

Every smile  
tells a story



# Adults Cleft Conference

Camden Lock, London, England

Saturday 17 November 2018







The **Cleft Lip and Palate Association (CLAPA)** is the only national charity supporting people and families affected by cleft lip and/or palate in the UK from diagnosis through to adulthood.



# Timetable

- 10:00am Welcome & Introductions
- 10:10am Overview of Adult Services Project, Summary of Findings from Roadshow and Survey
- 10:30am Beth's Cleft Story
- **11:00am Morning Tea**
- 11:15am Cleft Collective Update
- 11:30am Decision Making Around Having Treatment
- 11:45am Surgery and Ongoing Medical Concerns as an adult – when should I consider treatment? If I leave it will it get better? Will it get worse?
- 12:15pm Teeth - why not to be afraid of the dentist, how to look after teeth and what treatment options are there for teeth?
- **12:45pm Lunch**
- 1:45pm Relationships & Intimacy with a Visible Difference
- 2:30pm Thinking about starting a family – getting your head around genetic counselling and what to do with that information
- **3:15pm Afternoon Tea**
- 3:30pm MRI in the management of patients with repaired cleft palate: could its role be increased?
- 4:00pm Identity, Self-Confidence and Social Anxiety
- 4:45pm Closing thoughts, next steps, things you can be involved with.
- **5:00pm Finish**



# What's today all about?

- The highlight on CLAPA's adult calendar, the CLAPA Adults Conference is an opportunity for people affected by cleft from across the UK to come together, share their stories, ideas, highlights and frustrations with likeminded people.
- A unique opportunity for health professionals and individuals with cleft to come together in a more casual environment.
- The content in today's conference has been hand-picked based on what you told us in the 2018 roadshow and survey as being important to you.
- During the breaks and during the workshops, having a chance to talk with others affected by cleft, health professionals and the friendly CLAPA team.



# Some ground rules and caveats

- Recognise that although people will have a lot in common, we also are all different, and therefore what may not have been a big deal for you may have felt insurmountable to somebody else (and vice versa).
- Unless stated otherwise, in one to one conversations, or round-table discussions, assume that you've been told information in confidence – please don't share anybody else's information without their permission.
- Respect that for some people, it has been really hard to bring themselves to be here today, please be friendly and welcoming to all.
- Please use Slido to submit questions during sessions to avoid interrupting the flow of the day.
- Above all else, please exercise kindness and compassion.





# About the Adult Services Project

- There are an estimated **75,000** people over the age of 16 living in the United Kingdom who were born with a cleft.
- Understanding and supporting the unique needs and experiences of adults affected by cleft is very important to CLAPA.
- From March 2018-February 2021, CLAPA is undertaking an exciting project looking at improving services for adults who were born with a cleft funded by the VTCT Foundation.
- The goals are to research and understand the experiences, challenges and unmet needs of adults in the UK who were born with a cleft lip and/or palate.
- The Adult Services Coordinator is the primary contact for this piece of work.



# What we did in Year One

- **Adults Engagement Roadshow** – 12 events in 12 cities across the UK where we asked you about your experiences growing up with cleft, and what you continue to experience as an adult with cleft, as well as what CLAPA can do for you
- **Whole of Life Survey** – In conjunction with the Centre for Appearance Research at the University of the West of England (UWE) we designed and undertook the world's most extensive survey ever given to adults who were born with a cleft
- **Adult Voices Council → Adult Representation Committee** – We updated and rebranded CLAPA's adult group to be less admin intensive and to enable it to focus more of its time and energy on doing what it does best
- **Lots behind the scenes** – Linking in with the UK cleft teams, developing information for adults (both in printed and online form), meeting with individuals and organisations keen to support the project to unearth synergies
- **Continuity of existing services** – peer support service, Facebook page etc.



# So...what did we find at the roadshow?

- **We were humbled by how candidly people shared some of their most pivotal moments with us.**
- As you would expect, there were many different (oftentimes unique) experiences in the community, however there were some common themes that came up many times – these included:
  - The struggle of obtaining a successful referral to the cleft team as an adult
  - Being unsure what to expect at cleft team appointments
  - Not knowing (and health professionals not knowing) what you are entitled to receive on the NHS in adulthood as someone who was born with a cleft
  - That emotional wellbeing is often impacted, at least in part, by experiences that result from being born with a cleft
  - That dating experiences are often delayed or not as healthy as people would like them to be with some gender differences
    - Men – routinely mentioned not asking people out on dates for fear of rejection
    - Women – reported staying in unhealthy/unproductive relationships as they felt they “couldn’t do any better”. A number of women also mentioned offering sex as a way of feeling accepted.



# So...what did we find at the roadshow?

- As you would expect, there were many different (oftentimes unique) experiences in the community, however there were some common themes that came up many times – these included:
  - Being unsure about the likelihood of having a child with a cleft, and consequently in some cases being unsure about the decision to have children or not
  - Social anxiety – a number of people commented that this had almost prevented them from attending the roadshow
  - Media – the value placed on appearance perfection is too high. Visible differences and speech difficulties are often portrayed negatively in the media, often cast in roles as outcasts, simpletons or antagonists.
  - CLAPA – that we too could do better by portraying a more honest picture of the cleft experience, ensuring that we validate the feelings of people with both good and bad cleft experiences.
- The full report is available at [www.clapa.com/roadshowreport](http://www.clapa.com/roadshowreport).



# Whole of Life Survey

- A **comprehensive snapshot** of what life is like for adults who were born with a cleft.
- Was available online and in paper form from July – October 2018.
- Featured over 200 questions and consisted of 12 sections:
  - About You
  - Your Health
  - Emotional Wellbeing
  - Bullying & Discrimination
  - Family & Friendships
  - Dating & Relationships
  - Genetics & Children
  - Education
  - Employment
  - Eating & Drinking
  - Additional Demographic Information
  - Engaging with the Cleft Community



# Whole of Life Survey

- The survey was open to anyone living in the UK who was aged 16 or over on the 1<sup>st</sup> of June 2018.
- The survey consisted of questions specifically related to cleft, as well as many standardised questionnaires which can be compared to a population that weren't born with cleft to see whether there are differences in the cleft community.
- The data in the survey and roadshow has directly influenced the choice of topics for the talks in today's conference – these are some of the topics that you've told us are most important and of interest to you.



# Whole of Life Survey

- **Who completed the survey?**

- 259 responses, 71% completion rate averaging 51 minutes
- ~75% female
- ~95% white British
- ~73% had cleft lip **and** palate
- ~11% had a confirmed syndrome
- ~93% heterosexual
- ~97% English as a first language
- ~50% of people had a bachelor's degree or higher
- ~85% of participants were between aged 25-60 (range was 18-84)
- The sample as a whole had an above average income
- Most respondents were already engaged with CLAPA having discovered the survey through the CLAPA e-newsletter and social media.





# Beth Angella

Patient Story



# Hello

---

21 years old

Finished treatment (yay!)

Finished university (wahoo)

Specialised in medical  
communication

Cleft career – Smile Train





# Talk Overview

---

Earlier treatment overview

Later surgeries as an adult  
with cleft

Challenges and complications

Communication and Psychology

Questions





# **Unilateral cleft lip and palate**

---

3 months – lip repair

9 months – palate  
repair





# Early treatment

---

Grommets fitted at 2  
and 9 years old

Bone graft at 9 (nearly  
10) years old

False tooth on retainer





# **Lower levels of self-esteem**

More self-conscious

Tried to prove myself

Constantly on my mind





# **The problem of my nose**

---

Profile

Mis-attribute negative  
events

Difficulty breathing





## The answer

Ready for university

Ready for the change  
I'd been 'promised'

The  
disappointment...





# **Postponed with good reason, but...**

Frustration / anger / hurt

TRUST

Two hospitals

Need clarity, not confusion





**Not everything  
goes to plan...**

---

Scar tissue not bone

Second time lucky  
(+ bone graft)





# **Good and bad communication**

---

Reassured, but  
ignored

Lost trust

Regained with clear,  
inclusive  
communication





# **Psychological support**

---

Great help as I got  
older

‘Knew’ what I was  
going through





# **Coping mechanisms**

---

Use a notepad – be heard

Music

Let yourself be upset, talk  
to others

Have perspective

Identify what's rational and  
irrational





# **LIFE- CHANGING SURGERY**

---

Team effort

Self-love





# Beth's Cleft Lip and Palate

Degree

Patient-doctor  
communication

Success and a job  
offer





# Things to remember

---

Things aren't always what you **expect** (that's okay)

Let yourself **feel** what you need to

**Talk** to others

Keep things in **perspective**

Feel **empowered**







[www.bethscleft.com](http://www.bethscleft.com)

**Time to share my  
smile**

**THANK YOU!**

**Please feel free to ask  
any questions...**

**Treatment  
Journey**

**Cleft  
Psychology**

**Website**

**English Degree  
Work**

**Smile  
Train**



# Morning Tea



Be sure to check out the exhibit tables!





# The Cleft Collective

Closing the Gap in Cleft Research

A Scar Free Foundation Initiative

Evie Stergiakouli

on behalf of The Cleft Collective

Lecturer in Genetic Epidemiology

MRC Integrative Epidemiology Unit, University of  
Bristol



MAKING A WORLD WITHOUT SCARS A REALITY



University of the  
West of England





# What is The Cleft Collective?



National cohort study of families affected by cleft lip/palate  
in the UK, established in 2012



# Opportunities generated by The Cleft Collective

Huge resource of information on affected  
individuals and families

Open to clinicians and researchers around  
world for collaboration

Address key unanswered questions  
important to all stakeholders → improve cleft  
care

Investigate the causes of cleft and  
outcomes in children born with cleft





# Where are we now?

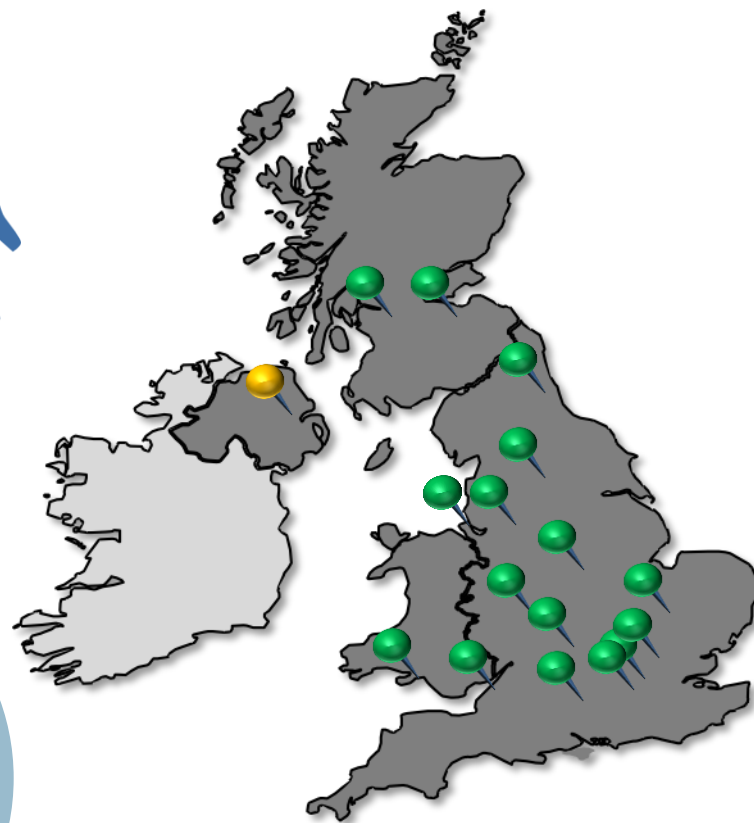
Total number of  
participants:  
**7159**



Mum, dad, baby,  
sibling

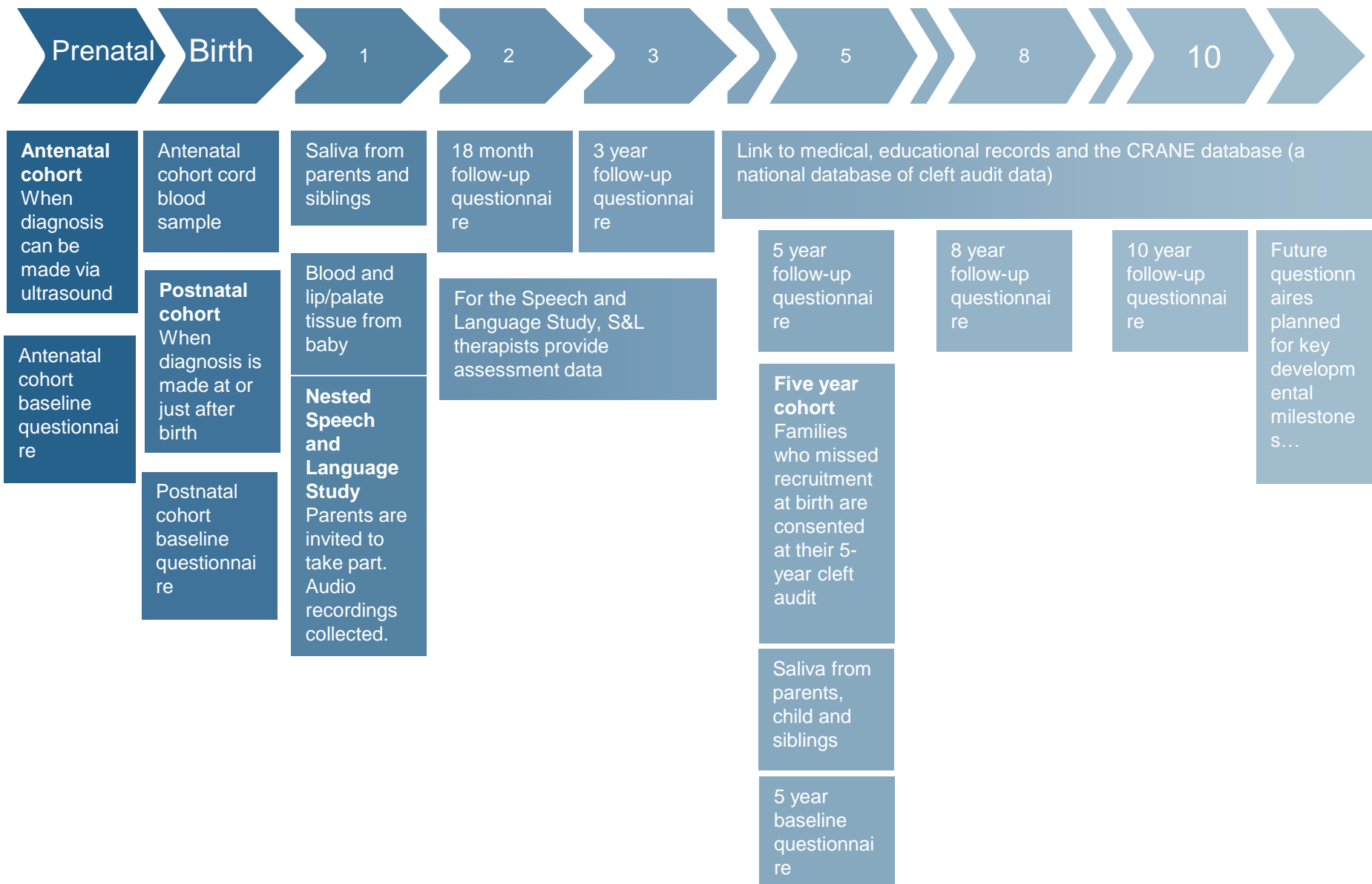
Total number of  
families:  
**2547**

Number of  
maternity units:  
80+





# Data collection timeline





# Biological samples

**Blood** from the baby  
(primary surgery)

**1517 samples**



**Discarded tissue** from the baby  
(primary surgery)

**1443 samples**



**Saliva samples**  
from Mum,  
Mum's Partner,  
some siblings  
(recruitment)



**4064 samples**

Antenatal only  
**Cord blood**  
(birth)

**83 samples**





# Child health

Experiences of breastfeeding or bottle feeding  
Eating difficulties  
Feeding habits  
Teeth and dental care

Gestational age  
Birth weight  
Birth length  
Head circumference



Cleft type  
Timing of diagnosis  
Timing of surgery

Infections  
Additional medical conditions  
Diagnosed syndromes / genetic conditions



# Child development

Hearing difficulties  
Glue ear  
Ear infections

Nested study of 600 children on  
Speech and Language led by  
Dr Yvonne Wren



**18 months – 5 years**  
**Ages and Stages Questionnaires:**  
Cognitive, Emotional and Social  
Development

Communication gestures  
Parent-child activities

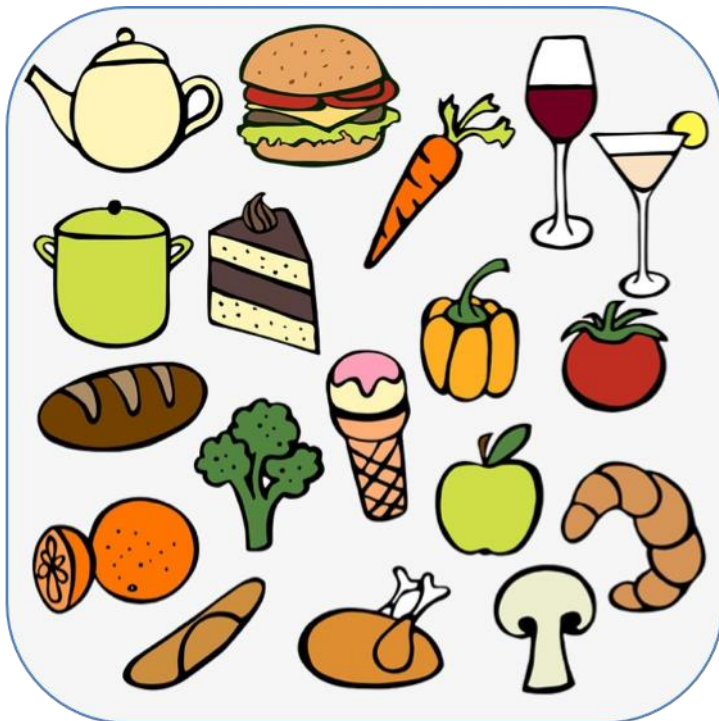
Intelligibility  
(to family, peers,  
acquaintances, strangers)

**5 years+**  
**Strengths and Difficulties  
Questionnaire (SDQ):**  
Emotional symptoms  
Conduct problems  
Hyperactivity/inattention  
Peer relationship problems  
Prosocial behaviour  
Impact on others



# Parent's lifestyle and wellbeing

- Parent's physical measurements
  - Diet, exercise, alcohol consumption and smoking



- Satisfaction with social support and marital relationship
  - Recent life events
- Family Impact: Physical, Emotional Social, Cognitive and Family functioning
- Satisfaction with healthcare received




- Perceived Stress Scale (PSS-10)
- Cleft Clinical Excellence Network Questionnaire (CEN-Q)
- Support received from CLAPA



# Genetic data = a vital component

A major strength of the Cleft Collective is our bank of DNA samples, the largest collection of its kind in the world.

