



# Centre for Appearance Research

## Moving forward Collectively: Looking ahead to Research with Impact

VTCT Foundation Team at the Centre for Appearance Research (CAR)

19<sup>th</sup> January 2023 Toynbee Hall, London



# An Overview of the CAR/VTCT Foundation Partnership Programme of Research

Amy Slater & Di Harcourt
Principal Investigators/Leads of the VTCT
Foundation Research Team at CAR

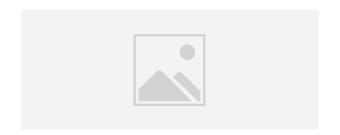


## Outline

- Centre for Appearance Research (CAR)
- VTCT Foundation
- Programme of Research Stage 1 2017-2022
- Stage 2 2022-2026



# Centre for Appearance Research



 The Centre for Appearance Research (CAR) is the world's largest research group focusing on the role of appearance and body image in people's lives.



~40 members including academics, clinicians, researchers & students.

Team includes health, clinical and social psychologists.

# Centre for Appearance Research: Our Mission

To use research to promote body acceptance & appreciation, and improve the lives of those adversely affected by appearance concerns.







# The Vocational Training Charitable Trust Foundation: Our Purpose

The VTCT Foundation seeks to invest in all forms of research and services that help people living with a visible difference and their families and carers to overcome any social, physical, psychological, emotional or other disadvantage.



# Stage 1: 2017-2022

- Working with the Appearance Collective to provide effective support for people with visible differences.
- Support the career development of researchers in this field



# Priority setting exercise (summer 2017)







# The priorities:

- 1. Social media & social media literacy
- 2. Support & interventions to promote acceptance of diversity
- 3. The incidence & experience of visible difference
- 4. Support throughout the treatment journey
- 5. Assessment tools to capture the patient experience/outcomes
- 6. Interventions for people adversely affected by visible difference
- Training materials to promote understanding & acceptance of diversity of appearance
- 8. The motivation of people volunteering with charities in this sector
- 9. The impact of patient and public involvement (PPI)



- 27 new studies conducted
- 3858 participants
- Growth of the Appearance Collective
- Full details in our final report to the VTCT Foundation



# Stage 2: 2022-2026



# **Priority Setting Exercise**

- February 2021 2 x online sessions + individual feedback
- The Appearance Collective ranked the following as their top 5 priorities for future research and workshops:
  - Support & Interventions
  - Social Media
  - Understanding Issues of Virtual/Online Support
  - Promoting Awareness & Acceptance of Diversity of Appearance Amongst the General Population
  - Appearance-Related Issues in Under-Represented Groups



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# Workstream 1: Support & Interventions

Lead: Professor Diana Harcourt

Research Fellows: Dr Fabio Zucchelli & Dr Maia Thornton

PhD Student: Clare Clement

Interns













# Workstream 1: Support & Interventions

### Research Objectives:

- To examine the effectiveness of interventions offering support to people whose lives are affected by visible difference.
- To implement effective interventions.
- To collect evidence of the impact of these interventions.

### Outcomes:

- A range of evidence-based psychosocial interventions easily available and used by charitable organisations, clinicians and people affected by visible difference.
- A tool to identify support and intervention needs of people affected by visible difference.



# Example studies...

- 1. Evaluating The Parenting Toolkit an intervention for parents of children with visible differences of any sort (lead: Maia Thornton)
- 2. Evaluating Loving ACTion a intervention to support adults with visible differences who are seeking support around intimate and romantic relationships (lead: Maia Thornton)
- 3. Developing and evaluating an app to deliver an ACT-based intervention for adults with visible differences of any sort (lead: Fabio Zucchelli)
- 4. Developing a tool to identify individuals' needs & signpost to appropriate support (PhD student: Clare Clement)



# Workstream 2: Social Media

Lead: Dr Amy Slater

Research Fellow: Dr Ella Guest

PhD Student: Abbi Matthews

Interns











# Workstream 2: Social Media

### Research Objectives:

- To better understand the experiences of individuals with appearancealtering conditions using social media.
- To inform strategies that encourage safe and healthy social media use for individuals with appearance-altering conditions.
- To investigate how social media can be used to further promote acceptance of diversity of appearance in the general population.



