



Centre for Appearance Research

Appearance Collective
Social Media Workshop

Session Notes

6th October 2020

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Workshop Overview

Part 1 – Social media and CAR’s research

- Mentimeter questions and discussion around how social media is used
- Background to social media
- Overview of CAR’s research

Part 2 – Getting the most out of social media

- Practical tips for using social media as a charitable organisation
- Discussion about which tips would benefit your charity most

Part 3 – Improving how your organisation uses social media

- Identifying your organisation’s social media goals
- Social media action-planning
- Next steps for social media research
- Q&A and closing remarks

Part 1 – Social media and CAR’s research

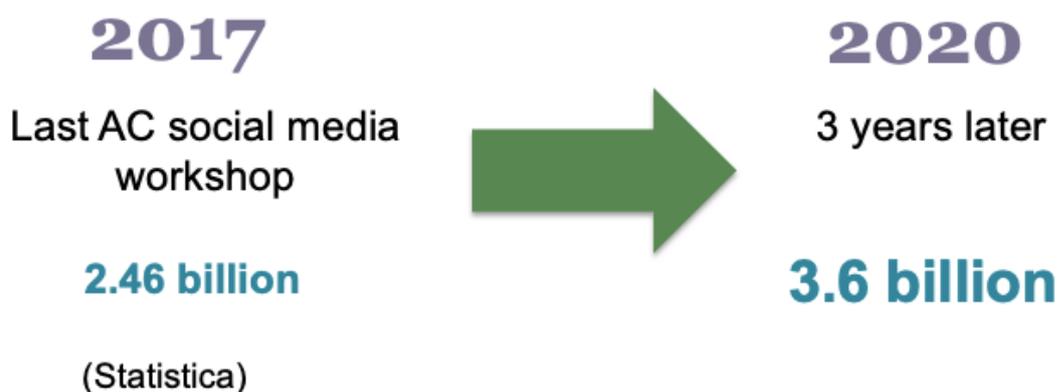
What is social media?

- “A group of internet-based applications ... that allow the creation and exchange of user generated content” (Kaplan & Haenlein, 2010)
- “Social media are computer-mediated technologies that facilitate the creation and sharing of information, ideas, career interests and other forms of expression via virtual communities and networks.” (Wikipedia)
- Popular sites include Facebook, Instagram, Twitter, Reddit, WhatsApp, TikTok, Snapchat and many more...

What is a social networking site?

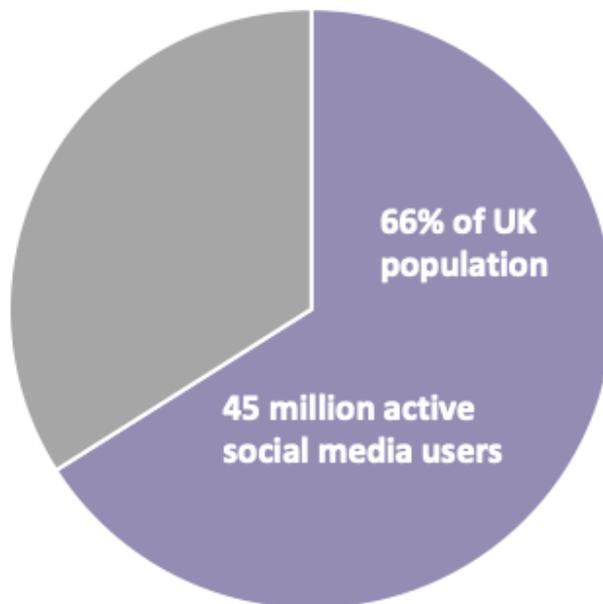
- Social networking sites are web-based services that allow individuals to:
 - create a public or semi-public profile
 - create a list of users with whom they share connections
 - view and cross connections within the system

How many people use social media worldwide?



What percentage of people in the UK use social media?

UK Social Media Users



How much time do we spend on social media?

- On average, people spend 2 hours and 23 minutes per day on social media
- 83% of people on the internet use social media
- 91% of people who use the internet on their mobile use social media

What do charitable organisations use social media for?

