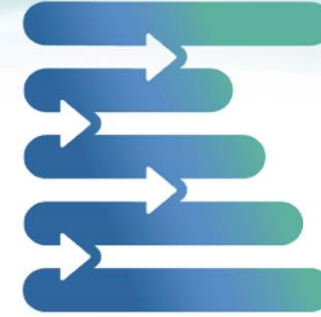




The **Ehlers-Danlos** Society

# 2025 INTERNATIONAL SCIENTIFIC SYMPOSIUM

PATHWAYS TO PROGRESS A Decade of Insights and Innovations in EDS & HSD



## PRESENTATION

# Allied Health Professionals Workshop: Moving Through the Lifespan

## SPEAKER

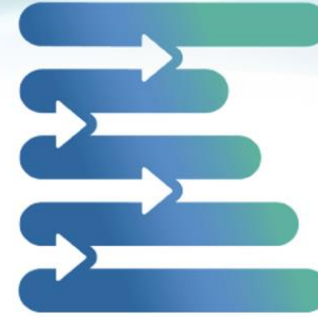
- **11:15-12:45 – Pediatric: Cylie Williams**
  - Assisted by M. Scheper, N. Streekstra, L. Russek, E. Rich, J Di Bon
- **2:00-3:30 – Adolescent/Young Adult: Mark Scheper & Nienke Streekstra**
  - Assisted by C. Williams, L. Russek, E. Rich, J Di Bon
- **4:15-5:45 – Adults over 25: Leslie Russek, Emily Rich & Jeannie Di Bon**
  - Assisted by C. Williams, M. Scheper, N. Streekstra



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# 2025 INTERNATIONAL SCIENTIFIC SYMPOSIUM

**PATHWAYS TO PROGRESS** A Decade of Insights and Innovations in EDS & HSD



PRESENTATION

## **Allied Health Professionals Workshop: Moving Through the Lifespan – Adults Over 25 Years Old**

SPEAKER

**Leslie Russek, Emily Rich & Jeannie Di Bon**

• Assisted by C. Williams, M. Scheper, N. Streekstra



# Conflict of Interest & Financial Interests

- Jeannie Di Bon owns *The Zebra Club (TZC)* app, which she will be demonstrating during the workshop. No purchase or subscription is required for participation.
- **Otherwise, speakers for this workshop have declared that they have no conflicts of interest or financial ownership interests relevant to the content being presented.**

# You Might Want to Download...

- You will select one of the following tech activities to participate in.
- You might want to download one of the following onto your smartphone or device:
  - ❖ Using activity trackers & wearables: No download
  - ❖ The Zebra Club: No download
  - ❖ Using augmented reality and ‘exergames’
    - If you want to try the activity, download **Active Arcade™** on your smartphone/tablet. It is free. Otherwise, you may observe others using the app.

# Handouts Available for Tech Activities

*(We will have scan codes to access these later slides)*

- Activity Trackers & Wearables (Emily)
  - <https://www.otemily.com/technology>
- The Zebra Club (Jeannie)
  - Handout to give patients explaining TZC resources: <https://zebraclubstructure.s3.eu-west-2.amazonaws.com/TZC+Handout+for+Health+Care+Professionals.pdf>
- Exergames (Leslie)
  - handout to give patients explaining exergame options:
  - <https://webpace.clarkson.edu/~lrusse/docs/hypermobility/RussekExergames.pdf>

# Objectives:

At the end of this workshop, participants will be able to:

- Promote physical activity in adults (25+) with EDS/HSD
  - Address challenges to movement and function in adults with HSD
  - Highlight innovative tools and strategies to support active living
  - Integrate physical, psychosocial, and environmental considerations
- 
- After the workshop, participants will have access to ideas generated by the group on Miro Board



# Outline of Activities

- Issues affecting adults with HSD/EDS
  - Introduction to Miro Board (participant involvement on Miro Board)
- Maintaining an active lifestyle for adults (presentation)
- Obstacles to activity, and strategies for overcoming (Miro)
- Discussion of the group's ideas (presentation viewing Miro)
- Using technology to encourage movement (you will select one activity)
  - Using activity trackers & wearables (Emily Rich, OT, PhD)
  - Using The Zebra Club app (Jeannie Di Bon, MA, MSc)
  - Using augmented reality and 'exergames' (Leslie Russek, PT, PhD)

# Introduction to Miro Board

Scan the QR code with your phone or tablet camera.

