



Centre for Appearance Research

Moving forward Collectively: Looking ahead to Research with Impact

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

19th 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.

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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

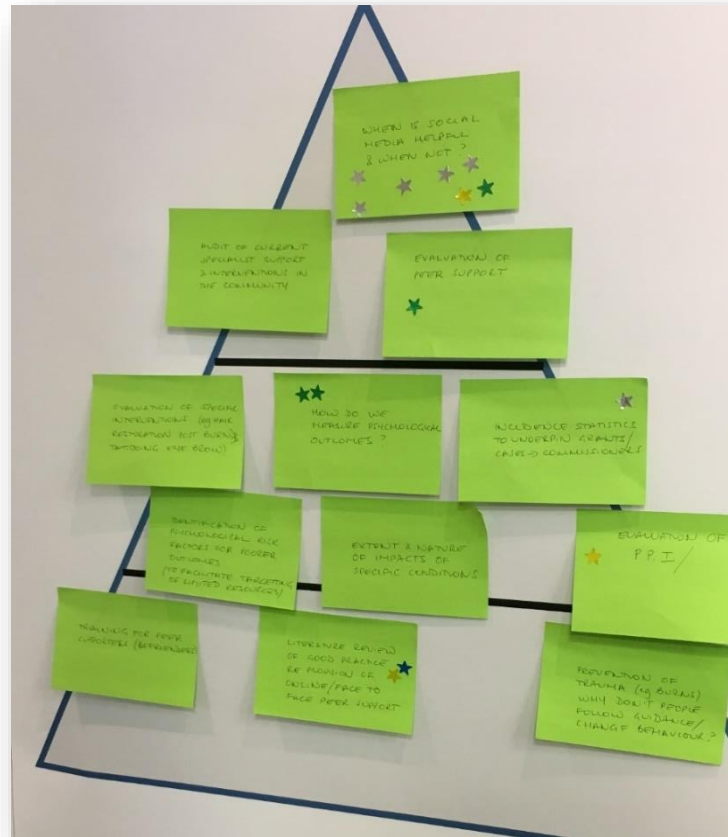
- Working with the Appearance Collective to provide effective support for people with visible differences.
- Support the career development of researchers in this field



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Priority setting exercise (summer 2017)



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The priorities:

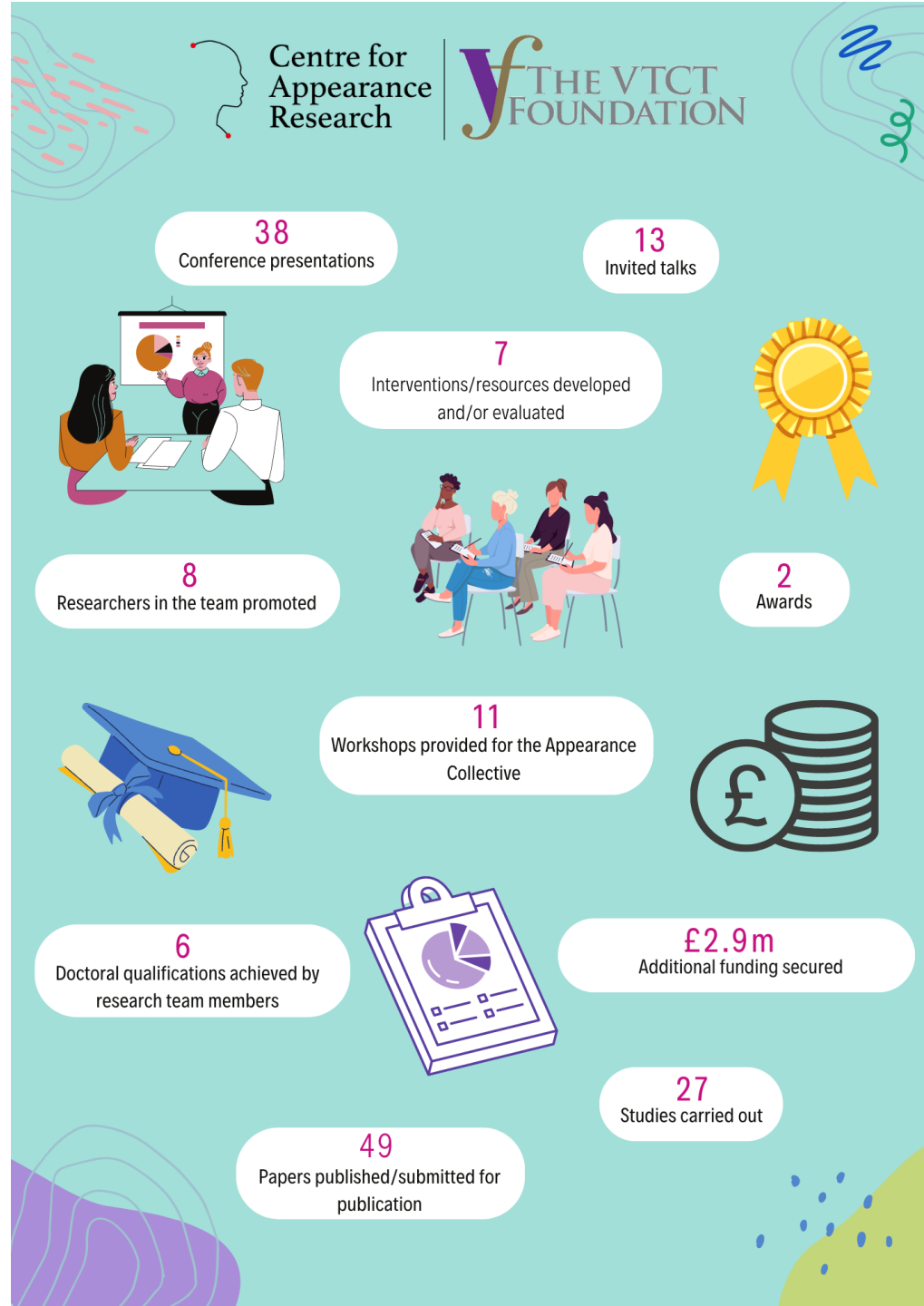
1. **Social media** & social media literacy
2. Support & interventions to promote **acceptance of diversity**
3. The incidence & **experience** of visible difference
4. Support throughout the **treatment journey**
5. **Assessment tools** to capture the patient experience/outcomes
6. **Interventions** for people adversely affected by visible difference
7. **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**)



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- 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



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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



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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.



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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)



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Workstream 2: Social Media

- Lead: Dr Amy Slater
- Research Fellow: Dr Ella Guest
- PhD Student: Abbi Matthews
- Interns



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Workstream 2: Social Media

- **Research Objectives:**

- To better understand the experiences of individuals with appearance-altering 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.



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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.



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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: ella.guest@uwe.ac.uk

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



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General points

- Across condition (rather than condition specific)
- Evidence-based
- Timelines

- All leading to tangible outputs that benefit the charities – freely available resources.



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



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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 evidence-based, 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.



My eczema care plan!

Treatment notes





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

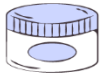
Crusty, weeping skin. Speak to a health professional



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

eczema.org

eczemacareonline.org.uk

[NICE guidelines for eczema](#)

skinhealthinfo.org.uk

For support

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.