- Funding
- Awareness raising
- Providing support
- Building communities
- Networking with influencers, organisations and individuals
- Positioning and thought leadership
- Reaching different audiences
- Promoting events
- Increase website traffic

Media Trust (2018)

Pros and cons of social media

Negatives	Positives
Cyberbullying	Connects people
Misinformation	User-driven - power to create own content
Links to poor mental health, negative body image etc.	Access to information and support
Distracting	Platform to raise awareness
Reduces face-to-face interactions	Often free to use
Encourages comparisons with others	Facilitates social interaction (especially during COVID)
Unregulated?	Reach a wide audience

Appearance-altering conditions and social media

- There has been some research into how people with appearance-altering conditions use social media...
- Share information and experiences
- Find out treatment information
- Give and receive emotional support
- Benefits – flexibility of use, sense of identity/ meaning, reduces issues of face-to-face support
- Challenges: misinformation, inappropriate language on posts

(Stock, Martindale & Cunniffe, 2018; Keim-Malpass & Steeves, 2012; Merolli, Gray & Matrin-Sanchez, 2013; Giordano, 2014)

- Parents...
- Connect with others in a similar situation
- Share positive and negative experiences
- Seek and provide support and information

(Stock, Martindale & Cunniffe, 2018)

This workshop

- In 2017, we ran our first workshop on social media, which covered research into the potential positive and negative impacts of social media.
- Today, we will focus on how charitable organisations can use social media in a positive way, including looking at what we have learnt so far from the social media research conducted by the VTCTF Team at CAR

Social media research at CAR

Since 2017, we have been carrying out research on social media using the Appearance Collective priorities set in 2017:

- Social media
- Interventions to promote acceptance of diversity of appearance
- The experience of visible difference
- Support during the treatment journey
- Assessment tools
- Interventions for people who are adversely affected
- Training materials
- Motivation of volunteers
- Patient and public involvement (PPI)

Study 1 – Guest, Slater & Mikkola (in progress)

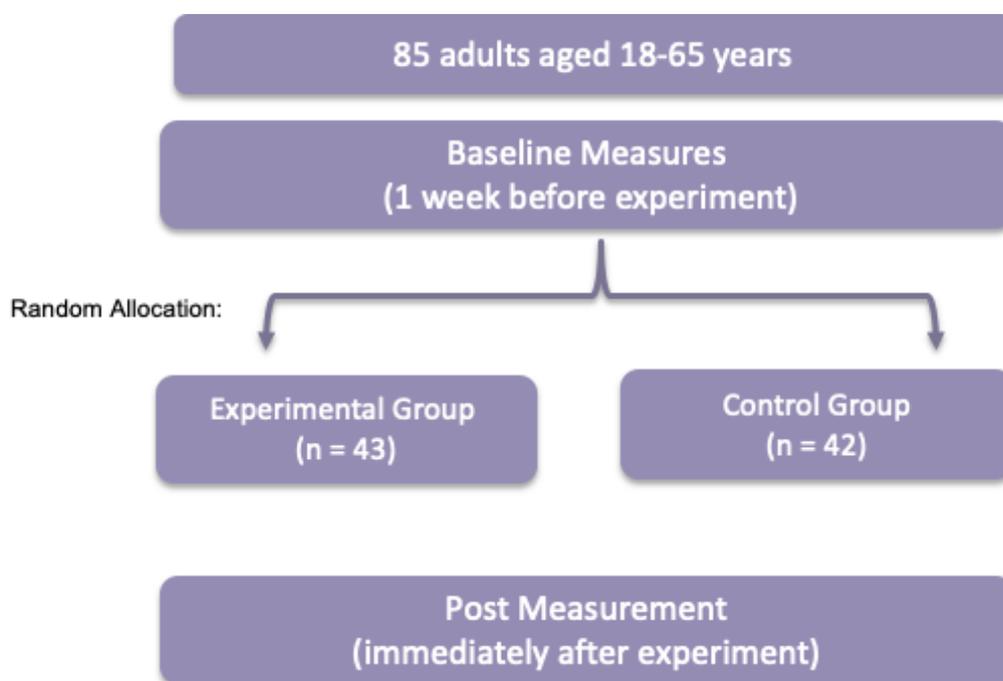
- **Can we increase acceptance of appearance diversity and reduce stigma relating to appearance altering conditions using social media?**
- Previous research (e.g. Cohen et al., 2019) has found viewing photos that present diverse appearances and body positivity can increase positive mood, body satisfaction and body appreciation...so could it also change attitudes towards visible differences?

Method

- Aim: Can we increase acceptance of appearance-altering conditions and reduce stigma by exposing people to Instagram posts representing people with a range of appearance altering conditions?

