevant solutions. While designing the most appropriate and cost-effective strategies must undergo a separate process, we can outline some suggestions below, which follow both from the unmet needs identified in the literature, and from our primary data collection (patient survey and interviewees' ideas). Since we mainly identified the melanoma-related unmet needs in Belgium, the following suggestions apply to the Belgian context; however, some may also be relevant to other countries.

1. **Increase accessibility to dermatologists:** implement policies to reduce waiting times and improve financial accessibility for appointments with dermatologists.
2. **Enhance training and education for general practitioners:** (in order to mitigate dermatology waiting times and financial access barriers) invest in training of GPs in the screening of suspicious lesions, including in individuals with highly pigmented skin. Also increase awareness and recognition of atypical melanoma (e.g. mucosal melanoma, uveal melanoma).



3. **Raise awareness among professionals working with the skin:** inform professionals who come into contact with the skin, such as aestheticians, dentists, hairdressers, physiotherapists, to recognise suspicious lesions and encourage their clients to seek medical advice.
4. **Enhance education of dermatologists:** encourage training in the use of dermoscopy for all dermatologists, particularly those having graduated decades ago. Encourage the routine screening of nails. Also, further train dermatologists in the recognition of malignant lesions in individuals with pigmented skins.
5. **Improve awareness and education about UV protection:** Sustain public awareness campaigns to further educate individuals, especially young people and parents of young children, about the risks of melanoma and the importance of sun protection and avoidance of artificial tanning devices. Consider the variety in socioeconomic and cultural/linguistic backgrounds in these campaigns.
6. **Improve awareness and education about early melanoma detection:** Launch public awareness campaigns to educate individuals about early detection of suspicious lesions and about the importance of seeking medical advice promptly. Consider the variety in socioeconomic and cultural/linguistic backgrounds in these campaigns. Specifically include information on the existing risks of developing malignant lesions in individuals with pigmented skins (taking into consideration the specificities of these lesions- e.g. different sites and presentation).
7. **Enhance diagnostic tools:** Enhance research and development of better diagnostic tools for detecting rare melanoma types (mucosal and uveal), and atypical cutaneous lesions.
8. **Provide training for healthcare professionals in communication skills:** To optimise healthcare professionals' ability to break bad news appropriately and to convey clear and understandable information to patients based on their literacy levels, provide communication skills training to primary care and secondary care healthcare professionals, including both doctors and nurses.
9. **Improving treatment of advanced melanoma:** sustain efforts for the research and development of innovative treatments, particularly for individuals who are not eligible for targeted therapy, and for individuals with atypical melanoma.
10. **Enhance research:** Because most melanoma deaths occur due to recurrence of disease that was early stage when initially diagnosed, encourage research to develop reliable prognostic tools that can accurately identify patients at high risk of recurrence and who would benefit from closer monitoring and adjuvant immunotherapy.
11. **Patient associations to use the evidence** on patient and societal unmet needs associated with melanoma in prioritising information and activities directed at patients with melanoma and their caregivers.
12. **Provide a francophone equivalent to the Flemish organisation "Melanoompunt"**, which disseminates patient-friendly information and is accessible to provide answers to patients' questions.



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■ APPENDICES

APPENDIX 1. SUMMARY TABLES

Appendix 1.1. Summary table – Unmet health needs

Quality of life		
EQ-5D average utility score		
	<i>Before</i>	0.93
	<i>Today</i>	0.81
	<i>Delta</i>	-0.12**
Impact on physical health		
<i>Frequency of physical symptoms related to melanoma</i>		<i>n (%)</i>
	<i>Fatigue or exhaustion</i>	11 (29.7)
	<i>Change of mole or lump</i>	8 (21.6)
	<i>Swollen or painful lymph node</i>	8 (21.6)
	<i>Bleeding or purulent wound</i>	6 (16.2)
	<i>Painful wound</i>	6 (16.2)
	<i>Itchy or scratchy wound</i>	5 (13.5)
	<i>Tingling or numbness of skin</i>	5 (13.5)
	<i>Libido problems</i>	4 (10.8)
	<i>Constipation or diarrhoea</i>	3 (8.1)
	<i>Stomach ache</i>	2 (5.4)
	<i>Nausea or vomiting</i>	2 (5.4)
	<i>Loss of appetite</i>	2 (5.4)
	<i>Shortness of breath or difficulty breathing</i>	2 (5.4)
	<i>Weight loss</i>	1 (2.7)
	<i>Swelling or oedema</i>	1 (2.7)
	<i>Bone pain</i>	1 (2.7)
	<i>Joint pain</i>	1 (2.7)
	<i>Muscle weakness</i>	1 (2.7)
	<i>Speech problems</i>	1 (2.7)
	<i>Voice problems</i>	1 (2.7)



		<i>Fever</i>	1 (2.7)
		<i>Vision problem</i>	1 (2.7)
Pain/discomfort		Before (%)	Today (%)
			Delta (%)
	No problems	81.1	48.7
	Slight problems	13.5	32.4
	Moderate problems	2.7	13.5
	Severe problems	2.7	5.4
	Extreme problems	0	0
Impact on psychological health			
Frequency of psychological symptoms related to the melanoma			n (%)
		<i>Fear or anxiety</i>	11 (29.7)
		<i>Feeling down, depressed or sad</i>	9 (24.3)
		<i>Feelings of irritability, restlessness or nervousness</i>	8 (21.6)
		<i>Stress</i>	8 (21.6)
		<i>Insomnia</i>	7 (18.9)
		<i>Feeling abandoned</i>	6 (16.2)
		<i>Concentration problems</i>	4 (10.8)
		<i>Anger or aggressiveness</i>	2 (5.4)
		<i>Mood swings</i>	2 (5.4)
		<i>Difficulty or loss of memory</i>	1 (2.7)
Anxiety/depression		Before (%)	Today (%)
			Delta (%)
	No problems	86.5	40.5
	Slight problems	2.7	32.4
	Moderate problems	8.1	21.6
	Severe problems	2.7	5.4
	Extreme problems	0	0
Autonomy			
	Mobility	Before (%)	Today (%)
			Delta (%)
	No problems	86.5	67.6



	Slight problems	10.8	16.2	5.4
	Moderate problems	2.7	13.5	10.8
	Severe problems	0	2.7	2.7
	Extreme problems	0	0	0
Self-care	Before (%)	Today (%)	Delta (%)	
	No problems	100.0	86.5	-13.5
	Slight problems	0	13.5	13.5
	Moderate problems	0	0	0
	Severe problems	0	0	0
	Extreme problems	0	0	0
Usual activities	Before (%)	Today (%)	Delta (%)	
	No problems	89.2	62.2	-27.0
	Slight problems	2.7	18.9	16.2
	Moderate problems	8.1	16.2	8.1
	Severe problems	0	2.7	2.7
	Extreme problems	0	0	0

*Fisher's exact test, NS=Not significantly different, * p-value <0.05, ** p-value <0.01, *** p-value <0.001.

Appendix 1.2. Summary table – Unmet healthcare needs

Treatment				
Experienced burden of treatment				n (%)
			Very burdensome	1 (5.9)
			Quite burdensome	6 (35.3)
			Somewhat burdensome	6 (35.3)
			Not at all burdensome	4 (23.5)
Experienced burden of side-effects				
	Very burdensome	Rather burdensome	Slightly burdensome	Not at all burdensome



<i>Fatigue or exhaustion</i>	5 (55.6)	2 (22.2)	2 (22.2)	0
<i>Skin problems</i>	1 (16.7)	2 (33.3)	3 (50.0)	0
<i>Constipation and/or diarrhoea</i>	2 (40.0)	3 (60.0)	0	0
<i>Joint pain or arthritis</i>	3 (75.0)	1 (25.0)	0	0
<i>Nausea and/or vomiting</i>	1 (33.3)	2 (66.7)	0	0
<i>Liver problems</i>	2 (100.0)	0	0	0
<i>Heart problems</i>	1 (50.0)	1 (50.0)	0	0
<i>Eye problems</i>	1 (50.0)	0	1 (50.0)	0
<i>Headache</i>	1 (100.0)	0	0	0
<i>Loss of appetite</i>	1 (100.0)	0	0	0
<i>Hypertension</i>	0	0	1 (100.0)	0
<i>Lung problems</i>	1 (100.0)	0	0	0
<i>Kidney problems</i>	0	0	1 (100.0)	0
<i>Allergic reactions</i>	0	0	1 (100.0)	0
<i>Others</i>	2 (33.3)	2 (33.3)	2 (33.3)	0

Quality of care

Experience with the organisation of care

	Very satisfied	Rather satisfied	Rather unsatisfied	Very unsatisfied
<i>Specialist</i>				
<i>Dermatologist</i>	24 (72.7)	7 (21.2)	2 (6.1)	0
<i>Surgeon</i>	16 (61.5)	9 (34.6)	0	1 (3.8)
<i>Oncologist</i>	23 (92.0)	2 (8.0)	0	0
<i>Radiation oncologist</i>	8 (80.0)	2 (20.0)	0	0
<i>Others</i>	2 (50.0)	2 (50.0)	0	0
<i>General practitioner</i>	20 (76.9)	6 (23.1)	0	0
<i>Coordinating nurse for oncology care</i>	10 (76.9)	2 (15.4)	1 (7.7)	0
<i>Nurse on consultation in hospital</i>	8 (80.0)	2 (20.0)	0	0
<i>Psychologist</i>	7 (77.8)	2 (22.2)	0	0
<i>Physiotherapist</i>	7 (87.5)	1 (12.5)	0	0
<i>Home nurse</i>	5 (71.4)	2 (28.6)	0	0
<i>Radiotherapeutic technician</i>	5 (100.0)	0	0	0
<i>Dietitian</i>	2 (40.0)	2 (40.0)	1 (20.0)	0
<i>Social worker</i>	4 (100.0)	0	0	0
<i>Emergency services</i>	3 (100.0)	0	0	0
<i>Speech therapist</i>	1 (100.0)	0	0	0
<i>Other</i>	2 (40.0)	2 (40.0)	1 (20.0)	0



Quantity and clarity of information received		n (%)
	<i>Too much</i>	1 (2.7)
	<i>Sufficient</i>	33 (89.2)
	<i>Insufficient</i>	2 (5.4)
	<i>I didn't receive any information</i>	1 (2.7)
	<i>I don't know</i>	1 (2.7)
Involvement in treatment choice		n (%)
	<i>No</i>	13 (35.1)
	<i>Yes</i>	10 (27.0)
	<i>I don't know</i>	1 (2.7)
	<i>Not applicable</i>	13 (35.1)
Accessibility of care		
Reason for foregone care		n (%)
	<i>Transport problem</i>	1 (2.7)
	<i>Very long waiting times</i>	1 (2.7)
	<i>Lack of information</i>	1 (2.7)
Waiting time		n (%)
<i>Time between first symptoms and decision to consult</i>		
	<i>Less than 1 week</i>	6 (16.2)
	<i>1 week to 1 month</i>	10 (27.0)
	<i>1 to 3 months</i>	3 (8.1)
	<i>More than 3 months</i>	17 (45.9)
	<i>I don't know</i>	1 (2.7)
<i>Time between decision to consult and first consult</i>		
	<i>Less than 1 week</i>	15 (40.5)
	<i>1 week to 1 month</i>	8 (21.6)
	<i>1 to 3 months</i>	4 (10.8)
	<i>More than 3 months</i>	7 (18.9)
	<i>I don't know</i>	3 (8.1)
<i>Time between first consult and diagnosis</i>		
	<i>Less than 2 weeks</i>	18 (48.6)
	<i>2 weeks to 2 months</i>	16 (43.2)
	<i>2 months to 1 year</i>	2 (5.4)
	<i>More than 1 year</i>	1 (2.7)
	<i>I don't know</i>	0
<i>Time between diagnosis and first treatment</i>		



<i>Less than 1 week</i>	10 (27.0)
<i>1 to 2 weeks</i>	11 (29.7)
<i>2 weeks to 1 month</i>	12 (32.4)
<i>More than 1 month</i>	4 (10.8)
<i>I don't know</i>	0

Appendix 1.3. Summary table – Unmet social needs

Social support	
Social support not received	n (%)
<i>Talk to healthcare professionals</i>	10 (27.0)
<i>Talk to other patients about your disease</i>	9 (24.3)
<i>More help with day-to-day activities that you are currently receiving</i>	1 (2.7)
<i>Talk about things other than health problems</i>	1 (2.7)
<i>Work resumption support</i>	1 (2.7)
<i>Other</i>	3 (8.1)
Impact on work	
Unable to work because of health issue	n (%)
<i>Yes</i>	8 (26.7)
<i>No</i>	22 (73.3)
Returned to work	
<i>Yes, as before</i>	2 (25.0)
<i>Yes, less than before</i>	3 (37.5)
<i>No, due to current state of health</i>	3 (37.5)
<i>No, due to other reasons</i>	0 (0)
Financial impact because of health issue	
<i>Loss or lack of income</i>	8 (61.5)
<i>Medical expenses</i>	6 (46.2)
<i>Loss of employment or unemployment</i>	1 (7.7)
<i>Others</i>	1 (7.7)



APPENDIX 2. ORIGINAL TESTIMONIALS

[1] «Nu denk ik dat de melanoom op zich heeft energie gekost die eerste twee maanden, twee, drie maanden. Maar dat het op zich nu niet meer is. Ik had al een verleden. Dus ik denk dat het meer dan de borstkanker is. Ik had ook nog CVS, dus ja, het is een en-en-en-verhaal. Maar het melanoom zelf kan ik nu niet zeggen, het vreet energie op die momenten dat je van onderzoeken gaat en op uitslagen moet wachten en dergelijke. Maar ja, daarna is dat eigenlijk vrij goed verlopen.» (7N1)

[2] «Dat heeft natuurlijk impact gehad als ik geopereerd werd. Zowel... Alé, die je nog altijd impact, want vroeger ging ik ook... Nu ligt de voetbal wel even stil, maar dat gaat weer terug beginnen. Vroeger ging ik ook op maandag en woensdag naar de kantine, 's avonds tijdens de trainingen, om de kantine open te houden. Maar dat kan ik niet meer. Dat doe ik niet meer, omdat de ene dag zou dat wel kunnen, de andere niet. Maar de mensen moeten op u kunnen rekenen. Ik ga dat wel zien naar de toekomst toe, of ik dat terug kan opnemen, of één dag in de week. Maar 's avonds, laat ons zeggen, waarschijnlijk ook door die cortisol. In de avond, vanaf een uur of zes, half zeven, is mijn pijp uit, ik zal het zo zeggen, en dan ben ik echt... Omdat ik overdag ook niet... Ik zit niet stil, hè. » (12N1)

[3] « Et il vous envoie vers un hôpital... un gros hôpital universitaire, [name of the hospital], bon ça va et vous savez bien que c'est un très gros hôpital universitaire, donc ça aussi ça induit un stress parce qu'on se dit, "bon si on m'envoie là c'est que..." » (10F1)

[4] «Ja, dat is een slag op mijn kop als je dat hoort. Omdat je weet ten eerste: kanker, dat is al iets. Het woord kanker. Dan melanoom, dat je weet, dat is toch wel iets serieus. Alle kanker is wel serieus, maar ja. [...] Oh ja, psychologisch, gewoon het woord kanker is sowieso. Ze zeggen dat er is een leven, voor en na kanker, en dat is ook zo. En dan bedoel ik louter op psychologisch.» (12N1)

[5] « Mais on est dans le service onco quoi ! Donc c'est vraiment avec tout. Avec tous les patients qui sont sous chimio, etcetera. Donc ça c'est aussi en plus... enfin c'est encore plus... c'est confrontant. » (7F1)

[6] «Donc, entre chaque patient, ben je ne pensais qu'à une chose, je pensais à l'hôpital, et puis je pensais surtout...surtout aux enfants, et des choses comme ça [...] On est occupé avec le patient donc on n'y pense pas mais on arrive dans la voiture et voilà « si s'il se passe quelque chose, s'il m'arrive quelque chose, qu'est-ce que mes enfants vont devenir »...etcetera. Donc c'était ça. Tout le temps, tout le temps. » (7F1)

[7] «Want ik ben wel ziek, maar als ik dood ga, blijft mijn vrouw wel achter. Dus daar ook psychologisch hakt dat ook wel even diep in.» (3N1)

[8] «Dat mijn leven nu totaal verandert, ook al stopt de therapie. Ja, ik toch, om de paar maanden naar de dermatoloog. En je gaat altijd de schrik hebben dat er een vlekje... Ja, dat heb ik nu ook. Dus ik ben bepaald in de douche, en ik zie een vlekje dat ik dacht, 'dat was er nog niet'. » (4N1)

[9] «Maar het is moeilijker. Een probleem dat klein is, wordt nu uitvergroot. Ik merk ook dan, dat ik word dan zenuwachtiger. En dat is niet mijn karakter, want normaal gezien als er een probleem is ik moet kalm blijven.» (4N1)

[10] « On est très fragilisé quand on arrive à l'hôpital. [...] Enfin moi je me suis senti très fragilisée d'ailleurs quand je suis rentrée dans la chambre seule, puisque la dame m'a déposé à l'entrée, je suis rentrée dans cette chambre à 9h du matin et j'ai fondu en larmes quoi. [...] je me sentais abandonnée, totalement abandonnée et...voilà quoi. C'est comme si on vous amène en prison. » (10F1)

[11] «Dat vind ik wel heel belangrijk, van mensen die dan, bij wijze van spreken, uitbehandeld zijn. Of dat die dan toegang kunnen hebben naar



eventuele, toch, therapieën die dat misschien toch nog hoopvol kunnen zijn. Dat vind ik... Want ik denk dat als je dat woordje krijgt; dat je uitbehandeld bent, dat het een serieuze kloep is. En dat denk ik toch nog op manieren zou proberen om toch nog iets te vinden dat toch nog zou kunnen aanslaan.» (12N1)

[12] «[...] on a installé maintenant une pergola, en me disant que maintenant si je veux aller, je vais dehors. Ce n'est pas moi qui vais changer mes habitudes pour aller manger ou des choses comme ça. Si je veux aller au soleil ben non, je ne vais pas au soleil, mais si je veux aller dehors je peux aller dehors. Donc je vais en me disant voilà, c'est moi qui aura le dessus. J'ai mis de la verdure dans le jardin en fait, tout simplement. Pour avoir des zones d'ombre, des choses comme ça. Donc euh oui psychologiquement comme ça en me disant « non, je ne vais pas me laisser faire. » (7F1)

[13] «Het enige wat ik nu wel ga doen als ik de volgende keer naar [name of the hospital] ga, is inderdaad, is op advies bij psycholoog of psychiater, eens te praten, want ik probeer dat zelf te verwerken en ik merk dat dat niet altijd echt lukt, omdat je blijft in een soort van vicieuze cirkel zitten, want ik zeg altijd, elke keer als ik naar [name of the hospital] ga, 'waarom doe ik dat, waarom doe ik dat?' En uiteindelijk zou ik daarmee moeten stoppen en zeggen, 'goed ik doe het'. En niet elke keer de vraag stellen, want dan komt dat bij mij ook andersom. Dus die twijfel altijd, die eeuwige twijfel. Dus dat is wel een van de prioriteiten nu wel, ja.» (4N1)

[14] «Non, je n'en ai pas éprouvé le besoin. Puis j'ai eu la famille qui était là. Des personnes qui étaient... qui sont dans le milieu médical. Donc, c'est aussi plus facile. Mais oui je peux comprendre que quelqu'un va avoir... devrait avoir besoin... allez d'avoir ce soutien psychologique en plus. J'ai quand même eu un accident de voiture, aussi. Donc ouais un suivi psychologique ça aurait été peut être bien pour beaucoup de personnes. » (7F1)

[15] « Après combien de temps je peux redonner mon plasma ? Donc

j'ai été transférée directement au médecin. Le médecin me dit....enfin je repose directement la question et le médecin me dit « oui, ben c'est fini. » Il n'y a pas... Vous ne pouvez plus donner votre plasma. » Donc de nouveau on se dit la maladie est finie, mais au final elle n'est pas finie, elle ne sera jamais finie puisque c'est à vie qu'on ne peut plus donner son sang. » (7F1)

[16] «Ja. Het kan die massa niet meer aan. Ik heb meer nu met die scootmobiel is dat beter. Ik zit en nu moet want ik doe nu ook altijd mijn wandelstok mee. Want ja, als we ergens zitten en ik moet iets gaan plassen, moet ik mijn wandelstok nemen. Voor alle plaatsen die je niet kent. Thuis, ga ik hier wel om en 't weer. Dat is iets anders. Dan heb ik mijn wandelstok gelukkig nog niet nodig.» (11N1)

[17] «Nu zijn we in de fase dat we dus eigenlijk de bijwerkingen van de immunotherapie proberen te kaderen, maar voor mij is het elke keer als ik naar het dagcentrum oncologie ga, toch weer zo iets van wat kom ik hier doen? Omdat het is niet bewezen, ook niet in de literatuur dat die therapie die ze me nu geven, het is niet standaard, maar wat is standaard natuurlijk... Dus ik zit altijd nog in de twijfel van wat kunnen ze... Ik bekijk het zo, als je geen hoofdpijn hebt, ga je dan hoofdpijnstillers nemen? En als er geen tumors zijn, wat doet eigenlijk die immunotherapie dan in mijn lichaam?» (4N1)

[18] « Je ne sais pas si ça existe déjà, un peu comme les campagnes où on peut aller directement chez le médecin, où ils font un jour mélanome. Voilà, c'est un jour pour tout le monde, on inspecte la peau de tout le monde. Donc euh... peut-être ça ? [...] Mettre des étudiants en dermatologie, à leur demander aussi quoi. Sous supervision d'un prof, ou quoi que ce soit. [...] De faire... oui, un dépistage à l'échelle nationale. » (7F1)

[19] «Voorkomen. Daar een campagne rond. Zorgen dat er een goede identificatie kan gebeuren op tijd. Vroege detectie.» (11N2)

[20] «Maar ik denk dat als er dan in de medische wereld nog iets kan



gebeuren, dan denk ik dat je eigenlijk het vroegtijdig opsporen belangrijk is. Omdat ik ga nu eigenlijk al ieder jaar naar de dermatoloog en toch hebben we het gemist. Dus, ik vraag mij af of dat er geen andere mogelijkheden of methoden of toestellen zijn die het beter kunnen opsporen.» (11N2)

[21] «Chemo heb ik nog, chemo, chemo, dat weet ik niet. Ja, dat weet ik niet zo goed allemaal. Dus wacht, ze hebben eerst chirurgie gedaan, dan hebben ze de lymfeklier verwijderd, dan een stuk long verwijderd. Als je dat allemaal zo vertelt, dan zit er nog radiotherapie tussen, dan een stukje long verwijderd, dan immuuntherapie en nu targeted therapie. Dus ik denk dat ik zo alles heb gehad dat er momenteel op de markt is.» (3N1)

[22] «Dat heeft een oncoloog bepaald, daar heb ik mij volledig moeten in vertrouwen zetten met de oncoloog. Want er zijn natuurlijk veel verschillende producten. Er zijn ook, want je gaat dat inderdaad ook liever opzoeken zo, van... Met mij was dat [name treatment], heb ik gekregen. Maar er zijn ook, ik zie dan ook, dat er soms combineren met twee verschillende medicaties, medicamenten. Dus ja, dat is puur vertrouwen op een dokter. Omdat met het soort kanker dat ik heb, dat zij dat de beste behandeling vond.» (12N1)

