



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

Haemophilia and Physical Activity Research

Irish Haemophilia Society, October Members' Conference.

Dr. Megan Kennedy, PhD.

Physiotherapist and Postdoctoral Research Fellow.

22nd October 2023

Regular physical activity reduces the risk of numerous health issues

Unhealthy body composition

Falls and related injuries

Low bone mineral density

Cardiovascular disease

Hypertension

Oesophageal cancer

Anxiety and depression

Type 2 diabetes

Hyperlipidaemia

Stomach cancer

Kidney cancer

Cognitive decline

Bladder cancer

Colon cancer

Dementia

Lung cancer

Breast cancer

Endometrial cancer

Insomnia

All-cause mortality

Physical/ functional disability



(Piercy et al., 2018; Bull et al., 2020)

Physical activity for people with haemophilia

WFH Guidelines for the Management of Hemophilia, 3rd edition

RECOMMENDATION 2.3.1:

- For people with hemophilia, the WFH recommends promotion of regular physical activity and fitness, with special attention on bone health maintenance, muscle strengthening, coordination, physical functioning, healthy body weight, and positive self-esteem. **CB**

RECOMMENDATION 2.3.2:

- For people with hemophilia, the WFH recommends promotion of non-contact sports. High-contact and collision sports and high-velocity activities should be avoided unless the individual is on a prophylactic regimen that is adequate to cover such activities and is properly educated on the potential risks and other required protective measures.
- **REMARK:** The choice of sports activities should take into consideration the individual's physical condition and ability, preferences and interests, local customs, and available resources. **CB**

RECOMMENDATION 2.3.3:

- For people with hemophilia, the WFH recommends consultation with a physical therapist or other musculoskeletal specialist before engaging in sports and physical activities to discuss their appropriateness specific to the individual's condition and their requirement for particular physical skills and/or protective gear. **CB**



(Srivastava et al., 2020)



iPATH Physical Activity (2018-2021)

REVIEW ARTICLE



A systematic review of physical activity in people with haemophilia and its relationship with bleeding phenotype and treatment regimen

ORIGINAL ARTICLE



Pain and functional disability amongst adults with moderate and severe haemophilia from the Irish personalised approach to the treatment of haemophilia (iPATH) study

ORIGINAL ARTICLE



Physical activity, physical fitness and cardiometabolic risk amongst adults with moderate and severe haemophilia

ORIGINAL ARTICLE



A cross-sectional follow-up study of physical activity in adults with moderate and severe haemophilia

