



Centre for Appearance Research

Translating Visible Difference Research into Practice

The VTCT Foundation Research Team
at CAR

VTCT Foundation Showcase
14th July 2023

The VTCT Foundation Team at CAR



Di Harcourt



Amy Slater



Alex Clarke



Paul White



Rosie Thomas



Wyld Robert-Mills



Ella Guest



Maia Thornton



Pippa Tollow



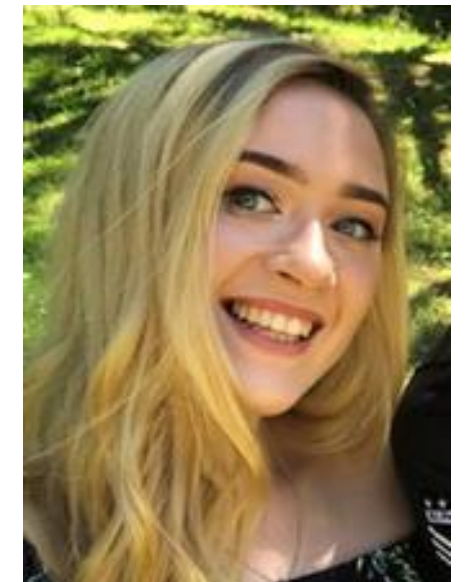
Fabio Zucchelli



Clare Clement



Abbi Mathews

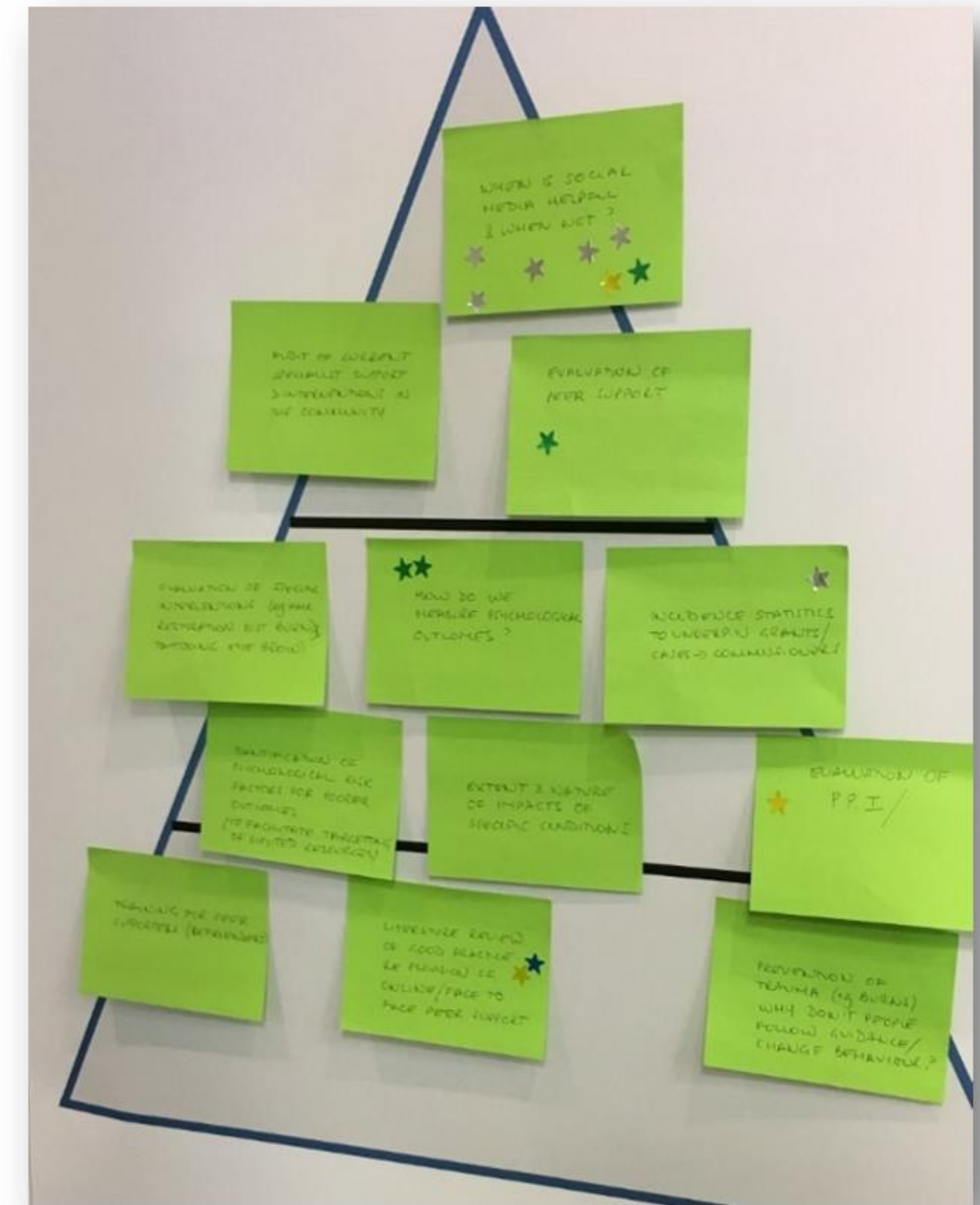


Christia Huntington

Building on Stage 1 (2017 – 2022)

Priority setting in May 2017

1. The impact of social media
2. Interventions to promote acceptance of diversity of appearance
3. The incidence & experience of visible difference
4. Support during the treatment journey
5. Assessment tools
6. Interventions for people who are adversely affected
7. Training materials
8. Motivation of volunteers
9. Patient and public involvement (PPI)



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8. Motivation of volunteers
9. Patient and public involvement (PPI)

- **27** studies carried out
- **49** papers published/submitted
- **11** workshops provided
- **7** interventions/resources developed and/or evaluated
- **13** invited talks
- **38** conference presentations
- **2** awards
- **6** doctoral qualifications achieved
- **8** researchers promoted

- Additional grants from a range of funders to build the capacity in this field further

Stage 2: 2022-2026

Appearance Collective charities' priorities (Feb 2021)

- Support & interventions
- Social media
- Under-represented groups
- Virtual/online support
- Promoting acceptance of diversity in the general population
- Supporting treatment decision making
- Impact of COVID on the visible difference community
- Enhancing the role of the Appearance Collective
- Generic vs condition-specific issues & support

Appearance Collective charities' priorities (Feb 2021)

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Appearance Collective charities' priorities (Feb 2021)

- **Support & interventions**
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 - Impact of COVID on the visible difference community
 - Enhancing the role of the Appearance Collective
 - Generic vs condition-specific issues & support
- } Focus of 2 workstreams for 2022-2026

Progress to date:

- Team in place
- Meetings w collaborators including health economics
- 2 workshops:
 - working collaboratively to achieve impact (Jan 2023)
 - supporting parents of children with visible differences (May 2023)
- 5 events hosted by Appearance Collective charities
- 11 academic conference presentations
- 9 papers published
- Participant pool continued to grow (>700)
- Newsletter (July 2023)
- Funding applications submitted for new projects
- Supervising UWE student research & placements in this field