[23] «Osteopathie en acupunctuur, als je dry-needling spreekt en in acupunctuur, voornamelijk ook stressgerelateerde klachten, dat die daar wel mee kunnen behandeld worden. Uiteindelijk heb je een hele hoop... Je zit constant onder stress en je begint klachten te krijgen. Dus die worden wel... Ik ga ook naar een osteopaat en die kraakt er alles goed uit. Dat helpt, ik heb ondervonden. Wat ik nog over de laatste tijd een beetje heb leren kennen, is gewoon zorgmassages en dergelijke.» (3N1)

[24] «Nee, vanaf dat ik eigenlijk bij de oncoloog ben geweest, de eerste dag eigenlijk al, heeft hij gezegd, we gaan je op ziekteverlof zetten, want je gaat veel aan je hoofd hebben, je gaat veel afspraken hebben in het ziekenhuis, en ook emotioneel zei hij, is het beter dat je op ziekteverlof

staat. Dus hij heeft me eigenlijk direct, voltijds, op ziekteverlof gezet, en dat is nu op dit moment nog altijd zo.» (11N2)

[25] «Dat is een daguitstap. Ik zie dat als een daguitstap. Het is vijf, zes uur, want het is in [city]. Dat is een uur en een half dat ge daar dan nog ligt op dat bedje.» (8N1)

[26] «Het is pas als het ja, als het erger wordt en het zaait uit natuurlijk, dan kan het ineens snel gaan natuurlijk hé. [...] Dus dan word je er echt wel mee geconfronteerd, maar de eerste keer, als ik zoiets van oké het is weg, het is weg hé, dan ga je er vrij snel over, het is niet zoals bij een andere kijk, als het in een orgaan zit of weet ik wel, maar dat zit binnenin je, is dat is een totaal ander gevoel dan op je huid zit en ze snijden dat weg en dat is weg hé.» (3N1)

[27] «Volgende week moet ik de maandag een PET-scan hebben, en dan heb ik de woensdag daarvan de consultatie. Dat zijn wel zeer stressmomenten. Dat voel ik wel weer. Dat de laatste week, dat dat zo weer aan het opbouwen is, de stress van die scan.» (11N2)

[28] «Ik zeg het, de meeste symptomen zijn, waar ik meeste last van heb is misselijkheid, spontane misselijkheid, pijnlijke gewrichten. Ja, dat slecht slapen, dat is voor mij het grootste probleem, dat is voor iedereen trouwens, slecht slapen.» (4N1)

[29] «Die zijn bij mij heel ernstig, de gevolgen. In die zin dat ik een hypofysitis heb gekregen door de immunotherapie. Mijn hypofyse dus niet meer werkt, niet op dat gebied. Ik heb geen diabetes, of nog niet. En daarom moet ik cortisol nemen. Iedere cortisol. En dat is natuurlijk, ja, niet gemakkelijk om de juiste dosering en zo verder. Met andere woorden: vermoeidheid.» (12N1)

[30] «Dat was na de bestraling eigenlijk, dan had de dokter eigenlijk, ja er zat eigenlijk een ontsteking, er was een open wond in onder mijn oksel en die is ontstoken geraakt en eh, dan ook weer, ik had begin van de sepsis, dus mijn lymfeklieren en de dingen waren helemaal



ontstoken.» (3N1)

[31] «Moments de gros stress comme quand je me suis rendue compte que je devais changer mes pansements et que je n'avais pas de solution. Et alors j'ai fait à ma première sortie, au bout de quelques jours je me suis dit « bon ben je vais quand même aller faire un petit tour en ville, ça me fera du bien », et en fait quand je suis rentrée bah j'avais fait une allergie aux pansements ici. » (10F1)

[32] «Het is geen slaappil, maar een inslapertje. Dat is een half tabletje. Maar dat is psychologisch, denk ik, als ik dat doe. Maar mijn gemiddeld slaappatroon is zes uur. Dat heeft ook een beetje met de ouderdom te maken. Maar ik merkte wel wat er gebeurde als ik dat pilletje niet nam, dan werd ik nachts wakker en dan begon ik te hyperventileren eigenlijk. Ik ben dat niet gewend, ik ben een heel goeie slaper voor die therapie.» (4N1)

[33] «En het feit dat daar een tumor in de lymfeklier zat, dat op zich en nu de immunotherapie, dat op zich beïnvloed mijn dagelijks leven niet zo veel. Maar de operatie wel. Dat heeft ook een enorme impact op mijn mobiliteit. En ja, ik voel me op dat vlak eigenlijk niet echt goed ondersteund. Ik was bedlegerig als ik uit het ziekenhuis kwam. Wat ik eigenlijk ook niet verwacht had.» (11N2)

[34] «Ja, als je een put moet boren, bij wijze van spreken, kan je er geen mooi oppervlak van maken. Hoe ervaar ik dat? In het begin heb ik daar eigenlijk... eventjes wel gedacht: "amai, wat is dat hier? Moet ik nu altijd lange broeken dragen?" Nee, toch niet. Ik loop daarmee bloot. Dan draag ik een keer een korte broek en dan valt dat wat minder op. Maar die diepe zie je altijd, want ik moet erbij zeggen... Echt. Spannende broeken kan ik niet meer dragen. Ik heb al mijn lange broeken weg moeten doen. Dus... Chirurgisch heeft hij gezegd: "Kijk [naam], daar ga je met moeten leren leven. Het ene been gaat altijd dikker zijn dan het andere.» (11N1)

[35] «Want bij mijn eerste operatie ging er vanonder de grote kuil uit.

Mijn haaienbeet zeg ik daartegen. Toen heb ik even... Ben ik drie maal tot bij de psychologe geweest.» (11N1)

[36] «Ik wist ook totaal niet wat gedaan met mijn tijd. Ik lag daar maar, ik kon eigenlijk fysiek bijna niks, maar mijn geest stond wel niet stil. En dan kan ik u verzekeren, iedereen zegt van, oh, ik je kan Netflix series kijken, zo leuk. Nee, dat is niet leuk. Om te beginnen, verveelt dat op de duur, van heel de tijd maar naar de tv te kijken [...] Dus ja, het was echt lastig om iets te vinden, om zoiets betekenisvol activiteit te vinden.» (11N2)

[37] «Ik ben zou ook ondertussen wel terug onder de PET-scan moeten. [...] Waarom heb ik "nee" gezegd? Ik voel mijn eigen lichaam en ik ben nog altijd recupereren. En die PET-scan, dat moet ik jou niet zeggen, dat is twee uur veel radioactief spul. Ergens kan dat voor mijn andere organen, of weet ik veel, ook niet goed zijn. Vooral voor die nieren niet. Want waar slaagt dat op? In de nieren. Dus ik heb dat gewoon geweigerd, want ik voelde dat ik dat niet aankon.» (11N1)

[38] « [Est-ce que vous avez dû suivre un traitement au-delà de l'opération ?] Non. [Et vous avez pris des médicaments suite à l'opération ?] Non [Peut-être des antidouleurs?] Ah oui, sur la feuille il était marqué donc j'ai un peu pris les premiers jours mais très peu parce que j'essaie d'éviter. » (10F1)

[39] «En het pakt wel wat tijd, ik noem die om de twee weken, op donderdag op consultatie en op vrijdag een baxter gaan halen. Ja, dat pakt tijd. En op de duur heb je zoiets van ja. Want je moet dan naar de dermatoloog om zoveel maanden, drie maanden denk ik. En dan nog eens naar de oogarts, want een melanoom kan ook in die oog zitten. Dan kan een dermatoloog dat niet zien. En dan moet je ook nog eens naar de gynaecoloog, want ook daar ga je melanomen hebben. En zo blijf je bezig met veel onderzoeken.» (11N2)

[40] «En ja, ik voel me op dat vlak eigenlijk niet echt goed ondersteund. Het begint al met het verhaal van je hebt dan eigenlijk een oncoloog



nodig omdat je kanker hebt. Maar hij opereert niet. Hij stuurt u door naar de chirurg die dan gespecialiseerd is. Hij stuurt u gewoon door naar chirurgie. En dan begint in chirurgie het verhaal van welke dokter gaat u dan opereren. Ik zat eerst bij één chirurg, maar die had dan zoiets van ik ben eigenlijk niet gespecialiseerd in die streek. Dus dan kom je bij een andere chirurg terecht. Ik heb dikwijls een metafoor gebruikt van ze zijn een estafette aan het spelen met mij en ik ben de stok. Ik was al eerst bij een chirurg die heeft mij doorgegeven aan de oncoloog. De oncoloog heeft zijn werk gedaan. Die geeft mij terug aan de chirurg. En ik had nooit echt het gevoel dat er daar communicatie was.» (11N2)

[41] « Les salles d'attente l'une à côté de l'autre donc euh... celui qui ne fait pas attention il a l'impression qu'il est chez le dermatologue. Ouais, et puis ça permet aussi d'avoir un traitement global, vous ne devez pas vous soucier de savoir où vous allez, c'était pris en charge au niveau de l'hôpital, et j' imagine la prise de rendez-vous, tout ça se faisait automatiquement. » (7F1)

[42] « Donc moi j'ai gardé mon téléphone toujours près de moi en donnant cours, en me disant « bon ben elle va m'appeler », je vous dis c'était le mardi. Fin de semaine toujours pas de nouvelle. Le lundi comme j'avais toujours pas de nouvelle ben j'ai rappelé [name of the hospital], et là on m'a dit « ah mais la secrétaire elle était en congés, elle revient demain ». (10F1)

[43] « Pour retirer les fils il m'a envoyé chez mon généraliste une dizaine de jours après, je suis allée chez mon généraliste qui m'a retiré les fils, et qui devait recevoir les résultats... ben d'après ce qu'on avait calculé : quelques jours après. Et donc le généraliste qui est débordé m'a dit, « voilà vous m'envoyez un sms vendredi à 10h et je vous répondrai tout de suite ». [...] jamais eu de réponse de mon généraliste » (10F1)

[44] « Meer geïntegreerde zorg dat je, die controle artsen dat moet er zijn en er moet ergens controle zijn en dergelijke, maar je denkt in het geval van kanker, als je naar een oncoloog gaat die zegt dat je kanker hebt en dat je een bepaalde tijd moet thuisblijven of voor langere tijd

moet thuisblijven, wat is het nut dan om nog eens een keer naar een controle arts te gaan en daar nog eens een keer alle problemen van dien te hebben en weet ik wel nog allemaal, dat je dan elke maand opnieuw een papier moet gaan invullen om te zeggen ik ben nog een maand ziek en weet ik nog allemaal. Dat kan op een andere manier gebeuren en dat hoeft niet per se via de patiënt te lopen op die manier, ik denk dat dat ook wel belangrijk is, dat je kunt zeggen van oké als je een dokter u ziek schrijft dat dat gewoon ook doorgegeven wordt aan de ziekenkas zonder dat er nog eens een keer een papier moet ingevuld worden voor, allee, een heel papier moet ingevuld worden dan naar het ziekenhuis gebracht moet worden of dat je, en dan moeten die datums nog een keer goed matchen en weet ik wat nog, hoeveel papieren dat ik opnieuw heb moeten binnen doen omdat er een en ander verschil was, dat er dan ene van de vrijdag is en dan ene van de maandag en dan zeg dat niet want dan moet dat van de zaterdag lopen en weet ik, mannetjes.» (3N1)

[45] « Maar dat vind ik niet vervelend, maar ik denk dat soms het proces, de assistenten komen naar mij met vragen, terwijl ik elke dag een dagboek in voer via de Nexus-app health, dus ik moet elke dag een dagboek ingevoerd hebben, waar ik de symptomen doorgeef, en daar gaat wel te veel tijd tussen. [...] Zowel psychologisch als symptomen. Voor onze patiënten hebben ze een dagboek, waar ik dan moet zeggen, misselijkheid, vermoeidheid, psychologische belasting, temperatuur, daar zet ik maar wat in, want ik ga niet elke keer temperatuur, maar ik doe dat dagelijks.» (4N1)

[46] « Voilà je lui ai juste signalé que j'avais quand même mal... Chaque fois que je mangeais, que j'avais mal, alors juste derrière la cicatrice, et là il m'a coupée. Et il m'a dit : « non ». » (10F1)

[47] « Voornamelijk het gevoel dat er niet geluisterd wordt en dat je niet au sérieux genomen wordt hé. Dat was de voornaamste reden dat we gewoon gereden van oké we gaan naar een andere huisarts in de toekomst.» (3N1)



[48] «Wat ik gemist heb, dat is de aandacht vanuit verpleging naar de patiënt die wat emotioneel is. Als ze daar wat meer op letten, dan hebben ze geen psychologen nodig. Dus dat is belangrijk, meer aandacht voor in de opleiding en het werk van verpleegkundigen, voor dat psychosociale. Ik denk dat dat wil zeggen dat ze ook betere processen op de afdeling moeten hebben, dat de mensen dat kunnen doen. Het ligt meestal niet aan hun persoonlijke in ingesteldheid, maar aan het feit dat er geen ruimte is, of dat er geen aandacht voor is op de afdeling zelf.» (11N2)

[49] «Maar als je zegt, luister, een of twee mensen die eens een goeie dag komen zeggen, maar niet over oncologie praten, maar over de mens praten, maar over de mens zelf, want ik krijg altijd dezelfde vraag, hoe voel je je? Ja, wat moet ik zeggen? Dan zeg ik, ja ik voel me goed, maar ik voel me niet goed. Allez, ik vind dat geen domme vraag, maar als je dat 20 keer moet horen, nee, er zijn andere zaken waar je zou zeggen, luister, ik maak het iets psychologisch anders.» (4N1)

[50] « Je sais qu'au niveau suivi social, ça ne fonctionne pas. Les assistantes sociales sont débordées par rapport à toutes les situations etcetera, mais donc, sinon oui, c'est vrai que dans l'idéal ben voilà, un coordinateur.... voilà. Je sais qu'il devrait être le généraliste, mais qui lui n'a plus le temps. Les généralistes, ils sont tous [...] débordés. Ils n'ont pas le temps de jouer le rôle d'assistante sociale qui suit bien le dossier de Madame « Trucnuch » qui doit aller là, qui doit appeler là, qui doit faire ça. » (10F1)

[51] «Ik denk dat het algemeen probleem is dat dat wel mag aangekaart worden [...] is zeker die keuze van het hospitaal. Waar je je laat opereren, dat maakt zo niet uit. Maar ik heb voor [name university hospital] gekozen, omdat we wisten dat daar goede specialisten zaten. Maar daar stopt het. En dan moeten ze niet zeggen, als er dan iets gebeurt, dan moet het openstaan. Dat moet gewoon openstaan, want dan zeggen ze goed, je bent een patiënt, maar je kan XYZ je immuuntherapie halen. Ik weet niet of daar winst op gemaakt wordt, maar dat zal niet. Maar goed, voor mij zou dat anders zijn moesten ze

zeggen 'dat is geen probleem' we zullen contact nemen met iedereen, want dat zie ik ook in die app uit. Al de uitslagen die ik bijvoorbeeld leer uit het hospitaal of bij mijn hartspecialisten, de cardioloog, dat komt ook in die app. Dus ze kunnen dat allemaal kijken. Dus ik denk dat dat een van de hoofdpunten zou zijn, niet voor mij alleen, maar voor veel patiënten, dat er een soort van vrijheid is van keuze.» (4N1)

[52] «En daar, ja, ik wist dat natuurlijk niet, wat gaat er moeten gebeuren, kan dat zo gehecht worden? Dat wisten ze zelf ook nog niet. Moet dat met plastische chirurgie? Moet er een stukje huid getransplanteerd worden? Omdat het wel een, ja, eigenlijk een groot kankergezwel, relatief groot kankergezwel, was. Dus daar was ik eigenlijk naartoe gegaan met de bedoeling van er iets over te horen. [...] Ik kreeg er niet direct een antwoord, maar dan uiteindelijk, ik denk een nieuwe afspraak moeten maken, een gewone consultatie. En dan, ja, werd dat wel een beetje meer besproken, wat we vroeger besproken en heeft hij gezegd: "Van kijk, we zullen zien op de moment van de operatie of dat er, wat er kan en wat er niet kan."» (12N1)

[53] « Pour ce qui est post-opératoire, donc quand je suis venue le jeudi, je devais aussi passer aux inscriptions, où on m'a expliqué... pas suffisamment de choses, et en tout cas...absolument rien par rapport à ce qui était post-opératoire...et on ne m'a posé aucune question. » [...] « Le chirurgien ne m'a pas du tout dit lors de la consultation, voilà après une intervention comme ça moi je ne me rendais pas du tout compte, il y a autant de semaines de convalescence. » [...] « Personne ne m'a demandé après l'opération, si j'avais quelqu'un près de moi pour me surveiller, pour m'aider, pour euh... et on ne m'a pas non plus expliqué que j'aurais besoin d'une infirmière pour changer les pansements. On ne m'avait rien dit. » (10F1)

[54] « Oui, sur le traitement, sur l'avancée dans la recherche sur le mélanome, comment soutenir la recherche sur le mélanome, s'il y a des choses aussi... L'espérance de vie par rapport au stade, parce qu'on voit plein de choses, euh... qui sont contradictoires aussi. » (7F1)



[55] «Dus ja, het is een beetje zoeken naar informatie. Ik heb nu wel begrepen van de dokter dat ze bezig zijn aan een interactieve brochure of zo, in verband met melanoom. Maar ik weet nu niet juist van hoe of waar dat in elkaar zit. Waarin je specifiek informatie kan gaan zoeken. Oké, waar is de behandeling? In welke stadium zit jij? Welke behandeling ga jij krijgen?» (3N1)

[56] « C'est en faisant les recherches sur internet aussi que je le fais comme ça. Parce que les infos je ne les ai pas par lui... Il m'a dit « oui il faut vous protéger » mais sans plus. Ici, j'ai différentes associations, ou on voit sur Youtube aussi des personnes qui parlent du mélanome, et qui disent « voilà, toutes les trois heures » ils se remettent de la crème solaire ; de la cinquante. Des choses comme ça. Oui, mais oui. Internet, un peu Youtube parce qu'il y a des expériences. Du partage d'expérience. Mais comme du tout... ma formation, ben je vais sur Pubmed : je sais où chercher les informations qui sont pertinentes quoi. Je ne vais pas directement... enfin je ne vais pas sur Google, et je ne cherche pas comme ça. Donc je sais pas du tout où ça en est par rapport à ça, si on donne des bonnes informations ou pas. Je ne fais pas attention. » (7F1)

[57] « Ils m'ont toujours demandé hein... « est ce que vous avez encore des questions ? ». Mais sur le moment on n'a pas vraiment de question. [...] C'est vrai qu'ils m'ont toujours demandé « est ce que vous avez encore des questions ? », etcetera... mais pas si vous avez des questions, vous pouvez téléphoner à un numéro ou... Non, ça il n'a pas eu. Donc ce serait peut-être bien aussi, de mettre quelque chose à disposition pour euh... quelque chose d'officiel quoi. » (7F1)

[58] «Ik had een papiertje meegekregen. Ik heb die mevrouw ook gezien. Wat ze een onco-coach noemen. Die je mocht bellen als er iets was. En ik heb een keer gedacht van, ik krijg hier uitslag, maar dat was dan niks. En ik heb toen gebeld en de madame heeft me gezegd, doe dit of doe dat of... Allee, ja. En dan heb ik nooit iets meer gehad. Ik heb nooit meer moeten bellen.» (8N1)

[59] «Maar ik moest binnen de tien dagen daar zijn voor de draadjes eruit te doen. Oké. Maar wie er niet belde? Dat was mijn dermatoloog. En ik wist dat er stront aan de knikker was. Want ik kende haar te goed, we waren zo bevriend. Dat ze tegen mij alles zou zeggen en nu belde ze niet. Dus oké, ik ga naar haar om de draadjes eruit te doen. "[Naam], kom maar!" En ik zeg vlakaf tegen haar: "Geen goed nieuws, zeker?" "Nee", zegt ze "Ik durfde je niet bellen."» (11N1)

[60] « Ce que je reproche un petit peu [...] c'est qu'elle n'en n'a jamais employé le mot quoi. Elle m'a dit « bon, ça il faut enlever, il faut prendre rendez-vous avec le chirurgien, vous appelez le chirurgien demain ». Et elle avait mis « tache à l'abdomen », quelque chose comme ça. Euh... « tache colorée » [...] Oui, peut-être, d'être plus explicite parce que j'aurais pu continuer de me dire « oui bon, c'est pas grave, je ne prends pas rendez-vous tout de suite ». Peut-être employer le mot, et l'expliquer clairement. » (10F1)

[61] «Van die klinische bioloog, je krijgt gewoon een brief hé, een ding van ja het is melanoom en eh, dan moet je naar de dermatoloog, je moet weer een paar weken wachten, naar de dermatoloog om dan te kijken van oké hoe gaat het behandeld worden verder.» (3N1)

[62] «Eigenlijk moet ik zeggen dat die dokter, de plastische chirurg, heel correct was. [...] Nee, op een... Ja, toch een kalme manier van spreken. Ik mocht vragen stellen, hij antwoordde correct.» (11N1)

[63] « Vraiment très bien. Tellement bien que sur le coup moi j'étais tellement choquée que je lui ai dit... je suis partie en disant « ah ben je vous remercie parce que j'imaginais pire que ça » ! Alors que voilà, en dermato il n'y aurait pas eu pire que ça finalement. » (7F1)

[64] «Maar ik moet ook wel zeggen, mijne oncoloog die heeft ook wel de nodige informatie verstrekt. Niet alleen aan mij, maar ook aan mijn vrouw, mijn kinderen. Ik denk dat mijn ouders er een keer mee gebeld hebben. En hij heeft elke keer tijd genomen om dat uit te leggen, van oké, dat is het. Hier zitten we nu. Dat zijn de behandelmogelijkheden.»