Our long term goals are to...	Genetic data will enable us to identify...
Identify causes of cleft	Genetic and non-genetic causes of cleft
Prevent cleft-related physical, functional and emotional scarring	Genetic and non-genetic causes of suboptimal outcomes in cleft

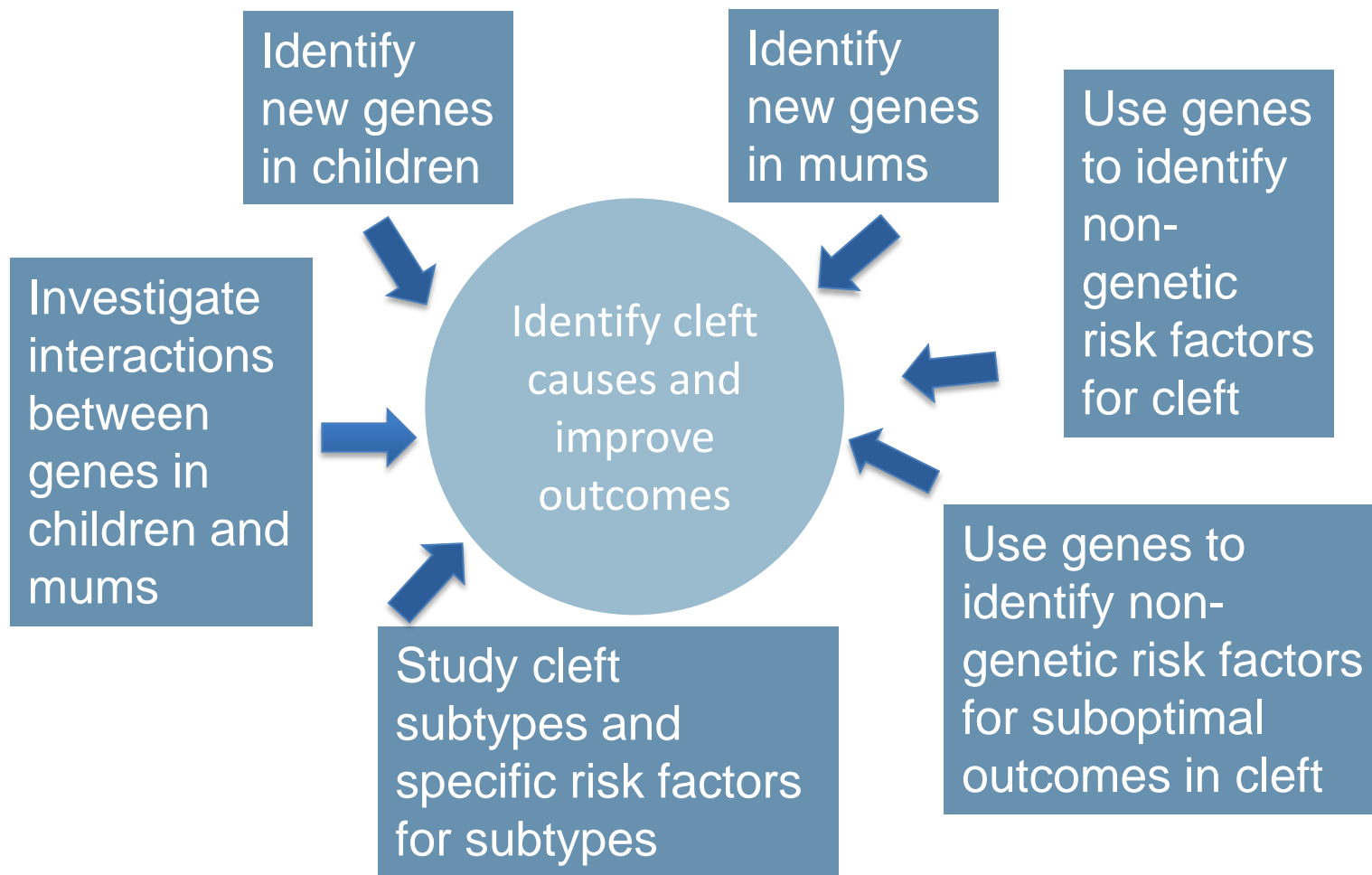


Understanding these causes  
will be crucial for prevention  
and intervention



# What can we do with genetic data?

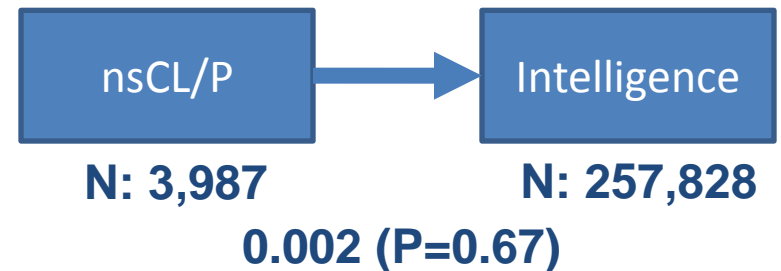
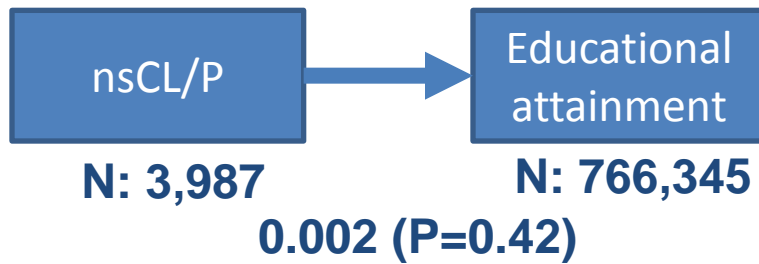
We now have funding from the Scar Free Foundation to generate genetic data for participants in the Cleft Collective. This will enable us to:





# Using genetics to study outcomes in cleft

- **Example: Is genetic liability to cleft associated with low intelligence and educational attainment? [Dardani, 2018]**
- i.e. are children born with cleft genetically predisposed to do worse at school?
- Mendelian randomization using public genetic data showed **NO** evidence.



- Factors influencing the learning process are more likely to influence low educational attainment
- Interventions to provide supportive learning environments and reducing time off school might be effective



# Using the data

[www.bristol.ac.uk/cleft-collective/professionals/access/](http://www.bristol.ac.uk/cleft-collective/professionals/access/)

The screenshot shows the University of Bristol Cleft Collective website. The header includes the University of Bristol logo, the text 'The Cleft Collective', and navigation links for 'Current students', 'Current staff', and 'Alumni'. A search bar is also present. The main content area is titled 'Accessing the resource' and contains a sidebar with a menu of links: 'Information for families and the public', 'Information for professionals', 'Accessing the resource' (highlighted), 'How was the study set up?', 'How is the research being carried out?', 'What information are you collecting?', 'Research progress', 'Publications', 'How can I get involved?', 'Meet the team', 'News', 'About', and 'Contacts'. The main text area explains that the Cleft Collective provides a detailed observational resource for research on cleft lip and/or palate, and encourages collaborators to apply to use the resource. It includes links to the 'Data Access policy (PDF, 331kB)', 'The Cleft Collective Data Dictionary (PDF, 511kB)', 'Research Proposal Form (Office document, 69kB)', 'Confidentiality form (Office document, 68kB)', and 'Checklist for publishing papers (Office document, 45kB)'.

- A detailed data dictionary that is updated monthly
- Set up as a resource to facilitate Academics, Collaborators, Clinicians, Early Career Researchers and students, e.g. Dental students



# Approved research proposals



## **Speech and Language**

- Is there a relationship between hearing loss and cleft speech characteristics in children born with cleft palate?
- Exploring relationships and associations between children's cleft type and early speech and language development



## **Genetics**

- DNA methylation in blood and tissue of children with cleft lip/palate
- Cellular characterisation of the human cleft palate with clinical correlation



# Approved research proposals



## **Views on Clinical aspects and healthcare**

- Families' Views on Anaesthesia and Surgery for Repair of Oral Cleft: A Qualitative Analysis of a Focus-group Discussion
- Satisfaction with healthcare among parents of children born with cleft lip and/or palate



## **Psychology**

- Parental psychological adjustment following a diagnosis of cleft lip and/or palate and associated risk factors
- Cognitive, social and emotional development among children born with cleft lip and/or palate at 18 months
- What is the impact of cleft lip/palate on families' quality of life, and how might healthcare and support be improved?



# Any questions?

- Email: [cleft-collective@Bristol.ac.uk](mailto:cleft-collective@Bristol.ac.uk)
- Website: [www.cleftcollective.org.uk](http://www.cleftcollective.org.uk)
- Twitter: @CleftCollective
- Facebook:  
[www.facebook.com/CleftCollective](http://www.facebook.com/CleftCollective)







# Decision making around having treatment

Dr. Amanda Bates, Patient Experience and Public Involvement Lead,  
Chartered Psychologist  
Centre for Health Services Studies  
University of Kent





**Many thanks to** *KennyArdouin.com*

*Don't let the world change your smile, let your smile change the world.*

Check out Kenny's blog:

<https://kennyardouin.com/2018/08/23/makingtreatmentdecisions/>





# Everyone is different

- Different levels of decision making:
- Lead the decision
- Share the decision
- Hand over the decision
- Could be different for each decision



# Why is it important to have a say in your treatment?

- Improve health and wellbeing – choosing treatment that is in line with personal preference and goals – making decisions which help physical and mental wellbeing
- Improves care and quality – patients say they are more satisfied with their treatment and service they have received – have less regret about decisions made – make fewer complaints
- Appropriate use of resources
- **The NHS Constitution** states that 'You have the right to be involved in discussions and decisions about your healthcare, and to be given information to enable you to do this.'






# Why is it important to have a say in your treatment?

- Increased patient satisfaction and trust
- Higher patients' quality of life
- Reduced anxiety and emotions
- Empowerment
- Increased self-esteem







‘Being involved in treatment decisions made me feel like I mattered as an individual and I wasn’t just a patient. It wasn’t about my treatment, it was about me.’

(Alansari et al., 2014)







# What are my motivations for having the treatment?

- Why are you considering the surgery?
- Is it to improve a function or appearance? Or both?
- There are no right or wrong answers
- Be sure that your expectation of what surgery can achieve is realistic
- Talk to your surgeon or psychologist about what your goals and ambitions are to see where your treatment fits within that
- Be mindful that a surgery isn't going to be the solution to *all* your worries and problems.



# What is the best case scenario? (1)

- If you undergo the surgery and all goes to plan, what does that mean for you? In what ways would you be better off than you are now? If you won't be better off, what might that mean?

"I mean they've all said like "even though you were beautiful before it's like, you know, just enhanced your beauty" so have to really, just makes me feel like I'm, you know, a superstar or whatever (laughs), like a model or something." (Anita) (Liddle et al. 2018)







## Best case scenario (2)

‘After I had a number of surgeries I fit into the, ‘normal world’ fairly well so I didn’t deal with it (bullying) anymore.’

‘In high school, when I started having some procedures done, that definitely started correcting my appearance to the point where you could hardly notice it, I started to almost go overboard and become too social! I was, like, people like me! People are talking to me! They care about what I have to say.’

(Alansari et al. 2014)



# What is the worst case scenario?

- What is the worst case scenario of having the surgery? Might you be back where you started, or in a position that it's an improvement on where you started out.
- Some surgeries carry a few more risks and if they fail, you could be in a worse or *different* situation. E.g. your jaw may be in a better position, but you may experience pain where you didn't before.

'One of my main worries is, just if I'm unhappy with how I look afterwards. I'm, if I don't like it because it's like I've got to live with it for the rest of my life.' (Emily) (Liddle et al. 2018).






## Worst case scenario (2)

‘ I had an operation and I was thinking that it’s gonna change everything and everything is gonna be okay. And it wasn’t. It didn’t even look like they did a change. So I was so sad about that and went through a little depression. Enough that I was a whole month at home, I didn’t wanna go out. I didn’t wanna go back to school. I was so depressed I didn’t even to go prom because of that.”

“I remember having to wait for different surgeries as you grew up, and I thought this last surgery was is going to be ‘the one’... Magical...everything was going to be fixed. It made a difference, but you realise there’s no magical surgery that’s going to change it all. That was a bit difficult. It’s almost like that’s the end of the road, that last surgery.”

(Alansari et al. 2014)





“I remember when I had that last operation, that I was saying to my Mother that I didn’t want to have any kids because I didn’t want them to live through what I was living through... it was hard... I had the tubes... I still wake up at night trying to pull out tubes”

(Alansari et al., 2014)



# What does the short term look like?

- ▶ What are the immediate consequences of the surgery?
- ▶ How much time will you need to take out of school/university/work?
- ▶ How long will you be in hospital for?
- ▶ What level of independence are you able to maintain during the recovery phase?
- ▶ Will you be able to do all the things that you normally do?
- ▶ Will you need to be on a modified diet for a while?
- ▶ Who can help out?
- ▶ Where are you going to stay while you recover?





# What does the long term look like?

- What will the long term look like?
- What are the benefits?
- What is it that you are struggling with now that the surgery should ease for you in the future?
- Equally, if you don't have the surgery, what is your long term prognosis?
- Are you coping okay just now, but life will get harder without having the surgery?
- How long is it going to take before the recovery is complete and you can reap the rewards of the surgery?





# Who am I doing it for? (1)

- Good idea to talk to friends, family and partners about this decision and to value their input; use their input to help you become clearer about the pros and cons – not to say yes or no because it's what your partner or parents want you to do.
- If open discussion with family/friends is difficult, accessing a psychologist via your local health service could be a good option to help talk things through.



'I think because I'd been coming for so long and I wanted my teeth to improve as well I just thought, yeah, I'll go along with it.' (Emily) (Liddle et al. 2018)

'It was mainly my mum that pushed me into it to be honest.' (Joe) (Liddle et al. 2018)





## Who am I doing it for? (2)

'My surgeon wanted me to have more done but I said "no, I really can't do this" and he obviously wasn't impressed...He told me "you don't look right," and I was doing a science degree and he said "if you want to work at a higher level you will need to get your face [fixed]."' (Spencer, 46, UCLP) (Stock et al. 2016).

'Most of my friends said "oh you don't need it." Most of my relatives said you don't need it. Apart from my mum...who said I do need it.' (Joe) (Liddle et al. 2018)

'Everyone's supported me and they'd all just think that it's my decision, whatever I decide I want to do.' (Emily) (Liddle et al. 2018)

**It is ultimately your decision.**



# Can I change my mind?

- ▶ If you're feeling uncomfortable about consenting to and going ahead with the surgery at this very moment in time, but think it may be something that you're interested in later on when circumstances are different
- ▶ Find out whether it would be possible to have the surgery be done in the future, as well as any pros and cons of delaying treatment.





# What questions do I have? What information do I need?

- Take a notepad and pen – before you get to the appointment, write down any questions that you want to know the answers to as a prompt to remind you to ask the questions.
- Write down the answers to the questions as well as other key bits of information that you may want to refer back to later or to share with others.
- Often, it is helpful to take someone along with you who is not as emotionally invested in the consultation as you are who can keep a level head and help you to process and remember the information later on.







## When you see health professionals

- Ask if you need more information or you don't understand something.
- Let them know if you need information in a different way, such as large print or easy read, or if you need someone to help you understand what is being said.
- If you don't understand any words, ask for them to be written down and explained.
- Check you know what should happen next, and when. Write it down.
- Find out who to contact if you have any problems or questions.
- Ask for copies of letters written about you - you are entitled to see these.

<https://www.nice.org.uk/about/nice-communities/public-involvement/your-care>



# What are the alternatives?

- ▶ What happens if you don't have the surgery?
- ▶ E.g. if you choose not to have orthognathic surgery, does that mean that you can still have a rhinoplasty if you wish?
- ▶ Are there non-surgical approaches (e.g. speech therapy) that could be explored?
- ▶ There may not be other options but by asking the question, you will be satisfied that you have explored all possibilities.





# Who can support me?

- Going through a surgery is exhausting both physically and emotionally.
- Identify people who can support you both in practical terms (e.g. relieving you of some of your usual responsibilities, helping with meals, taking you to appointments etc.)
- You might also need people who can provide you with companionship on those days where you may be feeling scared, down, overwhelmed, upset or unsure.





## Who can support me? (2)

'It's just about realizing for the first time that you're not the only person in the world with a cleft... . Just seeing somebody else and talking to somebody else who has been through similar experiences to you.' (Leah, 35, BCL) (Stock et al. 2016)

'CLAPA didn't exist when I was younger, the Internet didn't exist ... so there wasn't really that external support network other than the family ... an outside point of reference would have been useful.' (Jacob, 37, UCLP) (Stock et al. 2016)

'It was having my family around me that, you know, helped me through the day.' (Joe) (Liddle et al. 2018)

'Some level of counselling, psychological support ... someone just to be very honest with ... in my teens especially I definitely would have benefited from that.' (Jason, 37, BCLP) (Stock et al. 2016)





# Patient decision aids

- General ones available online
- Some are condition specific
- Ottawa Personal Decision Guide:
- <https://decisionaid.ohri.ca/docs/das/OPDG.pdf>



## Ottawa Personal Decision Guide

For People Making Health or Social Decisions



### 1 Clarify your decision.

What decision do you face?

What are your reasons for making this decision?

When do you need to make a choice?

How far along are you with making a choice?

☐ Not thought about it  
☐ Thinking about it

☐ Close to choosing  
☐ Made a choice

### 2 Explore your decision.



#### Knowledge

List the options and benefits and risks you know.



#### Values

Rate each benefit and risk using stars (★) to show how much each one matters to you.



#### Certainty

Choose the option with the benefits that matter most to you. Avoid the options with the risks that matter most to you.

	Reasons to Choose this Option Benefits / Advantages / Pros	How much it matters to you: 0 ★ not at all 5 ★ a great deal	Reasons to Avoid this Option Risks / Disadvantages / Cons	How much it matters to you: 0 ★ not at all 5 ★ a great deal
Option #1				
Option #2				
Option #3				

Which option do you prefer?

☐ Option #1

☐ Option #2

☐ Option #3

☐ Unsure



#### Support

Who else is involved?

Which option do they prefer?

Is this person pressuring you?

☐ Yes

☐ No

☐ Yes

☐ No

☐ Yes

☐ No

How can they support you?

What role do you prefer in making the choice?

☐ Share the decision with...

☐ Decide myself after hearing views of...

☐ Someone else decides...



### 3 Identify your decision making needs.

Adapted from The SURE Test © 2008 O'Connor & Legare.



#### Knowledge

Do you know the benefits and risks of each option?

☐ Yes

☐ No


#### Values

Are you clear about which benefits and risks matter most to you?

☐ Yes

☐ No


#### Support

Do you have enough support and advice to make a choice?

☐ Yes

☐ No


#### Certainty

Do you feel sure about the best choice for you?

☐ Yes

☐ No

If you answer 'no' to any question, you can work through steps two and four, focusing on your needs. People who answer "No" to one or more of these questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes.

### 4 Plan the next steps based on your needs.

#### Decision making needs

#### Things you could try



#### Knowledge

If you feel you do NOT have enough facts

- ☐ Find out more about the options and the chances of the benefits and risks.
- ☐ List your questions.
- ☐ List where to find the answers (e.g. library, health professionals, counsellors):



#### Values

If you are NOT sure which benefits and risks matter most to you

- ☐ Review the stars in step two to see what matters most to you.
- ☐ Find people who know what it is like to experience the benefits and risks.
- ☐ Talk to others who have made the decision.
- ☐ Read stories of what mattered most to others.
- ☐ Discuss with others what matters most to you.