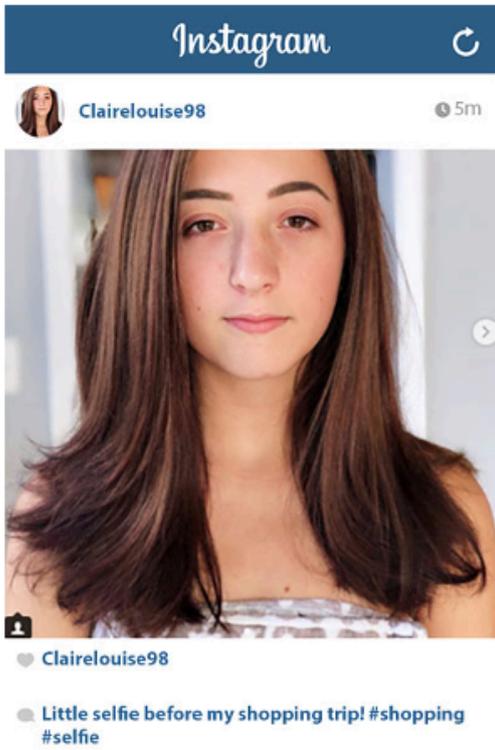
- Experiment in university laboratory with 2 conditions
 - Experimental group – saw 20 Instagram posts of people with visible differences
 - Control group – saw 20 matched Instagram posts of people without visible differences, that were as similar as possible to the visible difference posts
- Completed measures of stigmatisation towards people with visible differences one-week before the experiment and immediately afterwards

Experimental design



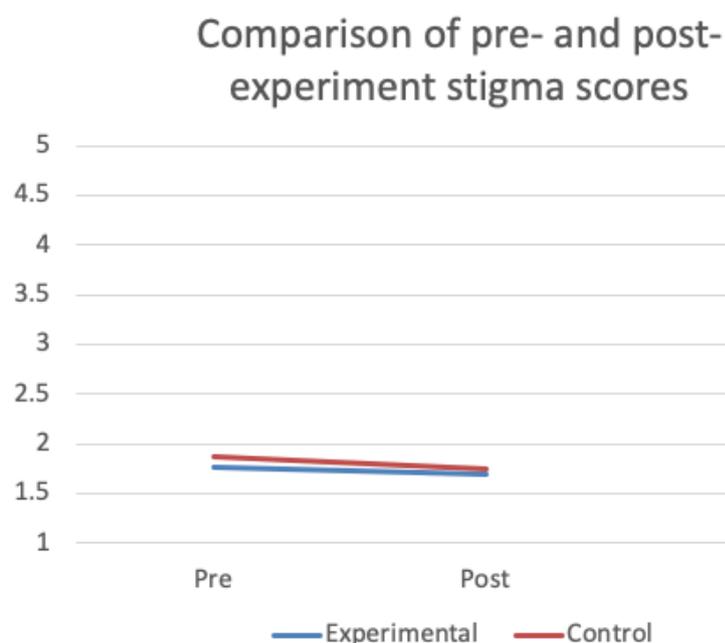
Experimental images

- Selected from stock images and social media
- Visible difference and non-visible difference versions sourced
- Two pilot studies carried out to decide which images were most similar in terms of age, ethnicity, pose, setting etc.
- Images were put on Instagram templates and given captions that did not relate to having a visible difference



Example images/ posts for experiment

Results



There were no significant differences in stigma between the groups after viewing the Instagram posts

Exposure to images of people with visible differences alone does not change attitudes

Study 2 - Slater, Guest, Treneman-Evans & Rush (in progress)

- VTCTF Small Grant project carried out with Emma Rush from Vitiligo Support UK
- Building on the findings from Study 1, we aimed to see whether including educational information and increasing exposure time could reduce stigma.
- We focussed on one condition – vitiligo
- We compared text-based educational information to personalised Instagram posts containing text-based information and photos

