



# Centre for Appearance Research

## Welcomes you!

Whilst you get comfortable & we wait to start, we have some quick questions for you to answer (please!)

To do this, go to <https://www.menti.com/> code **6096 5511**

Or scan this QR code by lining it up with your phone's camera

*~Please: do mute when not talking today but indicate as and when you have a question or comment, raise hand, post in the chat, or interrupt us if it's urgent or imperative...*



Thank you!

**UWE  
Bristol**

University  
of the  
West of  
England



# Centre for Appearance Research

Understanding men's  
experiences of visible  
difference: Learning from  
an Alopecia study

Workshop with

**Professor Diana Harcourt, Nick Sharratt,  
Fabio Zucchelli, & Radhika Bhatia**

Date 29 April, 2021



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Research

# Welcome, Appearance Collective & Guests



*Professor Diana Harcourt*

# Introductions



*Fabio Zucchelli*

*Radhika Bhatia*

*Nick Sharratt*

# Introductions



*Kerry Montgomery*

*Psychological Wellbeing Lead, Alopecia UK*

*Catherine Deakin*

*Director of Fundraising & Comms & Deputy CEO*



# Objectives... consider...

- What do we know about men's experience of visible difference?
- What can we learn from the research and from experiences of supporting men?
- Do we offer any support that is focussed specifically on men? Do we need to?

# Overview

- **Welcome & introductions**
- **Changing Faces: understanding & sharing men's experiences of visible difference**
- **Men's experience of visible difference – the research**
  - *Break*
- **Alopecia UK: improving support provision for men with alopecia**
- **Small group discussions & feedback: men's experiences and support provision**
  - *Break*
- **Preliminary findings from CAR / Alopecia UK 'men's project'**
- **Group discussions & feedback: moving forward**
  - *Close*

# Language, participation, & binaries

- Visible difference
- Binaries
- Focus on men
- Privacy
- IT...
- *Please comment!*



...Now....

- Mentimeter results

...Then....

- Catherine Deakin, Changing Faces  
Men and visible difference



Go to [www.menti.com](http://www.menti.com) and use the code 6096 5511

What three words would you use to describe men's experiences of visible difference (or appearance altering conditions)?

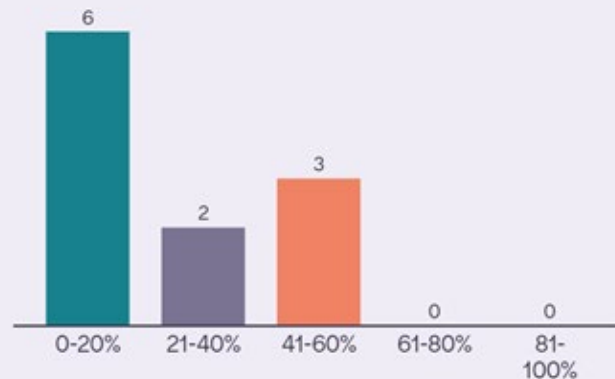


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Go to [www.menti.com](http://www.menti.com) and use the code 6096 5511

Approx. what percentage of your organisation's member, service users, or clients are men?



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# Changing Faces resources on men with visible differences

<https://www.changingfaces.org.uk/news/new-research-reveals-two-thirds-men-with-visible-difference-feel-embarrassed-worried-afraid/>

<https://comresglobal.com/polls/changing-faces-male-perspectives-survey/>

...Now...

- Fabio & Radhika examine the research literature

...Then...

- Break: well earned!



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Men's experiences of visible difference

The research

# Male participation in research

## Health research

- Historically, men overrepresented.
- Modern health behaviour & psychology research:
  - E.g. <20% men from 100,000 participants of health behaviour research studies (Maher et al., 2014).

# Male participation in research

## Visible difference

- Appearance Research Collaboration study (Rumsey et al., in Clarke et al., 2014)
  - N = 1265; 28% male
    - Clinic sample; 36%
    - Community sample; 19%
- Psychological intervention research (Norman & Moss, 2007, 2015)
  - N = 563; ~35% male



# Male participation in research

## Visible difference

- Zucchelli et al. (2020; under review) – ACT (type of therapy)
  - Interviews N = 12; 2 men
  - Quantitative N = 220; 22% male
- Sharratt et al. (2018; in preparation) – Intimacy.
  - Interviews N = 22; 6 men
  - Quantitative N = 397; 24% male

# Male participation in research

## Why the low representation?

- Gender differences in individuals' participation motives?
  - Amenability; Altruism (Lobato et al., 2014).
- Masculinity norms (e.g. stoicism)?
- Unintentional gendering of research?
  - Material (e.g. images, language; Ryan et al., 2019)
  - Recruitment sources (e.g. social media differences; Statista, 2018)

# Literature Review

# Men's Mental Health

- Societal expectations and pressure (Vogel et al., 2014)
- Men are less likely to seek help or support (Cochran & Rabinowitz, 2000)
- Men are more likely to engage in self-destructive behaviours (Gross & Levenson, 1993)
- $\frac{3}{4}$  of 5,691 registered suicides in 2019 were by men
  - This has been the case since the mid-1990s (ONS, 2020)
- Factors that influence engagement in therapy (Holloway et al., 2019; Malec, 2020)