#### Support

If you feel you do NOT have enough support

If you feel PRESSURE from others to make a specific choice

- ☐ Discuss your options with a trusted person (e.g. health professional, counsellor, family, friends).
- ☐ Find help to support your choice (e.g. funds, transport, child care).
- ☐ Focus on the views of others who matter most.
- ☐ Share your guide with others.
- ☐ Ask others to fill in this guide. (See where you agree. If you disagree on facts, get more information. If you disagree on what matters most, consider the other person's views. Take turns to listen to what the other person says matters most to them.)
- ☐ Find a person to help you and others involved.



#### Certainty

If you feel UNSURE about the best choice for you

- ☐ Work through steps two and four, focusing on your needs.

Other factors making the decision DIFFICULT

List anything else you could try:





## Moving forward (1)

Quote taken from research with adult 'returners' to cleft treatment in UK cleft services (Stock et al., 2018)

'Because of my own experiences, I didn't really want to have a family in the beginning... I thought 'I don't want to put anybody else through this.'... Now it's getting on to 40 years of research and streamlining processes and improvements, and I know that my son is in great hands.'  
(Toby)



## Moving forward (2)

'At that point I started realising, that's how I was born, you can correct some things but I have to accept that I'll have this scar all my life. And I better deal with that and move on. I said: No more surgeries. I'm done. I'm good. And that was a key moment.'

(Alansari et al., 2014)





# Summary

- Have honest conversations
- Identify your motivations
- Pros and cons
- Who can help you prepare?
- Managing expectations
- **It's all about you!**







**THANK  
YOU!**





# References

- Alansari, R., Bedos, C., & Allison, P. (2014). Living with cleft lip and palate: the treatment journey. *The Cleft Palate-Craniofacial Journal*, 51(2), 222-229.
- Hamilton, K. V., Ormond, K. E., Moscarello, T., Bruce, J. S., Bereknyei Merrell, S., Chang, K. W., & Bernstein, J. A. (2018). Exploring the Medical and Psychosocial Concerns of Adolescents and Young Adults With Craniofacial Microsomia: A Qualitative Study. *The Cleft Palate-Craniofacial Journal*, (55)10, 1430-1439
- Liddle, M. J., Baker, S. R., Smith, K. G., & Thompson, A. R. (2018). Young Adults' Experience of Appearance-Altering Orthognathic Surgery: A Longitudinal Interpretative Phenomenologic Analysis. *The Cleft Palate-Craniofacial Journal*, 55(2), 238-247.
- Stock, N. M., Feragen, K. B., & Rumsey, N. (2016). Adults' narratives of growing up with a cleft lip and/or palate: Factors associated with psychological adjustment. *The Cleft Palate-Craniofacial Journal*, 53(2), 222-239.
- Stock, N. M., Anwar, H., Sandy, J. R., & Rumsey, N. (2018). Centralization of Cleft Lip and Palate Services in the United Kingdom: The Views of Adult "Returners". *The Cleft Palate-Craniofacial Journal*, 55(5), 676-681.



# Surgery and on-going medical concerns as an adult

---

When should I consider treatment?

Will it get better if I leave it?

Will it get worse?

CLAPA Adult Conference - Saturday 17<sup>th</sup> November 2018

Kana Miyagi and Karine Edme

Cleft.NET.East



East of England Cleft Lip and Palate Service





# Overview

---

- Common clinical concerns for adults born with Cleft
  - Nose
  - Lip
  - Jaw
  - Fistulas
  - Speech
  - Dental
- Questions around surgeries
  - When to consider treatment?
  - Will it get better if left alone?
  - Will it get worse?
  - When to stop?



# Nose Surgeries

Commonly considered for:

- Breathing difficulty
- Concern with the appearance





# Lip Surgeries

Commonly considered for:

- Concern with appearance
- Asymmetry at rest and on movement
- Impact on function (unusual)





# Jaw- orthognathic treatment

Commonly considered for:

- Concern regarding facial appearance
  - Maxillary primary hypoplasia
  - Mandibular growth reduced
  - Maxillary retrusion from hard palate surgery
- Occlusion problem





# Fistula closure

Often considered for:

- Nasal regurgitation impacting eating / socially
- Air leak impacting speech

## **Treatment options:**

- Prosthesis- Obturator
- Direct closure or local flap
- Repair with graft (cartilage, bone)/ synthetic material
- Facial Artery Musculomucosal (FAMM) flap





# Speech surgeries

Considered following assessments by MDT:

- Speech unclear, hypernasal, nasal emission of air
- Tires towards the end of the day
- Having to repeat sentences

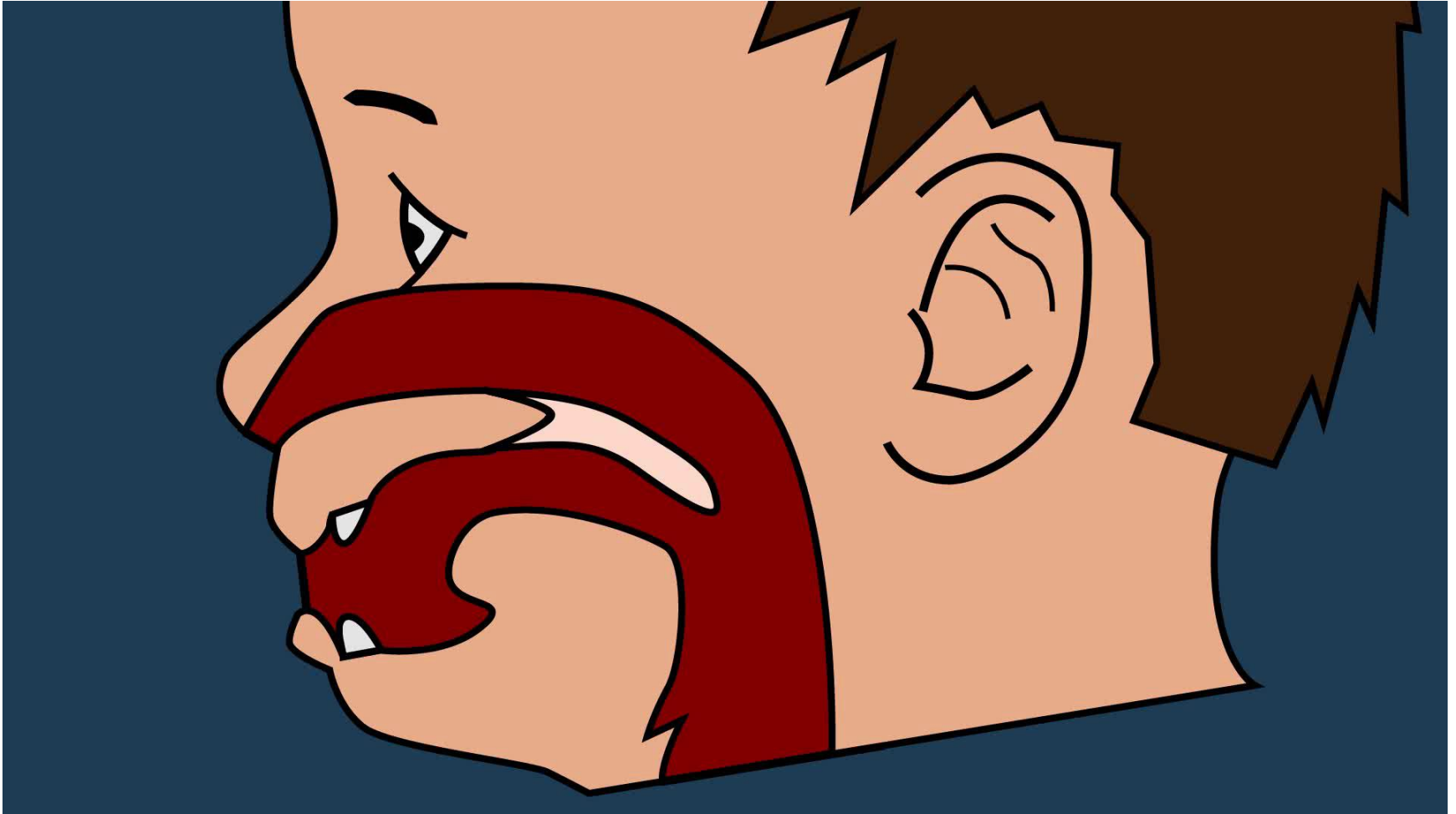
## **Treatment options:**

- Re-repair palate so muscles work better
- Make palate longer
- Adjust back of the throat





# Buccinator flap





# Pharyngoplasty





# Pre-op lateral video fluoroscopy





# Post-op pharyngoplasty





# Psychology and surgeries

---

- Struggling to come back in Cleft service
- Born in countries that did not offer the care (no follow up, no multidisciplinary care)
- When surgeries are considered because they were missed in childhood (move, neglect)
- Anger / unfair feelings that life would have been different if received the care that is being received now



# Will it get better/ worse psychology perspective

---

- Why did I not do it before?
- Triggers for wanting to do it now
- Significant others' role: encouraging / neutral/ discouraging
- Evolving perception/ focus



# Trusting the team

---

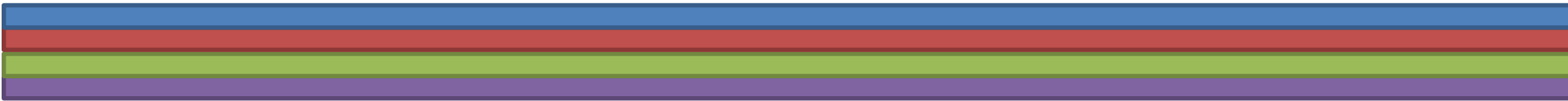
- Different team as childhood team
- Trusting the team / surgeon/ hospital
- Previous medical experiences
- Worry about being judged for life path



# After Surgery

---

- Accepting the “new me”
- Other people’s reaction to the “new me”
- Feeling unprepared for new interactions
- How do I reconcile having surgery and being happy with the “now me”?





# Mental health and surgery

---

- Risk assessment of current mental health and impact of surgery on stability
- Combined support: specialist services, community services and cleft psychology team
- Wanting to access treatment but struggling with feeling of not being worthy of it / Feeling entitled even when not suitable
- Body Dysmorphic Disorder (BDD)



# When surgery is not an option

---

Coping with being told “no surgery”

- ☐ Feeling rejected
- ☐ Frustrated
- ☐ Not being heard
- ☐ Not taken seriously
- ☐ Denied treatment
- ☐ Hopelessness



# Questions?

---

**THANK YOU**





# Lunch

Served in the restaurant 😊







# Centre for Appearance Research

## Relationships & intimacy with a visible difference

Presentation by  
**Nick Sharratt**

17/11/2018 CLAPA Adults Cleft Conference, London



Hello

Created by Balasoiu - Freepik.com

Thank  
you

designed by  freepik.com





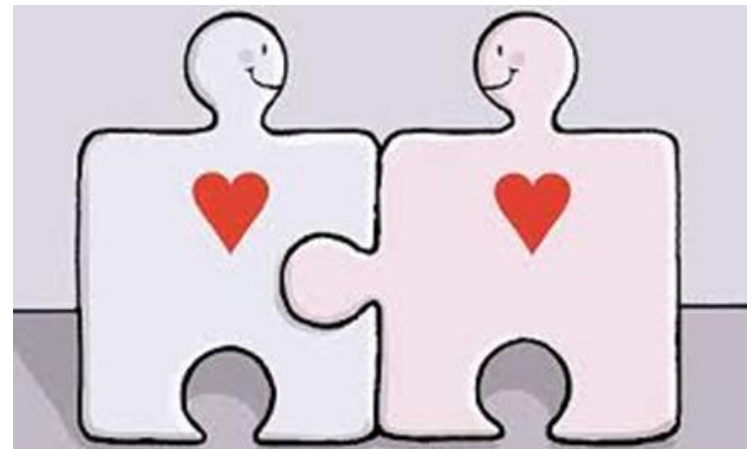
## Warning Signs

- **Use of 'cleft'**
- **Focus = visible difference**
- **Research status**
- **Sensitive topic**



# Overview

- What is 'visible difference?'
- Why is intimacy important?
- How can visible difference impact intimacy & romantic relationships?
  - Include issues from CLAPA Adult Engagement Roadshow
- Discussion





# Context

## CLAPA 2018 Adult Engagement Roadshow: Report



### DATING/RELATIONSHIPS

#### KEY FINDINGS:

- Entering and remaining in abusive relationships as they were looking for acceptance, forgiving behaviours feeling that “I couldn’t do any better”.
- Promiscuity – using sex as a social currency, sleeping with people and “being easy” was a way to be accepted.
- Not asking people on dates due to a fear of rejection. Assuming rejection is because of cleft.
- Being unsure at what point to disclose that they have a cleft, particularly with online dating – do they put it in their profile? Tell them in chat? Tell them on the first date? Not tell them?
- If cleft palate only and speech is good, it’s easy to put off discussing the subject and then becomes too awkward to raise.
- A perception that prospective partners are interested in the perfect body rather than personality and can be very judgmental.
- A feeling of missing out – particularly in the teenage years when everyone else was dating.



# What is ‘visible difference?’

- “potentially noticeable differences in appearance that are not culturally sanctioned”

(Kent &

Thompson, 2002)

- Distinguish from ‘the norm’
- Result from
  - congenital conditions
  - traumatic events
  - disease process
  - medical treatment / surgery
- Include cleft





# What impact can visible difference have?

- Stigmatised by others (Goffman, 1963)  
intrusion / stereotyping / avoidance
- Fear & avoid activities (Newell, 1999)
- Significant minority = psychosocial difficulties
  - anxiety / depression
  - social avoidance / social anxiety
  - reduced quality of life

(Rumsey, Clarke, & White,  
2003)





# What predicts impact?

- Not well predicted by nature / size / severity

(Rumsey et al., 2003;  
2004)

- Individual's subjective assessment better predictor than:

- objective physical measures

(Ong et al., 2007)

- plastic surgeons' ratings

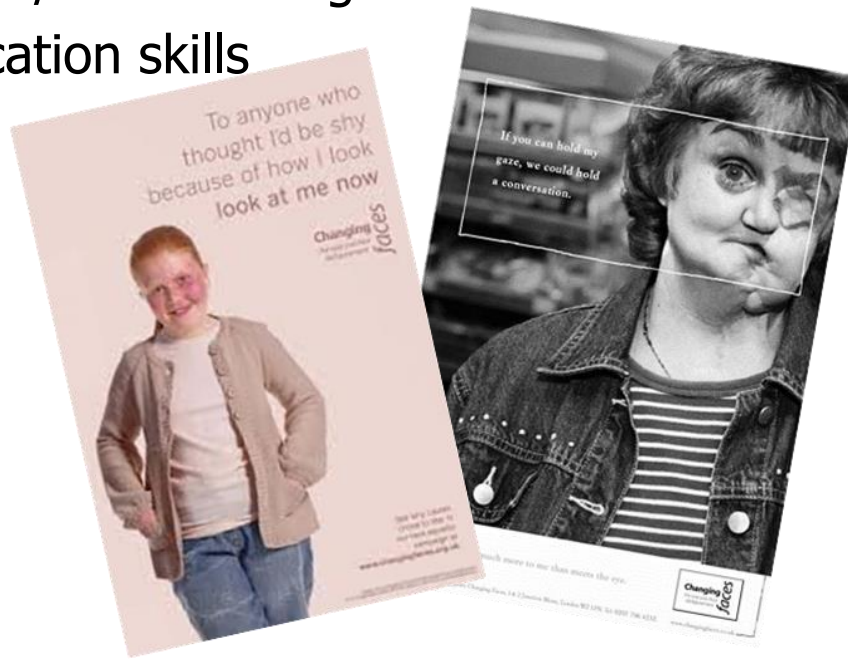
(Moss, 2005)





# What impact can visible difference have?

- Desire understand & ultimately help... but risk pathologising
  - Visible difference (Egan, Harcourt, & Rumsey, 2011)
    - personal growth: resilience / resourcefulness / calmness
    - improved relationships with / understanding of others
  - Craniofacial conditions (Eiserman, 2001)
    - meaning / coherence / inner strength
    - enhanced communication skills
    - valuable social circle





# Why is intimacy/romance important?

- Close, satisfying & desired sexual & social relationships = improved (Popovic, 2005)
  - health
  - happiness
  - functioning
  - sense of meaning
  - ability to adapt
- Potential source of support
  - social
  - economic





# Why is intimacy/romance important?

- **Maslow's Hierarchy of Needs**

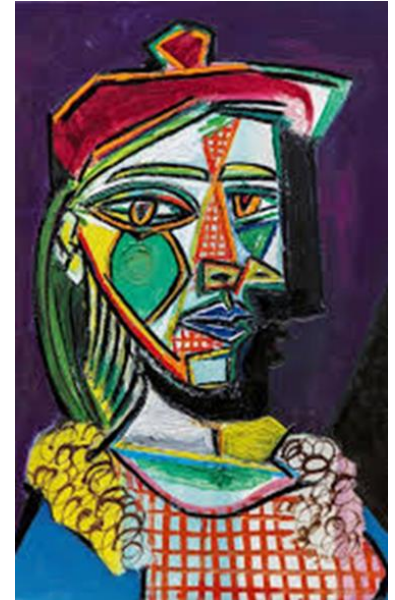
- Deficiency need
- Love and belonging
  - trust and acceptance
  - affection / love
  - affiliation
  - belonging





# How can visible difference impact intimacy?

- Judgements of the **other**... (Halioua et al, 2011)
  - experiment, altered photos, lower:
    - intelligence
    - trustworthiness
    - capability
    - attractiveness
- Feelings about the **self**....
  - Shaban (2010) intimacy requires:
    - self-confidence, trust, openness...
    - opposite of negative body image...
    - visible difference...?





# How can visible difference impact intimacy?

## CLAPA 2018 Adult Engagement Roadshow: Report

What have been the hardest things that have arisen from having been born with a cleft?

- Acceptance
- Making friends
- Accepting how I look
- Shyness / lack of confidence
- Being judged by people / reactions from others
- Thinking no one would ever love me and want me

*...conducive to intimacy / romantic relationships...?*



# Visible difference & intimacy

- Historically neglected in research (& clinically...?)
- Referred to in condition specific studies
- Quantitative research:
  - significant minority report relational / sexual difficulties
  - ARC study = intimacy affected (Clarke et al., 2014)
- Qualitative research:
  - unattractive / outside beauty norm
  - fear negative evaluation & rejection
  - concealment & avoidance
  - revelation difficult





## ***CLAPA Adult Engagement Roadshow***

***Vs.***

### ***Sharratt, Jenkinson, Moss, Clarke, & Rumsey (2018)***

*Understandings and experiences of visible difference and romantic relationships: A qualitative exploration*



- Kenny introduced CLAPA AER findings / report
- 22 interviews, 16 women, 6 men, age 25-64
  - Phone / Face-to-Face / Skype



#### 10 conditions

- |                     |                                    |
|---------------------|------------------------------------|
| ○ cleft (6)         | ○ Ichthyosis (1)                   |
| ○ alopecia (5)      | ○ ankylosing spondylitis (1)       |
| ○ psoriasis (3)     | ○ facial palsy & breast cancer (1) |
| ○ breast cancer (2) | ○ facial scarring (1)              |
| ○ facial palsy (1)  | ○ facial birthmark (1)             |



## Sharratt et al. (2018)

- Thematic analysis
- Three main themes
  - Appearance Attracts and Detracts
  - Looking Different: Physicality and Physical Reality
  - Looks Help Delineate and Define Relationships





# CLAPA 2018

## DATING/RELATIONSHIPS

### KEY FINDINGS:

- Entering and remaining in abusive relationships as they were looking for acceptance, forgiving behaviours feeling that “I couldn’t do any better”.
- Promiscuity – using sex as a social currency, sleeping with people and “being easy” was a way to be accepted.
- Not asking people on dates due to a fear of rejection. Assuming rejection is because of cleft.
- Being unsure at what point to disclose that they have a cleft, particularly with online dating – do they put it in their profile? Tell them in chat? Tell them on the first date? Not tell them?
- If cleft palate only and speech is good, it’s easy to put off discussing the subject and then becomes too awkward to raise.
- A perception that prospective partners are interested in the perfect body rather than personality and can be very judgmental.
- A feeling of missing out – particularly in the teenage years when everyone else was dating.