Alternatively, open the link in your browser or slide PDF



Use either the Miro app or website to log in and access the board

[https://miro.com/app/live-embed/uXjVJU4r9O4=/?embedMode=view\\_only\\_without\\_ui&moveToViewport=-472%2C-4256%2C33125%2C16303&embedId=128029701616](https://miro.com/app/live-embed/uXjVJU4r9O4=/?embedMode=view_only_without_ui&moveToViewport=-472%2C-4256%2C33125%2C16303&embedId=128029701616)

**SCAN ME**





# Using Miro Board

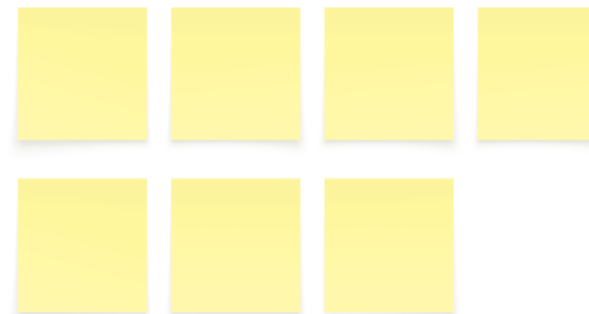
1. Right click and drag to move around the board.
2. Use your mouse wheel or trackpad to zoom in and out.
3. Select a sticky note to edit.  
Click to type directly to add text.
4. Click and hold to drag stickies to reposition them on the board.

## Barriers and enablers for physical activity

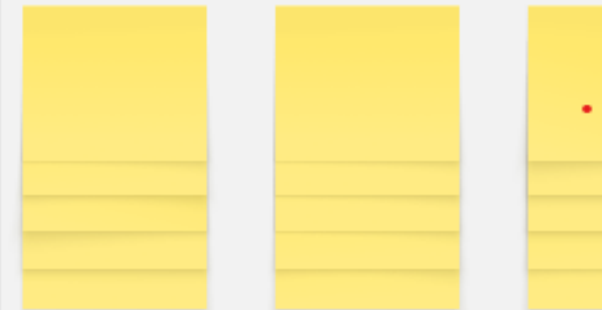
### Barriers



### Enablers



### Spare stickies to add more



# Issues Affecting Adults with HSD/EDS

- **What issues are particularly important for adults with HSD/EDS? (not limited to exercise and activity)**
- For example:
  - Accumulation of injuries over time
  - Balancing self-care and family/life demands
  - Costs associated with healthcare/wellness activities
- **Take 10 minutes to enter ideas on Miro Board**



# Importance of Movement As We Age

- Movement, activity and exercise are important for:
  - Physical health
  - Mental health
  - Function
  - Social interaction
- Physical inactivity is a key contributor to mortality & medical costs
  - Falls, fractures, hypertension, diabetes, sleep dysfunction, overweight, disability, dementia, depression, mental health, cancer, all-cause mortality,

Yang, 2024;

WHO: <https://www.who.int/en/news-room/fact-sheets/detail/physical-activity>



# How Much Exercise for (Typical) Adults

18-64 yrs	US <sup>1</sup>	Canada <sup>2</sup>	UK <sup>3</sup>	WHO <sup>4</sup>
<b>Total activity per week</b>	150 min moderate OR 75 min vigorous	150 min moderate to vigorous, ≥10 min sessions	150 min moderate OR 75 min vigorous spread over 4-5 days	150 min moderate OR 75 min vigorous
<b>Strength</b>	2x/wk	2x/wk	2x/wk	2x/wk
<b>Balance</b>			2x/wk	
<b>Flexibility</b>			2x/wk	
<b>Other</b>			Decreased time sitting; some activity daily	300 min moderate activity better

