

## NEWSLETTER

**In this issue:**

- Psychological Resilience.
- Sussex & Surrey Cancer Alliance
- News from the World of Melanoma—Cancer research UK
- Buddies report
- .....and more.



### PSYCHOLOGICAL RESILIENCE

I feel sure we are all aware that the World’s largest sporting event is taking/took place during July and August. At the Tokyo 2020 Olympic Games there are 33 sports with 50 disciplines, and a total 339 events. In all a total of 11,091 athletes are expected to compete. Doing the maths and ignoring the fact that a few events give out 2 bronze medals indicates that the chance of winning a medal is about 9%.

Over the years much has been written on the characteristics that make-up Olympic medal winners. But have you ever considered how those same characteristics are also represented in the Best Melanoma Patients (BMP)? Dr David Fletcher and Mustafa Sarkar from Loughborough University published a paper entitled “A grounded theory of psychological resilience in Olympic champions”. Psychological resilience can be defined simply as one’s ability to face adversity in ways that may preserve well-being and quality of life.

They interviewed 12 Olympic champions and found they share a unique mental resilience characterised by five key psychological attributes:

**A positive personality:** Olympic champions possess positive personality characteristics including openness to new experiences, conscientiousness, competitiveness, optimism and proactivity.

**Motivation:** Gold medallists have multiple internal (i.e. passion for the sport) and external (i.e. proving their worth) motives for competing at the highest level. Champions consciously judge external pressures as important and so choose to perform in challenging sports environments.

**Confidence:** Gained from various sources including multifaceted preparation, experience, self-awareness, visualisation, coaching and team mates.

**Focus:** Champions are able to focus on themselves without distraction, and to concentrate on the process rather than the outcome of events.

**Perceived social support:** Olympic gold medallists believe high quality social support is available to them, including from family, coaches, team mates and support staff.

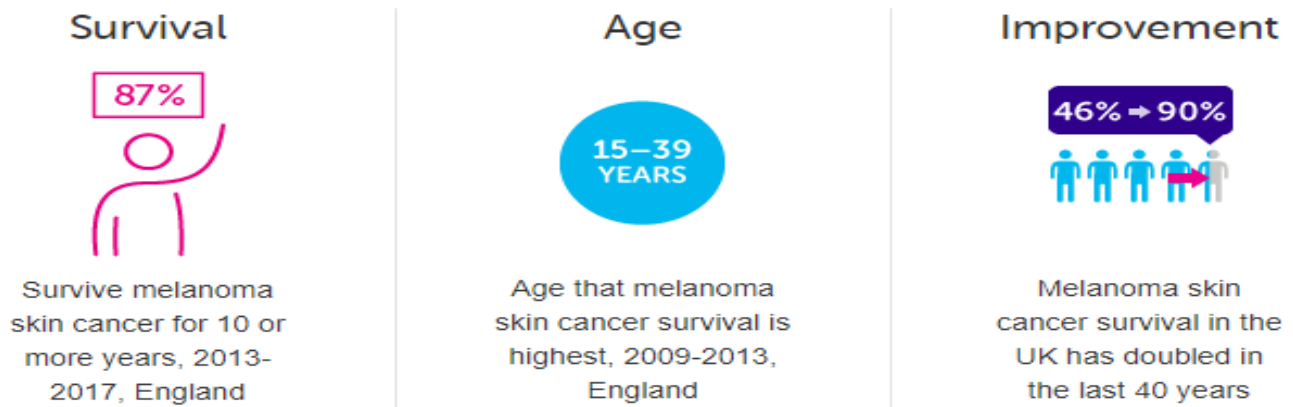
Now let’s consider these characteristics in respect of the BMP :

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## NEWSLETTER

First, let's consider the odds:

So noting that there is just a 9% chance of winning a medal at the Olympics, Cancer Research UK have published the following facts and figures (see images below). It can be seen that with 87% of the melanoma skin cancer population surviving for 10 or more years after diagnosis, the odds are much better than winning a medal within the Olympic athletic population.



Next, let's consider those characteristics of the top athletes.

