The Non-Melanoma Skin Cancer Patient Pathway: *improving patient journeys and experience of care*

sanofi

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NMSC Patient Support

Contents

Abbreviations

NMSC	Non-Melanoma Skin Cancer
NICE	National Institute of Health and Care Excellence
BCC	Basal cell carcinoma
CSCC	Cutaneous squamous cell carcinoma
PDT	Photodynamic therapy
UV	Ultraviolet
MDT	Multi-Disciplinary Team
HCP	Health care professional
BAD	British Association of Dermatologists
SIGN	Scottish Intercollegiate Guidelines Network
GP	General Practitioner
LSMDT	Local Skin Multi-Disciplinary Team
SSMDT	Specialist Skin Multi-Disciplinary Team
GPwSIs	GPs with special interests
H&NMDT	Head and Neck Multi-Disciplinary Team
GIRFT	Getting It Right First Time
CNS	Cancer Nurse Specialists

Foreword

Gill Nuttall, CEO of Skin Cancer UK

When we think about the prominent organs that make up our bodies, we think of the heart, the lungs, the brain and perhaps the liver. Despite being the largest organ of our body, seldom would we think about our skin.

Non-melanoma skin cancer (NMSC) is the most common cancer in the UK[1] and becoming increasingly prevalent, yet it is still under recognised, and under prioritised by national and local health systems.

Additionally, the unprecedented challenges created by the pandemic, notably the COVID-19 backlog, have significantly impacted the diagnosis and treatment of skin cancers. There is no better time to discuss skin cancer than right now; focus on NMSC is particularly urgent.

What can we do about it? One way to support optimised care for NMSC patients is through updating the National Institute for Health and Care Excellence (NICE) guideline, which is more than a decade old, and establishing a national NMSC guideline in Scotland and Wales. Updated national guidelines would have a significant impact on patient experiences. They would support consistent care across the country, high quality care based on best practice, a benchmark to evaluate across local health systems and reduce the 'postcode lottery'.

NICE and equivalent bodies in the devolved nations must work with national and local health systems to develop and implement updated guidelines and pathways, improve data collection, and find solutions to the workforce crisis.

Patients are at the heart of everything we do at Skin Cancer UK; decision-makers should prioritise working with people who have a lived experience of NMSC. This report provides powerful new evidence on the NMSC patient pathway, explores in detail what the barriers are to improved patient care, and what can be done to achieve the greatest change.

Skin Cancer UK has been established to address the needs of people with an NMSC in the UK. With the support of our existing parent organisation, Melanoma UK, it is our aim to offer support and to deliver policy reform that will help shape the way NMSC is considered and managed in the UK.

Executive summary

NMSC – non-melanoma skin cancer – refers to a group of cancers that develop in the upper layers of the skin. The two most common forms of NMSC are basal cell carcinoma (BCC) and cutaneous squamous cell carcinoma (CSCC).[2] Around 230,000 cases of NMSC are reported in the UK annually[3], yet the actual number is likely to be higher due to poor data collection and under-reporting.[1]

Despite being the most common cancer in the UK[1], it is significantly under prioritised by policy makers and the NHS. Yet, this report finds clear challenges in the diagnosis, treatment and management of NMSC. With this report, we hope to raise awareness of the disease and the clear, achievable steps that can be taken to help improve outcomes for people living with NMSC, their carers and the health system.

This report takes a fresh view, building on insights from clinicians, on the challenges that patients face seeking treatment for NMSC. Despite the burden that NMSC creates on the health system in the UK, there is a lack of appropriate resourcing, and significant variation in management and care. This is exacerbated by having too many pieces of inconsistent and out-of-date guidance.

The urgent need to prioritise NMSC to improve patient outcomes is clear, but there are steps that can be taken, including the following critical recommendations:

- **National bodies in the nations of the UK must update and publish a comprehensive national guideline on the referral and management of NMSC**
- **NMSC should be established as a priority in national cancer policy, and progress monitored through improved data collection**
- **The workforce crisis must be addressed to successfully improve NMSC patient care in the long-term**

Non melanoma skin cancer in the UK

Impact on patients and the health system

The single biggest risk factor for NMSC is exposure to UV light. Over 80% of tumours occur on the head, face and neck, which are the areas most regularly exposed to the sun.[4]

Surgery is the primary treatment for NMSC. This involves removing the cancerous tumour and some of the surrounding skin. Other treatments include freezing (cryotherapy), radiotherapy and a form of light treatment called photodynamic therapy (PDT): the treatment used will depend on the type, size, and location of the tumour, as well as its stage.[2]

Most NMSCs can be successfully treated, but in a small number of cases the cancer spreads and can be fatal.[5] Even when treatment is successful the disfiguring nature of tumours can lead to lasting damage, including itchiness, bleeding, soreness and problems sleeping.[6] The highly visible nature of the disease caused by both the tumour and surgery often leaves a lasting psychological impact.[7]

NMSC is often treated as a minor condition, however the high incidence is placing a significant burden on the NHS.[1] Ongoing workforce shortages, the ongoing impact of COVID-19 and rising rates of NMSC mean that services are struggling to meet demand.[8,9,10]

NMSC: the facts

Prevalence, survival and trends

NMSC is the most common cancer in the UK – more than breast, bowel and prostate cancer combined.[11]

1 in 5

People in England will develop NMSC in their lifetime[12]

90%

NMSC accounts for 20% of all new cancers and 90% of all skin cancers[1]

720

People die from NMSC every year in the UK, this equates to two deaths every day[13]

Avoidable risk factors

There are multiple avoidable risk factors for NMSC, with exposure to UV rays by far the greatest.

