

# STATE OF THE NATION: NON-MELANOMA SKIN CANCER



SANOFI GENZYME

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# FOREWORD

**Sir Edward Leigh MP,  
Chair of the All Party Parliamentary Group on Skin (APPGS)**

Non-melanoma skin cancer (NMSC) is the most common cancer in the UK, yet most people haven't heard of it, and would struggle to correctly identify its symptoms. Despite the significant physical and emotional distress it can cause, NMSC is still all too often regarded as a minor condition that is easily treatable.

Worryingly, although the biggest risk factor for developing NMSC is over exposure to the sun's UV rays, new cases of this largely preventable disease are rising steeply. By 2025 there are expected to be almost 400,000 NMSC diagnoses a year, with potentially devastating consequences for those affected and for the health system at large. At a time when dermatology services across the UK are already stretched thin, the rising tide of NMSC requires urgent attention.

As the health system continues to adapt to the exceptional circumstances brought about by the COVID-19 pandemic, it is even more important to ensure that the policies and systems are in place to help prevent, as far as possible, new cases of NMSC from arising - and to ensure that high-quality care is provided for the growing number of patients who need access to treatment and support.

Action needs to be taken across the system, from continuing efforts to improve sun safety and early symptom recognition through to ensuring that all NMSC patients are able to access the care they need, including help to deal with the considerable psychological impact of this condition.

For the first time, this report shows a picture of outstanding need in NMSC. It provides a benchmark for the current state of the nation in NMSC and identifies opportunities to help improve all aspects of a patient's care. Challenges highlighted within the report include the low levels of current understanding and awareness of NMSC amongst the public, continuing shortfall in the workforce that are able and equipped to diagnose and manage NMSC, and the significant outstanding gaps in our understanding of its scale and the quality of care offered to those diagnosed.

Ultimately, we hope that through the publication of this report, action on NMSC will be taken by policy makers and service commissioners across the UK. The scale and increasing burden of NMSC means that we can ill afford to postpone these actions.



# EXECUTIVE SUMMARY

NMSC can have a significant impact on patients. However, this may not be well understood and multiple challenges exist in how it is prevented, identified, treated and managed in the UK.

Particular issues include:

## Low public knowledge and understanding

Public awareness about the disease is concerning low. A survey of over 3,600 members of the UK public conducted by Sanofi Genzyme in March 2020 found that:<sup>1</sup>

# 69%

of respondents did not recognise NMSC as a form of skin cancer

# 38%

of respondents did not know what the risk factors for NMSC are, and of those only 28% would take more precautions had they known

# 56%

of respondents were unaware that some types of skin cancer can spread to other organs in the body

## Under-reporting of NMSCs

The under-reporting of NMSCs is a well-documented challenge.<sup>2</sup> NMSCs are not consistently registered and due to the high volume of tumours are frequently excluded from national cancer statistics.<sup>3</sup> This leaves the true extent of the disease unknown and makes prioritisation and effective management by healthcare professionals a challenge.

## Insufficient number of consultant dermatologists

The healthcare workload burden of NMSC is substantial within dermatology departments, particularly as these cancers are often seen urgently within 2 weeks of referral.<sup>4</sup> Yet, there is just one full-time dermatology consultant to every 80,500 people in the UK.<sup>5</sup> This pressure will continue to grow given the increasing incidence of skin cancer.

## Confusion in the care pathway

Inconsistency exists across the UK in the referral and management of patients between relevant multidisciplinary teams (MDTs).<sup>6</sup> Without consistent management pathways, there may be variation in the quality of care that patients across the country receive.

## Lack of clinical trial evidence

Academic research related to skin cancer has focused mostly on melanomas. There is a comparative lack of clinical research into non-melanoma skin cancers and no large prospective randomised, controlled trials in which different management approaches and treatments for NMSC have been compared.<sup>7</sup> This is a challenge for healthcare professionals as it limits knowledge and understanding of optimal practice and leaves patients with fewer treatment options.

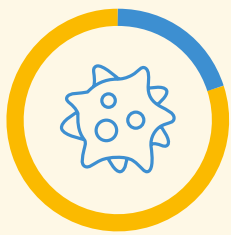
## With the ageing population and increasing incidence of NMSCs, unless urgent action is taken these challenges will only become more acute.

Our recommendations for policymakers are as follows:

- 1 The UK government and devolved administrations should seek to improve awareness of skin cancer symptoms, including those of NMSC, and promote sun safety measures to prevent skin cancer.
- 2 All patients with NMSC should be provided with access to high-quality information and support to deal with the physical and psychological impacts of the disease and its treatment.
- 3 Governments, health systems and research communities across the UK should work towards improving data and evidence on NMSC.
- 4 Health workforce planning across the UK, including the upcoming NHS People Plan, should recognise the rapidly increasing prevalence of NMSC and plan for the impact that this will have on health systems.
- 5 Skin cancer MDTs should have access to a range of specialisms and competencies, to ensure patients receive the full range of appropriate care options.

# NMSC IN NUMBERS

NMSC is the most common cancer in the UK - in fact, it accounts for



**20%** of all new cancers<sup>8</sup>



**90%** of all skin cancers<sup>8</sup>



**152,000+** new cases of NMSC diagnosed in the UK each year<sup>9</sup>



Approximately **720** people die from NMSC every year in the UK - or 2 deaths a day<sup>9</sup>



Almost half of new NMSC cases are in people over **75**<sup>9</sup>



The two most common forms of NMSC are basal cell carcinoma (BCC) and cutaneous squamous cell carcinoma (CSCC)<sup>10</sup>

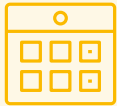
### NMSC rates are rising rapidly across the UK



**166%** increase in NMSC diagnoses since the early 1990s<sup>9</sup>



Almost



**400,000** estimated number of NMSC cases per year by 2025<sup>11</sup>



The UK has the fastest growing rate of CSCC diagnosis in Europe<sup>12</sup>

### Exposure to ultraviolet radiation from the sun and tanning beds is the biggest risk factor for NMSC, especially for people with fair skin<sup>13</sup>



More than

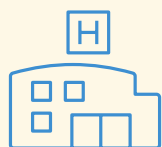
**80%** of all skin cancers are considered preventable by reducing exposure to UV<sup>14</sup>



Outdoor workers are at least twice as likely to get NMSC as those that work indoors<sup>15</sup>

### NMSC costs the health system a significant amount and costs are growing year on year

**£150m**



cost of NMSC hospital admissions in 2019 in England<sup>16\*</sup>

**8.2%**



increase in the cost of in-patient care for NMSC in England between 2018 and 2019<sup>16</sup>

\* Due to differences in how data is collected across the UK it is not possible to provide a UK-wide figure for NMSC-related hospital costs or admissions

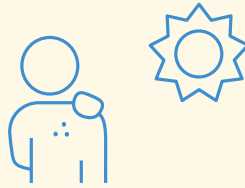


## WE ASKED 3,638 ADULTS ACROSS THE UK WHAT THEY KNOW ABOUT NMSC AND WHAT NEEDS TO HAPPEN TO HELP PREVENT IT. THIS IS WHAT OUR SURVEY FOUND:<sup>1</sup>



**69%**

of adults in the UK don't recognise NMSC as a form of skin cancer



**38%**

of adults do not know what the risk factors for NMSC are



**23%**

of UK adults are able to correctly identify the four most common signs of NMSC



**56%**

are unaware that skin cancer can spread to other organs in the body



**66%**

of UK adults think that the government could do more to raise awareness of and help prevent skin cancer



**58%**

of people who work outside would like more help from their employer to protect them against skin cancer

## What is non-melanoma skin cancer?

Non-melanoma skin cancer (NMSC) refers to a group of cancers that develop in the upper layers of the skin. It is the most common cancer in the UK.<sup>8</sup> There are around 152,000 new cases of NMSC every year.<sup>9</sup> This is more than breast, prostate and lung cancers combined.<sup>17</sup>

The actual number of cases of NMSC is likely to be considerably higher than this due to under-reporting and inconsistent data collection.<sup>8</sup> It is known however that incidence is increasing. By 2025 it is estimated there will be almost 400,000 cases a year.<sup>11</sup>

The single biggest risk factor is exposure to the sun.<sup>18</sup> Over 80% of tumours occur on the head, face and neck – the areas most regularly exposed to the sun – and it most commonly affects those with fair or light skin, which easily burns.<sup>18</sup>

Most NMSC can be successfully treated with surgery or radiotherapy but in a small number of cases the cancer can spread and be fatal.<sup>19</sup> However even when treatment is successful the disfiguring nature of tumours associated with surgery means NMSC can have a significant lasting psychological impact.<sup>20</sup> This is made worse as the risk of developing further tumours, and therefore needing more surgery, is high.<sup>21</sup>

