Accessing brilliance: Universal design for Heriot-Watt University

DR KATHERINE DEANE, ASSOCIATE PROFESSOR HEALTHCARE RESEARCH AND ACCESS AMBASSADOR

MR BRENDAN BURRILL, LEAD TECHNICIAN FOR PHYSICS AND ELECTRONICS LAB

UNIVERSITY OF EAST ANGLIA, NORWICH

Agenda

- 9:00 - 9:30 Lecture: Accessing Brilliance
- 9:30-10:00 Q&A: #It's OK to ask session
- !0:00 – 10:15 Coffee
- !0:00-12:00 Workshop: Universal design for HWU

Who are we?

What impact?

WHY?

TO REMOVE THE BARRIERS TO ACCESSING LIFE, SO PEOPLE CAN EXPRESS THEIR BRILLIANCE

Values

- Respect
- Fair
- Honest

© HAJICON

Social model of disability - and activism

- Social model of disability shifts responsibility for change from the disabled person to their society

- Training should focus on everyone's responsibility to take action
  - Informed by disabled people
  - BUT not solely enacted by them

- Activism / advocacy necessary to overturn societal norms

© Freepik
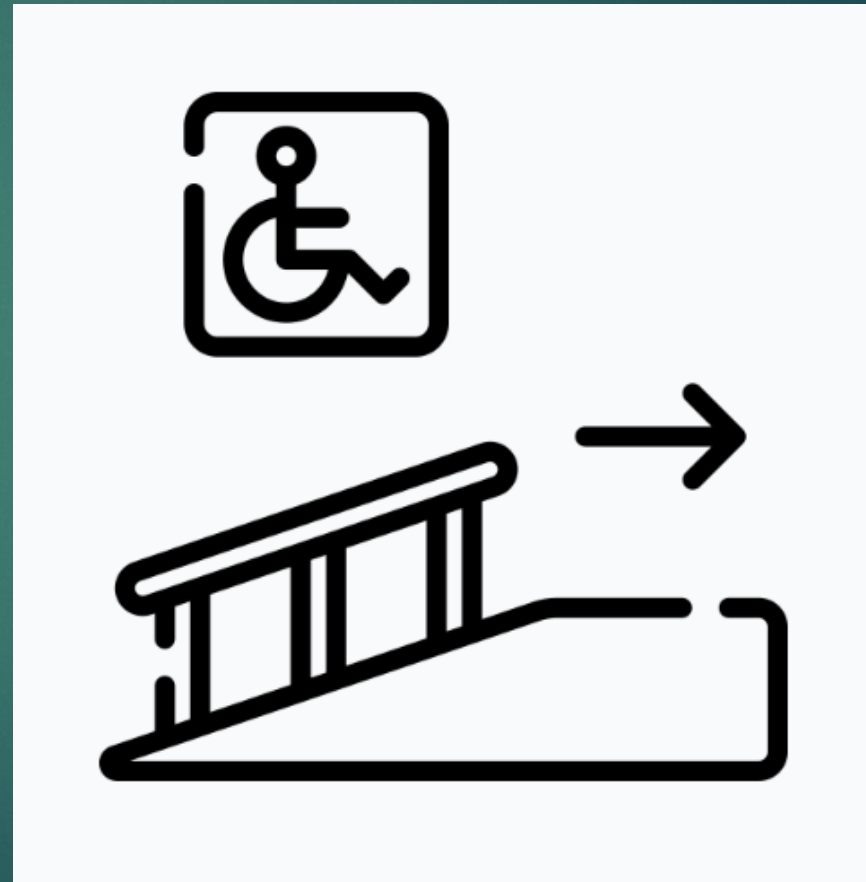
# Isn't everywhere accessible nowadays?

WHY ARE YOU MAKING A FUSS?

WHAT'S THE BIG DEAL IF YOU CAN'T GET INTO A FEW BUILDINGS?

Survey of lab accessibility

- Recruited scientists with interest in lab access
- 152 respondents
  - 55% disabled, 93% experience of lab working, 87% UK based
- Biology & biomedical dominated, mostly in universities or healthcare settings
- Invisible impairments most common
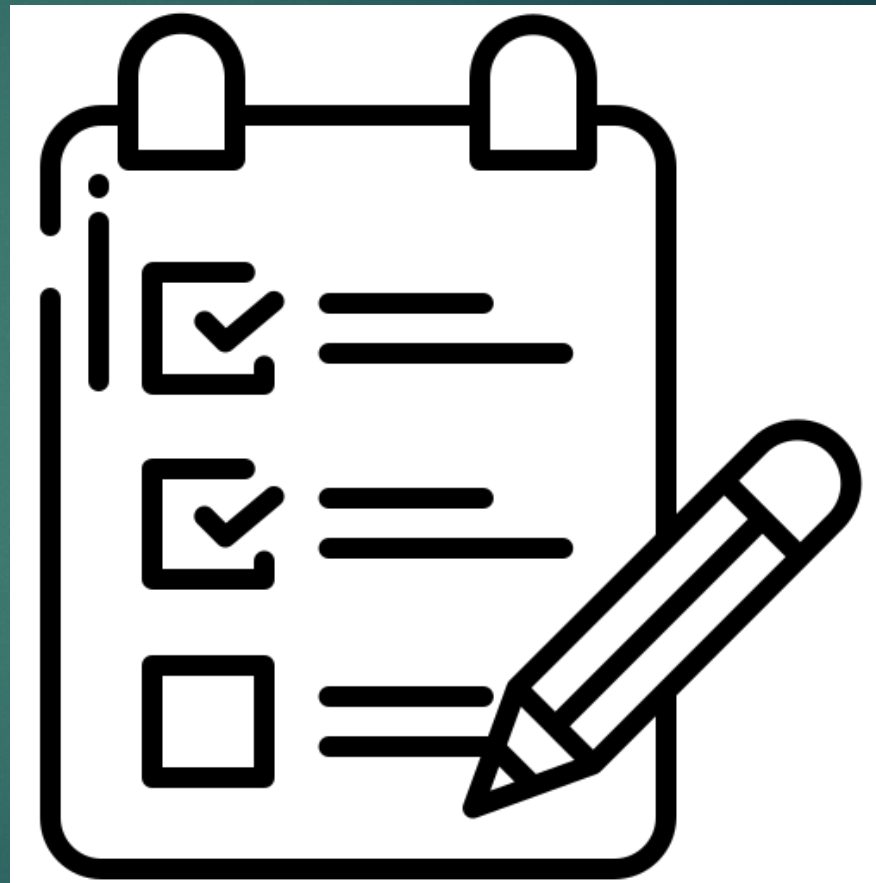
"My lab broke me – I hope others are better"
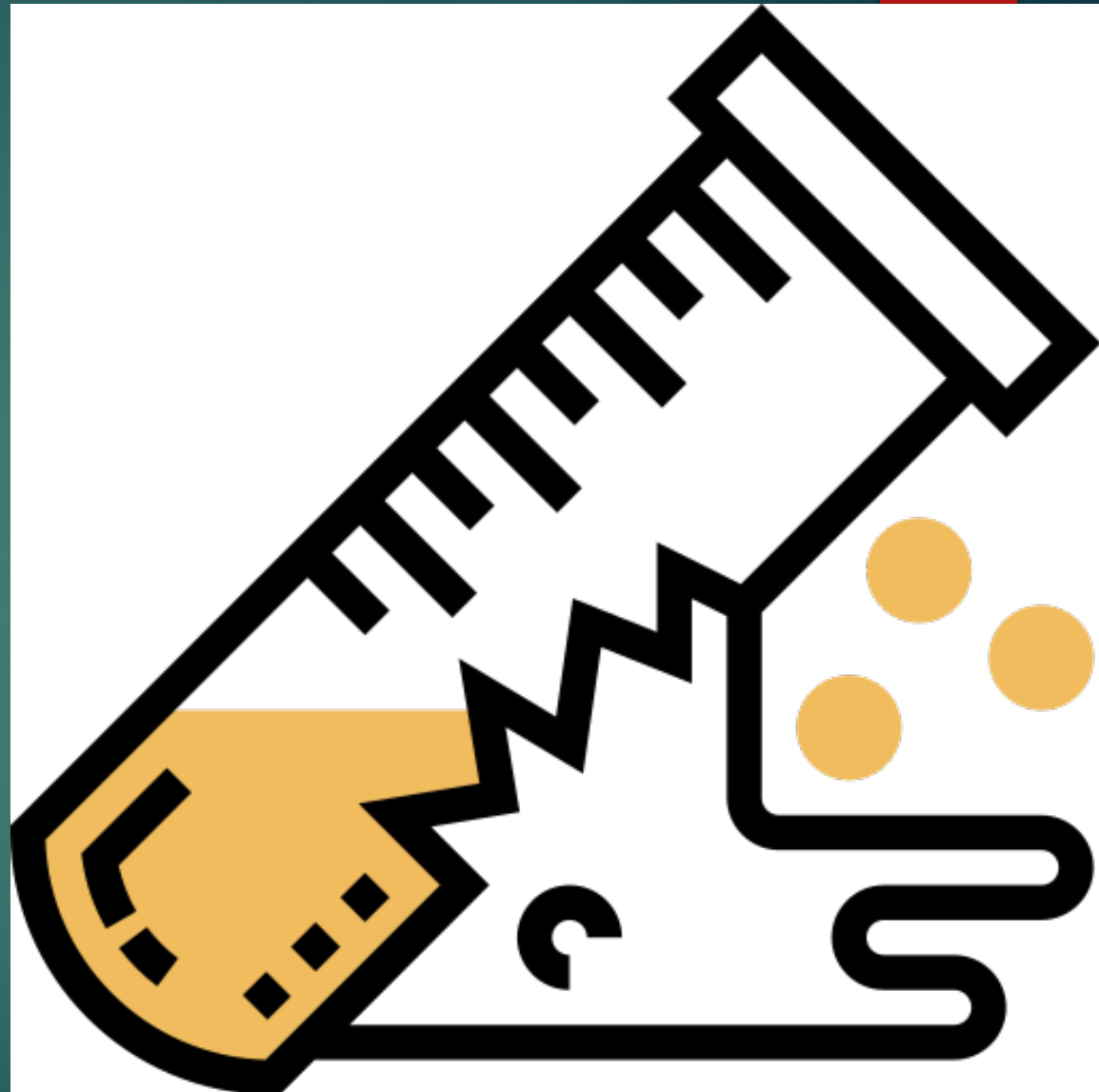
Survey results