80%

Of all skin cancers are considered preventable by reducing exposure to UV[14]

2x

Outdoor workers are at least twice as likely to develop NMSC as those that work indoors[15]

Artificial sources of UV rays can damage the skin.

67%

CSCC risk is at least 67% higher and risk is 29% higher in people who have used a sunbed[16]

Unavoidable risk factors

There are also unavoidable risk factors.

1/2

Risk of NMSC increases with age, almost half of all new cases in the UK §are in people aged 75 or above[13]

70%

The risk of BCC is 70% higher in people with skin types that burn easily[17]

Incidences of NMSC are increasing.

166%

Since the early 1990s, NMSC incidence rates have increased by 166% in the UK[13]...

42%

...and over the last decade, NMSC incidence rates have increased by more than 42% in the UK[13]

400k

Incidence rates predicted to reach almost 400,000 per year by 2025[8]

The cost of NMSC

£465m

Costs are expected to rise from £289-£399 million a year in 2020 to £338-£465 million in 2025[18]

£1,226

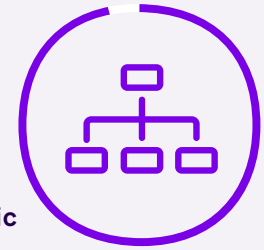
The cost to the NHS per case of NMSC is estimated at between £889 and £1,226[19]

Insights from multi-disciplinary clinicians on the NMSC pathway

Between 6th and 27th June, Sanofi conducted a survey of dermatologists, oncologists and surgeons*, to understand their perspectives on the management of NMSC and what could support them to improve patient care. The results of the survey found:[20]

97%

of respondents agree that NICE should publish a specific national guideline on the referral and management of NMSC patients



96%

agree that, if published, their local health system should implement the national NMSC guideline including a pathway

93%

believe that a national guideline would improve patient outcomes

87%

of survey respondents agree that a comprehensive national NMSC guideline would reduce time to definitive diagnosis

1 in 5

survey respondents spontaneously mention guidelines as a barrier to NMSC patient care and as requiring urgent attention

88%

of respondents think that the post-COVID care backlog is contributing to more patients being diagnosed with NMSCs at more advanced stages

88%

agree that there is a lack of capacity to manage the increasing demand for NMSC services and increased referrals of NMSC patients

65%

of respondents disagreed with the fact that NMSC is adequately prioritised by NHSE, despite rhetoric that skin cancer is prioritised nationally

* 95 healthcare professionals responded to the survey. Country breakdown: England (86), Scotland (8), Wales (1). No responses from healthcare professionals in Northern Ireland were received.

Speciality breakdown: Dermatology (35), Surgery (30), Oncology (30).

The Case for a National Clinical Guideline

There is no comprehensive national clinical guideline on the referral and management of NMSC patients.

Guidelines and pathways do exist, but most are either outdated or do not focus on the full NMSC pathway, including those with advanced disease. The lack of a comprehensive national guideline has led to multiple inconsistent local pathways and guidelines, with some areas not having any pathway in place for these patients.[20]

Yet, comprehensive national clinical guidelines for individual conditions have a vital role to play in ensuring high quality and timely care. These national guidelines, which local health systems can adapt based on local context, can help reduce unwarranted variation in care and improve outcomes.

The benefits of having national clinical guidelines in place are widespread and can be seen at every level.

Patients

Standardised care.

Better experience of care.

Quality and timely care.

Clinicians

Clear guidance.

Standardised care.

Benchmark of resource needs, which could support business cases.

Locally

Template for local implementation.

Financial sustainability.

Sustainable cancer waiting times.[21]

Nationally

Financial sustainability.

Sustainable cancer waiting times.[21]

National standard to evaluate against.

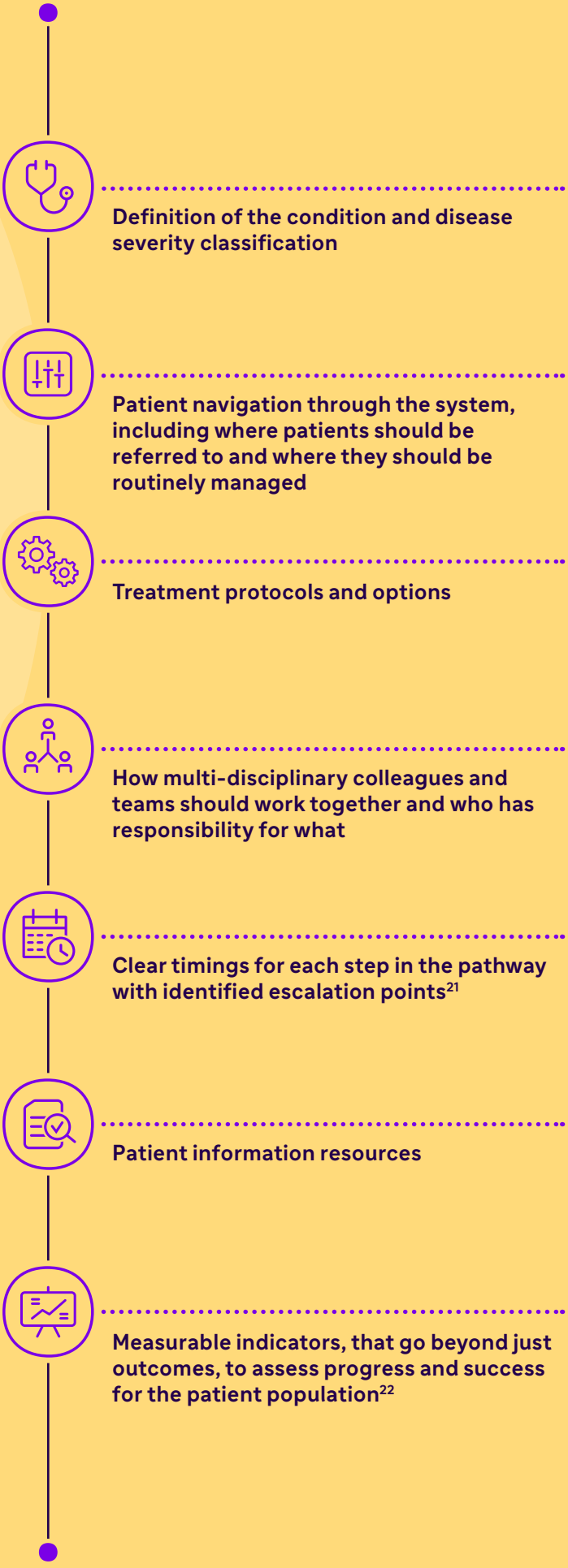
What should a new NMSC guideline include?