(3N1)

[65] «Ja. Maar bij mijn huisarts had ik wel het gevoel dat ik daar echt geen tijd voor had. Maar voor niets. Dan moet ik maar twee, drie afspraken maken, want daarvoor had hij geen tijd. Voor al mijn vragen. Dus ja, daar ga ik zeker niet meer.» (8N1)

[66] « Et alors il m'a tout expliqué, par le détail, et avec les mots...euh les mots scientifiques, et heureusement j'avais prévu une feuille de papier et un bic, tous les mots que je comprenais pas du tout ce qu'il me disait, en même temps il expliquait un petit peu quand même, mais il y avait des choses que je ne comprenais pas, ce qui m'ont permis après d'aller chercher sur internet et de bien comprendre à mon aise. » (10F1)

[67] «Het juiste niveau van informatie, dat vind ik eigenlijk niet. Allez, bijvoorbeeld, ik heb nu de laatste keer dat ik bij hem was, echt nog eens stap voor stap alles overlopen. Omdat, ik weet dat, ik geef dat zelf aan mijn studenten, dat als ze slechte boodschap overbrengen, dan weet je dat de patiënten maar de helft horen. Ofwel horen ze het verkeerd, ofwel onthouden ze het niet. Maar ik dacht altijd van, ja, dat overkomt mij niet, want ik ben getraind eigenlijk, als het erop aankomt. Maar dat is niet waar, dat gebeurt bij mij ook. Dus ja, de laatste keer heb ik zo nog eens echt alles overlopen met een oncoloog van, wat heb ik daar nu goed begrepen, heb ik dat niet goed begrepen. En dan legt hij dat wel weer opnieuw uit. Ik zeg dat tegen hem, maar laat het mij eerst een keer met mijn eigen woorden zeggen. En bevestig dan, of corrigeer dan.» (11N2)

[68] «Als je informatie opzoekt, dan vind je twee dingen. Ofwel, heel eenvoudige informatie, echt super eenvoudige, dat iedereen kan begrijpen, waarbij dat de dingen zo zwart-wit worden voorgesteld, dat je er eigenlijk ook niks mee bent, want dat gaat dan eigenlijk niet echt over u. Plus dat je daar ook niet wilt in herkennen, want dat gaat dan meestal over slechte prognose, goede prognose. Dus dat is niet goed. Allez, dat is zo, dat er op de website Kom op tegen Kanker staat, daar

ben ik niks mee. Maar de andere dingen dat je dan zoekt, de wetenschappelijk artikels, die zijn dan eigenlijk zo specifiek voor oncologen, en ik ben geen oncoloog, dus die zijn dan weer te gecompliceerd en daar snap ik dan eigenlijk ook weer niet voldoende van. En dan nog, dan weet je nog altijd niet of je dan in die onderzoekspopulatie valt of niet. Dus nee, ik vind eigenlijk niet de juiste informatie dat mij kan helpen.» (11N2)

[69] « J'ai juste dit « voilà, est-ce que vous allez avoir un rendez-vous chez le dermato ? » et il [other patient] m'a dit « oui mais le médecin de toutes façons m'a dit c'est pas pressé, et on ne meurt plus du mélanome ». Donc ça c'était aussi dur. Aussi dur à entendre, ben pour moi, pour le patient... Moi je ne sais pas comment c'est possible des choses pareilles. » (7F1)

[70] « Qui m'a dit « non, en principe y'a pas de problème ; ça doit rien être du tout, une petite verrue quelque chose comme ça, mais bon par précaution on va l'enlever ». Voilà. Et donc il l'a enlevée. Moi je me suis pas inquiétée plus que ça. » (7F1)

[71] «Eigenlijk moet ik zeggen dat die dokter, de plastische chirurg, heel correct was [...] Ja, toch een kalme manier van spreken. Ik mocht vragen stellen, hij antwoordde correct. Ondertussen zegt hij al lang niet meer "mevrouw", want nu is het: "[Naam], kom maar af" "Kom maar, want ja, je bent al klant van 2019." Ik heb er een vertrouwensband mee. » (11N1)

[72] «En dan wilde hij mij per se niet in dat oncoprogramma steken, maar dan wilde hij mij naar mijn personal trainer sturen of naar een



BOV-coach^b. En dan heb ik weet niet hoe hard moeten pleiten en zeg ik, ik wil naar dat revalidatieprogramma, want ik voel dat ik dat nodig heb. » (11N2)

[73] « En Flandre, il y a le « Melanoompunt », le premier jour où j'ai été à [name Flemish hospital], j'étais encore à l'hôpital qu'on me téléphonait déjà du Melanoompunt, qui disait « voilà, on organise maintenant... », c'était deux semaines après, « on organise la réunion annuelle, avec tous des patients qui ont eu des mélanomes, et donc vous faites partie aussi de la famille mélanome », quoi. (7F1)

[74] « Donc euh, voilà. Et en Belgique il n'y a pas trop. On n'a pas trop d'infos. J'ai plus dû aller voir sur les sites, mais de nouveau, hollandais etcetera. Et américains aussi j'ai regardé euh... Mayo-Clinic il y a des choses comme ça. Ici, on n'a pas accès à une information qui est vérifiable. » (7F1)

[75] « Ja, daar wordt natuurlijk een stukje over gesproken. Langs de andere kant is een arts ook beperkt in de mogelijkheden. Ik kan maar zeggen, vanuit de mutualiteiten en dergelijke, er zijn maar een beperkt aantal mogelijkheden om te nemen. En als je aan die en die voorwaarden voldoet, dan kun je die therapie nemen. En ik wil maar zeggen, ook dat behandelplan, ligt vast. Daar heeft een arts ook niet zo... Hij heeft wel een aantal keuzes en ik kan er wel... Maar zoveel keuzes bij melanoom zijn er niet natuurlijk. Om te zeggen, we gaan nu totaal iets anders doen. » (3N1)

[76] « En dan zei de chirurg tegen mij op een van de consultaties, ja, wat zouden we doen? Zouden we ze een keer durven wegdoen die drain? En dan dacht ik, ik ben geen experiment, ofwel weet je het en doe je het weg, ofwel niet. Het is een uitspraak, dat moeten mensen meer op letten. Ik kreeg het gevoel dat ik zo mocht zelf beslissen of we

dat eens gingen durven of niet. En ik denk dat dat een manier van spreken was van die mens, maar eigenlijk vond ik dat wel niet gepast. Dat gaf mij niet echt vertrouwen, moet ik zeggen. » (11N2)

[77] « C'est clair que la tâche était vraiment un cas d'école, ça ressemblait très fort à ce qu'on voit sur les affiches, et en même temps ben je me disais « bah non » euh, voilà, donc j'ai vraiment été dans le déni, et c'est parce que euh... Ben il y a un an cette tâche a commencé vraiment à suinter, à chatouiller très fort, que...que je me suis dit...puis je l'ai montrée à mon fils, qui m'a dit « maman, c'est pas beau », et je me suis décidée à aller chez la dermato à ce moment-là quoi. » (10F1)

[78] « Eigenlijk is mijn broer de aanleiding. Een paar jaar geleden heeft hij een melanoom gehad en dat is operatief verwijderd en dat was het. Het is daar geen behandeling geweest, geen na-traject of zo. [...] Extra redenen was ook omdat mijn schoonzus overleden is aan een melanoom. Dat maakte de urgentie des te groter. » (11N2)

[79] « Je n'y ai pas pensé. Quand j'avais 19 ans, j'ai fait un check-up complet de tous les points de beauté car j'ai énormément de points de beauté. Donc j'ai fait un check-up complet à l'hôpital à ce moment-là. Mais depuis, j'ai été suivie par des dermatos à l'époque pour des points de beauté aussi que j'ai enlevés. Mais sans raison, des points de beauté disgracieux que j'avais fait enlever, mais je n'ai jamais éprouvé le besoin en disant « voilà je dois aller voir mon dermato régulièrement parce que je suis à risque ». Je n'ai jamais eu cette notion de risque en tête quoi. » (7F1)

[80] « Maintenant parcours de combattant pour avoir un rendez-vous. [...] Donc voilà, aussi un peu compliqué et j'ai eu une superbe chance quoi c'est-à-dire que mon mari avait rendez-vous deux jours après pour lui, chez le dermatologue. Alors que j'y avais pas pensé, c'est lui qui

^b BOV-coach: 'Bewegen Op Verwijzing-coach; Coach linked to physical activity on prescription.



m'a dit « oh j'ai rendez-vous dans deux jours... » et on a échangé parce que moi mon rendez-vous était six mois après. » (7F1)

[81] « Avant le confinement, et donc j'ai eu un rendez-vous chez la dermatologue juste avant le confinement, début 2020. Je ne sais même plus si elle m'avait dit d'aller chez le chirurgien ou pas. Ou j'avais de nouveau un rendez-vous avec elle, mais comme tous les rendez-vous ont été annulés. Voilà, c'est un peu tombé à l'eau. » (10F1)

[82] « Maar mijn echtgenote was natuurlijk wel kwaad op die dermatologen, omdat die niet gezien hadden dat het een kwaadaardig gezwel was. Maar ik zeg het dan, is mijn echtgenote in, hoe dat ze het gedaan heeft, dat weet ik niet, dan op nog geen maand tijd heb ik alle testen kunnen doen. Want het is ook in het hospitaal niet zo eenvoudig om een PET-scan te regelen, zelfs een MRI, er zijn wachttijden. Maar heel toevallig is zij ook op een post gekomen waar mensen zijn die afzeggen, dan word jij gebeld en dan maakt ze een afspraak. » (4N1)

[83] « Nee, het is niet door jaarlijkse controle gesteld, want er is nooit niks gevonden. Het is eigenlijk wel omdat ik een symptoom had, omdat ik het gezwollen lymfeklier had. En die bleek dan te gevolgen van een melanoom te zijn dat er ooit eens goed geweest zijn. » [...] « Dus dat betekent dat ik met die uitzaaiing in de klier, dat zat in de klier, eigenlijk in een fase 3 zat al, terwijl dat eigenlijk nooit een melanoom is gezien. Dus al die jaren is er geen melanoom gevonden. We hebben daar naar gezocht, gezien het verhaal van mijn broer, maar er is geen melanoom gevonden. » (11N2)

[84] « Ik had een gezwel op mijn linker elleboog en dat werd nagekeken door dermatologen. En in september 2022 ben ik nog naar de dermatoloog gegaan en dat was een banaal, een onschuldig gezwel eigenlijk. En na de covid dacht ik, ik ga dat laten verwijderen. Dan ben ik naar de plastische chirurg gegaan, maar die zei ik ga toch een biopsie nemen. En bleek het eigenlijk geen onschuldig te zijn en een maligne melanoom. Dus dat was even natuurlijk schrikken, want ik ga jaarlijks naar de dermatoloog. Dus ja, dat is dan in mijn ogen, kan je geen

medische fout noemen, maar een medische misinterpretatie, die voor mij natuurlijk zware gevolgen heeft. » (4N1)

[85] « Maar ik denk dat als er dan in de medische wereld nog iets kan gebeuren, dan denk ik dat je eigenlijk het vroegtijdig opsporen belangrijk is. [...] Want ik wil nu wel zeggen, als ik zie hoe dat een dermatoloog mij onderzoekt, ja, ik versta wel dat ze dat kunnen missen. » (11N2)

[86] « Beaucoup de rendez-vous chez le dermato que j'ai eu après, j'ai eu plein de grains de beauté, qu'il me disait « non, ça ne risque rien », mais comme j'ai eu cette expérience-là au départ qui me disait « ça ne risque rien »... Je n'ai plus eu trop confiance, donc au fond on le fait quand même, donc je crois qu'au total j'ai eu 8 ou 9 points de beauté qu'on a enlevés quoi. » (7F1)

[87] « Ja, we moeten verder, dus het is eigenlijk een samenloop van omstandigheden en dan tijdens het onderzoek in [name of the hospital], zelfs daar wisten ze niet of dat het een primair melanoom was of een metastase, dus voor mij is het echt een moeilijke zaak, omdat ik ben van het principe dat de technologie toch ergens verder moet staan, dat dus eigenlijk in het eindverslag zelfs nog getwijfeld wordt in deze situatie, maar ik denk dat dat kan in de medische wereld, maar mijn hersenen begrijpen het wel niet. » (4N1)

[88] « Ik denk dat ze op mijn scans nog nooit iets gezien hebben. Ik denk dat ze mijn scans doen om te zien of er uitzaaiingen komen ergens. Ze hebben nog nooit iets gezien op mijn scans. En ook nu op mijn vorige MRI ook niet. [...] Dus mijn melanoom was 2,4 mm of zo iets. Dat was al stadium 3B. En dan zeggen ze, ja, maar ik kan nu mis zijn hè. In een puntscan of een MRI zien ze iets al vanaf 5 mm. En dan denk ik, als ze het dan maar zien, dan zijn ze wel goed geïnst. Want dus daar heb ik wel angst. » (8N1)

[89] « En dan, dat vond ik wel vervelender, dan is er evengoed een biopsie genomen. En niet direct uitgehaald, omdat de dokter zei dat het



is beter eerst een biopsie te nemen, omdat dan ook kan gezien worden welke soort kanker dat is en welke behandeling dat best zou zijn. Ik heb dat ook gevolgd, dan is de biopsie genomen. Maar dan tussen de biopsie, de biopsie was dus een melanoom van een bepaald type, een agressief type. En dan was de bedoeling om dat chirurgisch te verwijderen.» (12N1)

[90] «Het was gewoon bijna onmogelijk om hier in de buurt in een praktijk binnen te geraken. Ik denk dat dat vooral een issue is op alle gezondheidsvlakken. Dat is niet alleen dermatologen. Dat is een groot issue. De toegankelijkheid naar een dermatoloog. Maar de goede dermatologen in de buurt hebben allemaal een patiëntenstop.» (7N1)

[91] « Quand on téléphone pour un rendez-vous, on nous donne des dates, mais voilà, des jours où vous donnez cours donc vous dites « ben non, je ne vais pas m'absenter ». D'abord parce que ce n'est couvert, on n'est pas couvert pour des rendez-vous médicaux, on ne peut pas s'absenter pour des rendez-vous médicaux. Et donc on renonce, on reporte tout le temps, on renonce quoi, parce que on sait que dans l'agenda ben ça ne va pas se mettre quoi. » (10F1)

[92] « Alors moi je vis seule. Donc ben j'ai déjà dû me démerder dans l'urgence, heureusement que l'épicière du coin m'a dit « il y a des services pour te conduire à l'hôpital ». Par contre, et pour le retour, ben j'avais trouvé quand même un ami, j'avais appelé un ami, sans savoir exactement l'heure forcément du retour et donc j'ai eu quelqu'un pour juste pour me ramener à la maison. Donc au final, je me suis démerdée toute seule ; j'ai trouvé quelqu'un dans le quartier - merci Facebook - qui a été me chercher. » (10F1)

[93] «Ik vind ook dat in dit geval immuuntherapie moet kunnen door de patiënt in welk hospitaal dat hij dat wil doen, dat vind ik heel belangrijk, dat wij niet naar [city] moeten, dus dat zou veel beter moeten gecoördineerd worden» (4N1)

[94] «En op mentaal gebied, ja... dat de zorg voor psychologen, dat

weten we allemaal, dat die heel moeilijk toegankelijk is. Dus dat de zorg voor psychologen meer toegankelijk moet worden. Maar ja, dat is een probleem, niet alleen voor kankerpatiënten. Zelfs de mensen met mentale problemen hebben er al moeilijk toegang toe, dus dat vind ik wel.» (12N1)

[95] «Dus ook daar zeker, ik denk dat er nu een tussenkomst is het is van een aantal psychologische beurten, maar dat mag zeker nog uitgebreid worden. En dat daar misschien ook nog meer aandacht aan gegeven mag worden. Oké, dat is er als je met... want een verpleegkundige, een oncoloog heeft niet de tijd om al die gesprekken te hebben. Maar het verwijzen daarnaar is in mijn geval nu niet gebeurd. En ik denk dat dat ook nog niet veel gebeurt. Maar ja, dat weet ik eigenlijk niet. Het is bij mij meer op eigen initiatieven. En omdat ik het in het verleden al de nut ervan ondervonden heb, dat ik het nu ook weer terug heb ingezet.» (7N1)

[96] «Dus dan had ik het daar moeilijk mee, maar ik moet heel eerlijk zeggen, bij ons op het ziekenhuis zijn we heel goed begeleid geweest, psychologisch. Ik zeg wij ook, mijn vrouw ook, die heeft, wij konden direct bij de psychologen terecht, wij hebben daar samen gepraat, we hebben apart sessies gehad en dingen, het was nooit eigenlijk, er is nooit een probleem van gemaakt en weet ik nog allemaal.» (3N1)

[97] « Les effets c'est que j'adorais aller au soleil. Mon été était vraiment ponctué de mes expositions au soleil sur ma petite terrasse, même si depuis 2020 j'étais... C'était toujours avant 11h et après 16h mais donc voilà ça programmait mes petites journées, je lisais au soleil le matin etcetera et je me faisais bronzer, donc euh effectivement depuis l'opération je ne me suis plus tout exposée au soleil, donc ça, ça n'a pas été évident au niveau de la vie quotidienne parce que comme je vous dis, j'adorais ça. » (10F1)

[98] « Il a vraiment fait magnifique tous les jours [...] et donc je ne suis pratiquement même pas sortie. Parce que effectivement on peut mettre un chapeau, des lunettes et de l'écran total mais j'étais un peu dégoutée



quoi donc je n'ai pas bougé de la maison, je ne suis pratiquement pas sortie de la maison, donc ça c'est un effet effectivement du mélanome, ça m'a un peu désocialisée. » (10F1)

[99] «Meestal neem ik medicatie om iets rustiger te zijn, wat niet wordt aanbevolen dan om met de auto te rijden. Dan is er een vriendin die bij alle afspraken en ingrepen is, die vrij veel thuis is, of we proberen afspraken af te stemmen als zij thuis is, die bijna altijd meegaat. Dat is een luxe dat ik haar heb om mee te nemen telkens.» (7N1)

[100] «Ik vond niet dat iedereen dat moest weten. En ik wil zeker geen compassie. Ik wil geen medelijden compassie. Ik weet hoe ik zelf ben als ik iemand hoor die kanker heeft. Dat is echt... Allee dus ik denk van nee ik wil ook niet heel mijn leven zo bekeken worden.» (8N1)

[101] « Et puis comme ma mère était décédée au mois de février, et que j'avais toutes les caisses de succession, je sais que j'avais une caisse avec beaucoup de choses dedans, donc j'ai quelqu'un qui est venu à la maison, qui a regardé et on a trouvé tout ce qu'il fallait pour changer les pansements. J'ai fait ça moi-même. Voilà, j'ai géré ça toute seule. » (10F1)

[102] «Maar je moet dat wel alle keren doen. Dus je wordt er wel ook altijd een beetje mee geconfronteerd, terwijl ik zoiets heb: ze weten dat nu eigenlijk toch wel dat ik kanker heb, want je krijgt dan ook erachter via mail een ding van, ja, je kanker. Dus ze hebben geen schrik om over kanker te spreken, maar je moet het wel alle keren bijvoegen. Als je dat vergeet bij te voegen, dan heb je niks, bij wijze van spreken.» (12N1)

[103] «Dat is een beetje een overleven, maar de grootste stress komt niet zozeer van de ziekte, maar van alle papierwinkel die erbij komt kijken en in de ziekenkas, je moet die formulieren invullen. En als je vergeet van dat formulier vertrouwelijk in te vullen, dan vult de arts dat verkeerd in en dan krijg je de brieven en dan wordt dat heel veel rompslomp.» (3N1)

[104] «De eerste keer had ik geen punten genoeg. Een tweede keer erna wel, maar de dokter moet dat papier hebben, en het hangt dus min of meer van dokter af of dat die al wel genoeg punten geeft voor de tegemoetkoming. Dat vind ik een beetje, allee. Dus het ligt niet aan mij, het ligt aan dokters.» (11N1)

[105] «Dat er een zorgcoördinator is of een case manager of dat je een persoonlijke coach hebt die kan doorheen alle fases loodsen en dan nog niet zo zeer emotioneel. Alhoewel dat ik vind dat je dat niet mag uitsplitsen over verschillende functies. Ik denk dat je dan een onco-coach moet hebben die alles kan. Die en het administratieve voor jou kan volgen en, dat kan niet zoveel werk zijn, maar iemand die dat kan. Maar die ook emotioneel wat kan supporten. En dan volgens mij gaat dat meer uithalen. Volgens mij is een psycholoog eerder in de tweede lijn. En is niet voor iedereen nodig. Maar zo'n coach die naast jou even mee loopt, die het stokje die jou vasthoudt. Ik denk dat dat voor mij ideaal zou zijn. Die ook zorgt voor overdracht, eerste lijn, tweede lijn, contact, huisarts eventueel.» (11N2)

[106] «Maar ik weet natuurlijk niet hoe het traject loopt met iemand die al een vergevorderd stadium heeft en die meer chirurgie nodig heeft en die nabehandeling, zoals chemo, nodig heeft. Ik vermoed dat die dan ook weer in een traject komen met een begeleidende... Ik ben niet zeker. Maar bij het borstkanker was er bijvoorbeeld wel een heel duidelijk gesprek van dit mag je verwachten, dit bieden wij u aan, dit doen wij om de zorg te vergemakkelijken en al die dingen.» (7N1)

[107] « Oui, c'était chouette. Toute la famille était là. Mais bon on sait que c'est tous des gens [...] qui ont le mélanome et donc, ça fait déstresser en fait, simplement. On se dit « ben voilà ce sont des gens normaux finalement ». [...] Donc voilà. Et puis on a pu discuter avec pas mal de personnes, super gentilles évidemment. Et qui ont tous cette optique-là de partager leur expérience. De dédramatiser un peu la situation. » (7F1)

[108] «Alhoewel ik er nog niet veel gebruik van, maar in de toekomst,



en als ik tijd heb, in die zin dat ik niet verlet ben. Ook zeker altijd wel nog aan deelnemen. Er zijn ook al veel sprekers geweest. Ze zetten dat wel daarachter op hun Facebook en dan kan je die filmpjes zien. Er zijn ook al veel sprekers geweest, zoals bijvoorbeeld van in Nederland.» (12N1)

[109] «Nee, dat is zo om mee te lezen. Die [name patient organisation] heb ik ook direct niet geweten dat dat bestond. Ik heb daar eens een briefje zien liggen in het ziekenhuis en ik ben daar dan naar gegaan. En dan mag je daar maar op als je toch wel alleen een serieus meedoet met het melanoom. Maar ja, ik zie dat die wel bijeenkomen. In juli zijn die een dag naar Puyenbroek geweest, vorig jaar was het Pairi Daiza.» (8N1)

[110] «Absoluut en ik zit op die Facebookgroep melanoompunt en heel veel mensen zitten daar niet op. En om de maand, ofzo is er toch minstens een keer iemand die sterft, dat er daar iemand op zet die persoon is overleden. En dan sta je weer eens met voetjes op de grond hé. Maar ja, ik denk zeker altijd wel, het zal bij mij niet zijn dat het gaat weer komen, maar je weet het niet.» (8N1)

[111] «Dat heeft, vind ik, positieve en negatieve... kan gevolgen hebben. In die zin: je ziet er mensen die bijvoorbeeld al vijf jaar kankervrij zijn. Je ziet er mensen die kankervrij geweest zijn... dan bedoel ik naar melanomen toe. Die kankervrij waren drie, vier jaar en dan terug hervallen zijn. Die ondertussen terug kanker hebben, maar toch mits de behandeling. Het negatieve is, als er natuurlijk sterfgevallen zijn. Dan zeg je, ja kijk, die hebben het niet overleefd.» (12N1)

[112] « Donc euh...ben voilà mes collègues ont très bien réagi, j'ai trouvé des remplaçants très très vite, donc j'ai passé le mercredi après-midi avec mes remplaçants à leur expliquer tout. Pour qu'ils puissent reprendre la main dès le jeudi, et qu'ils puissent assurer ben la fin de l'année quoi. » (10F1)

[113] «Het voordeel natuurlijk van mijn job is, ik kan 99% van thuis uit werken, ik werk veel op afstand, maar het wordt moeilijker. Het is niet meer met dezelfde geest een probleem dat vroeger een probleem was, is nu hetzelfde probleem is een groot probleem. Ik moet moeite doen om niet te zeggen 'ik stop ermee, ja'.» (4N1)

[114] «Dat is voornamelijk door vermoeidheid en concentratieproblemen. Als ik een hele dag, ik heb een kantoorjob, maar als ik 's avonds thuiskom, dan ben ik gewoon dood op natuurlijk.» (3N1)

[115] « Juste le jour d'opération. On m'avait dit de pas porter etcetera, bon c'était pas possible. A cause des ganglions lymphatiques qu'on a enlevés dans l'aïne, pas porter des personnes ; ne pas faire de mouvements, allez m'abaisser et tout ça, c'était pas possible, donc j'ai travaillé le lendemain quoi. Ca j'aurais peut être pris une pause, ouais. Ici c'est pas le fait d'être indépendant, c'est simplement le fait qu'il y ait des gens qui sont... qui sont dépendants de moi. » (7F1)

[116] «Ja, ik werk op een intercommunale, dus dat is op zich al iets flexibeler dan een privé gegeven. En ik heb een goed diensthoofd en al, dus dat is ook nooit een zorg geweest. Ja, eerder van mezelf, ik ga dat niet meer kunnen die voltijds, waar ik ook niet echt hoeft. Maar ik heb er altijd begrip gekregen. Ja, ik kan dat niet. Maar je mag ook aangeven welke dagen of hoe of wat. Ook de controles vallen dikwijls op de dagen dat ik werk, dat is ook geen probleem. Dus, ze zijn volledig mee in het verhaal en gewoon altijd blij dat ik terug ben.» (7N1)

