



Physical Activity for Women and Girls with Inherited Bleeding Disorders

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3rd December 2023

Today I will talk about...

- **Physical activity (PA)!**
- **PA and menstrual health.**
- **PA for Women and Girls with Bleeding Disorders (WGBD).**
- **Optimising PA.**



Regular PA is extremely beneficial for our overall health!



PA terminology

Physical activity:

“Any bodily movement produced by the contraction of skeletal muscles that results in a substantial increase in caloric requirements over resting energy expenditure.”

PA terminology

Exercise:

**“A type of physical activity consisting of planned, structured, and repetitive bodily movement done to improve and/or maintain one or more components of physical fitness,”
(including sport).**

PA terminology

Physical activity domains:
Occupational, leisure-time, household,
personal care and transport.

Types of PA

Aerobic/ Endurance/Cardio

e.g. Brisk walking, swimming, cycling, dancing.

Muscle strengthening/ Resistance/ Weight training

e.g. Dumbbells, resistance bands, body weight, power lifting, Pilates.

Bone strengthening/ Weight bearing exercise

Can involve aerobic and resistance.

Types of PA

Balance activity

e.g. Yoga, tai-chi.

Flexibility/ Stretching

e.g. Yoga, static or dynamic stretching.

Multicomponent activity

Involves all or any combination e.g. Functional training, dancing, yoga, and sports.

Moderate or strong evidence for health benefit

Children	Adults	Older Adults
<p data-bbox="193 342 425 385">Bone Health</p> <p data-bbox="135 428 483 471">Cognitive function</p> <p data-bbox="212 514 405 556">CV fitness</p> <p data-bbox="173 599 444 642">Muscle fitness</p> <p data-bbox="173 685 444 728">Weight status</p> <p data-bbox="193 771 425 813">Depression</p> 	<p data-bbox="772 342 1120 385">All-cause mortality</p> <p data-bbox="714 428 1178 471">Stroke and heart disease</p> <p data-bbox="811 514 1081 556">Hypertension</p> <p data-bbox="792 599 1101 642">Type 2 diabetes</p> <p data-bbox="850 685 1043 728">8 cancers</p> <p data-bbox="830 771 1062 813">Depression</p> <p data-bbox="772 856 1120 899">Cognitive function</p> <p data-bbox="850 942 1043 985">Dementia</p> <p data-bbox="811 1028 1081 1071">Quality of life</p> <p data-bbox="888 1113 1004 1156">Sleep</p> <p data-bbox="753 1199 1139 1242">Anxiety/depression</p> <p data-bbox="811 1285 1081 1328">Weight status</p> 	<p data-bbox="1526 342 1622 385">Falls</p> <p data-bbox="1506 428 1642 471">Frailty</p> <p data-bbox="1410 514 1738 556">Physical function</p> 

Intensity of exercise

As the intensity increases, heart rate, respiratory rate and energy consumption also increase further

Sedentary

To not moving,
working at a desk



Light

Cleaning, carrying
out rubbish, yoga



Moderate

Walking, cycling,
shopping



Vigorous

Playing football,
dancing, swimming



Very vigorous

Sprinting up hills, weight
exercises, press ups



Heart rate Respiratory rate Energy consumption



Heart rate Respiratory rate Energy consumption



Heart rate Respiratory rate Energy consumption



Heart rate Respiratory rate Energy consumption



Heart rate Respiratory rate Energy consumption

Can you sing? Can you talk?

Light	Moderate	Vigorous
Can talk/ sing comfortably. Not heavy breathing/ body.	Can speak a sentence but cannot sing. Somewhat heavy breathing/ body.	Difficult to speak. Heavy/very heavy breathing/ body.



How much PA should we be doing? WHO Guidelines (2020)



Adults aged 18-64 years:

- Limit sedentary time (replace with light intensity PA).
- Aerobic: 150-300 min/week moderate intensity OR 75-150 min/week vigorous intensity OR equivalent combination.
- Strengthening: 2+ days/ week targeting major muscle groups.
- Some activity is better than none (even light PA).
- More is better!!



How much PA should we be doing? WHO Guidelines (2020)



Adults aged 65+ years:

- Same as for adults 18-64 years.
- Varied multicomponent PA that emphasizes functional balance and strength at moderate or greater intensity on 3+ days/week to enhance functional capacity and to prevent falls.
- E.g., Tai chi, dancing, Yoga, functional training.

How much PA should we be doing? WHO Guidelines (2020)



All pregnant and postpartum women
without contraindication:

- **Aerobic: 150 min/week moderate-intensity.**
- **Aerobic and muscle-strengthening activities.**
- **Gentle stretching.**
- **Limit sedentary time (replace with light intensity PA).**
- **If physically active or engaged in regular vigorous aerobic PA before pregnancy, can continue during pregnancy and postpartum (always discuss with healthcare professional if uncertain or concerned).**

How much PA should we be doing? WHO Guidelines (2020)



Children and adolescents (5-17 years):

- 60 min/day moderate-to-vigorous intensity, mostly aerobic PA.
- Incorporate vigorous-intensity aerobic PA, as well as those that strengthen muscle and bone, at least 3 days/week.
- Limit the amount of time spent being sedentary, particularly the amount of recreational screen time.
- Infants and younger children available at:
<https://www.who.int/news-room/fact-sheets/detail/physical-activity>

National PA levels: Healthy Ireland Report (2019)