Workstream update: Social Media

The Team



**Lead
Dr Amy Slater**



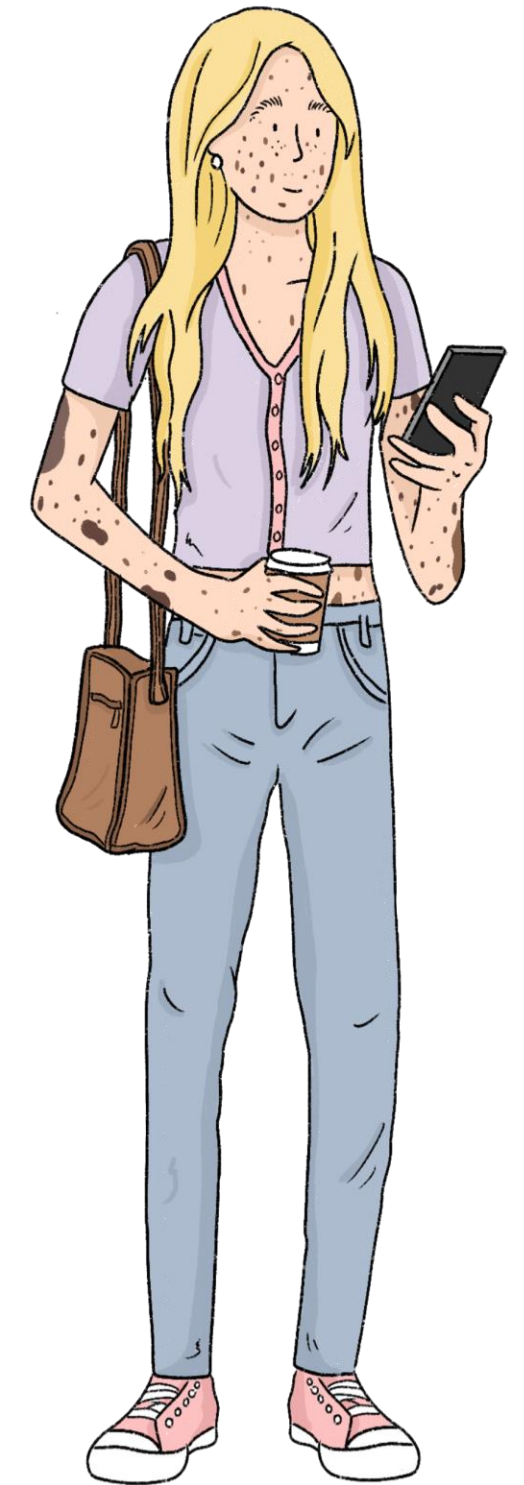
**Senior Research Fellow
Dr Ella Guest**



**PhD Student
Abbi Mathews**

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.



Illustrations by Celyn Hunt

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.



Illustrations by Celyn Hunt

Research Studies

Year 1 – Understanding the Experiences of Adults

- Photo-elicitation interviews with 20 adults with visible differences.
- Used to explore their experiences of using social media.

Year 2 – Understanding the Experiences of Children and Young People

- Photo-elicitation interviews with children and 20 young people with visible differences.
- Used to explore their experiences of using social media.

Year 3 – Understanding the Experiences of Influencers

- Photo-elicitation interviews with 20 social media influencers with visible differences.
- Used to explore their experiences of using social media to educate and raise awareness of visible differences.

Research Studies

Year 1 – Understanding the Experiences of Adults

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Year 2 – Understanding the Experiences of Children and Young People

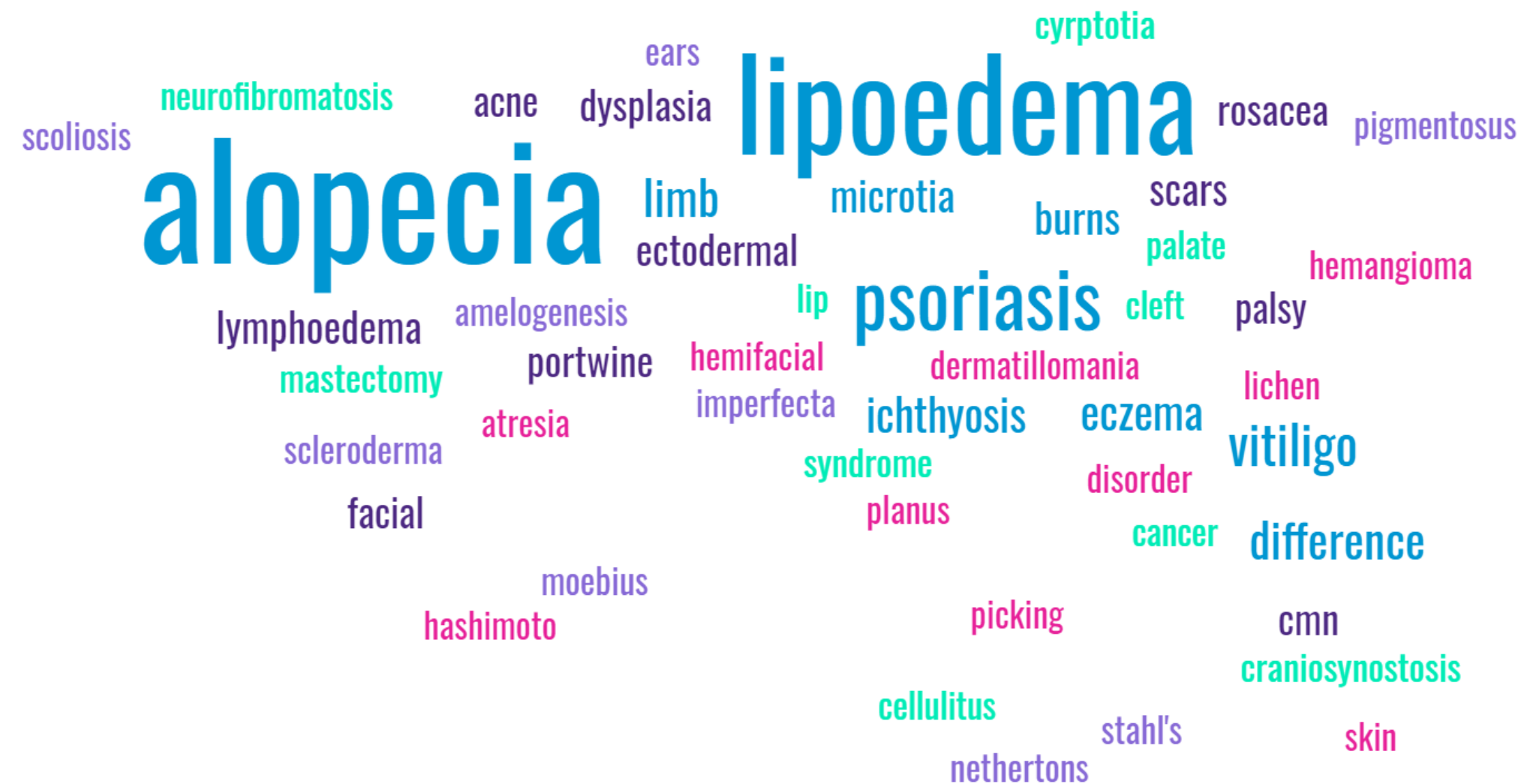
- Photo-elicitation interviews with children and young people with visible differences.
- Used to explore their experiences of using social media.

Year 3 – Understanding the Experiences of Influencers

- Photo-elicitation interviews with social media influencers with visible differences.
- Used to explore their experiences of using social media to educate and raise awareness of visible differences.

Study 1- Experiences of Adults

- Advertised via Appearance Collective charities.
- 326 adults, with 37 conditions, signed up.
- Invited one person per condition to take part (spread of ages, genders, ethnicities, and sexual orientations).
- To enable as many people as possible to share their experiences, we put in an ethics amendment for an online qualitative survey.



Study 1- Experiences of Adults

- Currently carrying out interviews.
- Topic guide includes questions relating to how they use social media, positive and negative aspects, how it can be used to raise awareness of visible differences and reduce stigma.
- Participants also asked to discuss social media posts (photo-elicitation):
 1. A post that you feel is typical of what YOU post of social media.
 2. A post that you feel is less typical of what YOU post on social media (not your usual style of post).
 3. Your FAVOURITE post on YOUR social media account.
 4. Please select a photo/post from YOUR account OR from ANOTHER account that you think shows a POSITIVE representation of appearance-altering conditions.
- Reflexive thematic analysis (Braun & Clarke, 2020) being carried out to identify common experiences of using social media as an adult with a visible difference.

**Survey includes similar questions, but participants are not asked to discuss photographs.*

Research Studies

Year 1 – Understanding the Experiences of Adults

- Photo-elicitation interviews with adults with visible differences.
- Used to explore their experiences of using social media.

Year 2 – Understanding the Experiences of Children and Young People

- Photo-elicitation interviews with children and young people with visible differences.
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Year 3 – Understanding the Experiences of Influencers

- Photo-elicitation interviews with social media influencers with visible differences.
- Used to explore their experiences of using social media to educate and raise awareness of visible differences.

Study 2 – Photo-elicitation interviews with children and young people

- Ethical approval received.
- Patient and public involvement used to develop topic guide and study documents.
- Recruitment will take place later in summer.



PhD research – Using social media to reduce stigma towards visible differences

- Abbi started October 2022
- Ethical approval for study 1 received.
- Experimental study looking at the impact of following an influencer with a visible difference on Instagram.