An effective clinical guideline on NMSC must be comprehensive, evidence-based, and encompass the full patient pathway, including the treatment of those with advanced disease.

It should provide detail to healthcare professionals and commissioners on how patient populations should flow through the system and receive their care, including which multi-disciplinary team (MDT) should manage the patient.

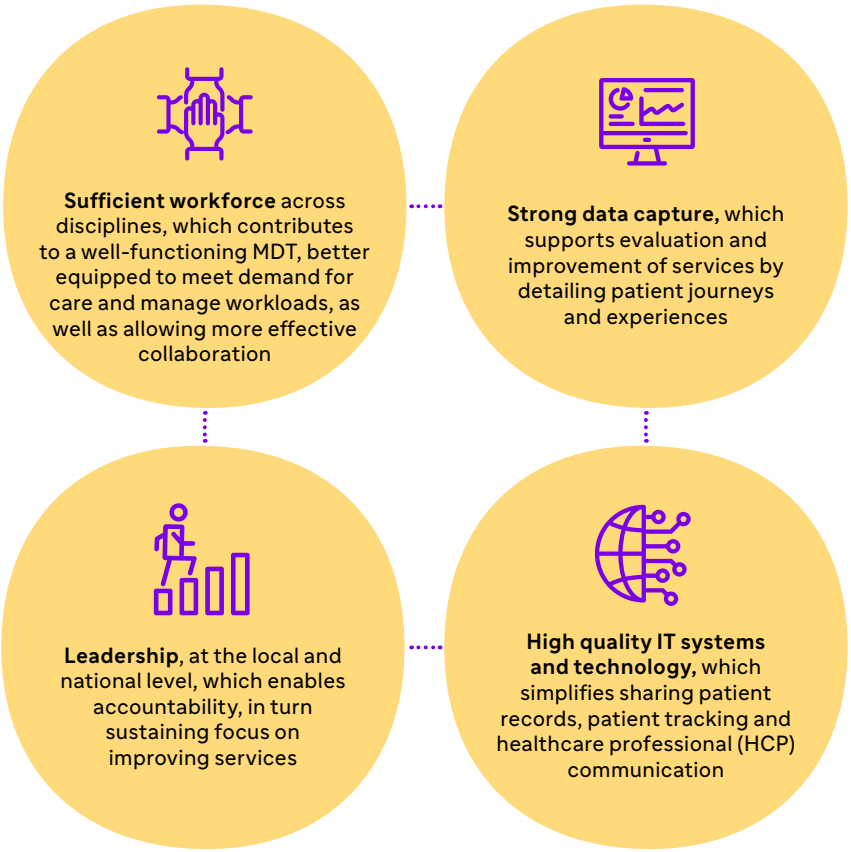
Given the wide range of healthcare professionals involved in the care of NMSC, collaboration must be at the centre of the guideline development process, including allowing for regular updates.

As a minimum, a new clinical guideline should include:



What are the wider requirements of the system?

Successful implementation of a clinical guideline is most effective in a well-supported healthcare system, including through:



The current NICE guideline on NMSC, used by England, Northern Ireland, and Wales is 10-years old.[23] Scotland does not have a recent or comprehensive national guideline.

Although it is positive that some more up-to-date and high-quality pathways and guidelines have been developed, there is inconsistency in which are used locally which may lead to regional variation.

There is an urgent need to capture latest clinical best practice, establish ideal resourcing requirements and support consistent NMSC management. This can be achieved by guideline setting bodies publishing a comprehensive national NMSC guideline, a call to action that has widespread support among clinicians.