- ▶ Structural access to buildings and labs is poor
- ▶ Behaviour, attitudes, and knowledge is poor
- ▶ Initiatives to change ableism are tokenistic and ineffective
- ▶ Web pages and conferences are often inaccessible

- ▶ Poor access = poor safety, unlawful practices, poor recruitment, poor retention
- ▶ Suite of access guidelines

© Freepik
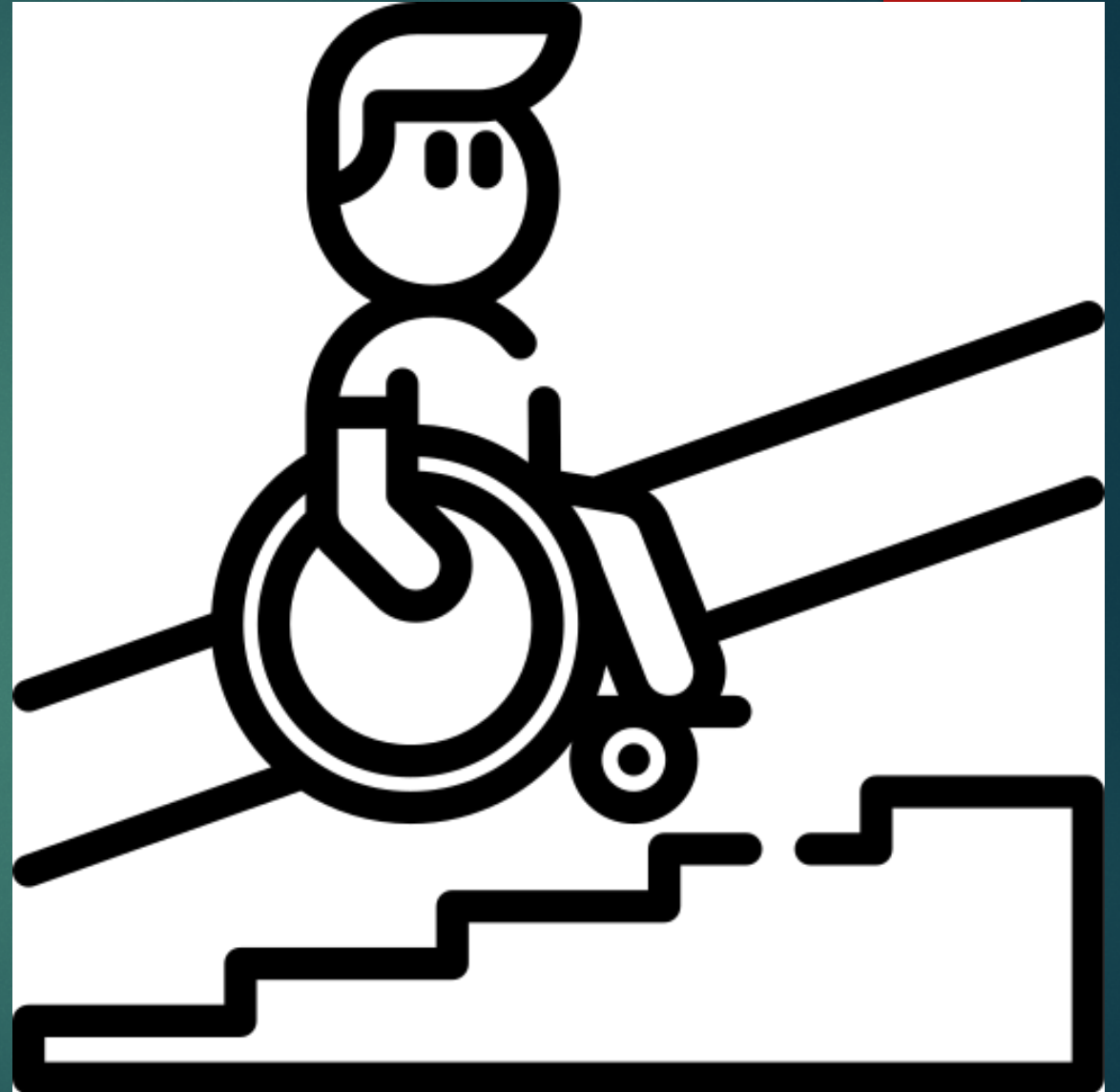
Getting the basics wrong

- Ergonomics
  - 46% ergonomic adjustable seating
  - >90% benches & equipment not height adjustable
- Toilets
  - 68% labs in building with accessible toilet
  - 26% accessible toilets had good visual access
  - 12% had a Changing Place accessible toilet
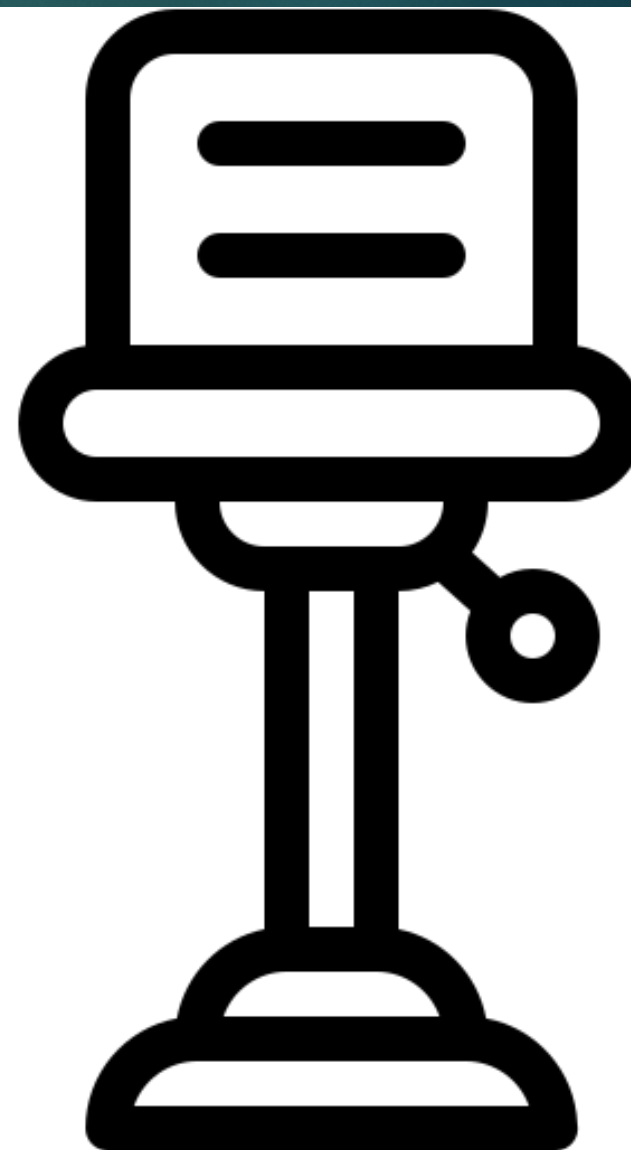
Change makers toolkit

How have I done it?
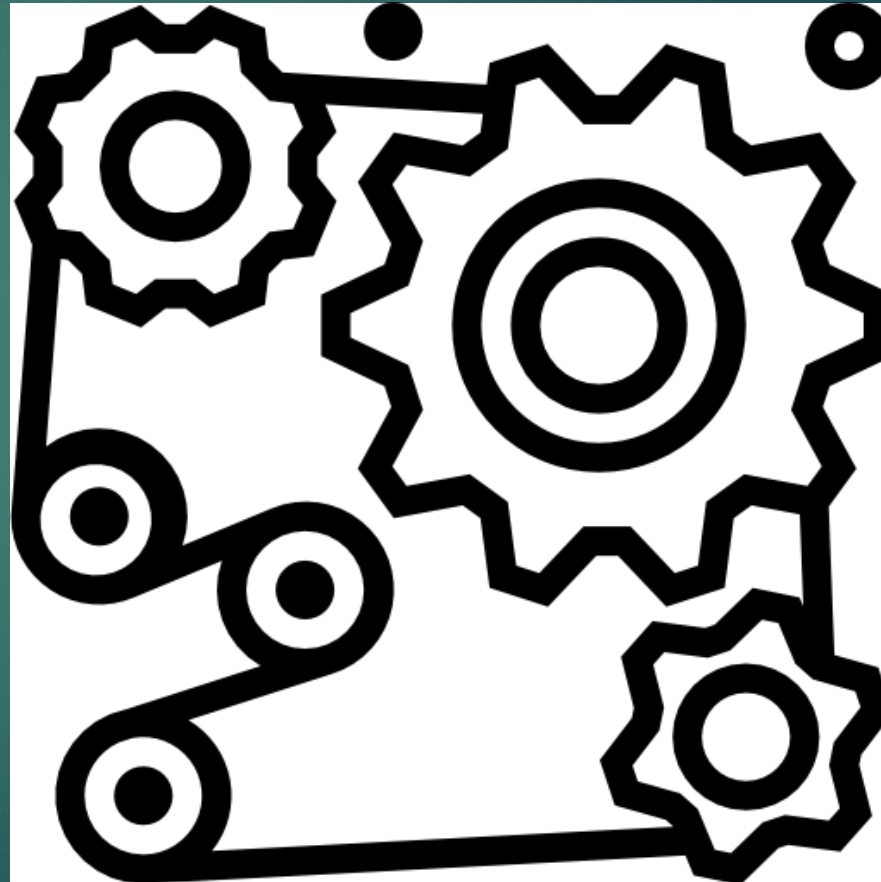
- Focus on action
  - Fudge the paperwork later
- Acceptance of personal risk
- Intuitive
  - BUT retrospective application of COM-B model of behaviour change