[117] «Ik werk nu momenteel met, ik vergeet de naam altijd, ik werk drie en een halve dag per week en anderhalf ben ik nog in ziekenkas. Progressieve werkhervatting zeker, gedurende drie jaar ondertussen bij de behandeling. Dat is voornamelijk door vermoeidheid en concentratieproblemen. Als ik een hele dag, ik heb een kantoorjob, maar als ik 's avonds thuiskom, dan ben ik gewoon dood op natuurlijk. [...] Dus die tijd heb ik echt wel nodig om een beetje te recupereren en dingen.» (3N1)



[118] « Parce que voilà, je me dis qu'il vaut mieux profiter de la vie et en tout cas... je voyais bien que j'étais trop fatiguée, que je n'aurais pas pu gérer, et plutôt que de mal gérer, autant être à la pension. J'étais pensionable depuis plus de deux ans de toute façon. » (10F1)

[119] «Ja, het is sowieso altijd een derde minder dat je hebt op het einde van de maand. Dus daar moet je wel wat rekening mee houden. Ik val direct terug op de voltijdse ziekte.» (7N1)

[120] «Dat is volledig terugbetaald. Daar ben ik wel blij voor. Ik denk dat ik per maand 15.000 euro aan pillen neem. Dus dat is volledig terugbetaald. Dus dat valt... Dus daar heb ik absoluut geen problemen. Zo heb ik eigenlijk geen raadpleging. Maar als ik gewoon naar daghospitaal ga, dan worden eigenlijk de kosten ook via de hospitalisatieverzekering terugbetaald. Dus aan zich heb ik daar financieel weinig impact.» (3N1)

[121] «Ik heb bijvoorbeeld voor mijn heupoperatie, ik heb me dan een douchestoel moeten aanschaffen, een verhoogd wc, ik moest daar nog krukken. Ik wil maar zeggen: dat brengt ook extra kosten mee omdat dat eigenlijk apart als een ziekte wordt gezien.» (12N1)

[122] «Als je het hebt over een andere aandoening hebt, medicatie, krijg je terugbetaald. Maar eigenlijk is onze medicatie nu de zonnecrème. Of in mijn hoofd is dat daar aan gerelateerd. Maar daar krijg je, naar mijn weten, niet veel van terug of niks van terug. Dat is eigenlijk wel je dagelijkse medicatie.» (7N1)

[123] «En dan twee keer een consultatie. Want als je op, je baxter gaat halen, moet je ook een consultatie bij de oncologen betalen. Als ik me niet vergis. Zelfs als ze er niet is. En wat ik ook heel straf vind, dat is die je kent het MOC-overleg. Het multidisciplinair oncologisch overleg. Daar staat bij wie er allemaal aanwezig is. Maar ook wie dat er terugbetaling mag vragen. En met welk nomenclatuurnummer. Dus als daar bijvoorbeeld met een huisarts daarbij, terwijl die er nooit is. Dan denk ik, dat is ook wel iets dat je kan besparen.» (11N2)

[124] «Ja, parking, dat vind ik wel... Ik vind dat ze voor dat dagcentrum een aparte parking zouden mogen maken, want dat is zes euro elke keer. En ik vind dat eigenlijk iets te veel voor... Het is niet dat ik op bezoek kom, maar ik kan er ook niet aan doen dat ze zo'n lang een tijd... Soms moet ik daar drie uur in dat stoeltje zitten, of op het bed. Dat is niet een hoofdzonde, maar ik vind 6 euro toch te veel voor eigenlijk zo'n patiënt te zijn, een kankerpatiënt. [...] Dat is niet onze keuze, dus dan noemen ze dat een sociaal tarief, 6 euro vind ik niet een sociaal tarief.» (4N1)

[125] «Dacht ik van, moesten ze nu eens zoiets maken gelijk het openbaar vervoer, dat je een app hebt waarop je kan zien wanneer de verpleging, of waar ze zitten, dat je kan inschatten of het gaat een kwartier duren, of het gaat een half uur duren, maar kan je tenminste daar hun rekening mee houden, en heel banaal aar het toilet gaan op uw gemak.» (11N2)

[126] «Maar bepaalde ziekenhuizen die gespecialiseerd zijn, bijvoorbeeld in Melanoom, gaan zich dan ook meer, specifiek op die studies organiseren en hebben dus misschien meer resultaten, meer deelnemers, die studies zijn misschien meer betrouwbaar... Met andere woorden, ik denk, met Europa, dat dat ook wel goed zou zijn, dat ze ook Europees kunnen samenwerken. Zoals ze dat uiteindelijk voor de Covid ook gedaan hebben.» (12N1)

[127] «We hebben ooit een keer een boete gehad omdat we op de parking van de gehandicapten stonden. 160 euro. Ik heb heel lang met een drain gezeten in de wonde. En dat begon te lekken. Dus wij zijn met zeven haasten naar het ziekenhuis gereden. We hadden ons op de gehandicaptenparking gezet, rap ziekenhuis binnen. Als mijn man terugkwamen, was de politie aan het schrijven. 160 euro boete.» (11N2)

[128] «Neen, want mijn man rijdt met mij omdat er te weinig, en dat is overal, de parkeerplaatsen voor gehandicapten. Dus ik moet er niet aan denken van alleen te rijden, want de parkeerplaatsen zijn meestal ingenomen. Voor mijn part rijdt iedereen met een kast van een villa, ik



trek me dat niet aan. Ik ben nooit jaloers geweest en ik zou nooit jaloers zijn, maar dan worden die gehandicaptenplaatsen ingenomen of ze zitten nog in de auto te wachten op hun, op wie? Naar iemand die in de kliniek is...? En ik met mijn man zijn afgesproken, 'als hij met mij rijdt, en hij wil niet mee naar boven, dan zet je mij af aan de ingang en ga je ergens ander gaan staan'. Zodanig dat er mensen die inderdaad die plaats kunnen gebruiken, dat die die kunnen gebruiken.» (11N1)

[129] «Mijn echtgenote, die gaat op haar manier ermee om, maar natuurlijk, ik maak prioriteit van mij, terwijl dat dat niet correct is. Een beetje egoïstisch. Maar ik heb wel kanker. Dus je moet dat allemaal kunnen plaatsen, maar het heeft wel een impact op onze relatie.» (4N1)

[130] «Ik verwacht in België ook waarom er moet meer aandacht aan besteed worden. Bij mij was het een atypisch, ik heb geen vlekken, ik kwam niet in de zon, dus ik heb wel heel pech gehad. Ik heb het gevraagd aan een dermatoloog, de oncologische dermatoloog, die zegt nee, het komt van de zon, het melanoom komt van de zon.» (4N1)

[131] « Puis simplement prévention pour informer les générations d'après. C'est nous qui devons faire attention aux plus petits. [...] On en parle de plus en plus hein, du mélanome. [...] Mais on voit encore des enfants qui sont dehors sans protection, qui courent à la plage tout nus et...il est seize heures quoi. » (7F1)

[132] «Ja, dat is bij mijn kinderen en kleinkinderen. Maar zelfs mijn kleindochter, als die een voet buiten zet, oma, eerst smeren. Dus ik weet niet, die is vier jaar. Ik denk dat ze daar zelfs een liedje over geleed hebben in de klas. Ik denk dat het echt van de kleutertjes belangrijk is om ze te leren.» (8N1)



APPENDIX 3. SURVEYS

Appendix 3.1. French version

ENQUÊTE SUR LES BESOINS DES PATIENTS ATTEINTS DE MÉLANOME

Introduction

Merci d'avoir accepté de participer à notre enquête.

Notre étude vise à identifier les besoins des patients **atteints de mélanome** afin d'améliorer leur prise en charge.

Ce questionnaire vous concerne si:

- Vous êtes atteint(e) ou avez été atteint(e) de mélanome
 - Votre dernier diagnostic de mélanome date de 2 mois minimum et 3 ans maximum
 - Vous avez 18 ans ou plus
 - Vous habitez en Belgique (résidence principale)
- Ou**
- Vous vous exprimez au nom d'une personne adulte qui est atteint(e) ou a été atteint(e) de mélanome diagnostiqué depuis plus de 2 mois et moins de 3 ans, qui habite en Belgique et qui n'est pas en mesure de répondre elle-même

Avant d'accepter de participer à cette enquête, nous vous demandons de lire les informations suivantes sur la confidentialité de vos données, et de donner votre consentement à l'utilisation de vos données.

Confidentialité de vos données et consentement éclairé

1. Confidentialité des données

Vos données seront traitées conformément à la loi belge du 30 juillet 2018 sur la protection des personnes physiques relative au traitement des données à caractère personnel et conformément au règlement (UE) 2016/679 du 27 avril 2016, qui est entré en vigueur le 25 mai 2018, sur la protection des personnes physiques relative au traitement des données à caractère personnel et à la libre circulation de ces données.

Vous avez le droit de demander au Centre Fédéral d'Expertise des Soins de Santé (KCE) l'accès à vos données personnelles, de les rectifier, de les supprimer, de les transférer, d'en limiter le traitement et de vous opposer à leur traitement. Pour cela, il vous suffit de contacter le KCE, responsable de leur traitement, par mail (charline.maertens@kce.fgov.be) ou par voie postale à l'adresse Doorbuilding (10e étage), Boulevard du Jardin Botanique 55, 1000 Bruxelles. Si vous avez des questions ou des commentaires sur le traitement de vos données, vous pouvez contacter le responsable de la protection des données du KCE via l'adresse stephan.devriese@kce.fgov.be. Il pourra, si nécessaire, vous fournir davantage d'informations sur la protection de vos données personnelles.

Si cela ne vous semble pas suffisant, vous pouvez adresser une réclamation concernant le traitement de vos données à l'autorité belge de surveillance chargée de l'application de [la législation en matière de protection des données \(APD\)](#), Rue de la Presse 35, 1000 Bruxelles, ou contact@apd-gha.be. Pour l'implémentation et l'analyse des résultats de cette enquête du KCE, il a été fait appel à un sous-traitant (Deloitte) travaillant dans le cadre du mandat qui lui a été attribué par le KCE. Le traitement des données se fait sous la responsabilité du KCE.

2. Période de conservation



Les données sont sauvegardées pendant une période de deux ans après la publication du rapport.

3. Finalité du traitement

Cette étude a pour objectif d'identifier les besoins des patients qui ont développé un mélanome afin d'améliorer leur prise en charge.

4. Déclaration de consentement

Je déclare par la présente avoir été informé(e) par écrit de la nature, de la méthode et du but de cette étude, de manière compréhensible pour moi. J'accepte de participer à cette étude. Je comprends que je peux me retirer à tout moment de cette étude jusqu'au moment où les données seront stockées dans la base de données, et ce sans avoir à faire de déclaration et sans que cela ait de conséquences pour moi.

Je comprends que mes données sont collectées et enregistrées de manière confidentielle et que l'enquêteur principal garantit leur confidentialité.

- ☐ NL - Gelieve akkoord te gaan met het privacybeleid inzake gegevens om verder te gaan. (1)
- ☐ FR - Pour continuer, veuillez d'abord accepter la politique de confidentialité des données. (3)

Vous remplissez ce questionnaire :

- ☐ Pour vous-même (1)
- ☐ Pour un autre adulte (veuillez répondre à toutes les questions comme si vous étiez la personne. Vous pouvez indiquer "je ne sais pas" si vous ne savez pas comment la personne répondrait). ① La personne que vous représentez n'est pas en mesure de prendre une décision éclairée de participation pour le moment. En cochant cette case, vous participez à cette étude en fonction de sa volonté probable de participer. (2)

À quel genre vous identifiez-vous ?

- ☐ Homme (1)
- ☐ Femme (2)
- ☐ Autre (3)

Informations générales



Quelle est votre année de naissance ?

▼ 2023 (4) ... 1920 (212)

Dans quelle province habitez-vous ?

- ☐ Anvers (1)
- ☐ Brabant wallon (13)
- ☐ Bruxelles (14)
- ☐ Hainaut (15)
- ☐ Liège (16)
- ☐ Limbourg (17)
- ☐ Luxembourg (18)
- ☐ Namur (19)
- ☐ Flandre orientale (20)
- ☐ Brabant flamand (21)

☐ Flandre occidentale (22)

☐ Je n'habite pas en Belgique (23)

Quel est le diplôme ou le degré le plus élevé que vous ayez obtenu jusqu'à présent ?

☐ Pas de diplôme ou enseignement primaire (1)

☐ Enseignement secondaire inférieur (2)

☐ Enseignement secondaire supérieur (3)

☐ Enseignement supérieur de type court (p.ex. Bachelier) (4)

☐ Enseignement supérieur de type long (p.ex. Master) (5)

☐ Doctorat (6)

☐ Autre diplôme: (7)

☐ Je ne sais pas (8)



Vous vivez ...

- ☐ Seul(e) (1)
- ☐ Seul(e) avec enfant(s) (8)
- ☐ En couple sans enfants (9)
- ☐ En couple avec enfants (10)
- ☐ En maison de repos (11)
- ☐ Autre (12)
-

Quel est votre pays de naissance ?

- ☐ Belgique (1)
- ☐ Autre pays (2)
-

Sélectionnez le pays concerné

▼ Afghanistan (1) ... Suisse (199)

Quel était votre principal statut professionnel **juste avant** votre diagnostic du mélanome?

- ☐ Ouvrier (1)
- ☐ Employé (3)
- ☐ Indépendant (4)
- ☐ Sans emploi (5)
- ☐ Etudiant (6)
- ☐ Retraité (7)
- ☐ Invalidité (8)
- ☐ Autre (9)
-



Quel est votre principal statut professionnel **maintenant** ?

- ☐ Ouvrier (1)
- ☐ Employé (4)
- ☐ Indépendant (5)
- ☐ Sans emploi (6)
- ☐ Etudiant (7)
- ☐ Retraité (8)
- ☐ Invalidité (9)
- ☐ Autre (10)
-

Avez-vous eu un emploi rémunéré depuis que vous avez eu un mélanome ?

- ☐ Oui (1)
- ☐ Non (2)
-

Avez-vous été en incapacité de travail (absence du travail pendant plus d'un mois consécutif) en raison de votre mélanome ?

- ☐ Oui (1)
- ☐ Non (2)
-

Êtes-vous de retour au travail ?

- ☐ Oui, je travaille à nouveau comme avant, le même nombre d'heures par semaine ou plus (1)
- ☐ Oui, mais moins qu'avant (2)
- ☐ Non, parce que mon état de santé ne le permet pas (encore) (3)
- ☐ Non, pour une autre raison : (4)
-



Concernant votre mélanome

Pour toutes ces questions, veuillez répondre par rapport au dernier mélanome dont vous êtes ou avez été atteints(e). Si vous avez plusieurs mélanomes en même temps, diagnostiqués depuis plus de 2 mois et moins de 3 ans, veuillez répondre par rapport au mélanome le plus avancé.

Depuis combien de temps approximativement avez-vous reçu le (dernier) diagnostic de mélanome ?

- ☐ Moins de 2 mois (1)
- ☐ 2 à 6 mois (12)
- ☐ 6 mois à 1 an (13)
- ☐ 1 à 2 an(s) (14)
- ☐ 2 à 3 an(s) (15)
- ☐ Plus de 3 ans (16)
- ☐ Je n'ai pas reçu de diagnostic posé par un médecin (17)

Combien de temps est passé entre vos premiers symptômes et votre décision de consulter un médecin ?

- ☐ Moins d'une semaine (1)
 - ☐ Entre 1 semaine et 1 mois (6)
 - ☐ Entre 1 et 3 mois (7)
 - ☐ Plus de 3 mois (8)
 - ☐ Je ne sais pas (9)
-

Combien de temps est passé entre votre décision de consulter un médecin et le premier rendez-vous ?

- ☐ 1 semaine ou moins (1)
 - ☐ Entre 1 semaine et 1 mois (6)
 - ☐ Entre 1 et 3 mois (7)
 - ☐ Plus de 3 mois (8)
 - ☐ Je ne sais pas (9)
-



Combien de temps est passé entre votre premier rendez-vous médical et le diagnostic ?

- ☐ Moins de 2 semaines (1)
- ☐ Entre 2 semaines et 1 mois (6)
- ☐ Entre 1 et 2 mois (7)
- ☐ Plus de 2 mois (8)
- ☐ Je ne sais pas (9)

Combien de temps est passé entre le diagnostic et le premier traitement médicamenteux et/ou chirurgical ?

- ☐ Moins d'une semaine (1)
- ☐ Entre 1 et 2 semaine(s) (6)
- ☐ Entre 2 semaines et 1 mois (7)
- ☐ Plus d'1 mois (8)
- ☐ Je ne sais pas (9)

Quel(s) type(s) de mélanome avez-vous (eu)?

- ☐ Acral ou lentigineux acral (par exemple sur les paumes des mains, plantes des pieds, ou ongles) (1)
- ☐ De la peau (cutané) (par exemple sur le dos, sur la jambe) (9)
- ☐ De la muqueuse (par exemple dans la bouche, anus, ou vagin) (10)
- ☐ De l'œil (appelé uvéal ou oculaire) (11)
- ☐ Autre (12)
-
- ☐ Je ne sais pas (13)



A quel stade était votre mélanome au moment du dernier diagnostic (lorsque plusieurs mélanomes ont été diagnostiqués, considérez le mélanome le plus avancé)

- ☐ Précoce/localisé (pas de diffusion du cancer)- stade 0, I, ou II (1)
- ☐ Moyen (avec atteinte de ganglions lymphatiques)- stade III (4)
- ☐ Avancé (présence de métastases)- stade IV (5)
- ☐ Je ne sais pas (6)
-

Où se situe votre/vos mélanome(s) ?
(plusieurs réponses possibles)

- ☐ Tête, visage, ou cou (en excluant l'intérieur de la bouche ou du nez) (1)
- ☐ Intérieur de la bouche ou du nez (4)
- ☐ Poitrine, dos, ou ventre (5)
- ☐ Bras ou dos des mains (6)
- ☐ Paumes des mains ou plantes des pieds (7)
- ☐ Jambes ou pieds (8)
- ☐ Ongles (9)
- ☐ Yeux (10)
- ☐ Organes génitaux (11)
- ☐ Intestin (12)
- ☐ Autre (13)
-



Avez-vous déjà été hospitalisé(e) à cause de votre mélanome? Considérez uniquement les hospitalisations avec nuitée(s)

- ☐ Oui (1)
- ☐ Non (2)
- ☐ Je ne sais pas (3)

Quelle était la durée (en jours) de votre dernière hospitalisation en lien avec votre mélanome?

En lien avec votre mélanome, combien de fois avez-vous été hospitalisé(e) durant la dernière année écoulée (0 étant possible)? Considérez uniquement les hospitalisations avec nuitée.

Votre état de santé général

Nous aimerions connaître votre état de santé tel que vous le percevez. Veuillez cocher la case à côté de l'affirmation qui décrit le mieux votre santé **juste AVANT votre (dernier) diagnostic de mélanome.**

Votre mobilité **avant** le mélanome

- ☐ Je n'avais aucun problème pour me déplacer à pied. (1)
- ☐ J'avais des problèmes légers pour me déplacer à pied. (2)
- ☐ J'avais des problèmes modérés pour me déplacer à pied. (3)
- ☐ J'avais des problèmes sévères pour me déplacer à pied. (4)
- ☐ J'étais incapable de me déplacer à pied. (5)

Votre autonomie **avant** le mélanome

- ☐ Je n'avais aucun problème pour me laver ou m'habiller tout(e) seul(e). (1)
- ☐ J'avais des problèmes légers pour me laver ou m'habiller tout(e) seul(e). (2)
- ☐ J'avais des problèmes modérés pour me laver ou m'habiller tout(e) seul(e). (3)
- ☐ J'avais des problèmes sévères pour me laver ou m'habiller tout(e) seul(e). (4)
- ☐ J'étais incapable de me laver ou de m'habiller tout(e) seul(e). (5)
-

Vos activités courantes **avant** le mélanome (Par exemple: travail, études, travaux ménagers, activités familiales ou loisirs)

- ☐ Je n'avais aucun problème pour accomplir mes activités courantes. (1)
- ☐ J'avais des problèmes légers pour accomplir mes activités courantes. (2)
- ☐ J'avais des problèmes modérés pour accomplir mes activités courantes. (3)
- ☐ J'avais des problèmes sévères pour accomplir mes activités courantes. (4)

- ☐ J'étais incapable d'accomplir mes activités courantes. (5)
-

Votre douleur ou gêne **avant** le mélanome

- ☐ Je n'avais ni douleur ni gêne. (1)
- ☐ J'avais des douleurs ou une gêne légère(s). (2)
- ☐ J'avais des douleurs ou une gêne modérée(s). (3)
- ☐ J'avais des douleurs ou une gêne sévère(s). (4)
- ☐ J'avais des douleurs ou une gêne extrême(s). (5)
-

Votre anxiété ou dépression **avant** le mélanome

- ☐ Je n'étais ni anxieux(se), ni déprimé(e). (1)
- ☐ J'étais légèrement anxieux(se) ou déprimé(e). (2)
- ☐ J'étais modérément anxieux(se) ou déprimé(e). (3)
- ☐ J'étais sévèrement anxieux(se) ou déprimé(e). (4)
- ☐ J'étais extrêmement anxieux(se) ou déprimé(e). (5)
-



Nous aimerions savoir dans quelle mesure votre santé était bonne ou mauvaise **AVANT votre (dernier) diagnostic de mélanome** sur une échelle de 0 à 100. L'échelle de mesure ci-dessous va de 0 à 100. 100 correspond à **la meilleure santé** que vous puissiez imaginer 0 correspond à **la pire santé** que vous puissiez imaginer

Nous aimerions savoir votre état de santé actuel, tel que vous le vivez aujourd'hui. Maintenant, veuillez cocher la case à côté de l'affirmation qui décrit le mieux votre santé **AUJOURD'HUI**.

Votre mobilité aujourd'hui

- ☐ Je n'ai aucun problème pour me déplacer à pied. (1)
- ☐ J'ai des problèmes légers pour me déplacer à pied. (2)
- ☐ J'ai des problèmes modérés pour me déplacer à pied. (3)
- ☐ J'ai des problèmes sévères pour me déplacer à pied. (4)
- ☐ Je suis incapable de me déplacer à pied. (5)
-

Votre autonomie aujourd'hui

- ☐ Je n'ai aucun problème pour me laver ou m'habiller tout(e) seul(e). (1)
- ☐ J'ai des problèmes légers pour me laver ou m'habiller tout(e) seul(e). (2)
- ☐ J'ai des problèmes modérés pour me laver ou m'habiller tout(e) seul(e). (3)
- ☐ J'ai des problèmes sévères pour me laver ou m'habiller tout(e) seul(e). (4)
- ☐ Je suis incapable de me laver ou de m'habiller tout(e) seul(e). (5)
-



Vos activités courantes (exemples : travail, études, travaux ménagers, activités familiales ou loisirs) aujourd'hui

- ☐ Je n'ai aucun problème pour accomplir mes activités courantes. (1)
- ☐ J'ai des problèmes légers pour accomplir mes activités courantes. (2)
- ☐ J'ai des problèmes modérés pour accomplir mes activités courantes. (3)
- ☐ J'ai des problèmes sévères pour accomplir mes activités courantes. (4)
- ☐ Je suis incapable d'accomplir mes activités courantes. (5)
-

Votre douleur ou gêne aujourd'hui

- ☐ Je n'ai ni douleur ni gêne. (1)
- ☐ J'ai des douleurs ou une gêne légère(s). (2)
- ☐ J'ai des douleurs ou une gêne modérée(s). (3)
- ☐ J'ai des douleurs ou une gêne sévère(s). (4)
- ☐ J'ai des douleurs ou une gêne extrême(s). (5)
-

Votre anxiété ou dépression aujourd'hui

- ☐ Je ne suis ni anxieux(se), ni déprimé(e). (1)
- ☐ Je suis légèrement anxieux(se) ou déprimé(e). (2)
- ☐ Je suis modérément anxieux(se) ou déprimé(e). (3)
- ☐ Je suis sévèrement anxieux(se) ou déprimé(e). (4)
- ☐ Je suis extrêmement anxieux(se) ou déprimé(e). (5)
-



Nous aimerions savoir dans quelle mesure votre santé était bonne ou mauvaise **AUJOURD'HUI** sur une échelle de 0 à 100. L'échelle de mesure ci-dessous va de 0 à 100. 100 correspond à **la meilleure santé** que vous puissiez imaginer. 0 correspond à **la pire santé** que vous puissiez imaginer.