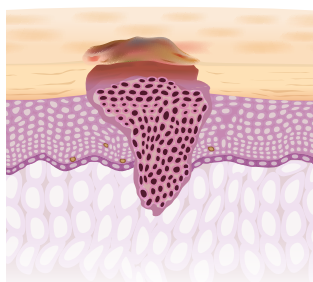
## Types of non-melanoma skin cancer

### Basal Cell Carcinoma

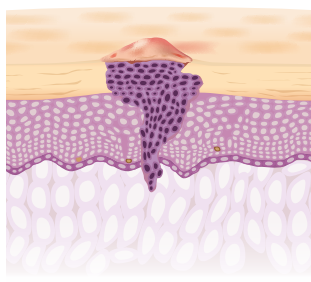
Basal cell carcinoma (BCC) is the most common type of NMSC.<sup>10</sup> It accounts for about 75% of all non-melanoma skin cancers and mostly develops on skin damaged by the sun.<sup>10</sup> It rarely spreads to other parts of the body and is seldom fatal.<sup>8</sup> However, it can be highly disfiguring and destructive when treatment is inadequate or delayed.<sup>22</sup>

### Cutaneous Squamous Cell Carcinoma

Cutaneous squamous cell carcinoma (CSCC) accounts for about 23% of non-melanoma skin cancers.<sup>8</sup> While deaths from CSCC are rare overall, the prognosis for metastatic CSCC is poor.<sup>23</sup> Patients in whom CSCC has spread to other parts of the body survive on average for only 10.9 months.<sup>24</sup> Where advanced CSCC is located on the head and neck, average survival is even lower at 8.4 months.<sup>25</sup> This is further reduced in patients with tumours that cannot be surgically removed to just 5 months.<sup>25</sup>



Basal Cell Carcinoma



Cutaneous Squamous Cell Carcinoma

### Other types of NMSC

There are also less common types of NMSC, which make up fewer than 1% of all skin cancers in the UK:<sup>26</sup>

- ▶ **Merkel cell carcinoma (MCC)** starts in the outer layers of the skin. MCC is very rare, with just over 1,500 people diagnosed with MCC in England between 1999 and 2008.<sup>27</sup>
- ▶ **Kaposi's sarcoma (KS)** develops in the cells lining the inside of lymph or blood vessels. As well as the skin, it can also develop in the lymph nodes, lungs, bowel, liver and spleen.<sup>28</sup>
- ▶ **Cutaneous T-cell lymphoma (CTCL)** is a rare type of non-Hodgkin lymphoma that affects the skin. CTCL is the most common type of skin lymphoma. It causes patches on the skin that look like eczema and can be itchy.<sup>29</sup>
- ▶ **Sebaceous gland carcinoma** develops in the sebaceous glands, which are found all over the body. This means that this type of cancer can be diagnosed anywhere. The most common site for the cancer is the upper eyelid and 3 out of 4 of these cancers are diagnosed around the eye.<sup>30</sup>

# NMSC risk factors

While the exact cause of someone’s NMSC may not be known, there are a number of significant risk factors:

## AVOIDABLE RISK FACTORS



### SUN EXPOSURE

The biggest risk factor for NMSC is exposure to the sun’s ultraviolet (UV) rays. The more time spent in the sun, without adequate protection, the greater the risk of developing NMSC.<sup>31</sup>



### TANNING BOOTHS & SUNLAMPS

Artificial sources of UV rays can damage the skin. CSCC risk is at least 67% higher, and BCC risk 29% higher in people who have used a sunbed (at any age), compared with those who have never used one.<sup>32,33</sup>



### CARCINOGENIC CHEMICALS

People who have been exposed to tar, arsenic and other cancer-causing chemicals have an increased risk of NMSC, although the amount of exposure that increases the risk is unclear.<sup>31</sup>

## UNAVOIDABLE RISK FACTORS



### AGE AND GENDER

Skin cancer can occur at any age, but NMSC is more common over the age of 40 years. Men are more likely to get non-melanoma skin cancers than women.<sup>9</sup>



### CERTAIN COLOURS OF SKIN, HAIR, AND EYES

People with pale skin, or red or blond hair, have an increased risk of NMSC.<sup>31</sup> The risk of BCC is 70% higher in people with skin types that burn easily.<sup>31</sup>



### CERTAIN RARE INHERITED CONDITIONS

People with genetic conditions such as basal cell nevus syndrome (Gorlin syndrome) or xeroderma pigmentosum have a much higher risk of skin cancer.<sup>34</sup>



### A PERSONAL OR FAMILY HISTORY OF SKIN CANCER

People who have had skin cancer before are at increased risk of getting it in the future. There is a 44% risk of developing another BCC within three years while the risk of developing another CSCC within five years is 37%.<sup>3</sup> The risk of developing SCC or BCC is also increased in people with a family history of the skin cancer.<sup>10</sup>



### A WEAKENED IMMUNE SYSTEM

People who have a weak immune system, such as those who have had an organ transplant, have a higher risk of skin cancer.<sup>34</sup> Their skin cancer is also more likely to be more aggressive.<sup>35</sup> The incidence of BCC and CSCC is 10 times and 100 times higher respectively in recipients of solid organ transplants than in non-recipients.<sup>36</sup>

# THE IMPACT OF NMSC

## The physical and psychosocial impact on patients

### The physical impact

NMSC can have significant negative physical impacts, with tumours most often developing on the head, face, neck and hands – the areas most exposed to the sun.<sup>10</sup> This can lead to lasting physical damage, disfigurement and other side-effects. Tumours can cause itchiness, bleeding, soreness and problems sleeping.<sup>37,38</sup> Larger tumours that develop around the mouth and nose can cause disfigurement and lead to difficulty with eating, speaking, or breathing, while those on the eyes and ears can affect the ability to see or hear.<sup>39</sup> They can also become infected, causing damage to the skin and surrounding tissue.<sup>40</sup> In advanced cases, these wounds can release unpleasant smells that require frequent dressings.<sup>40,41</sup>

Surgery to remove NMSC can have a lasting physical impact on patients. The removal of large tumours may leave significant scarring and in some cases treatment requires the removal of parts of the ear, eyes or nose.<sup>37,42</sup> Some patients may require a skin graft involving a hospital stay and a lengthy recovery process.<sup>43</sup>

Around half of patients with NMSC develop more than one tumour, with some patients known to develop over 100 tumours over time.<sup>21,44</sup> This can require extensive repeat treatment and leave patients with significant cosmetic disfigurement and loss of function.<sup>3</sup>

In rare cases NMSC can become metastatic, spreading to other parts of the body.<sup>10</sup> CSCC is more likely to spread than other forms of NMSC, and when it does it is almost always fatal – under 10% of people survive for 10 years.<sup>45</sup> Metastatic CSCC can cause a variety of symptoms depending on where it has spread, including kidney failure, bowel blockages and collapsed lungs.<sup>40</sup>

As the risk of developing NMSC increases with age, the majority of NMSC patients are elderly – almost half of all new cases in the UK are in people aged 75 or above.<sup>9</sup> Older NMSC patients often have other co-morbidities, including heart disease, pneumonia and Alzheimer's, and older and more complex NMSC patients are much more likely to die from their co-morbidities within 5 years of diagnosis.<sup>46</sup>

### The psychosocial impact

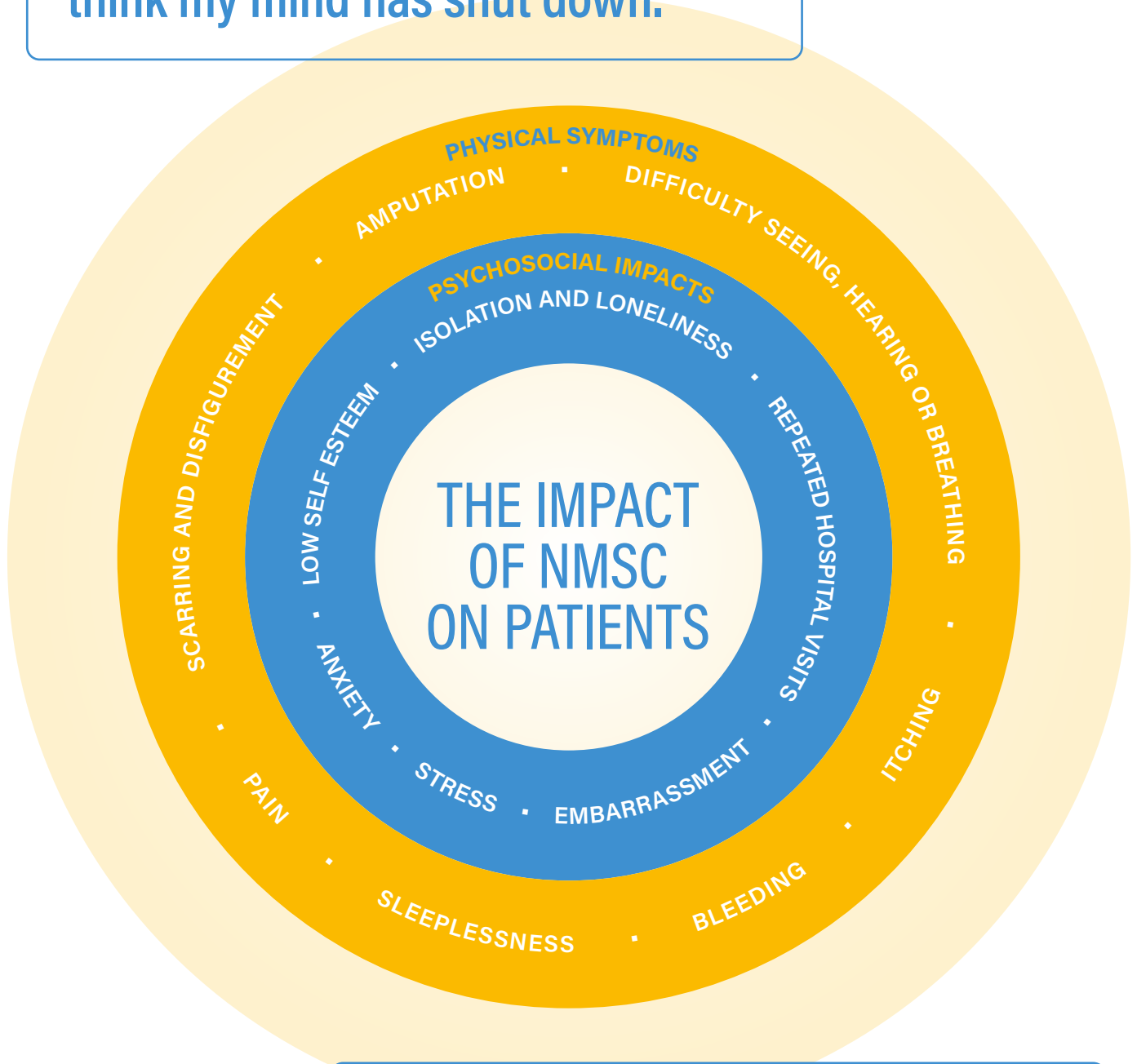
Due to the highly visible nature of many NMSCs and the disfigurement it can cause, the psychological impact on patients of the disease and its treatment can be considerable.