© Muhammad_Usman

COM-B Model

- ▶ Changing behaviour requires change of one or more
  - ▶ Capability
  - ▶ Opportunity
  - ▶ Motivation
- ▶ Put system into new configuration
- ▶ Minimise risk of reverting
  - ▶ Push back

© Pause08

Improving access – systemic and cultural problem

- Capability
  - Structural and attitudinal barriers
  - Knowledge and skills
  - Training – allyship and bystander
- Opportunity
  - All new builds & refurbishments
  - All equipment purchases
  - Every hire, recruitment
  - All processes and procedures
- Motivation
  - Because it could be you
  - Diversity = improved quality and profits
  - Funder requirements
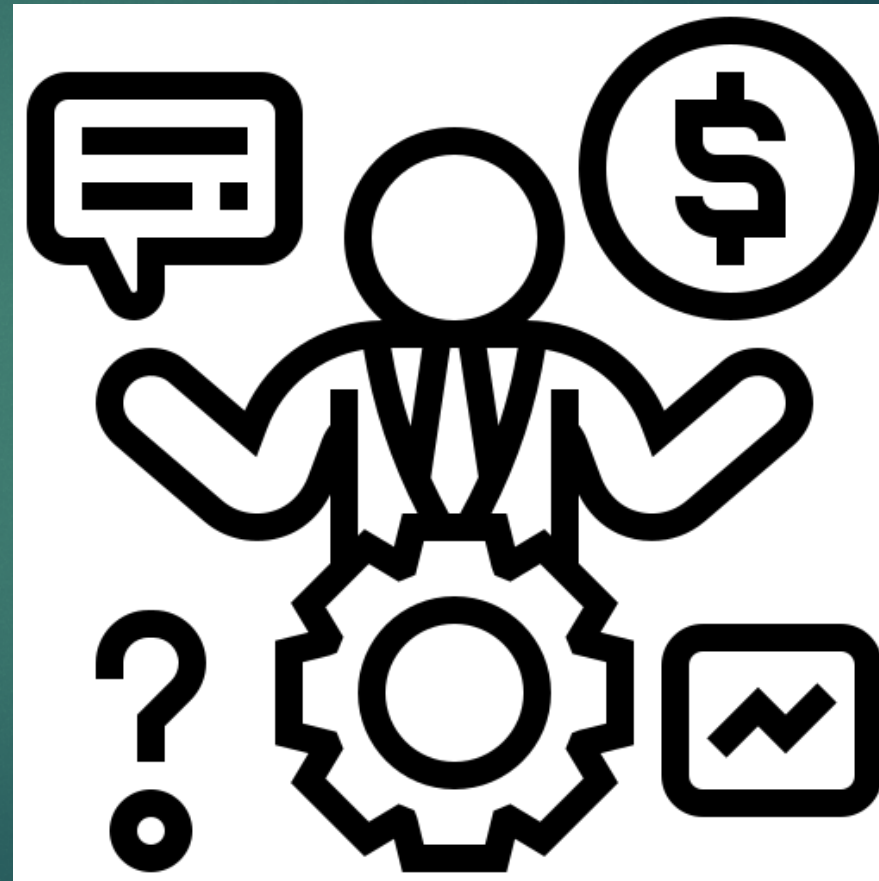
© Eucalyp

Lund University – Core Values Work

Suppression technique	Counter strategy	Affirmation technique
Making invisible	Demand attention	Acknowledge
Ridiculing	Question	Respect
Withholding information	Be honest	Inform
Double blinding	Break the pattern	Enforce double reward
Blaming & shaming	Intellectualise	Affirm reasonable norms

Who

- Two types of people:
  - Those with a disability
  - Those who will have one

- Visible/ invisible
- Physical / Mental / Deaf / Neurodiverse
- Disability is inherently intersectional
- Everyone has to rise up together
- No-one left behind

© Freepik
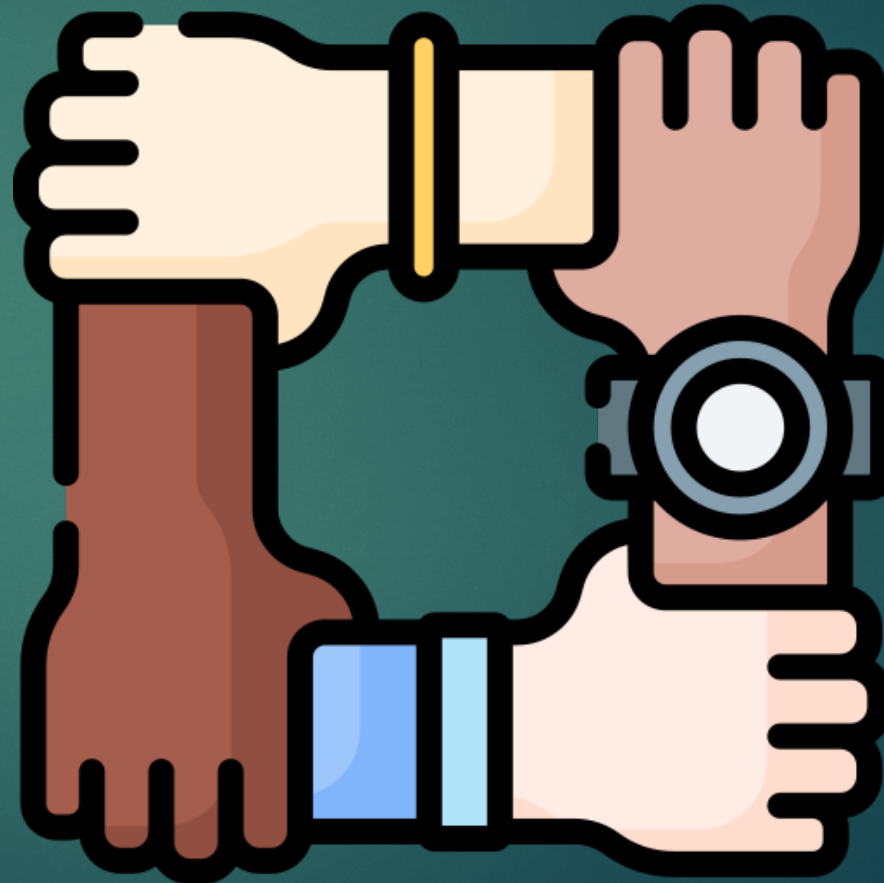
Deeds not words

- Impatient – since 1995
- Hold people accountable to their mission statements
  - UKRI: Research by everyone, for everyone
  - Manchester: To advance education, knowledge and wisdom for the good of society.
- Perfect is the enemy of done
- Take action
  - Best guess (informed by evidence & those impacted)
  - With feedback loops
  - Don't need RCT for a ramp

Disability Discrimination Act 1995

Disability Discrimination Act 2005

The Equality Act 2010

What deeds?

- Embrace the all-access attitude.

- You have to test for accessibility with real users.

- Accessibility is cheaper when it's done up front.

▶ Small increments more achievable and sustainable

▶ Take advantage of serendipity

▶ Never fear going big

Accessible Teaching

- Web pages achieve max. access
  - And provide access info
- Resources provided in advance, & in accessible formats
  - Standard template for all slides
  - Documents provided in screen reader friendly formats
- Ask about accommodations rather than diagnoses
  - Don't only label as disabled
  - Don't gaslight
- Build in access
  - all first years timetabled to fully accessible rooms for first semester
  - All accessible student rooms have hoists
- Train, support, promote staff