Autres problèmes de santé

Souffrez-vous également d'un ou de plusieurs autre(s) problème(s) de santé ?

☐ Oui (1)

☐ Non (2)

☐ Je ne sais pas (3)

Veuillez cocher toutes les maladies qui s'appliquent. **Vous pouvez cocher plusieurs cases.** Veuillez également indiquer le nom précis de votre/vos problème(s) de santé si vous le(s) connaissez. Si vous ne connaissez pas (encore) votre diagnostic, cochez la case "pas de diagnostic connu".

☐ Maladie du cœur ou des vaisseaux sanguins (1)

☐ Maladie du système respiratoire (2)

☐ Maladie de l'appareil digestif (3)

☐ Maladie de la peau (4)

☐ Maladie des os, articulations, ou muscles (5)

☐ Trouble de santé mentale ou psychologique (6)

☐ Maladie du sang (hématologique) (7)

☐ Maladie immunitaire (15)



☐ Maladie endocrinienne, nutritionnelle, ou métabolique (8)

☐ Maladie du système nerveux (neurologique) (9)

☐ Maladie de l'œil (10)

☐ Maladie de l'oreille ou du système vestibulaire (11)

☐ Maladie des organes reproducteurs ou du système urinaire (par exemple vessie, reins) (12)

☐ Maladie qui touche plusieurs systèmes (13)

☐ Pas de diagnostic connu (14)

☐

Symptômes (physiques ou psychologiques) liés à votre mélanome

Ressentez-vous ou avez-vous ressenti un ou plusieurs symptôme(s) lié(s) à votre mélanome **(en excluant les effets secondaires du traitement)**?
Précisez lesquels. (plusieurs réponses possibles)

☐ Plaie qui saigne ou suinte (1)

☐ Plaie qui démange ou gratte (33)

☐ Plaie douloureuse (34)

☐ Modification d'un grain de beauté : changement de couleur, de forme, ou apparition d'un nodule (35)

☐ Ganglion(s) gonflés ou douloureux (36)

☐ Picotements ou engourdissement de la peau (37)

☐ Problèmes de vision (38)

☐ Douleurs thoraciques (39)

☐ Essoufflement ou difficultés respiratoires (40)

☐ Toux (41)

☐ Douleurs abdominales (42)



- | | |
|--|--|
| ☐ Constipation ou diarrhée (43) | ☐ Convulsions ou épilepsie (56) |
| ☐ Nausées ou vomissements (44) | ☐ Faiblesses musculaires (57) |
| ☐ Incontinence (fuites urinaires ou fécales) (45) | ☐ Difficulté à marcher ou à coordonner les mouvements (58) |
| ☐ Bouche sèche ou maux de bouche (46) | ☐ Problèmes d'audition (59) |
| ☐ Problèmes de déglutition (47) | ☐ Problèmes d'élocution (difficulté à prononcer ou à trouver ses mots) (60) |
| ☐ Perte de l'appétit (48) | ☐ Problèmes de voix (voix rauque, perte de voix, etc.) (61) |
| ☐ Perte de poids (49) | ☐ Jaunisse ou ictère (coloration jaunâtre de la peau) (62) |
| ☐ Gonflements ou œdème (p.ex. des jambes ou du ventre) (50) | ☐ Température élevée ou fièvre (63) |
| ☐ Douleurs dans les os (51) | ☐ Fatigue ou épuisement (64) |
| ☐ Fracture osseuse (52) | ☐ Problèmes de concentration (65) |
| ☐ Douleurs articulaires (53) | ☐ Sentiments d'agitation, de nervosité, ou d'irritabilité (66) |
| ☐ Maux de tête (54) | ☐ Colère ou agressivité (72) |
| ☐ Difficultés ou pertes de mémoire (55) | ☐ Changements d'humeur (67) |



- ☐ Peur ou anxiété (68)
- ☐ Sentiment d'abattement, de déprime, ou de tristesse (69)
- ☐ Sentiment d'abandon (73)
- ☐ Stress (70)
- ☐ Problèmes de libido (baisse du désir sexuel) (74)
- ☐ Insomnie (75)
- ☐ Autre (71)

- ☐ Aucun symptôme (76)
-

A quel point ces symptômes étaient/sont dérangement?

	Très dérangeant (1)	Assez dérangeant (2)	Pas très dérangeant (3)	Pas dérangeant du tout (4)
Plaie qui saigne ou suinte (x1)	☐	☐	☐	☐
Plaie qui démange ou gratte (x33)	☐	☐	☐	☐
Plaie douloureuse (x34)	☐	☐	☐	☐
Modification d'un grain de beauté : changement de couleur, de forme, ou apparition d'un nodule (x35)	☐	☐	☐	☐
Ganglion(s) gonflés ou douloureux (x36)	☐	☐	☐	☐
Picotements ou engourdissement de la peau (x37)	☐	☐	☐	☐
Problèmes de vision (x38)	☐	☐	☐	☐



Douleurs thoraciques (x39)	☐	☐	☐	☐	Perte de poids (x49)	☐	☐	☐	☐
Essoufflement ou difficultés respiratoires (x40)	☐	☐	☐	☐	Gonflements ou œdème (p.ex. des jambes ou du ventre) (x50)	☐	☐	☐	☐
Toux (x41)	☐	☐	☐	☐	Douleurs dans les os (x51)	☐	☐	☐	☐
Douleurs abdominales (x42)	☐	☐	☐	☐	Fracture osseuse (x52)	☐	☐	☐	☐
Constipation ou diarrhée (x43)	☐	☐	☐	☐	Douleurs articulaires (x53)	☐	☐	☐	☐
Nausées ou vomissements (x44)	☐	☐	☐	☐	Maux de tête (x54)	☐	☐	☐	☐
Incontinence (fuites urinaires ou fécales) (x45)	☐	☐	☐	☐	Difficultés ou pertes de mémoire (x55)	☐	☐	☐	☐
Bouche sèche ou maux de bouche (x46)	☐	☐	☐	☐	Convulsions ou épilepsie (x56)	☐	☐	☐	☐
Problèmes de déglutition (x47)	☐	☐	☐	☐	Faiblesses musculaires (x57)	☐	☐	☐	☐
Perte de l'appétit (x48)	☐	☐	☐	☐	Difficulté à marcher ou à coordonner les mouvements (x58)	☐	☐	☐	☐



Problèmes
d'audition (x59)

☐☐☐☐

Colère ou
agressivité (x72)

☐☐☐☐

Problèmes
d'élocution
(difficulté à
prononcer ou à
trouver ses mots)
(x60)

☐☐☐☐

Changements
d'humeur (x67)

☐☐☐☐

Peur ou anxiété
(x68)

☐☐☐☐

Problèmes de
voix (voix rauque,
perte de voix,
etc.) (x61)

☐☐☐☐

Sentiment
d'abattement, de
déprime, ou de
tristesse (x69)

☐☐☐☐

Jaunisse ou
ictère (coloration
jaunâtre de la
peau) (x62)

☐☐☐☐

Sentiment
d'abandon (x73)

☐☐☐☐

Température
élevée ou fièvre
(x63)

☐☐☐☐

Stress (x70)

☐☐☐☐

Fatigue ou
épuisement
(x64)

☐☐☐☐

Problèmes de
libido (baisse du
désir sexuel)
(x74)

☐☐☐☐

Problèmes de
concentration
(x65)

☐☐☐☐

Insomnie (x75)

☐☐☐☐

Sentiments
d'agitation, de
nervosité, ou
d'irritabilité (x66)

☐☐☐☐

Autre (x71)

☐☐☐☐

Aucun symptôme
(x76)

☐☐☐☐



Recours et accessibilité aux soins de santé

Au cours des 12 derniers mois, y a-t-il des soins pour votre mélanome que vous n'avez pas obtenus alors que vous en auriez eu besoin ? Il peut s'agir d'un traitement, d'une consultation, d'analyses médicales, de rééducation, ou autre.

- ☐ Oui (1)
- ☐ Non (2)
- ☐ Je ne sais pas (3)
-

Pour quelle(s) raison(s) principale(s) n'avez-vous pas reçu les soins dont vous aviez besoin? (plusieurs réponses possibles)

- ☐ Distance entre le domicile et le lieu de soins (1)
- ☐ Problème de transport (par exemple pas de transport en commun à proximité, pas de véhicule personnel, impossibilité de conduire votre propre véhicule, personne pour vous emmener sur le lieu de vos soins) (2)
- ☐ Manque de personnel compétent pour vous administrer les soins dont vous avez besoin (3)
- ☐ Délais d'attente très longs (4)

- ☐ Difficultés pour payer les soins (5)
- ☐ Peur des examens médicaux, de l'hôpital, ou d'autre chose (6)
- ☐ Manque de temps à cause du travail, des enfants, ou autre (7)
- ☐ Manque d'information (8)
- ☐ Difficultés liées à la langue (9)
- ☐ Autre (10)
-

Avec quel(s) prestataire(s) de soins avez-vous été en contact dans le cadre de votre mélanome ? (plusieurs réponses possibles)

- ☐ Médecin généraliste (1)
- ☐ Médecin spécialiste (42)
- ☐ Équipe du service des urgences (43)
- ☐ Équipe d'un centre de révalidation (64)
- ☐ Kinésithérapeute (44)



- ☐ Infirmier à domicile (55)
 - ☐ Infirmier de coordination de soins en oncologie (56)
 - ☐ Infirmier (en consultation à l'hôpital) (57)
 - ☐ Technicien de radiothérapie (58)
 - ☐ Psychologue (59)
 - ☐ Logopède (60)
 - ☐ Diététicien (65)
 - ☐ Ergothérapeute (66)
 - ☐ Assistant social (61)
 - ☐ Equipe de soins palliatifs (62)
 - ☐ Autre (63)
-

Avec quel(s) médecin(s) spécialiste(s) avez-vous été en contact dans le cadre de votre mélanome? (plusieurs réponses possibles)

- ☐ Chirurgien (1)
 - ☐ Dermatologue (10)
 - ☐ Oncologue (spécialiste du cancer) (13)
 - ☐ Radiothérapeute-oncologue (11)
 - ☐ Gériatre (12)
 - ☐ Autre (8)
-



Indiquez dans quelle mesure vous êtes ou vous avez été satisfait(e) de leurs services

	Très satisfait(e) (1)	Plutôt satisfait(e) (2)	Plutôt insatisfait(e) (3)	Très insatisfait(e) (4)					
Médecin généraliste (x1)	☐	☐	☐	☐	Technicien de radiothérapie (x58)	☐	☐	☐	☐
Médecin spécialiste (x42)	☐	☐	☐	☐	Psychologue (x59)	☐	☐	☐	☐
Équipe du service des urgences (x43)	☐	☐	☐	☐	Logopède (x60)	☐	☐	☐	☐
Équipe d'un centre de révalidation (x64)	☐	☐	☐	☐	Diététicien (x65)	☐	☐	☐	☐
Kinésithérapeute (x44)	☐	☐	☐	☐	Ergothérapeute (x66)	☐	☐	☐	☐
Infirmier à domicile (x55)	☐	☐	☐	☐	Assistant social (x61)	☐	☐	☐	☐
Infirmier de coordination de soins en oncologie (x56)	☐	☐	☐	☐	Equipe de soins palliatifs (x62)	☐	☐	☐	☐
Infirmier (en consultation à l'hôpital) (x57)	☐	☐	☐	☐	Autre (x63)	☐	☐	☐	☐



	Très satisfait(e) (1)	Plutôt satisfait(e) (2)	Plutôt insatisfait(e) (3)	Très insatisfait(e) (4)
Chirurgien (x1)	☐	☐	☐	☐
Dermatologue (x10)	☐	☐	☐	☐
Oncologue (spécialiste du cancer) (x13)	☐	☐	☐	☐
Radiothérapeute- oncologue (x11)	☐	☐	☐	☐
Gériatre (x12)	☐	☐	☐	☐
Autre (x8)	☐	☐	☐	☐

Traitements liés à votre mélanome

Recevez-vous (ou avez-vous reçu) un traitement pour votre mélanome?

- ☐ Oui (1)
- ☐ Non (2)
- ☐ Je ne sais pas (3)

Quels traitements recevez-vous (ou avez-vous reçu) pour votre mélanome?
(plusieurs réponses possibles)

- ☐ Excision chirurgicale du mélanome (1)
- ☐ Excision des ganglions lymphatiques (12)
- ☐ Immunothérapie Exemples Par exemple: ipilimumab (Yervoy®), nivolumab (Opdivo®), pembrolizumab (Keytruda®), relatimib (Opdualac®), cemiplimab (Libtayo®), avelumab (Bavencio®) (13)
- ☐ Thérapie ciblée Exemples Par exemple: inhibiteurs BRAF ou MEK: dabrafenib (Tafinlar®), trametinib (Mekinist®), vemurafenib (Zelboraf®), cobimetinib (Cotellic®), Encorafenib (Braftovi®), binimetinib (Mektovi®), Tebentafusp® (14)
- ☐ Chimiothérapie (15)



Dans quelle mesure le ou les traitement(s) que vous recevez (ou avez reçu(s)) pour traiter votre mélanome est (sont)/était(en)t pénible(s) pour vous?

- ☐ Extrêmement pénible(s) (1)
- ☐ Très pénible(s) (2)
- ☐ Assez pénible(s) (3)
- ☐ Pas du tout pénible(s) (4)
- ☐ Je ne sais pas (5)

Pour quelle(s) raison(s) le traitement est-il ou a-t-il été pénible? (plusieurs réponses possibles)

- ☐ A cause des effets indésirables (1)
- ☐ Parce que cela m'oblige/m'obligeait à m'occuper constamment de ma maladie/de mon traitement (2)
- ☐ Parce que cela exige/exigeait une discipline de vie très stricte (prise de médicaments à des horaires stricts, hygiène...) (3)
- ☐ Parce que je suis ce(s) traitement(s) depuis longtemps (4)
- ☐ Autre (5)
-

Quel(s) effet(s) indésirable(s) avez-vous ressenti(s) ou ressentez-vous lors du traitement de votre mélanome ? (plusieurs réponses possibles)

- ☐ Problèmes de peau (p.ex. démangeaisons, éruptions cutanées, eczéma, vitiligo) (1)
- ☐ Fièvre (16)
- ☐ Fatigue ou épuisement (17)
- ☐ Hyperglycémie (taux élevé de glucose ou sucre dans le sang) (18)
- ☐ Maux de tête (19)
- ☐ Nausées ou vomissements (20)
- ☐ Perte d'appétit (21)
- ☐ Constipation et/ou diarrhée (22)
- ☐ Perte de cheveux (23)
- ☐ Problèmes de foie (24)
- ☐ Douleurs articulaires, ou arthrites (25)



Indiquez dans quelle mesure chacun d'entre eux sont/étaient dérangerant(s).

	Très dérangerant (1)	Assez dérangerant (2)	Pas très dérangerant (3)	Pas dérangerant du tout (4)
☐ Problèmes au cœur (26)				
☐ Hypertension (27)				
☐ Problèmes du sang (p.ex. saignements) (28)				
☐ Problèmes aux poumons (29)				
☐ Problème de reins (30)				
☐ Problème aux yeux (31)				
☐ Réaction allergique (32)				
☐ Complications de la chirurgie (33)				
☐ Autre (34) _____				
☐ Aucun effet indésirable (35)				
<hr/>				
Problèmes de peau (p.ex. démangeaisons, éruptions cutanées, eczéma, vitiligo) (x1)	☐	☐	☐	☐
Fièvre (x16)	☐	☐	☐	☐
Fatigue ou épuisement (x17)	☐	☐	☐	☐
Hyperglycémie (taux élevé de glucose ou sucre dans le sang) (x18)	☐	☐	☐	☐
Maux de tête (x19)	☐	☐	☐	☐
Nausées ou vomissements (x20)	☐	☐	☐	☐
Perte d'appétit (x21)	☐	☐	☐	☐



Constipation
et/ou diarrhée
(x22)

☐☐☐☐

Perte de cheveux
(x23)

☐☐☐☐

Problèmes de
foie (x24)

☐☐☐☐

Douleurs
articulaires, ou
arthrites (x25)

☐☐☐☐

Problèmes au
cœur (x26)

☐☐☐☐

Hypertension
(x27)

☐☐☐☐

Problèmes du
sang (p.ex.
saignements)
(x28)

☐☐☐☐

Problèmes aux
poumons (x29)

☐☐☐☐

Problème de
reins (x30)

☐☐☐☐

Problème aux
yeux (x31)

☐☐☐☐

Réaction
allergique (x32)

☐☐☐☐

Complications de
la chirurgie (x33)

☐☐☐☐

Autre (x34)

☐☐☐☐

Aucun effet
indésirable (x35)

☐☐☐☐

Est-ce que le(s) traitement(s) que vous recevez/avez reçu est/a été efficace
contre le mélanome, selon vous ?

☐ Oui (1)

☐ Oui, mais seulement pendant une période (4)

☐ Non (5)

☐ Je ne sais pas (6)

Informations sur le mélanome



La **quantité d'explications** que vous avez reçue de la part de vos soignants au sujet de votre mélanome et du traitement était selon vous:

- ☐ Excessive (1)
- ☐ Adéquate (8)
- ☐ Insuffisante (9)
- ☐ Je n'ai pas reçu d'information (10)
- ☐ Je ne sais pas (11)

Les explications que vous avez reçues de la part de vos soignants au sujet de votre mélanome et du traitement étaient :

- ☐ Très claires (1)
- ☐ Raisonnablement claires (8)
- ☐ Pas très claires (9)
- ☐ Pas claires du tout (10)
- ☐ Je ne sais pas (11)

Avez-vous cherché ou demandé des informations supplémentaires sur le mélanome?

- ☐ Oui (1)
- ☐ Non (2)
- ☐ Je ne sais pas (3)

Quelle(s) information(s) avez-vous cherché ou demandé sur le mélanome?
(plusieurs réponses possibles)

- ☐ Votre maladie (1)
- ☐ La manière dont votre diagnostic a été posé (2)
- ☐ L'évolution de votre état de santé (3)
- ☐ Les possibilités de traitement (4)
- ☐ Les essais cliniques liés à votre traitement (5)
- ☐ Le coût du traitement et les frais à votre charge (ce qui n'est pas remboursé par votre mutuelle) (6)



- ☐ Les lieux où le traitement est possible (7)
- ☐ Les droits des patients (8)
- ☐ L'accès à vos propres données (9)
- ☐ Les associations de patients (10)
- ☐ Les aides disponibles (11)
- ☐ Le retour à domicile et les aménagements possibles (ou logement alternatif) (12)
- ☐ L'éducation thérapeutique (éducation pour apprendre à faire face à son problème de santé et à son traitement ; cela inclut la sensibilisation, l'information, le soutien psychosocial, etc.) (13)
- ☐ Les droits des aidants proches (14)
- ☐ L'accompagnement, le soutien psychologique, le coaching (15)
- ☐ Autre (16)
-

Indiquez également votre degré de satisfaction par rapport aux informations cherchées/trouvées.

	Très satisfait(e) (1)	Plutôt satisfait(e) (2)	Plutôt insatisfait(e) (3)	Très insatisfait(e) (4)
Votre maladie (x1)	☐	☐	☐	☐
La manière dont votre diagnostic a été posé (x2)	☐	☐	☐	☐
L'évolution de votre état de santé (x3)	☐	☐	☐	☐
Les possibilités de traitement (x4)	☐	☐	☐	☐
Les essais cliniques liés à votre traitement (x5)	☐	☐	☐	☐
Le coût du traitement et les frais à votre charge (ce qui n'est pas remboursé par votre mutuelle) (x6)	☐	☐	☐	☐
Les lieux où le traitement est possible (x7)	☐	☐	☐	☐
Les droits des patients (x8)	☐	☐	☐	☐



L'accès à vos
propres données
(x9)

☐☐☐☐

Les associations de
patients (x10)

☐☐☐☐

Les aides
disponibles (x11)

☐☐☐☐

Le retour à domicile
et les
aménagements
possibles (ou
logement alternatif)
(x12)

☐☐☐☐

L'éducation
thérapeutique
(éducation pour
apprendre à faire
face à son problème
de santé et à son
traitement ; cela
inclut la
sensibilisation,
l'information, le
soutien
psychosocial, etc.)
(x13)

☐☐☐☐

Les droits des
aidants proches
(x14)

☐☐☐☐

L'accompagnement,
le soutien

☐☐☐☐

psychologique, le
coaching (x15)

Autre (x16)

☐☐☐☐

Souhaiteriez-vous ou auriez-vous souhaité être davantage impliqué(e) dans
les choix relatifs à votre/vos traitement(s) pour votre mélanome?

☐ Oui (1)

☐ Non (2)

☐ Non applicable (3)

☐ Je ne sais pas (4)

Conséquences financières



Votre mélanome a-t-il (eu) des répercussions financières?

- ☐ Oui (1)
- ☐ Non (2)
- ☐ Je ne sais pas (3)

Quel genre de répercussions a (ont) eu votre mélanome?
(plusieurs réponses possibles)

- ☐ Perte ou absence de revenus (1)
- ☐ Perte ou absence d'emploi (2)
- ☐ Frais médicaux (3)
- ☐ Autre (4)
- _____

Réseau d'aide autour de vous

Avez-vous (eu) parfois besoin d'aide pour les activités de la vie quotidienne suite à votre mélanome?

- ☐ Oui (1)
- ☐ Non (2)
- ☐ Je ne sais pas (3)

Indiquez de quel(s) type(s) d'aide logistique vous avez (eu) besoin.
(plusieurs réponses possibles)

- ☐ Hygiène corporelle (1)
- ☐ Habillage (2)
- ☐ Déplacements (3)
- ☐ Ménage (4)
- ☐ Préparation des repas (5)
- ☐ Garde d'enfants (6)
- ☐ Autre (7)
- _____



Qui vous fournit/vous a fourni cette aide ?

- ☐ Un aidant proche (1)
- ☐ Un aidant professionnel (2)
- ☐ Autre (3)

- ☐ D'un accompagnement spirituel ou religieux (8)
- ☐ Autre (9)

- ☐ Non (10)

À cause du mélanome, avez-vous (eu) besoin, **sans y parvenir**:
(plusieurs réponses possibles)

- ☐ D'une aide logistique plus importante que celle que vous recevez actuellement/avez reçu (1)
- ☐ De parler à d'autres patients atteints de mélanome (2)
- ☐ De parler à des professionnels de santé (y compris un psychologue) (3)
- ☐ De parler d'autres choses que de vos problèmes de santé (4)
- ☐ D'une aide administrative ou sociale (6)
- ☐ D'un soutien pour le retour au travail (7)

Avez-vous (eu) des difficultés à trouver quelqu'un de confiance à qui parler du mélanome ?