# Literature Search for Men with Visible Differences

- 327 generated results
- Only 62 seemed relevant based on the title and abstract
  - Alopecia: 4
  - Burns: 8
  - Amputations: 12
  - Other: 13
  - Cancer: 25

# Literature Review – Main Findings

- Stoicism and using humour
- Shifts in perceived masculinity and focus on body functionality
- Gender differences

## Main Findings: Stoicism and using humour

- Stoicism prevents comprehensive and representative responses (Gentili et al., 2019)
- Professionals' assumptions of stoicism (Alexis et al., 2020)
- Using humour to facilitate peer support (Hamilton et al., 2015)
- Using humour to facilitate social adjustment (Saradjian et al., 2008)

## Main Findings: Shifts in perceived masculinity and focus on body functionality

- The distressing impact on masculine identity (Gentili et al., 2019)
- Seeing scars as a masculine rite of passage (Thakrar, 2018)
- Focus on body functionality to retain masculinity Hamblin (2013)
- Exercise interventions decrease stoicism without compromising masculinity (Langelier et al., 2019)
  - Humour facilitates this process



## Main Findings: Gender differences

- Women experience greater distress and dissatisfaction than men (Al Ghriwati et al., 2017; Benavent et al., 2020; Borimnejad et al., 2006; Can et al., 2013; Knight et al., 2017)
- Women have better physical and mental QoL than to men (Mohammed et al., 2014)
- Not a gendered phenomenon (Rosińska et al., 2017; Trusson & Quincey, 2021)
- Reviews reveal mixed results (Dua et al., 2017; Hotton et al., 2020)
  - Indicate a need for more male-focused research

# Break... #1

- If you return early / while you wait... we have another Mentimeter question
- To do this, go to <https://www.menti.com/> code **6384 0203**
- Or scan this QR code by lining it up with your phone's camera



# ...Now....

- Mentimeter results

# ...Then....

- Kerry Montgomery, Alopecia UK:  
improving support provision for men with Alopecia



Go to [www.menti.com](http://www.menti.com) and use the code 6384 0203

## From the research we've heard about so far, what has surprised you?

Occasionally a visible difference can increase sense of strength, positive war wound

How using humour can be so helpful.

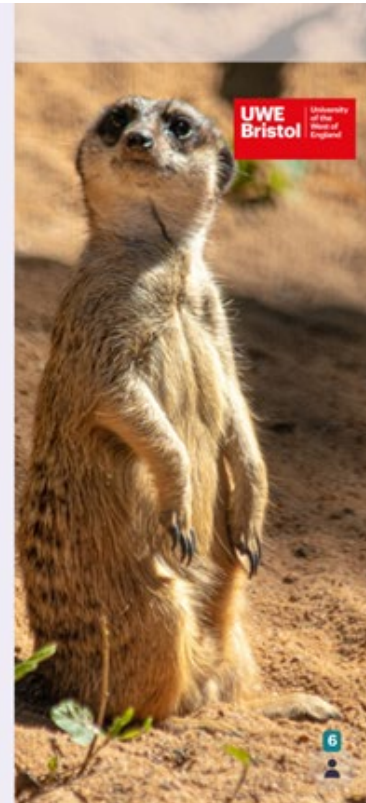
How little research there has been

75% of men do not talk about their appearance

It fits with what I've seen clinically

they are forgotten

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# Improving support provision for men with alopecia

Kerry Montgomery  
Psychological Wellbeing Lead, Alopecia UK

# What do Alopecia UK do?

## In a nutshell

Alopecia UK aims to improve the lives of those affected by alopecia through our aims of Support, Awareness and Research

## COVID-19 update

We have extended how we offer support to include;

- Alopecia Café (Adults and parents)
- Online kids meetings
- Podcasts

We regularly review our support provision and have identified a number of areas where we need to develop our provision to reach particular groups.

## Experiences of supporting men with alopecia

- A good balance of calls from both men and women
- No difference in distress levels of men and women
- Our 'experience of men with alopecia' was our most popular video filmed for our 15 for 15 birthday series

BUT.....

Men do not go on to engage with the other support on offer in the charity

- 11% of Facebook group are male
- Men only Facebook group very quiet
- Very few men attend support groups and events
- Its harder to engage male volunteers than female volunteers

Interestingly these differences don't apply to CYP groups/events where we tend to see a 50/50 split of males and females.

So, although men appear to present with similar levels of distress they rarely engage with support

# Improving support provision for men with alopecia

Before making any changes we need to understand what men want!