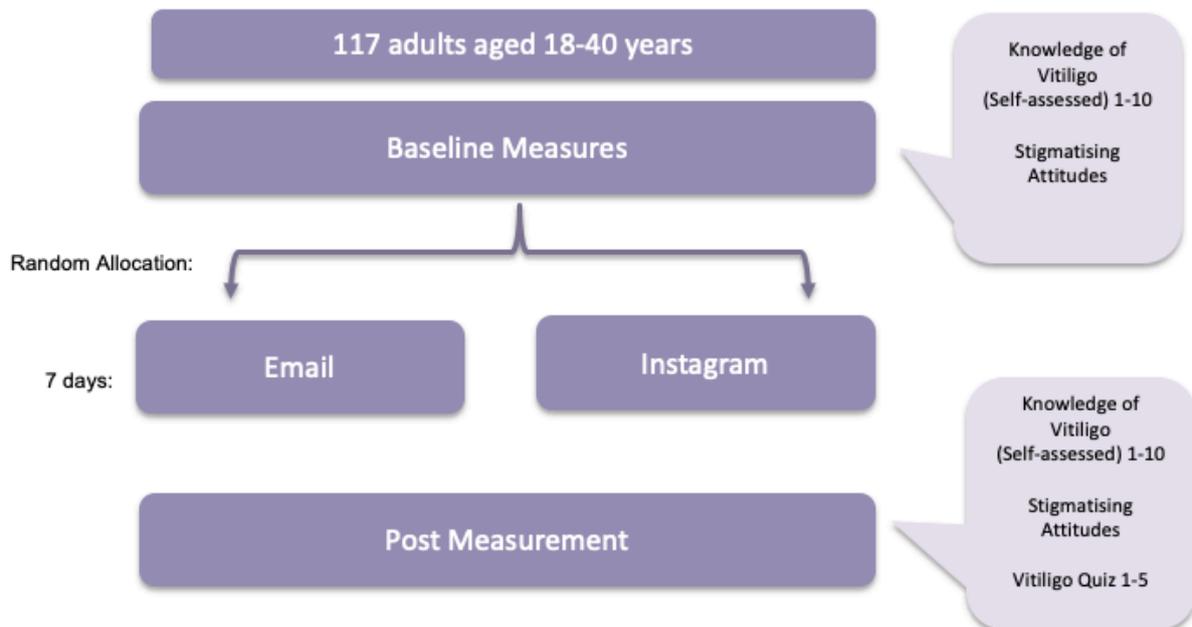


- Aim: to evaluate the effectiveness of *Instagram* as a platform to provide educational information about vitiligo to the general population.
- Question: Are social media posts more effective than traditional educational resources at increasing knowledge of vitiligo and reducing stigma surrounding vitiligo?

Method

- Online experiment with 2 conditions – email group and Instagram group.
- Over 7 days, participants either received daily emails, giving them text-based educational information OR received the same educational information but in the form of an Instagram post accompanied by a social media-style photograph of an individual with vitiligo.
- Public involvement – to develop the educational information and source appropriate images.