Abbi.Mathews@uwe.ac.uk



Rationale and theory

- People with visible differences are subject to societal stigma from the general public, which can cause, maintain and exacerbate psychosocial problems.
- One method to reduce stigma includes **intergroup contact** with members of the stigmatised group.
- Recent research suggests this contact can be **parasocial** i.e., imagined, for example through watching a television character or social media influencer.

Methods

- A social media profile will be made by an influencer with a visible difference, including images and videos, using evidence-based methods to create a **parasocial bond**.
- Participants will be randomly allocated to view this content, or a matched control, during a 30-minute session once a week for 3 weeks.
- Participants will fill out **questionnaires assessing attitudes** towards visible differences, body esteem and conceptualisation of beauty.

Workstream update: Support & interventions

The Team



Lead
Prof Di Harcourt



Senior Research Fellow
Dr Fabio Zucchelli



Research Fellow
Dr Maia Thornton



Senior Research Fellow
Dr Pippa Tollow



PhD Student
Clare Clement



Clinical Psychologist
Prof Alex Clarke



Statistician
Prof Paul White

Research Objectives

- To conduct a range of studies using a variety of methods to examine the **effectiveness of a portfolio of interventions** offering support to people whose lives are affected by visible difference.
- To **implement effective interventions** through appropriate charitable organisations and clinicians.
- To collect **evidence of the impact** of these interventions

Survey of support needs & preferences:

Sample:

- 550 adults (489 female) aged 18-82yrs
- 43 parents/carers
- Range of conditions/injuries

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What are the support needs, and preferences for the delivery of support, of adults impacted with a visible difference?

In 2022 a team at the Centre for Appearance Research (CAR), conducted an online survey that was completed by **593 people** with a visible difference (550 adults and 43 parents/carers of children and young people with a condition or injury that impacts on appearance). This is a summary of what we learnt from **550 adults** who told us they had a visible difference.

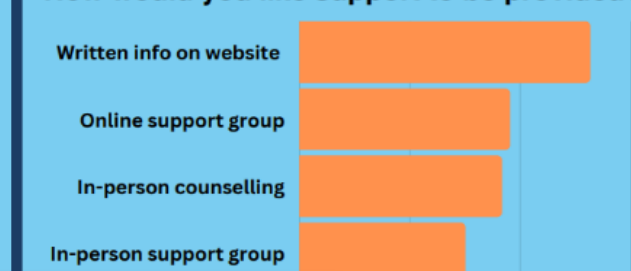


Ages 18 - 82

What would you like support with?



How would you like support to be provided?



Survey of support needs & preferences:

Sample:

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- 43 parents/carers
- Range of conditions/injuries

Support wanted around:

- Accepting appearance
- Information about treatment & causes
- Confidence & self esteem
- Body image
- Talking to others about appearance & managing reactions
- Managing social situations
- Intimacy & romantic relationships
- Employment/education issues
- Social media (using it positively & managing negativity)

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Wanted support via:

- Info on websites
- In-person counselling
- Phone/online counselling
- Online support groups
- Printed information/leaflets
- Self help books
- Residential weekends
- Podcasts
- Apps
- Videos
- Health professionals

What is important when accessing support?

1. That it is specific to my condition
2. That it is evidence based*
3. That the provider is reputable*
4. The location
5. The cost
6. The format
7. Accessibility

*ranked in reverse order by Parents/carers

- Summary infographics sent to Appearance Collective charities
- Further analysis in progress
- Paper in preparation

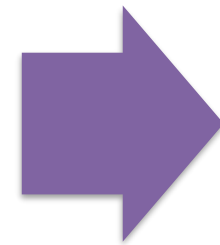
CREATING AN EVIDENCE-BASED TOOL TO IDENTIFY THE SUPPORT NEEDS OF ADULTS AFFECTED BY VISIBLE DIFFERENCES (TIDES)



CLARE
CLEMENT, PHD
PROJECT

Background and aim

People with a visible difference can experience negative psychosocial impacts without adequate support.



There are many ways in which people with visible differences can be supported.



However, currently, there is no way to identify adults' support needs.

The PhD aims to develop a user-focused tool to identify the support needs of individual adults with visible differences and the level of support required.

How will the tool be developed?

Phase 1 – identifying what people's support needs are

- Interviews and focus groups to find out about people's experiences with having a visible difference and support needs.
- Support needs survey
- Literature – what's been found before?

Phase 2 – developing the tool with service users

- A series of workshops with adults with a visible difference and support providers to develop a tool in partnership with the researcher.

Phase 3 – assess acceptability and usability

- People using the tool and providing feedback to the researcher about their experiences and thoughts about it.

How can I find out more?

Contact Clare at
clare.clement@uwe.ac.uk
or 07902246225

Follow the study on
Twitter @tidesstudy

Dr Fabio Zucchelli

Senior Research Fellow



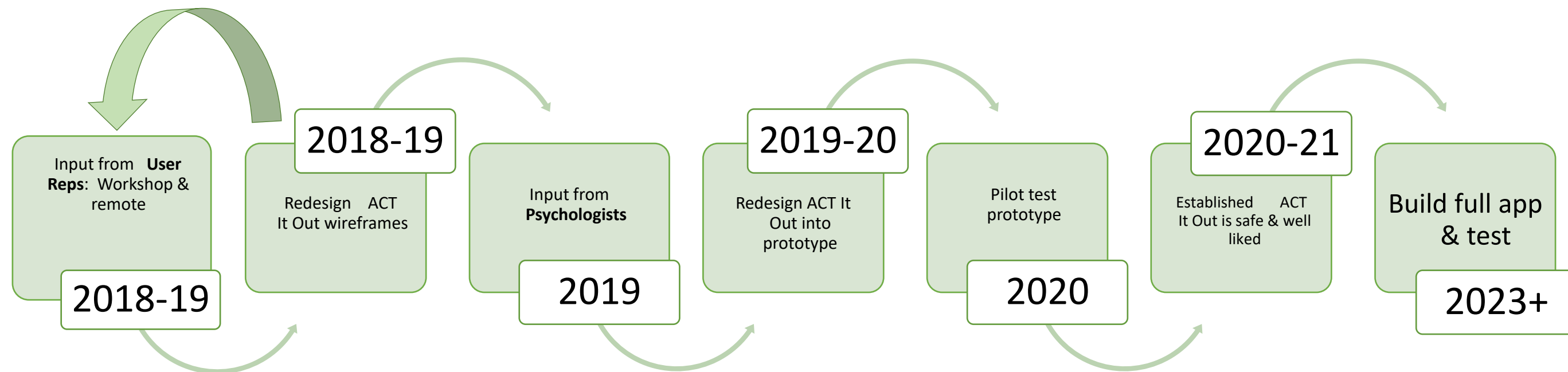
Long-term aim



Develop an openly available, standalone mobile app based on ACT to support quality of life in adults with visible differences who are affected by appearance distress