97%

of multi-disciplinary clinicians involved in the care of NMSCs agree that NICE should publish a specific national guideline on the referral and management of NMSC patients.[20]

The NMSC Patient Pathway

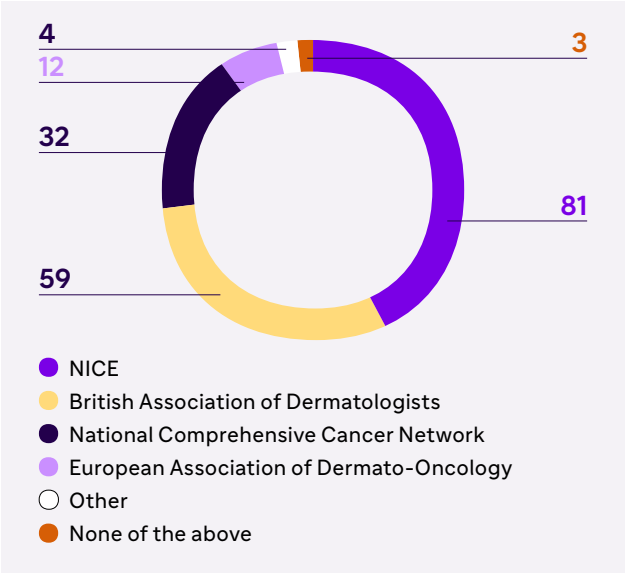
Establishing consensus on how to manage and treat people living with NMSC

Multiple guidelines exist that support the referral, management and treatment of NMSC. However, no national body has provided a unified, up-to-date and comprehensive guideline.

Some of the guidelines currently in use in the UK

- NICE, Improving outcomes for people with skin tumours including melanoma (update): The management of low-risk basal cell carcinomas in the community, 2010[23]
- NICE, Improving outcomes for people with skin tumours including melanoma, the manual, 2006[24]
- NICE, Suspected cancer: recognition and referral, 2021[25]
- NICE, Skin cancers – recognition and referral, 2021[26]
- British Association of Dermatologists (BAD) guidelines for the management of adults with basal cell carcinoma, 2021[27]
- British Association of Dermatologists guidelines for the management of people with cutaneous squamous cell carcinoma, 2020[28]
- Scottish Intercollegiate Guidelines Network, Management of primary cutaneous squamous cell carcinoma, 2014[29]

In addition, local guidance has been created by Cancer Alliances and Cancer Networks; in our survey, **91% of respondents note that they have some local guidelines in place**.[20] While many of these take information from available national guidelines the level of detail and recommendations vary.



Our survey of clinicians found that NICE guidelines were the most commonly used, followed by BAD guidelines and then the guideline from the American National Comprehensive Cancer Network.[20] It is important to note that some UK clinicians are using guidance that is not built around their own health system.

The existence of multiple resources for the referral and management of NMSC may be contributing to inconsistent patient experiences: **87% of clinicians agree that updates and improvements are needed for the guidelines they use locally**.[20] This includes capturing the latest science, latest clinical practice and providing better detail for each disease stage.

"Due to the lack of elaborate guidelines, there is no national consensus on treatment"

England (East Midlands) Oncologist*[20]

*In response to question: Considering the way that NMSC patients are currently managed, please tell us about any barriers and challenges that you feel most negative impact management and care of patients?

The lack of a comprehensive national guideline impacts patient outcomes more than anything else, **according to almost two thirds of clinicians who responded to our survey (62%).**[20]

They state that a national guideline would ensure:[20]

94%
High-quality care

91%
Consistent management

94%
Improved access to innovative therapies

The clinical community also agree that guidelines must be updated to include:[20]

64%
Detail on the full pathway

56%
Latest clinical practice

97%

of multi-disciplinary clinicians involved in the care of NMSCs agree that NICE should publish a specific national guideline on the referral and management of NMSC patients, with 96% agreeing that, if published, their local health system should implement the national NMSC guideline including a pathway.[20]

Referral and diagnosis

- **Available guidelines are inconsistent on the referral and diagnosis of NMSC. For instance, there are differences between which clinical team should be treating cases and variation between the definitions used to distinguish NMSCs.[20]**
- **The lack of national guideline is impacting time to definitive diagnosis.[20]**
- **Timely referral and diagnosis have also been impeded by limited training opportunities for GPs in dermatology and the ongoing ramifications of the COVID-19 pandemic and backlog.[30,31]**

What do available guidelines say?

Timely diagnosis of NMSC and appropriate patient referral are vital for the best possible patient outcomes: late diagnosis can lead to tumours spreading and becoming more advanced.[4]

The pathway to a diagnosis depends on the type of NMSC a patient presents with.

Diagnosing BCC

Most BCCs are easily identifiable by their appearance; however, in some cases a skin biopsy is required to confirm the diagnosis.[2]

A GP with specialist training can diagnose low-risk BCC. In cases where the risk is higher or the GP does not have specialist training, available guidelines often suggest that the patient is referred to the Local Skin Multi-Disciplinary Team (LSMDT), for diagnosis.[32]

Diagnosing CSCC

CSCC diagnosis is normally made in a specialist setting, by examining skin removed from the tumour site under a microscope.[28] As CSCC is more likely to spread than BCC, leading to poor prognosis, clinical guidelines recommend that suspected CSCC should be considered for an urgent referral to a LSMDT.[26,33]

When asked what barriers need most urgent attention, survey respondents highlighted:[20]

"No clear pathway which leads to delays in accessing correct professionals"
England (North West)
Oncologist

"Guidelines for referral"
England (London)
Surgeon

"Speed to get assessed by the most appropriate team"
England (North West)
Dermatologist

Challenges in referral and diagnosis

Variation in definitions of NMSCs

The definitions used to distinguish between BCC and CSCC vary between locally adopted guidelines: some areas utilise growth rates and documented expansion of lesions, but other guidelines do not provide specific parameters.[34,35,36]

BCC and melanoma cancers have established definitions of advanced tumours;[23,25] however, there is no consistent clinical definition of advanced CSCC (locally advanced or high risk).[37]

This may contribute to inconsistent approaches to care. The BAD guideline recommends categorising CSCCs into three groups and suggests actions: low risk (no MDT discussion is needed); high risk (LSMDT discussion is needed) and very high risk (SSMDT discussion is needed).[28] The NICE guideline does not categorise in this way, and instead suggests that all suspected CSCCs should be referred to a specialist service.[26,24] This inconsistent guidance may contribute to variation in when and through what pathway advanced CSCC patients access advanced treatment.