This can cause substantial distress and impact on the self-esteem and confidence of patients.<sup>47</sup> As a result, people with NMSC may avoid taking part in day-to-day activities due to concerns about their appearance, leading to feelings of loneliness and isolation.<sup>48</sup>

NMSC patients also experience significant anxiety around the potential of developing further NMSCs or it spreading to other parts of the body.<sup>37</sup> The repeated need for hospital visits and recovery time also causes additional stress and knock-on burdens on patients' economic and social wellbeing.<sup>37</sup>

**“Well, I don't like it when people stare at me. It makes me a little bit uneasy; especially the little children. That bothers me.”<sup>37</sup>**

“I wear the hat and the wig because after all these surgeries I – I have no hair, it’s all scar tissue and I think my mind has shut down.”<sup>37</sup>



“A great, gaping wound on my face and no ears, I mean as soon as you look at me you can tell something is definitely wrong with this guy.”<sup>37</sup>

## Katy Flynn: My story with BCC

At the age of just 30 I was diagnosed with basal cell carcinoma (BCC).

It started with a small speck that suddenly appeared on the side of my nose. I didn't think much of it at the time. I thought it may have just been caused by a scratch. The scab would fall off but then regrow and then it started to become quite dry and scaly. So I took to using creams and lotions; hoping that would get rid of it but it would keep growing back. It would bleed every time I washed my face and dried it with a towel. It never occurred to me that it could be skin cancer. In fact I thought it might be eczema.

Eventually 12 months later I went to see my GP about something else entirely and mentioned the mark on my nose. My GP didn't think it was serious but because I'd had it so long, I was referred to a dermatologist for a second opinion. By this time the small speck on my nose had grown to the size of a 5p coin.

The dermatologists took some pictures of the scab and sent those away to be analysed. About 8 weeks after my appointment I was told I had a pre-cancerous growth and was prescribed a gel. I wasn't able to get hold of this for about a month as the treatment wasn't available in any of my local pharmacies. Eventually a nurse at the GP practice was able to source it but after a year of using the gel the mark continued to grow larger.

I went back to the GP who referred me again to the dermatologist. More photos were taken but this time I was sent to have a biopsy. The results came back that I had BCC.

When the doctor told me I had BCC I felt relieved to finally have a confirmed diagnosis. I had been on such a long journey and had done all my research from when I found out I had pre-cancerous growth. I had already mentally prepared myself for that moment.

Luckily BCC is treatable. I had a 6 hour operation to remove any cancerous cells from my face, following this I was sent for plastic surgery. The surgeon had to use skin from my forehead to cover the parts of my nose they had to cut away. **It took four weeks for the skin to grow back on my forehead. But I now have a four inch scar across my face. It was a really tough time. I was worried what my little girls would think. I didn't want them to be scared when mummy came home from surgery.** So I showed them pictures of



Katy now, having recovered from surgery



1. Katy during reconstructive surgery after removal of the BCC  
2. After final reconstructive surgery

what I would look like beforehand so they would know what to expect.

I didn't really leave the house apart from to pick the kids up from school. I couldn't face all the questions. I didn't want to have to answer them. I felt nervous going back to work and really self-conscious of the scar on my forehead. For me the biggest challenge is gaining the confidence following the disfigurement it causes. You can't hide your face. So I'm getting used to how my skin looks now. It is something I have to live with. But to be honest I'm lucky to be alive.

I was quite young when I got diagnosed and I didn't feel there was enough information and support for someone my age. My mum would come with me to my appointments and people would think the appointments were for her rather than me! I turned to Facebook communities and it made such a difference to me. Just to have someone else to talk to; to know that I wasn't the only one and that there are others going through the same thing as me. Having a community to talk to has been a huge source of help and support.

I do think there should be more symptom awareness but it needs to be balanced. You don't want to panic people. Before I was diagnosed, I wasn't aware of the symptoms of NMSC. It's not like a lump or a bump you get with other cancers. I just had a bit of dry skin. I didn't think anything of it. To be honest I felt stupid going to the doctors about it. I thought it was something I could deal with myself; that I didn't need to bother the doctor about. My advice is that - you know your body best. If there is something that doesn't feel quite right, that isn't normal for you then see your GP. It is treatable but the impact on my life and recovery has been huge.

## John Longworth: My experience with CSCC



I was 73 when I was first diagnosed with advanced cutaneous squamous cell carcinoma (CSCC). I noticed a scabby lump on the back of my head. I didn't really know what it could be. I didn't have any other symptoms, so the fact that it might be cancer didn't occur to me. I thought it would just go away.

My daughters encouraged me to go to the GP to get it checked out and I was referred to the local skin clinic straight away where the scab was removed. It was at this point I was told I had CSCC. I didn't have a big reaction to it. I just tried not to panic and let the health care professionals do their job. They seemed to have it all in hand. My daughters on the other hand asked all the questions and wanted all the information.

A further lump developed – the size of a ping-pong ball on the back of my neck. I was referred to have surgery to have the lump removed where I spent 4 or 5 days in hospital. As well as the lump, they had to take some of the surrounding area to make sure they didn't miss anything, so I had a big hole at the back of my head. After that I needed to go back for a skin graft and had radiotherapy and then more surgery. This time to remove lymph nodes in my neck. I then had another round of surgery about 2-3 months later. This was all in the space of about 6 months, so it was a lot.

Following the removal of the lump, my daughter would change the dressing daily, this was later changed to the district nurse. Because the wound on the back of my head was still healing there was a huge risk that it could get infected and it did. On one occasion my granddaughter who had offered to change the dressing found that my wound was infested with maggots! The dressing had clearly come loose at some point which had allowed flies to get in and lay their eggs. We immediately went to A&E where they

spent 2-3 hours removing about 50 maggots. After that I'd spray insect repellent around the wound to keep the flies out. Four years on the wound is still there but it's reduced in size and the skin is starting to grow back.

When I first came back from surgery I was quite self-conscious about it, so I'd wear a cap when I'd go out to cover it and I grew beard to hide the scarring on my neck.

The worst part of the treatment was the chemotherapy. I experienced a lot of side effects. It made me tired. I lost my appetite. I lost weight. It was difficult finding suitable food that I could easily eat. I had constipation and a very sore mouth. My tongue was delicate. If I drank fruit juice or wine it would really hurt. My weeks would constantly go from good to bad. **It was a tough time but I was still trying to get on with it. I was constantly having to go into hospital for appointments. In any one week I could have as many as 8 appointments.** By the time I was diagnosed I was retired, so I had more time and I also had a car so I could drive to appointments. But for someone else who did work or didn't have a car this would've been a huge burden.

Even now, four years on I still have multiple appointments – about 2 to 3 a week, whether that is to have my dressing changed or for blood tests. But everyone has been fantastic; from the receptionists to consultants. They have all been brilliant.

Following all the treatment, my life has now returned to normal. My appetite has returned, and my energy level has gone back up, which gave me the confidence to go for a weekend break and play golf. Something I couldn't do before.

# The impact of NMSC on the health service

## Impact on the health workforce

The sheer volume of patients with NMSC has considerable implications for the healthcare workforce, and its rapidly rising incidence means that NMSC will account for an increasing proportion of healthcare professionals' time without adequate planning.

This is particularly important in dermatology, where a significant ongoing shortage of dermatologists means that services will struggle to meet the rise in demand if no action is taken.

GP referrals to dermatology increased by 15% between 2013/14 and 2017/18, reaching 1.16 million a year, yet an estimated quarter of dermatology posts in the UK are unfilled.<sup>49,50</sup> There is just one full-time equivalent dermatologist per 80,500 people, falling far short of the baseline ratio of one per 62,500 recommended by the Royal College of General Practitioners (RCGP) and the British Association of Dermatologists (BAD).<sup>5</sup> In certain regions of the UK dermatology coverage is stretched particularly thin, with four NHS Trusts in England and one Health Board in Wales employing no permanent or full-time dermatology consultants but instead relying on locums (as of January 2019).<sup>5</sup>

Other healthcare professionals also play important roles caring for people with NMSC. GPs lead the management of low-risk cases, and oncologists, surgeons and specialist skin cancer nurses are integral in managing more complex NMSC cases.<sup>51</sup> Psychologists and other mental health professionals are also vital to help NMSC patients deal with the psychological effects of the disease.<sup>52</sup> Workforce shortages have been identified across all of these roles.<sup>53,54</sup> Without action to ensure that the healthcare workforce can meet the forecast rise in NMSC there is a clear risk that the standard of care for patients with skin conditions will fall.