**A positive personality:** The Best Melanoma Patient (BMP) is open to new experiences and embraces the treatments on offer for both immunotherapy and well-being. They are conscientious and abide by the routines. They are competitive and are determined to beat this cancer. Just as an athlete is optimistic they will win, the BMP knows they will beat the foe. They will be pro-active in understanding their treatment and will seek out information.

**Motivation:** BMP's motivation tends to be about beating the odds and surviving melanoma. Unlike athletes they are not fighting competitors but are fighting the foe and the motivation is the zest for life.

**Confidence:** BMPs gain confidence from various sources including prehabilitation, their own experience of the effects of treatments and their likely reaction to them i.e. self-awareness, they can visualise the death of the melanoma cell. Also by coaching new patients and learning from team mates, e.g. in MelaNoMore terms the Friend/Buddy relationship and Happy Hour gatherings.

**Focus:** BMPs are able to focus on themselves without distraction, emotions are controlled and negative thoughts, which will always be there, are suppressed. The ability to focus on the process i.e. the treatment and mitigations to ill effects, rather than the outcome of events which maybe good or disappointing.

**Perceived social support:** BMPs have high quality social support available to them, including from family, carers, MelaNoMore members and medical staff.

We can't all be Olympic athletes, but all the traits found in medallists can be learned and the Best Melanoma Patients will strive to achieve these traits to the best of their abilities. Remember athletes need coaches and we sometimes need help. Help is available and if you can't find it just ask.

**REMEMBER — WE ALL HAVE THE CAPACITY TO BE CHAMPION MELANOMA PATIENTS**

## NEWSLETTER

The Virtual Café



23rd June



Attendance: 7



**Guest: Speaker: Boba Rangelov, SSCA Patient and Public Engagement Manager**

**Topic: Surrey and Sussex Cancer Alliance**

The Surrey and Sussex Cancer Alliance was established as a part of the NHS to work in partnership with the local healthcare organisations (hospitals, community health services etc.) to enable them to provide excellent cancer services across Surrey and Sussex. Boba gave a detailed presentation to the Café introducing the SSCA and encouraging us to get involved.

### What is Surrey and Sussex Cancer Alliance?- Introduction

**The Surrey and Sussex Cancer Alliance (SSCA) is one of the 19 cancer alliances established across England and covers a population of just over 3 million people.**

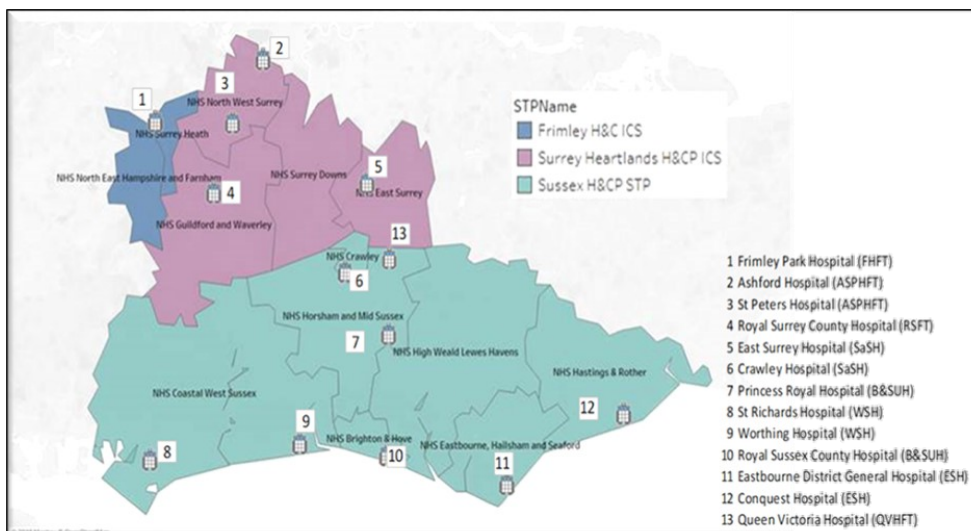
We work in partnership with healthcare organisations, including Primary Care colleagues-GPs, nurses; thirteen Acute hospitals, Surrey and Sussex Local authorities - Public Health, Voluntary and Community sector organisations, Patient support groups and Charities on various cancer related projects.