What have been the hardest things that have arisen from having been born with a cleft?

- Shyness
  - Being judged by people / reactions from others
- Thinking no one would ever love me and want me
  - Acceptance



# Appearance Attracts and Detracts

## Looking to Love

- Initiation
- Judgements re characteristics
- Attractiveness / desirability
- Societal ideals
- Gendered
- Barrier
- Friends First
- Natural?

**Appearance  
Attracts and  
Detracts**

**Looking to  
Love**





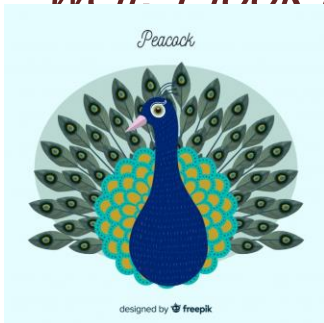
# Appearance Attracts and Detracts:

## Looking to Love

*"it does make it a lot harder because... the **first instinct**, it **is a physical thing**, it is... can you live with that person and **are you attracted to them?**"*  
(Ryan,  
Facial Palsy)

*"I am conscious of the fact that I did feel **I was at the end of the queue on the handsomeness scale**"*  
(David,  
Cleft)

*"**I'm** probably the **world's worst for judging people on looks** as well. I look at people and think "Oh, I don't want to look like **I think it's kind of programmed into you**"*



*th, Facial Scarring)*







# CLAPA 2018

## DATING/RELATIONSHIPS

### KEY FINDINGS:

- Entering and remaining in abusive relationships as they were looking for acceptance, forgiving behaviours feeling that "I couldn't do any better".
- Promiscuity – using sex as a social currency, sleeping with people and "being easy" was a way to be accepted.
- Not asking people on dates due to a fear of rejection. Assuming rejection is because of cleft.
- Being unsure at what point to disclose that they have a cleft, particularly with online dating – do they put it in their profile? Tell them in chat? Tell them on the first date? Not tell them?
- If cleft palate only and speech is good, it's easy to put off discussing the subject and then becomes too awkward to raise.
- A perception that prospective partners are interested in the perfect body rather than personality and can be very judgmental.
- A feeling of missing out – particularly in the teenage years when everyone else was dating.

What have been the hardest things that have arisen from having been born with a cleft?

- Lack of confidence / low self-esteem



# Appearance Attracts and Detracts:

## The Discounted Self

### Deficient Me

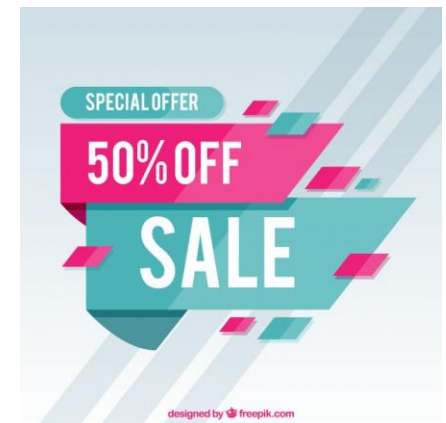
- Internalised value judgements
- Deficient / devalued as partner
- Disbelief
- Compensation / bargain

### Lucky in Love

- Accepted 'despite' difference
- Gratitude / luck (disempowered)
- Vulnerability: sub-optimal relationships

**Appearance  
Attracts and  
Detracts**

**The  
Discounted  
Self**





# Appearance Attracts and Detracts:

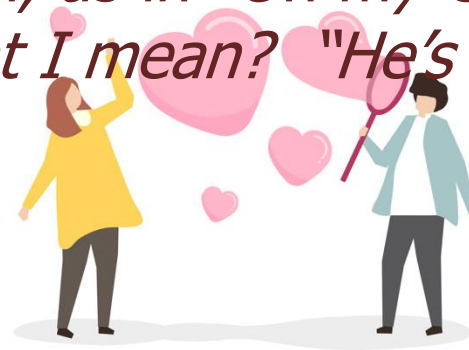
## The Discounted Self

*"It didn't click so I **thought oh well she didn't fancy me I just thought she fancied my mate.** That was a **self-esteem** thing again. I would never have ever looked at anybody. I'd have thought she'd never ever like me, do you know what I mean?"*

*(Pete, Cleft)*

*"as a teenager any **attention** that a male or boy gave me, I **kind of jumped on** as such, as in "Oh my God, he thinks I'm alright" do you know what I mean? "**He's paying me attention**" and that kind of thing."*

*(Charlotte, Cleft)*





# Appearance Attracts and Detracts:

## The Discounted Self

*I've **always thought that I'm not good enough** sometimes, you know, **why would someone good looking want to be with me?...** I've gone for **older men** who haven't been as youthful. Then, when I was 27, I ended up with a 44 year old and he just turned out to be the biggest idiot ever. But I kind of latched onto him because I was thinking "It's **safer**. He's **not going to leave me**" and "**He should be grateful** he's with someone so young, you know, **regardless of what I look like**, you know."*

*(Beth, Facial Scarring)*







# CLAPA 2018

## DATING/RELATIONSHIPS

### KEY FINDINGS:

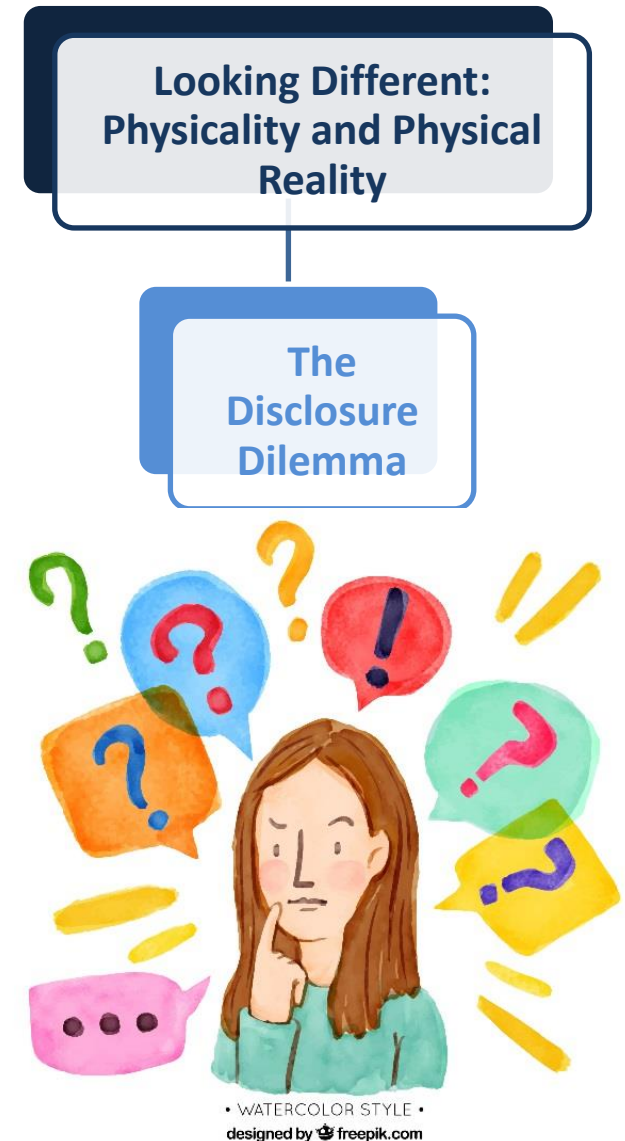
- Entering and remaining in abusive relationships as they were looking for acceptance, forgiving behaviours feeling that “I couldn’t do any better”.
- Promiscuity – using sex as a social currency, sleeping with people and “being easy” was a way to be accepted.
- Not asking people on dates due to a fear of rejection. Assuming rejection is because of cleft.
- Being unsure at what point to disclose that they have a cleft, particularly with online dating – do they put it in their profile? Tell them in chat? Tell them on the first date? Not tell them?
- If cleft palate only and speech is good, it’s easy to put off discussing the subject and then becomes too awkward to raise.
- A perception that prospective partners are interested in the perfect body rather than personality and can be very judgmental.
- A feeling of missing out – particularly in the teenage years when everyone else was dating.



# Looking Different: Physicality and Physical Reality

## The Disclosure Dilemma

- Not normally visible / internet dating
- Early in relationship: hurdle
- Presentation vs. reality
- Uncertainty how / when
  - strategies / timing
- Obligation / dishonesty
- Negative reactions:
  - feared & experienced
- Transition:
  - discreditable > discredited





# Looking Different: Physicality and Physical Reality

## The Disclosure Dilemma

Describing internet dating... Beth told her match...

*"before we meet, this **has been an issue in the past** with other people, I just want to say I've got, you know, a rather large scar on my face and it's not for everybody and I'd **rather be upfront** before we met **than** feel like the date went well and **not get a second date**... this has happened in the past. It's nothing personal but I'd rather you know, rather than go through the whole stress of meeting and then not get a second date because of it."*

*(Beth, Facial Scarring)*



# Looking Different: Physicality and Physical Reality

## The Disclosure Dilemma

*"I had various different thoughts off people as to what I should do... from "No, make sure all your photos on there you have got wigs on" [or]"let them get to know you as a person first." But then I **feel I'm being quite deceitful** in that regard so, after lots of trials we have now settled on my page with **photos of me with wigs** and a **couple of daft ones of me polishing my head with a can of Brasso** [laughs]"*

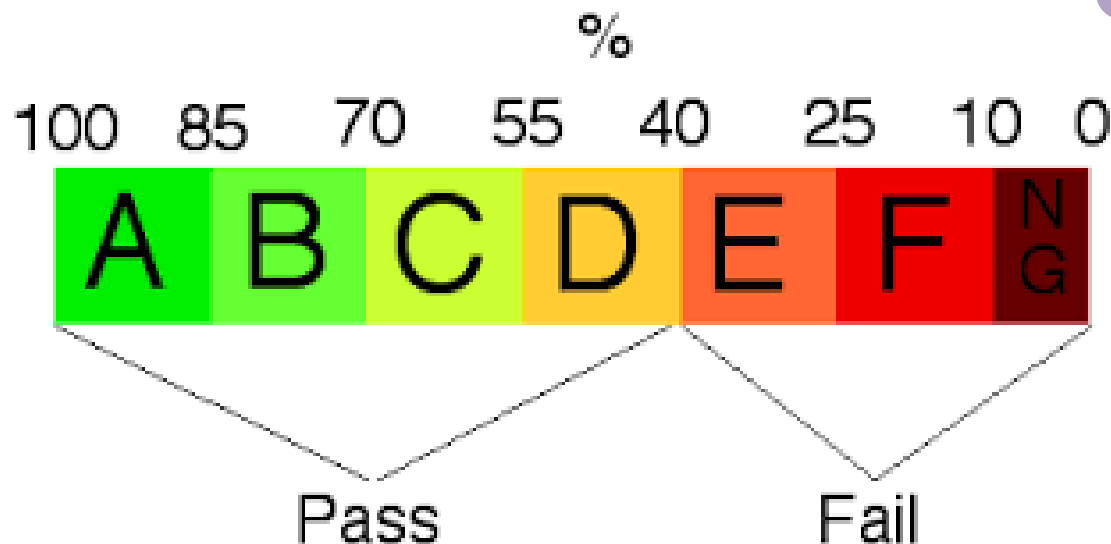
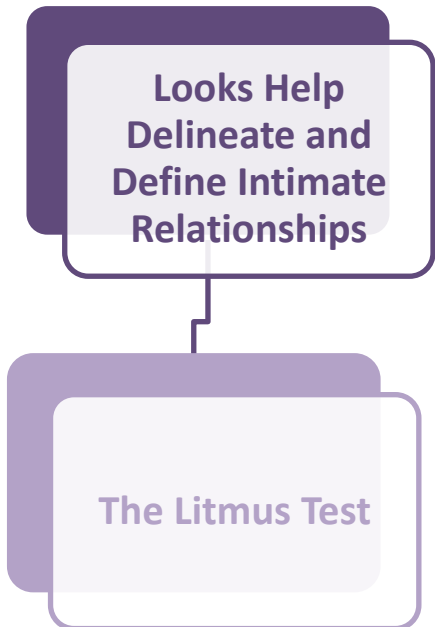
(Michelle, Alopecia)



# Looks Help Delineate and Define Intimate Relationships

## The Litmus Test

- Response to difference = filter
- Speak to character of the other (shift)
- Desire / require empathy & compassion
- Indicator of relationship potential





# Looks Help Delineate and Define Intimate Relationships

## The Litmus Test

“obviously if anyone did react negatively **you’d know that *they* were an idiot** so you wouldn’t give them the time of day after that anyway!”

(Chloe, facial birthmark)







# CLAPA 2018

## DATING/RELATIONSHIPS

### KEY FINDINGS:

- Entering and remaining in abusive relationships as they were looking for acceptance, forgiving behaviours feeling that “I couldn’t do any better”.
- Promiscuity – using sex as a social currency, sleeping with people and “being easy” was a way to be accepted.
- Not asking people on dates due to a fear of rejection. Assuming rejection is because of cleft.
- Being unsure at what point to disclose that they have a cleft, particularly with online dating – do they put it in their profile? Tell them in chat? Tell them on the first date? Not tell them?
- If cleft palate only and speech is good, it’s easy to put off discussing the subject and then becomes too awkward to raise.
- A perception that prospective partners are interested in the perfect body rather than personality and can be very judgmental.
- A feeling of missing out – particularly in the teenage years when everyone else was dating.



# Looking Different: Physicality and Physical Reality

## Invading Physical Intimacy

- Reduced desire & activity
  - reject advances
- Feel unattractive
  - de-feminised
- Sexual self-consciousness
  - salience of area(?)
- Avoidance
- Covering up
- Partner communication & intimacy

Looking Different:  
Physicality and Physical  
Reality

Invading  
Physical  
Intimacy





# Looking Different: Physicality and Physical Reality

## Invading Physical Intimacy

*"I couldn't see why someone would want to have sex with me when I wouldn't if I... was in their shoes. Yeah, **my sex drive definitely dropped down quite considerably**"*  
(Ryan, Facial Palsy)

*I've rejected him, sort of **rejected his advances** from time to time, simply **because I feel unattractive**"*  
(Eleanor, Psoriasis)

*"I think it's feeling how I felt about myself and **worrying what he would think** about that... and I just didn't really want him to... I mean he's never, **he never actually saw 'it'.....** "I don't know if he sees me in the same way but **I've never spoken to him about it**, which is quite bad really. I think I should"  
(Karen, Breast Cancer)*







# CLAPA 2018

## DATING/RELATIONSHIPS

### KEY FINDINGS:

- Entering and remaining in abusive relationships as they were looking for acceptance, forgiving behaviours feeling that “I couldn’t do any better”.
- Promiscuity – using sex as a social currency, sleeping with people and “being easy” was a way to be accepted.
- Not asking people on dates due to a fear of rejection. Assuming rejection is because of cleft.
- Being unsure at what point to disclose that they have a cleft, particularly with online dating – do they put it in their profile? Tell them in chat? Tell them on the first date? Not tell them?
- If cleft palate only and speech is good, it’s easy to put off discussing the subject and then becomes too awkward to raise.
- A perception that prospective partners are interested in the perfect body rather than personality and can be very judgmental.
- A feeling of missing out – particularly in the teenage years when everyone else was dating.



# Adolescents / young people

*"the **worst period for me** was during the periods **when I was a young person and wanted to be courting**, or should have been courting. That was the **very worst period**. And again perhaps I was out of the people insulting me time but I was then into the period of how do I make myself presentable to the opposite sex?" (David, Cleft)*

- Griffiths, Williamson, & Rumsey (2012) mixed-methods, on-line
- N = 40 (22 young men, 18 young women), aged 13-20
  - variety visible differences: 27 = cleft
  - quantitative findings
    - 31 single, 28 (90%) desire relationship
    - 17/40 (43%) report romantic concern
    - 29/40 experience of boyfriend / girlfriend
      - 7/29 feel prevented intimacy with partner



# Adolescents / young people

- Qualitative findings: highlight concern & protective factors
  - **Appearances are important**
    - attractiveness central in securing relationship esp. re: teenagers
  - **'I am unattractive'**

*'I feel that no one would ever want to kiss me; that I look repulsing and my lip is gross' (female, 16, cleft lip repair)*

    - matter less when older
  - **Teasing and bullying**
    - reinforce perception as unattractive
    - reduce self-esteem and confidence
  - **Difficulty talking to the other sex**
    - reduced opportunities
    - persist despite previous success





# Adolescents / young people

- 'Feeling unattractive is normal for teens' (normalise)

*'I don't think that I am very attractive, but many teenagers feel like this, I don't think I feel much different than everybody else' (female, 15, cleft lip repair)*

- Good social skills

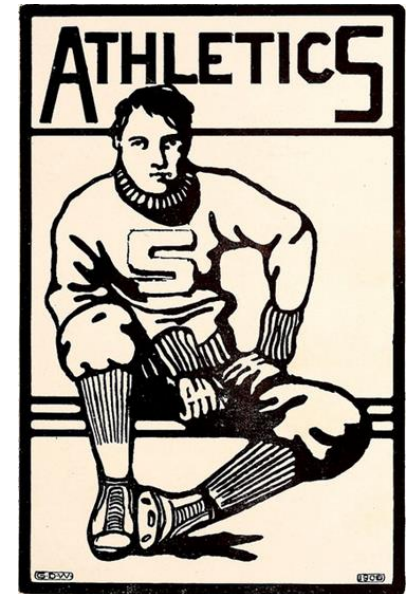
- high self efficacy in romantic relationships

- Valuing other attributes

- importance of 'good personality'

- Perceptions of social support

- friends, family, partners
  - other sex friends reinforce acceptance





# CLAPA 2018

## DECISIONS TO HAVE CHILDREN

### KEY FINDINGS:

- Wanting to know the likelihood of having a child with a cleft.
- Receiving genetic counselling, but then being unsure as to how to interpret that information – e.g. I was given a one in five chance, what decisions do I make now?
- Some adults reported that they would not be concerned if their child had a cleft, as they felt that they would be in a good position to raise that child having known what the journey was like, whilst others felt that a cleft is not something they would wish upon their enemies, let alone their own children. Some adults had chosen not to have children out of concern that they would be born with a cleft.
- Unique set of circumstances where “the whole world comes crashing down” when you are told that your child is going to be born with a cleft – you are given lots of information about cleft (which you already know), but no support to process the unique feelings that come with being an adult with a cleft about to become a parent of a child with a cleft – greater support is needed – a different intervention strategy that provides tailored support.
- A number of people would consider terminating a pregnancy if their child was born with a cleft.
- Feelings of guilt and responsibility when their child is born with a cleft. Some adults had even felt that some family members had assigned blame to them.
- It raised the issue that people did not know what had caused their cleft and they had a desire to know.
- People were keen to know about the environmental factors associated with cleft as they felt these were things that they may be able to mitigate better than the genetic factors.
- People felt they hadn't seen many stories of people being born with a cleft and having had a child with a cleft.
- Feelings of disappointment at not having the perfect child that was expected was reported.
- A lot of adults with a cleft have a lot of anxiety around having a child with a cleft – it is felt that this isn't generally recognised and therefore the first 20 weeks of the pregnancy are very stressful.