Barriers you feel have a negative impact on management

"There is no NICE guideline to help diagnosis. Diagnosis is delayed due to variability in definition of diagnosis and therapeutic protocols."
England (South East) Dermatologist

"Precise and concise definitions need to be put in place at least on a National level."
Oncologist (South East) England*[20]

"Lack of consensus regarding definition"
England (East Midlands) Oncologist[20]

Inappropriate referrals

Our research shows that there is a lack of consistency regarding who can and should be treating NMSC. In some cases, patients are referred to Head and Neck Specialists, as NMSC typically appears in these areas. However, other local guidelines recommend patients are referred to an LSMDT / SSMDT. As such, access to appropriate treatment may be delayed, which can lead to negative physical and psychological outcomes for patients.[4]

It is essential that national guidance includes clearly defined and comprehensive referral pathways. This should eliminate variation in who is responsible for treating NMSC, alleviate pressure on specialist teams, and allow patients to receive appropriate and timely care.

Research has shown that NMSC is being inappropriately referred through the two-week wait pathway.[38] The pathway is intended for suspected CSCC or high-risk BCC lesions, but since the introduction of the pathway, there has been an increase in non-urgent skin cancers being referred to specialist teams. **In a study of referrals made via the two-week wait pathway between April and June 2019, 83.1% of patients were diagnosed with a benign condition, whilst only 3.6% were diagnosed with CSCC.** This compounds the overall burden on already stretched dermatology services.[38]

*In response to question: Considering the way that NMSC patients are currently managed, please tell us about any barriers and challenges that you feel most negative impact management and care of patients?

74%

Of survey respondents agree that there is a lack of consistency regarding which clinical team manages advanced NMSC patients, specifically between specialist skin or Head & Neck MDT[20]

80%

Of survey respondents agree that having a national guideline would have a positive impact on the time taken to definitive diagnosis[20]

Supporting GPs

GPs are the first point of contact for most people with a skin condition, and as a result are critical in identifying and referring suspected NMSC.[39] In fact, skin conditions are the most common reason for a patient to visit their GP, with around **13 million primary care consultations for skin disease each year**.[30] As such, a significant proportion of GP time is spent diagnosing and managing skin conditions.

Despite these volumes, GP training in dermatology is limited.[30] This means that GPs are poorly prepared to distinguish between benign skin conditions and those, such as NMSC, that may require more urgent treatment.[38] As a result, local and specialist services are experiencing heightened referrals for patients who don't require their services.[38]

Some measures have been taken to remedy this, including a programme to accredit GPs with Extended Roles in Dermatology and Skin Surgery; however, awareness of the programme remains low, affecting recruitment and reducing the impact of the initiative. Additionally, although the Government ringfenced funding to increase training posts in dermatology by 15 following the 2021 Spending Review, this will only apply to England.[41]

"There has been a doubling in patient referrals from primary care, often patients have not been seen face to face. This is clogging the system with obviously benign lesions."

England (North West) Dermatology[20]

The impact of COVID-19 on referral and diagnosis

A stark reduction in the number of skin cancer diagnoses and referrals has been seen as a result of the pandemic.[31,42]

The number of BCCs and CSCCs biopsied in April 2020 was just 22% and 58% respectively compared to April 2019.[43]

People staying inside through lockdowns and reducing their exposure to the sun may have contributed to this lower number. However, we also know that many people did not contact their GPs in cases where, outside of the pandemic, they would ordinarily have done so to avoid placing further burden on an already stretched health system.[44]

Despite advice to GPs and secondary care professionals to maintain normal cancer services throughout the pandemic, there was a reduction in 2-week wait referrals. From the middle of March to the end of June 2020 there were 43% fewer 2-week wait referrals than in the same weeks in 2019.[45]

These factors have contributed to skin cancer being one of three cancers that comprise two-thirds of the national pandemic backlog in England. As a result, the *NHS 2022/23 Priorities and Operational Planning Guidance for England* identified skin cancer as a priority area for increasing diagnostic and treatment capacity. **However, despite the rhetoric of national prioritisation, 65% of healthcare professionals believe that NMSC is not adequately prioritised by NHS England.**[20]

88%

Of healthcare professionals agree that the post-COVID care backlog is contributing to more patients being diagnosed with NMSCs at more advanced stages.[20]

The backlog of cases caused by the pandemic has a two-fold impact. Clinical teams are working through a huge waiting list, one they feel is insurmountable with current workforce.[47] This is compounded by reports that many healthcare professionals are already seeing cases where the disease is more advanced as a result of later presentation in primary care.[20]

A study into Scotland's North Cancer Alliance (NCA), a collaboration of six NHS Boards in the north of Scotland, found that the COVID-19 pandemic had a significant impact on Skin Cancer care. The study found that in 2019, 5103 non-melanoma skin cancer cases were diagnosed across the NCA, which reduced significantly to 4071 in 2020. More widely in Scotland, 21,626 non-melanoma skin cancer cases were diagnosed in 2019, with only 16,193 diagnosed in 2020. [31]