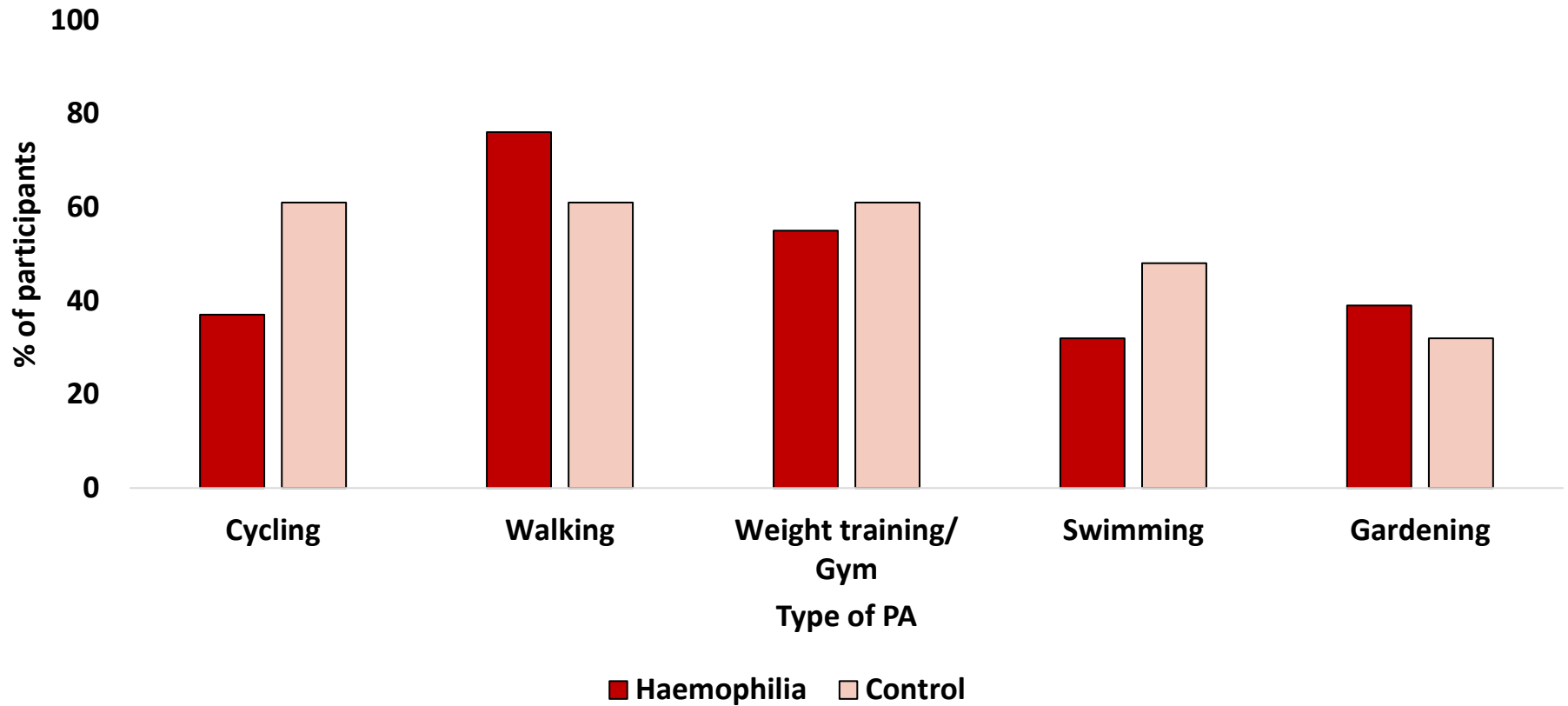
(Kennedy et al., 2021; Kennedy et al., 2022; Kennedy et al., 2023; Kennedy et al., 2023)

Main findings

73% of PwH met moderate-vigorous physical activity guidelines.

19% met these guidelines via sustained bouts of activity.

Main findings



(Kennedy et al., 2023)

Main findings

73% of PwH met moderate-vigorous physical activity guidelines.