1. <https://www.cdc.gov/physical-activity-basics/guidelines/index.html>
2. <https://www.canada.ca/en/public-health/services/publications/healthy-living/physical-activity-tips-adults-18-64-years.html>
3. <https://www.nhs.uk/live-well/exercise/physical-activity-guidelines-for-adults-aged-19-to-64/>

# How Much Exercise for (Typical) Older Adults

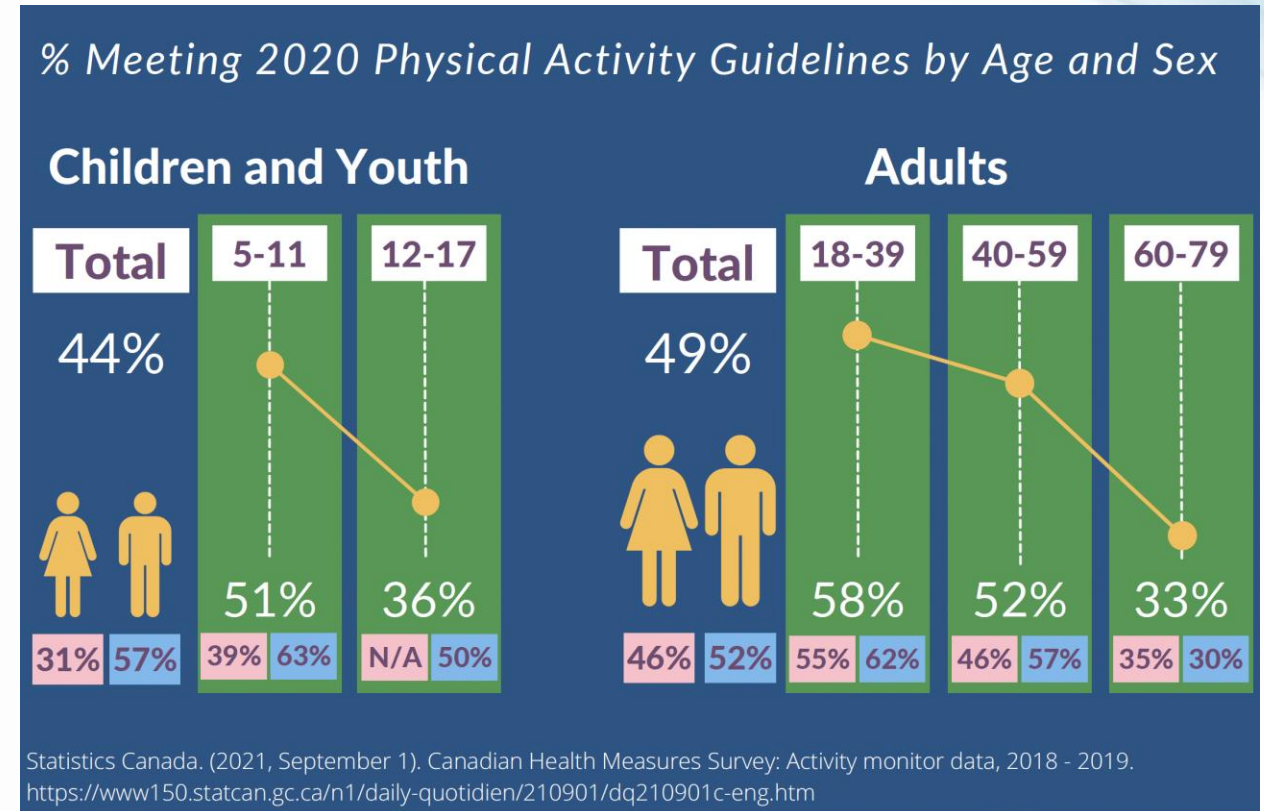
<b>≥ 65 yrs</b>	<b>US<sup>1</sup></b>	<b>Canada<sup>2</sup></b>	<b>UK<sup>3</sup></b>	<b>WHO<sup>4</sup></b>
<b>Total activity per week</b>	150 min moderate OR 75 min vigorous	150 min moderate to vigorous, ≥10 min sessions	150 min moderate OR 75 min vigorous	150 min moderate OR 75 min vigorous
<b>Strength</b>	2x/wk	2x/wk	2x/wk	2x/wk
<b>Balance</b>	Yes		2x/wk	Yes if person has poor mobility
<b>Flexibility</b>			2x/wk	
<b>Other</b>			Decreased time sitting; some activity daily	300 min moderate activity better