Experimental Design

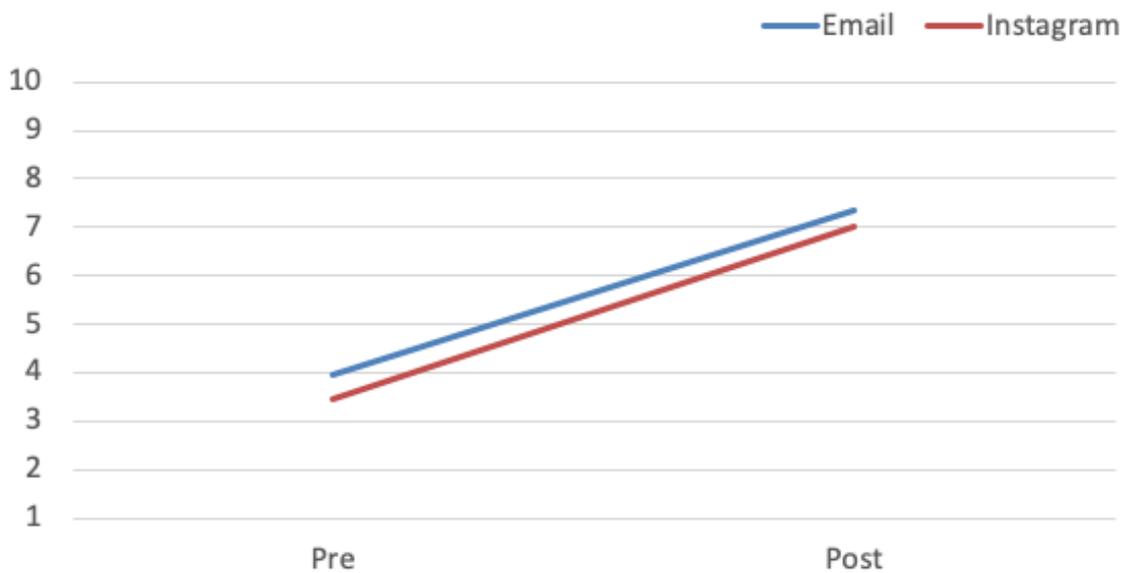


Example educational information used in the experiment

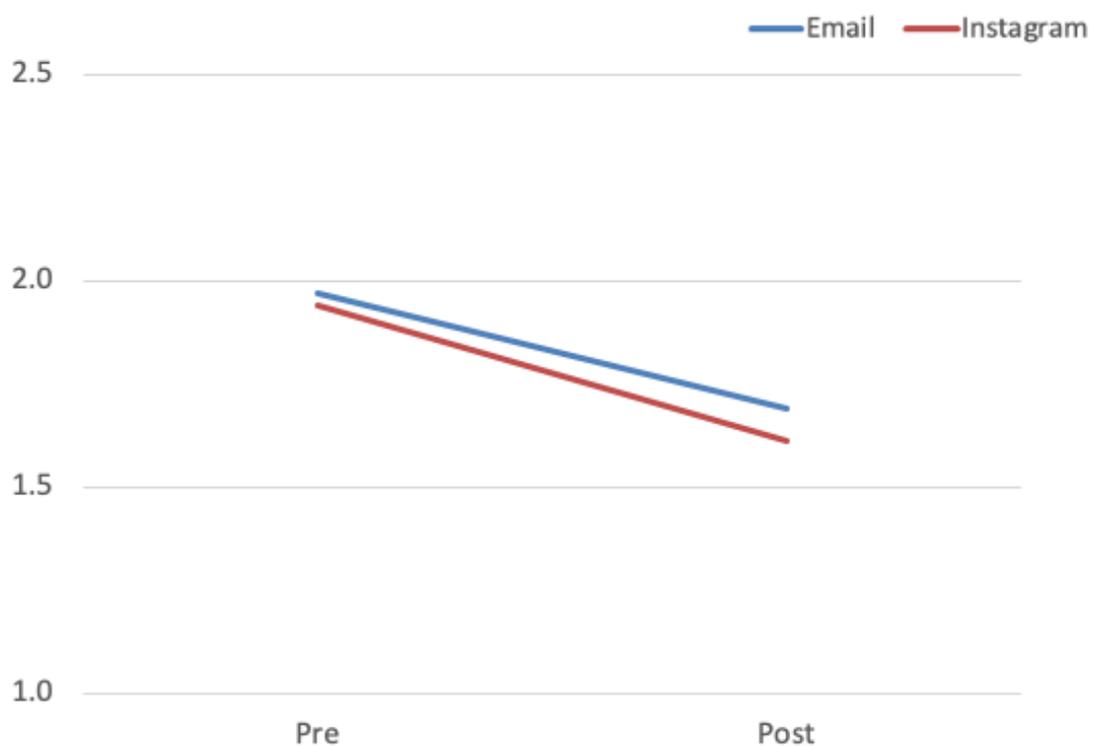
DAY	Email Group	Instagram Group
1	Vitiligo is a chronic skin condition that causes the skin to lose its natural colour and become white or pink. Patches of vitiligo can also vary in size. Notably, it is estimated that the global prevalence of vitiligo ranges between 0.5 and 2%.	My name is Sam and I've had vitiligo for 3 years. When I first noticed that my skin was changing colour, I had no idea that I was developing a skin condition. I was then informed by my doctor that I had vitiligo. For those of you who don't know what vitiligo is, it is a chronic skin condition that causes the skin to lose its natural colour and become white or pink. It is also estimated that vitiligo affects between 0.5 and 2% of the global population! As you can see, patches of vitiligo can vary in size #WhatsVitiligo.
2	Vitiligo is not an infectious or contagious skin condition, nor does it usually cause discomfort. However, patches of vitiligo can burn very quickly in the sun which could cause pain for the individual.	Hi, I'm Pam and I've had vitiligo for 6 years. Lots of people usually look at my vitiligo and wonder what has happened to my skin. Vitiligo is not an infectious or contagious skin condition, nor does it usually cause discomfort. However, patches of vitiligo can burn very quickly in the sun which would cause pain, so I always use a high factor sunscreen #Vitiligo #ProtectYourSkin.



Results: Knowledge of Vitiligo



Results: Stigmatising Attitudes



Results: Stigmatising Attitudes



Summary and Discussion

- Educating the general public about a specific skin condition resulted in increased knowledge of the condition and decreased stigmatising attitudes – regardless of format.
- Participants in the INSTAGRAM group had higher scores on the Vitiligo Quiz
- Participants reported personalised stories on social media were engaging and helped them understand what it's like to live with vitiligo
- Participants said it was important for them to know that the information came from a credible source
- SOCIAL MEDIA (Instagram) might be better way for increasing specific knowledge – more engaging?



Next steps for research

- Qualitative interviews to assess usefulness of social media for health education.
- Understanding whether we can enhance this effect (e.g. following an account for a longer period of time, including video content)
- How to harness positives of social media in reducing stigma around a wide range of appearance-altering conditions.

What can we learn from these findings?