© Eucalyp
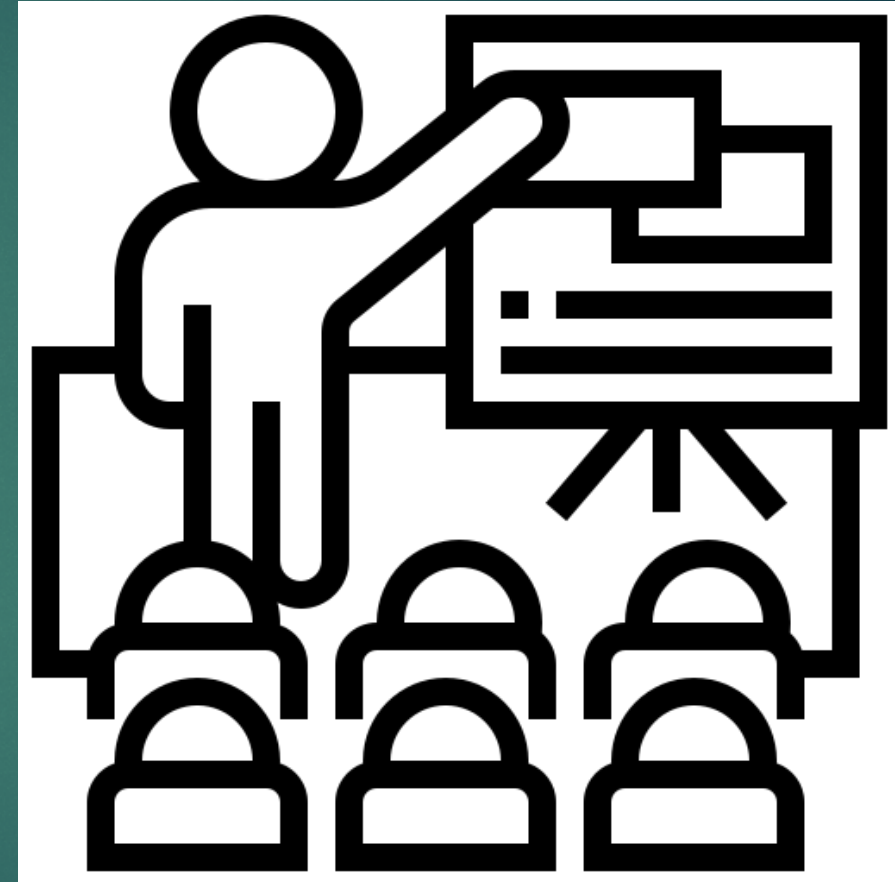
Accessible Research

- EXPECT DISABLED PARTICIPANTS
- Good quality PE/ PPI
- Audit EDI of researchers & participants
- Accessible written info
  - Simple
  - Clear text/ large font etc
  - "How we made this project accessible" section in info sheet
- PI/ Ethics committee training
- Budget for access costs
  - Venues
  - BSL, captions, audio descriptions, videos, Easy Read
 - Carers, travel, food, etc.

© lutfix

Evidence-based dissent

- Stories plus numbers

- Be critical but creative

- Important to support the awkward squad

- Find teams used to implementing change / principles

  - E.g. Estates used to being challenged on green principles

- Sometimes you have to weaponise embarrassment

© noomtah
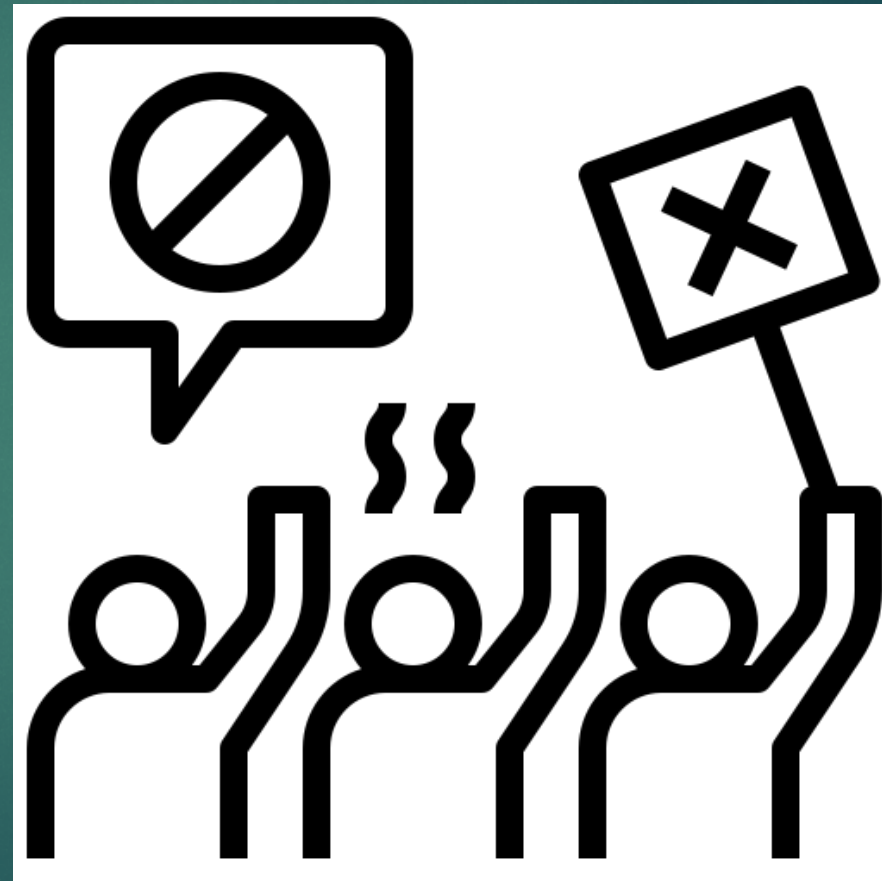
Anti-ableist training Allyship

- Social model
- Audit existing policies, buildings, & equipment against guidelines
  - List all deficits even if the money isn't currently available
  - Upgrade access standards for new builds, refurbishments, and equipment
  - Have a all staff report faults policy, with access faults prioritised
- Regularly check function of accessible equipment
- Annual review includes reasonable adjustments passport for ALL staff
  - Can cover other protected characteristics that need accommodations

© ranksol graphics
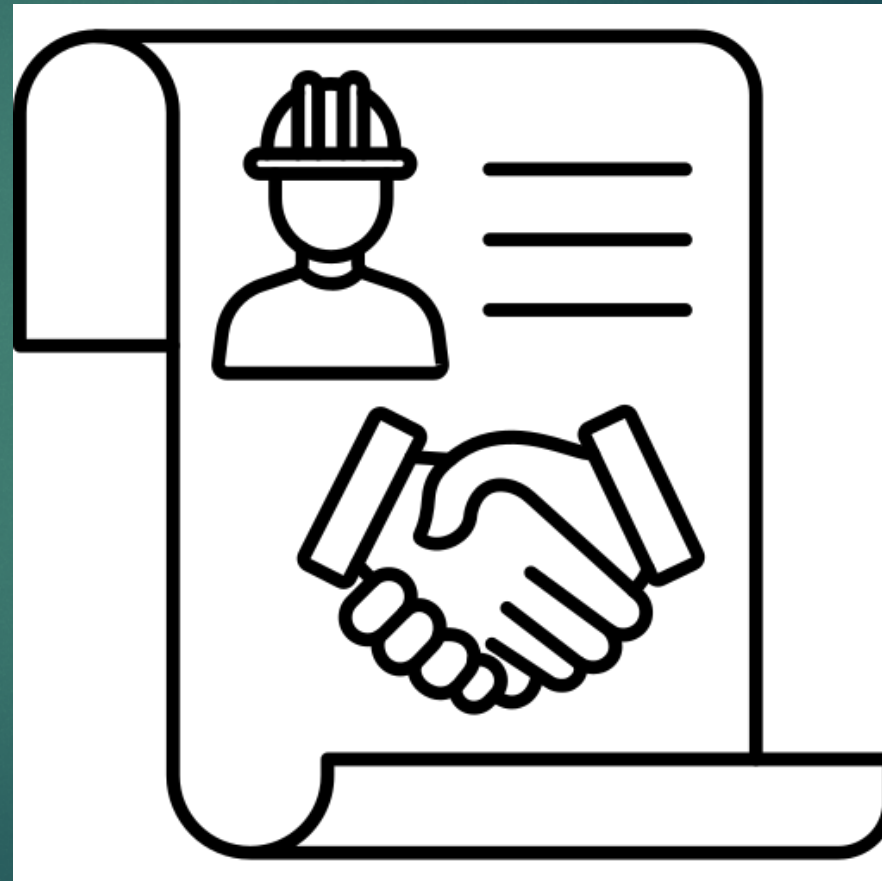
Bystander training

- May wish to reinforce with role play
- Challenge ableist assumptions
  - Dumbing down
  - Too hard, complex, time consuming, unsafe
  - No value added
- Challenge ableist language (but don't get bogged down in it)
  - Wheelchair bound, suffering from, offensive terms
- Challenge ableist practices and design

© Freepik

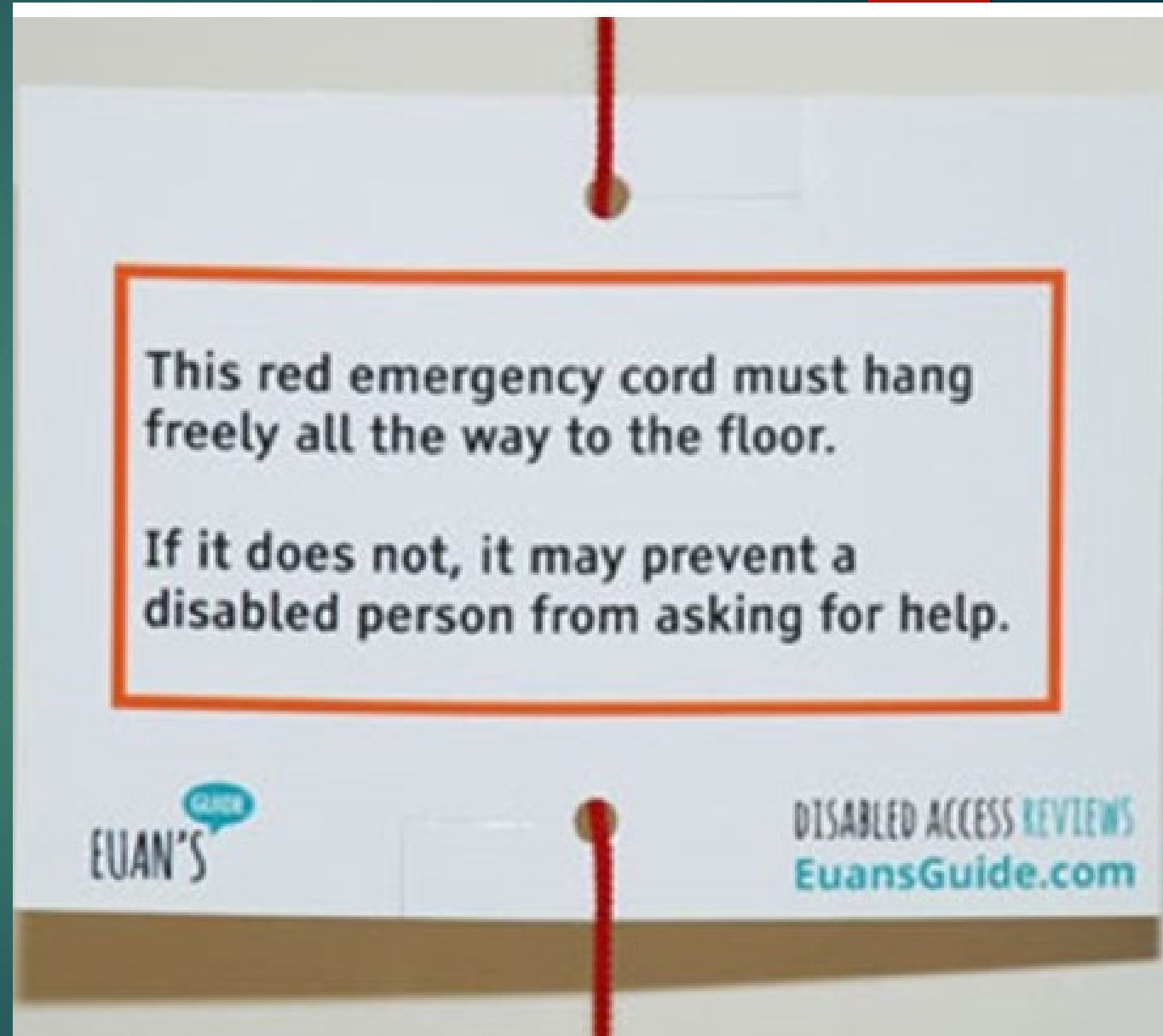# Accessibility behaviour targets – immediate to 5 years