# Workstream 2: Social Media

### Outcomes:

- The development of resources on 'How to navigate social media when you have a visible difference' for both adolescents and adults with a visible difference made freely available to Appearance Collective charities.
- The development of a resource 'How to use social media to promote acceptance of diversity of appearance" made freely available to Appearance Collective charities and the general public.
- The development of resources (e.g., short animations) aimed at reducing stigmatising attitudes and discriminatory behaviours from the general public towards those with visible differences.



# Example studies...

- 1. To understand how people with visible differences use social media in relation to their condition. Including:
  - how they portray themselves online,
  - their overall experiences,
  - how people with visible differences in general are portrayed on social media,
  - how social media could be best used to reduce stigma.

Individual interviews with adults and adolescents from February 2023

For more details: <a href="mailto:ella.guest@uwe.ac.uk">ella.guest@uwe.ac.uk</a>

2. Experiences of 'influencers' or individuals with large social media followings.



# General points

- Across condition (rather than condition specific)
- Evidence-based
- Timelines
- All leading to tangible outputs that benefit the charities freely available resources.



Support Survey results (these will be sent in a separate report when analysis is complete)



Examples of previous or existing CAR-Appearance Collective VTCT Foundation Small Grant Collaborations



# Benefits of collaborating

- Develop resources / carry out research that is relevant to your organisation and members
- Help meet your organisation's aims/priorities
- Ensure your work is evidencebased, acceptable and effective





# Eczema Outreach Support Eczema Self-Management Care Plan

- Ella Guest (CAR), Pippa Tollow (CAR), Di Harcourt (CAR), Christine Roxburgh (EOS), Suzi Holland (EOS)
- Self-management care plan to help families manage childhood eczema.
- Aims to help families feel more confident when managing their child's eczema and facilitate decision-making with health professionals (e.g., dermatologists, nurses, GPs)
- Developed with input from families and health professionals including online surveys, workshops, and feedback interviews.





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before your appointment

# my eczema care plan!

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ican the QR code eos.org.uk/care plan to get a new

### About this eczema care plan

This eczema care plan has been developed by Eczema Outreach Support (EOS) and the Centre for Appearance Research in collaboration with children with eczema, their parents, GPs, dermatologists, dermatology nurses, and health psychologists to help families feel more confident about looking after their child's skin.



### How are you?



This section is for parents to complete with their child at home. The faces are for children and the numbers are for parents.



Has eczema made your skin itchy in the past week? 1 = not itchy, 5 = very itchy	<u>:</u> : 1 2 3 4 5
Has eczema made it hard to sleep in the past week? 1 = not at all, 5 = very hard	<u>:</u> : 1 2 3 4 5
Has eczema affected your life (e.g., going to school, playing with friends, doing hobbies)?  1 = not at all, 5 = a lot	<u></u> • • • • • • • • • • • • • • • • • • •
Do you worry about how your eczema makes you skin look? 1 = not at all, 5 = a lot	<u>:</u> 1 2 3 4 5
What treatments do you like using?	
What treatments don't you not like using (e.g., cream that is greasy or stings)?	
My eczema tiggers are	l avoid them by









Complete this part with a health professional!