Teledermatology

- **Teledermatology presents a strong opportunity to improve patient access to care and increase capacity[48]**
- **However, it is essential that it is implemented in line with best practice**
- **Embedding teledermatology in the pathway through a new national clinical guideline would ensure effective roll out of the digital pathway**

The COVID-19 pandemic catalysed rapid innovation in consulting and treating patients remotely. Dermatology is one area that benefited from this. There is broad consensus that teledermatology has and will be a positive for patient care, most notably through increasing capacity for patients who need face-to-face appointments.[48]

By triaging cases virtually, teledermatology frees up clinicians' capacity to focus on more complex and advanced cases.[48] Digital tools also streamline care by shortening waiting times, providing more flexibility in appointments for patients and ensuring equitable access to care.[49]

Central to the successful use of teledermatology is the presence of guidance and sharing of best practice. When updating a national NMSC guideline, national bodies should embed the role of teledermatology in the pathway and signpost to learning platforms, such as the dermatology digital playbook, and BAD resources.[51, 48]

Cardiff and Vale University Health Board had a mandatory teledermatology route in place prior to the pandemic. Results from an evaluation questionnaire sent to GPs and dermatologists in this area clearly showed appreciation for the service, with the removal of unnecessary appointments, a fast-track route for urgent referrals and opportunities for GP's professional development through their involvement in the consultant's feedback.[50]

Data

- **Poor data collection impacts understanding of service demand, capacity planning and resource allocation[20]**
- **Patient outcomes are not adequately recorded[52]**
- **Improving data collection creates an opportunity to respond to resourcing needs and deliver care which improves patient experiences[20]**

Despite the scale of the disease in the UK, accurate and reliable data collection on a whole range of datasets ranging from prevalence, routes to diagnosis, time to treatment and patient experience is lacking.[1] Patient experience is not routinely collected for NMSC patients. In England, the Cancer Patient Experience Survey does not include NMSC patients[52] and the Welsh Cancer Patient Experience Survey groups cancers by tumour type and not by specific cancer.

Furthermore, there are huge variations in how NMSC is recorded across different areas: England and Northern Ireland record only the first NMSC a patient is diagnosed with and in Scotland, while all CSCCs are recorded, only the first BCC is recorded in the national cancer registry. Wales does not publish its NMSC records.[1] This is important as people with NMSC can go on to develop multiple tumours over time, requiring repeat treatment.[2] Without this information, it is difficult for health bodies to effectively plan care and to ensure there is capacity to meet growing demand for services.[53]

This is reflected in responses to our survey, with clinicians listing the following as being the most impacted by poor data collection:[20]

66%
Understanding of service demand

65%
Capacity and resource allocation

63%
Evaluation of the quality and efficiency of service

53%
Analysis of patient outcomes

Treatment and management

- **MDTs are critical for the treatment and management of patients with NMSC.[54]**
- **However, existing guidelines incorporate varying levels of detail on MDTs, and often do not account for communication between teams.[20,24,35]**
- **The COVID-19 pandemic had a significant impact on the management of skin cancer,[46] meaning that some NMSCs may require more intensive treatment.[20]**

Local and specialist multi-disciplinary teams

NMSC is primarily managed by an MDT. Ideally MDTs should convene various clinical disciplines, who together can offer patients high-quality care and support for their holistic needs.

Clinical teams also maintain close contact with other professionals who support patients' wider needs, such as counsellors, psychologists, physiotherapists, and occupational therapists.[24]

Whilst a LSMDT and SSMDT will have a similar make-up, they have different responsibilities. LSMDTs deal with lesions that are lower risk and less urgent. For these patients, they will provide a rapid diagnostic and treatment service, and information and advice.[24]

Higher risk NMSC should be managed by SSMDTs. Given that these cases may require more intensive treatment, SSMDTs tend to be established in larger hospitals with specialist tertiary services.[24]

MDT members[24]

Treatment

Treating BCC

Specially trained GPs can treat low-risk BCC patients. This usually involves conducting localised surgery to remove the tumour.[55]

If the tumour is a high-risk BCC, the patient is referred to the LSMDT. 24 High-risk BCCs are usually treated through surgery and/or radiotherapy.[56]

94%

Indicated that access to innovative therapies would be a positive consequence of having a national guideline[20]

Treating CSCC

CSCC is generally faster growing than BCC . CSCC is normally managed by specialists in secondary care and thus patients are referred from a dermatologist or LSMDTs to SSMDTs.[24] The primary treatment option for CSCC is surgery, but radiotherapy and photodynamic therapy may also be used.[28,58]

Challenges in management

Variation in guidance

There is variation in the level of detail provided in local guidelines on the management of NMSC. For example, some guidelines detail which team is responsible for certain skin cancers, the pathways between each team and MDT contact details.[59] Others do not contain this level of detail, instead they predominately focus on referral and diagnosis and do not detail management or follow up care.[35]

Barriers you feel need most urgent attention[20]

"A robust and clear pathway especially for head and neck non-melanoma SCC patients as there are 3 different specialties managing this."

Scotland, Surgeon

"In the place where I work, there seems to be no clear direction with management of H&N skin cancers."

Scotland, Surgeon*[20]

Poor communication between MDTs

Guidelines state that CSCC and high-risk BCC should be managed by Local and Specialist Skin MDTs.[24] However, in practice, patients are sometimes referred to the Head and Neck MDT (H&NMDT) as these are the areas where NMSC often develops.[4,20]

In these instances MDTs should work together to provide the best possible care for patients. However, our survey would suggest this may not be happening in practice, as **88% of respondents said there could be better communication between LSMDTs, SSMDTs and H&NMDTs**.[20]

A clear pathway detailing which MDTs should manage which patients could help to better streamline care to enable the most appropriate treatment decisions to be made rapidly and in the best interests of patients.