**Our Vision is to develop and deliver world-class outcomes in cancer care and treatment for the populations of Surrey and Sussex.**

Our areas of work include:

1. Diagnostics and prevention-cancer prevention and screening,
2. Diagnosing cancer faster and treatments
3. Ensuring the best treatment and care by working with Primary Care, Hospital Trusts and other partners
4. Involving patients and public in planning and delivering cancer services
5. Personalised care, ensuring that each patient and carer has their own individual care plan

### SSCA Geographical area



(cont'd).....

## The Virtual Café (Cont'd)



### Surrey and Sussex Cancer Alliance Partners

Our partners-Surrey	Our partners-Sussex
Healthwatch Surrey	<ul style="list-style-type: none"> <li><b>Sussex Health and Care Partnership ICS</b></li> </ul>
Community and voluntary sector organisations	<b>CCGs and Patient Participation Groups</b>
<ul style="list-style-type: none"> <li><b>Frimley Health ICS</b></li> </ul>	NHS Coastal West Sussex
<b>CCGs</b>	NHS Brighton and Hove
NHS Surrey Heath	NHS Crawley
NHS North East Hampshire and Farnham	NHS Horsham and Mid Sussex
<b>Trusts</b>	NHS Horsham and Mid Sussex
Frimley Health FT (FHFT)	NHS Hasting and Rother
Surrey and Sussex Healthcare (SaSH)	NHS Eastbourne, Hailsham and Seaford
<ul style="list-style-type: none"> <li><b>Surrey Heartlands ICS</b></li> </ul>	NHS High Weald Lewes Havens
<b>CCGs and Patient Participation Groups</b>	<b>Trusts</b>
NHS Surrey Downs ICS	Western Sussex Hospitals FT (WSHFT)
NHS North West Surrey	Queen Victoria Hospitals FT (QVHFT)
NHS Guildford and Waverly	Brighton and Sussex
NHS East Surrey	University Hospitals (BSUH)
<b>Trusts</b>	East Sussex Healthcare (ESHT)
Ashford and St Peters Foundation Trust (ASPHFT)	Brighton and Hove Healthwatch
Royal Surrey Foundation Trust (RSFT)	East Sussex Healthwatch
	West Sussex Healthwatch
	Community and voluntary sector organisations

**ICS — Integrated care systems** (ICSs) are partnerships that bring together providers and commissioners of NHS services across a geographical area with local authorities and other local partners to collectively plan health and care services to meet the needs of their population.

**CCG — Clinical Commissioning Groups** (CCGs) commission most of the hospital and community NHS services in the local areas for which they are responsible. Commissioning involves deciding what services are needed for diverse local populations, and ensuring that they are provided.

**FT — Foundation Trust**

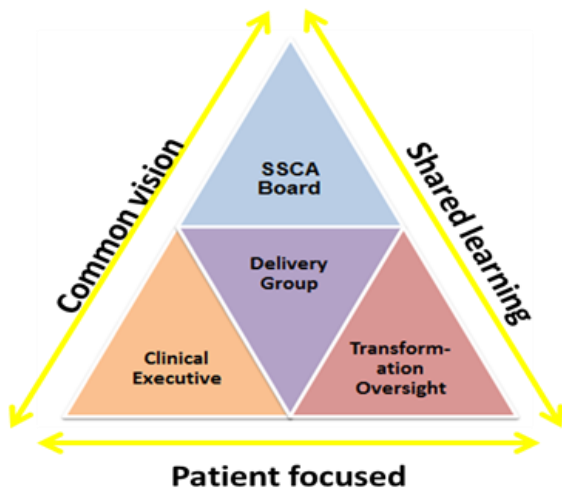
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## The Virtual Café (Cont'd)



## Surrey and Sussex Cancer Alliance Governance



**SSCA Board:** The Board is the highest reporting body in our Alliance which provides organisational leadership to deliver our vision, values and mission. It also oversees all SSCA project proposals and oversees our budget. All three groups below report to the SSCA Board.