### My eczema treatment



moisturiser/ emollient, steroid)  where on body (e.g., face, arms, legs)?  whore on body (e.g., face, arms, legs)?  whore on body (e.g., face, arms, legs)?  whore on body (e.g., face, arms, twice a day)?  whore on body (e.g., face, arms, twice a day)?  whore on body leveryday)?  who fine (e.g., a handful)  luse (e.g., a handful)  brush my teeth)  who often (e.g., when I brush my teeth)  who often (e.g., when I brush my teeth)  who often (e.g., a handful)  who where on body legs (e.g., a) how much should luse (e.g., a) handful)  who often (e.g., b)  who where on body legs (e.g., a) handful)  who often (e.g., b)  who where on body legs (e.g., a) handful)  who often (e.g., b)  who where on body legs (e.g., a) handful)  who often (e.g., b)  who where on body legs (e.g., a) handful)  who often (e.g., b)  who where on body legs (e.g., a) handful)  who often (e.g., b)  who where on body legs (e.g., a) handful)  who where							
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Treating a flare	Steroid cream	Flare area (hands)	Once per day	flared. Usually 5-7	enough to cover		8
Treating a flare	Daily maintenance plan						
Next steps if things don't improve				Treating a flare			
Next steps if things don't improve							
Next steps if things don't improve							
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Next steps if things don't improve							
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\*Health professionals: if confidence is tess shown, ==, adapt this treatment to make it easier for the family to Lease Trouble Township To \*Health professionals: if confidence is less than 7/10,



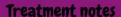








# My eczema care plan!







### Skin without flare

Moisturise and use soap substitute

Visit DFTB Skin Deep for more examples of eczema on different skin





### Flare up

Use moisturiser and flare cream









### Infected skin

Crusty, weeping skin. Speak to a health professional













# Top tips for managing eczema

### Use emollients & moisturisers

They are used to keep control of eczema and are very important. Most people with eczema will have to use them at least once a day. There are different types: creams, lotions, gels and ointments. Recent research shows one isn't better than the other, the most important thing is to work with your GP/Dermatologist to find one you like. Follow the Eczema Care Online (ECO) Golden Rules of using moisturisers.



### Use flare control creams

Steroid creams or Topical Calcineurin Inhibitors (TCIs) help get eczema under control and most people will need to use them at some point. A thin layer is usually applied once a day to the eczema flare area while the skin is flared, usually 5-7 days. They are safe if used as prescribed, but if you are concerned talk to your GP/Dermatologist. Follow the ECO Golden Rules of flare control creams.



### Recognising an eczema flare

A flare-up is where the skin is more sore or itchy than usual. In lighter skin, an eczema flare-up may make the skin look red. In darker skin, an eczema flare-up may make the skin look grey, purple, or brown. Look at the photographs on page 3 for examples of flares on different skin tones.



### **Recognising infection**

Sometimes you can see white or yellow blisters, or pus-spots under the skin. If you are concerned about a change in the skin, get in touch with your GP/Dermatologist and if possible, get a face-to-face appointment.



### Controlling the itch

Eczema can be very itchy, but there are things you can try to beat the itch. Tips like putting a cool gel pack on the itchy skin or using a fidget toy to keep hands busy instead of scratching can make a difference. For a list of tips to help beat the itch see the ECO website



Finding reliable information about eczema online can be difficult. These are a great place to start:

For information

For support

eczema.org

eczemacareonline.org.uk

skinhealthinfo.org.uk

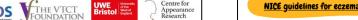
eos.org.uk













# Caring Matters Now Online Teen's Resource

- Ella Guest (CAR), Abbi Mathews (CAR), Bruna Costa (CAR), Jodi Whitehouse (CMN) & Hannah Cree (CMN)
- Online psychoeducational resource for adolescents with congenital melanocytic naevi (CMN) on Caring Matters Now's website.
- Developed in collaboration with adolescents with CMN.
- Self-guided intervention with option for support from Hannah Cree, Support Pathway Practitioner.
- Psychoeducational information, videos and toolbox.









Catch it, Check it, Change it



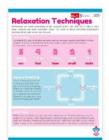
Fear Ladders



Plan a Response



REACHOUT



Relaxation Techniques



Supporting a Young Person with CMN



Teachers' Support Guide



Thinking Traps

### **MEED HELP?**

If you are struggling with this or would like some advice on how to use this resource, please contact our Support Pathway Practitioner, Hannah, who will be able to help you.

Email Hannah

### **SOCIAL SITUATIONS**

Question: what do you do when you feel like people are looking at you? How do you behave, how does it make you feel?