1. Although it's important to have a representation of appearance diversity in the media and social media, seeing photographs of appearance diversity/ appearance-altering conditions in isolation is not enough to change attitudes and reduce stigma.
2. Including educational information about a condition alongside photographs increases knowledge and reduces stigma towards appearance-altering conditions
3. Personalising information makes it more interesting and engaging for viewers
4. Including information about your organisation on your profile shows you are a credible source

Part 2 – getting the most out of social media

Choosing a platform

facebook

- 1.69 billion
- 63,206 character limit on posts
- Good for developing information and support communities and having longer conversations – particularly using groups and events
- Good to know - less young people use Facebook now
- Use Facebook Insights to look at engagement (likes, shares etc.).
- You can look at how other organisations are doing in comparison to yours



Instagram

- 1 billion users
- 2200 character limit on posts
- Quickly increasing in popularity
- Image-based platform
- Good for awareness raising and sharing a small number of photos
- Lots of younger people use Instagram
- Create a free business account to use Instagram Insights and learn about engagement with your account



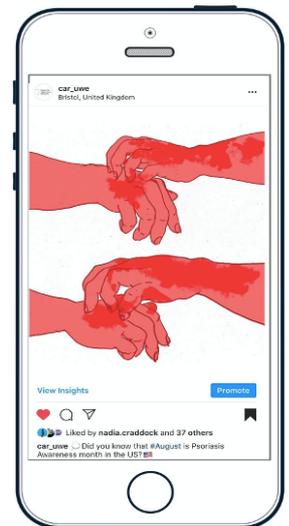
- 330 million users
- 280 character limit on posts
- Good for sharing short pieces of information and engaging with others (likes, retweets, comments)
- Important to interact with others on Twitter to build network
- Use Twitter analytics to track engagement with your account
- Create a Twitter Party...



- 330 million users
- 40,000 character limit on posts
- Good for starting conversations and creating communities
- People create Reddit communities and use them to ask for advice or share information with others
- May help you engage with people who would not normally reach out to a charity – more anonymous
- Higher proportions of men using Reddit

Images

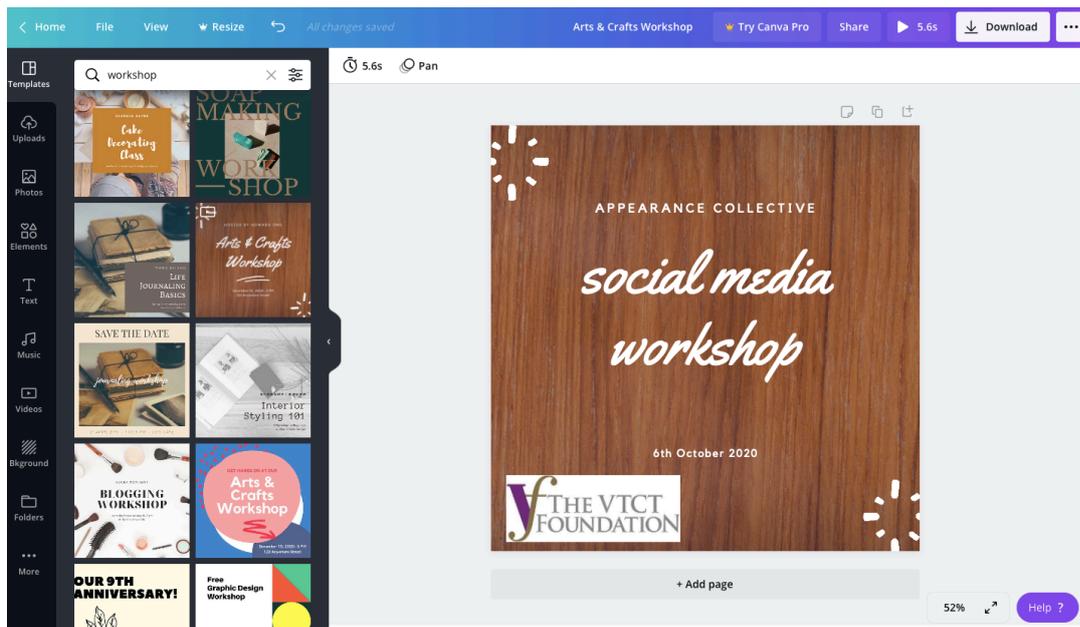
- Very important to make posts engaging and interesting
- Posts with images get 50% more likes!
- Use images that are...
 - eye-catching
 - relevant
 - good quality
 - represent diversity
 - right size/ dimensions for the platform