What have been the hardest things that have arisen from having been born with a cleft?

- The possibility of passing cleft onto my children
  - Effect of cleft on my children
  - & indication may feel unwelcome in cleft community if terminated pregnancy



# Looking Different: Physicality and Physical Reality

## Our Selfish Genes

- Conditions with (potential) genetic component
- Impact on child's life
  - gendered
- Guilt / responsibility
- Contemplate continuation of pregnancy
  - mention even if to disregard option



**Looking Different:  
Physicality and Physical  
Reality**

**Our Selfish  
Genes**





# Looking Different: Physicality and Physical Reality

*if it was a **girl** I, well, like I said, if, I would've been really, really **heartbroken**. **Not for me but for them** and the impact it would have on their lives (Pete, Cleft)*

*"I actually made a **choice not to have children** and I made that choice very, very young. A) I wouldn't have been able to cope but B) **I didn't want to pass this on**. I wasn't even aware that I could pass it on but **I wasn't taking any chances**. That wasn't a hard decision to make, I'm not that maternal ..."*  
(Pauline, Ichthyosis)

*A plea...*





# CLAPA 2018

## WHAT DO YOU FEEL ARE THE MOST POSITIVE THINGS THAT HAVE COME OUT OF THE FACT THAT YOU WERE BORN WITH A CLEFT?

- Resilience (stated >50 % of the time)
- Empathy/Compassion/Kindness being able to relate to others (stated >60 % of the time)
- Being less judgmental (stated >30 % of the time)
- Led to a fulfilling career (stated >10 % of the time)
- Nothing (stated >10 % of the time)
- CLAPA groups and residentials
- Met friends who saw beyond the cleft
- Being witty

- High pain tolerance
- Increased confidence
- A resolve to do more and work hard
- Awareness of cleft
- Determination (stated >30 % of the time)
- Strength
- Perspective – not sweating the small stuff
- “Made me who I am”
- Spent extra time with parents going to hospital visits etc.





# Looks Help Delineate and Define Relationships:

## Enriching and Fortifying Us



Superficial & fleeting

VS.

Enduring & legitimate

- Knock on effect – relationships
- Support from partner
- Acceptance, trust, commitment
- Personal growth, confidence

Looks Help  
Delineate and  
Define Intimate  
Relationships

Enriching and  
Fortifying Us



# Looks Help Delineate and Define Relationships: Enriching and Fortifying Us

*"I believe that... being born with a cleft has certainly had an influence on how I am now as an adult... and that's probably been to an extent fairly positive in that it colours the way I approach things and stuff. I think my cleft has made me who I am and that led to us having our relationship"*

*(Anthony, Cleft)*

*"a lot of marriages around us have crumbled along the wayside and they've gone for looks and it hasn't, perhaps it hasn't work..... it makes the relationship much stronger in that it's not shallow, because a lot of people I know, you go for looks, they go for money or they go for a combination of both and you cannot then, if the relationship has a slightest bump in the road it derails... whereas... I know that [wife's name] sees me for what I am"*

*Pete, Cleft*





# Visible difference & intimacy

Nearly there...

Just a little more research...



# Visible difference & intimacy



- **Quantitative work**

- Developed research measure "CARRIS"
- EFA 250 participants (but only small no. craniofacial conditions)
- CFA 148 participants (only small no. craniofacial conditions)
  - Included in CLAPA Adult Voices Survey
- Three main domains
  - **sexual anxiety / self consciousness**
  - **negative evaluation**
  - **partner support / understanding**





# Visible difference & intimacy: who needs help?

- **Age** no significant correlation
- **Years since acquired** no significant correlation
- **Visibility** no difference
- **Cause** no effect
- **Nature** few effects
- **Location** few effects
- **Treatment** receiving 'worse' vs. not
- **Gender** women 'worse' than men
- **Relationship status** generally 'worse' if single





# Visible difference & intimacy:

## CLAPA 2018 Adult Voices Data

- 'My' data
  - 243 people, min 16, max 100
    - Mean 59.09
  - 148 people, min 24, max 99
    - Mean 62.36
  - 51 people (re-test), min 19, max 93
    - Mean 58.57
- CLAPA data
  - 148 people, min 16, max 100
    - Mean 47.59
    - Significantly less than all above... but...





# Visible difference & intimacy:

## CLAPA 2018 Adult Voices Data

- **Age** no significant effect
- **Religion** no significant effect
- **Cleft type** no significant effect  
(C-Pal 45.6 / C-Lip & P 47.6 / C-Lip 49.0)
- **Gender** no significant difference  
(women 48.7 men 45.5)
- **Relationship status** significant effect

Cohabit	55.8
Divorce or Sep	52.1
Single	52.1
Married or CP	43.9
R-ship live apart	41.3





# Visible difference & intimacy: summary

- Visible difference understood impact adults & adolescents
- Spans:
  - attraction / initiation
  - early interactions
  - physical intimacy
  - life of relationship
- Challenging for some
- Can be lack of support (inc. HCPs)
- Potential for positive impacts... but

**More support required**





# Visible difference & intimacy: summary

- Acknowledge as difficult area
- Don't feel alone / that it's wrong
- Consider discussing with those close to
  - consider talking to partner / other
  - utilise social support
- Plan disclosure / discussions, ensure comfortable
- Possible anything that > self-esteem / acceptance = help
- Try to identify & value positives
- Value who and what you are
- Question & challenge why (& whether) appearance matters
- Conceptualise responses as other's responsibility





# Thank you...

- Participants
- Support groups / organisations
- CLAPA, Kenny, and colleagues
- Colleagues & supervisors at CAR
- VTCT Foundation







## **The Centre for Appearance Research**

Soundcloud / iTunes:  
Appearance Matters: The  
Podcast!

Twitter:  
Appearance Research  
@CAR\_UWE

Facebook:  
@AppearanceResearch

*Episode 24: Visible Difference and Romantic Relationships*  
*Qualitative article recently published in [Body Image](#)*



# Afternoon Tea



Be sure to check out the exhibit tables!





MRI in the management of  
patients with a repaired cleft  
palate:  
could its role be increased?

Matthieu Ruthven

*Barts Health NHS Trust*



# The project

- Collaboration between SLTs and Medical Physicists
- Started in 2008
- Aim to increase the role of MRI in the management of patients with a repaired cleft palate

Great Ormond Street  
Hospital for Children

NHS Foundation Trust



**Barts Health**  
NHS Trust



# What is MRI?

- Magnetic Resonance Imaging
- A way to take pictures and videos of the inside of the body
- The pictures and videos help clinicians make diagnoses





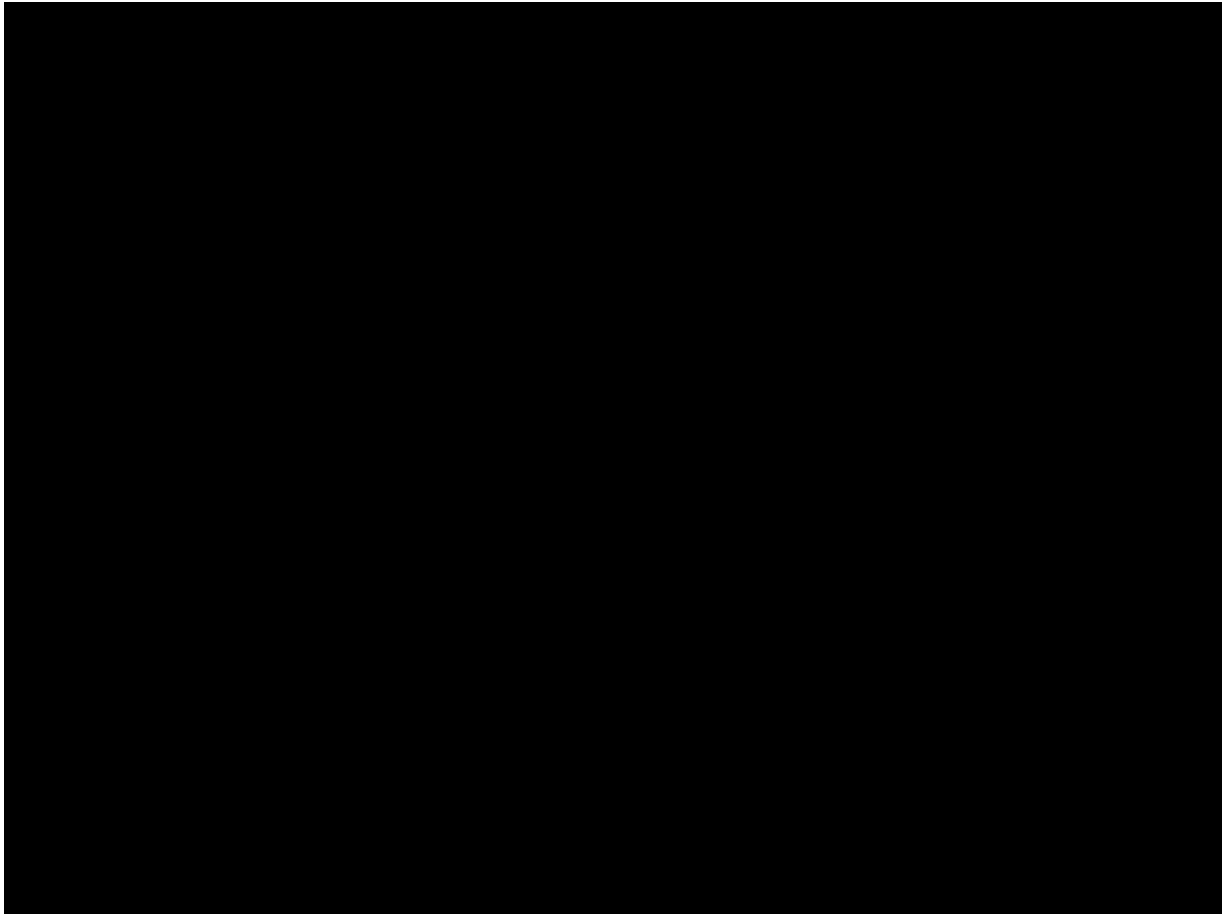
# What is MRI?

- Magnetic Resonance Imaging
- A way to take pictures and videos of the inside of the body
- The pictures and videos help clinicians make diagnoses





# Why should its role be increased?





# Why should its role be increased?

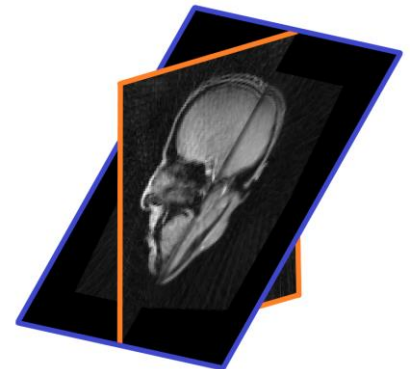
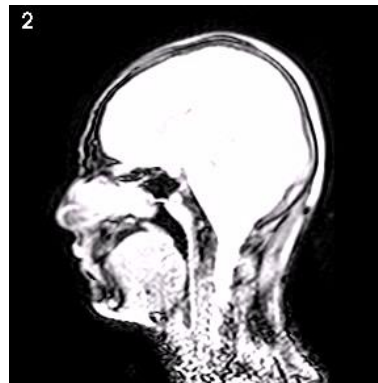
- MRI can take:
  - 2D and 3D pictures
  - 2D videos
- The pictures show the muscles that move the soft palate
  - Help clinicians decide on the best treatment for a patient





# Stages of the project

1. Develop ways to take 3D pictures & 2D videos using MRI
2. Take 2D videos & 3D pictures of patients with a repaired cleft palate
3. Develop ways to take 2D MRI videos from two different views





# Stages of the project

1. Develop ways to take 3D pictures & 2D videos using MRI
2. Take 2D videos & 3D pictures of patients with a repaired cleft palate
3. Develop ways to take 2D MRI videos from two different views





# Stage 1: 3D pictures & 2D videos

- Medical Physicists developed several different ways
- Tested these on 6 adult volunteers
- Found the ways that took the best videos





# Stage 1: 3D pictures & 2D videos

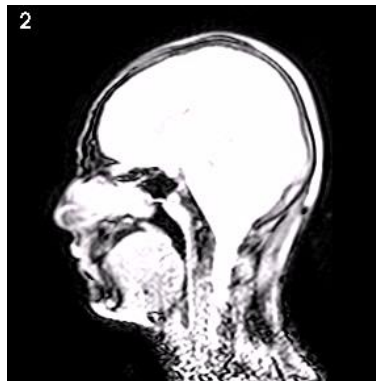
- Medical Physicists developed several different ways
- Tested these on 6 adult volunteers
- Found the ways that took the best videos





# Stages of the project

1. Develop ways to take 3D pictures & 2D videos using MRI
2. Take 2D videos & 3D pictures of patients with a repaired cleft palate
3. Develop ways to take 2D MRI videos from two different views





# Stage 2: repaired cleft palate study

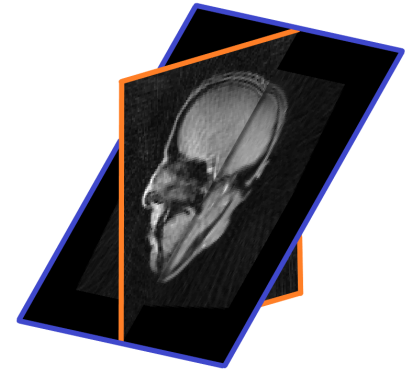
- 10 patients (2 before and after surgery)
- SLTs assess videos
- Compare MRI assessment with X-ray videofluoroscopy and nasendoscopy assessment





# Stages of the project

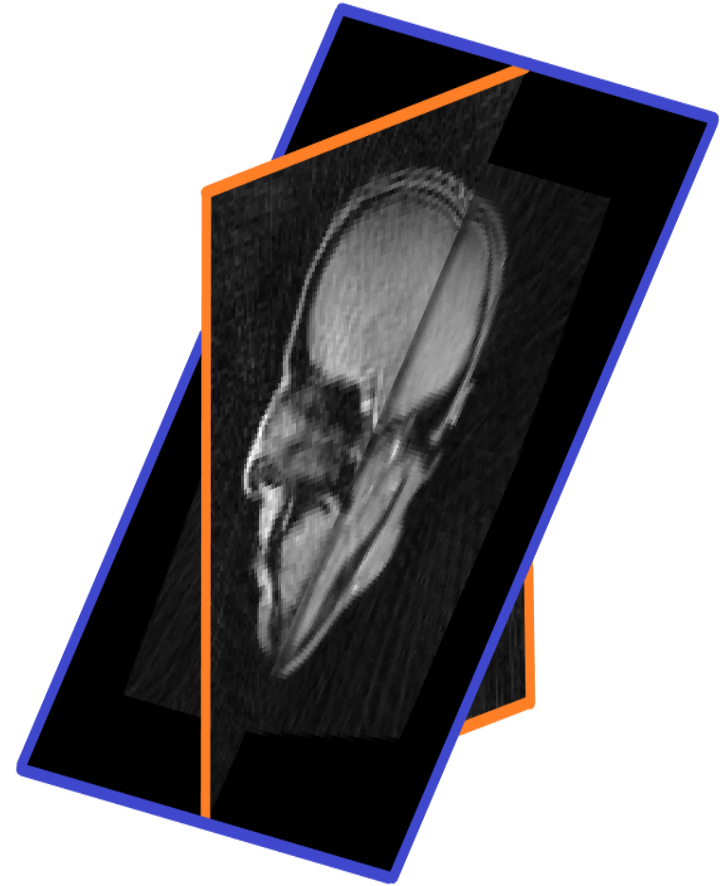
1. Develop ways to take 3D pictures & 2D videos using MRI
2. Take 2D videos & 3D pictures of patients with a repaired cleft palate
3. Develop ways to take 2D MRI videos from two different views





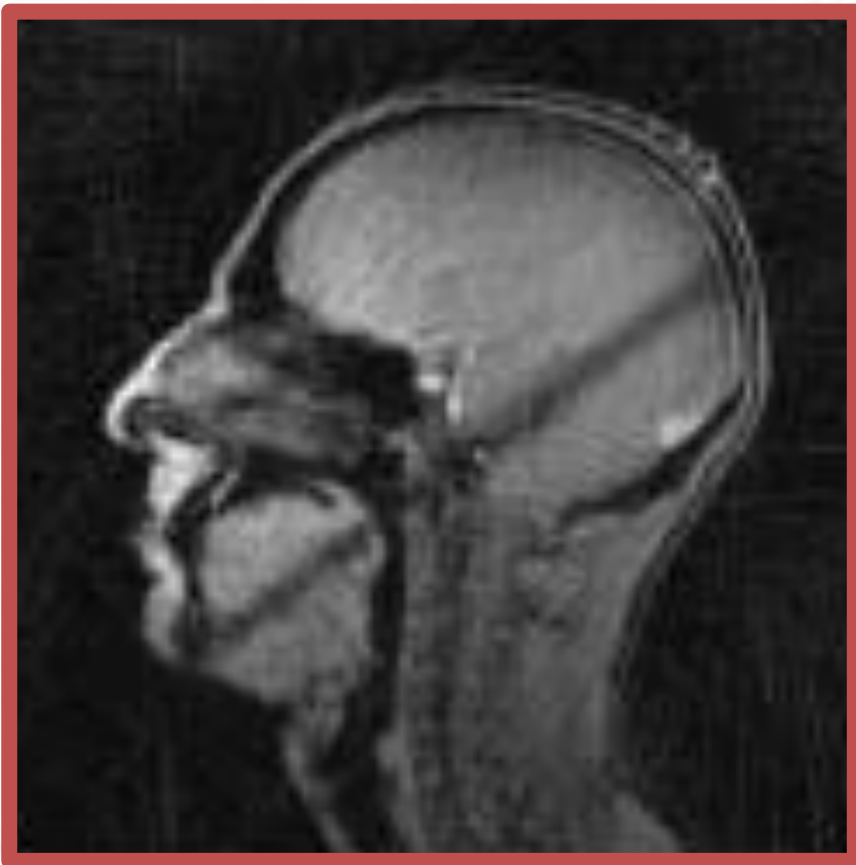
# Stage 3: two-view imaging

- Medical Physicists developed a way
- Tested it on 7 adult volunteers
- 1<sup>st</sup> view like X-ray videofluoroscopy view
- 2<sup>nd</sup> view like nasendoscopy view





## Stage 3: two-view imaging





# Future work

- Develop ways of taking 3D videos of the inside of the mouth using MRI
- Develop resources to explain speech MRI examinations to patients and their families





# Thanks

## Team:

- Marie Pinkstone
- Debbie Sell
- Malcolm Birch
- Marc Miquel
- Matthieu Ruthven
- Andrew Scott
- Marzena Wylezinska

## Funders:





The background is a light blue gradient with several realistic water droplets of various sizes scattered across it. Some droplets are in the top left, some in the bottom right, and others are smaller and more numerous in the center and bottom. The droplets have highlights and shadows, giving them a three-dimensional appearance.