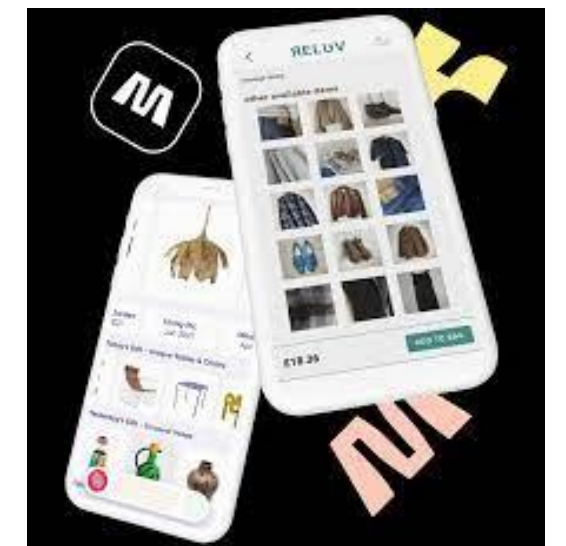
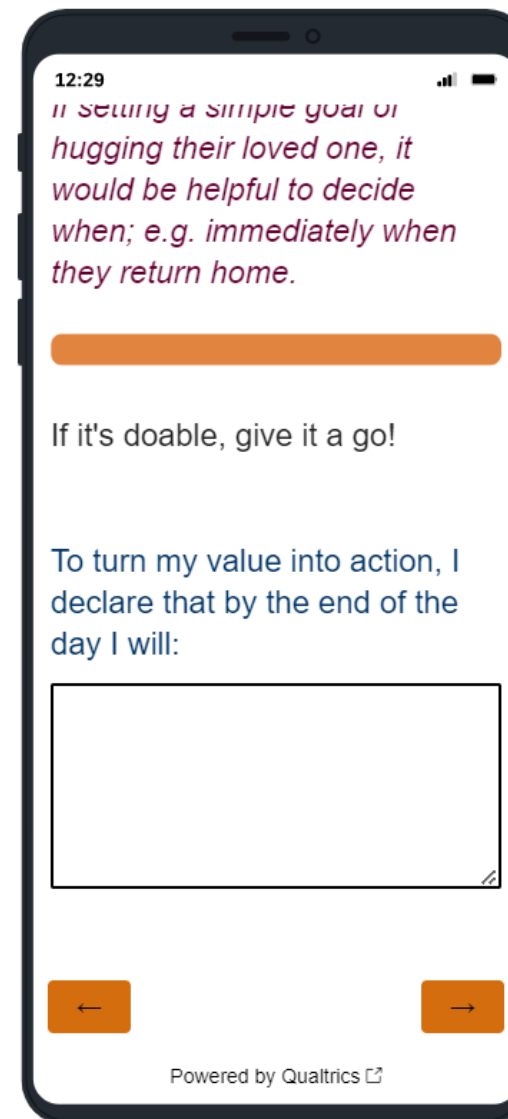
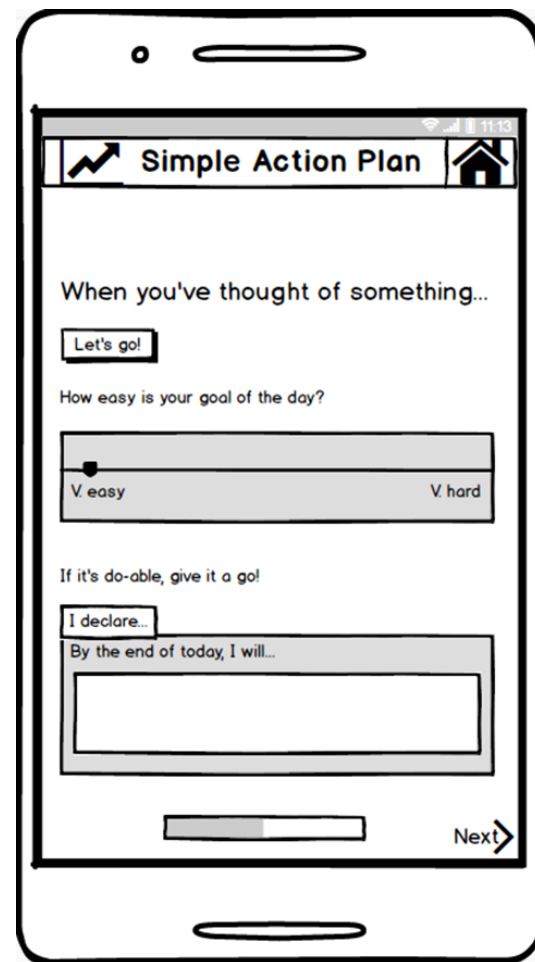
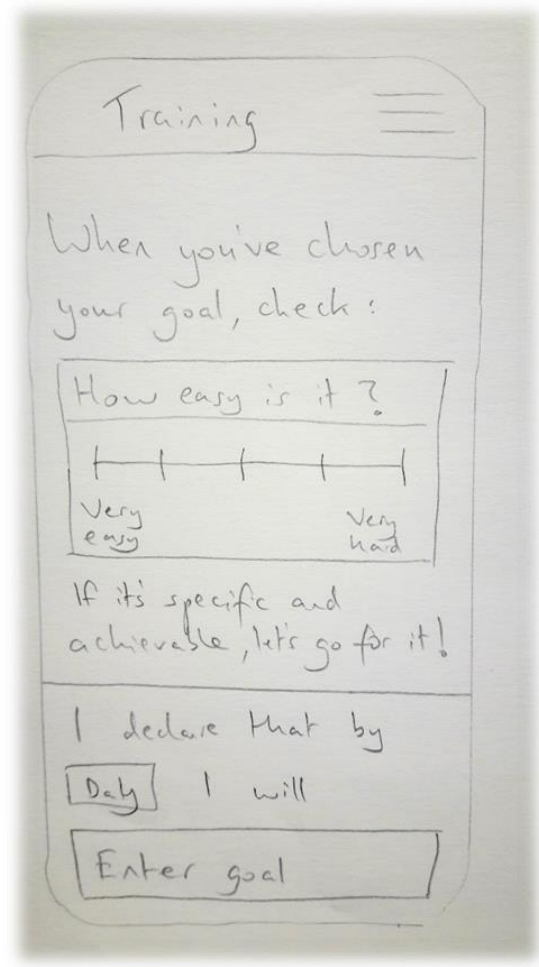


Project Lifecycle





Look different, Live well.
A mobile guide



Dr Maia Thornton

Research Fellow

Intimacy and romantic relationships

No psychosocial support focussed specifically on intimacy and romantic relationships.

Clinical and expert advisor consensus:

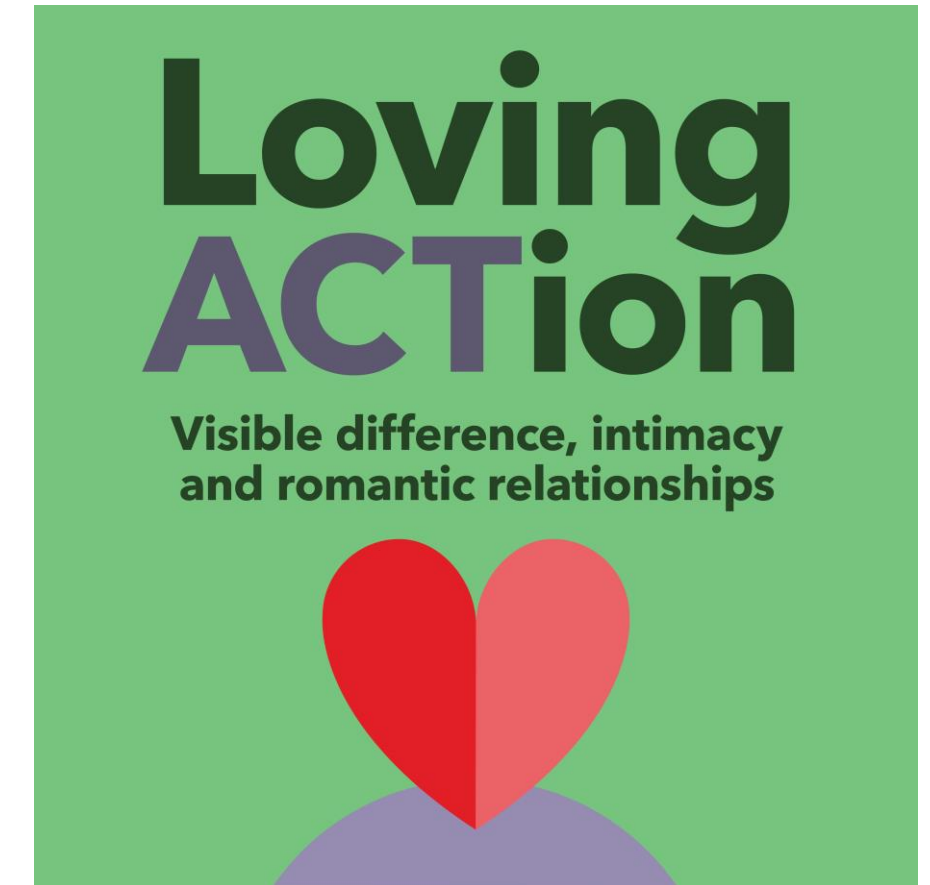
- Acceptance and Commitment Therapy
- Appearance-related concerns
- Social withdrawal and associated behaviours

An evidence-based series of podcast episodes.

Developed and produced alongside adults with lived experience.