“As a dermatologist, skin cancer accounts for around half of my workload and the number of cases is growing year on year. Non melanoma skin cancer (NMSC) is by far the most common form, and around a third of these patients develop multiple tumours over time, requiring repeat treatment. The sheer number of patients and tumours places a huge burden on the healthcare system. The prevention of second and subsequent tumours is an important part of trying to reduce the ever-increasing numbers of cases. Many centres simply don't have the capacity to follow up all patients after their first NMSC because of the large numbers of patients requiring support. To deliver the care required to patients and effectively manage the increasing incidence of NMSC, we urgently need a significant increase in clinical capacity.”

**Professor Catherine Harwood, Consultant Dermatologist at Barts Health NHS Trust**



### Impact of inconsistent data collection on planning and research

While NMSC diagnoses are known to be rising steeply, the full impact of NMSC on the health system remains unknown due to a lack of accurate and comparable data on the scale of NMSC across the UK.

Cancer registries are responsible for recording all cases of cancer and in doing so provide important information on cancer trends over time. This means services can be appropriately planned and delivered to ensure there is capacity to meet any potential increase in demand.

**“While important steps have been taken to improve the registration of some NMSCs, giving us a better understanding of how they affect the population, there is still marked variation across the UK in how data is collected. Cancer registries must be supported to record all NMSCs beyond the primary tumour alone. Without this information our ability to plan for the capacity and workforce required to deal with the tidal wave of NMSC is severely hampered.”**

**Professor Charlotte Proby, Professor of Dermatology, University of Dundee**

However, many cancer registries do not fully record NMSCs due to the high volume of tumours, and the quality of data on NMSC is known to be unreliable due to variations in how NMSC is recorded across different areas. This has led to the number of cases of NMSC being under-reported. For example, in Scotland while all CSCCs are recorded only the first BCC is recorded in the national cancer registry.<sup>3</sup> When registries do choose to count secondary tumours, an additional 30% to 50% are counted.<sup>3</sup> As a result the incidence of NMSC across the UK is significantly under-reported and the true burden of NMSC remains unknown.<sup>23</sup> This makes prioritisation and effective management by healthcare professionals a challenge.<sup>55</sup>

This lack of reliable cancer registration data on NMSC also means it is often excluded from national-level analyses of cancer trends, leading to under-recognition of NMSC as a significant, and increasing, cause of cancer-related ill-health.

### Direct costs of care for NMSC

The frequency and rising incidence of NMSC means that it accounts for a significant proportion of health service resources, and these costs are growing. There were over 158,000 hospital admissions and 97,000 bed days in 2019 in England alone.<sup>16</sup> The total cost of in-patient care for NMSC in England was an estimated £150.5 million in 2019, an increase of 8.2% from the previous year.<sup>16</sup> Data on the costs of NMSC in Wales, Scotland and Northern Ireland is not readily available, meaning the figure across the UK is likely to be even higher.

NMSC costs to health services are even higher when outpatient services are taken into account. Most care for skin cancer is delivered in an outpatient setting – up to 45% of specialist referrals to dermatologist outpatient services relate to skin lesions, and this rises to 60% in some regions in the country.<sup>18</sup> Up to 50% of dermatologists' workload in England is taken up by delivering outpatient skin cancer care.<sup>55</sup>



# PREVENTING NMSC

The case for the government to take action to prevent NMSC is clear given its known link to UV exposure – yet neither the Health and Social Care Secretary’s vision for prevention, “Prevention is better than cure”, nor the Prevention Green Paper that followed, included ambitions for skin cancer prevention.<sup>56,57</sup>

Charities such as Skcin and MASScot have been driving efforts across the country to prevent skin cancer through improving awareness of sun safety and tanning bed regulation. These efforts should be supported by government and provided at scale throughout the country in order to help address the growing negative impacts of skin cancer to the population.

There are many simple ways in which preventive measures against NMSC can be taken and which the government should seek to raise greater awareness of. For instance, people can protect themselves from sunburn by:<sup>10</sup>

- ▶ Using high-factor sunscreen.
- ▶ Covering up in the sun.
- ▶ Limiting the amount of time spent in the sun during the hottest part of the day.
- ▶ Avoiding sunbeds and sunlamps.

Our survey found that only 15% of respondents would apply sunscreen and wear a hat when going outside in the sun, and over half who wear sunscreen do not apply it sufficiently.<sup>1</sup> Worryingly, over a quarter (26%) of respondents would only take precautions against sun damage if they were going sunbathing, and a further 13% would take no precautions at all.<sup>1</sup> A sustained programme of education and awareness on sun safety is required to mitigate this and should start from an early age – particularly as there is a link between sun exposure in childhood and the development of BCC in later life, while cumulative sun exposure over time is known to increase the risk of both BCC and CSCC.<sup>58</sup> It is therefore critical that education around being sun safe is started at an early age.

**Our survey of over 3,600 UK adults found that:<sup>1</sup>**

## 15%

**of adults in the UK would apply sunscreen and wear a hat when outside in the sun**

## 39%

**would only take precautions against sun damage (such as applying sunscreen or wearing a hat) if they were sunbathing, but not otherwise**

## 13%

**would take no precautions at all to avoid direct sunlight in the summer months**

“Non melanoma skin cancer rates are increasing rapidly. Just over the last decade there has been a 45% increase and almost 400,000 cases of NMSC are predicted annually by 2025. But research shows that 86% of skin cancers are largely preventable as they are due to over-exposure to the sun. There needs to be a much stronger focus on intervention and prevention strategies and with over £350 million being spent by the NHS to treat the disease we need to act now.

Charities such as Skcin have developed a suite of interventions for key at-risk groups across the UK, such as outdoor workers. These robust and scalable solutions need to be embraced by government and Public Health England. If we worked together we could make even more of a difference and reduce the huge burden to the NHS and save lives.”

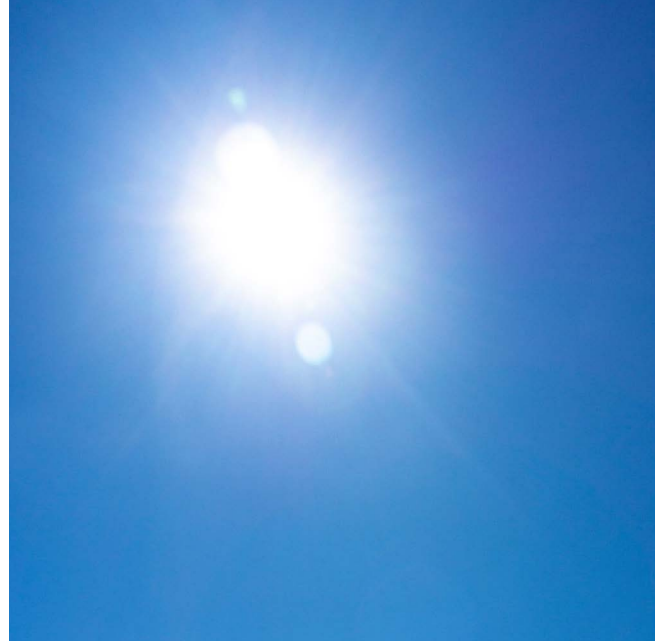
**Marie Tudor,**  
**CEO of National Skin Cancer Charity Skcin**

**Given the projected increase in the number of cases of NMSC and the expected impact of this on the health service and on individuals, the government must ensure that the prevention of non-melanoma skin cancer forms a central part of any government strategy on prevention.**

#### **Preventing NMSC in outdoor workers**

Individuals who work outdoors for example, postal workers or construction workers, are at increased risk of developing skin cancer. This risk can increase by up to 100% after five years of outdoor work.<sup>59</sup>

There is a legal responsibility for employers in England to protect the long-term health of their employees under the Health and Safety at Work Act.<sup>60</sup> This includes providing information and training to minimise exposure to cancer-causing agents (carcinogens) at work. UV radiation is included in the official list of hazards known to cause cancer.<sup>61</sup>



#### **Sun-safe awareness programmes**

There are a number of innovative charity-led programmes that aim to increase awareness of being sun safe from an early age:

The Scottish skin cancer charity **MASScot** trains teachers to deliver interactive lessons to school children on the effects of over-exposure to sunlight and the dangers of using tanning beds. To date their educational programmes have reached a total of over 60,000 students.

In England the charity **Skcin** run accreditation schemes – **Sun Safe Schools** and **Sun Safe Nurseries**. These schemes educate children on the importance of sun safety and assist primary schools/nurseries to implement a suitable sun safe policy, fulfil their duty of care to keep children safe and promote the reinforcement of sun safety at home in order to embed knowledge and cultural change at a young age.