# **Strategies for dealing with chronic pain and discomfort**

Dr. Amanda Bates, Patient Experience and Public Involvement Lead

Chartered Psychologist

Centre for Health Services Studies

University of Kent



# What is pain?



**THE BRITISH  
PAIN SOCIETY**  
EXPERTISE WHERE IT MATTERS

- Health professionals use different terms for different types of pain.
- Short-term pain is called Acute Pain. An example is a sprained ankle.
- Long-term is called Persistent or **Chronic Pain**. Back trouble or arthritis are examples.
- Pain that comes and goes is called Recurrent or Intermittent Pain. A toothache could be one.

(The British Pain Society, <https://www.britishpainsociety.org/people-with-pain/frequently-asked-questions/#what-is-pain>)



# Chronic pain (1)



**THE BRITISH  
PAIN SOCIETY**  
EXPERTISE WHERE IT MATTERS

- Many acute pains are like an alarm telling us something is wrong. Here the pain is helpful.
- Chronic pain often serves no useful purpose. Medical assessment and diagnosis does not usually lead to the pain going away and over time it may affect what we can including ability to work and sleep patterns may be interrupted. It can affect mood and relationships with our family and friends too.



- Pain signals from injury normally travel to the brain via specialised nerve fibres and the spinal cord. these nerves also process the pain signals. All together they work like a very powerful computer.

(The British Pain Society <https://www.britishpainsociety.org/people-with-pain/frequently-asked-questions/#what-is-pain>)



# Chronic pain (2)



- Sometimes this computer system can go wrong. The messages get confused and the brain cannot understand the signals properly. This is one reason for chronic pain, which can be very difficult to treat because we cannot just re-boot the system.
- Pain usually causes strong emotions and these can interact with our other feelings. If we are angry, depressed or anxious, our pain may be worse.
- Alternatively if we are feeling positive and happy, our pain may be less and we are able to cope better.



# Complexity of pain



- Pain is never ‘just in the mind’ or ‘just in the body’. It is a complicated mixture of signals from the body and how the brain interprets them. You know your pain, even though it cannot be seen. The challenge for you and those treating you is to understand the complicated nature of long-term pain and the best way to manage it.

(The British Pain Society, <https://www.britishpainsociety.org/people-with-pain/frequently-asked-questions/#what-is-pain>)





# Current available information on cleft treatment and chronic pain

- Very little!
- Survey information and information from Adults Roadshows is as much as I can find
- 15% of people commented on the experience of chronic pain/discomfort at the Adults Roadshows
- Own personal experience...
- How about you?





## NHS quote



“The old-fashioned treatment for persistent pain, also known as chronic pain, was bed rest for weeks or months on end. We now know this is the worst possible approach.”

<https://www.nhs.uk/live-well/healthy-body/ways-to-manage-chronic-pain/?tabname=head>



# Drawing on wider information about pain management

- Everyone is different!
- We all experience pain/sensations differently
- So different management techniques for different people and even different types of pain
- Develop own ways of coping
- Will share some strategies which have proved successful for different types of pain
- Dr. Kate Hamilton-West (book) and information from the British Pain Society, Pain Concern UK, and the NHS, including the Pain Toolkit (therefore backed up by evidence)



# Pain clinics

- People with chronic pain may be able to attend a specialist Pain Clinic for assessment and possible pain management, together with advice on living a fuller life in spite of pain.
- Pain Clinics vary in the treatments offered and not all hospitals may have a specific pain clinic. Sometimes a Consultant with an interest in pain will prescribe drugs or give injections to try to control pain. Other clinics have teams of doctors, psychologists, nurses, physiotherapists, occupational therapists and others.





# Pain Management Programmes

- Available in some areas. Provides many self-management tools
- Delivered in a group setting by a team of experienced health care professionals working closely with patients
- Aim to teach a group of patients with similar problems about pain how best to cope with it and how to live a more active life, others may offer acupuncture and other complementary therapies
- Your GP can help you find a local PMP or visit the [British Pain Society](#)



# Acceptance

- Acceptance is not about giving up
- It's recognising that you need to take more control with regards to how you can better self manage your pain
- Willingness to do things differently.

(The Pain Toolkit)

<https://www.paintoolkit.org/>





# **‘Effective’ coping**

- Distraction
- Venting emotions
- Relaxation
- Arranging pleasant activities
- Reaching out – social support

(See Hamilton-West, 2011)





# Distraction

- Distraction means shifting or moving your attention away. It does not mean that the pain is no longer there
- It just means that you use your brain to focus your attention onto something else
- You can put your pain in the background and focus instead on using breathing techniques, listening to music, audio books, and many other activities
- One of the things that you can do to limit the amount of time you spend worrying about or being afraid of pain, is to use distraction.

(see Pain Management Network)

<https://www.aci.health.nsw.gov.au/chronic-pain>





# Venting emotions

- Let it out! Don't bottle it up.
- Expressing emotion associated with better outcomes rather than avoiding and holding back emotion
- Some people find writing about stressful and or/positive experiences helpful (Pennebaker & Beall, 1986; King & Miner, 2000)
- Mindful of who to confide in and where
- Be careful that it doesn't spiral into 'victimhood'.





# Stress and how it is linked to pain

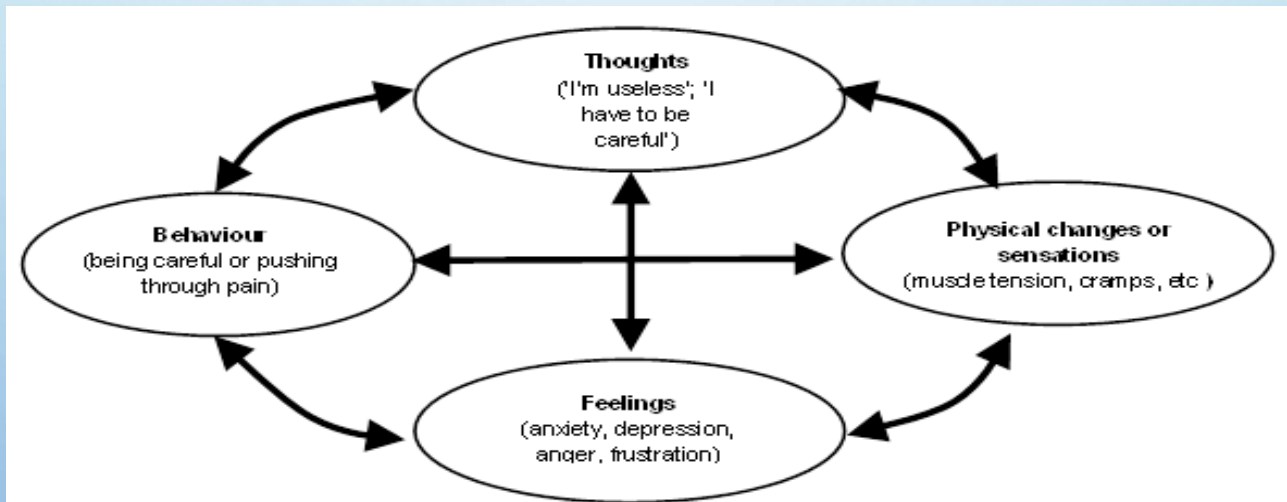
- Stress leads to physical reactions that can increase pain, e.g. increased muscle tension around an area that is already sore is likely to make it even more painful.
- Stress also produces changes in the body's hormonal systems. These changes are thought to affect the pain system, making it more sensitive.

(Pain Concern UK, <http://painconcern.org.uk/>)





# Pain and stress cycle (Pain Concern UK)





# Relaxation techniques

- Calming breathing exercise:

<https://www.nhsinform.scot/healthy-living/mental-wellbeing/stress/breathing-and-relaxation-exercises-for-stress>

- Progressive Muscle Relaxation

<https://www.youtube.com/watch?v=adewguFHjGM>





# Mindfulness (1)

- NHS info on Mindfulness - <https://www.nhs.uk/conditions/stress-anxiety-depression/mindfulness/>
- “Paying attention to something on purpose and with fresh eyes”
- Instead of focusing on wanting the pain to stop, we pay attention to our pain with curiosity and without judgment. Pain sensations typically result in our minds making judgments and having negative thoughts.
- “We judge the pain, and that only makes it worse.” Negative thoughts and judgments make the pain worse and can also fuel anxiety and depression.
- Minds start scrambling for solutions to ease the pain. This “creates a lot of frustration, stress and feeling trapped.” (Goldstein, 2012)

(see <https://psychcentral.com/lib/using-mindfulness-to-approach-chronic-pain/>)



# Mindfulness (2)

- You can't necessarily control your pain sensation but you can choose how to respond to it
- You are not your pain.
- Pain is a physical sensation, not your identity.
- You are a whole human being who is dealing with a medical condition.
- By learning to be mindful, you can observe pain with a stable, compassionate and curious mind. You can identify pain sensations and your physical, mental and emotional reactions to pain sensations. This alone is helpful.
- By training your mind to be in the **present moment**, you also worry less about the future and put your energy into skillful choices and living well today.



<https://www.swedish.org/services/pain-services/pain-management-guide/mindfulness>



# Mindfulness (3)

- Mindfulness meditation involves sitting silently and paying attention to thoughts, sounds, the sensations of breathing or parts of the body, bringing your attention back whenever the mind starts to wander

- <https://www.youtube.com/watch?v=uZEHwEtnaak> (exercise)

- <https://www.youtube.com/watch?v=3TK2zTuqRmg> (exercise)

- <https://bemindful.co.uk/> (includes online course)





# Reaching out - social support

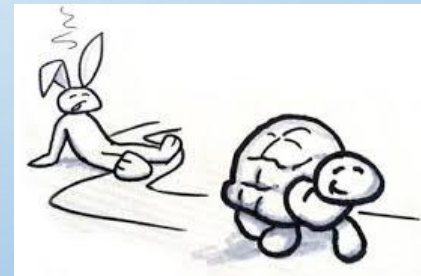
- Peer group sessions
  - Telephone peer contacts
  - Internet based peer communications
- (Van Dam et al. 2005)
- Family and friends





## Further strategies

- Pacing activities, alternating them, planned breaks
- Hot / cold compress
- Desensitisation – although seek advice first





# Other resources

- **Retrain Pain** – free online course - a science based approach to reducing symptoms
- **Expert Patient Programmes** - free self management course for people with a long-term condition. There are schemes in England and in Wales
- The six week course is delivered by accredited tutors. Most tutors have a long-term health condition. The course aims to give people the confidence to self-manage their health and to be active participants in the care of their condition. Rather than focussing on specific conditions, the course looks at general topics including healthy eating, dealing with pain and fatigue, relaxation techniques and coping with negative feelings (taken from <https://www.mstrust.org.uk/a-z/expert-patients-programme>)
- **NHS Fitness Studio** - <https://www.nhs.uk/conditions/nhs-fitness-studio/?tabname=pilates-and-yoga>



## Over to you!

- What has been helpful to you in managing pain/tightness/altered sensations?

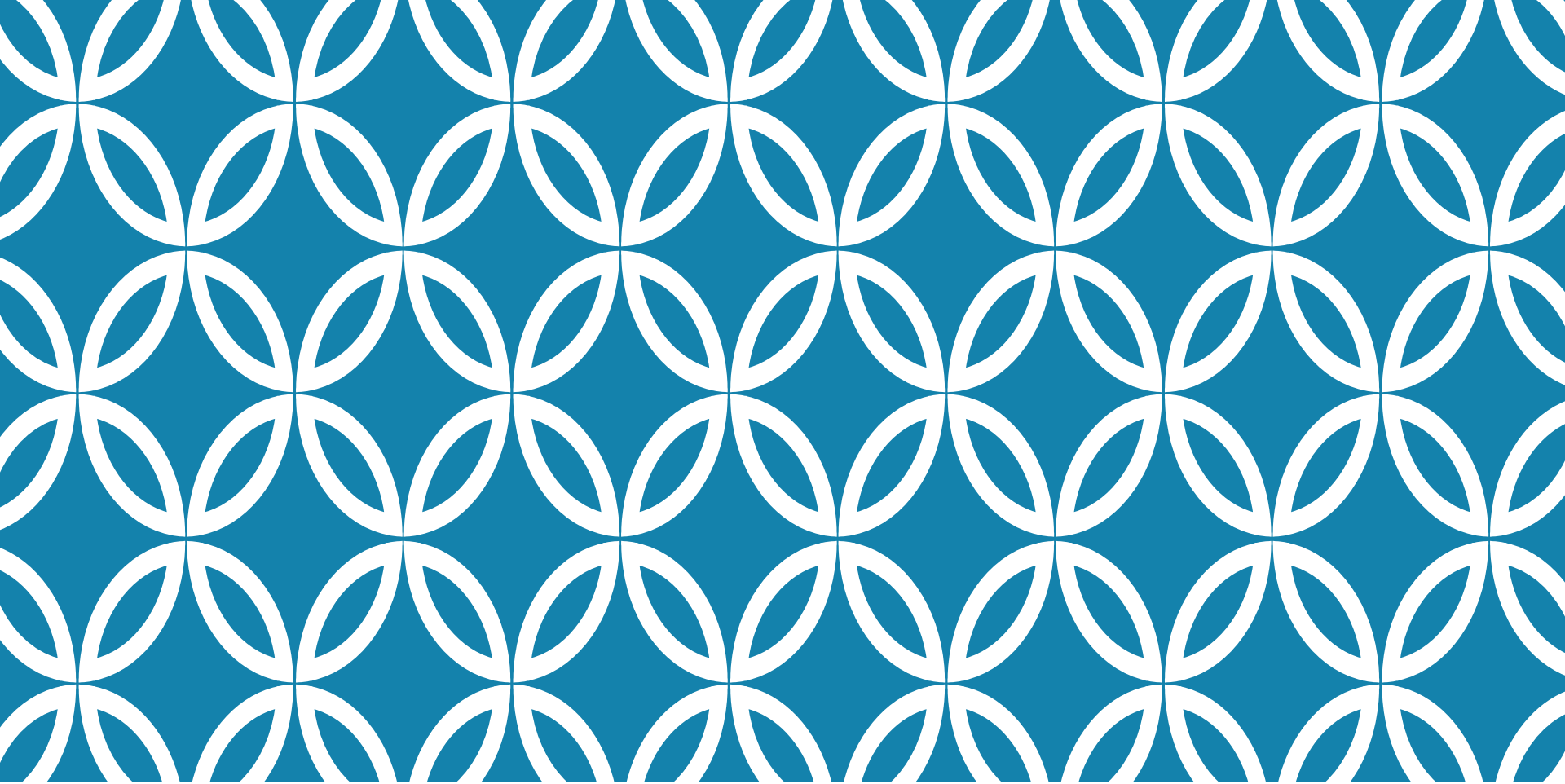




# References

- van Dam, H. A., van der Horst, F. G., Knoop, L., Ryckman, R. M., Crebolder, H. F., & van den Borne, B. H. (2005). Social support in diabetes: a systematic review of controlled intervention studies. *Patient education and counseling*, 59(1), 1-12.
- Goldstein, E. (2012). *The now effect: How this moment can change the rest of your life*. Simon and Schuster.
- Hamilton-West, K. (2011). *Psychobiological Processes in Health and Illness*. Sage Publications.
- King, L. A., & Miner, K. N. (2000). Writing about the perceived benefits of traumatic events: Implications for physical health. *Personality and social psychology bulletin*, 26(2), 220-230.
- Moore, P. (2018). The Pain Toolkit. Retrieved from <https://www.paintoolkit.org/>
- Pennebaker, J. W., & Beall, S. K. (1986). Confronting a traumatic event: toward an understanding of inhibition and disease. *Journal of abnormal psychology*, 95(3), 274.





# IDENTITY, SELF- CONFIDENCE AND ANXIETY

Kate and Chrissy





# OUR IDEAS ABOUT OURSELVES

What makes up who we  
are, and how we can  
recognise our positives.