- Audit PEEPs and lone working plans
- Implement reasonable accommodations passport into annual reviews
- Normalise reasonable workloads and flexible working
- Allyship and bystander training
  - All staff responsibility for fault reporting
- Mentorship programs
- Access hackathons/ Pride events
- Access to external advocacy expertise

© Vectors Tank

Structural access targets - immediate

- New builds and refurbishments to guideline standards
- New equipment and its placement to guideline standards
- Evac chairs or alternatives
- Microphones, PA systems, and portable hearing loops
- Euan's guide red cord cards
- Colour contrast in accessible toilets (pot of paint)

This red emergency cord must hang freely all the way to the floor.

If it does not, it may prevent a disabled person from asking for help.

EUAN'S

DISABLED ACCESS REVIEWS
EuansGuide.com

Structural & equipment access targets – 5 years

- Funders require minimum access standards for eligibility for funds
  - Includes mandatory training and audits
- An accessible toilet in any building with standard toilets
- Dual alert fire alarms
- Equipment connectivity standards
- Hearing technology standards
- Ergonomics – seating, lighting, acoustic environment
- Key routes – light doors, step free
- Lever taps and D handles
- Changing Place accessible toilets within 20 min

© Freepik

Structural & equipment access targets – 10 years

- "Maximum" access requirements necessary for funding
- Disinvest / repurpose buildings that cannot be made accessible
- Where possible
  - Fire safe lifts
  - Step free fire exits
- Most routes – light doors, step free
- Changing Place accessible toilets within 10 min
- Accessible fieldwork, boats, planes, etc etc

© Freepik

Contact details and thanks

- Guideline link
- https://www.uea.ac.uk/web/groups-and-centres/projects/access-all-areas-in-labs

- Katherine Deane
- k.deane@uea.ac.uk
- Brendan Burrill
- b.burrill@uea.ac.uk

Working to make Heriot-Watt universally accessible

KATHERINE DEANE & BRENDAN BURRILL

K.DEANE@UEA.AC.UK & B.BURRILL@UEA.AC.UK

WHY?

TO REMOVE THE BARRIERS TO ACCESSING LIFE, SO PEOPLE CAN EXPRESS THEIR BRILLIANCE


© Freepik

Agenda

- 10:00 -10:15   Coffee break
- 10:15 -10:45   Brief overview of key principles and ideas
- 10:45 – 11:05   Core Values work break out group
  - 11:05 – 11:15   Feedback
- 11:15 – 11:35   Targets and timescales break out group
  - 11:35 – 11:45   Feedback
- 11:45 – 12:00   Round up of workshop

Social model of disability - and activism

- Social model of disability shifts responsibility for change from the disabled person to their society
- Training should focus on everyone's responsibility to take action
    - Informed by disabled people
    - BUT not solely enacted by them
- Activism / advocacy necessary to overturn societal norms
- Access is a right – not a priviledge
- Disabled people should be trusted to identify their own needs

© Freepik
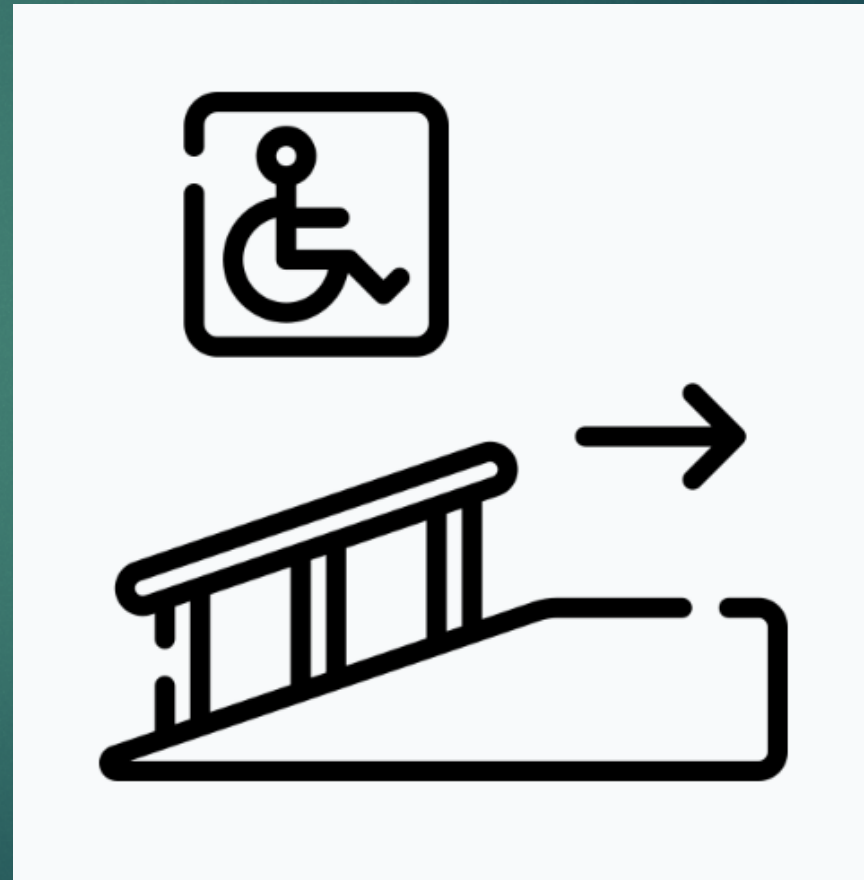
# Be brave
Be gentle

- Be brave
  - Speak up
  - Ask questions
  - Challenge assumptions
  - Aim high
- Be gentle
  - Everyone comes here from a different place
  - Expect mistakes (language/ ideas) and respond gently
  - Don't judge

Chatham House Rules PLUS

- Please keep what is said here confidential
- Do not identify anyone here outside the room
- Take care when discussing specific cases and people
  - Be sure you have gained consent to disclose any disability
- Limited time and resources – we may not solve all problems to the depth and detail required
- But I want everyone to go away from the workshop with specific ACTIONS they will undertake THIS YEAR.

Lund University – Core Values Work
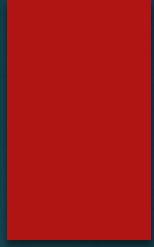
Suppression technique	Counter strategy	Affirmation technique
Making invisible	Demand attention	Acknowledge
Ridiculing	Question	Respect
Withholding information	Be honest	Inform
Double blinding	Break the pattern	Enforce double reward
Blaming & shaming	Intellectualise	Affirm reasonable norms