Further advice and guidance set out by the Trades Union Congress (TUC) recommends companies that employ outdoor workers should take the following steps to minimise the risk of outdoor workers developing skin cancer:<sup>60</sup>

- ▶ Establish working practices so that employees spend less time outdoors during the hottest time of the day and in the hottest months of the year.
- ▶ Provide protective canopies or shaded areas for outdoor working spaces.
- ▶ Supply information and advice to employees on avoiding exposure to UV radiation, including in different languages to reflect the workforce.
- ▶ Provide workers with sunscreen of at least SPF20 and preferably SPF30, including UVA protection, and encourage its regular and correct use.

Despite this legislation and official guidance, in our survey of UK adults almost two thirds (64%) of people who work outdoors for more than 1 hour per day said that their employers don't do anything to help protect them against skin cancer.<sup>1</sup> 58% of respondents who work outdoors said they would like their employers to do more to help protect them against skin cancer.<sup>1</sup>

Some companies with a primarily outdoor-based workforce are leading the way in helping to protect their workers' skin health. For instance, Royal Mail Group has developed a comprehensive sun safety strategy focusing on raising awareness amongst its thousands of postal workers of the risks of working in the sun without protection.<sup>62</sup> It also provides wide-brimmed hats, long-sleeved tops and trousers to all employees, which are approved by the British Association of Dermatologists for UV radiation protection.

Last year to mark skin cancer awareness month in June, Sanofi Genzyme in partnership with Skcin hosted a parliamentary drop-in for MPs and peers, as well as skin cancer and occupational health representatives including the British Skin Foundation, Melanoma Focus and Royal Mail. The event was focused on raising awareness of skin cancer, including non-melanoma skin cancer, amongst parliamentarians; and providing them with the knowledge to advocate for greater understanding of its risk factors and the needs of those affected – especially those who are exposed to UV rays in their line of work.

It is important that all employers of outdoor workers put in place similarly robust measures to reduce the risks of UV exposure to their employees as much as possible. Support and advice for implementing sun safety measures at work is available from various sources, including the Institution of Occupational Safety and Health (IOSH) and charities such as Skcin.

**Sun Safe Workplaces** is an accreditation scheme run by the skin cancer charity **Skcin**. It aims to prevent skin cancer through the promotion of sun safety in the workplace. The scheme advises employers on how to educate outdoor workers on the importance of sun safety as a serious health and safety issue. Skcin provides online tools for all UK companies that employ outdoor workers to help them fulfil their duty of care to keep employees safe from risk of over exposure to the sun/UV radiation.

# THE NMSC PATIENT PATHWAY

## Referral and diagnosis

Timely diagnosis of NMSC and appropriate referral to specialists is vital for optimal patient outcomes. Late diagnosis and inadequate treatment can lead to tumours destroying significant anatomical features such as the nose, eye, ear and lip, requiring disfiguring surgery, or even becoming inoperable.<sup>18</sup>

Patients who show potential symptoms of NMSC should be referred to a dermatologist to confirm their diagnosis.<sup>63</sup> However, the pathway to a diagnosis depends on the type of NMSC a patient presents with.

The symptoms and signs of non-melanoma skin cancer are not always easy to identify. A common misconception is that all skin cancers start as a mole. In reality NMSC do not start as moles, but may present as lumps, ulcers, patches of scaly or discoloured skin. This can make recognising potential NMSC and referring to the right specialists challenging. Members of the public need to be made aware of the risk of NMSC and supported with health educational approaches aimed at helping them to spot the signs early. Supporting GPs through education and awareness programmes to ensure they correctly identify potential NMSC and appropriately refer patients onwards is also important.”

**Professor Catherine Harwood, Consultant Dermatologist at Barts Health NHS Trust**

### Diagnosing basal cell carcinoma

Most BCCs are easily identifiable by their appearance, however in some cases a skin biopsy is required to confirm the diagnosis.<sup>10</sup> BCC can be diagnosed by GPs who have had specialist training, or by dermatologists after referral from primary care.<sup>51</sup> In England and Wales, NICE guidance recommends that suspected BCC is referred to secondary care under the routine (non-urgent) pathway, unless a delay may have a significant impact on the patient due to its location or size.<sup>4</sup> Similarly, Scottish guidelines state that low-risk BCC may not require an urgent referral, while high-risk tumours (those that are more likely to spread or cause damage due to their location) should be referred urgently.<sup>64</sup>

### Diagnosing cutaneous squamous cell carcinoma

CSCC diagnosis is normally made in a specialist setting, by examining skin removed from the tumour site under a microscope.<sup>65</sup> As CSCC is more likely to spread than BCC, leading to very poor prognosis, clinical guidelines across the UK recommend that suspected CSCC should be considered for an urgent referral to a specialist.<sup>4,23,64</sup>

## Common symptoms of NMSC and related skin conditions<sup>10</sup>

- ▶ NMSC most often develops on sun-exposed areas such as the face, ears, hands, shoulders, upper chest and back.
- ▶ Basal cell carcinoma (BCC) often appears as a shiny pink or pearly-white small lump that is translucent or waxy, but can also appear as a scaly red patch.
- ▶ Cutaneous squamous cell carcinoma (CSCC) usually looks like a firm pink lump with a crusty or rough surface which can include a spiky horn.
- ▶ NMSCs persist for weeks and can progress slowly over a period of months or sometimes years.

## Challenges in diagnosing and referring NMSC

While there are slight differences in how BCC and CSCC are diagnosed, there are common challenges in the referral and diagnostic pathway for both. These include:

### Delays in presenting to primary care:

Our survey showed that 40% of over 3,600 adults were not at all confident about identifying the signs of NMSC, and when presented with the four most common symptoms (a scab or sore that won't heal, a scaly or crusty patch of skin, a flesh coloured bump that grows, or a volcano like growth) only 23% – under a quarter – were able to correctly identify them.<sup>1</sup>

It's vital that individuals are able to identify symptoms to ensure they do not delay seeing their GP to avoid tumours from progressing further.

### Lack of GP training in dermatology:

GPs have a vital role to play in identifying and referring suspected NMSC as most skin cancer patients in the UK initially see their GP to have their skin checked.<sup>14</sup> An increasing proportion of GP time that is spent on diagnosing and managing skin conditions – 24% of the entire population see their GP for skin disease every year, and most GPs see several people with a skin disease every day.<sup>66,67</sup>

Despite these volumes, GP training in dermatology is limited – making it challenging for GPs to distinguish between non-cancerous skin conditions and those, such as NMSC, that may require more urgent treatment.<sup>68</sup> As has been noted earlier in this report, this contributes to the high number of referrals to specialists for diagnosis, adding to the overall burden of skin conditions on stretched dermatology services.

And although the RCGP has introduced a trial system to accredit GPs with Extended Roles (GPwER) in Dermatology and Skin Surgery, only 79 such GPwERs have been trained as of April 2020.<sup>69</sup>

### Inappropriate referrals:

Healthcare professionals have described instances where patients diagnosed with advanced CSCC are referred inappropriately in contradiction of national clinical guidelines for NMSC, leaving them unlikely to be able to access the full range of appropriate treatment and support options. Inappropriate referrals can also result in many NMSC patients experiencing delays in access to the appropriate treatment and support which can lead to negative physical and psychological outcomes.

“The patients I see are primarily complex and advanced where the tumour has spread and patients may also require facial reconstruction. For these patients it's important that they reach me as quickly as possible to ensure I can give them the best outcomes. But quite often they experience delays in the pathway and this effect is frequently worsened in areas of deprivation where patient presentation can also be significantly delayed. Sometimes this can be many years too late. Any delay can be the difference between life and death for some skin cancers types, but even in the less life threatening cases it can alter a patients treatment course from full recovery through straightforward surgery to significant disfigurement from complex surgery. It can have a dramatic impact.”

**Jonathan Pollock, Consultant Plastic and Reconstructive Surgeon, Nottingham University Hospital**

Jonathan Pollock, Consultant Plastic and Reconstructive Surgeon, Nottingham University Hospital, told us **“NMSC should be managed by local and specialist skin MDTs as per national guidance but in reality patients can be funnelled through various health care professionals such as head and neck specialists, as NMSC typically develop in these areas. Ideally where this is the case there should be clear communication between both specialists to enable treatment decisions to be rapidly reached in the correct skin MDT setting. This may require discussion with members of both MDTs to ensure the correct and most appropriate treatment decisions are made in the best interest of the patient, but the responsibility for treatment decisions must remain in the skin MDTs.”**

These challenges illustrate that there is a clear need to improve the awareness of NMSC symptoms to support diagnosis, both in terms of educating the public on its signs and symptoms and in the form of improved GP training in dermatology.

There is also confusion over who can and should be treating NMSC, requiring clearly defined referral and treatment pathways to ensure that NMSC patients receive appropriate and timely care.

## Management

NMSC is treated in different ways depending on how advanced it is and whether it is deemed to be low or high risk. In most cases patients are first referred to a local skin MDT and then to a specialist skin MDT depending on the level of risk and how complex the case is.