Free image editing tools

- Useful for resizing or editing images
- Where you don't have an image, they can be used to make text-based content more interesting
- Canva can be used to create Instagram and Facebook posts, stories and videos
- Comes with free templates that you can edit and upload content to
 - Upload your own pictures
 - Use existing templates/shapes
 - Add music or videos
 - Link QR codes
 - Access stock images





Captions

- Think about who your audience is and what they will want to know
- Using questions can make the caption more interesting
- Write for a lay audience (imagine you were talking to a friend)
- Keep within the character count
- Think about layout and paragraph spacing

car_uwe Men have alopecia, too! 🧑🏻🧑🏻🧑🏻🧑🏻

➡️ #Alopecia is an umbrella term for conditions associated with hair loss or #balding, usually on the scalp, but it can also occur on other parts of the body where hair grows, such as with beards, eyebrows, and eyelashes. There are various types of alopecia: some cause temporary hair loss and others can lead to permanent loss.

If you've seen examples of alopecia, they've probably featured photos of women, but as we've mentioned above, it can also impact #men.

? So, how do men experience alopecia? What #support do they want? What information do they need? Unsure? So are we. Very little #research has explored this topic.

🔍 In the name of learning more and better supporting people with this condition, @car_uwe (@uwebristol) will soon begin investigating these questions in collaboration with @alopeciauk, starting with an online survey 📄.

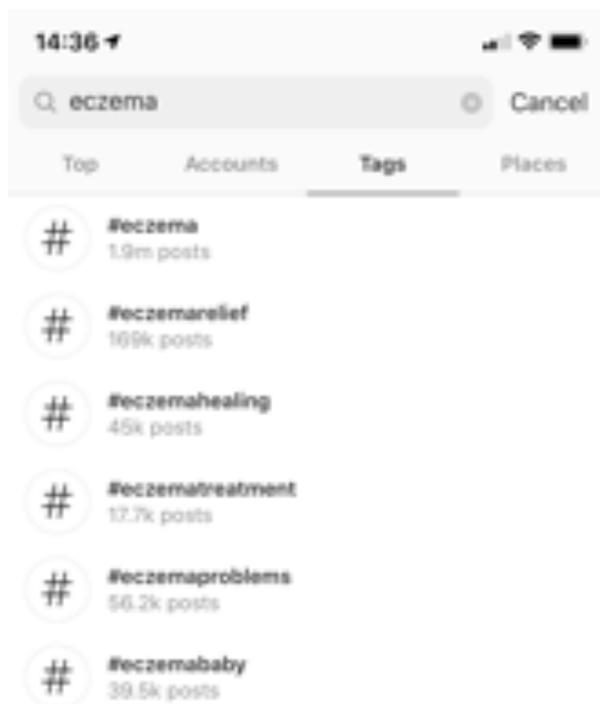
💬 If you are interested in learning more, helping us in any way with this research, or taking part, be sure to follow us @car_uwe as well as @alopeciauk and their various social media accounts.

✉️ Also feel free to contact Fabio.Zucchelli@uwe.ac.uk or Nick.Sharratt@uwe.ac.uk at CAR for more information.

And should you have a platform to help us reach more participants, please do email, DM us or comment below 🙌🙌

Tags and Hashtags

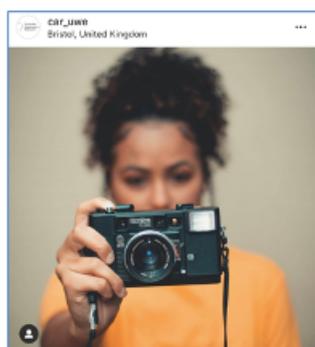
- Tagging others in your posts helps to build relationship and increase the reach of your content, especially if they then interact with it
- Hashtags increase reach because people who are searching them will come across your post, rather than relying on them finding your account
- Tip: search potential hashtags on Instagram before posting to see which are most popular
- Use 2-3 # per post



Making your posts more accessible

Those who are partially sighted rely on screen readers to use social media

- Capitalise each word in a hashtag so that the screen reader can pick it up i.e., #AppearanceCollectiveWorkshop
- Use alt text to describe photos you upload to social media. Keep the text concise and describe the key features of the photograph.



#WorldPhotographyDay #CaringMattersNow
#CongenitalMelanocyticNaevus
#PhotoElicitation #PhotoVoice #NovelResearchMethods
#PhotoMethods #QualitativeResearch #Interviews
#YoungPeople #Adolescents

[Image: A young Black woman wearing an orange t-shirt holds a camera directly out in front of her. The camera and her hand are in focus while the rest of the photo is not.]