Topics including:

- Appearance-related concerns in relationships
- Disclosure of visible difference
- Communication in relationships
- Being present in relationships
- Values in relationships



Loving ACTion

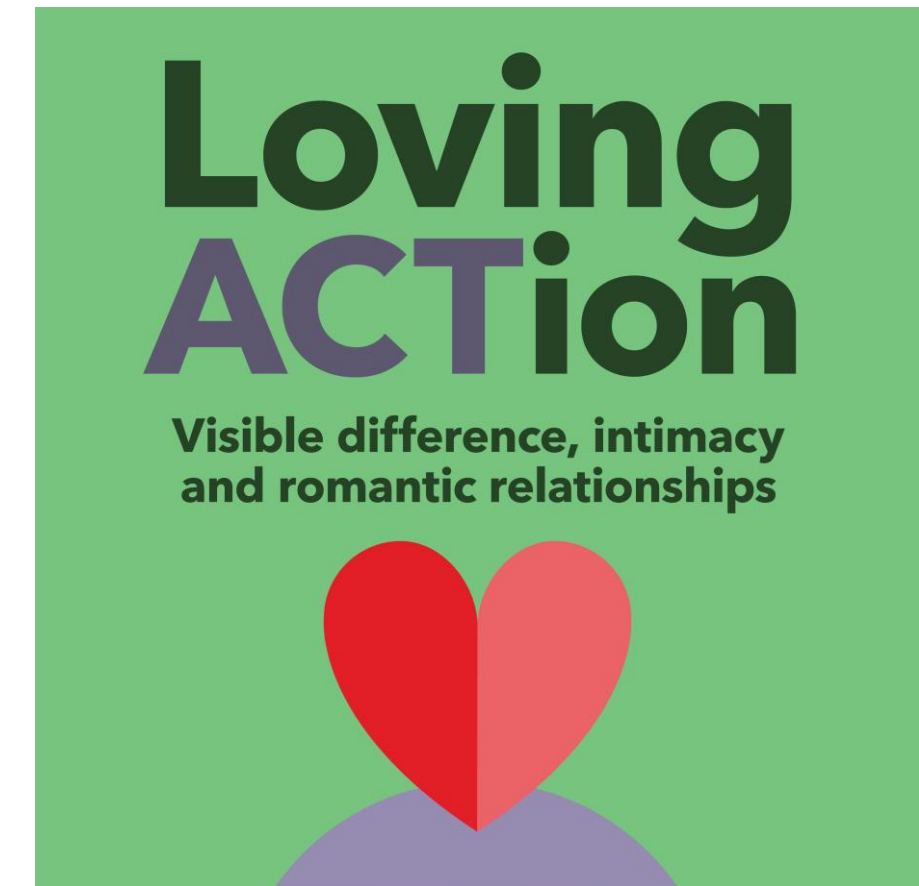
Initial feedback from 22 adults

- Podcast series addressed an important gap in support
- Provided skills to manage own thoughts, feelings, and concerns related to intimacy and romantic relationships
- Enjoyed the podcast format.

Evaluation of Loving ACTion due to begin 2023.

Looking for user representatives to advise, adults with lived experience.

Email Maia.Thornton@uwe.ac.uk for more details.



The Parenting Toolkit

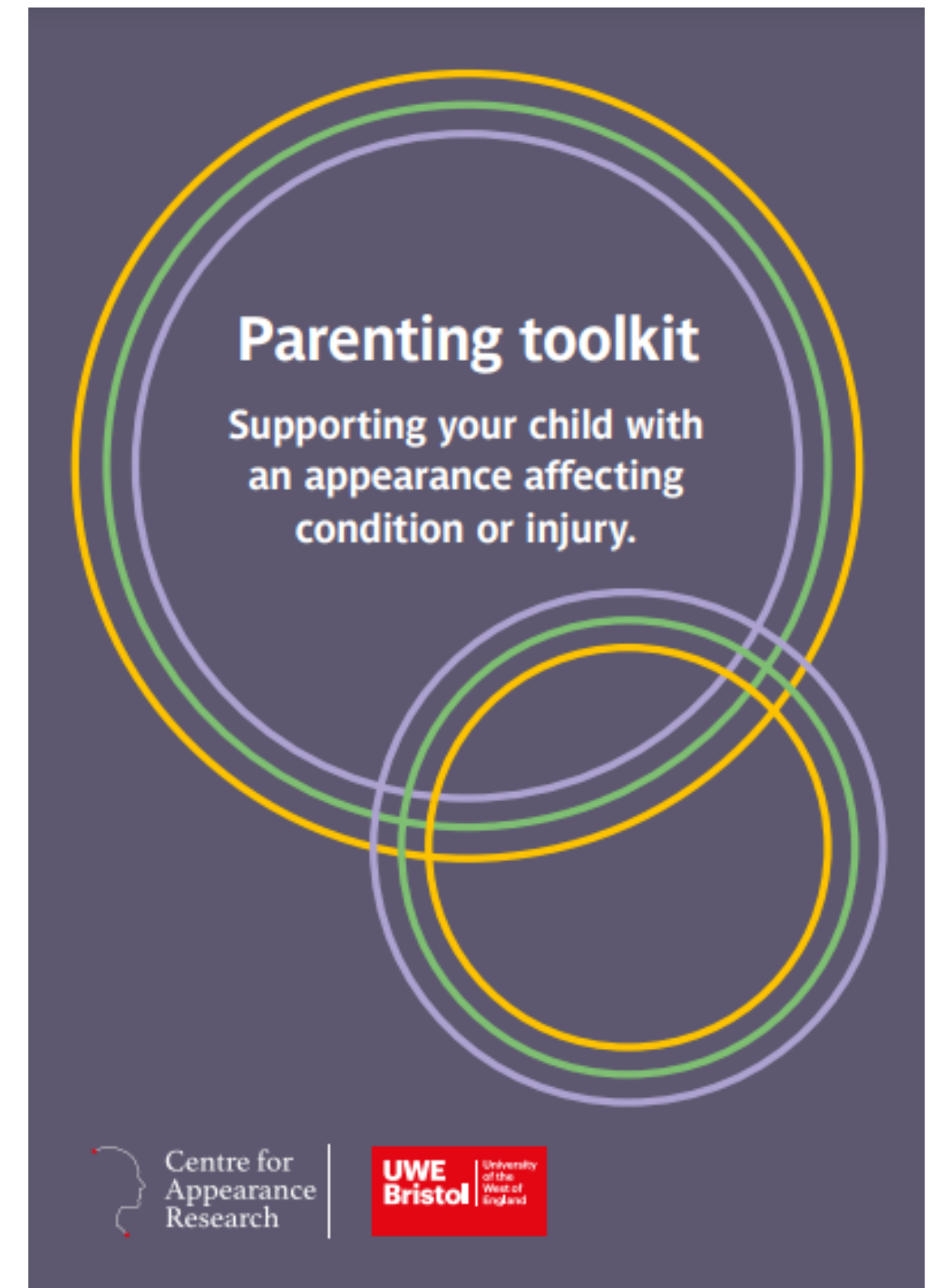
Working alongside parents with lived experience and clinical advisors

The Parenting Toolkit is an evidence-based e-workbook intervention aimed at promoting psychosocial adjustment in parents of children with a visible difference.