Sometimes, we all feel like other people are looking at us or judging us because of how we look. If you have CMN, that might involve being worried that people are noticing your birthmarks. Or, you might even have thought you saw people starting or talking about them. When that happens, it can make us want to hide away or avoid talking to or looking at the person.

People might react differently to those with visible differences (including CMN), and this might include:

- Staring
- · Unwanted questions and/or comments

# withy middly PEOPLE ACT LIKE THIS? Our minds are trained to assess anything we haven't seen before as a potential threat (remember the fight or flight response?). Because CMN may be new to someone, they

before as a potential threat (remember the fight or flight response?). Because CMN may be new to someone, they might do a 'double take' or look for a longer period of time to make sure this 'new thing isn't a threat to either you or them. If they realise that they have been starring, they will likely feel embarrassed about their reaction.

Understandably, these reactions from others can make

Understandably, these reactions from others can make people feel uncomfortable, awkward or worried about social situations.

If we feel worried about these problems or about the way that we look, it can cause us to appear anxious, selfconscious or distracted when in social situations. For example, we might be quiet, avoid eye-contact and have closed body language (like having our arms crossed or looking down). When this happens, we can appear unfriendly or uninterested to other people.



Remember the Hot Cross Bun/CBT model? Take a look below to see how this interaction might take place. If you want to find out more about the hot cross bun model, please click here.









# Headlines survey and support resources

- Bruna Costa (CAR), Nicola Stock (CAR), Wendy Edwards (Headlines), Karen Wilkinson-Bell (Headlines)
- Survey assessing psychological wellbeing in adults and parents with craniosynostosis which led to booklet and video for parents.
- Co-producing online support resources for adults (ACCORD study).



# My baby has craniosynostosis:

A parent's guide to managing a diagnosis





# Vitiligo Support UK Social Media Evaluation

- Ella Guest (CAR), Amy Slater (CAR), Georgia Treneman-Evans, Emma Rush (Vitiligo Support UK)
- Developed educational Instagram posts about vitiligo with members of the charity.
- A randomised controlled trial found viewing the account increased knowledge of vitiligo and decreased stigma towards appearance-altering conditions.







# Alopecia UK

- Nick Sharratt and Fabio Zucchelli (CAR) & Jen Chambers (Alopecia UK)
- Two-year project to learn more about the experiences and support needs of men with alopecia.
- Their findings, which overall paint a picture of men experiencing alopecia in a distinct way to women, were used by Alopecia UK to update and create tailored resources for men.







## Children's Burns Trust

- Pippa Tollow (CAR), Maia Thornton (CAR), Jo Myers (Children's Burns Trust).
- Evaluation of 3 family weekends held in 2022
- Parents completed an online feedback survey after they attended the weekend at 10 weeks follow-up
- Staff completed an online feedback survey after attending the weekend

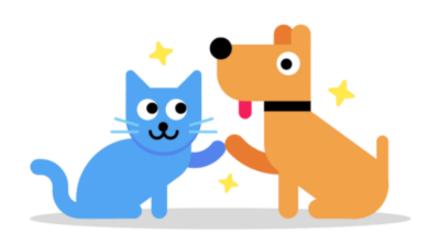






# **Small Group Discussions**

- What are the benefits of collaborations?
- What are the benefits of collaborations for your organisation?
- How could collaborating on a project help you meet your organisation's aims?
- What would the collaboration involve?





# What does success look like?

2 x rounds of Breakout groups

### Round 1

What does success look like for each of your organisations in terms of outcomes, and how could we reach these?

Feedback to whole group

### Round 2

What might the barriers be and how we might overcome these together?

Feedback to whole group



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# Save the date!!!

Next workshop:

Wednesday 24th May 2023, online

Support for parents of children with visible

differences

Led by Maia





Final comments & questions

 Feedback – survey link in your email later today

Thank you!



## **Further information:**



www.uwe.ac.uk/car



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@AppearanceResearch



@car\_uwe



Appearance Matters: The Podcast



CAR@uwe.ac.uk