19% met these guidelines via sustained bouts of activity.

- **Bleeding events**
- **Joint health issues (pain, stiffness, function)**
- **General psychosocial barriers (lack of time, lack of motivation, social influences)**

(Kennedy et al., 2019; Kennedy et al., 2023)

Main findings

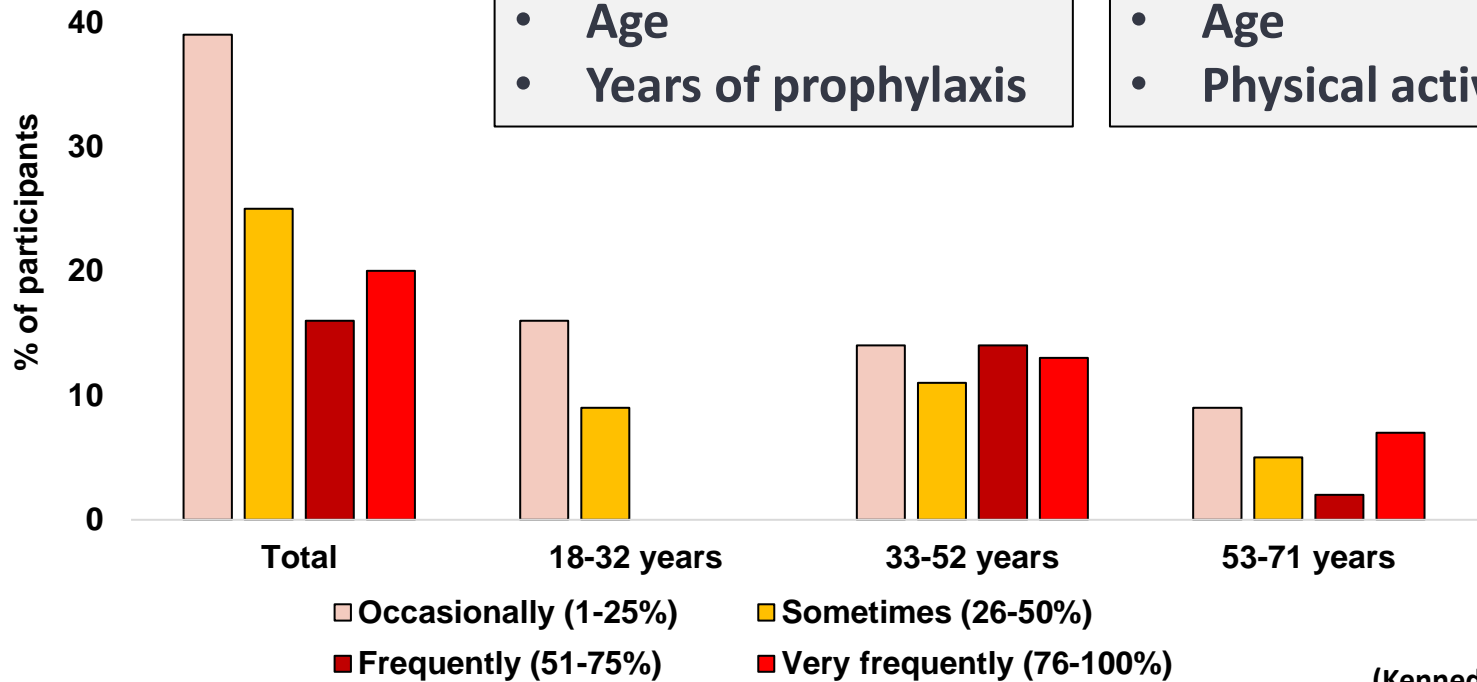
92% medicated for pain management.