1. <https://www.cdc.gov/physical-activity-basics/guidelines/older-adults.html>
2. <https://www.canada.ca/en/public-health/services/publications/healthy-living/physical-activity-tips-older-adults-65-years-older.html>

# Prevalence of Inactivity, Overall

- Inactivity increases as we age
- Inactivity is higher in women than men
- Inactivity is higher in high-income countries than low-income
- Adherence to exercise programs is typically low in mature adults

Yang, 2024; WHO, 2022; Thornton, 2023



Thornton, 2023



# WHO Global Action Plan on Physical Activity (GAPPA)

WHO, 2022;  
Thornton, 2023



# Are Zebras any Different?

- Exercise, overall, leads to physical and psychological improvements in people with EDS
- People with hEDS are more likely to exercise if:
  - Given professional guidance
  - They realize the importance of exercise for long-term maintenance.
- Pain, fatigue and fear are common barriers to exercise in hEDS

(Buryk-Iggers, 2022, syst rev; Simmonds, 2017)

# Factors Impacting Exercise Engagement in HSD

## Facilitators & Barriers

## Outcomes





# Eliciting Behavior Change in HSD/EDS

- Education about HSD, coping, self-help programs, evaluating sources of information
- Training to improve communication, pacing
- Environmental restructuring to improve independence and access to emotional/cognitive support
- Modelling of successful coping

(Bennet, 2022)

# Research on Motivating Activity

- Specifically addressing motivation improved activity compliance
  - Various approaches can be successful
    - CBT: planning, improving self-efficacy, coping skills
    - Social support/coaching
    - Motivational interviewing: identifying client goals and obstacles
    - Self-determination: internal motivation based on autonomy, competence, and relationships
- McGrane, 2015