**Delivery Group:** This group oversees the running of our alliance, support effective communication with our partners and sharing of good practices. It also agree project proposals.

**Clinical Executive Group:** This group approves any work/changes across the Alliance that might have impact on patient journey e.g. change to breast cancer referrals or any project that may result in a change to clinical practice.

**Transformation Oversight Group:** This group monitors if funding is being used across SSCA to improve our performance, share the best practice and lessons learned and recommend service improvements.

## “Our promise to You” - Patient and Public Engagement Charter

- The Surrey and Surrey Sussex Cancer Alliance will:
- listen to people and ensure in every way possible that patients and the public views are heard and acted upon
- involve the public early in developing our projects and plans and how we plan to deliver improvements in local cancer services
- involve patients and the public early in our projects and decision making processes about how we redesign them.
- demonstrate what impact patients and the public has had on the decisions we make
- always feed back to people who have worked with us
- use the information provided to ensure that we improve the quality of our cancer services, support equality and identify inequalities in access to healthcare
- be honest about when we are engaging, when we are consulting and when we are providing information
- make sure that everyone who works with us will recognise and promote the value of involving patients and the public.

(cont'd).....

## The Virtual Café (Cont'd)



### Different ways to get involved

- Participating/attending specific focus groups
- Attending events (virtually at present)
- Reviewing written material
- Completing surveys
- Telling us your story by sharing your experience
- Tell us what you think about cancer information
- Attend and participate in some of our meetings
- Sit as a member on a specific committee or a group
- Other activities

\* **Time scale:** very flexible, no minimum or no maximum time

\* **Frequency:** depends on each engagement activity

### SSCA Patient's and Public Cancer Champions members' quotes:

- "I am interested in joining the Champions as I want to help improve the welfare of cancer patients and the process of their treatment."
- "I wanted to have the opportunity to have a say on what happened next in cancer services."
- "My experiences might be helpful in the organisation of treatment pathways for the benefit of other patients and their families"

### Engagement opportunities and projects at SSCA

- **Monitoring and evaluation of specific services and staff roles** (i.e. Care Navigator's role: Care Navigator acts as a main point of contact for patients, carers and the wider healthcare team, including primary, secondary and tertiary services)
- **Supporting uptake increase of the screening programmes** (i.e. bowel cancer screening programme, cervical cancer screening programme, and many other national and local programmes)
- **Raising awareness of local and national cancer campaigns** (i.e. lung cancer awareness, smoking cessation and other)
- **Development of the Rapid Diagnostic Service (RDS):** GPs will be able to refer patients to this service if they feel the patient has symptoms that need further investigation in the hospital, enabling them to have quicker and more effective treatment.
- **An example of the engagement activity:** Our Cancer Champions participated in development of the Health and Wellbeing Virtual Resource pack for staff and patients.

(cont'd).....

## The Virtual Café (Cont'd)



SSCA covers all types of cancers and projects which are undertaken by them are selected in competition with other cancer types. Having said that all cancer types share similar care issues, it is therefore important that melanoma skin cancer has a representative in their organisation.

If you wish to get involved with the SSCA as a “Melanoma Champion”, then please let us know and we will put you in touch with Boba.

**[melanomore@googlegroups.com](mailto:melanomore@googlegroups.com)**

*Our thanks go to Boba for providing a comprehensive presentation of the work of SSCA and we wish her and her team every success in the future.*

## Happy Hour

The Happy hour meeting took place at the Onslow Arms, West Clandon, U4 7TE as planned. A few of our members that were due to come were self isolating as a precaution but a good time was had by all the attendees with interesting discussions on treatment side effects!

The Onslow Arms was the perfect venue; they were well organised; all tables were booked and allocated to you on arrival. Drinks could be ordered via their App if preferred and it felt very safe.

We will continue to hold our Happy Hour meetings there at 6—7 pm every second Tuesday of the month. Remember the first drink is on MelaNoMore.