- Collaboration with Centre for Appearance Research
  - To help understand what support is needed/ wanted
  - To look at the psychological impact of alopecia areata on men

Plan

To understand

- Men's experiences of alopecia
- Men's experiences of engagement with Alopecia UK
- Barriers to engagement with Alopecia UK
- Establish the support services and materials desired by men with alopecia



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**Thank  
you.**

[Kerry.Montgomery@alopecia.org.uk](mailto:Kerry.Montgomery@alopecia.org.uk)

## Breakout Groups & Feedback

Your experiences

# Your experiences

## **To discuss & feedback:**

- 1. Observations of how men may experience condition(s) / injury(s)?*
- 2. How much do men engage in your services?*
- 3. Relevance of existing provision to men?*
- 4. Challenges in engaging & supporting men?*

# Break... (last one!)

- We have another Mentimeter question
- To do this, go to <https://www.menti.com/> code **2245 4133**
- Or scan this QR code by lining it up with your phone's camera



...Now...

- Mentimeter results

...Then...

- Fabio & Nick introduce the Alopecia research



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Go to [www.menti.com](https://www.menti.com) and use the code 2245 4133

## What is the most interesting thing you will take away from the exercise with the other delegates?

Offering services for men only can work

Challenges in engaging men are fairly universal across services and sectors

the increase in engagement of men accessing help with more offered on line through covid

Increase in accessing services. Need there but engagement is issue.

More thought is needed in how we engage with men, to reduce barriers to services.

Press ENTER to resume scroll Press S to show image





# Research with Alopecia UK

# VTCTF Alopecia UK men's study

- To understand:
  - Men's experiences of alopecia.
  - Men's experiences of engagement with Alopecia UK.
  - Barriers to engagement with Alopecia UK.
  - Establish the support services & materials desired by men with alopecia.

**AND** Develop knowledge & skills for broader engagement work.

- Included men with Alopecia Areata (AA) & Androgenetic Alopecia (male pattern baldness).



# Engaging men in the study

- Consulted 4 men on research Qs, design, materials, adverts etc.
- Design feedback:
  - Choice of sharing experiences via text & conversation.
- Design:
  1. Survey for men with AA & MPB (engagement & experiences).
  2. Interview men with AA (experiences).
- Recruited via social media (including Reddit & men's BAME organisations)

# Engaging men in the study

- Examples of how we incorporated feedback:
  - Shortened survey.
  - Added media representation Qs to interview schedule.
  - In ads:
    - Emphasised being part of a “mission”.
    - Attempted to normalise sharing of experiences.



**Appearance Research**

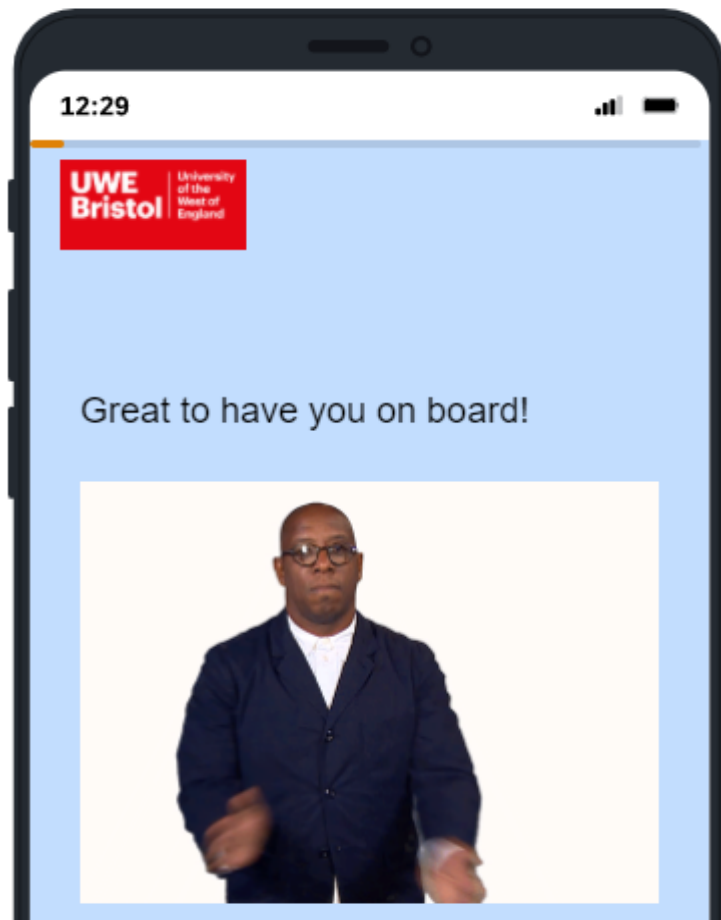
@CAR\_UWE



How do men experience hair loss? What help would they like? We need to LEARN MORE! Men are already talking about it – see the [@AlopeciaUK](#) clip below 🙌 If you're a UK-based man (16+) with any form of hair loss, take the survey & add your voice 🗑️

[go.uwe.ac.uk/MensHairLossSu...](https://go.uwe.ac.uk/MensHairLossSu...) #alopecia





# Feedback on survey style

I enjoyed the less formal writing style, I think it works well for what could be a potentially sensitive subject matter.