### Treating basal cell carcinoma

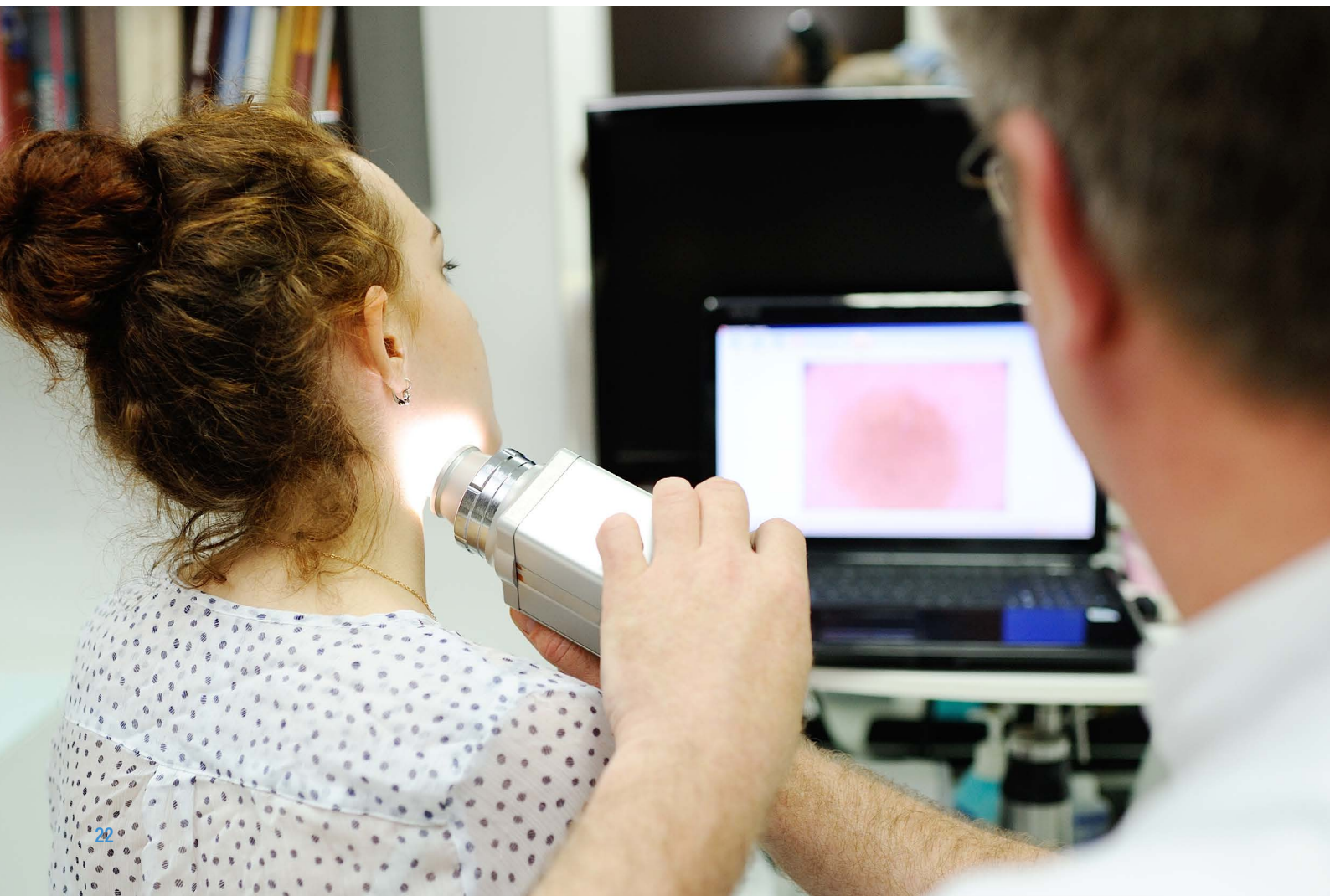
BCC is classified as "low risk" if it is small in size, located away from the face, major blood vessels or nerves, and is in an easily accessible area.<sup>68</sup> Specially-trained GPs can treat low-risk BCC patients in primary care, which usually involves conducting localised surgery to remove the tumour.<sup>70</sup>

Patients with high-risk BCC (such as those with larger or advanced tumours, tumours on the face or other highly visible areas, or who have had an organ transplant) will be referred to specialist skin cancer multidisciplinary teams. High-risk BCCs are usually treated by surgery and/or radiotherapy.<sup>71</sup>

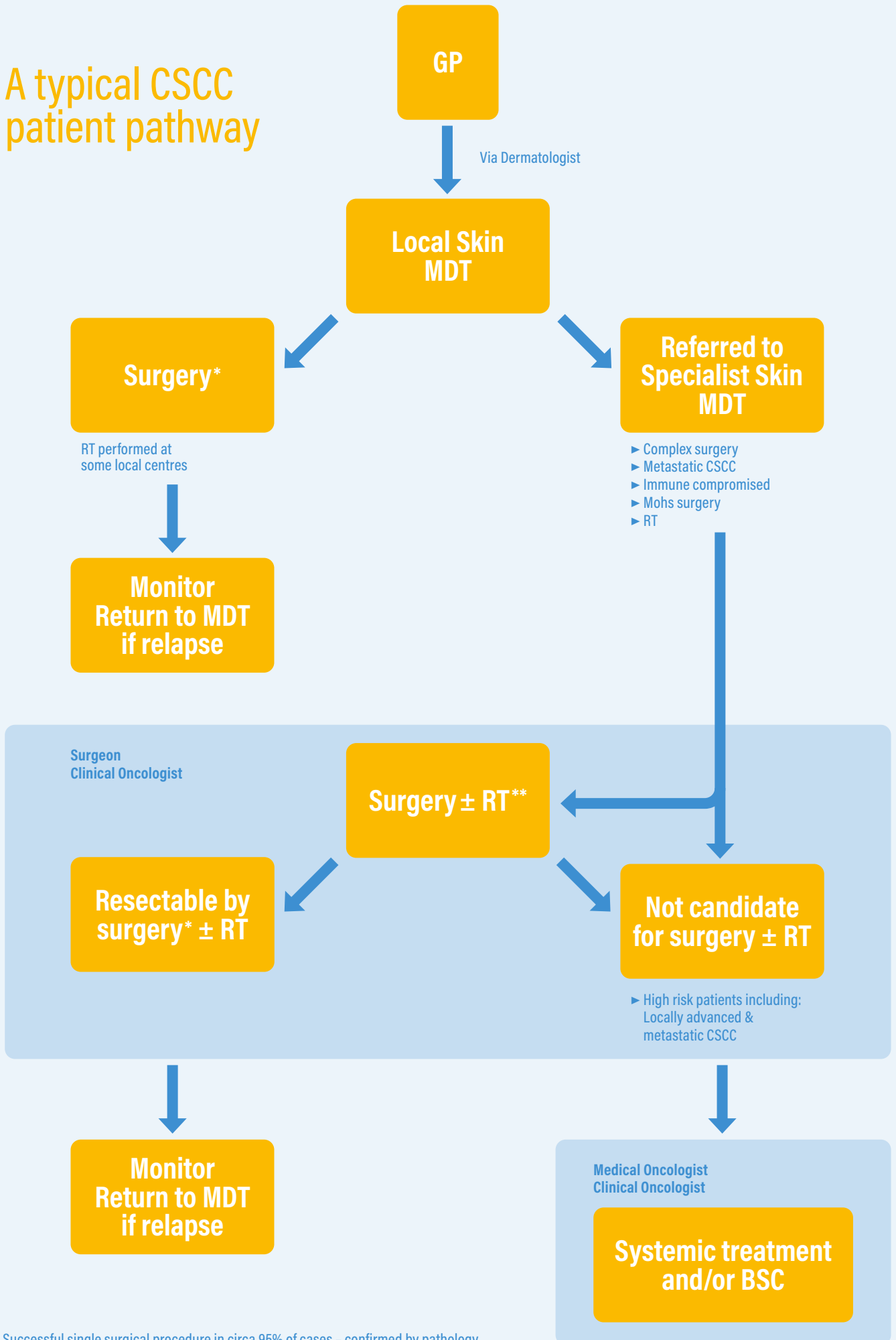
### Treating cutaneous squamous cell carcinoma

As they are more likely to spread, all CSCCs are normally managed by specialists in secondary care. The primary treatment option for CSCC is surgery, but radiotherapy, photodynamic therapy, and systemic therapies may also be used for advanced or metastatic cases.<sup>72</sup>

While the vast majority of NMSC can be treated successfully, for the small minority of patients with advanced disease treatment is unfortunately unlikely to control the disease long term. If advanced NMSC is not diagnosed early and treated, it can result in tumours destroying important structures like the nose, eye, ear and lip.<sup>18</sup> If left to develop, tumours can become extremely challenging to treat with an increased likelihood of significant cosmetic disfigurement.<sup>18</sup> Tumours left untreated may even become inoperable, with devastating results for patients.<sup>18</sup>



# A typical CSCC patient pathway



\* Successful single surgical procedure in circa 95% of cases – confirmed by pathology  
 \*\* Where there is a narrow or positive margin, confirmed by pathology, RT is often used  
 BSC = Best supportive care RT = Radiotherapy





# Challenges in the management of NMSC

## Lack of capacity to manage NMSC in the community

Low-risk BCC can be managed in primary care by suitably qualified GPs. However, few GPs have undertaken training in the management of skin diseases or performing skin surgery, and there is no requirement for this in the GP specialist training programme.<sup>52</sup> This means that patients who could be managed in primary care are sent to specialist dermatology services, adding to what has been called a “tsunami of skin cancer” in hospitals.<sup>73</sup>

Teledermatology is a potential solution to help manage the demand on dermatology services. It uses technology to enable GPs to securely share images of the affected skin area with a specialist clinician (such as a GP with specialist dermatology training or a dermatology consultant) for advice and review.