- ☐ Oui (1)
- ☐ Non (2)
- ☐ Je n'ai pas (eu) besoin d'une personne de confiance à qui parler du mélanome (3)
- ☐ Je ne sais pas (4)



Souhaitez-vous nous faire part d'un ou plusieurs autres besoins importants que vous n'avez pas pu exprimer dans le questionnaire ?

☐ Oui (1)

☐ Non (2)

Quel(s) besoin(s) n'a(ont) pas été abordé(s) dans le questionnaire ?

Poursuite de l'étude

Nous aimerions poursuivre la conversation sur les besoins et les difficultés que vous éprouvez dans le contexte de votre mélanome. Si vous le souhaitez, vous pouvez participer à **un entretien individuel (en ligne ou en face à face avec un chercheur)** pour aborder plus en détail votre expérience et vos besoins. Il est prévu que **24 patients (12 francophones et 12 néerlandophones)** soient interrogés. Cet entretien individuel **durera environ une heure et demie**.

Si vous êtes intéressé(e) par l'entretien individuel, merci de nous indiquer vos coordonnées (numéro de téléphone et adresse mail) afin que nous puissions vous contacter.

☐ Email (1)

☐ Confirmer l'email (2)



☐ GSM (3)

Souhaitez-vous nous communiquer le nom de cette association ou de ce groupe de discussion?

☐ GSM supplémentaire (optionnel) (3)

Êtes-vous impliqué(e) dans une association ou un groupe (par exemple un groupe Facebook) de patients?

☐ Oui (1)

☐ Non (4)

☐ Je ne souhaite pas répondre (5)



Appendix 3.2. DUTCH VERSION

ENQUÊTE OVER DE BEHOEFTE VAN PATIËNTEN MET EEN MELANOOM

Inleiding

Hartelijk dank voor uw deelname aan onze enquête.

Onze studie heeft als doel de behoeften van patiënten met een **melanoom** te identificeren om de zorg te verbeteren.

Gelieve **deze vragenlijst enkel in te vullen** als u :

- Een melanoom heeft of een melanoom heeft gehad
- Minstens 2 maanden en ten laatste 3 jaar geleden de laatste diagnose van uw melanoom kreeg
- 18 jaar of ouder bent
- In België woont (hoofdverblijfplaats)

Of

- Deelneemt in naam van een volwassene met een melanoom, die ten minste 2 maanden en ten laatste 3 jaar geleden is gediagnosticeerd en woonachtig is te België, maar zelf niet in staat om de vragen te beantwoorden

Voordat u akkoord gaat met deelname aan deze enquête, vragen wij u om onderstaande informatie over de vertrouwelijkheid van uw gegevens te lezen en uw toestemming te geven voor het gebruik van uw gegevens.

Vertrouwelijkheid van uw gegevens en geïnformeerde toestemming

1. Vertrouwelijkheid van de gegevens
Uw gegevens worden verwerkt in overeenstemming met de Belgische wet van 30 juli 2018 betreffende de bescherming van natuurlijke personen met betrekking tot de verwerking van persoonsgegevens en de Verordening (EU) 2016/679 van 27 april 2016, die op 25 mei 2018 in werking trad, betreffende de bescherming van natuurlijke personen in verband met de verwerking van persoonsgegevens en betreffende het vrije verkeer van die gegevens.

U hebt het recht het Federaal Kenniscentrum voor de Gezondheidszorg (KCE) te verzoeken om toegang tot uw persoonsgegevens, te corrigeren, te verwijderen, over te dragen, de verwerking te beperken en bezwaar aan te tekenen tegen de verwerking ervan. Hiervoor kan u contact opnemen met het KCE, die verantwoordelijk is voor de verwerking ervan (charline.maertens@kce.fgov.be) of via brief naar het KCE (KCE 10e verdieping, Kruidtuinlaan 55, 1000 Brussel). Indien u vragen of opmerkingen heeft over de verwerking van uw gegevens, kunt contact opnemen met de verantwoordelijke voor gegevensbescherming bij het KCE via stephan.devriese@kce.fgov.be. Hij zal u indien nodig meer informatie kunnen verstrekken over de bescherming van uw persoonsgegevens.

Indien dit niet voldoende zou blijken, kan u een klacht indienen over de verwerking van uw gegevens bij de Belgische toezichthoudende instantie die verantwoordelijk is voor de toepassing van de [wetgeving inzake gegevensbescherming](#): Gegevensbeschermingsautoriteit (GBA), Drukpersstraat 35, 1000 Brussel, of via contact@apd-gba.be. Voor de implementatie en analyse van de gegevens van deze KCE-enquête, doet het KCE beroep op een externe equipe (Deloitte) die werkt binnen het mandaat dat haar door het KCE werd toegewezen. De verwerking van de gegevens gebeurt onder de verantwoordelijkheid van het KCE.



2. Bewaartermijn

De gegevens worden bewaard tot twee jaar na publicatie van het rapport.

3. Verwerkingsdoel

Het doel van deze studie is om de behoeften van patiënten met een melanoom in kaart te brengen om hun zorg te verbeteren.

4. Toestemmingsverklaring

Hierbij verklaar ik dat ik schriftelijk en op een voor mij begrijpelijke wijze ben ingelicht over de aard, de methode en het doel van deze studie.

Ik ga akkoord met deelname aan deze studie. Ik begrijp dat ik mij op elk moment kan terugtrekken uit dit onderzoek tot op het ogenblik dat de gegevens in de database worden bewaard zonder dat ik hiervoor een verklaring hoeft af te leggen en zonder dat dit op enigerlei wijze gevolg zal hebben voor mij.

Ik begrijp dat mijn gegevens vertrouwelijk zullen worden ingezameld en geregistreerd, en dat de hoofdonderzoeker de vertrouwelijkheid ervan garandeert.

☐ NL - Gelieve akkoord te gaan met het privacybeleid inzake gegevens om verder te gaan. (1)

☐ FR - Pour continuer, veuillez d'abord accepter la politique de confidentialité des données. (3)

Algemene informatie

U vult deze vragenlijst in:

☐ Voor uzelf (1)

☐ Voor een andere volwassene (gelieve alle vragen te beantwoorden alsof u de persoon zelf bent. U kan aangeven 'ik weet het niet' als u niet weet hoe de persoon zou antwoorden). ^① De persoon die u vertegenwoordigt is op dit moment niet in staat om een weloverwogen beslissing te nemen om deel te nemen aan dit onderzoek. Door dit vakje aan te kruisen, neemt u deel aan dit onderzoek op basis van zijn of haar waarschijnlijke bereidheid om deel te nemen. (2)

Met welk geslacht identificeert u zich?

☐ Man (1)

☐ Vrouw (2)

☐ Andere (3)

In welk jaar bent u geboren?

▼ 2023 (4) ... 1920 (212)



In welke provincie woont u?

- ☐ Antwerpen (1)
 - ☐ Waals-Brabant (13)
 - ☐ Brussel (14)
 - ☐ Henegouwen (15)
 - ☐ Luik (16)
 - ☐ Limburg (17)
 - ☐ Luxemburg (18)
 - ☐ Namen (19)
 - ☐ Oost-Vlaanderen (20)
 - ☐ Vlaams-Brabant (21)
 - ☐ West-Vlaanderen (22)
 - ☐ Ik woon niet in België (23)
-

Wat is het hoogste diploma of graad die u tot nu toe hebt behaald?

- ☐ Geen diploma of basisonderwijs (1)
 - ☐ Lager secundair onderwijs (2)
 - ☐ Hoger secundair onderwijs (3)
 - ☐ Hoger onderwijs van het korte type (vb. bachelor) (4)
 - ☐ Hoger onderwijs van het lange type (vb. master) (5)
 - ☐ Doctoraat (6)
 - ☐ Ander diploma, specificeer: (7)

 - ☐ Ik weet het niet (8)
-

U woont ...

- ☐ Alleen (1)
- ☐ Alleen met kinderen (8)
- ☐ Samen zonder kinderen (9)
- ☐ Samen met kinderen (10)



☐ In een woon- en zorgcentrum (11)

☐ Andere (12)

In welk land bent u geboren

☐ België (1)

☐ Ander land (2)

Selecteer desbetreffend land

▼ Afghanistan (1) ... Zwitserland (199)

Wat was uw voornaamste beroepsstatuut **net voor uw diagnose** van melanoom?

☐ Bediende (1)

☐ Arbeider (3)

☐ Zelfstandige (4)

☐ Werkloos (5)

☐ Student (6)

☐ Gepensioneerd (7)

☐ Invaliditeit (8)

☐ Andere (9)

Wat is uw voornaamste beroepsstatuut **momenteel**?

☐ Bediende (1)

☐ Arbeider (4)

☐ Zelfstandige (5)

☐ Werkloos (6)

☐ Student (7)

☐ Gepensioneerd (8)

☐ Invaliditeit (9)

☐ Andere (10)



Heeft u betaald werk gehad voor uw melanoom?

- ☐ Ja (1)
- ☐ Nee (2)

Bent u door uw melanoom arbeidsongeschikt geweest (langer dan 1 maand onafgebroken afwezig van het werk)?

- ☐ Ja (1)
- ☐ Nee (2)

Bent u opnieuw aan het werk?

- ☐ Ja, ik werk terug zoals voordien, hetzelfde aantal uren per week of meer (1)
- ☐ Ja, maar minder dan voordien (2)
- ☐ Nee, mijn gezondheidstoestand laat dit (nog) niet toe (3)
- ☐ Nee, om een andere reden: (4)

Over uw melanoom

Gelieve voor al deze vragen te antwoorden met betrekking tot het laatste melanoom dat u heeft of heeft gehad. Als u meer dan één melanoom tegelijk heeft, dat meer dan 2 maanden en minder dan 3 jaar geleden is gediagnosticeerd, geef dan antwoord met betrekking tot het verst gevorderde melanoom.

Hoe lang geleden werd (voor het laatst) de diagnose van melanoom bij u gesteld?

- ☐ Minder dan 2 maanden (1)
- ☐ 2 maanden tot 6 maanden (12)
- ☐ 6 maanden tot 1 jaar (13)
- ☐ 1 tot 2 jaar (14)
- ☐ 2 tot 3 jaar (15)
- ☐ Meer dan 3 jaar (16)
- ☐ Ik heb nog geen diagnose gekregen van een arts (17)



Hoeveel tijd is er verstreken tussen het optreden van uw eerste symptomen en uw beslissing om op consultatie te gaan bij een arts?

- ☐ Minder dan 1 week (1)
- ☐ 1 week tot 1 maand (6)
- ☐ 1 maand tot 3 maanden (7)
- ☐ Meer dan 3 maanden (8)
- ☐ Ik weet het niet (9)

Hoeveel tijd is er verstreken tussen uw beslissing om op consultatie te gaan bij een arts en de eerste consultatie?

- ☐ Minder dan 1 week (1)
 - ☐ 1 week tot 1 maand (6)
 - ☐ 1 maand tot 3 maanden (7)
 - ☐ Meer dan 3 maanden (8)
 - ☐ Ik weet het niet (9)
-

Hoeveel tijd is er verstreken tussen de eerste consultatie met een arts en de diagnose?

- ☐ Minder dan 2 weken (1)
- ☐ 2 weken tot 1 maand (6)
- ☐ 1 maand tot 2 maanden (7)
- ☐ Meer dan 2 maanden (8)
- ☐ Ik weet het niet (9)

Hoeveel tijd is er verstreken tussen de diagnose en het krijgen van uw eerste behandeling (chirurgisch of medicamenteus)?

- ☐ Minder dan 1 week (1)
 - ☐ 1 week tot 2 weken (6)
 - ☐ 2 weken tot 1 maand (7)
 - ☐ Meer dan 1 maand (8)
 - ☐ Ik weet het niet (9)
-



Welk(e) type(s) van melano(o)m(en) heeft u (gehad)?

- ☐ Acraal of lentigineus acraal melanoom (bv. op handpalmen, zolen of nagels) (1)
- ☐ Van de huid (cutaan) (bv. op de rug, op het been,...) (9)
- ☐ Van het slijmvlies (bv. in de mond, anus of vagina) (10)
- ☐ Van het oog (uveaal of oculair) (11)
- ☐ Andere (12)

- ☐ Ik weet het niet (13)

In welk stadium bevond uw melanoom zich ten tijde van uw laatste diagnose (wanneer er meerdere melanomen zijn vastgesteld, neemt u het verst gevorderde melanoom)?

- ☐ Vroeg stadium/ gelokaliseerd – stadium 0,I of II (geen uitzaaiingen van kanker) (1)
- ☐ Gemiddeld stadium (met lymfeklierbetrokkenheid) – stadium III (4)
- ☐ Gevorderd stadium (met aanwezigheid van uitzaaiingen) – stadium IV (5)

☐ Ik weet het niet (6)

Waar bevinden/situeren zich uw melano(o)m(en)?
(meerdere antwoorden zijn mogelijk)

- ☐ Hoofd, gezicht of hals (met uitzondering van de binnenkant van de mond of de neus) (1)
- ☐ Binnenkant van de mond of neus (4)
- ☐ Borst, rug of buik (5)
- ☐ Armen of de rug van de handen (6)
- ☐ Handpalmen of voetzolen (7)
- ☐ Benen of voeten (8)
- ☐ Nagels (9)
- ☐ Ogen (10)
- ☐ Geslachtsorganen (11)
- ☐ Darmen (12)

☐

Andere (13)

Werd u ooit gehospitaliseerd (enkel hospitalisaties met overnachting) omwille van uw melanoom?

☐

Ja (1)

☐

Nee (2)

☐

Ik weet het niet (3)

Wat was de duur (in dagen) van uw laatste ziekenhuisopname voor uw melanoom?

Hoe vaak bent u het afgelopen jaar in het ziekenhuis opgenomen voor uw melanoom (enkel hospitalisaties met overnachting)? (0 is mogelijk)

Uw algemene gezondheid

We willen graag uw gezondheidstoestand kennen zoals u die ervaart. Gelieve het vakje aan te kruisen bij de uitspraak die het best uw gezondheid beschrijft **VOOR uw (laatste) diagnose van uw melanoom**.

Uw mobiliteit **vóór** uw melanoom

☐

Ik had geen problemen met rondwandelen. (1)

☐

Ik had een beetje problemen met rondwandelen. (2)

☐

Ik had matige problemen met rondwandelen. (3)

☐

Ik had ernstige problemen met rondwandelen. (4)

☐

Ik was niet in staat om rond te wandelen. (5)

Uw zelfzorg **vóór** uw melanoom

☐

Ik had geen problemen met mijzelf te wassen of aan te kleden. (1)

☐

Ik had een beetje problemen met mijzelf te wassen of aan te kleden. (2)



☐ Ik had matige problemen met mijzelf te wassen of aan te kleden. (3)

☐ Ik had ernstige problemen met mijzelf te wassen of aan te kleden. (4)

☐ Ik was niet in staat mijzelf te wassen of aan te kleden. (5)

Uw dagelijkse activiteiten **vóór** uw melanoom (bv. werk, studie, huishouden, gezins- en vrijetijdsactiviteiten)

☐ Ik had geen problemen met mijn dagelijkse activiteiten. (1)

☐ Ik had een beetje problemen met mijn dagelijkse activiteiten. (2)

☐ Ik had matige problemen met mijn dagelijkse activiteiten. (3)

☐ Ik had ernstige problemen met mijn dagelijkse activiteiten. (4)

☐ Ik was niet in staat mijn dagelijkse activiteiten uit te voeren. (5)

Uw pijn of ongemak **vóór** uw melanoom

☐ Ik had geen pijn of ongemak. (1)

☐ Ik had een beetje pijn of ongemak. (2)

☐ Ik had matige pijn of ongemak. (3)

☐ Ik had ernstige pijn of ongemak. (4)

☐ Ik had extreme pijn of ongemak. (5)

Uw angst of depressie **vóór** uw melanoom

☐ Ik was niet angstig of depressief. (1)

☐ Ik was een beetje angstig of depressief. (2)

☐ Ik was matig angstig of depressief. (3)

☐ Ik was erg angstig of depressief. (4)

☐ Ik was extreem angstig of depressief. (5)



We willen weten hoe goed of slecht uw gezondheid was **VOOR uw (laatste) diagnose van uw melanoom**, op een schaal van 0 tot 100. Hieronder ziet u een meetschaal genummerd van 0 tot 100. 100 staat voor de **beste gezondheid** die u zich kunt voorstellen. 0 staat voor de **slechtste gezondheid** die u zich kunt voorstellen.

We willen graag uw huidige gezondheidstoestand kennen zoals u die vandaag ervaart. Gelieve het vakje aan te kruisen bij de uitspraak die het best uw gezondheid **VANDAAG** beschrijft.

Uw mobiliteit vandaag

- ☐ Ik heb geen problemen met rondwandelen. (1)
 - ☐ Ik heb een beetje problemen met rondwandelen. (2)
 - ☐ Ik heb matige problemen met rondwandelen. (3)
 - ☐ Ik heb ernstige problemen met rondwandelen. (4)
 - ☐ Ik ben niet in staat om rond te wandelen. (5)
-

Uw zelfzorg vandaag

- ☐ Ik heb geen problemen met mijzelf te wassen of aan te kleden. (1)
 - ☐ Ik heb een beetje problemen met mijzelf te wassen of aan te kleden. (2)
 - ☐ Ik heb matige problemen met mijzelf te wassen of aan te kleden. (3)
 - ☐ Ik heb ernstige problemen met mijzelf te wassen of aan te kleden. (4)
 - ☐ Ik ben niet in staat mijzelf te wassen of aan te kleden. (5)
-

Uw dagelijkse activiteiten vandaag (bv. werk, studie, huishouden, gezins- en vrijetijdsactiviteiten)

- ☐ Ik heb geen problemen met mijn dagelijkse activiteiten. (1)
 - ☐ Ik heb een beetje problemen met mijn dagelijkse activiteiten. (2)
 - ☐ Ik heb matige problemen met mijn dagelijkse activiteiten. (3)
 - ☐ Ik heb ernstige problemen met mijn dagelijkse activiteiten. (4)
 - ☐ Ik ben niet in staat mijn dagelijkse activiteiten uit te voeren. (5)
-



Uw pijn of ongemak vandaag

- ☐ Ik heb geen pijn of ongemak. (1)
- ☐ Ik heb een beetje pijn of ongemak. (2)
- ☐ Ik heb matige pijn of ongemak. (3)
- ☐ Ik heb ernstige pijn of ongemak. (4)
- ☐ Ik heb extreme pijn of ongemak. (5)

Uw angst of depressie vandaag

- ☐ Ik ben niet angstig of depressief. (1)
- ☐ Ik ben een beetje angstig of depressief. (2)
- ☐ Ik ben matig angstig of depressief. (3)
- ☐ Ik ben erg angstig of depressief. (4)
- ☐ Ik ben extreem angstig of depressief. (5)

We willen weten hoe goed of slecht uw gezondheid **VANDAAG** is, op een schaal van 0 tot 100. Hieronder ziet u een meetschaal genummerd van 0 tot 100. 100 staat voor de **beste gezondheid** die u zich kunt voorstellen. 0 staat voor de **slechtste gezondheid** die u zich kunt voorstellen.

Andere gezondheidsproblemen

Heeft u last van een of andere gezondheidsproblemen?

- ☐ Ja (1)
- ☐ Nee (2)
- ☐ Ik weet het niet (3)

Duid in de lijst hieronder die andere aandoeningen aan. **U kan meer dan één vakje aankruisen.** Geef ook de specifieke naam van uw aandoening aan als u die kent. Als u uw diagnose (nog) niet kent, vink het vakje "geen bekende diagnose" aan.

☐ Hart- en vaataandoeningen (1)



- ☐ Aandoeningen van het ademhalingsstelsel (2)

- ☐ Aandoeningen van het spijsverteringsstelsel (3)

- ☐ Huidaandoeningen (4)

- ☐ Aandoeningen van het bewegingsstelsel (beenderen, gewrichten, spieren) (5)

- ☐ Mentale/psychische aandoeningen (6)

- ☐ Hematologische aandoeningen (bloed) (7)

- ☐ Immuunziektes (15)

- ☐ Endocriene, voedings- of stofwisselingsaandoeningen (8)

- ☐ Aandoeningen van het zenuwstelsel (9)

- ☐ Oogaandoeningen (10)

- ☐ Ooraandoeningen of aandoeningen aan het evenwichtsorgaan (11)

- ☐ Aandoeningen aan het urine- (bv. blaas, nieren) en voortplantingsstelsel (12)

- ☐ Aandoeningen die meerdere systemen aantast (13)

- ☐ Geen bekende diagnose (14)

Symptomen (lichamelijk of psychologisch) die verband houden met een melanoom



Ervaat u (of heeft u ervaren) één of meerdere van de volgende symptomen die verband houden met uw melanoom **(Bijwerkingen van uw behandeling hoeft u hier niet aan te duiden)**? Welke zijn of waren deze symptomen?

(meerdere antwoorden mogelijk)

- | | |
|---|---|
| ☐ Bloedende of etterende wonde (1) | ☐ Constipatie of diarree (43) |
| ☐ Jeukende of krassende wonde (33) | ☐ Misselijkheid of braken (44) |
| ☐ Pijnlijke wonde (34) | ☐ Lekken van urine of ontlasting (45) |
| ☐ Verandering van een moedervlek: verandering van kleur, vorm, of uiterlijk van een knobbel (35) | ☐ Droge mond of pijn in de mond (46) |
| ☐ Gezwollen of pijnlijke lymfeklier(en) (36) | ☐ Slikproblemen (47) |
| ☐ Tintelingen of gevoelloosheid van de huid (37) | ☐ Verlies van eetlust (48) |
| ☐ Problemen met het gezichtsvermogen (38) | ☐ Gewichtsverlies (49) |
| ☐ Pijn op de borst (39) | ☐ Zwelling of oedeem (bv. In benen of buik) (50) |
| ☐ Kortademigheid of moeite met ademen (40) | ☐ Botpijn (51) |
| ☐ Hoesten (41) | ☐ Botbreuk (52) |
| ☐ Buikpijn (42) | ☐ Gewrichtspijn (53) |
| | ☐ Hoofdpijn (54) |
| | ☐ Moeilijkheden of verlies van geheugen (55) |



- ☐ Epilepsie of convulsies (56)
- ☐ Spierzwakte (57)
- ☐ Moeilijkheden met stappen of met de coördinatie van bewegingen (58)
- ☐ Gehoorproblemen (59)
- ☐ Spraakproblemen (moeilijkheden met het uitspreken of vinden van woorden) (60)
- ☐ Stemproblemen (heesheid, stemverlies,...) (61)
- ☐ Geelzucht of icterus (gelige verkleuring van de huid) (62)
- ☐ Hoge temperatuur of koorts (63)
- ☐ Vermoeidheid of uitputting (64)
- ☐ Concentratieproblemen (65)
- ☐ Gevoelens van prikkelbaarheid, rusteloosheid of nervositeit (66)
- ☐ Woede of agressie (72)

- ☐ Stemningswisselingen (67)
 - ☐ Angst of ongerustheid (68)
 - ☐ Zich neerslachtig, depressief of verdrietig voelen (69)
 - ☐ Zich in de steek gelaten voelen (73)
 - ☐ Stress (70)
 - ☐ Libidoproblemen (verminderd seksueel verlangen) (74)
 - ☐ Slapeloosheid (75)
 - ☐ Andere (71)
 -
 - ☐ Geen symptomen (76)
-



Hoe storend zijn of waren deze symptomen?