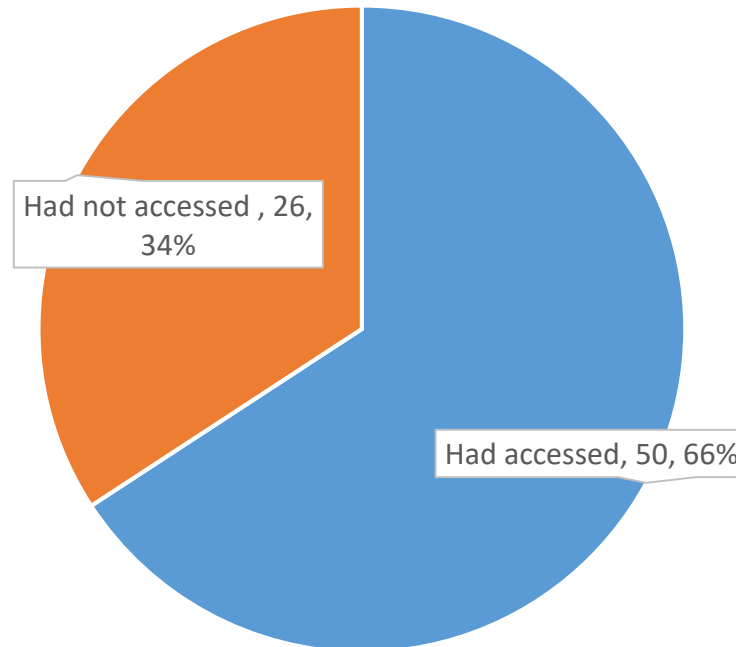
I like the gifs, pics and wording.

I didn't think the jokes worked that well and would have appreciated a more 'clinical' approach. But it didn't bother me that much, to be honest.

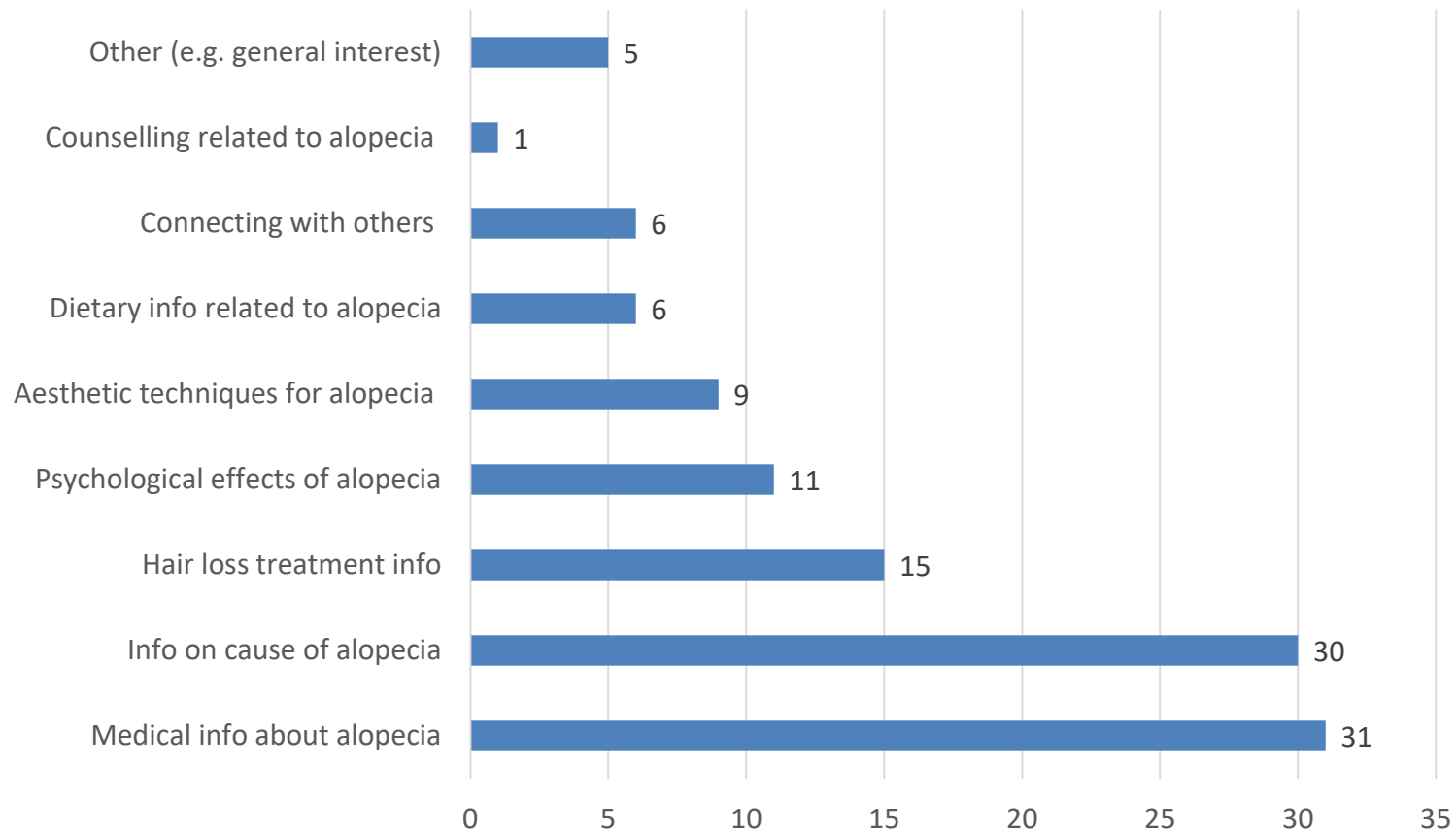
# Preliminary (selected) survey findings