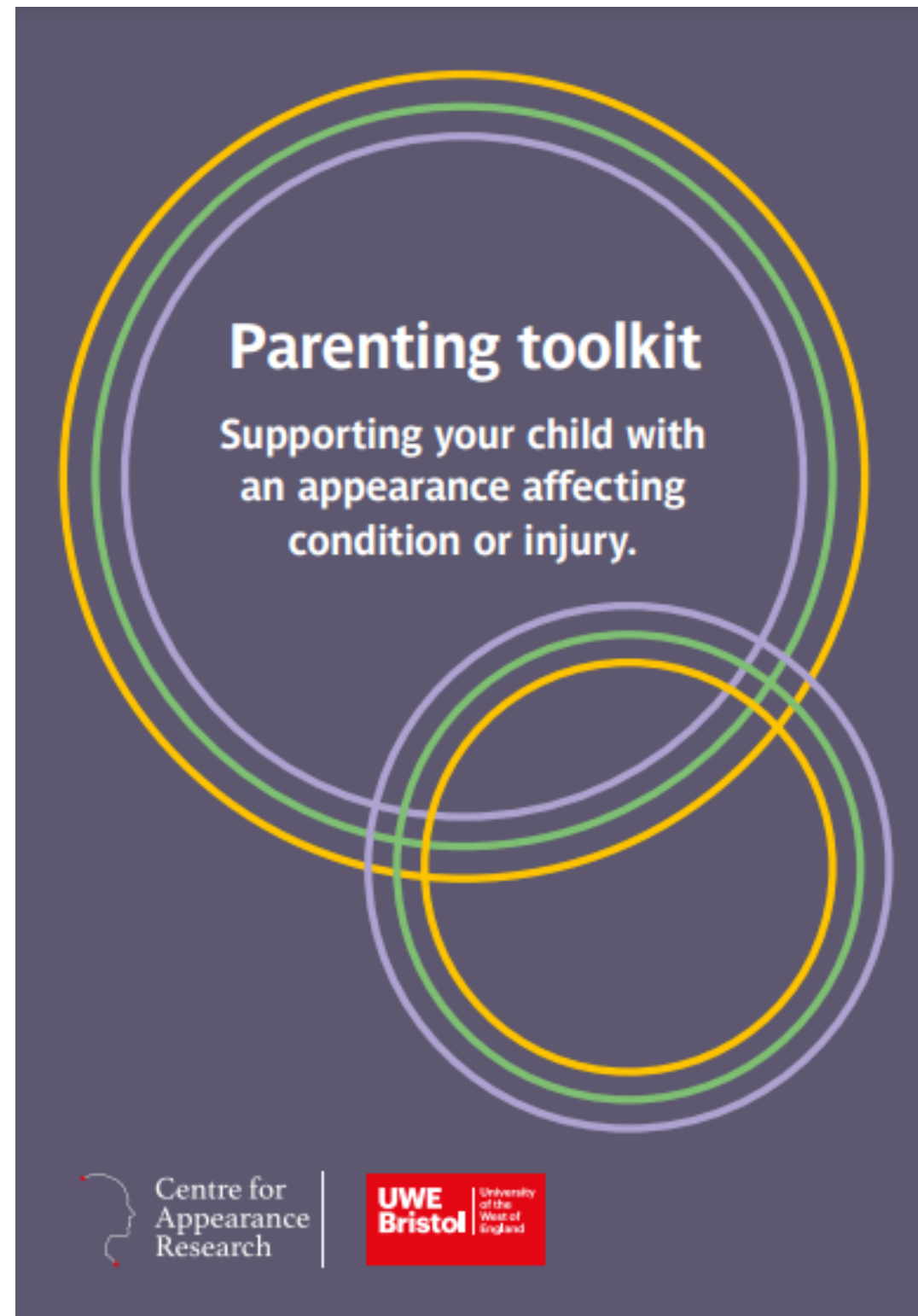
Section 1: Managing difficult thoughts and feelings for parents.

Section 2: Practical advice and guidance to help parents support their child

- Managing reactions of others
- Talking to your child and others
- Managing appointments
- Advocacy for your child



The Parenting Toolkit



Knowing your values

My values, doing what is important to me and my family

As we discussed earlier on, we want to be able to act in a way that is in line with what is important to us in life.

When we are at the crossroads where we make decisions about how we behave, it is helpful to know what is important in family life. For example, what matters to you as a parent and a family? Is it quality time together? Or being able to speak and share things openly? Or taking part in shared interests or hobbies?

Whatever it is that is important to you as a parent, we hope that this toolkit will help you to move in the direction of these values.

What are values?

Values are our deepest desires for how we want to act, how we want to treat ourselves, others, or the world around us. Values can be described in one word e.g. **loving, caring, fairness, enthusiasm, honesty**. Or in a sentence: "I want to live my life with courage and kindness", or "I want to prioritise those I love, or I want to act with loyalty or courage."

Values are not surface-level qualities like attractiveness, you cannot act with attractiveness. Nor are they feelings like happy or relaxed, because it's much easier to choose how to act than how to feel.

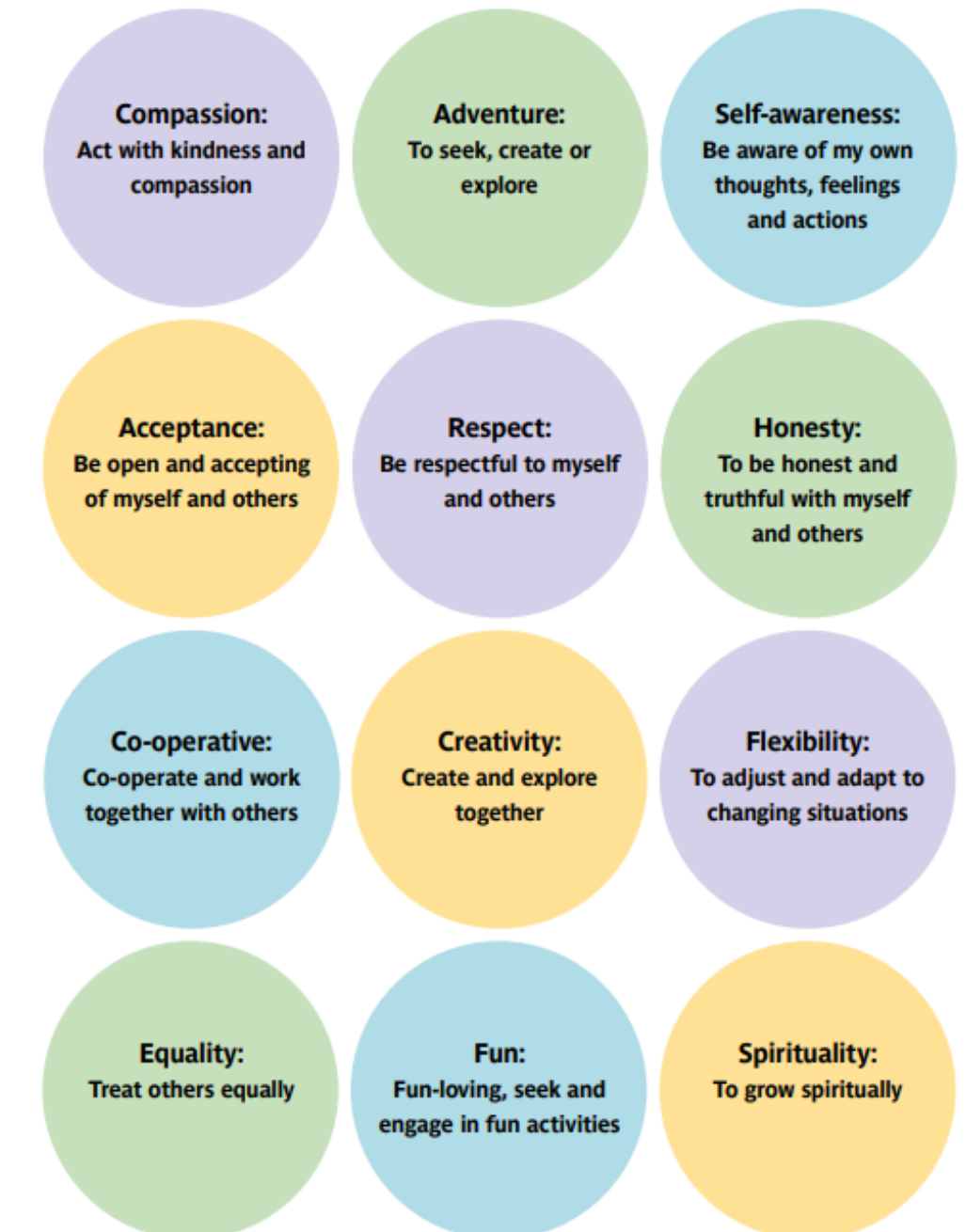
Think back to your journey on the bus. When you are driving your bus, your values act as a compass, or SatNav, that we can use to direct us in life.



To figure out what is important to you and your family, it might be helpful to spend a bit of time thinking about this and completing the values exercise on the next page.

Exercise: What is important to me and my family?

Take a look at the values below. Are there any that represent what is important to you and your family? Select the ones that you feel are important. There is also space to add your own values on the next page, so you can pick some of the examples or come up with your own.



Initial feedback

22 parents

- Content was relevant and they identified closely with the topics
- Presentation and layout was clear and accessible

Participants rated their overall experience with The Parenting Toolkit as either **“Good”** (32%) or **“Very good”** (64%)

Participants said they would be either **“Likely”** (18%) or **“Very likely”** (78%) to recommend The Parenting Toolkit .