Making invisible
Demand attention
Acknowledge

- Society invisibles disability

- Lack of accommodation

- Lack of representation

- Out and proud

- Demand accommodations

- Mentoring, promoting,

- Paying for extra costs, mandatory access standards

© Paul J

UNDERGRADUATE STUDENTS >

UNDERGRADUATE ALUMNI >

POSTGRADUATE STUDENTS >

INTERNATIONAL ALUMNI >

FOUNDATION STUDENTS >

Make visible - Disability Pride 2019: 50 stalls, 6000 visitors
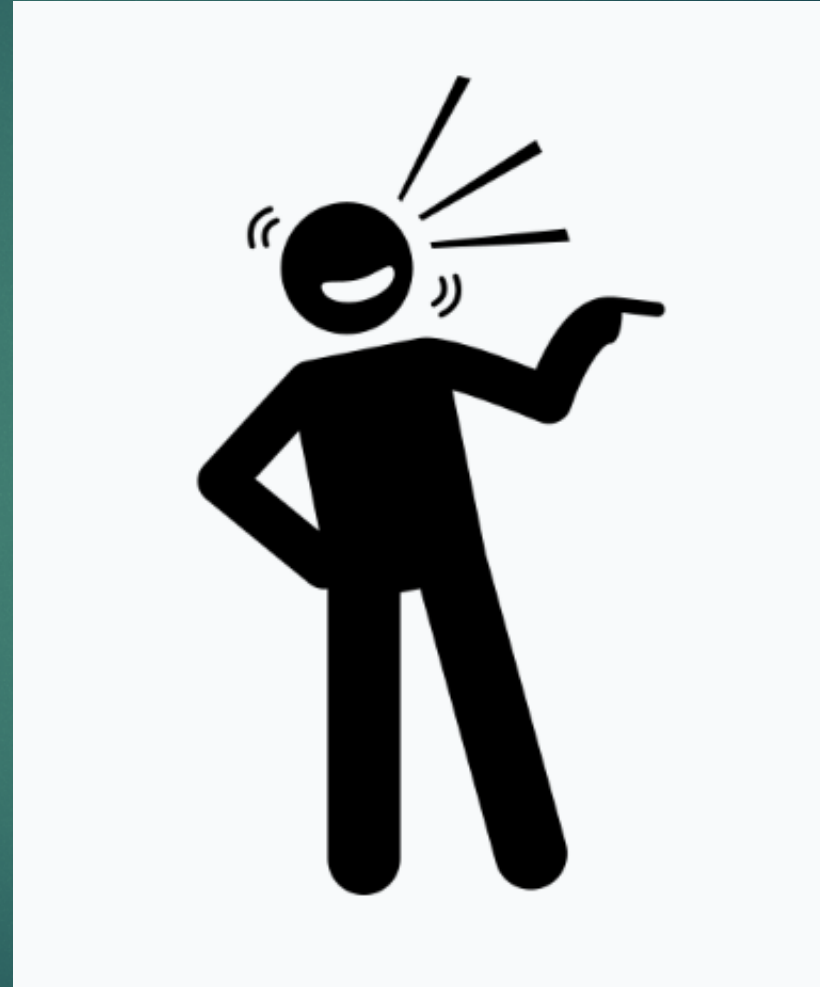
Demand attention / acknowledge

Purple Reach

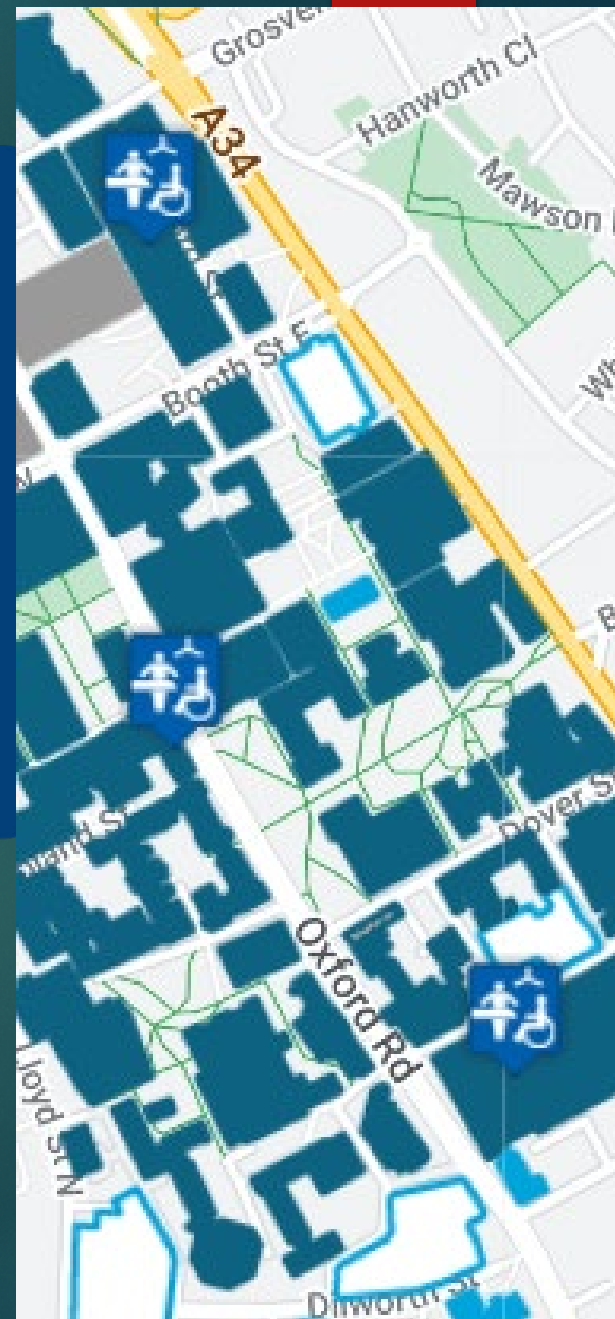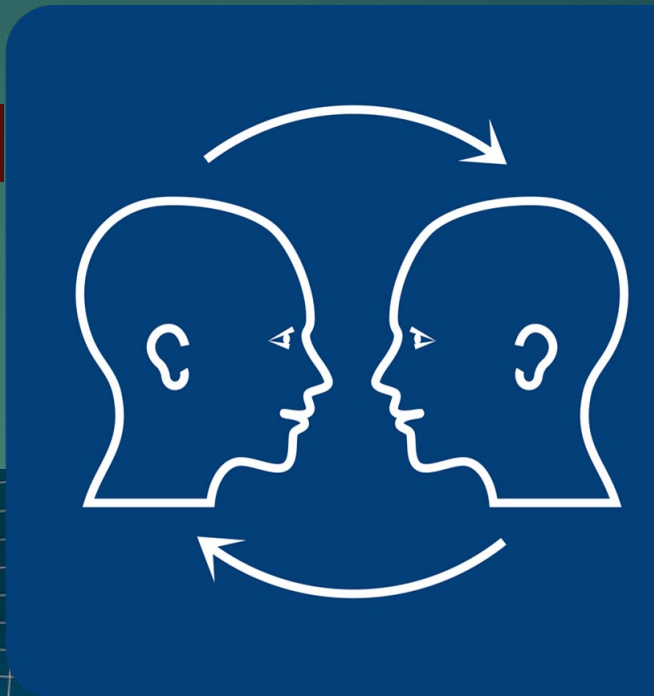Your Student Record ☐

Access your student academic record on e:Vision

Ridiculing Question Respect

- Language choices
- Poor assumptions

- What do you mean by that?
- Flip the protected characteristic

- Demonstrate respect for all diversities and variability

© Leremy

Demonstrate respect

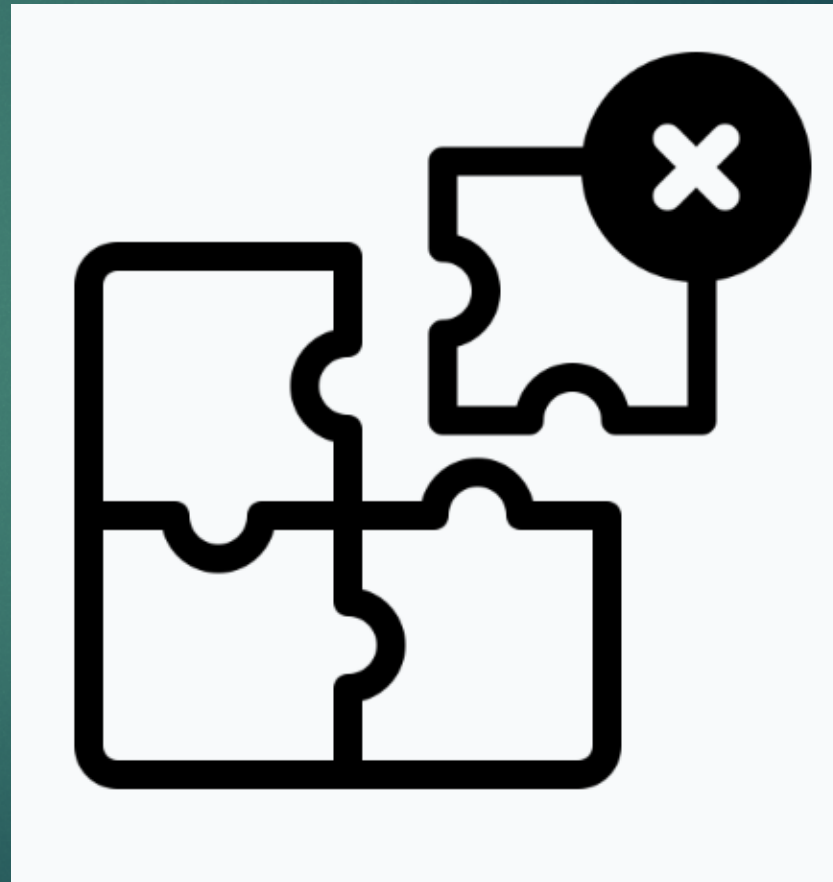Staff must provide slides a week in advance

Withholding information
Be honest
Inform

- ▶ Who is not invited to the table
- ▶ Whose information isn't shared

- ▶ Adult conversations about limitations
- ▶ Explicitly invite diversity

- ▶ Mandatory inclusion of diverse advisers to inform work
- ▶ Implementation of access guidelines

© Freepik

Inform - Access Guidelines
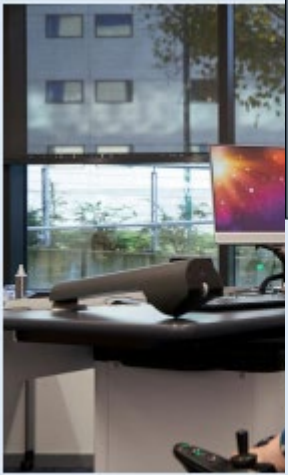
Include: quality engagement