*In response to question: What areas need urgent attention to improve patient outcomes?

Access to innovative treatments differs by area

Access to innovative treatments in NMSC varies across cancer centres. This means that some patients must travel further than others to receive treatment. As NMSC is more prevalent in older people, who may be less able to travel longer distances with ease, this distance to travel for treatment may be contributing to a postcode lottery.[13]

69%

Of HCPs agree that the travel time to centres delivering innovative therapies for NMSC is a barrier to patients being able to access these treatments[20]

The impact of COVID-19 on NMSC treatment and surgery

The COVID-19 pandemic had a significant impact on NMSC treatment and surgery in the UK.[60] NHS England has subsequently identified skin cancer treatment capacity as a priority area for 2022/23.[46]

A recent study looked at patients receiving NMSC surgery in 32 plastic surgery units within the first lockdown period between mid-March and mid-June 2020. It found a significant reduction in the number of patients being treated: treatment for NMSC fell by 27% - 47% throughout April and May. The surgical removal of CSCC was prioritised over BCC, and at the pandemic's peak, CSCCs made up 71% of excisions (normal percentage is 28%). [60]

High risk tumours were particularly affected. In the same study, 77% of surgeons reported that Mohs micrographic surgery stopped and 70% experienced a reduced radiotherapy service. Many high-risk BCCs did not receive treatment therefore these delays could mean wider excisions are required.[60]

93%

Of NMSC surgeons felt that patient wait times were impacted by the COVID-19 pandemic.[20]

Workforce

- **Workforce shortages are especially present in skin cancer, with shortages across the entire NMSC pathway[61,62]**
- **Long-term workforce efforts are welcome, but short-term solutions are needed for NMSC to plug the gap and deal with the COVID-19 backlog**
- **A comprehensive national guideline with workforce requirements detailed would streamline pathways and set the benchmark**

The effective implementation of a comprehensive national guideline requires a sufficiently resourced workforce. It is even more urgent to address this given the increasing prevalence of NMSC. Without progress in workforce capacity, it is estimated that more than 340,000 people between 2019 and 2028 will miss out on an early cancer diagnosis.[61]

Shortages exist in all the specialisms involved in the skin cancer patient pathway and skin MDTs.

88% of respondents to our survey agreed that there is a lack of capacity to manage the increasing demand for NMSC services and increased referrals of NMSC patients.[20]

Consultant dermatologists

Data from the 2021 Getting It Right First Time (GIRFT) on dermatology report show that, at the time of publication, there were 159 whole time equivalent consultant dermatology vacancies.[62]

Cancer Nurse Specialists

The shortfall of Cancer Nurse Specialists (CNS) is expected to grow to 3,371 in England, 100 in Northern Ireland, 166 in Wales and 347 in Scotland by 2030.[63]

Clinical Oncologists

England and Wales face the highest shortfall of clinical oncologists, at 17%, followed by Scotland at 13% and Northern Ireland at 8%.[64]

In our survey, each specialism noted insufficient workforce in their own area, and there was agreement across all specialisms that CNSs are particularly understaffed, with 71% observing the shortage.[20]

The Government's 2021 Spending Review ringfenced funding for 15 additional dermatology training posts.[41] Whilst this is a positive step, much more needs to be done in the short- and long-term. Health and care workforce plans must be developed and continuously updated; the Royal College of Nursing recommended that these are enshrined in legislation and Government-funded.[65]

Establishing a comprehensive national NMSC guideline which clearly recommends workforce requirements along the pathway is an important first step for improving patient management. In the short-term, it would reduce unnecessary burden by clearly setting responsibilities for specialties and streamlining the patient journey. In the long-term, the guideline would set the benchmark of workforce requirements for national health bodies to strive towards in their training and education efforts.

Leadership

- **Local and national leadership can increase prioritisation of the disease in order to continually improve patient outcomes**
- **New and existing leadership roles can be used to promote best practice and information sharing locally, regionally, and nationally**
- **Implementation of a new national clinical guideline could be driven locally by NMSC Clinical Champions**

The shift to health and social care being managed and provided locally requires a local and national approach to leadership. Both levels of leadership ensure accountability, play a role in increasing disease prioritisation and drive momentum in service improvement.

Clinicians who spend some of their time upskilling and sharing information with colleagues across their Cancer Alliance have an especially important role to play in the implementation of guidelines and roll out of patient pathways. As such, an NMSC focused Clinical Champion should be appointed in every Cancer Alliance and provided with the capacity to play this leadership role alongside their clinical responsibilities.