71% reported chronic pain.

58% reported functional difficulties.

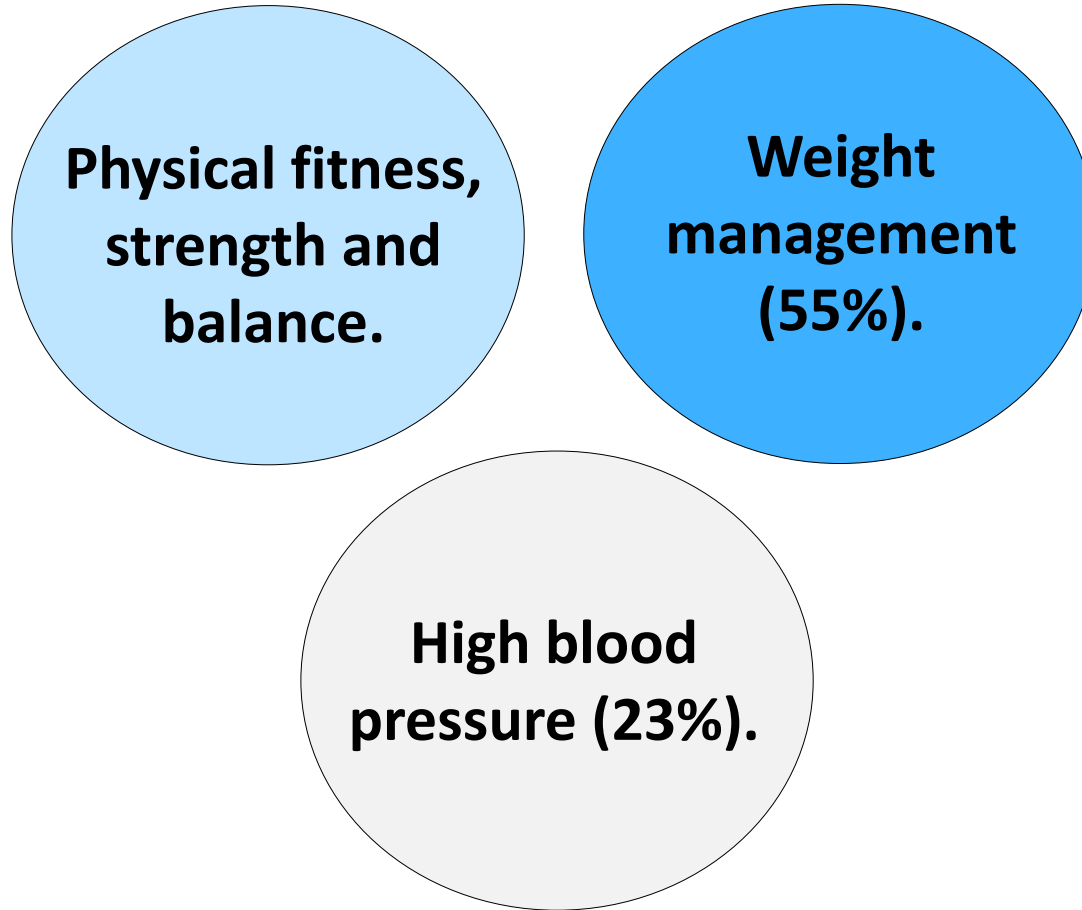
- Age
- Years of prophylaxis

- Age
- Physical activity



(Kennedy et al., 2022)

Main findings



Conclusion

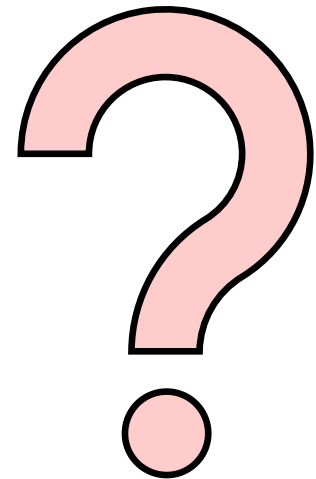
- **Adult PwH may experience variable levels of physical activity.**
- **Barriers to physical activity and the experiences of physical health may also vary.**
- **Personalised, multidisciplinary informed health interventions are required to optimise physical activity and physical health for adult PwH.**

Focus groups and interviews with adult PwH, family members, caregivers and healthcare professionals.

(Kennedy et al., 2019; Kennedy et al., 2023)

Women with inherited bleeding disorders: Filling the gap in research

- **Musculoskeletal bleeding and joint health issues may impact physical activity.**
- **Tailored physical rehabilitation after a bleed.**
- **Pain and joint health.**
- **Muscle strength, aerobic fitness, balance.**
- **Bone density.**
- **Studies predominantly in male population.**



(Srivastava et al., 2020; van Galen et al., 2021)

Women with inherited bleeding disorders: Filling the gap in research

- Musculoskeletal bleeding and joint health issues may impact physical activity.
- Tailored physical rehabilitation after a bleed.
- **Encouragingly, the provision of treatment and care for women with bleeding disorders has gained significant recognition as an important clinical unmet need.**
- Studies predominantly in male population.

(Srivastava et al., 2020; van Galen et al., 2021)

Women with inherited bleeding disorders: Filling the gap in research

- **Musculoskeletal bleeding and other bleeding symptoms common in men.**
- **Heavy menstrual bleeding (55-77%).**
- **Iron deficiency/ anaemia.**
- **Pregnancy and childbirth.**
- **Quality of life.**
- **Physical health (physical activity, pain, joint health, body composition, menstrual health.)**

(Noone et al., 2019; Khair et al., 2022)

Women with inherited bleeding disorders: Filling the gap in research

- Musculoskeletal bleeding and other bleeding symptoms common in men.
- Heavy menstrual bleeding (55-77%).
- Iron deficiency/ anaemia.
- **We need more detailed research regarding the physical health impact of bleeding symptoms in WBD.**
- Physical health (physical activity, pain, joint health, body composition, menstrual health.)

(Noone et al., 2019; Khair et al., 2022)

Menstrual health awareness

Why periods must no longer be a taboo subject in sport

Athletes who incorporate menstrual cycle into preparation are reaping the benefits

Periods in sport: Why female teams in Ireland are moving away from white shorts

Get your **free** period products here



**Positive
Period
IRELAND**

**KNOW
YOUR
FLOW**



**Women's Opinions and experiences of
Menstrual health on Exercise and
physical activity Nationally (WOMEN)**



Researchers from Trinity College Dublin and St. James's Hospital are seeking volunteers to participate in an anonymous survey titled:

Physical activity, menstrual health and bleeding experiences in the inherited bleeding disorder and general populations of Ireland.

WHO? Women/people with potential to menstruate aged 18+

WHY? We want to learn about menstrual health, bleeding experiences and physical activity. Survey open to both people who have a bleeding disorder and the general public.

Please copy the link below or scan the QR code to access the survey:

<http://bit.ly/43sSJ0F>



Research team contact: Megan Kennedy at haemexercise@tcd.ie

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Thank You