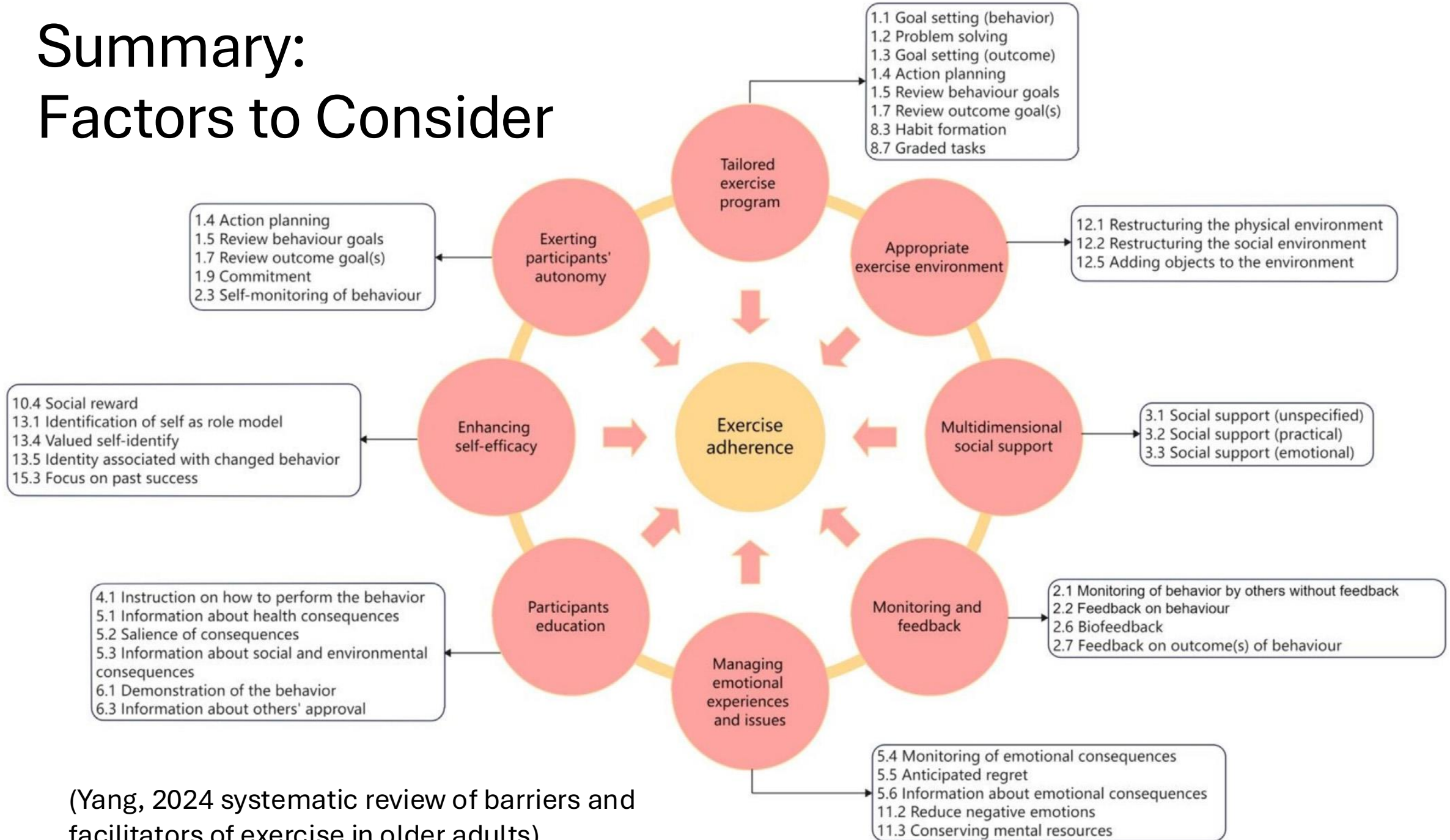
# Modifying the Environment

- Access to location and/or equipment
- Sensory considerations
  - Visual cues and supports
  - Lighting considerations
  - Tactile issues
  - Sound environment
- Social support



# Summary:

## Factors to Consider



(Yang, 2024 systematic review of barriers and facilitators of exercise in older adults)



# WORKSHOP ACTIVITY



- Use Miro Board, posting in the section for your group
- Post each idea once per group (e.g., have a designated person or coordinate postings in another way)
- Group your ideas as seems appropriate
- **QUESTIONS**
  1. What are the Obstacles to activity, movement, exercise specific to adults (over 25 years)?
  2. What are some Strategies for overcoming these obstacles?

**You have ~20 minutes for this activity**

# Full Group Review of Obstacles/Strategies

- 1. What are the Obstacles to activity, movement, exercise specific to adults (over 25 years)?**
- 2. What are some Strategies for overcoming these obstacles?**



# Technology for Increasing Physical Activity

- Benefits
  - Technology can be more motivating, so adherence is good
  - Wearable tech is practical, usable and effective
  - Many people already own wearable tech, some exergame apps are free
  - Exerdance/games can enhance balance, provide dual-task training, support physical, cognitive and psychological well-being
  - Tech can make activity more accessible and convenient to do independently

# Technology for Increasing Physical Activity

- Cautions
  - Using technology can be challenging, especially for older individuals
  - For some people, dual tasking may be overwhelming
  - Some apps are too difficult, and it can be difficult to find appropriate apps
  - Technology may require purchase of app or equipment
  - Use is unsupervised and cannot always be customized to user needs and abilities

# Technology Activities for Adults

- Each participant will select **ONE** of the following activities
- There is a handout for each station that everyone can access
  1. Using activity trackers/wearables (Emily Rich)
  2. The Zebra Club app (Jeannie Di Bon)
  3. Exergames and augmented reality, e.g. Active Arcade (Leslie)



