



European Academy of
Dermatology and Venereology



European Cancer
Patient Coalition

2020 Follow-Up Workshops of the Multi-Stakeholder Summit on Occupational Skin Cancer

ACTION BRIEF

BACKGROUND

On October 8th and October 12th, the follow-up workshops of the Multi-Stakeholder Summit on Occupational Skin Cancer (OSC) by solar UV radiation (UVR) at the workplace brought together more than 30 participants from across the world, representing patient advocacy groups, workers unions, occupational safety and health professionals, social security representatives, dermatologists, and oncologists.

A representative of the European Commission's team working on Europe's Beating Cancer Plan (EBCP), and two Members of the European Parliament sitting on the Parliament's Special Committee on Beating Cancer (BECA) also took part. Over the course of the two interactive online sessions, featuring a range of enlightening speakers, discussions and debate, the workshops built off of the work of the 2019 Multi-Stakeholder Summit on OSC.

Last year, a [Call to Action](#) was launched at the Summit held at the European Association of Dermato Oncology (EADO) Congress,¹ calling on the stakeholders to take five actions to address the unmet needs of NMSC patients:

1. Policy makers should improve legislation to protect outdoor workers and build accessibility for regular screenings and earlier treatments.
2. Doctors, other health professionals and policy makers should work together to ensure standardised EU-wide registration of NMSC.
3. Employers should use tools to quantify exposure levels to UVR in the workplace, and implement cost-effective techniques for sun-safe

¹ The Call to Action was issued by EADO, the European Academy of Dermatology and Venereology (EADV), the Association of European Cancer Leagues (ECL), the International League of Dermatological Societies (ILDS), the European Dermatology Forum (EDF), the International Commission on Occupational Health (ICOH), the European Cancer Patient Coalition (ECPC), the Federation of Building and Woodworkers (EFBWW) and the European Federation of Food, Agriculture and Tourism Trade Unions (EFFAT).

behaviour and ensure regular skin cancer screenings for outdoor workers.

4. Doctors and other health professionals should improve reporting of occupational NMSC (including actinic keratosis).
5. Patient advocacy groups, employers, doctors and other health professionals should collaborate to promote skin cancer prevention and sun-safe working practices, and to address the unmet needs of retired outdoor workers with persisting NMSC.

Additionally, the Multi-Stakeholder Summit in 2019 led to the preparation of a white paper, [Improved Protection of Outdoor Workers from Solar Ultraviolet Radiation](#), addressed to all key stakeholders involved in the protection of workers' health, such as policy makers, doctors and other health professionals, employers, workers, social security and patient advocacy groups. The paper has recently been submitted for publication by the Journal of the European Academy of Dermatology and Venereology (JEADV).

THE CHALLENGE AND THE OPPORTUNITY TO CONTINUE THE WORK OF THE MULTI-STAKEHOLDER SUMMIT

Comprised of cutaneous squamous cell carcinoma (CSCC) and basal cell carcinoma (BCC), non-melanoma skin cancer (NMSC) is the world's most frequently diagnosed cancer, with an estimated 7.7 million cases diagnosed every year,² increasing by 3-8% annually.^{3,4} In 2018 alone, NMSC is estimated to have caused 65,000 deaths globally.⁵ Despite being one of the most common occupational diseases (OD) in Europe, it is yet to be widely recognized and recorded as such. While the prevalence of the disease is continuously increasing, patients are still left behind by healthcare systems, with prevention efforts, screening and access to treatment and care needing significant improvement.

With the European Commission set to present its milestone strategy on cancer, Europe's Beating Cancer Plan by the end of 2020, the follow-up workshops of the Multi-Stakeholder Summit on OSC provided the optimal opportunity to build consensus around the key necessary steps to improve NMSC and OSC reporting, the needs of the NMSC community and the potential benefits of official recognizing NMSC as an OD.

²Fitzmaurice Ch, Abate D, Haghmei A, et al. Global, Regional, and National Cancer Incidence, Mortality, Years of Life Lost, Years Lived With Disability, and Disability-Adjusted Life-Years for 29 Cancer Groups, 1990 to 2017. A Systematic Analysis for the Global Burden of Disease Study. *JAMA Oncol* 2019;5(12):1749-1769. doi: 10.1001/jamaoncol.2019.2996.

³ John, SM et al. (2016) CONSENSUS REPORT: Recognizing non-melanoma skin cancer, including actinic keratosis, as an occupational disease – A Call to Action. *JEADV*. Doi: 10.1111/jdv.13608.

⁴ Didona et al. (2017) Non-Melanoma Skin Cancer Pathogenesis Overview. *Biomedicines*. Doi: 10.3390/biomedicines6010006.

⁵ Bray F, Ferlay ME, Soerjomataram I, Siegel R, Torre LA, Jemal A (2018) Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: A Cancer Journal for Clinicians* 68 (6). Doi: 10.3322/caac.21492.

The exact disease burden of NMSC remains worryingly unclear in many European countries due to a dearth of registries and a lack of accurate data on patients. Beyond being simply a health system issue, the inadequate registration and coding of patients means that an unknown number of patients are left without access to treatment and necessary care.

