

UK clinician helps create scalp cooling registry

A comprehensive database will track and record patient experience of scalp cooling, in an effort to reduce chemotherapy-induced hair loss.

A nursing professor at University Hospitals Coventry and Warwickshire, has helped to develop the world's first global scalp cooling website to allow clinicians to share best practice patient care.

Professor Annie Young, who also works at Warwick Medical School is one of six global cancer care experts behind the CHILL (Cancer-related Hair Loss, International Leadership CHILL and Linkage) initiative and is the only UK clinician involved in the project.

Speaking to the *Clinical Services Journal*, Prof Young explained that the website, scalpcooling.org will serve as a global hub for patients and care providers seeking information about the treatment. It will collect and track evidence-based patient information and clinical guidance on cancer-related hair loss.

"Hair loss in patients having chemotherapy can be devastating on top of the cancer diagnosis and other side effects of anti-cancer treatments," said Prof Young.

"Our patients want to use scalp cooling and we need to ensure best practices are developed to improve patients' quality of life and make it a choice for all. By working together and sharing information we will have a huge database so that we can establish best clinical practices for the individual patient and help ensure that scalp cooling is as effective as possible in minimising chemotherapy-induced hair loss."

According to the World Cancer Research Fund International, there were an estimated 14.1 million patients diagnosed with cancer worldwide in 2012. Cancer is a significant global health issue affecting every region and socioeconomic group. It is estimated that in patients with solid tumours ie in an organ or tissue (blood cancer and lymphomas excluded) 25% will receive chemotherapy as an initial treatment and 50% are at risk of severe alopecia.

The damage that chemotherapy causes to the hair follicle can be alleviated by using scalp cooling, also known as the 'cold cap'.



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Understanding cancer-related hair loss

The CHILL Registry therefore strives to become a platform that allows clinicians to understand cancer-related hair loss. By working together and sharing vital information it will help improve supportive care by comparing their own data with international estimates, and access the extensive resources of comprehensive cancer treatment teams around the world.

Prof Young explained that by inputting information from all over the world, UK patients will have more real-world evidence to enable them to make a more informed, 'personalised' choice. This will allow patients

to understand what their chances of losing their hair would be for their particular type and dose of chemotherapy, both with and without scalp cooling.

She added: "The UK is behind the Netherlands in implementing scalp cooling in the NHS, despite having the highest number of machines of any country. This is because nurses and oncologists are sometimes the gatekeepers of use or not. Extra space and extra 'chair time' is required for patients having chemotherapy, because of the coolers. There are many excellent cancer centres in the UK offering scalp cooling to all women and men who will lose their hair because of the chemotherapy, and we can all learn how they organise their services in order to meet a growing patient demand.

"We know from studies that healthcare professionals do not hold the same feelings about scalp cooling, for example, regarding tolerability and efficacy. We will collect all of this data from as many countries as possible, analyse and shout the findings aloud – first to patients and their carers and next, to healthcare professionals in the UK with our new CHILL Registry."

Accessible information

The online database will make communication and global research accessible to all healthcare professionals interested in using scalp cooling with their chemotherapy patients. Data about the severity of hair loss according to patients and standardised measures will be collected. For patients undergoing treatment with scalp cooling, physicians can also gather information on tolerance and satisfaction with the results of treatment. The following types of information will be included on the database:

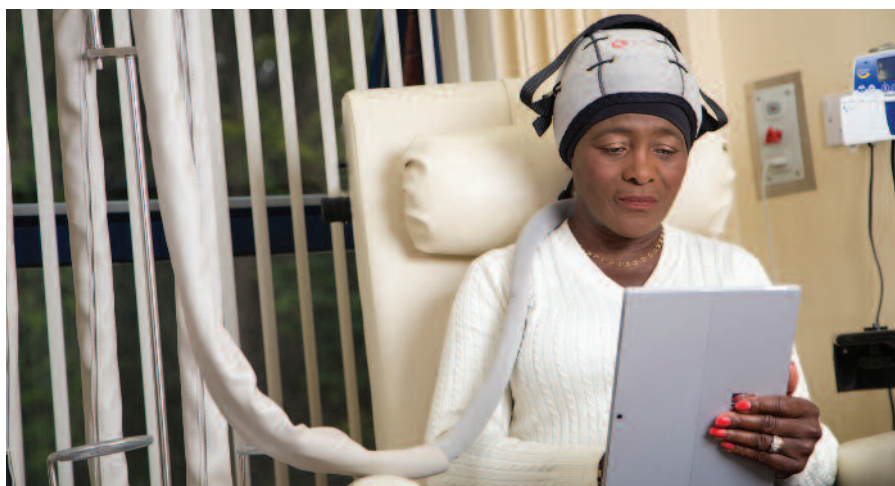
- **Clinical:** type and dose of chemotherapy, chemotherapy infusion time, post chemotherapy cooling time with scalp coolers
- **Patient characteristics:** age, ethnic background, hair thickness, chemical treatment of hair, smoking, body mass index
- **Efficacy:** severity and pattern of hair loss, and in case of scalp cooling; tolerance and satisfaction ►

- Follow up information: dependent on availability and willingness of the patient to be contacted six months after treatment to evaluate hair growth and results to determine incidence of persistent hair loss.

This data will inform clinicians about the added value of scalp cooling, its effectiveness per type of chemotherapy, and also about the factors attributing to why it may be successful for one patient but not for another.