	Zeer storend (1)	Redelijk storend (2)	Niet erg storend (3)	Helemaal niet storend (4)					
					Kortademigheid of moeite met ademen (x40)	☐	☐	☐	☐
Bloedende of etterende wonde (x1)	☐	☐	☐	☐	Hoesten (x41)	☐	☐	☐	☐
Jeukende of krassende wonde (x33)	☐	☐	☐	☐	Buikpijn (x42)	☐	☐	☐	☐
Pijnlijke wonde (x34)	☐	☐	☐	☐	Constipatie of diarree (x43)	☐	☐	☐	☐
Verandering van een moedervlek: verandering van kleur, vorm, of uiterlijk van een knobbel (x35)	☐	☐	☐	☐	Misselijkheid of braken (x44)	☐	☐	☐	☐
Gezwellen of pijnlijke lymfeklier(en) (x36)	☐	☐	☐	☐	Lekken van urine of ontlasting (x45)	☐	☐	☐	☐
Tintelingen of gevoelloosheid van de huid (x37)	☐	☐	☐	☐	Droge mond of pijn in de mond (x46)	☐	☐	☐	☐
Problemen met het gezichtsvermogen (x38)	☐	☐	☐	☐	Slikproblemen (x47)	☐	☐	☐	☐
Pijn op de borst (x39)	☐	☐	☐	☐	Verlies van eetlust (x48)	☐	☐	☐	☐
					Gewichtsverlies (x49)	☐	☐	☐	☐
					Zwelling of oedeem (bv. In benen of buik) (x50)	☐	☐	☐	☐



Botpijn (x51)	☐	☐	☐	☐	Stemproblemen (heesheid, stemverlies,...) (x61)	☐	☐	☐	☐
Botbreuk (x52)	☐	☐	☐	☐	Geelzucht of icterus (gelige verkleuring van de huid) (x62)	☐	☐	☐	☐
Gewrichtspijn (x53)	☐	☐	☐	☐	Hoge temperatuur of koorts (x63)	☐	☐	☐	☐
Hoofdpijn (x54)	☐	☐	☐	☐	Vermoeidheid of uitputting (x64)	☐	☐	☐	☐
Moeilijkheden of verlies van geheugen (x55)	☐	☐	☐	☐	Concentratieproblemen (x65)	☐	☐	☐	☐
Epilepsie of convulsies (x56)	☐	☐	☐	☐	Gevoelens van prikkelbaarheid, rusteloosheid of nervositeit (x66)	☐	☐	☐	☐
Spierzwakte (x57)	☐	☐	☐	☐	Woede of agressie (x72)	☐	☐	☐	☐
Moeilijkheden met stappen of met de coördinatie van bewegingen (x58)	☐	☐	☐	☐	Stemmingswisselingen (x67)	☐	☐	☐	☐
Gehoorproblemen (x59)	☐	☐	☐	☐	Angst of ongerustheid (x68)	☐	☐	☐	☐
Spraakproblemen (moeilijkheden met het uitspreken of vinden van woorden) (x60)	☐	☐	☐	☐	Zich neerslachtig, depressief of verdrietig voelen (x69)	☐	☐	☐	☐



Zich in de steek gelaten
voelen (x73)

☐ ☐ ☐ ☐

Stress (x70)

☐ ☐ ☐ ☐

Libidoproblemen
(verminderd seksueel
verlangen) (x74)

☐ ☐ ☐ ☐

Slapeloosheid (x75)

☐ ☐ ☐ ☐

Andere (x71)

☐ ☐ ☐ ☐

Geen symptomen (x76)

☐ ☐ ☐ ☐

☐ Ik weet het niet (3)

Om welke reden(en) heeft u zorg die u nodig had niet gekregen?
(meerdere antwoorden mogelijk)

- ☐ Afstand tussen mijn woonst en de plaats van zorg (1)
- ☐ Vervoersproblemen (geen openbaar vervoer in de buurt, geen eigen voertuig, niet in staat om eigen voertuig te besturen, niemand om u naar de plaats van zorg te brengen) (2)
- ☐ Gebrek aan bekwaam personeel om u de zorg te bieden die u nodig had (3)
- ☐ Lange wachttijden (4)
- ☐ Moeilijkheden om de zorg te betalen (5)
- ☐ Angst voor medische-, ziekenhuis- of andere onderzoeken (6)
- ☐ Tijdsgebrek door werk, kinderen of andere (7)
- ☐ Gebrek aan informatie (8)
- ☐ Taalproblemen (9)

Zorggebruik en toegankelijkheid van zorg

Hebt u in de afgelopen 12 maanden bepaalde zorg voor uw melanoom niet gekregen terwijl u die wel nodig had? Dit kan gaan om een behandeling, consultatie, medische tests, revalidatie of andere.

- ☐ Ja (1)
- ☐ Nee (2)



☐ Andere (10)

Met welke zorgverlener(s) heeft u contact gehad in verband met uw melanoom?
(meerdere antwoorden mogelijk)

☐ Huisarts (1)

☐ Arts-specialist (42)

☐ Team van de spoeddienst (43)

☐ Team van het revalidatiecentrum (64)

☐ Kinesitherapeut (44)

☐ Thuisverpleegkundige (55)

☐ Coördinerende verpleegkundige voor oncologische zorg (56)

☐ Verpleegkundige (op consultatie in het ziekenhuis) (57)

☐ Radiotherapeutisch technicus (58)

☐ Psycholoog (59)

☐ Logopedist (60)

☐ Diëtist (65)

☐ Ergotherapeut (66)

☐ Maatschappelijk assistent (61)

☐ Team van de palliatieve zorgen (62)

☐ Andere (63)



Met welke arts-specialist(en) heeft u contact gehad in verband met uw melanoom?

(meerdere antwoorden mogelijk)

- ☐ Chirurg (1)
- ☐ Dermatoloog (10)
- ☐ Oncoloog (arts gespecialiseerd in kanker) (13)
- ☐ Radiotherapeut - oncoloog (11)
- ☐ Geriater (12)
- ☐ Andere (8)
-

Hoe tevreden bent u of was u met hun diensten?

	Zeervredenen (1)	Eerder tevreden (2)	Eerder ontevreden (3)	Heel ontevreden (4)
Huisarts (x1)	☐	☐	☐	☐
Arts-specialist (x42)	☐	☐	☐	☐
Team van de spoeddienst (x43)	☐	☐	☐	☐
Team van het revalidatiecentrum (x64)	☐	☐	☐	☐
Kinesitherapeut (x44)	☐	☐	☐	☐
Thuisverpleegkundige (x55)	☐	☐	☐	☐
Coördinerende verpleegkundige voor oncologische zorg (x56)	☐	☐	☐	☐
Verpleegkundige (op consultatie in het ziekenhuis) (x57)	☐	☐	☐	☐
Radiotherapeutisch technicus (x58)	☐	☐	☐	☐



						Zeer tevreden (1)	Eerder tevreden (2)	Eerder ontevreden (3)	Heel ontevreden (4)	erg
Psycholoog (x59)	☐	☐	☐	☐						
Logopedist (x60)	☐	☐	☐	☐	Chirurg (x1)	☐	☐	☐	☐	
Diëtist (x65)	☐	☐	☐	☐	Dermatoloog (x10)	☐	☐	☐	☐	
Ergotherapeut (x66)	☐	☐	☐	☐	Oncoloog (arts gespecialiseerd in kanker) (x13)	☐	☐	☐	☐	
Maatschappelijk assistent (x61)	☐	☐	☐	☐	Radiotherapeut - oncoloog (x11)	☐	☐	☐	☐	
Team van de palliatieve zorgen (x62)	☐	☐	☐	☐	Geriatr (x12)	☐	☐	☐	☐	
Andere (x63)	☐	☐	☐	☐	Andere (x8)	☐	☐	☐	☐	



Behandeling voor uw melanoom

Wordt u momenteel behandeld (of werd u behandeld) voor uw melanoom?

- ☐ Ja (1)
- ☐ Nee (2)
- ☐ Ik weet het niet (3)

Welke behandelingen krijgt u (of hebt u gekregen) voor uw melanoom?
(meerdere antwoorden mogelijk)

- ☐ Chirurgisch verwijderen van melanoom (1)
- ☐ Chirurgisch verwijderen van lymfeklieren (12)
- ☐ Immunotherapie Voorbeelden Bijvoorbeeld: ipilumumab (Yervoy®), nivolumab (Opdivo®), pembrolizumab (Keytruda®), relatimib (Opdualac®), cemiplimab (Libtayo®), avelumab (Bavencio®) (13)
- ☐ Doelgerichte therapie Voorbeelden Bijvoorbeeld: inhibitoren BRAF of MEK: dabrafenib (Tafinlar®), trametinib (Mekinist®), vemurafenib (Zelboraf®), cobimetinib (Cotellic®), Encorafenib (Braftovi®), binimetinib (Mektovi®), Tebentafusp® (14)
- ☐ Chemotherapie (15)

- ☐ Radiotherapie (16)
- ☐ Geneesmiddel op voorschrift (medicatie die niet behoort tot immunotherapie, doelgerichte therapie, chemotherapie of radiotherapie) (17)
- ☐ Geneesmiddel zonder voorschrift (18)
- ☐ Kinesitherapie (19)
- ☐ Ander (20)

Hoe tevreden bent u over deze behandeling(en)?

	Zeervredenen (1)	Eerder tevredenen (2)	Eerder ontevredenen (3)	Heel erg ontevredenen (4)
Chirurgisch verwijderen van melanoom (x1)	☐	☐	☐	☐
Chirurgisch verwijderen van lymfeklieren (x12)	☐	☐	☐	☐
Immunotherapie Voorbeelden Bijvoorbeeld: ipilumumab (Yervoy®), nivolumab (Opdivo®), pembrolizumab (Keytruda®), relatimib	☐	☐	☐	☐



(Opdualac®), cemiplimab
(Libtayo®), avelumab
(Bavencio®) (x13)

Doelgerichte therapie
Voorbeelden Bijvoorbeeld:
inhibitoren BRAF of MEK:
dabrafenib (Tafinlar®),
trametinib (Mekinist®),
vemurafenib (Zelboraf®),
cobimetinib (Cotellic®),
Encorafenib (Braftovi®),
binimetinib (Mektovi®),
Tebentafusp® (x14)

Chemotherapie (x15)

Radiotherapie (x16)

Geneesmiddel op voorschrift
(medicatie die niet behoort tot
immunotherapie,
doelgerichte therapie,
chemotherapie of
radiotherapie) (x17)

Geneesmiddel zonder
voorschrift (x18)

Kinesitherapie (x19)

Ander (x20)

☐ ☐ ☐ ☐

☐ ☐ ☐ ☐

☐ ☐ ☐ ☐

☐ ☐ ☐ ☐

☐ ☐ ☐ ☐

☐ ☐ ☐ ☐

☐ ☐ ☐ ☐

In welke mate is of was de behandeling(en) die u krijgt (of heeft gekregen) voor uw melanoom pijnlijk of vervelend?

- ☐ Zeer pijnlijk of vervelend (1)
- ☐ Behoorlijk pijnlijk of vervelend (2)
- ☐ Enigszins pijnlijk of vervelend (3)
- ☐ Helemaal niet pijnlijk of vervelend (4)
- ☐ Ik weet het niet (5)

Om welke reden(en) is of was de behandeling pijnlijk of vervelend?
(meerdere antwoorden mogelijk)

- ☐ Door de bijwerkingen (1)
- ☐ Het dwingt me om constant rekening te houden met mijn aandoening en/of behandeling (2)
- ☐ Het vereist een strikte levensdiscipline (innemen van medicatie op vaste tijdstippen, hygiëne...) (3)
- ☐ Omdat ik deze behandeling(en) al een lange tijd volg (4)



☐ Andere (5)

Hebt (of had) u last van bijwerkingen van de behandeling voor uw melanoom?
(meerdere antwoorden mogelijk)

☐ Huidproblemen (bv. Jeuk, huidirritatie, eczeem,...) (1)

☐ Koorts (16)

☐ Vermoeidheid of uitputting (17)

☐ Hyperglycemie (verhoging van de glucose of suiker in het bloed) (18)

☐ Hoofdpijn (19)

☐ Misselijkheid of braken (20)

☐ Verlies van eetlust (21)

☐ Constipatie en/of diarree (22)

☐ Haaruitval (23)

☐ Leverproblemen (24)

☐ Gewrichtspijn of artritis (25)

☐ Hartproblemen (26)

☐ Hoge bloeddruk (27)

☐ Bloedproblemen (bv. Bloedingen,...) (28)

☐ Longproblemen (29)

☐ Nierproblemen (30)

☐ Oogproblemen (31)

☐ Allergische reacties (32)

☐ Complicaties van operatie (33)

☐ Andere (34)

☐ Geen bijwerkingen (35)



Geef aan hoe storend elke bijwerking is of was.

	Zeer storend (1)	Redelijk storend (2)	Niet storend (3)	erg storend (4)	Helemaal niet storend (4)						
						Gewrichtspijn artritis (x25)	of	☐	☐	☐	☐
						Hartproblemen (x26)		☐	☐	☐	☐
Huidproblemen (bv. Jeuk, huidirritatie, eczeem,...) (x1)	☐	☐	☐	☐	☐	Hoge bloeddruk (x27)		☐	☐	☐	☐
Koorts (x16)	☐	☐	☐	☐	☐	Bloedproblemen (bv. Bloedingen,...) (x28)		☐	☐	☐	☐
Vermoeidheid of uitputting (x17)	☐	☐	☐	☐	☐	Longproblemen (x29)		☐	☐	☐	☐
Hyperglycemie (verhoging van de glucose of suiker in het bloed) (x18)	☐	☐	☐	☐	☐	Nierproblemen (x30)		☐	☐	☐	☐
Hoofdpijn (x19)	☐	☐	☐	☐	☐	Oogproblemen (x31)		☐	☐	☐	☐
Misselijkheid of braken (x20)	☐	☐	☐	☐	☐	Allergische reacties (x32)		☐	☐	☐	☐
Verlies van eetlust (x21)	☐	☐	☐	☐	☐	Complicaties van operatie (x33)		☐	☐	☐	☐
Constipatie en/of diarree (x22)	☐	☐	☐	☐	☐	Andere (x34)		☐	☐	☐	☐
Haaruitval (x23)	☐	☐	☐	☐	☐	Geen bijwerkingen (x35)		☐	☐	☐	☐
Leverproblemen (x24)	☐	☐	☐	☐	☐						



Werkt de behandeling die u gekregen heeft voor uw melanoom volgens u?

- ☐ Ja (1)
- ☐ Ja, maar enkel gedurende een bepaalde periode (4)
- ☐ Neen (5)
- ☐ Ik weet het niet (6)
-

Informatie over uw melanoom

De **hoeveelheid uitleg** die u van uw zorgverleners gekregen heeft met betrekking tot uw melanoom was volgens u:

- ☐ Te veel (1)
- ☐ Voldoende (8)
- ☐ Onvoldoende (9)
- ☐ Ik heb geen informatie ontvangen (10)
- ☐ Ik weet het niet (11)
-

De uitleg die u van uw zorgverleners krijgt of heeft gekregen over uw melanoom en de behandeling ervan is of was:

- ☐ Zeer duidelijk (1)
- ☐ Redelijk duidelijk (8)
- ☐ Niet erg duidelijk (9)
- ☐ Helemaal niet duidelijk (10)
- ☐ Ik weet het niet (11)
-

Hebt u bijkomende informatie gezocht of gevraagd over uw melanoom?

- ☐ Ja (1)
- ☐ Nee (2)
- ☐ Ik weet het niet (3)
-

Welke bijkomende informatie heeft u gezocht of gevraagd over melanoom? (meerdere antwoorden mogelijk)

- ☐ Uw aandoening (1)



- | | |
|--|--|
| ☐ De manier waarop de aandoening (diagnose) is vastgesteld (2) | ☐ Therapeutische educatie (informatie om te leren omgaan met de aandoening en behandeling; dit omvat o.a. bewustwording, voorlichting, psychosociale ondersteuning) (13) |
| ☐ De evolutie van uw gezondheidstoestand (3) | ☐ De rechten van mantelzorgers (14) |
| ☐ De behandelingsmogelijkheden (4) | ☐ Begeleiding, psychologische ondersteuning, coaching (15) |
| ☐ Klinische studies over uw behandeling (5) | ☐ Andere (16) |
| ☐ De kosten van de behandeling en de uitgaven voor eigen rekening (die niet worden terugbetaald door het ziekenfonds) (6) | <hr/> |
| ☐ De plaatsen waar behandeling mogelijk is (7) | |
| ☐ Patiëntenrechten (8) | |
| ☐ De toegang tot uw eigen gegevens (9) | |
| ☐ Patiëntenverenigingen (10) | |
| ☐ Beschikbare ondersteuning (11) | |
| ☐ De terugkeer naar huis en eventuele regelingen (of alternatieve huisvesting) (12) | |



Geef aan in welke mate u tevreden bent over opgezochte of opgevraagde informatie.

	Zeervredenen (1)	Eerder tevreden (2)	Eerder ontevreden (3)	Heel erg ontevreden (4)
Uw aandoening (x1)	☐	☐	☐	☐
De manier waarop de aandoening (diagnose) is vastgesteld (x2)	☐	☐	☐	☐
De evolutie van uw gezondheidstoestand (x3)	☐	☐	☐	☐
De behandelingsmogelijkheden (x4)	☐	☐	☐	☐
Klinische studies over uw behandeling (x5)	☐	☐	☐	☐
De kosten van de behandeling en de uitgaven voor eigen rekening (die niet worden terugbetaald door het ziekenfonds) (x6)	☐	☐	☐	☐
De plaatsen waar behandeling mogelijk is (x7)	☐	☐	☐	☐
Patiëntenrechten (x8)	☐	☐	☐	☐

De toegang tot uw eigen gegevens (x9)	☐	☐	☐	☐
Patiëntenverenigingen (x10)	☐	☐	☐	☐
Beschikbare ondersteuning (x11)	☐	☐	☐	☐
De terugkeer naar huis en eventuele regelingen (of alternatieve huisvesting) (x12)	☐	☐	☐	☐
Therapeutische educatie (informatie om te leren omgaan met de aandoening en behandeling; dit omvat o.a. bewustwording, voorlichting, psychosociale ondersteuning) (x13)	☐	☐	☐	☐
De rechten van mantelzorgers (x14)	☐	☐	☐	☐
Begeleiding, psychologische ondersteuning, coaching (x15)	☐	☐	☐	☐
Andere (x16)	☐	☐	☐	☐



Zou u meer betrokken willen zijn (geweest) bij het maken van keuzes over uw behandeling(en) voor uw melanoom?

- ☐ Ja (1)
- ☐ Nee (2)
- ☐ Niet van toepassing (3)
- ☐ Ik weet het niet (4)

Financiële gevolgen

Heeft uw melanoom financiële gevolgen (gehad)?

- ☐ Ja (1)
- ☐ Nee (2)
- ☐ Ik weet het niet (3)

Welke financiële gevolgen heeft uw melanoom (gehad)?
(meerdere antwoorden mogelijk)

- ☐ Verlies van of gebrek aan inkomen (1)
- ☐ Verlies van werk of werkloosheid (2)

☐ Medische kosten (3)

☐ Andere (4)

Ondersteuningsnetwerk

Hebt u ooit hulp nodig (gehad) bij uw dagelijkse activiteiten als gevolg van uw melanoom?

- ☐ Ja (1)
- ☐ Nee (2)
- ☐ Ik weet het niet (3)

Geef aan waarvoor u logistieke hulp nodig heeft of heeft gehad.
(meerdere antwoorden mogelijk)

- ☐ Persoonlijke hygiëne (1)
- ☐ Aankleden (2)



- ☐ Verplaatsingen (3)
 - ☐ Huishouden (4)
 - ☐ Bereiden van maaltijden (5)
 - ☐ Kinderopvang (6)
 - ☐ Andere (7)
-

Wie verleent of heeft u deze ondersteuning verleend?

- ☐ Een mantelzorger (1)
 - ☐ Een professionele zorgverlener (2)
 - ☐ Andere (3)
-

Hebt (of had) u door uw **melanoom** behoefte aan ondersteuning die **u niet gekregen** heeft:
(meerdere antwoorden mogelijk)

- ☐ Meer logistieke hulp bij dagdagelijkse activiteiten dan u momenteel krijgt (1)
 - ☐ Praten met lotgenoten over uw melanoom (2)
 - ☐ Praten met professionele zorgverleners (bv. Psycholoog,...) (3)
 - ☐ Praten over andere zaken dan uw gezondheidsprobleem (4)
 - ☐ Administratieve of sociale ondersteuning (6)
 - ☐ Ondersteuning bij werkhervatting (7)
 - ☐ Spirituele of religieuze ondersteuning (8)
 - ☐ Andere (9)
 - ☐ Neen (10)
-



Hebt (of had) u problemen om iemand te vinden met wie u in vertrouwen kan (of kon) praten over uw melanoom?

- ☐ Ja (1)
- ☐ Nee (2)
- ☐ Ik heb geen vertrouwenspersoon nodig (gehad) om te praten over mijn melanoom (3)
- ☐ Ik weet het niet (4)

Hebt u nog andere belangrijke behoeften die niet aan bod kwamen in de vragenlijst en die u met ons zou willen delen?

- ☐ Ja (1)
- ☐ Nee (2)

Wat is of zijn deze behoefte(n) die niet aan bod kwamen in de vragenlijst?

Vervolg van de studie

We wensen graag dit gesprek verder te zetten omtrent uw behoeften en de moeilijkheden die u ervaart of hebt ervaren met uw melanoom. **Indien u wenst**, kunt u deelnemen aan een **individueel interview (online of ter plaatse met een onderzoeker)** om uw ervaringen en behoeften meer in detail te bespreken. Dit gesprek zal vertrouwelijk worden gevoerd en staat los van de zorg die u van uw zorgverleners ontvangt. Er zullen **24 patiënten (12 Franstalige en 12 Nederlandstalige)** worden geïnterviewd. Het individuele interview zal ongeveer **anderhalf uur** duren.

Als u geïnteresseerd bent in het interview, geef ons dan uw contactgegevens (telefoonnummer en e-mailadres) zodat we u kunnen contacteren.

- ☐ Email (1)

- ☐ Bevestig email (2)

- ☐ GSM (3)



Extra GSM (optioneel) (3)

Bent u betrokken bij een patiëntenvereniging of discussiegroep (bv. Facebook-groep) van patiënten met een melanoom?

☐ Ja (1)

☐ Nee (4)

☐ Wens ik niet te beantwoorden (5)

Wenst u de naam van deze vereniging of discussiegroep met ons te delen?



APPENDIX 4. INTERVIEW GUIDE

Interview guide - Dutch

Hartelijk dank voor uw deelname aan dit interview in het kader van het project "Evaluatie van de behoeften van patiënten met de ziekte van Crohn" van het Federaal Kenniscentrum voor de Gezondheidszorg.

Mijn naam is en ik ben

Het doel van ons project is om uw ervaringen en behoeften na de ziekte van Crohn te begrijpen, zodat we indien nodig verbeteringen kunnen voorstellen.

We willen dit interview graag opnemen om het gesprek te vergemakkelijken, om te voorkomen dat wat er gezegd wordt vertekend wordt en om het interview te kunnen uitwerken voor analysedoeleinden. De opname wordt gewist zodra de notities zijn gemaakt. De inhoud van de interviews wordt geanonimiseerd en er wordt geen informatie gepubliceerd waarmee de persoon kan worden geïdentificeerd.