Patient Engagement Quality Criteria

- QUALITY
- 01 Shared purpose
- 02 Respect and accessibility
- 03 Representativeness of stakeholders
- 04 Roles and responsibilities
- 05 Capacity and capability for engagement
- 06 Transparency in communication and documentation
- 07 Continuity and sustainability

I know a lot – which is why I have to ask so many questions (Deane 2019 *BMJ Innovations*. 13. https://innovations.bmj.com/content/5/1/43)

Double-blinding
Break the pattern
Enforce double reward

- Exercise: Yes = not really disabled; No = laziness causes disability

- No access > no visible disabled people > so no access needed

- Hold onto your personal integrity

- Recognise internalised ableism

- Everyone needs support sometimes

- Only robots don't need flexibility

- Value diversities

Value diversity – challenge ableism (internal and external)

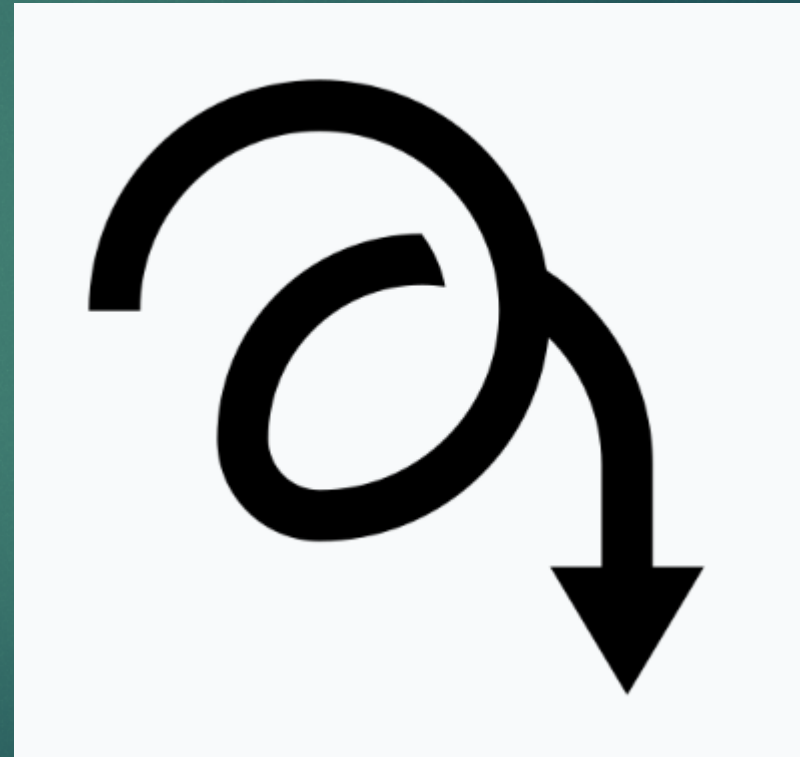To find a good work/life balance for me and my family, I sometimes send emails outside of traditional office hours. I have no expectation you'll do the same.

****

I mostly work virtually in order to best manage my disabilities. If we are meeting face-to-face indoors I will be wearing a mask and would appreciate it if you could do so as well (unless medically exempt).

****

Reasonable adjustments disability passports

Mental Health First Aider

MHFA England

© tonefotografia

Blaming and shaming
Intellectualise
Affirm reasonable norms

- Your inability to overwork is why the project failed
- You saying "no" overloaded the rest of the team

- Good project planning allows for variability
- Diversity enhances quality

- Sensible working loads are effective
- Holidays etc are mandatory
- Flexibility valuable for all
- Not brains on sticks

© Nualnoi Kinkaeo

"Ideal academic"

- "Brain on a stick"
- Disembodied, unemotional
- No social responsibilities
- Able and willing to work 24/7/365
- Able to work at 100% at all times
- Male, white, well financed
- Meet all deadlines
- Say yes to all work requests
- Respond immediately to all emails
- Willing to be on/ chair any committee
- Enjoys social networking

© Kalashnyk
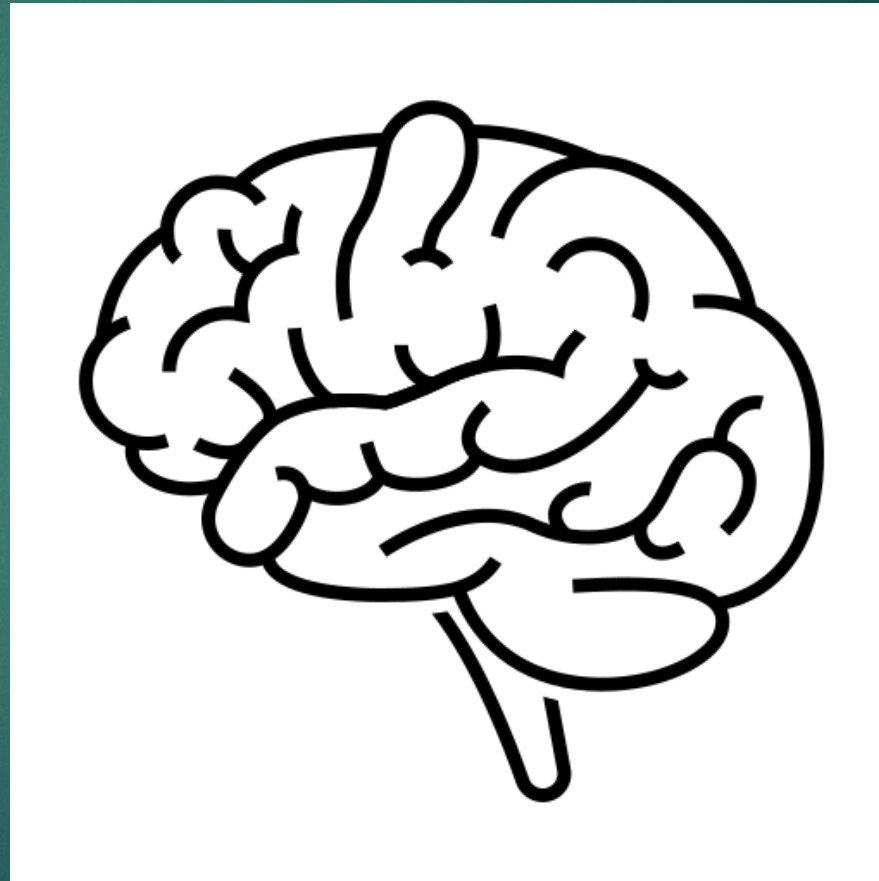
Affirm reasonable norms

Workload survey 2021
Data report

A REPORT BY UNIVERSITY AND COLLEGE UNION

Thanks to Empower Ability Consulting

Affirm reasonable norms

- Perfect is the enemy of done
- You have to say "no" in order to have the time to say "yes"
- Stand on the shoulders of giants
- Build teams – solo isn't sustainable
- Be generous with information – charge for implementation
- Change systems so they support positive behaviours
    - Fail safe
    - Redundancy
    - Just the way we always do it

© Parzival' 1997
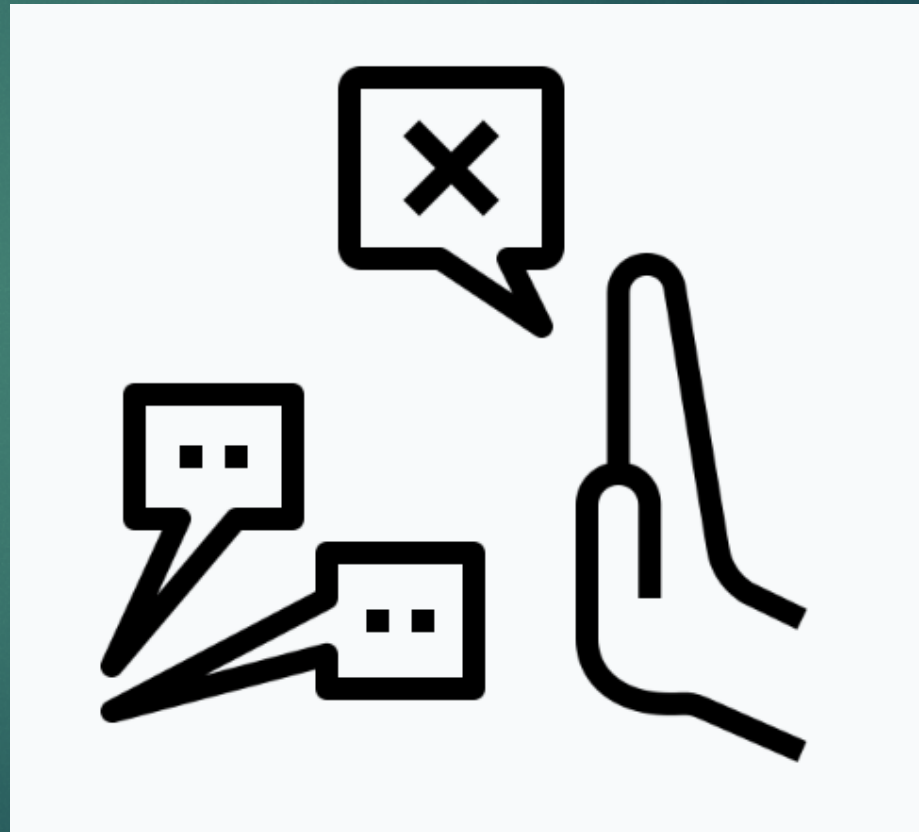
What is your Core Values Work for Heriot-Watt University?