Block Out the Date:			Topic	Guest Speaker
Virtual Café	25th Aug	10.00 am	Macmillan	Mark Witcombe
Happy Hour	14th Sep	6:00 pm	Meet your colleagues	Onslow Arms
Virtual Café	22nd Sep	10.00 am	TBA	TBA

## News From The World of Melanoma

We are intending to provide information on this page of what other charities and support groups are doing within the world of melanoma.

This month we are focussing on **Cancer Research UK**



**CANCER RESEARCH UK**

Together we will beat cancer

**Cancer Research UK** is the world's leading charity dedicated to saving lives through research, influence and information.

**Our vision** is to bring forward the day when all cancers are cured, from the most common types to those that affect just a few people.

**What we do**  
**Saving lives**  
**through research**

To achieve our ambition, we're pioneering new ways to prevent, diagnose and treat cancer, and empowering patients, policymakers and the public to make sure advances in research improve

Our strategy focuses on four key objectives:

- preventing cancers,
- diagnosing cancer earlier,
- developing new treatments,
- optimising cancer treatments to make them more effective for each patient.

We do this through the three key pillars of our work:

- funding world-class discovery research and supporting the translation of this research into clinical practice to benefit people affected by cancer
- campaigning and influencing governments and other organisations to support research and improve cancer services
- providing expert cancer information that draws on our unique insights.

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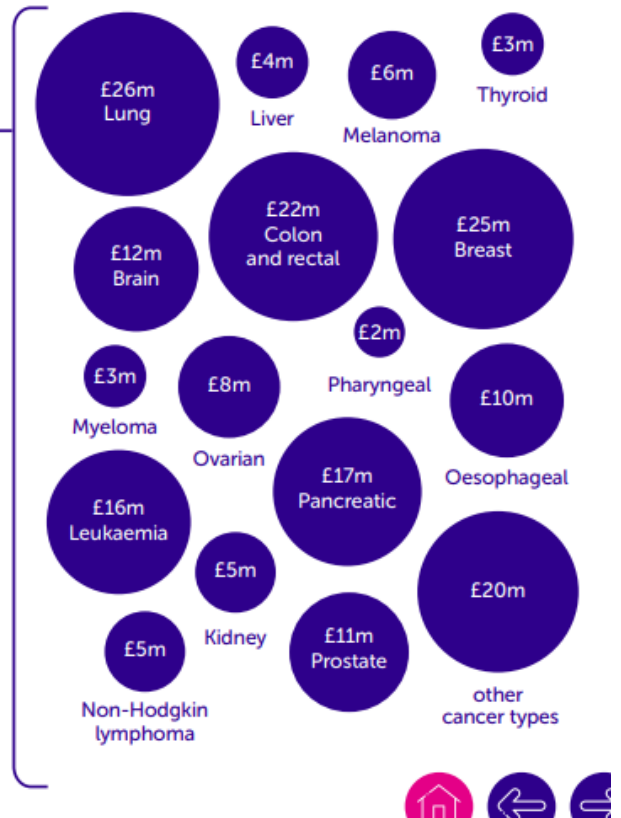
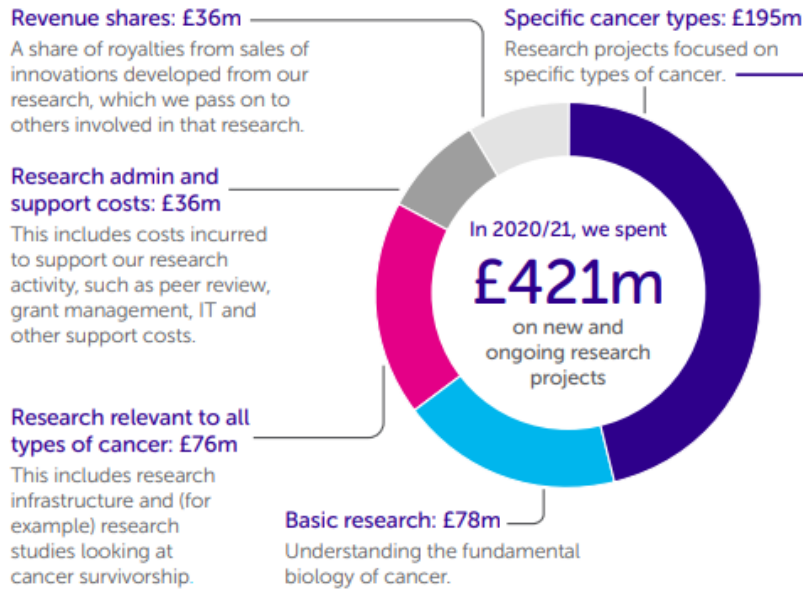