“I thought it was completely at the right level - no jargon or wording I didn't understand and also not condescending.”

“This would be a favourite, long time resource for us”



Next steps

How effective is The Parenting Toolkit at supporting parents?

- Full access to The Parenting Toolkit
- Questionnaires before and after receiving the toolkit
- Option to take part in an interview to discuss experiences of using The Parenting Toolkit
- Email Maia.Thornton@uwe.ac.uk for more information



Online support for people affected by burn injuries

Partnership PhD funded by
The VTCT Foundation in partnership with
UWE, Bristol

- PhD student: Christia Huntington
- Supervisory team: Prof Di Harcourt, Dr Pippa Tollow, Dr Catrin Griffiths, Dr Toity Deave
- Collaborators: Dr Abi McNiven, Prof Sue Ziebland, Ruth Sanders, Health Experiences Research Group,

University of Oxford
- Adam Barnett, DiPEX charity

PSYCHOSOCIAL CHALLENGES AND SUPPORT



Psychological effects

Including depression, anxiety, and PTSD.



Wider social effects

e.g. perceived stigmatisation.



Support may include...

CBT, DBT, ACT, relaxation, mindfulness, practical skills, EMDR, peer support, and building social interaction skills.



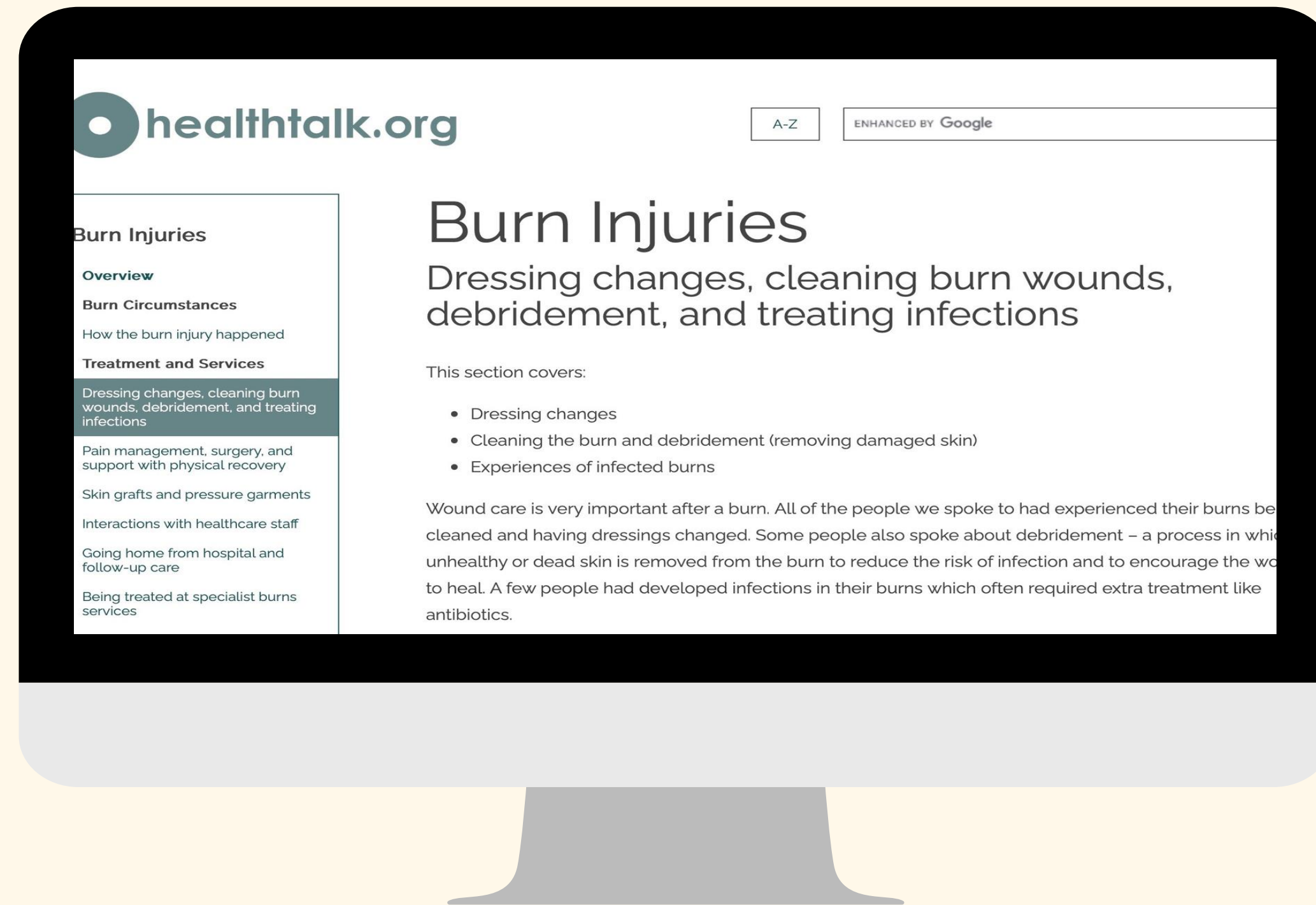
Difficulties providing psychosocial care

Though the importance of psychosocial support is widely accepted, there can be barriers to accessing/providing it.



Study 1:

To explore the lived experience of people affected by burn injuries and use the data to create a burn-specific web resource on Healthtalk.org



UWE
Bristol

Centre for
Appearance
Research

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WHO WAS INTERVIEWED?

- 37 people
- 10 males ♂ 26 females ♀
- 12 parents (9 mothers & 3 fathers)
- Aged 12 – 68 yrs
- 12 burnt as an adult (7 female & 5 male)
- 13 burnt as a child (10 female & 3 male)
- A range of types & size of burn, and length of time since burn
- Diversity within the sample was a priority



Themes from the interview data

1

Burn Circumstances

2

Treatment and Services

3

Living with a Burn

4

Adjusting to Life with a Burn

5

Information and Support

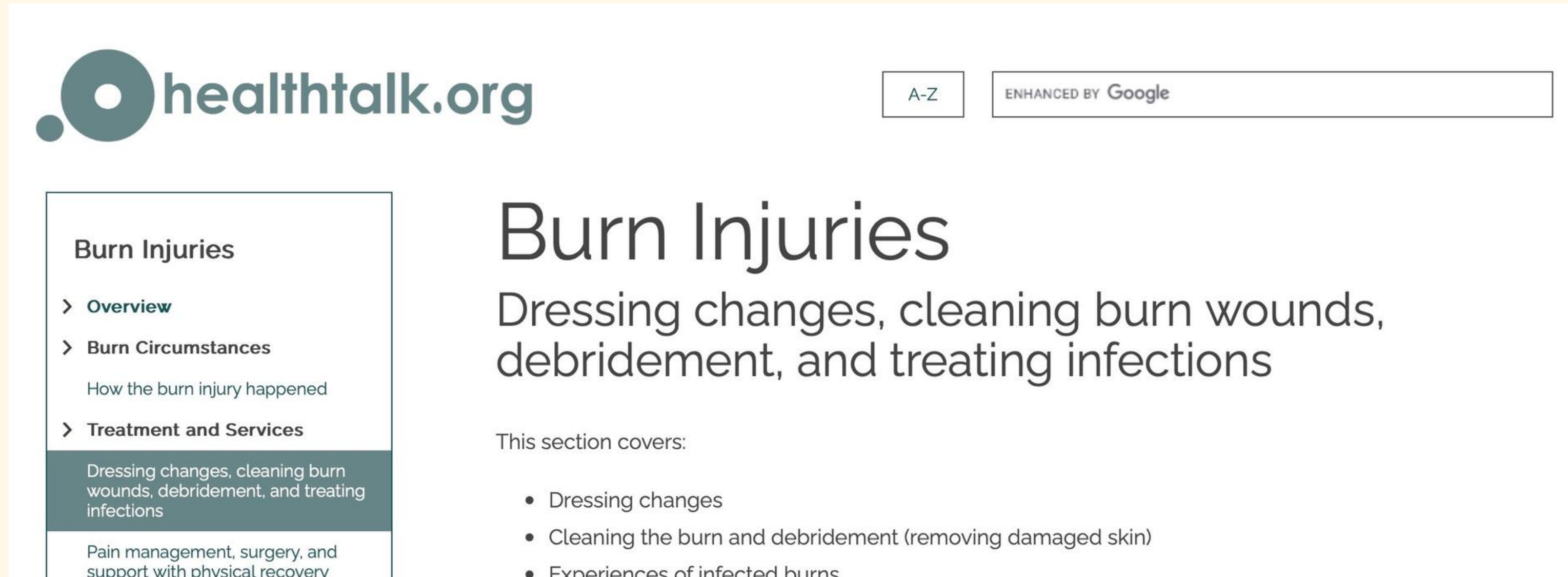
**UWE
Bristol**

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The Burns Healthtalk website

contains >180 video clips of people sharing their experiences of burn injuries.