- 197 participants
  - **94 AA**
  - 83 MPB
  - 8 both
  - 4 other
  - 8 unknown.
- Mean age of participants with AA = 44
- Average no. of years since alopecia onset = 13

Men with Areata who have accessed help/info from Alopecia UK  
(n = 76)

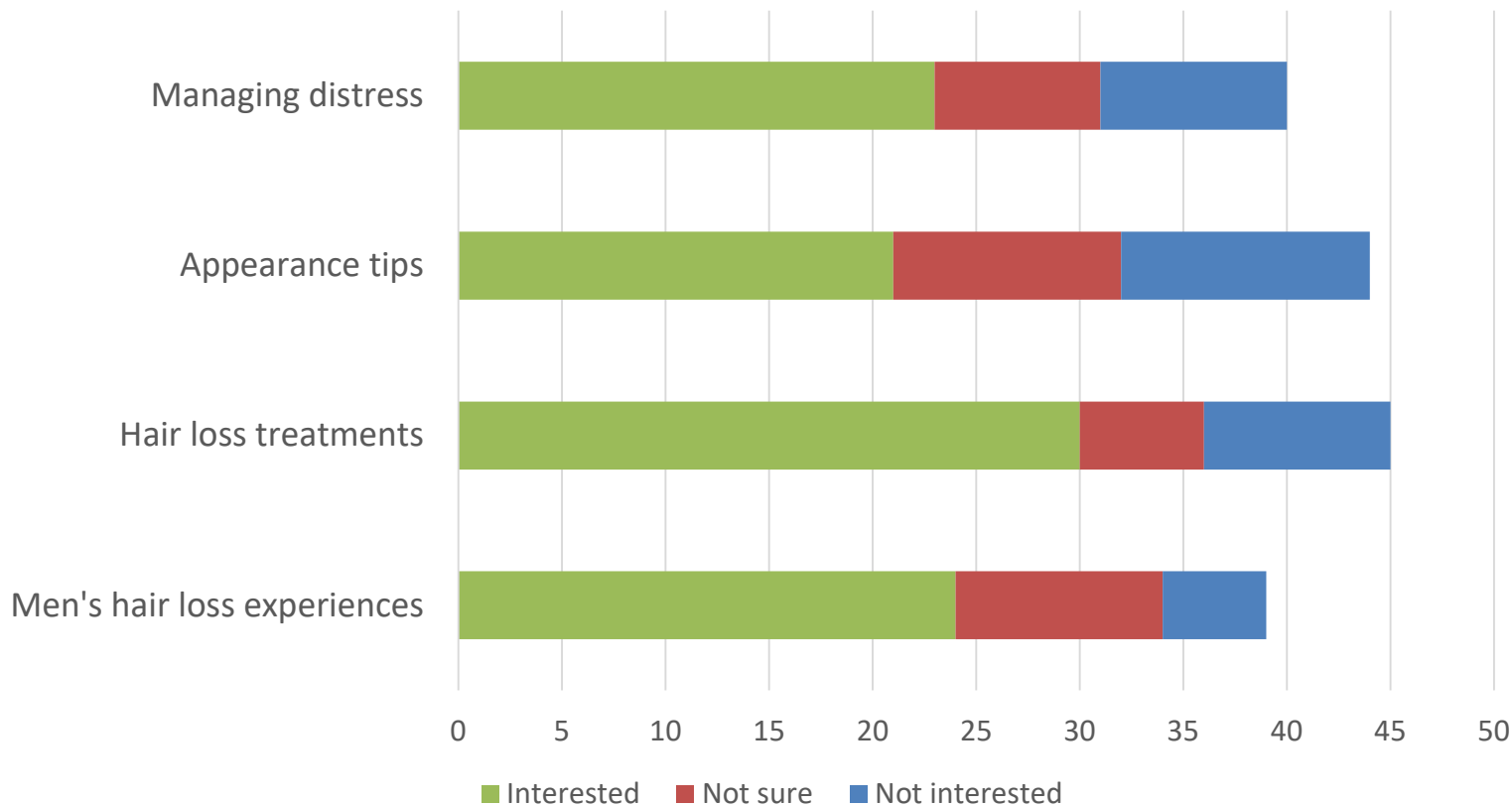