Recommendations

1. National bodies across the UK must update and publish comprehensive national guidelines on the referral and management of NMSC

a. NICE (which sets guidelines for England, Wales and Northern Ireland), and the Scottish Intercollegiate Guideline Network (SIGN) should develop respective NMSC guidelines in close collaboration with the NMSC community

b. Health ministers in all nations should call on guideline setting bodies to publish national NMSC guidelines and provide adequate resourcing to support the implementation of the guideline

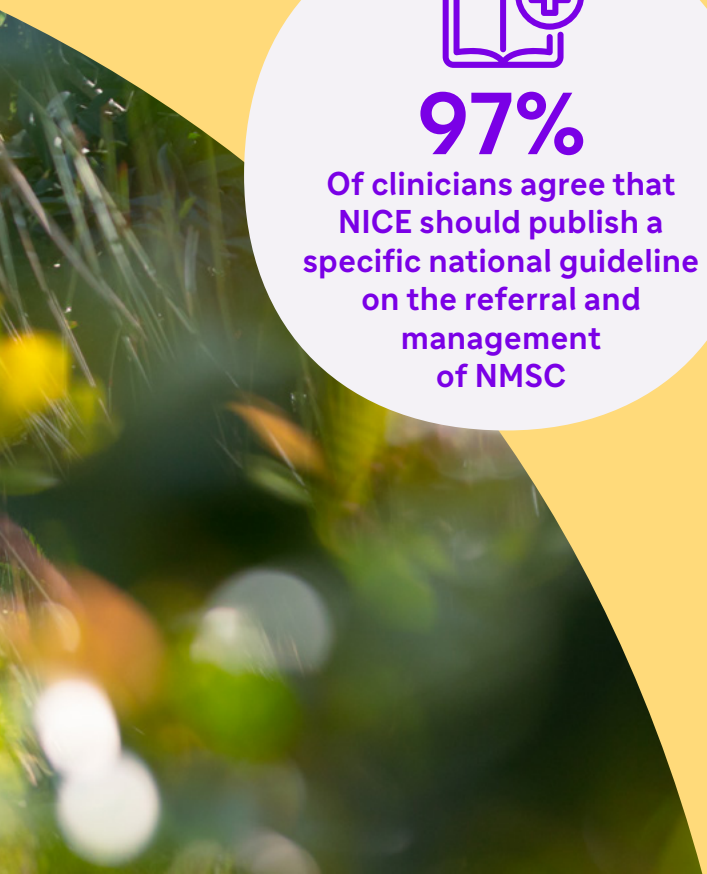
c. Parliamentarians, patient groups and clinicians should advocate for the publication of guidelines and call for the adequate resourcing of services to support the implementation of the guideline

96%

Of clinicians agree that, if published, their local health system should implement the national NMSC guideline

97%

Of clinicians agree that NICE should publish a specific national guideline on the referral and management of NMSC



2. Local health systems should implement the national NMSC guideline once published

a. Integrated Care Systems, Cancer Alliances (CA) and the Wales Health Collaborative should implement the pathway set out in the guideline

b. The national health bodies in each of the nations should take immediate steps to uplift resourcing (financial, workforce, data and IT systems) to support CAs to provide optimal NMSC care according to the guideline

c. The national health bodies in each of the nations should provide clear guidance and best practice to NMSC service leads on how funding requests for NMSC services should be made

d. CAs should appoint a 'Clinical Champion' for NMSC and provide them with the capacity to play a role in service evaluation, including access to data to do this

3. NMSC should be established as a priority in national cancer policy, and concrete action in driving progress in NMSC care should be taken

a. The Department of Health and Social Care and national health systems should use national cancer policy as an opportunity to clearly establish skin cancer, specifically NMSC, as a system priority

b. The body that leads the NHS in each of the nations should provide sufficient resourcing to local health systems to manage NMSC and rapidly cut the backlog

4. Improvements in the quality and quantity of NMSC data should be prioritised

a. Cancer registries in each of the nations should align on how NMSC prevalence data is recorded, ensuring that secondary and multiple tumours are also recorded

b. NHSX should include NMSC in all its datasets, including those that illustrate the patient journey

c. National patient experience surveys should include NMSC patients as respondents. Where skin is included, effort should be made to differentiate melanoma from NMSC

5. The workforce crisis should be addressed to successfully improve NMSC patient care in the long-term

a. Upcoming national workforce planning, such as England's NHS Workforce Strategy due to be published in 2022, should reflect the increasing prevalence of NMSC, significant backlog and lack of specialists

b. Short-term solutions should be developed in partnership with NMSC services and implemented. A NMSC guideline which clearly sets responsibilities for specialties would reduce unnecessary burden and streamline the patient journey

c. National health bodies in each of the nations should arrange training opportunities and educational resources for the primary care workforce, to allow them to upskill on skin cancers and in turn alleviate system burden later in the pathway. Health Education England should roll out and advertise its training modules on skin cancer

Conclusion

This report has detailed the widespread inconsistency in NMSC patient pathways and has highlighted the clear and urgent need for a national guideline on NMSC.

By surveying HCPs involved in treatment of NMSC, we have sought to understand in greater detail the barriers that patients experience at all stages of their treatment journey, and what can be done to overcome these challenges. What is clear is that respondents to our survey do not believe that NMSC is adequately prioritised by NHS England, highlighting that there is a lack of capacity to manage increasing demand and meet patient needs.[20]

As the report demonstrates, there are measures which can be put in place to overcome these challenges, in turn helping to alleviate wider system pressures like the pandemic backlog.

By developing comprehensive national guidelines which are applied locally, NICE and SIGN can ensure that, no matter where patients live, they are able to access the care that they need at the right time. Clinicians would be supported to refer patients, with appropriate urgency, to the best team for further investigation or treatment.

However, for national guidelines to make a meaningful difference to patient experiences, the workforce crisis must be addressed as a matter of urgency. Without sufficient resourcing, patients will continue to experience backlogs and delayed referrals; further, without adequate training, the burden of NMSC will continue to be felt by specialists rather than alleviated by ensuring that HCPs in primary care are able to refer patients to the most appropriate place.

Overcoming these barriers by prioritising NMSC is not only possible, it's essential; as incidences continue to grow, there has never been a more urgent need for a national guideline on NMSC.

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