## NEWSLETTER

### News From The World of Melanoma

#### Breakdown of annual research activity

These charts show how our £421m annual research activity breaks down into different areas of research.



Of the £421m we spent in 2020/21, £13m was spent on basic research, infrastructure and research projects that focused on cancers that affect 0-24-year olds, making us one of the biggest funders of research into children's and young people's cancers in the UK.

The importance of this charity is demonstrated by its patronage

The Patron: Her Majesty the Queen

Joint presidents: HRH The Duke of Gloucester KG, GCVO  
HRH Princess Alexandra, The Hon Lady Ogilvy KG, GCVO



A melanoma cell. Credit: Dr Erik Sahai

A melanoma cell:  
Beautiful, but potentially deadly.

#### Editor's

#### Comment

This is the World's leading cancer research society. It is run by professionals for professionals, yet it speaks plain English and is accessible to the public. It covers all types of cancer and last year it funded £6m of melanoma research. It is certainly worth a browse and even if it is just to catch up on the latest melanoma research. Do you know what Rac 'n' Rho is all about in relation to the shape of skin cancer cells and their ability to move through the body? No, neither did I—but it's all there.

## Buddies and Friends



Have you just received your diagnosis?    Are you still on the road to recovery?    Are you undertaking treatment?



Let's talk

Are you feeling Anxious, Fearful, Apprehensive?  
 Does your family/carer need help to understand your situation?  
 Do you just want to chat with someone who understands what you're going through?

MelaNoMore has now established '**Melanomore Buddies**' allowing Buddies and Friends to get together

For further information visit [www.melanomore.net](http://www.melanomore.net) (click on Support Icon) or email: [melanomore.buddy@gmail.com](mailto:melanomore.buddy@gmail.com)



**Chris Caswell, Lead – MelaNoMore Buddies**

The MelaNoMore Buddies system continues to offer support via the Buddy / Friend one to one pairing. A Buddy, who perhaps has had more experience of the melanoma path and process, is paired with a Friend, who is possibly newer and in need of support and a listening ear.

This pairing offers support to share information, to discuss worries and concerns on a one to one basis, without the constraints of appointment time slots. This support pairing is away from the standard clinical appointments, on a more frequent basis, probably weekly or more.

Contacts may be of quick ad hoc text or WhatsApp messages, interspersed with longer possibly weekly phone calls.

We currently have 10 Buddy /Friend pairs operating, and they have shared 126 phone calls, and sent 93 texts, WhatsApps or emails between them since the Buddy Scheme launch nine months ago, in October last year. Additionally there have been 3 face to face meetings.

It is good to see a few Buddies and Friends on the Happy Hour and Virtual Café zoom calls so they can put faces to the contact names.

If you wish to join this support group, as either a Buddy or a Friend, please send an email to

[Melanomore.buddies@gmail.com](mailto:Melanomore.buddies@gmail.com)

This page is for your contributions to the Newsletter. There are no limits on content.

With the Olympics dominating the month, it would be remiss of us not to have a few witticisms on this theme.  
So here they are.....

Why couldn't the bike finish the Olympic race?...*It was two-tired.*

\*\*\* The Winning Joke \*\*\*

An Englishman, Scotsman and an Irishman trying to get into the Olympics with no tickets.....