Furthermore, without proper education, screening, and prevention programmes in place, the OSC and NMSC epidemic continue expanding – leading to an accelerating number of patients forced to live with a debilitating chronic disease characterised by abundant lesions which affect the overall quality of life and functional ability, and entail a heightened risk of developing terminal advanced forms of the disease.

As the livelihoods of millions of outdoor workers are affected around the world, the economic costs of OSC, and in particular NMSC, continues to grow, with governments and healthcare systems facing significant growing economic pressure. Legislative protection of outdoor workers is still to provide for globally adequate prevention measures, diagnosis and effective treatments for NMSC and OSC overall.

KEY ISSUES IDENTIFIED AT THE FOLLOW-UP WORKSHOPS

Across the two workshops, the participants discussed the necessary steps to improve occupational skin cancer reporting and analysis of occupational diseases, looking at the main barriers that prevent physicians, dermatologists and other health professionals from reporting occupational skin cancer. They also looked at the legislative and soft measures to reduce exposure to natural UVR at the workplace and what are the priority areas and instruments to be used as a means to reduce exposure and improve awareness. Finally, the participants discussed how health education can be better integrated into national health policies and which local, regional and/or national channels could be used to disseminate the Europe's Beating Cancer Plan.

As much as **85% of all participants found that low usage of notification forms is the main barrier to reporting**, while **75% recognized the absence of NMSC registry** as one. Lack of recognition of OSC in national legislation, the labour-intensive aspect of the registration, and lack of digitalisation were recognized as relevant barriers by **64% of participants**.

Both **legislative measures (92%) and soft measures (85%)** are deemed as highly important to achieve the reduction of exposure to natural UVR in the workplace, an opinion that demonstrates the alarming need for regulation of this issue. Ranking **key priority areas to achieve the reduction of exposure and improving awareness**, the participants identified increasing health education as the **highest priority (94%)**, followed by social partner agreements, engaging and **amplifying patient voiced, and improving access**

to treatment (75%). Regular screenings are recognized as a highly important priority area by 63% of participants, while targeted digital tools are thought a highly important by just more than half of participants (54%).

ADDRESSING PERSISTING KEY ISSUES

Participants reached a consensus that there are two main priority areas to address the issue of lack of NMSC registries, to assure that OSC is recognized and addressed, and to further pursue recognition of NMSC as an occupational disease:

1. **Legislation**, i.e. establishing a legal framework necessary for the preparation or creation of cancer registries, introducing laws for reporting, for prevention activities, and introducing compensation rules.
2. **Raising awareness campaigns** aimed at employers, employees, but also at the wider public to educate people on the risk of skin cancer and focus on behavioural change.

National academic institutions and dermatological societies need to play an active role in informing their members that cases need to be registered in cancer registries. Notification of NMSC cases is essential and dermatologists need to help improve cancer registries.

To tackle the low usage of notification forms, the participants identified financial reimbursement as a tool to drive notification of cases, and also highlighted that raising awareness of policy makers of the prevalence of NMSC is crucial.

Regarding the potential that digitalisation presents, the European Health Data space might bring potential benefits in synergy with the Europe's Beating Cancer Plan when looking at securing patient data and building out much needed registries.

Health education should be incorporated in vocational training, and while social partner agreements are recognised as vital to achieve the reduction of exposure and improving awareness, an EU framework is needed as countries take different approaches.

In order to amplify the patients' voice, health literacy must be improved. Information campaigns as well as awareness raising campaigns targeting outdoor workers, healthcare professionals, employers and patient advocacy groups are crucial to empowering patients to engage in policy developments and with policy makers. Additionally, social media also presents an opportunity for effective patient engagement.

While skin cancer is not currently at the centre of the EBCP, the efforts of the Multi-Stakeholder Summit on OSC to make it a priority must continue.

Prevention options for skin cancer and screening must not be left out of the Europe's Beating Cancer Plan, as they are essential for protecting high-risk workers exposed to UV. Additionally, skin cancers and their prevention must be included in the cancer research support provided by the EU. **Adequate funding for the EU4Health programme** is essential to ensure that the Europe's Beating Cancer Plan does not become *another empty shell* initiative.

Regarding the dissemination of the Europe's Beating Cancer Plan in the Member States, participants noted that **prevention institutions in the Member States**, including institutions dealing with workplace setting in specific sectors are a potential channel. Additionally, national medical societies have been identified as having the potential to play an important role in disseminating the Europe's Beating Cancer Plan given that, generally, national medical societies have usually good relations with patients.

WAY FORWARD

Perseverance on the roadmap to ending the NMSC epidemic was highlighted as pivotal in continuing efforts of the Multi-Stakeholder alliance. With the priority areas and possible solutions to persisting issues set out, the full re-convening of the Multi-Stakeholder Summit on OSC is expected on 7 September 2021, at the 5th International UV and Skin Cancer Prevention Conference in Mechelen, Belgium.