The screenshot shows the Burns Healthtalk website interface. At the top left is the healthtalk.org logo. To the right of the logo is a search bar with the text "A-Z" and "ENHANCED BY Google". Below the logo, on the left, is a sidebar menu titled "Burn Injuries" with three main categories: "Overview", "Burn Circumstances", and "Treatment and Services". The "Treatment and Services" category is highlighted in a dark teal box. Below this category, there is a description: "Dressing changes, cleaning burn wounds, debridement, and treating infections". At the bottom of the sidebar, there is a link to "Pain management, surgery, and support with physical recovery". The main content area on the right has the title "Burn Injuries" in a large font, followed by the subtitle "Dressing changes, cleaning burn wounds, debridement, and treating infections". Below this, it says "This section covers:" followed by a bulleted list of topics: "Dressing changes", "Cleaning the burn and debridement (removing damaged skin)", and "Experiences of infected burns".

healthtalk.org

A-Z ENHANCED BY Google

Burn Injuries

Dressing changes, cleaning burn wounds, debridement, and treating infections

This section covers:

- Dressing changes
- Cleaning the burn and debridement (removing damaged skin)
- Experiences of infected burns

Burn Injuries

- > **Overview**
- > **Burn Circumstances**
How the burn injury happened
- > **Treatment and Services**
Dressing changes, cleaning burn wounds, debridement, and treating infections
Pain management, surgery, and support with physical recovery



Amy and Chris highlighted "the logistics of everything" they had to consider when their son was first burnt and discharged from hospital, including the longer term impacts.



View full
profile

> SHOW TEXT VERSION

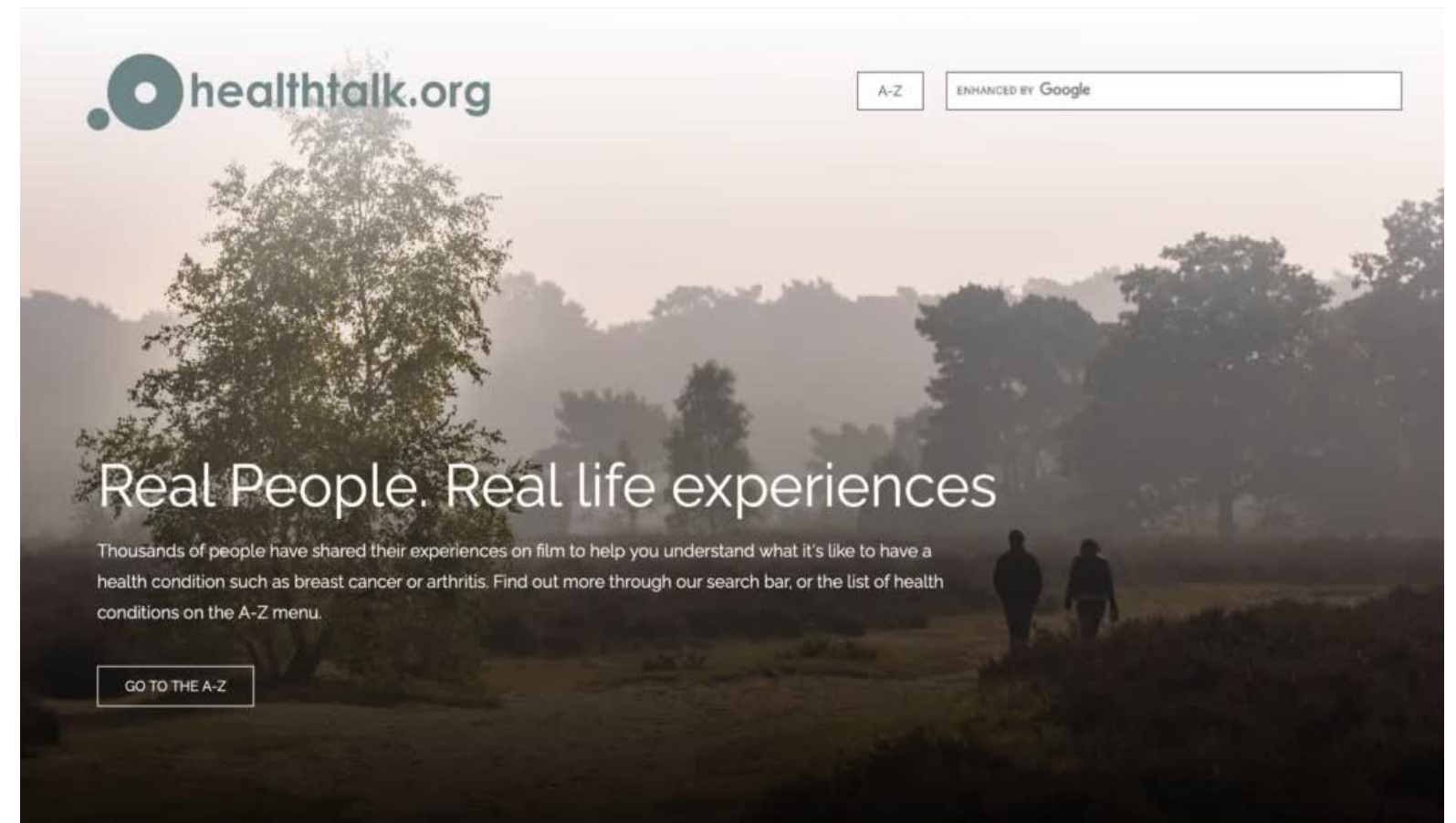
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🖨️ PRINT TRANSCRIPT

Progress & next steps

www.healthtalk.org/burn-injuries

- Burns Healthtalk launched May 2023
- Live webinar May 2023
- British Burn Association, Dublin June 2023 – First prize
- Feedback to date – v positive
- Evaluation study underway
- Next study: Evaluation of an online peer support scheme
- Completion: June 2024
- Contact: Christia.Huntington@uwe.ac.uk



Thank you!

The
Katie
Piper
Foundation


**CHANGING
FACES**


alopecia uk


**Caring
Matters
Now**


debra for people whose
skin doesn't work
we do

LipoedemaUK 
Charity No 1181312


Headlines
Craniofacial Support

CLAPA 
Cleft Lip & Palate Association

FacialPalsy^{UK}
INFORM • SUPPORT • RESEARCH


**DAN'S FUND
FOR BURNS**

**NERVE
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Eczema Outreach Support


MACS


Vitiligo Support UK


Reach

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HOPE • AWARENESS • SUPPORT

CBT 
CHILDREN'S BURNS TRUST

psoriasis
association


ectodermal dysplasia society


BASIS


**Childhood
Tumour
Trust**


**VITILIGO
SOCIETY**
EST 1985


**Microtia
UK**

**UWE
Bristol** | University
of the
West of
England


Centre for
Appearance
Research


**THE VTCT
FOUNDATION**


Limbless Association

Blesma
THE LIMBLESS VETERANS

Future events



Keynote speakers: **Dr Kathleen Bogart & Professor Phillippa Diedrichs**
Conference registration & abstract submission opens **1st August 2023**
Find out more by searching “**Appearance Matters conference**”



Next workshop for the Appearance Collective charities – October 2023
with **Kathleen Bogart & Di Harcourt**
(online, date tbc)



CAR's podcast:
Available for free
through
SoundCloud &
iTunes

80th episode
released June 2023

Further information:



www.uwe.ac.uk/car



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@AppearanceResearch



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Appearance Matters: The Podcast



CAR@uwe.ac.uk

Thank you

Questions?