Suppression technique	Counter strategy	Affirmation technique
Making invisible	Demand attention	Acknowledge
Ridiculing	Question	Respect
Withholding information	Be honest	Inform
Double blinding	Break the pattern	Enforce double reward
Blaming & shaming	Intellectualise	Affirm reasonable norms

BREAKOUT GROUPS

Targets and timelines

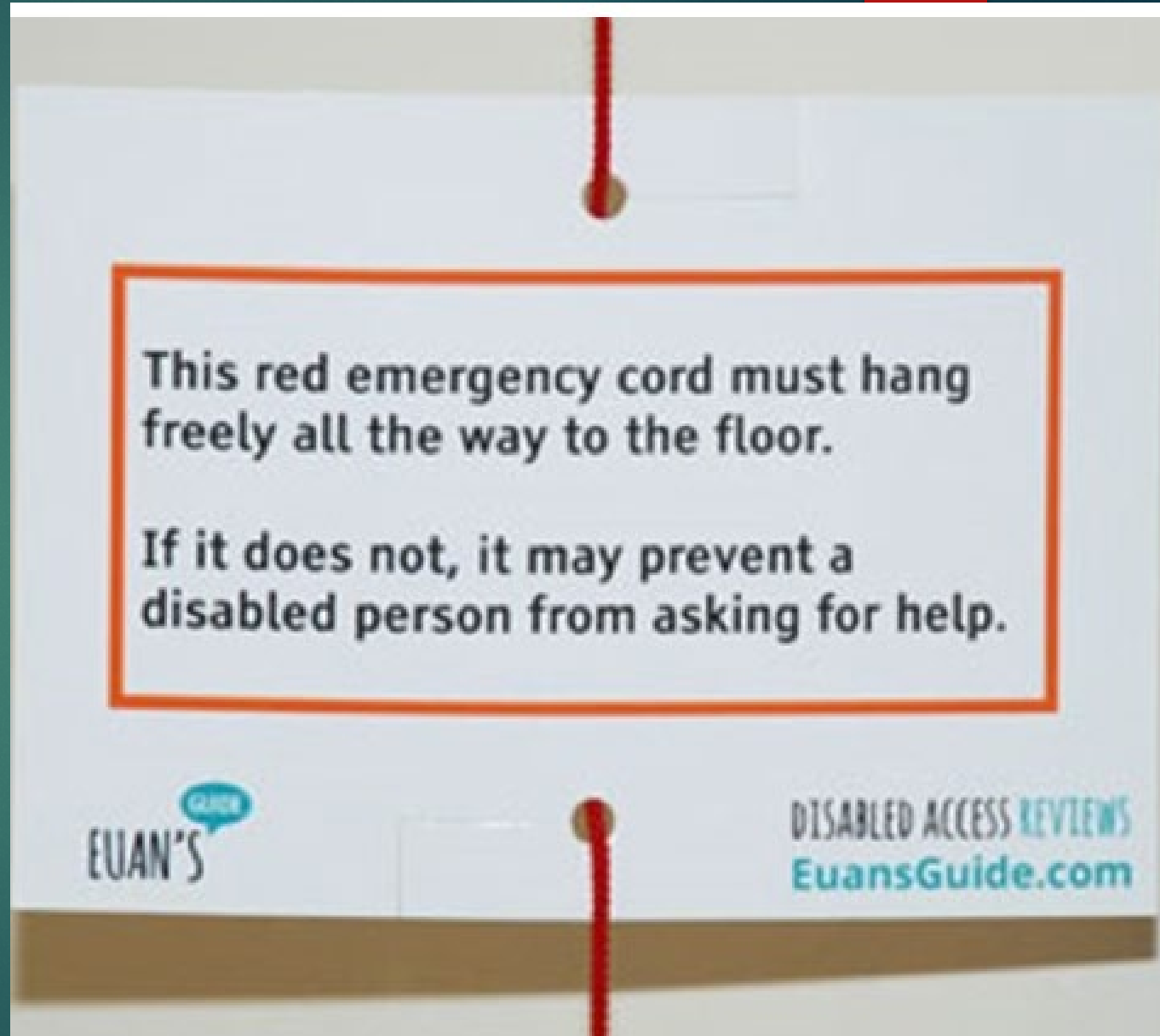# Accessibility behaviour targets – immediate to 5 years

- Audit PEEPs and lone working plans
- Implement reasonable accommodations passport into annual reviews
- Normalise reasonable workloads and flexible working
- Allyship and bystander training
  - All staff responsibility for fault reporting
- Mentorship programs
- Access hackathons/ Pride events
- Access to external advocacy expertise

© Vectors Tank

Structural access targets - immediate

- New builds and refurbishments to guideline standards
- New equipment and its placement to guideline standards
- Evac chairs or alternatives
- Microphones, PA systems, and portable hearing loops
- Euan's guide red cord cards
- Colour contrast in accessible toilets (pot of paint)

This red emergency cord must hang freely all the way to the floor.

If it does not, it may prevent a disabled person from asking for help.

EUAN'S

DISABLED ACCESS REVIEWS
EuansGuide.com

Structural & equipment access targets – 5 years

- ▶ Funders require minimum access standards for eligibility for funds
  - ▶ Includes mandatory training and audits
- ▶ An accessible toilet in any building with standard toilets
- ▶ Dual alert fire alarms
- ▶ Equipment connectivity standards
- ▶ Hearing technology standards
- ▶ Ergonomics – seating, lighting, acoustic environment
- ▶ Key routes – light doors, step free
- ▶ Lever taps and D handles
- ▶ Changing Place accessible toilets within 20 min

© Freepik

Structural & equipment access targets – 10 years

- "Maximum" access requirements necessary for funding
- Disinvest / repurpose buildings that cannot be made accessible
- Where possible
  - Fire safe lifts
  - Step free fire exits
- Most routes – light doors, step free
- Changing Place accessible toilets within 10 min
- Accessible fieldwork, boats, planes, etc etc

© Freepik

What are your targets for Heriot-Watt University?

- Immediate / 5 / 10 years
- Structural
  - Teaching
  - Research
  - Residences
  - Shops, sports facilities, grounds etc
- Equipment
- Protocol
  - Teaching (including fieldwork)
  - Research
  - People management
- Dissemination
- Working Practices

BREAKOUT GROUPS

References

▶ Deane KHO and the Access All Areas in Labs Team. 2023. Access All Areas in Labs: Access Guidelines. Version 1. March 2023. University of East Anglia, Norwich. https://www.uea.ac.uk/web/groups-and-centres/projects/access-all-areas-in-labs

▶ Deane K, Delbecque L, Gorbenko O, et al. Co-creation of patient engagement quality guidance for medicines development: an international multistakeholder initiative. 2019 *BMJ Innovations*. 13. https://innovations.bmj.com/content/5/1/43 (Table 3)

▶ Schroeder K, Bertelsen N, Scott J, Deane K, et al. Building from Patient Experiences to Deliver Patient-Focused Healthcare Systems in Collaboration with Patients: A Call to Action. 2022. *Therapeutic Innovation & Regualtory Science*. https://doi.org/10.1007/s43441-022-00432-x

▶ Brage T, Lövkrona I, Eldh C, et al. (2016). Core values work in academia: – with experiences from Lund University. Lund University https://eige.europa.eu/sites/default/files/core_values_work_brage_lovkrona.pdf

Useful books

- Ryder Carroll. "The Bullet Journal Method".
  https://bulletjournal.com/pages/book

- Susan Jeffers. "Feel the fear and do it anyway."
  https://susanjeffers.com/books/

- Robert Sutton. "The No Asshole Rule" and "The Asshole Survival Guide" https://en.wikipedia.org/wiki/The_No_Asshole_Rule

- Simon Sinek. "Start with Why" and "Find your Why".
  https://simonsinek.com/books/start-with-why/

- Brene Brown. "Dare to Lead"
  https://brenebrown.com/hubs/dare-to-lead/

- Stephen Trzeciak & Anthony Mazzarelli. "Compassionomics".
  https://www.compassionomics.com/

- Susan Michie et al. "The Behaviour Change Wheel."
  http://www.behaviourchangewheel.com/

Training resources

- Disability Awareness Training https://www.purplereach.co.uk/

- Guide dog etiquette
  https://www.guidedog.org/PuppyRaising/PuppyRaiserManual/Resources/Assistance_Dog_Etiquette.aspx

- Epilepsy first aid https://www.epilepsy.org.uk/info/firstaid

- Attitude is Everything resources for making music events accessible
  http://www.attitudeiseverything.org.uk./resources

Web access

- Web access https://www.w3.org/standards/webdesign/accessibility

- Low Vision web access https://www.w3.org/TR/low-vision-needs/

- Common web access problems for VIPs
  https://www.rnib.org.uk/rnibconnect/web-accessibility-people-disabilities

Toilets

- Changing Places http://www.changing-places.org/

Access Ratings

- Euan's Guide https://www.euansguide.com/

- AccessAble https://www.accessable.co.uk/

- Snowball App – available from Google Play and App Store
  https://apps.apple.com/gb/app/snowball-community/id1624679548

- Wheelmap, for ratings for wheelchair access https://wheelmap.org/

Other talks

- Lab access sucks – so here are guidelines to start solving this. Vitae 2023. https://www.youtube.com/watch?v=j9H9tdPjpQw&t=10s ▶
- Starting Change Making. Cultural   Forum Norwich. 2022. https://youtu.be/XZ72o4fbuh8
- Values, disability, saying no, and how fabulous it is to fail during the research process. 2021 https://emmaelvidge.wordpress.com/2021/10/26/episode_2_katherine_deane/
- Benefits of being a Disabled Scientist. UK Association for Science and Discovery Centres. 2020 https://www.youtube.com/watch?v=vjMHySCxY2k&feature=youtu.be

Contact details and thanks

- https://www.uea.ac.uk/web/groups-and-centres/projects/access-all-areas-in-labs

- k.deane@uea.ac.uk