Effective use of these technologies can reduce the number of unnecessary referrals, waiting times, and the cost of care.<sup>74</sup> These technologies are widely in use in the NHS and have been well accepted by patients and practitioners alike. But access and uptake is variable and barriers remain that will need to be overcome to increase more widespread adoption. These include:

- ▶ Assigning medicolegal responsibility
- ▶ Instituting a reimbursement system
- ▶ Privacy and security features
- ▶ GP skills and training
- ▶ Linking teleconsultations to patients’ existing health records

## Patient-centred care in NMSC

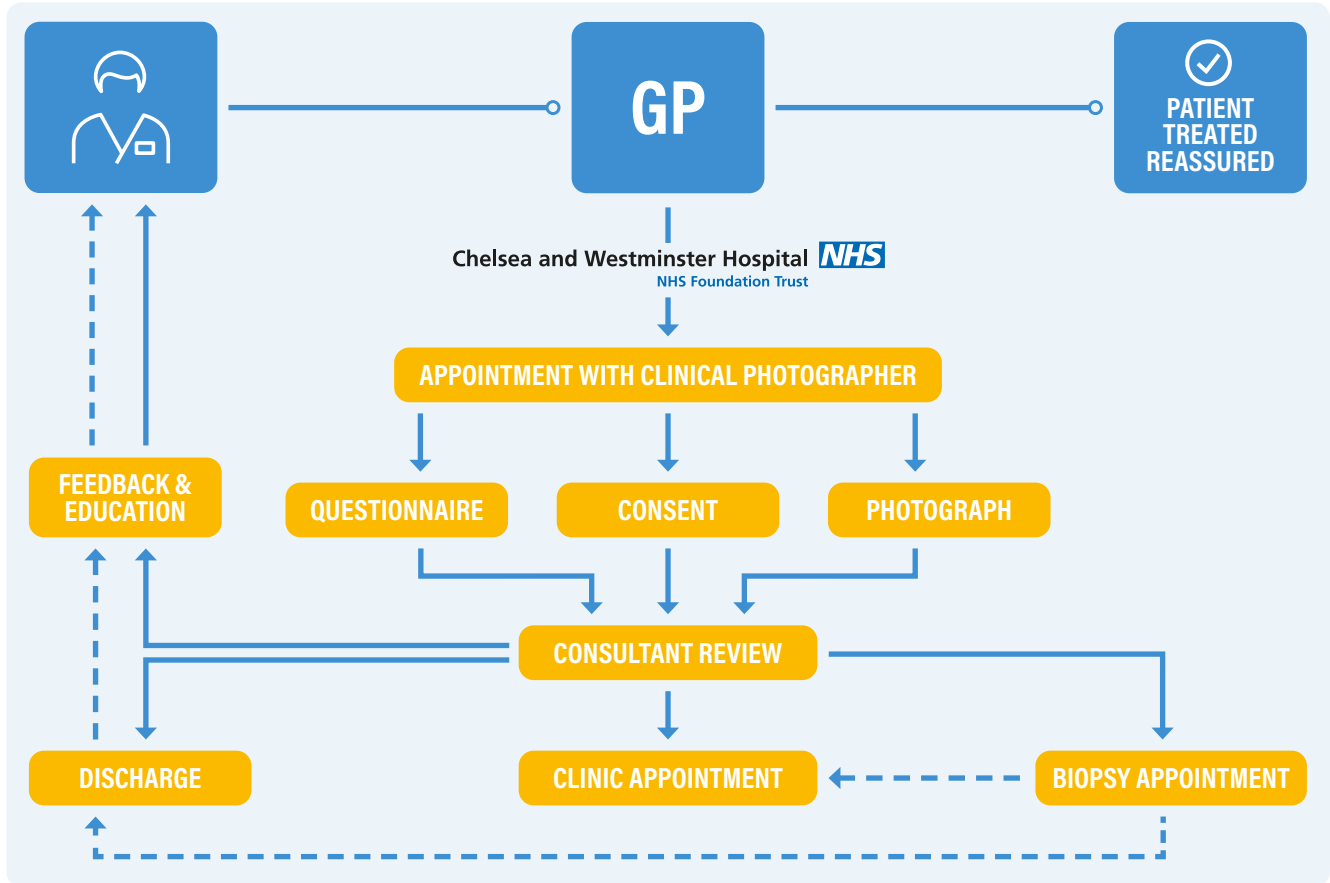
NICE guidance on managing BCC identifies the following patient care needs:<sup>68</sup>

- ▶ Patients want their BCC(s) to be treated effectively the first time, with minimal risk of recurrence and the best cosmetic result possible.
- ▶ If surgery is needed, patients want to keep the risk of damaging important features, such as nerves, as low as possible
- ▶ Patients want to be fully informed before treatment decisions are made, and for their doctors to be up to date with the choice of appropriate treatments available
- ▶ Patients want to be given full information on the advantages and disadvantages of treatment options and their likely impact
- ▶ Most importantly, patients want to be clearly informed of their diagnosis and involved in the decision on choice of treatment and where this is delivered

**Many of the above patient needs also apply to CSCC patients and those with other forms of NMSC**

“Technology has huge potential in helping us to manage non melanoma skin cancer efficiently. Artificial intelligence (AI) combined with imaging systems can help GPs and dermatologists identify new cases and decide which ones can be managed in primary care, reducing the pressure on over-stretched dermatology services. However in many areas of the UK this kind of technology is still being under-utilised. For example, in Scotland we already have systems in place to include digital images alongside all NMSC referrals – this could be further improved by using AI to automate more of the decision-making, which will free up specialists to focus on the more complex cases.”  
**Professor Charlotte Proby, Professor of Dermatology, University of Dundee**

Implementing a new tele-dermatology service in Chelsea and Westminster NHS Trust<sup>75</sup>



**In August 2017 Chelsea and Westminster Hospital established a tele-dermatology service using medical photographers based within the hospital.**

This was prompted by the growing volume of urgent skin cancer referrals received by the dermatology department. Every year, approximately 2,000 urgent referrals for suspected skin cancer are made to the dermatology service, requiring an average of 44 clinic slots per week. Of these, 95% do not have skin cancer, and 57% are entirely benign (non-cancerous).

To address the volume of inappropriate referrals, the hospital introduced a triage system using tele-dermatology to take highly-magnified images (with consent) of the affected area of skin on all patients before they attended the clinic in person. The aim was to identify which benign lesions could be managed by a GP or more appropriate clinic (such as a mole clinic).

Within 48h, a dermatology consultant reviews the image remotely and triages the case. The service also provides patients with information leaflets, and a system for taking patient histories and communicating outcomes to patients and their GPs.

A review of the service after 2 years and following 3,000 patients seen in this way found:

- ▶ The processing of cases by consultants takes **9-10 minutes**
- ▶ A third of patients can be immediately discharged without a face-to-face clinician appointment thanks to the system
- ▶ The hospital had an increased diagnosis rate of SCC and melanoma despite fewer biopsies (which reduced by 15%)
- ▶ The service was found to release additional capacity and be cost-effective financially
- ▶ **>80%** of patients would recommend the service to friends and family

Source: C. Edwards and C. Macedo. A pilot study to investigate the potential for teledermatology triage of 2-week-wait new skin cancer referrals at Chelsea and Westminster Hospital. *BJD British Association of Dermatologists* (2017) 177 (Suppl. 1), pp 185-189



### Variation in multidisciplinary teams

NMSC is primarily managed by a multidisciplinary team (MDT). Ideally MDTs should bring together different kinds of healthcare professionals, who together can offer patients high-quality care and support for all their needs, rather than just focusing on treating the cancer.<sup>6</sup> According to NHS England, all specialist MDTs for skin cancer should include:<sup>76</sup>

- ▶ Dermatologists with an interest in skin cancer
- ▶ Specialist plastic and reconstructive surgeons
- ▶ Skin cancer Clinical Nurse Specialists (CNS)
- ▶ Histopathologists
- ▶ Radiologists
- ▶ Clinical oncologists.
- ▶ Medical oncologists
- ▶ Palliative care specialists.
- ▶ The multidisciplinary team coordinator(s).
- ▶ Appropriate levels of secretarial support.

However, it is known that many of these roles – including dermatologists and oncologists – are in short supply, and it's likely that in some areas with high vacancy rates specialist skin MDTs are unable to include all of these roles.<sup>6</sup> This could have a knock-on effect on the ability of the MDT to offer skin cancer patients the full range of support or treatment options and lead to variation in quality between different areas.

### Lack of consensus over definitions of advanced CSCC

There is no consistent definition of advanced CSCC (locally advanced or metastatic disease) used in clinical practice across the UK.<sup>77</sup> This can lead to inconsistencies in providing patients with advanced CSCC access to appropriate treatment compared to patients with advanced BCC or melanoma, where definitions of advanced disease have been established, enabling these patients to be placed into the treatment pathway earlier.