## Type of info/help sought through Alopecia UK (n = 50)





## Interest levels in types of info from AUK



## Managing distress

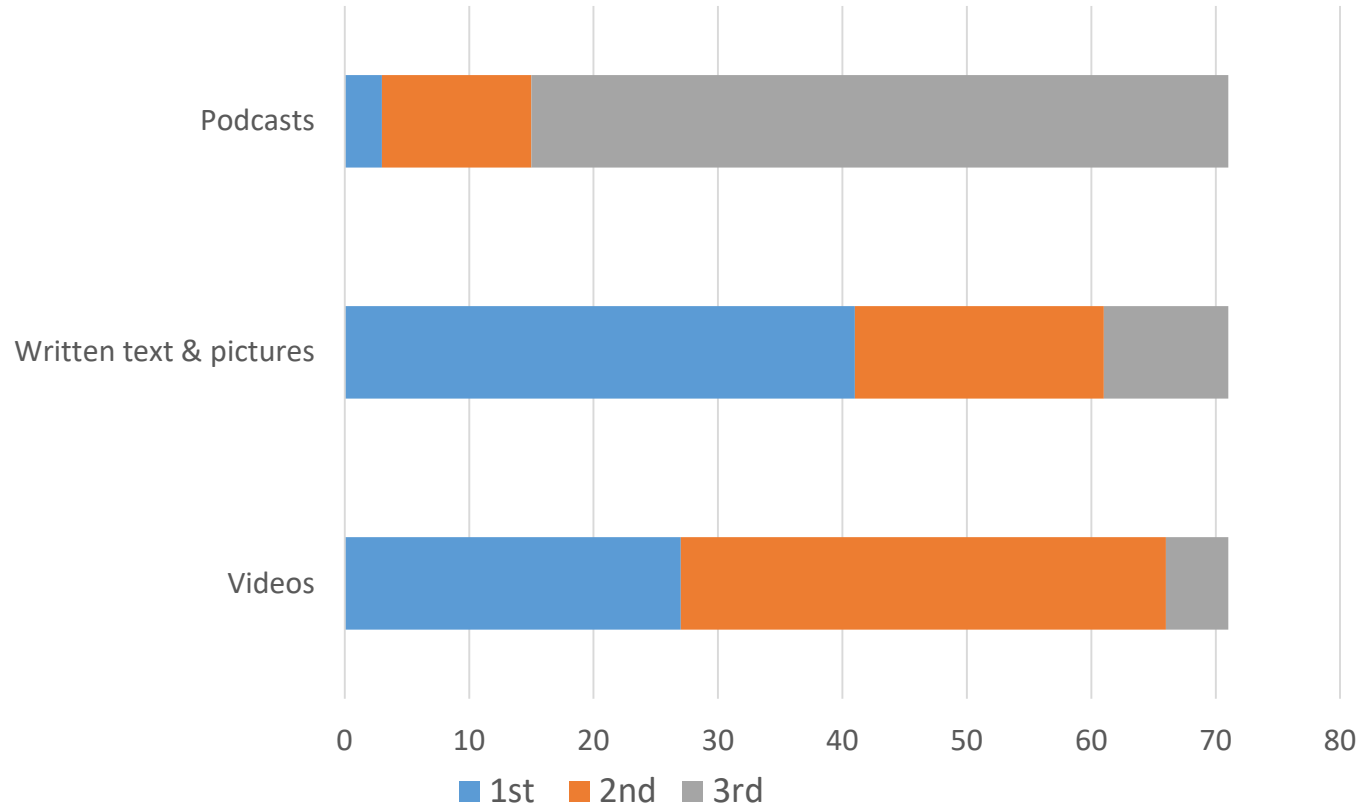
I suffer severe anxiety and depression caused by my appearance...

## Appearance tips

Fashion/styling information for men with alopecia. I find it hard to find clothes I think suit me with no hair and eyebrows.