Er zijn geen goede of foute antwoorden. Het gaat om uw ervaring en mening.

Ik zal u kort voorlezen en uitleg geven over de informatie op het informed consent formulier. Daarna nodig ik u uit om het te ondertekenen en daarna zal ik het zelf ondertekenen.

Questions	Follow-up	Objectif
ICE BREAKER		
1 Hoe voelt u zich over het algemeen vandaag?		Mensen aanmoedigen om te spreken
2 Wat motiveerde u om deel te nemen aan het online onderzoek en in te stemmen met het interview van vandaag?		Het interview contextualiseren
3 Als u een melanoom aan iemand zou moeten uitleggen, hoe zou u dat dan doen?	- Wist je al iets over een melanoom?	
We willen je nu graag door jouw "diagnostische traject" leiden.		
4 Hoe ontdekte je dat je een melanoom had?	- Heeft u reeds een andere melanoom gehad? - Wanneer besloot u uw arts te raadplegen? - Wie stelde de eerste diagnose? - Was de manier waarop de diagnose werd aangekondigd gepast?	



Questions	Follow-up	Objectif
5 Hoe beïnvloedt een melanoom je dagelijks leven?	<ul style="list-style-type: none"> - Wanneer werd de diagnose gesteld en hoe lang duurde dat? - Hoelang duurde het voordat de behandeling begon (indien van toepassing)? - Bent u bij verschillende zorgverleners geweest voordat de diagnose werd bevestigd? 	Contextualiser
We gaan nu bekijken welke moeilijkheden je ervaart of hebt ervaren als gevolg van een melanoom. We proberen ze te begrijpen voordat we kijken in hoeverre je suggesties hebt om de situatie te verbeteren.		
6 Ervaar je gezondheidsproblemen als gevolg van een melanoom?	<p>In termen van :</p> <ul style="list-style-type: none"> • Symptomen? • Psychologische gevolgen (stemming, emotioneel beheer, enz.) • Sociale gevolgen? • Professionele gevolgen? • Dagelijks functioneren? • Beschikbare informatie? • ... 	Vaststellen van therapeutische, informatieve en sociale behoeften in de breedste zin van het woord
7 Hoe behandel je jezelf?	<ul style="list-style-type: none"> - Geneesmiddelen op voorschrift (immunotherapie, chemotherapie) - Medicijnen zonder voorschrift - Chirurgie (melanoom of uitzaaiingen?) - Radiotherapie - Benodigde apparatuur - Niet-conventionele praktijken (acupunctuur, osteopathie, homeopathie, enz.) - Psychologische ondersteuning - Palliatieve zorg, etc. - Deelname aan klinisch onderzoek naar nieuwe medicijnen? 	Therapeutische behoeften identificeren
7- [INDIEN GEEN BEHANDELING].	<ul style="list-style-type: none"> - Geen raadpleging? 	



Questions	Follow-up	Objectif
Waarom neemt u geen behandeling?	<ul style="list-style-type: none"> ➔ Belemmeringen voor raadpleging : <ul style="list-style-type: none"> ○ Gebrek aan informatie over wie te raadplegen? ○ Angst om niet serieus genomen te worden ○ Angst dat gezondheidswerkers niet genoeg weten over het probleem ○ ... – Niets aangeboden – ... 	Eventuele moeilijkheden in het therapeutische traject identificeren
[INDIEN BEHANDELING].		
7+ Hoe ben je ertoe gekomen om deze behandeling(en) te nemen?		
a) Hoe duidelijk was het voor u wat u moest doen?		Eventuele moeilijkheden in het therapeutische traject identificeren
b) Wie heeft deze 'behandelingen' geadviseerd/voorgeschreven?		
c)	<ul style="list-style-type: none"> – Arts – Andere gezondheidsprofessional – Familieleden – Andere patiënten via groepen – Internet – Andere 	Netwerken en informatiebronnen over de ziekte en onderliggende behoeften identificeren
8 Ervaar je moeilijkheden met de verschillende behandelingen die je worden aangeboden?	<p>In termen van :</p> <ul style="list-style-type: none"> – Doeltreffendheid? – Bijwerkingen? – Belastend? – Type aanpak (bijv. gecompartmenteerd of te globaal)? – Beschikbaarheid? – Basisprijs? – Vergoeding? – Zorg beschikbaar? – Complicaties/gevolgen chirurgie 	Identificeren van de medische informatie en financiële behoeften met betrekking tot de behandeling



Questions	Follow-up	Objectif
	– ...	
9 In welke mate hebt u moeilijkheden ondervonden (of ondervindt u nog moeilijkheden) bij de verzorging van uzelf?	Bv. afstand/bereikbaarheid van de plaats van zorg; logistieke hulp nodig	Identificeren van informatiebehoeften en eventuele moeilijkheden in het therapeutische traject
10 Hoe beoordeelt u de follow-up van uw aan melanoom gerelateerde gezondheidsproblemen?	<i>Wat gaat er voor u niet goed op het gebied van opvolging?</i>	De therapeutische en ondersteuningsbehoeften vaststellen
11 Welke oplossingen zou u voorstellen om het beheer van uw medische problemen te verbeteren?	<ul style="list-style-type: none"> – Op het gebied van behandeling – Op het gebied van follow-up en zorgverlening – Op het gebied van informatie – Op administratief gebied – Op financieel gebied 	De therapeutische en ondersteuningsbehoeften vaststellen
12 Ervaart u moeilijkheden in uw relaties met verzorgers?	In termen van : <ul style="list-style-type: none"> – Het meest geschikte type dienstverlener identificeren – Luisteren – Respect – Serieus genomen worden – Betrokkenheid bij beslissingen – Duidelijke informatie – Toegang (wachtijd) – Basisprijs – Vergoeding – ... 	Informatie, ondersteuning en financiële behoeften vaststellen
12' [INDIEN MOEILIKHEDEN] Hoe kunnen deze moeilijkheden overwonnen worden?	<i>Wat kan er gedaan worden om de situatie te verbeteren?</i>	
13 Ondervindt u moeilijkheden op administratief vlak of met de administratieve diensten (ziekenfonds, RIZIV, enz.)?	Bijvoorbeeld : <ul style="list-style-type: none"> – Erkenning als ziek – Vergoedingen krijgen van je ziekenfonds 	Identificeren van administratieve behoeften met betrekking tot het



Questions	Follow-up	Objectif
	<ul style="list-style-type: none"> – Erkenning als beroepsziekte – Verzekering – ... 	gezondheidszorgsysteem in bredere zin
13' [indien problemen ondervonden] Hoe kunnen deze administratieve problemen opgelost worden?	<i>Wat kan er gedaan worden om de situatie te verbeteren?</i>	
14 In welke mate voel je je gesteund bij je huidige gezondheidstoestand?	<i>Welke positieve maatregelen zie je?</i> <i>Wat mis je eventueel aan ondersteuning?</i> <i>Van wie verwacht je ondersteuning die je niet krijgt?</i> <i>Wie zou je nodig hebben om je ondersteund te voelen?</i> <ul style="list-style-type: none"> – Professionals in de gezondheidszorg – Professionals in de geestelijke gezondheidszorg – Maatschappelijk werkers – Patiëntengroepen – Vrienden en familie – ... 	Ondersteuningsbehoeften identificeren
15 Tot slot, van alle behoeften en problemen die je tegenkomt, welke moeten volgens jou prioritair worden aangepakt door wetenschappers en/of politici?	<i>Als jij een politieke (of wetenschappelijke) beleidsmaker was, welke acties zou jij dan prioriteit geven om het dagelijks leven van patiënten met de ziekte van Crohn te verbeteren?</i>	
SLOT		
16 Zijn er nog andere kwesties die volgens jou moeten worden aangepakt in verband met de behoeften waarmee je wordt geconfronteerd als gevolg van de ziekte van Crohn?	<i>Welke andere elementen zijn belangrijk en moeten we weten?</i>	Volledigheid?

Nous vous remercions pour votre participation. Comme annoncé, cet entretien sera retranscrit, anonymisé et analysé avec les entretiens des différentes personnes que nous aurons rencontrées.

L'ensemble des résultats sera présenté dans un rapport publié sur le site internet du KCE d'ici mars 2024 <https://kce.fgov.be/>.



Interview guide - French

Nous vous remercions d'avoir accepté de participer à cet entretien dans le cadre du projet « Evaluation des besoins de patients ayant un mélanome », mené par le Centre Fédéral d'Expertise des Soins de Santé.

Je m'appelle et je suis

L'objectif de notre projet est de comprendre vos expériences et vos besoins suite à votre mélanome malin, et ce, afin de proposer des pistes d'amélioration si nécessaire.

Nous souhaitons enregistrer cet entretien dans le but de faciliter la discussion, de ne pas dénaturer les propos tenus et de retranscrire l'entretien à des fins d'analyse. L'enregistrement sera effacé lorsque les transcriptions seront faites. Le contenu des entretiens sera anonymisé et aucune information permettant d'identifier la personne ne sera publiée.

Il n'y a pas de bonnes ou de mauvaises réponses. Votre expérience et vos opinions sont ce qui importe.

Je vais brièvement vous lire et expliquer l'information du formulaire de consentement éclairé. Après je vous inviterai à le signer et je le signerai moi-même ensuite.

Questions	Relances	Objectif
ICE BREAKER		
1 De manière générale, comment vous sentez-vous aujourd'hui ?		Favoriser la parole
2 Quelles ont été vos motivations pour participer à l'enquête en ligne et pour accepter l'entretien de ce jour ?		Contextualiser l'entretien
3 Si vous deviez expliquer à quelqu'un ce qu'est un mélanome malin, comment le feriez-vous ?	- Connaissez-vous le mélanome auparavant ?	
Nous souhaiterions maintenant passer au travers de votre « parcours diagnostic »		
4 Comment avez-vous découvert que vous aviez un mélanome ?	- Aviez-vous déjà eu un autre mélanome auparavant ? - Quand avez-vous pris la décision de consulter ? - Qui a posé le premier diagnostic ? - La manière dont a été annoncé le diagnostic était-elle adéquate ?	



Questions	Relances	Objectif
5	<ul style="list-style-type: none"> - Quand a-t-il été posé et combien de temps a-t-il fallu pour obtenir le diagnostic? - Après combien de temps avez-vous commencé un traitement (le cas échéant) ? - Avez-vous rencontré plusieurs professionnels de soins avant que le diagnostic ne soit confirmé ? (Dermatologue, oncologue, médecin généraliste, infirmiers, équipe palliative, ...) 	Contextualiser
<p>Nous allons maintenant passer en revue toutes sortes de difficultés que vous pouvez ou avez pu éventuellement rencontrer suite à votre état de santé en raison de votre mélanome. Nous allons essayer de les comprendre avant de voir dans quelle mesure vous avez des propositions à faire pour améliorer la situation.</p>		
6	<p>Rencontrez-vous des difficultés par rapport à votre état de santé dû au mélanome ?</p> <p>En termes de :</p> <ul style="list-style-type: none"> - Symptômes ? - Conséquences psychologiques? (Humeur, gestion des émotions?) - Conséquences sociales ? - Conséquences professionnelles ? - Fonctionnement au quotidien ? - Informations disponibles ? - ... 	Identifier les besoins thérapeutiques, d'information et sociaux au sens large
7	<p>Comment vous soignez-vous ?</p> <ul style="list-style-type: none"> - Médicaments prescrits (immunothérapie, thérapie ciblée, chimiothérapie...) - Médicaments non-prescrits - Chirurgie (mélanome ou métastases ?) - Radiothérapie - Matériel nécessaire - Pratiques non conventionnelles (acupuncture, osteo, homeo...) 	Identification des besoins thérapeutiques



Questions	Relances	Objectif
<p>7- [SI AUCUN TRAITEMENT] Pourquoi ne prenez-vous aucun traitement ?</p>	<ul style="list-style-type: none"> – Soutien psy – Soins palliatifs... – Participation étude clinique pour de nouveaux médicaments ? – Pas de consultation ? → Obstacles à la consultation : <ul style="list-style-type: none"> – Manque d'info pour savoir qui consulter ? – Peur de ne pas être pris au sérieux – Peur que les professionnels de la santé n'aient pas assez de connaissances du problème – ... – Rien n'a été proposé – ... 	<p>Identifier difficultés éventuelles du parcours thérapeutique</p>
<p>7+ [SI TRAITEMENT] a) Comment en êtes-vous arrivé(e) à prendre ce/ces traitements ?</p> <p>Dans quelle mesure avez-vous su clairement ce que vous deviez faire ?</p>		<p>Identifier difficultés éventuelles du parcours thérapeutique</p>
<p>b) Qui vous a conseillé/ prescrit ces 'traitements'?</p>	<ul style="list-style-type: none"> – Médecin – Autre professionnel de santé – Proches – Autres malades via groupes – Internet – Autre 	<p>Identifier les réseaux et sources d'infos autour de la maladie et les besoins sous-jacents</p>
<p>c)</p> <p>8 Rencontrez-vous des difficultés par rapport aux différents traitements qui vous sont proposés ?</p>	<p>En termes de :</p> <ul style="list-style-type: none"> – Efficacité (/résistance) ? – Effets secondaires ? – Lourdeur ? – Type d'approche (compartimentée par ex ou trop globale...) – Disponibilité ? – Prix de base ? 	<p>Identifier les besoins médicaux, d'information et financiers relatifs aux traitements</p>



Questions	Relances	Objectif
	<ul style="list-style-type: none"> – Remboursement ? – Offre de soins disponible ? – Complications/conséquences chirurgie – ... 	
9 Dans quelle mesure avez-vous éprouvé (ou éprouvez-vous encore) des difficultés pour vous soigner ?	Ex : distance/accessibilité du lieu de soins ; aide logistique nécessaire. Information, navigation du système...	Identifier les besoins d'informations et les difficultés éventuelles du parcours thérapeutique
10 Comment évaluez-vous le suivi de vos problèmes de santé liés au mélanome?	<i>Qu'est ce qui ne se passe pas bien pour vous en termes de suivi ?</i>	Identifier les besoins thérapeutiques et de soutien
11 Quelles pistes de solutions verriez-vous pour améliorer la prise en charge de vos problèmes médicaux?	<ul style="list-style-type: none"> – En termes de traitement – En termes de suivi et offre de soins – En termes d'information – En termes administratifs – En termes financiers 	Identifier les besoins thérapeutiques et de soutien
12 Eprouvez-vous des difficultés dans vos relations avec les soignants ?	En termes de : <ul style="list-style-type: none"> – Identifier le type de prestataire le plus approprié – Ecoute – Respect – Prise au sérieux – Inclusion dans décisions – Informations claires – Accès (temps d'attente) – Prix de base – Remboursement – ... 	Identifier les besoins d'information , de soutien et financiers
12' [SI DIFFICULTÉS ÉPROUVÉES] Comment ces difficultés pourraient être surmontées ?	<i>Qu'est-ce qui pourrait être mis en place pour améliorer la situation ?</i>	



Questions	Relances	Objectif
13 Rencontrez-vous des difficultés d'un point de vue administratif ou avec les services administratifs (mutuelle, INAMI, etc.)?	Par exemple : <ul style="list-style-type: none"> – Reconnaissance comme malade – Obtention de remboursements par la mutuelle – Reconnaissance comme maladie professionnelle – Assurances – ... 	Identifier les besoins administratifs liés au système de santé au sens large
13' [SI DIFFICULTÉS RENCONTRÉES] Comment ces difficultés administratives pourraient être surmontées ?	<i>Qu'est-ce qui pourrait être mis en place pour améliorer la situation ?</i>	
14 Dans quelle mesure vous sentez-vous soutenu(e) face à votre état de santé actuel ?	<i>Quelles sont les mesures positives que vous percevez ?</i> <i>Qu'est-ce qui vous manque éventuellement en termes de soutien ?</i> <i>De la part de qui attendez-vous un soutien que vous n'obtenez pas ?</i> <i>Quelles sont les personnes dont vous auriez besoin pour vous sentir soutenu ?</i> <ul style="list-style-type: none"> – Professionnels de santé – Professionnels de la santé mentale – Assistants sociaux – Groupes de patients – Entourage – ... 	Identifier les besoins de soutien
15 Pour conclure, parmi tous les besoins et les difficultés que vous rencontrez, quels sont ceux que vous estimez devoir être prioritairement pris en charge par les scientifiques et/ou les politiques ?	<i>Si vous étiez décideur politique (ou scientifique), quelles actions prendriez-vous en priorité pour améliorer le quotidien des patients atteints d'un mélanome ?</i>	
CLOTURE		



Questions	Relances	Objectif
16 Est-ce qu'il y a d'après vous d'autres problèmes à aborder par rapport aux besoins que vous rencontrez suite au mélanome	<i>Quels autres éléments sont importants et devrions-nous connaître ?</i>	Complétude ?

Nous vous remercions pour votre participation. Comme annoncé, cet entretien sera retranscrit, anonymisé et analysé avec les entretiens des différentes personnes que nous aurons rencontrées.

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APPENDIX 5. QUALITATIVE ANALYSIS CODES

Name	Description
Administrative procedures	All aspects related to administrative procedures
Insurance	All aspects related to extra (private) insurances (ex: hospitalization insurances)
Sickness fund	All aspects related to procedures with sickness funds
Other administrative aspects	All other types of administrative aspects related to MM
Communication	Aspects related to general communication around MM
Promoting well-being	All aspects related to the promotion of well-being of the patients/population at large.
Raising awareness	All aspects related to awareness-raising of MM
Consequences	Consequences of the MM
Financial	Financial consequences (ex: cost of the treatment, financial difficulties because of loss of income, etc.)
Lifestyle	Consequences on the lifestyle in general
Other - consequences	Other types of consequences
Professional	Professional consequences (ex: reduced working hours, impact on career progression, work/life balance, etc.)
Psychological	Psychological consequences (ex: depression, sadness, feeling of abandonment, need to go to a psychologist, etc.)
Social	Social consequences
Diagnosis	All topics related to diagnosis
Announcing the diagnosis	How the diagnosis has been communicated to the patient (incl. human aspects)?
Negative - announcement	Negative aspects on the way the diagnosis has been announced
Positive - announcement	Positive aspects on the way the diagnosis has been announced
Decision to consult	How was taken the decision to consult? Why? When? Etc.
Other - diagnosis	Other elements related to the diagnosis
Patient journey	All the steps that have been taken and that led to the MM diagnosis
Exams	Types of tests/examinations performed



First contact	First contact with a healthcare professional about the MM?
Stages & routes	Steps taken by the patient, that ultimately led to the MM diagnosis?
Type of doctors	All types of doctors met during the diagnosis phase
Quality of the diagnosis	All elements related to the quality of the diagnosis
Negative - quality diagnosis	Negative elements related to the quality of the diagnosis
Positive - quality diagnosis	Positive elements related to the quality of the diagnosis
Timing	Timing between the different steps, appointment and results delivery times, etc.
Negative - timing	Negative aspects in terms of timing during the patient journey
Positive - timing	Positive aspects in terms of timing during the patient journey
Disease description	Topics related the description of the MM
Knowledge before diagnosis	Did the patient know about the disease before the diagnosis?
Lethal aspect	Elements of the description of MM related to its lethal characteristics
Other - disease description	Elements of the description of MM related to other characteristics
Worrying aspect	Elements of the description of MM related to its worrying characteristics
Follow-up therapy	How the therapy is being followed/managed
Compartmentalisation	Potential compartmentalisation in the way the therapy is organised, coordination between the different doctors, complementarity of the monitoring, etc.
Other - follow-up therapy	Other aspects related to the follow-up of the therapy
Psychological support	Any kind of psychological support offered during the therapy
Quality of the follow-up	Is the patient satisfied of the follow-up?
Relations with medical staff	What kind of interpersonal interactions with healthcare professionals?
Compassion & humanity	Aspects related to compassion & humanity when interacting with HC professionals
Involvement in decision-making	Feeling of being involved (or not) on the decisions related to therapy
Taken seriously	Sense of having been taken seriously (or not)
Information received	Information received (without proactivity)
Healthcare professional - info received	Information received from healthcare professionals (general information about MM, information regarding administrative actions, information about scientific progresses, new medicines, clinical trials, etc.)



Other - info received	Information received from other actors (general information about MM, information regarding administrative actions, information about scientific progresses, new medicines, clinical trials, etc.)
Patients groups - info received	Information received from patients groups (general information about MM, information regarding administrative actions, information about scientific progresses, new medicines, clinical trials, etc.)
Personal network - info received	Information received from personal network/relatives (general information about MM, information regarding administrative actions, information about scientific progresses, new medicines, clinical trials, etc.)
Infrastructures	All aspects related to infrastructures relevant in the context of MM
Access	Access to infrastructures
Other - infrastructures	Other aspects related to infrastructures
Quality of the infrastructures	Quality of the infrastructures
Motivations	Motivations to participate in the survey/interview
Advancing research	Motivations related to support research/science
Helping others to benefit	Motivations related to the wish to help others benefit from their experience/ideas
Other - motivations	Motivations related to other reasons
Share experiences	Motivations related to the need to share/confide a personal experience
Search for information	Behaviours when proactively searching for information
Healthcare professionals - search for info	When turning to healthcare professionals when looking for information
Internet	When searching on internet to find information related to MM
Other - search for information	When searching for information through other channels
Patients groups - search info	When searching information through patients groups
Personal network - search info	When searching information through personal network
Scientific literature	When searching for MM related information through scientific literature/academic papers
Suggestions	All recommendations formulated by interviewed patients
Financial - suggestions	Suggestions related to financial matters
Information & awareness	All recommendations related information & awareness



General public - information & awareness	All recommendations related to information & awareness of the general public/population at large
Healthcare professionals - information & awareness	All recommendations related to information & awareness of the healthcare professionals
Infrastructures - suggestions	Suggestions related to infrastructures
Regulations	Suggestions related to regulations
Status & recognition	Suggestions related to status/recognition of the disease and its consequences
Invalidity card	All suggestions related to an invalidity card
Treatment - suggestions	Suggestions related to treatment
Support	All types of support that MM patients can enjoy/benefit from
Family	Support received from the family
Friends and social networks	Support received from friends and social networks
Involvement patients groups	Experiences with patients groups/organisations
Negative - patients groups	Negative aspects of patients groups
Positive - patients groups	Positive aspects of patients groups
Online communities and forums	Support received from online communities and forums (excl. patients organisations)
Symptoms	All symptoms related to MM
Post-treatment	All symptoms post treatment
Pre-treatment	All symptoms prior to the treatment
Remission	Symptoms occurring while in remission
Requiring hospitalizations	All symptoms that led to a hospitalization
Treatment	Treatment of the MM
Alternative medicines	Use of alternative medicines and impact (positive or negative)
Availability	Availability of the medicines
Barriers & obstacles	All kinds of barriers & obstacles to the treatment
Coping mechanisms	Next to prescribed treatment, how to manage symptoms, emotions, etc.
Efficiency	Efficiency of the treatment



Resistance	Cancer treatment resistance
Non-prescribed medicines	Taking of non-prescribed medicines
Other - treatment	Other topics related to treatment/therapy
Prescribed medicines	Taking prescribed medication
Refusing therapy	When a person refused the therapy/to take prescribed medicine
Reimbursement	Reimbursement of the treatment
Side effects	Side effects of treatment
Surgery	Everything related to treatment through any kind of surgery
Complications surgery	Any complication related to surgery
Temporality of the treatment	Evolutions of the treatment over time / different steps of the treatment
Frequency treatment	What is the frequency of the treatment?
Start treatment	When the treatment did start