The damage that chemotherapy causes to the hair follicle can be alleviated by using scalp cooling, also known as the 'cold cap'. During scalp cooling treatment, a tight-fitting silicone cooling cap is placed directly on the head, and an outer neoprene cap that insulates and secures the silicone cap. The cooling cap is connected to a cooling and control unit. A liquid coolant circulates throughout the silicone cap, delivering consistent and controlled cooling to all areas of the scalp. Once the cap is fitted to the head, the temperature of the scalp skin is significantly lowered, resulting in vasoconstriction with reduced delivery of chemotherapy to the scalp skin, as well as reduced cellular uptake of drugs due to decreased intra-follicular metabolic rate. Together, these factors minimise the hair loss that is a side effect of many chemotherapy agents. The fit of the cap is the crucial factor.

CHILL executive board member Dr Corina van den Hurk, added that scalp cooling is



well-recognised around the globe as a therapeutic solution to one of the most troublesome side effects of chemotherapy.

"Over the last 10 years, hair loss has consistently been ranked as one of the worst side effects from patients, but things are changing and we are taking control of it through scalp cooling," said Dr van den Hurk, a researcher in clinical oncology and epidemiology at the Netherlands Comprehensive Cancer Organisation.

"There is more and more attention for quality of life and it is clear that worldwide, the use of scalp cooling increases exponentially. Offering patients the option of scalp cooling doesn't just treat the side effect

of chemotherapy-induced hair loss, it also helps people psychologically and socially. It helps them stay in control at what can be one of the most distressing times of their lives."

Developing best practice

Dr van den Hurk added that the launch of the CHILL Registry is a significant step forward as global clinicians work together to develop best practices in supportive care.

"There are many variables in scalp cooling, and they are increasing all the time," she said. "For instance, when we looked, we found that there were more than 30 different scoring methods used in different studies about scalp cooling. This is just an example of how

variable the information is, but if we collate all of this data we can present them to patients and doctors in a more useful way, to help inform their treatment decisions.

"The effectiveness of scalp cooling depends on type and dose of chemotherapy, and there are many cytotoxics and combinations of them.

This means high numbers of patients are needed to evaluate results and its

determining factors. Moreover, if you want to compare results between hospitals, it is desirable to have dozens of patients with one type and dose of chemotherapy per hospital to make reliable estimations.

"There are also constantly new chemotherapies on the market so it is helpful to have as many centres involved in the registry as possible so patients can be informed about the added value of scalp cooling as early as possible."

The registry also provides the opportunity to detect best practices. Centres around the globe that have previously not had positive scalp cooling results can learn from others, which have, to help improve future scalp cooling success for its patients. It was set up following the success of the Dutch registry on alopecia which includes the details of several thousand patients already. It shows that, even

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A number of cancer centres in the UK offer scalp cooling to women and men who will lose their hair because of chemotherapy.



in such a small country with a network on scalp cooling, there is much to learn from each other and many questions open for research to improve this supportive care.

Besides the variables mentioned above, in the registry patients are also asked about their opinion of the accessibility and expertise on scalp cooling of the nursing staff. Therefore, healthcare professionals can also learn whether there is some improvement possible in their routine daily care.

CHILL has launched a website that contains a range of information about cancer related alopecia. Patients can access information about hair loss in general, but also about coping with alopecia. There is also extensive information about scalp cooling, including practical advice, videos and pros and cons of the treatment. Finally, patients can enter the type of chemotherapy they will receive and get a personalised overview of the chance of hair loss with and without scalp cooling. They are guided through some statements about hair loss and scalp cooling and there is a summary to help them to decide whether scalp cooling is for them.

As well as Prof Young and Dr van den Hurk, the CHILL executive board also includes Hope Rugo, MD (UCSF), Helen Diller (Family Comprehensive Cancer Center, San Francisco), Mario Lacouture, MD (Memorial Sloan Kettering Cancer Center in New York City), Fran Boyle, MD and Julie Winstanley, PhD, MSc (Patricia Ritchie Centre for Cancer Care and Research, Mater Hospital and University



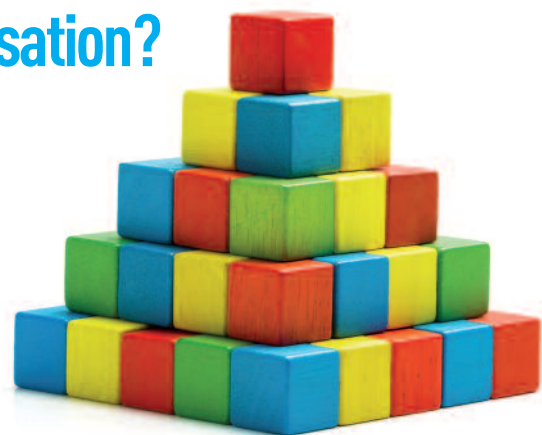
The effectiveness of scalp cooling depends on type and dose of chemotherapy.

of Sydney, Australia). CHILL has contacts with healthcare professionals from each continent; a network of clinicians, nurses and researchers that is expanding with several new countries each year.

The database and website has been funded by British manufacturer Paxman, maker of the Paxman Scalp Cooling System and Dignitana, maker of The DigniCap Scalp Cooling System.

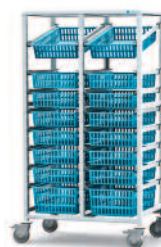
Dr van den Hurk added: "The participating hospitals invest themselves too, as they have to complete the clinical data in the database and provide the patient with a log in for the registry. In return, they have detailed information about hair loss and scalp cooling available that can be used to optimally inform the patients facing the prospect of alopecia. Their efforts are two-sided: useful for patient care and for science." **CSJ**

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