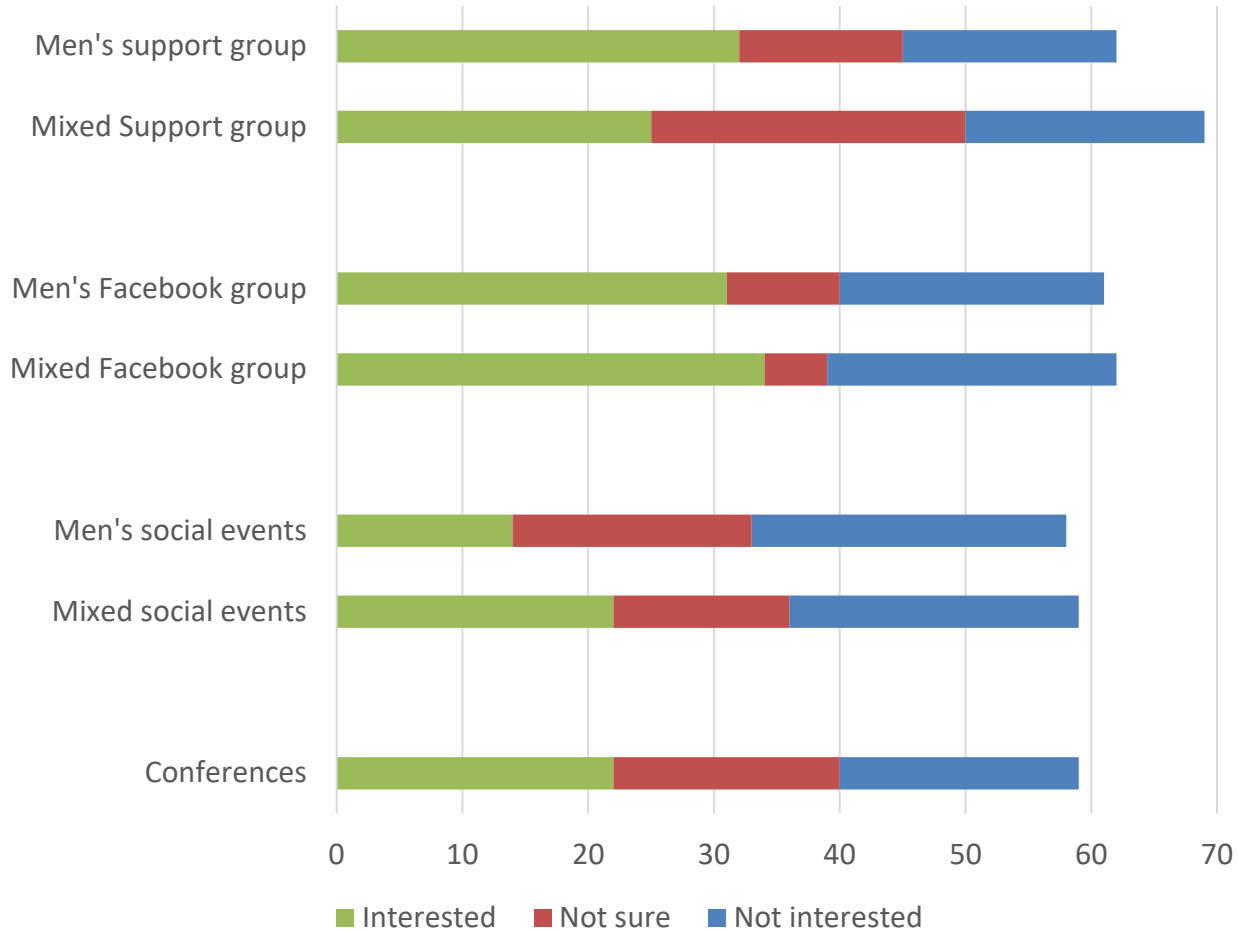
I think there's a lot about access to and advice for wigs for women or make-up but some male specific versions would be good. It's like my moisturiser, I know it's the same as the other bottle but it says 'men' on it, so I buy that one.

## Rankings of preferred information formats



[More] visuals  
of how men  
solve problems  
with hair loss.

## Interest levels in engagement activities from AUK



## Support groups

Similar to a support group but rather than groups of people, have individual buddies to support other people who are suffering from Alopecia

For me a group aimed at the gay community would be of help.

# Alopecia Areata: men's experiences

- Filter from survey
- Interest from >75 men
- Semi-structured, remote interviews
- Spoke with Fabio/Nick
- Thematic analysis

# Participants

- 38 invited, 18 interviewed
- 7 AA / 2 AA & MPB / 9 AAU
- 10 phone/audio only, 8 video call
- 38-81 mins: mean 63 mins (median 65)
- Aged 17-70: mean 39 (median 38)
- 6 gay / 12 straight/heterosexual
- 15 white / 2 mixed/multiple / 1 Asian/British Asian
- 7 single / 6 married/civil partnership / 5 dating/living with partner
- 3 secondary school / 7 vocational qualification / 3 undergrad / 5 postgrad

# Preliminary themes

<b><i>The Invisible Man</i></b>	<b><i>The unseen man</i></b>	
	<b><i>The unheard man</i></b>	
	<b><i>The disguised man</i></b>	
<b><i>The Same Difference</i></b>	<b><i>Being the same and being different</i></b>	
	<b><i>Being different and being different</i></b>	
<b><i>The Changing Man</i></b>	<b><i>Shouldering the burden: the emotional toll</i></b>	
	<b><i>Losing me(n)self: moderated masculinities</i></b>	<b><i>Personal emasculation</i></b>
		<b><i>Public emasculation</i></b>
	<b><i>Loosening the reins: subbing control with acceptance</i></b>	



# The Invisible Man: the unheard man

- Alone / lonely journey
- Talk: no-one / never / can't
  - Women talk, not men
- Others = no effort
- Those close = don't understand
  - Uncertainty how feel
- Harder for women: external/internal
  - Not allowed to care
- Potential value in talking (advice / opp.)
  - Disputed by minority

# The Invisible Man: the unheard man

as I said before, I don't ...  
never really talked about it  
before, not even to my  
husband really. Just one of  
those ones that I try and  
block out, which probably is  
a bad idea...