The Englishman found a large wooden pole lying on the ground near him. He picked it up, put it under his arm, walked in the gate and said 'Bentley, England, pole vaulting' and they let him in.

The Scotsman picked up a manhole cover, put it under his arm, walked in the gate and said 'McGregor, Scotland, discus and they let him in.

The Irish man picked up a roll of barbed wire, put it under his arm, walked in the gate and said 'Murphy, Ireland, fencing.'

What was the Olympic lifter missing from his bar ?  
Weight for it...

Why isn't suntanning an Olympic sport?  
Because the best you can get is bronze.

At the Olympics a man went up to a competitor who was carrying a very long pole.

"Are you a pole vaulter?"

"No, I'm German, but how did you know my name is Walter?"

Why is it so hot in a stadium after the Olympic games are over?... *Because all the fans have left!*

What is a banana's favourite gymnastics move?... *The splits!*

Why is basketball the messiest Olympic sport?... *The players dribble all over the court!*

"How to Do Gymnastics" by Tom E. Tuck.

"The Olympic Trials" by Willy Qualify.

What is the best part of an Olympic boxer's joke?...  
*The punch line.*

Why couldn't the athlete listen to music?  
*Because she broke the record!*

We hope you enjoy this Newsletter. Please let us know or if you have any suggestions for improvement or any articles may wish to publish. You can contact us on:  
**melanomore@googlegroups.com**



## MelaNoMore VACANCIES

We continue to have vacancies on the Committee and are also in need of volunteers to assist the Committee with tasks or roles - such as:

- \*Website designer
- \*Linked sites project
- \*Health & Wellbeing lead
- \*Deputy Newsletter Editor
- \*Linked Site leads

If you are interested in helping out with any of these roles or wish to join the Committee, then drop a line to

**[melanomore@googlegroups.com](mailto:melanomore@googlegroups.com)**

Include your phone number and we will ring you back to discuss with you.





# CANCER INSIGHT

FOR PRACTICE NURSES

Summer 2018

WHAT YOU NEED TO KNOW ABOUT

# SUN & SKIN CANCER

INSIDE:

A3 poster to  
display in your  
surgery



CANCER  
RESEARCH  
UK





# SUN SAFETY AND SKIN CANCER

86% of melanomas in the UK are caused by overexposure to UV

**T**here were around 15,400 new cases of melanoma skin cancer in the UK in 2014. Malignant melanoma mortality rates have almost tripled in the UK since the early 1970s.

Too much ultraviolet (UV) radiation from the sun (or sunbeds) is the main cause of skin cancer, including melanoma - the most serious form.

It's important that people protect themselves; getting sunburnt just once every two years can triple the risk of melanoma.

Almost 9 in 10 cases of melanoma could be prevented by enjoying the sun safely and avoiding sunburn and sunbeds.

We've pulled together some useful tips you can share with your patients to help them stay safe this summer, whether they're going abroad or staying in the UK.

## THE VITAMIN D DEBATE

Although excessive UV exposure is the main cause of skin cancer, sunlight is also the main source of vitamin D so getting the balance right is key. There is still uncertainty about vitamin D, including what levels qualify as 'optimal' but here are a few things to keep in mind:



The amount of time you need in the sun to make enough vitamin D is different for each person and can depend on skin tone. Lighter skinned people can get sunburn and skin damage more quickly, but need less sun to get enough vitamin D.



It also depends on things like time of day, time of year, and where you are in the world. For most white people, just going about their normal daily activities is sufficient to produce the required vitamin D levels.