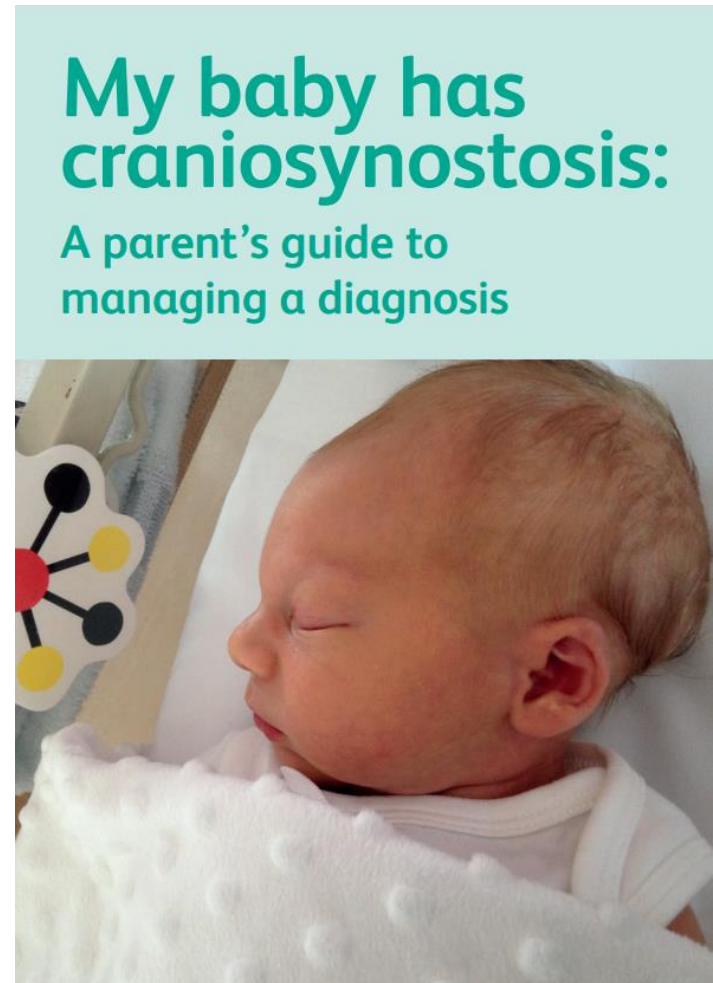


Headlines survey and support resources

- 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).

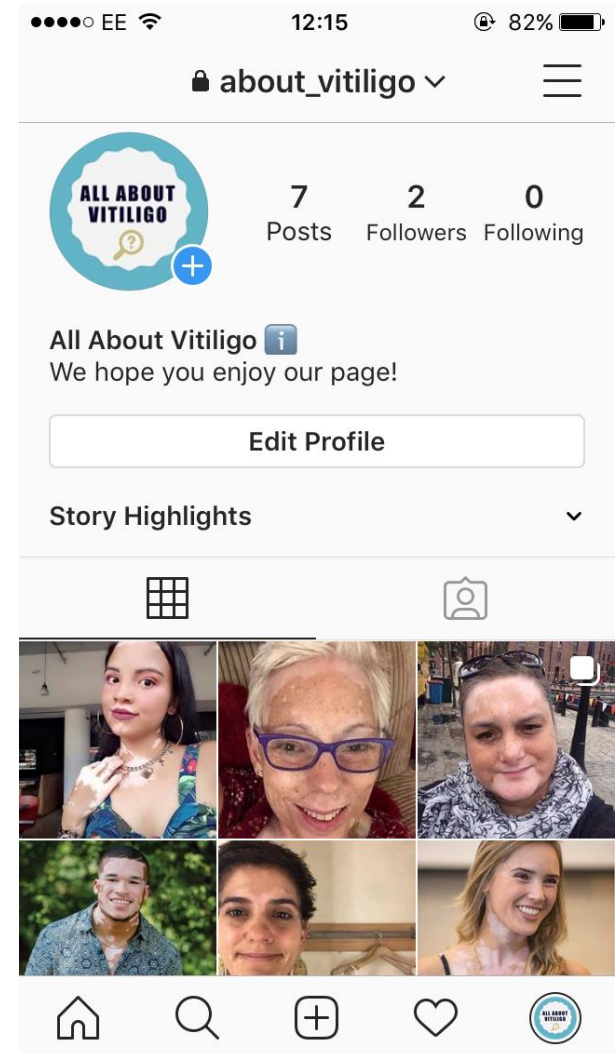


Headlines
Craniofacial Support



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



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- Final comments & questions
- Feedback – survey link in your email later today
- **Thank you!**



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Further information:



www.uwe.ac.uk/car



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Appearance Matters: The Podcast



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