So, females stereotypically, are more likely to discuss emotions...whereas, I would say... quite generally in male conversations, that feelings wouldn't really come up... typically we wouldn't really expect... expect them to. And I think generally they ... they don't.

# The Invisible Man: the disguised man

- Use of hats / powders / hoods / bodily positioning
- Wigs / dye / extensions / medical tattooing = unavailable
  - Daft / funny: '*comb-over*'
  - Denial / vanity: '*jet black wig*'
  - Poor quality / obvious / '*worse*'
  - Impractical '*cake balanced on head*'
- Shave off / '*get on with it*'

# The Same Difference: being the same and being different

- Society = conflate AA/MPB
- MPB can be difficult, AA different
  - Symmetry / predictability / progression
  - Eyelashes / eyebrows / beard / body hair
  - Age of onset
- MPB acceptable / normalized
- AA more noticeable, attract attention
- Feel forgotten

# The Same Difference: being the same and being different

because it superficially appears similar [to MPB], people conflate them... 'Oh, don't worry!' you know 'My brother lost all his hair, he just shaved it off' you know 'It's no big deal.' And, again, it really diminishes your experience. *[Acknowledgement that MPB can be traumatic]*

but the thing about alopecia areata is that the onset is different, right? And the... if somebody loses their hair through male pattern baldness, I guess there are associations with things like... losing virility, ageing, you know, stuff like that? But those are generally more accepted by society and... there's a particular process, it's kind of an expected pattern... With alopecia areata it's highly unpredictable for starters. Secondly, it's probably indicative of some underlying health issue, it's very poorly understood, so it's not just cosmetic, the person is thinking 'What the hell's wrong with me? There's something deeply wrong. I'm going in the shower and there are clumps of hair coming out in my hands.'

# The Changing man: Losing me(n)self: moderated masculinities

## Personal emasculation

- Compromised masculine identity
  - Beard / body hair – '*pre-pubescent*' / feminised
  - Ritual of shaving - Movember
- Attractiveness: concern / less confident
- Hyper vigilance / '*inner demons*'

## Public emasculation

- Public intrusion / questions / insult
  - '*Chemo*' / '*Drag Queen*' / '*WTF going on*'
  - Touched head '*like a pregnant woman*'
- Impacted spaces / activities / participation
  - Pub / sport / gym / crowds / socializing / work

## The Changing man: Losing me(n)self: moderated masculinities

*... look at other men, um, you know, with beards and haircuts and all of that and I do look sometimes and kind of, although the fact I don't have to shave or wash your hair or anything like that is great um... you know, I would go back to it in a heartbeat kind of thing. Because, I think it's [shaving / having a beard] your... part of what makes you a man really. You know, makes you feel... it's that one little bit that helps you feel like a man.*

# The Same Difference: being different and being different

- AA stacks with / compounded by....
  - Age
  - Autism
  - Health conditions
    - Physical (eg eczema, cystic acne)
    - Mental / emotional (eg anxiety, OCD, BDD)
  - Occupation (eg police / PT / army)
  - Race & racism – chronic prejudice
  - Sexuality: importance to ID
    - ‘effeminate’ assumption / masculine ‘rugby ID’ unavailable



# So... (so far)...

- **Men's engagement**

- Consult with... men
- Time limited
- Multiple avenues for engagement
- Normalise talking
- Informal style
- Information desire as initial 'in'
- Visual representation
- SM lurking
- Tailored content

- **Men's experiences**

- Lack of opportunity / permission to talk
- Forgotten / alone
- Disguise / concealment: unavailable / specific meanings
- Experienced within context of MPB: 'normal' / 'just get on with it'
- Importance of masculinities
- Recognition of intersectionalities

# Moving forward

- Group discussion & feedback
- From what we have heard today and your experiences
  - 1. What could we do to engage more with men?*
  - 2. What could we do to better support men?*
  - 3. Do we need to do anything differently?*
  - 4. Do we need to know/understand more?*

# Objectives: review

## Examine/answer

- What do we know about men's experience of visible difference?
  - *Research: published literature, Changing Faces, Alopecia study*
- What can we learn from the research and from experiences of supporting men?
  - *Research: as above*
  - *Changing Faces, Alopecia UK*
  - *Experiences of and feedback from delegates (esp. discussion #1)*
- Do we offer any support that is focussed specifically on men? Do we need to?
  - *Changing Faces, Alopecia UK*
  - *Experiences of and feedback from delegates (esp. discussion #2)*

Feedback: <https://go.uwe.ac.uk/ACMenVisDiff>

# Thank you – to you and...



- *Vocational Training Charitable Trust Foundation*
- *Appearance Collective, Amanda Shepard*
- *Alopecia UK, Kerry Montgomery*
- *Changing Faces, Catherine Deakin*
- *Participants in research*



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# Appearance Matters 9 Online Conference

13–15 July 2021

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