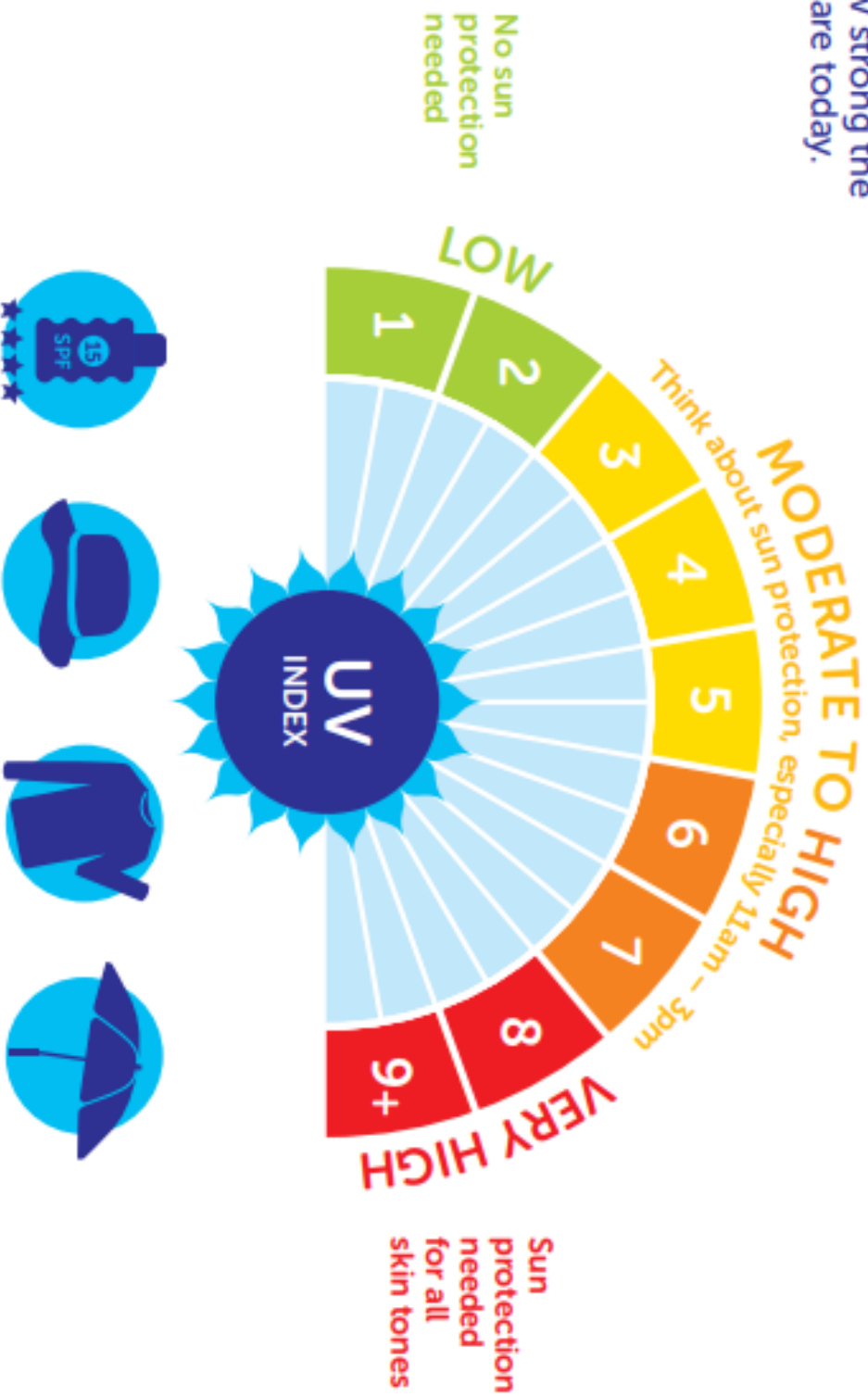


It's also important to keep in mind certain groups that might be more at risk of vitamin D deficiency, including people with darker skin and cultural groups who wear full body clothing. The government recommends that people in these groups should take a 10 mcg supplement of vitamin D a day.<sup>1</sup>

Get more advice and guidance at [po.st/NICE](https://www.gov.uk/government/organisations/nice)

# ARE YOU AT RISK OF SUNBURN TODAY?

Check the UV index now at [www.metoffice.gov.uk/uv](http://www.metoffice.gov.uk/uv) to see how strong the sun's rays are today.



If it's 3 or higher, think about protecting your skin.

**TOGETHER WE WILL BEAT CANCER**  
[cruk.org](http://cruk.org)