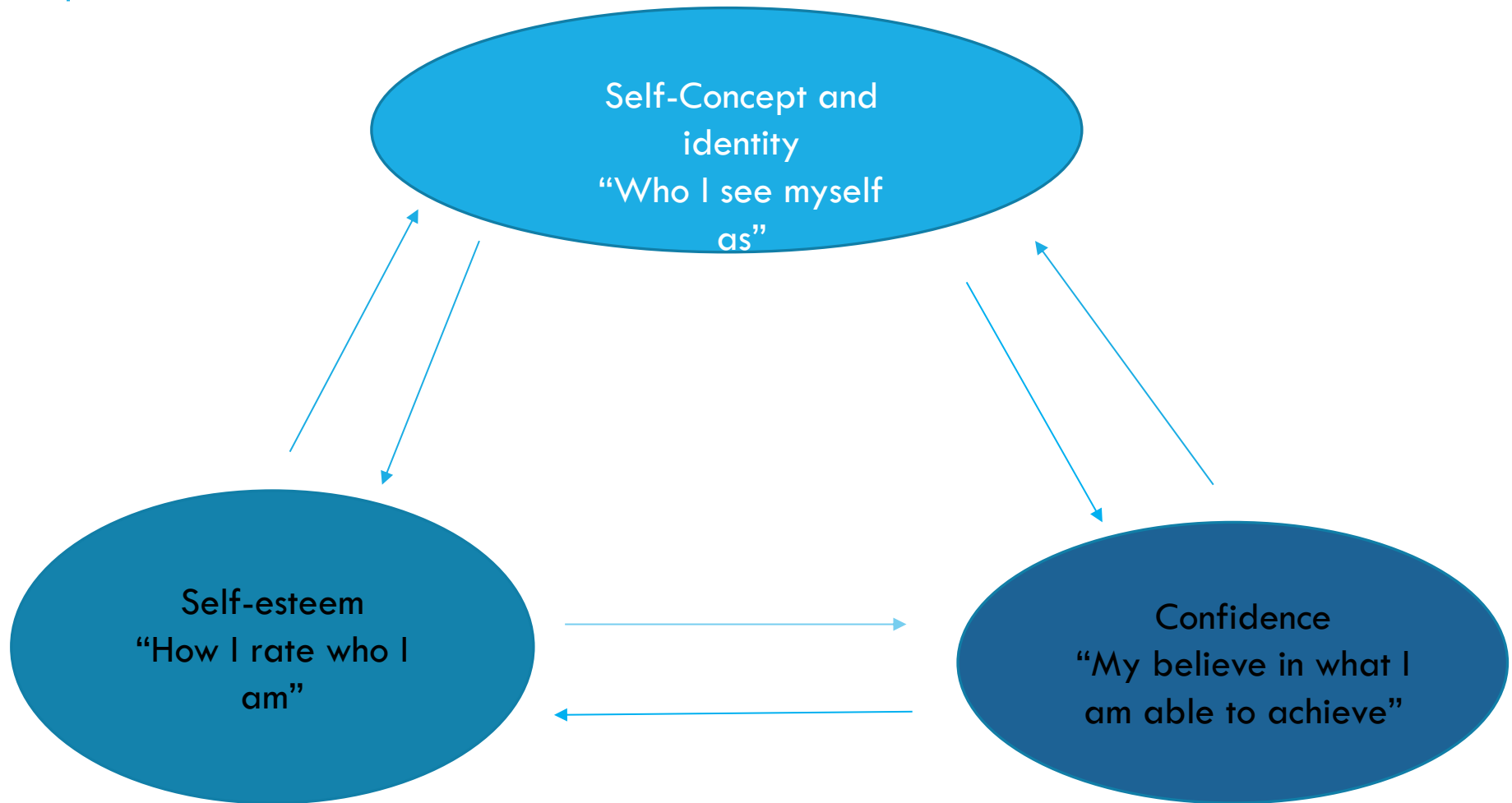


# WHAT ARE SELF-CONCEPT, SELF-ESTEEM AND SELF-CONFIDENCE?



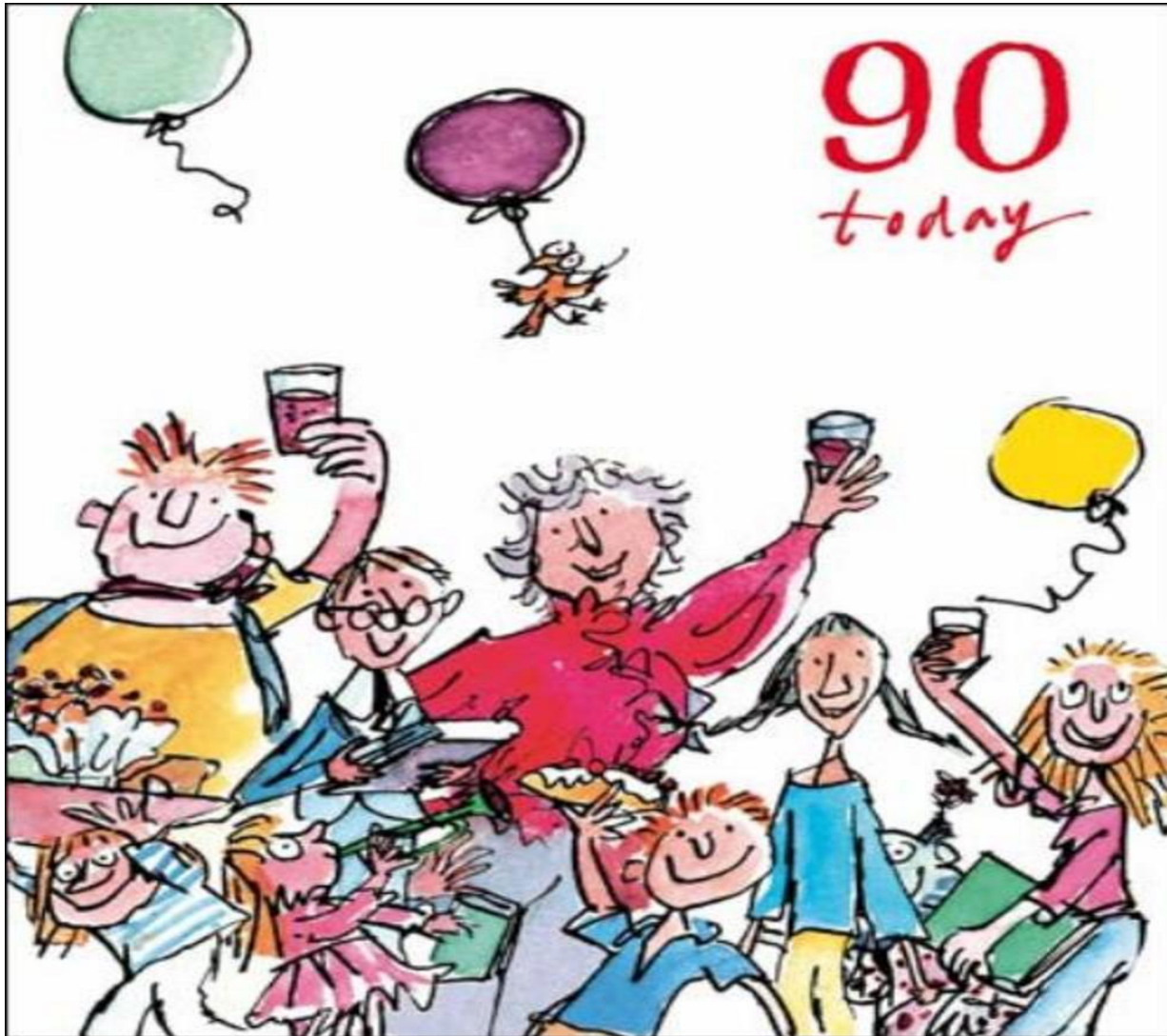


# HOW THESE CONCEPTS INTERACTS





# 90<sup>TH</sup> BIRTHDAY PARTY EXERCISE





# FEEDBACK

- How did it feel focusing on the positive things about you?
- Was there anything that surprised you?
- What do you think it showed you about your identity, self-concept, self-esteem and confidence?





# ANXIETY

Why it's there and how  
it can be managed.



# ANXIETY

- From our cave-man days, we are equipped with an internal alarm system designed to protect us from the dangers surrounding us in the wild.
- This system make us hyper-alert by giving us a boost of adrenaline that increases the heart rate and boost the amount of oxygen going to our limbs so we were better able to deal with danger. This is known as the “fight, flight or freeze” response.
- Nowadays, instead of being used to avoid immediate danger, it is often inappropriately activated during normal, everyday situations when stress has built up, often unknowingly.
- With no intervention, this response rises, and then decreases and abates on its own



## Fight Or Flight Response

When faced with a life-threatening danger it often makes sense to run away or, if that is not possible, to fight. The *fight or flight response* is an *automatic* survival mechanism which prepares the body to take these actions. All of the body sensations produced are happening for good reasons – to prepare your body to run away or fight – but may be experienced as uncomfortable when you do not know why they are happening.

### Thoughts racing

Quicker thinking helps us to evaluate danger and make rapid decisions. It can be very difficult to concentrate on anything apart from the danger (or escape routes) when the fight or flight response is active

### Changes to vision

Vision can become acute so that more attention can be paid to danger. You might notice 'tunnel vision', or vision becoming 'sharper'

### Dry mouth

The mouth is part of the digestive system. Digestion shuts down during dangerous situations as energy is diverted towards the muscles

### Heart beats faster

A faster heart beat feeds more blood to the muscles and enhances your ability to run away or fight

### Nausea and 'butterflies' in the stomach

Blood is diverted away from the digestive system which can lead to feelings of nausea or 'butterflies'

### Hands get cold

Blood vessels in the skin contract to force blood towards major muscle groups

### Muscles tense

Muscles all over the body tense in order to get you ready to run away or fight. Muscles may also shake or tremble, particularly if you stay still, as a way of staying 'ready for action'

If we don't exercise (e.g. run away or fight) to use up the extra oxygen then we can quickly start to feel dizzy or lightheaded

### Breathing becomes quicker and shallower

Quicker breathing takes in more oxygen to power the muscles. This makes the body more able to fight or run away

### Adrenal glands release adrenaline

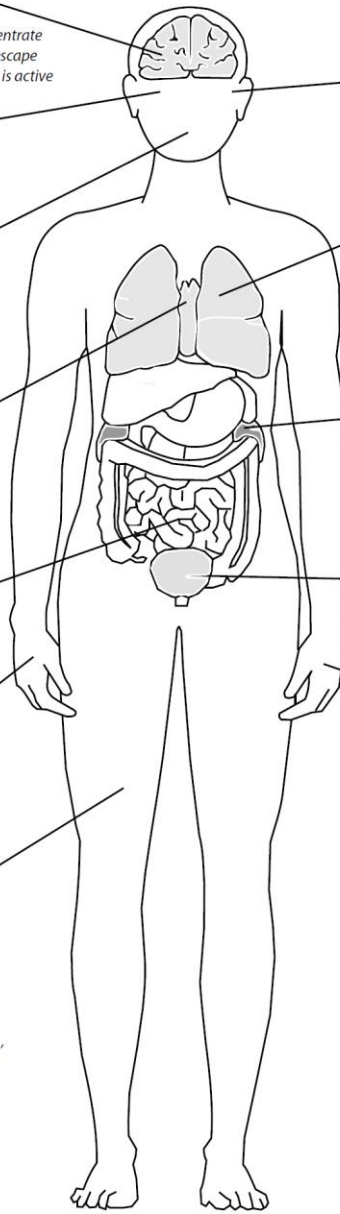
The adrenaline quickly signals other parts of the body to get ready to respond to danger

### Bladder urgency

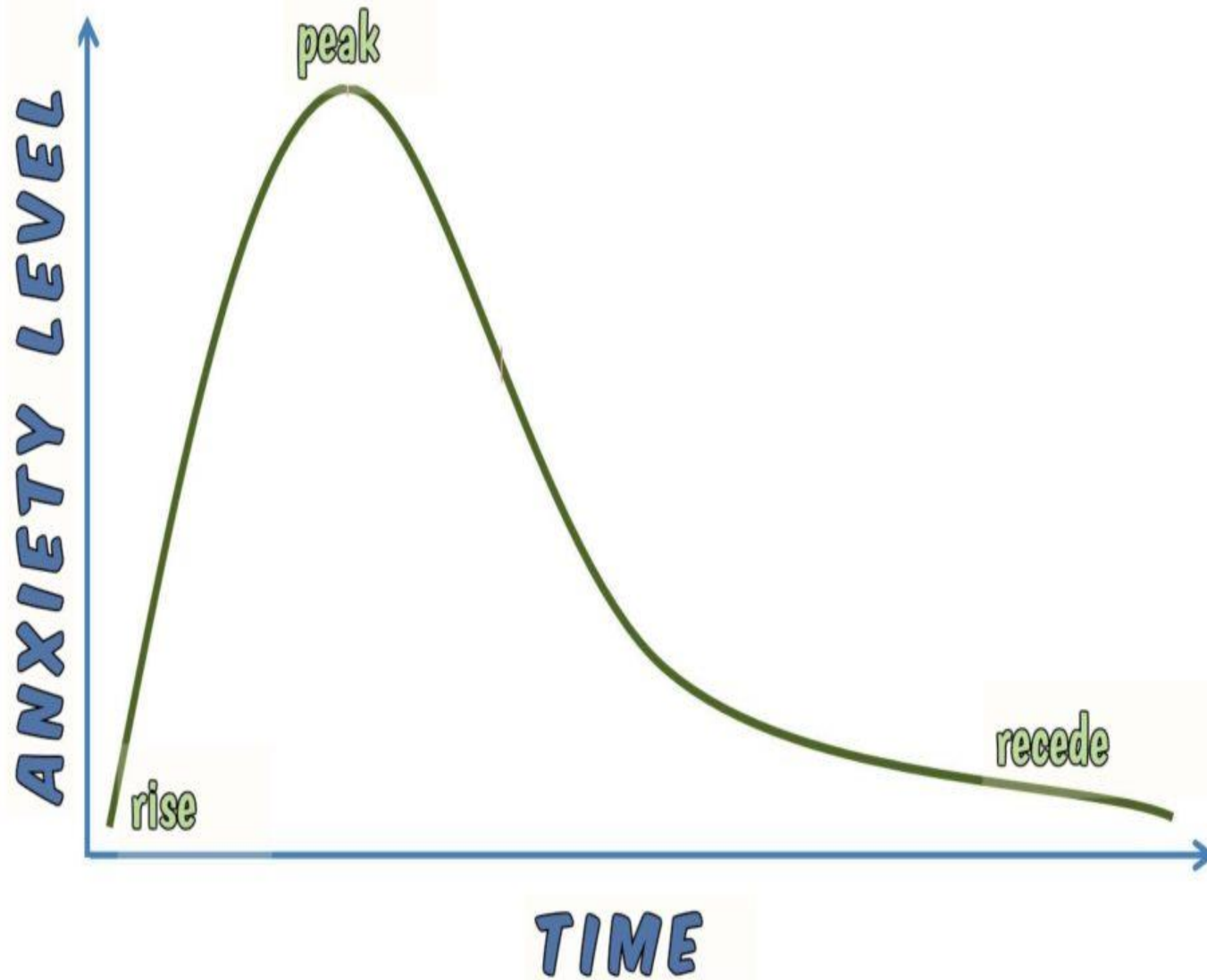
Muscles in the bladder sometimes relax in response to extreme stress

### Palms become sweaty

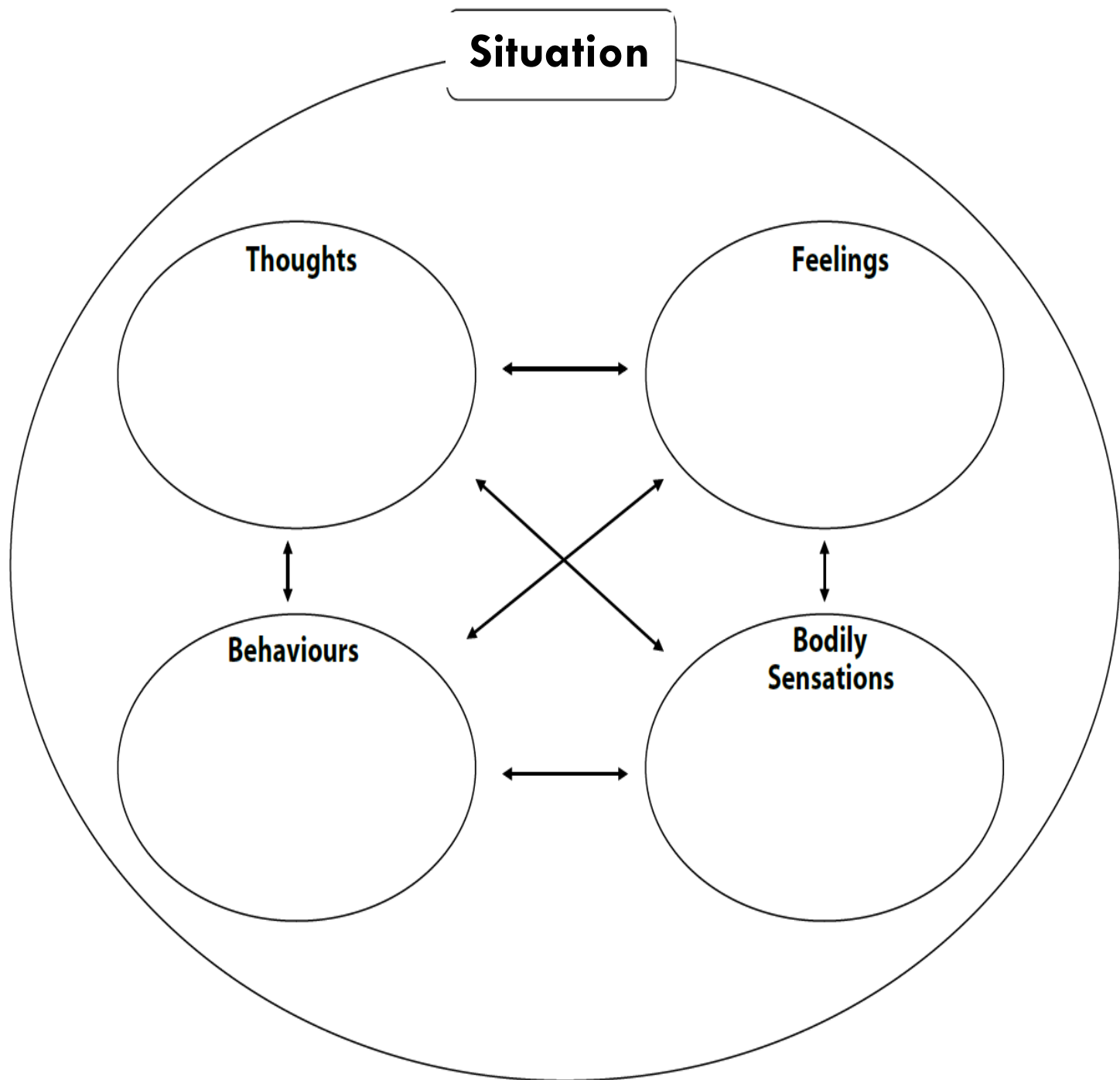
When in danger the body sweats to keep cool. A cool machine is an efficient machine, so sweating makes the body more likely to survive a dangerous event