### Shortage of high-quality evidence on managing NMSC

Despite its prevalence, there has been comparatively little research into the management NMSC, with academic research in skin cancer focusing predominantly on melanoma.<sup>78</sup> There are no large clinical trials comparing different treatments for NMSC, which limits the ability of healthcare professionals to make clinical decisions on how to approach treatment.<sup>79</sup>

More generally, research into the management of skin cancer has focused on Australia and North America, with limited relevance to the UK as the health systems and patterns of disease are likely to differ substantially.<sup>7</sup>

### Need for more data on patient experiences of treatment and follow-up

Due to the significant risk of developing further tumours, NMSC patients require regular follow-up even after their initial tumour has been treated. While some patients such as those with low-risk BCC can perform self-checks, high-risk NMSC patients require at least two to five years of follow up with a qualified healthcare professional.<sup>23</sup>

Clinical guidelines across the UK recognise the need for NMSC patients to be provided with information and support to deal with the physical and psychological impacts of the disease. NICE quality standards (applicable in England and Wales) state people with CSCC should have access to a skin cancer clinical nurse specialist to provide guidance at all stages of care and treatment, including follow-up.<sup>80</sup> Similarly, SIGN guidelines in Scotland recommend that CSCC patients should be referred for psychological support as appropriate.<sup>81</sup>

However it is not known what percentage of high-risk NMSC patients are offered regular follow-ups and provided information and support in line with best practice. In England the Cancer Patient Experience Survey does not collect information from NMSC patients, with data on skin cancer only collected for melanoma, and similarly other countries in the UK do not track NMSC patient experiences. This means that despite the importance of ensuring that high-risk NMSC patients are provided with ongoing follow-up and support, very little information is available to track how health services are performing in this area.

### Lack of waiting time data

There is an inconsistent approach to reporting waiting times for BCC and NMSC patients across the UK. In England, Wales and Northern Ireland, waiting times are only reported for CSCC and melanoma patients combined.<sup>82</sup> Scotland tracks waiting time data for patients with melanoma skin cancer but not NMSC.<sup>83</sup> None of the four nations report waiting time data for BCC, which is likely due to its volume. For skin cancer patients, short waiting times for diagnosis and access to treatment can help to reduce the risk of complications and improve outcomes.<sup>84</sup> The lack of data on waiting times for BCC (or in Scotland of any form of NMSC) means that health systems are unable to track how well services are meeting national standards for access to care for these patients, and take action to improve access where needed.

## BAD recommendations for skin cancer multidisciplinary teams

The increasing complexity and volume of cancer cases has resulted in substantial pressure on MDTs who have less time available to discuss individual patients.<sup>6</sup> The British Association of Dermatologists (BAD) has produced recommendations for improving the efficiency of skin cancer MDTs and to promote best practice, including:<sup>6</sup>

- ▶ Agree written management pathways so that the MDT can focus on more complex cases
- ▶ Develop a set of core principles and standards for skin cancer MDTs
- ▶ All MDTs should adhere to minimum standards regardless of the type of cancer being considered
- ▶ MDTs should be provided with appropriate supporting infrastructure and personnel
- ▶ Low-risk BCC should be managed by a community skin cancer clinician (a GP) associated with an MDT
- ▶ CSCC or newly diagnosed but high-risk BCC should be managed by a member of a skin cancer MDT, with the option of full MDT discussion
- ▶ CSCC or BCC that has recurred, or is found to be spreading locally during surgery, should always be managed by a MDT
- ▶ CSCC and BCC requiring reconstructive surgery, radiotherapy or other complex treatments should always be managed by a specialist skin cancer MDT



# CALL TO ACTION

The toll of NMSC on patients and the health system is substantial and growing, but there are opportunities for action. The following areas should be prioritised by government and other policymakers to stem the substantial burden of NMSC.

## 1

**The UK government and all devolved administrations should seek to improve awareness of skin cancer symptoms, including those of NMSC, and promote sun safety measures to prevent skin cancer.**

- ▶ Government policy on prevention should include a specific focus on NMSC as a largely preventable condition.
- ▶ To embed an awareness and understanding of good sun safety from the earliest age, the government should encourage schools to introduce a mandatory policy on sun safety.
- ▶ Employers of outdoor workers should be supported to implement measures that raise awareness of skin cancer among employees and take all possible measures to minimise their risk of exposure. Government should ensure employers are educated and provided with guidance about skin cancer, preventive measures, and psychological support available for workers living beyond skin cancer.

## 2

**All patients with NMSC should be provided with access to high-quality information and support to deal with the physical and psychological impacts of the disease and its treatment.**

- ▶ Information should be accessible and tailored to individual needs, including for elderly patients who may struggle to find information online.
- ▶ All patients with CSCC should receive access to a clinical nurse specialist, in line with NICE guidelines.
- ▶ All NMSC patients should be provided with information and support to cope with the mental health impacts of the disease, and patients undergoing potentially disfiguring surgery should have access to specialist mental health support before and after surgery to help cope with the psychosocial impacts.

# 3

## **Governments, health systems and research communities across the UK should work towards improving data and evidence on NMSC.**

- ▶ Accurate cancer registration is an essential element of understanding and managing NMSC. Health Services across the UK should ensure that cancer registries include NMSC in full and by type, including multiple and secondary tumours.
- ▶ All UK nations should seek to track waiting times performance for CSCC given its potential to spread to other parts of the body.
- ▶ Research into NMSC treatment options and patient care needs should be supported to increase the evidence base.
- ▶ Patient satisfaction audits such as the Cancer Patient Experience Survey in England should work towards including NMSC patients in their data collection to improve knowledge about how well the health system is meeting the care and support needs of this patient group.

# 4

## **Health workforce planning across the UK, including the upcoming NHS People Plan, should recognise the rapidly increasing prevalence of NMSC and plan for the impact that this will have on health systems.**

- ▶ Policymakers should address the severe shortage in the dermatology workforce and bring in measures to improve recruitment and retention in this field.
- ▶ Health authorities should ensure that GPs, nurses and pharmacists are given greater opportunities to specialise in dermatology and psychodermatology.
- ▶ GP training on managing skin cancer in the community should be expanded.
- ▶ Teledermatology services should be expanded across the health system.

# 5

## **Skin cancer MDTs should have access to a range of specialisms and competencies, to ensure patients receive the full range of appropriate care options**

- ▶ For patients with skin cancer, it is important for skin MDTs to include a medical oncologist as well as a dermatologist, surgeon, clinical nurse specialist and other relevant healthcare professionals. This is of particular importance for patients with advanced NMSC where surgery or radiation are not treatment options.



# CONCLUSION

**This report has highlighted that there is often a disparity between the perception of NMSC and its true impact on patients and the health system.**

As our survey showed, the potential severity of NMSC is all too often underestimated, with recognition of its risk factors, signs and symptoms all worryingly low. This is particularly concerning when viewed against the rapidly growing number of new NMSC cases.

Without urgent action, the tidal wave of NMSC has the potential to put further pressure on health services, at a time when it is under unprecedented pressure.

But as this report also shows, there are many areas of opportunity. Improving awareness of NMSC and placing a far greater emphasis on prevention could be transformational, and there is already a wealth of resources from charities such as Skcin and MASScot that can be scaled up with government support.

There are also clear opportunities to improve the care and support available to patients with NMSC.

As we have shown, the psychological impacts of the disease can be as substantial as its physical effects – yet little is known about how the mental health and ongoing support needs of patients are being met, and anecdotal evidence suggests that in many areas this long-term support is lacking. More needs to be done to ensure that NMSC patients are not being left to cope with its considerable effects alone.

Similarly, there are opportunities to improve what we know about the scale of NMSC by improving how cancer registries across the UK collect data on NMSC and to improve waiting times information for NMSC, which would vastly improve the health system's ability to plan ahead to meet demand effectively.

Finally, there are chronic issues in the workforce, where sustained action to increase the number of dermatologists and provide more training and support to GPs and other healthcare professionals in the management of skin lesions is needed.

Tackling these issues will need concerted effort at national and local level, however as recent experience has shown it is entirely possible to address wide-scale challenges at scale and pace. NMSC is one such challenge – action is needed now.



# USEFUL RESOURCES



Skcin are a national skin cancer charity, focused on promoting the importance of sun safety and early detection through national educational initiatives and targeted campaigns. Skcin produces awareness and prevention materials, which can be viewed on their website at [www.skcin.org](http://www.skcin.org)

## MACMILLAN CANCER SUPPORT

Macmillan provide physical, emotional and financial support to people with cancer. Their helpline can be reached on 0808 808 0000 every day of the week from 8am to 8pm. Practical advice, support and access to their online forums are available at [www.macmillan.org.uk](http://www.macmillan.org.uk)



## MELANOMA UK

Melanoma UK strive to increase awareness of melanoma, and how it can be prevented through advocacy, education, and research. They provide support to melanoma patients, caregivers, and medical professionals through coordinated information and services. Their website has practice advice and support available, as well as an online forum for melanoma patients. This can be viewed at [www.melanomauk.org.uk](http://www.melanomauk.org.uk)



## CANCER RESEARCH UK

Cancer Research UK provides information and support to anyone worried about cancer, or living with or affected by cancer. Their nurse helpline can be reached on 0808 800 4040, Monday to Friday from 9am to 5pm. Access to the charity's online Cancer Chat forum, practical advice and support materials can be reached at [www.cancerresearchuk.org](http://www.cancerresearchuk.org)

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This report was written and funded by Sanofi Genzyme.