Increasing reach

- Make your posts topical
 - Is it a national day or awareness week?
 - Can you link your post to something in the news?
- Build links by posting, liking, sharing, tagging, and commenting
- Use calls to action
 - Share, re-post, comment, share pictures etc.
 - Include polls in Instagram stories
- Have a clear bio (could include a link tree)
- Highlight reels (show specific stories/ events)

Social media insights

- Use to see who is viewing/ engaging with your social media
- Identify which types of posts have the widest reach
- Set up free Business Accounts (e.g. Instagram, Facebook), which will let you track engagement, look at demographics, and see what content is having the most reach (e.g., likes, shared, saves, page visits)

Issues of time

- Maintaining a social media account can be time-consuming, but there are some things you can do to help...
- Consider the purpose of your social media and choose one relevant site
 - Facebook – creating support communities
 - Instagram - Raising awareness
 - Twitter - Sharing short, factual information
- If you don't have time to post daily/weekly, try to like, share, or comment on other content to keep engagement up
- Consider asking volunteers to take over your social media site and post about themselves (e.g., behindthescars_)

Useful guidelines

Media Trust Guidelines – practical guide and strategy for using social media successfully

https://mediatrust.org/wp-content/uploads/2018/10/MediaTrust_StrongerVoices_Guides2018_SM-FINAL.pdf



CharityComms Insider's Guide – general guidance on using social media as a charity, including information relating to different social media sites



https://charitycomms.secure.force.com/resource/1441639717000/Social_media_guide_2015

Discussion – how well do you use social media?

Based on the information so far...

1. How engaging do you think your social media is right now?
2. How much do you know about the 'reach' of your social media?
3. Which of the tips would you like to start using more?

Part 3 – improving how your organisation uses social media

Activity – social media action planning

Three Media Strategy Questions

1. What kind of content can you create/ what is its purpose?
2. What is your target audience?
3. What can you get people to do by sharing content?

(Media Trust Guidelines)

Activity – social media action planning

Setting social media goals

1. What is your most important social media goal? Be specific!
2. How will achieving this goal benefit your charity?
3. How will you know whether you have achieved it?
4. How will you implement this goal?
5. Which of the tips or information from today might help you to achieve this?

Next steps for social media research at CAR

- Further explore the best ways to increasing acceptance of appearance diversity with different groups of people
- Qualitative research to understand how individuals use social media for information and support relating to appearance-altering conditions
- Explore the experiences of people who use social media to raise awareness of their own appearance-altering condition
- VTCTF collaborative small grants on social media?

Take part in research



Are you a parent or carer of a child with an appearance affecting condition or injury?



We are looking for parents and carers of children and young people with a condition or injury that affects their appearance to take part in an online survey.

You will be asked questions about your parenting experiences and your thoughts and feelings relating to your child's condition or injury.

Your answers will help to inform future support for parents.

The survey will take between 20 and 30 minutes to complete.

As a thank you for taking part, everyone who completes the survey will be entered into a prize draw to win a £50 Amazon voucher.

If your child has an appearance affecting condition or injury, they are under 18 and you live in the UK, we would love to hear from you!

For more information contact maia.thornton@uwe.ac.uk

Recruiting to the ACT It Out prototype app study!



What it is

- Prototype mobile app course based on Acceptance & Commitment Therapy (ACT).
- 6 weekly training sessions.
- Designed to help users do more of what matters to them and reduce impact of appearance concerns.

Who it's for

- UK adults.
- Anyone with a visible difference who has appearance concerns.

What it involves

- 6 weekly training sessions.
- Feedback embedded into app.
- Separate surveys before & after course.

For more info and to register interest: go.uwe.ac.uk/ACTItOutInterest

UWE Bristol University of the West of England

THE VTCT FOUNDATION

Centre for Appearance Research

Do you want to view yourself more positively?

- Take part in our online writing programme for adults with visible differences
- Complete three short writing tasks over 5 days

THE TASKS ENCOURAGE YOU TO FOCUS ON WHAT YOUR BODY CAN DO RATHER THAN HOW IT LOOKS

Email Ella.Guest@uwe.ac.uk to find out more



Evaluation survey

- In three months' time, we will be emailing you to ask how you have used what you've learnt during this workshop.
- The findings of the survey help us to understand what has been useful and what we could improve
- It also helps show the university that what we do has an impact

Useful links from workshop chat

- <http://best-hashtags.com/> is useful for finding similar hashtags that may not have the same key word
- <https://www.lightful.com/> - post scheduling
- <https://buffer.com/> - post scheduling



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Appearance Matters: The Podcast



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