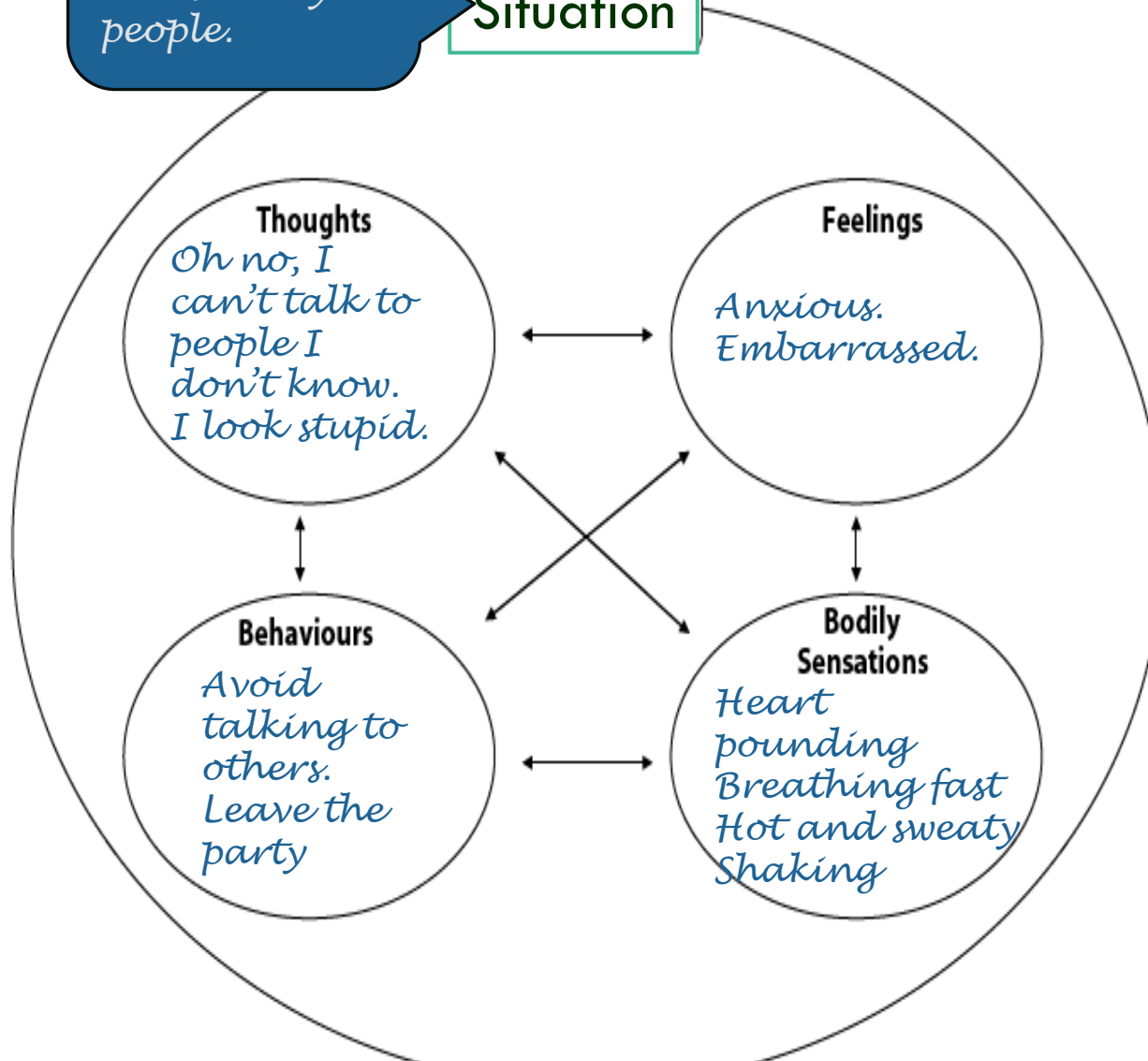






*You arrive at a party where you don't know many people.*

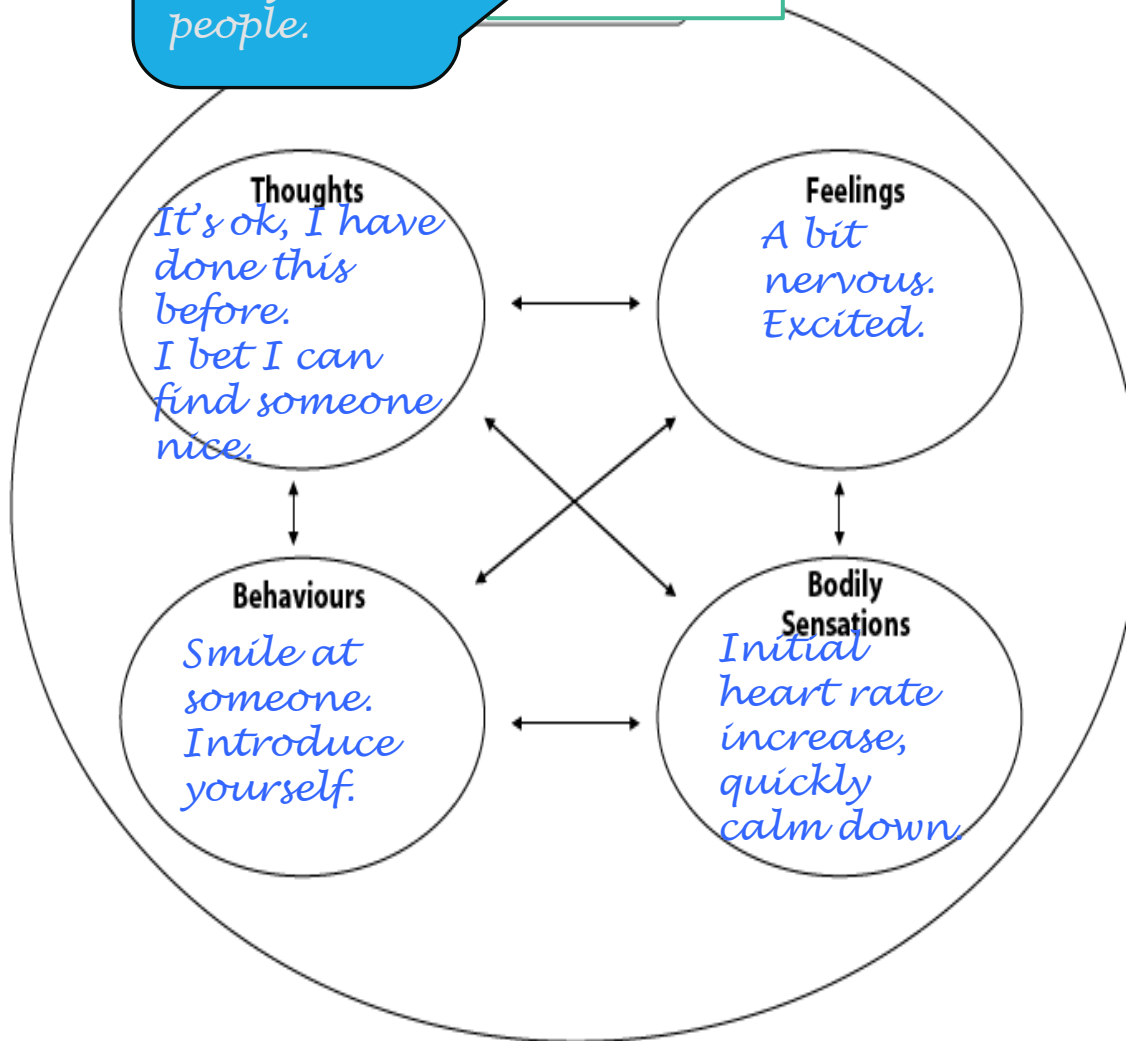
**Situation**





You arrive  
at a party  
where you  
don't know  
many  
people.

## Situation





# HOW CAN WE CHALLENGE UNHELPFUL ANXIETY RESPONSES?

## ➤ Challenging unhelpful cycles:

These strategies can be practiced to help maximise helpful behaviours and minimise ones which stop you doing things in situations in which you know you regularly become anxious.

## ➤ In the moment strategies:

These are things you can use in the moment when you feel your anxiety rising as a way to bring it down.



# CHALLENGING UNHELPFUL CYCLES

## ➤ Exposure.

The usual response is to avoid situations which cause us anxiety, however this can make our anxiety about something greater, and end up missing out. Exposure asks us to think of a situation which involves the most anxiety we could manage, and then go through it, showing us it is tolerable.

## ➤ Behavioural activation.

Anxiety can stop us doing things. Behavioural activations asks us to look at what we are not doing, and make plans which allow us to start, even just a little bit.



# BEHAVIOURAL ACTIVATION CHALLENGE

- What are you avoiding?
- How could you do it?
- Could you do it for 5 minutes?



# MANAGING ANXIETY IN THE MOMENT

There are a number of strategies, which can lead to feeling less anxious in general, and can also be used in the moment when you can feel yourself becoming anxious to manage the experience. These include:

- Mindfulness.
- Progressive muscle relaxation.
- Diaphragmatic breathing.
- Visualisation.

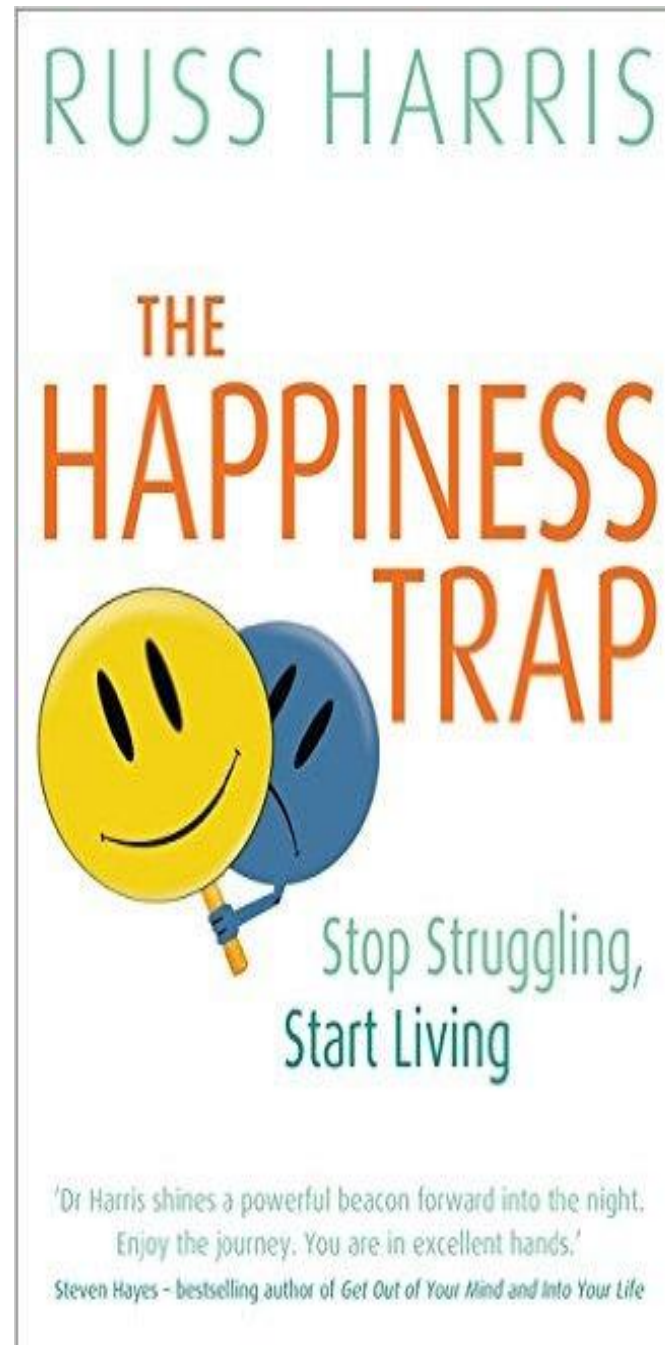


# RESOURCES

- Headspace app - <https://www.headspace.com/>
- Mind - <https://www.mind.org.uk/>
- <https://web.nrw.nhs.uk/selfhelp/>
- <https://www.clapa.com/treatment/nhs-cleft-teams/>
- See your GP – consider a referral to Psychological therapies (IAPT) services

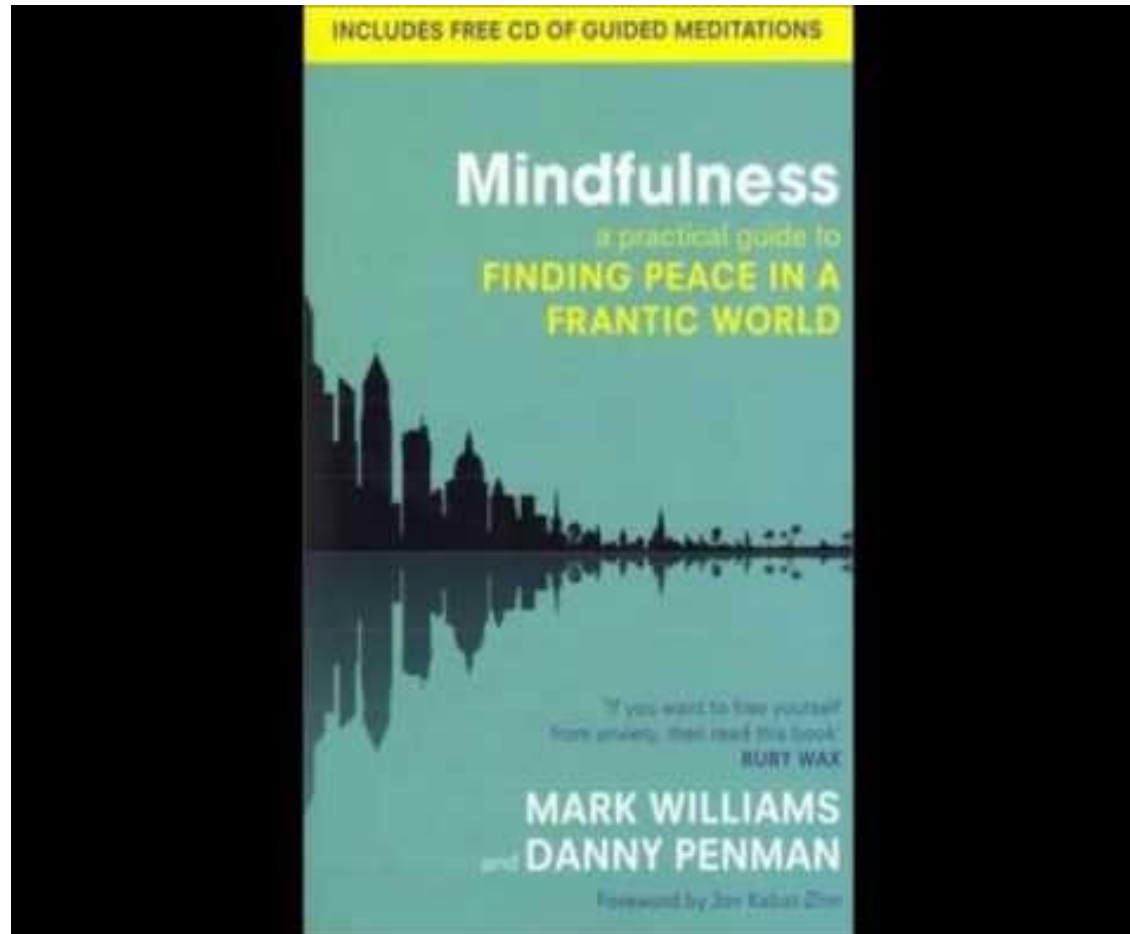


# RESOURCES

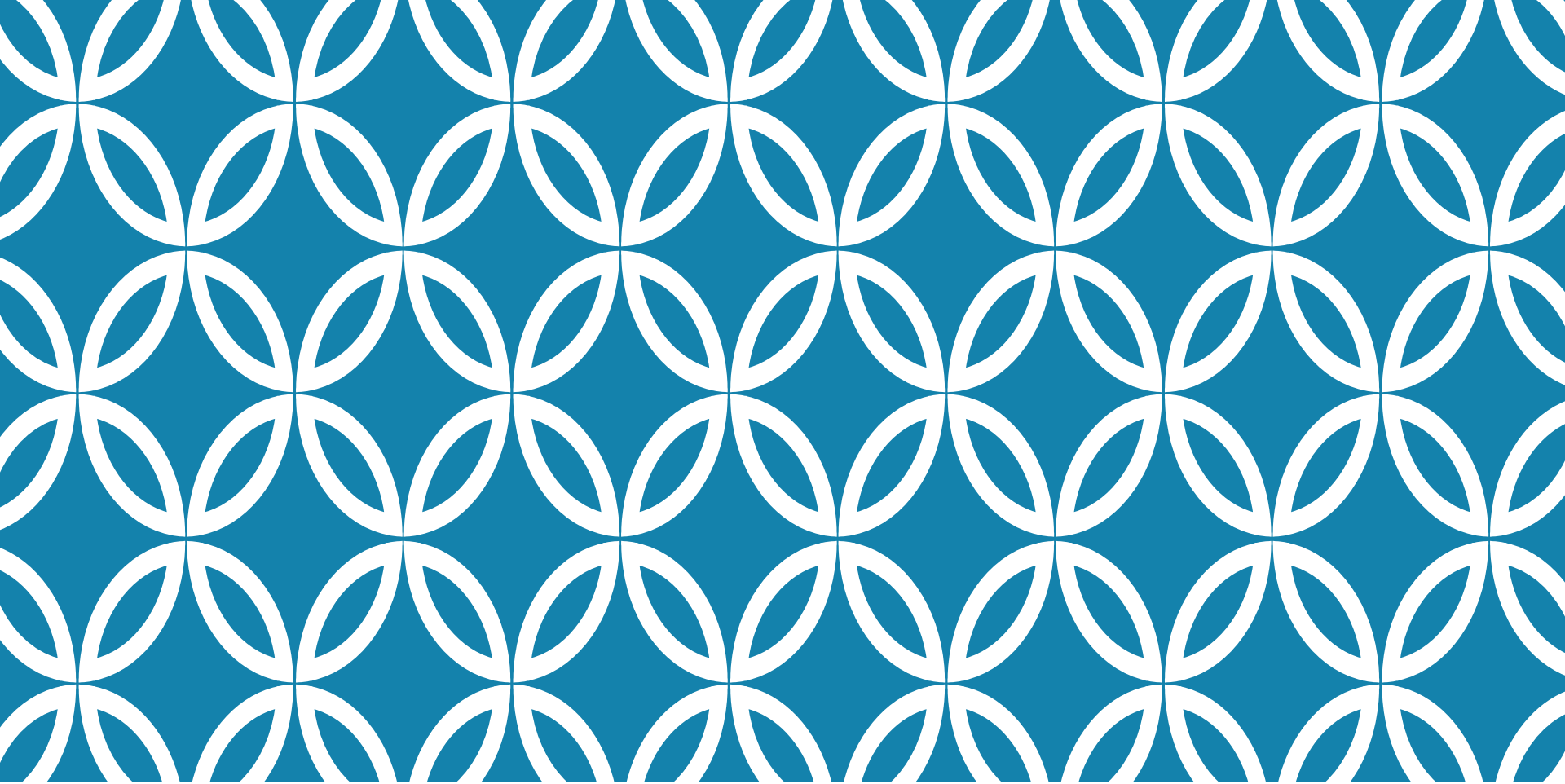




# THE THREE MINUTE BREATHING SPACE







**THANK YOU!**

Any Questions?



# Next Steps for the Adult Services Project - 2019

- Reporting back to the community
- Striving to make referrals to the cleft team easier
- Developing a leavers pack
- Access to high quality information
- Developing a register of dentists who understand cleft
- Adult Representation Committee
- Continuation of the Peer Support service



# Sometimes you can't make it on your own

- CLAPA is here for you as your community and support network
- We hope that today has been useful for you, that you've learned a few things about yourself and made some new connections.
- CLAPA is turning 40 next year and celebrating 40 years of supporting people in the UK who have been affected by cleft.
- In the same way that CLAPA has been there for 40 years to support the cleft community, CLAPA needs the cleft community's help to make the next 40 years even better.



# There's more than one way to help

## Challenge Events

- CLAPA has an extensive challenge events programme, with events across the UK.
- Support from CLAPA
- Fundraising Guide, Training Guide, CLAPA branded running vest/ t-shirt/ cycle jersey
- Just Giving Page set up advice
- [www.clapa.com/get-involved/challenge/](http://www.clapa.com/get-involved/challenge/)

## Fundraising At Work

- Does your work have a Charity Of the Year Scheme that you could nominate CLAPA for?
- One off fundraising event such as a cake sale, dress down day
- Encourage your office/ team to take part in a challenge for CLAPA. Raise money and train together as a team

## Who Do You Know?

- Who do you know that could help support CLAPA's work?
- Local pub landlord- could they hold a pub quiz or fundraising night in aid of CLAPA?
- Brownies, Scouts, Guides
- Freemason's, Women's Institute or similar groups- are they looking for a charity to support?
- Local Faith Group
- Owner of a local shop or business
- CLAPA can provide materials, proposals, information, support, share any donations on social media, thank you posters to display and more.



# There's more than one way to help

## Regular Giving

- Commit to supporting CLAPA through small regular donation
- Monthly, bi-monthly, quarterly- however you would like to give
- Allows CLAPA to predict income and commit to projects, events, services and more
- Simple to set up, easy to give each month
- Could today be the day you set up your regular giving?

## One off Fundraising Ideas

- Coffee morning- an excuse to bring friends and family together
- Bake Sale- at work, schools, local shops
- Dress Down Day- in the office, schools
- CLAPA can provide materials, advice, and support
- Little Guide to Fundraising (online and physical copy available here).

## Key Dates

- Giving Tuesday: 27<sup>th</sup> November
- Christmas Season: Christmas Cards, Christmas themed fundraisers
- Awareness Week: Middle of May
- CLAPA's 40<sup>th</sup>: 15<sup>th</sup> June 2019
- World Smile Day: Friday 4<sup>th</sup> October



# Thanks for coming

- Keep sharing your moments from the day on Twitter & Instagram using #CLAPAconf2018
- We like you, do you like us? [www.facebook.com/groups/CLAPAadults/](https://www.facebook.com/groups/CLAPAadults/)
- Keep up to date with the Adult Services Project at [www.clapa.com/adultservicesproject](http://www.clapa.com/adultservicesproject)
- Start planning a trip to Glasgow [www.clapa.com/ac2019](http://www.clapa.com/ac2019)

## Get in touch

### Adult Services Project

Kenny Ardouin

[kenny.ardouin@clapa.com](mailto:kenny.ardouin@clapa.com)

@kennyardouin 

### Fundraising

Rosalind Mason

Nicky Davis

[fundraising@clapa.com](mailto:fundraising@clapa.com)



Every smile  
tells a story



# 2019 Adults Cleft Conference

*Mid-late 2019 – Glasgow, Scotland*

*See you there!*

More info: [www.clapa.com/ac2019](http://www.clapa.com/ac2019)