# Using Wearables to Encourage Movement

- Includes wearables, with or without a smartphone app
- Benefits
  - Wearable tech is practical, usable, and effective for increasing activity levels.
  - Many people already own wearables or smartphones.
  - Tech is enhanced with supports of social media, user engagement, accuracy, and individualized, goals



**Handout for Wearables**

(Berry, 2025; Chan et al., 2024; Li et al., 2023; Schumann & Doherty, 2024)

# Breakout: Wearables and Technology

## Motivation

- Explore the variety of tools available and determine goodness-of-fit
- Consider how to increase client adherence and success
- Learn how to maximize data value in therapy success
- Anticipate and work to minimize risks
- Support clients through challenges with over-reliance



# TZC to Encourage Movement

- Benefits
  - Exercises developed specifically for people with HSD, safe and appropriate
  - Instructions are clear and highlight potential movement errors to avoid
  - Encourages mind-body integration and relaxation
  - Encourages social engagement with the TZC community
  - Offers coaching and mentoring from experienced members
  - Has a wide range of activities, from breathing and pain relief to strengthening and cardiovascular, allowing users to customize and modify based on their current needs
- Cautions
  - Numerous options can make it challenging to select appropriate modules
    - Russek, et al, 2024



# Using Exergames to Encourage Movement

- Benefits:
  - Exergames are fun and provide motivation to be active
  - Augmented reality allows users to see themselves, which may enhance body awareness
  - Games are goal-directed
  - Some games can be done with a partner or against an opponent, enhancing social interaction
  - Exergames monitor time spent in the activity, and sometimes provide a score to allow activity tracking
  - Many games can be done with just a smartphone



**Scan Code for Exergame Handout**

**Handout:**

<https://webpace.clarkson.edu/~lrussek/docs/hypermobility/RussekExergames.pdf>

# Using Exergames to Encourage Movement

- Cautions
  - Some game movements are not appropriate for people with HSD, depending on the individual
  - Games may be over-motivating and encourage too much activity

# ExerGame Options



- Active Arcade™ is a free augmented reality app with multiple games
  - Provides visual targets and visual feedback about movement
  - Most games can be done sitting or standing
  - Activity options range from slow to fast
  - Can be done alone or with a partner
- Party Fowl™ has several free game options with option to purchase
  - Games are silly and fun competition against a partner
- Plaicise™ has several free game options with option to purchase
  - Single and 2-person games and challenges



# ExerDance Options

- Benefits
    - Encourage pleasurable movement
    - May encourage social engagement
    - Music is motivating
  - Cautions:
    - Some apps are too vigorous for adults with HSD
    - Most have only standing options
    - Technology can be challenging
- Yoong, 2024a; Yoong, 2024b; Tao, 2024

# Technologies Activities

- Each participant will select **ONE** of the following activity stations
- There is a handout for each station that everyone can access
  1. Using activity trackers/wearables (Emily Rich)
  2. The Zebra Club app (Jeannie Di Bon)
  3. Exergames and augmented reality, e.g. Active Arcade (Leslie)
- Virtual participants can select a breakout room

**You have ~20 minutes for this activity**

**Before we split up, a few final slides...**

# Additional Resources

- Slide handouts for this session are on WHOVA
- Handouts for the exercise activities are available at (or use previous scan codes):
  - Using wearables (Emily Rich)
    - <https://www.otemily.com/technology>
  - Using The Zebra Club app (Jeannie Di Bon)
    - TZC: <https://www.thezebra.club>
  - Exergames and augmented reality (Leslie Russek)
    - <https://webpace.clarkson.edu/~lrussek/docs/hypermobility/RussekExergames.pdf>

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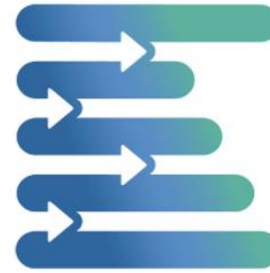




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# Thank you for your attention