PHYSICAL ACTIVITY

*% of those achieving
National Physical Activity Guidelines*



46%

ALL ADULTS



54%

MEN

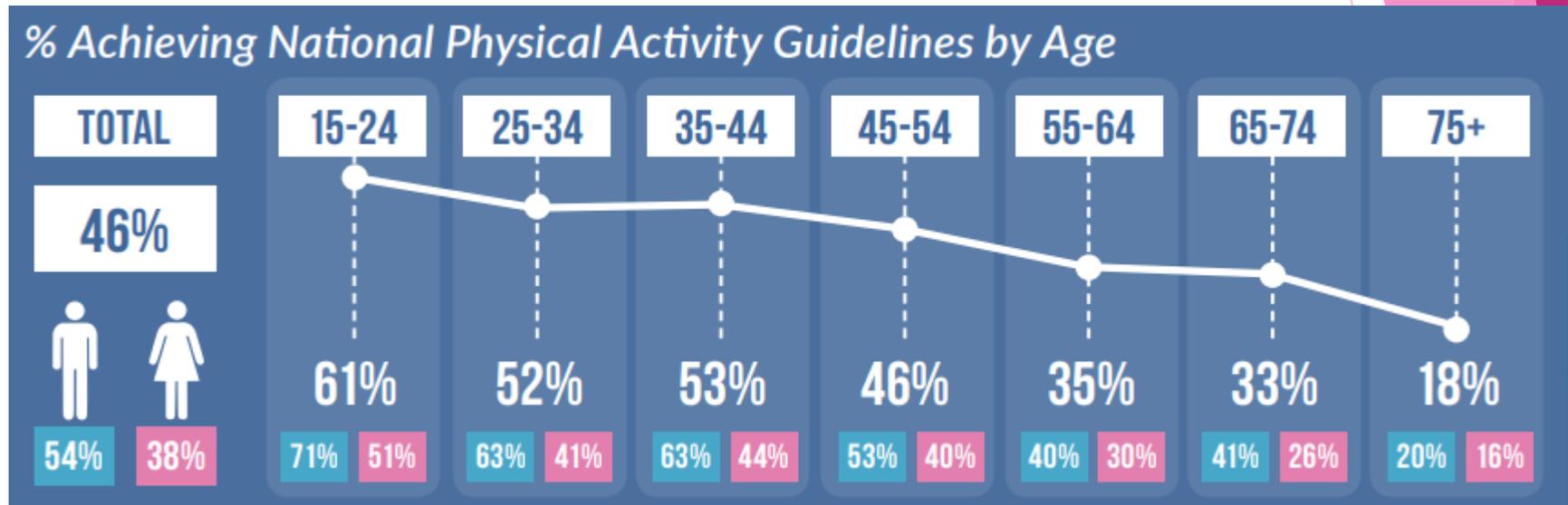


38%

WOMEN

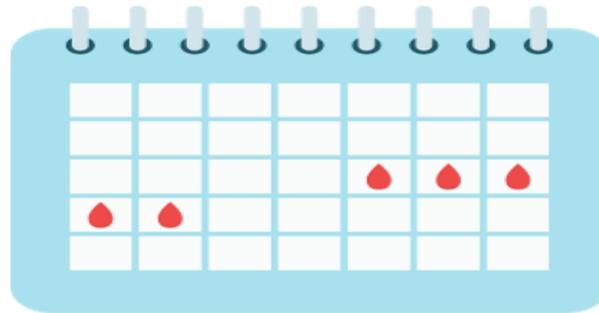


National PA levels: Healthy Ireland Report (2019)



Menstrual health and physical activity

- Causes of lower PA amongst women and girls can be multifactorial.
- Menstrual health issues may impact women and girls of reproductive age on a monthly/cyclical basis.



Menstrual health is the “complete physical, mental, and social wellbeing in relation to the menstrual cycle.”

Menstrual health issues: Healthy Ireland Report (2022)

67%
experienced
period pain

59%
experienced
period-related
fatigue

56%
experienced
premenstrual
syndrome

Menstrual health issues: Healthy Ireland Report (2022)

Missed experiences due to period related symptoms - by age (%)

	Total	15-24	25-34	35-44	44-54	55+	Currently have periods	No longer have periods
Missed work, school, or college	28	46	32	27	25	20	32	24
Felt unable to participate in sport	35	54	38	32	36	23	39	28
Felt less able to pay attention in work, school or college	37	56	38	38	35	28	42	31
Missed social events or meeting friends	33	50	36	31	30	25	36	28

*No longer have periods does not include those who are pregnant or have stopped their periods ie. using the pill or IUD.

Menstrual health issues: Healthy Ireland Report (2022)

49% limited in
daily activities
before/during
period

- Pain
- Fatigue
- **Heavy bleeding**
- Premenstrual syndrome

Heavy Menstrual Bleeding (HMB)

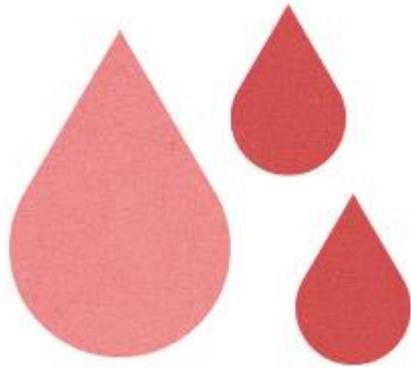
- Menorrhagia.
- “Menstrual blood loss \geq 80 ml.”
- “Excessive menstrual blood loss that interferes with the woman’s physical, emotional, social and material quality of life and this can occur alone or in combination with other symptoms.”
- Associated with an increased risk of iron deficiency and anaemia.

HMB impact on PA

- 53% of 330 with HMB reported major impact on PA.
- 36% of females undertaking 2015 London Marathon had HMB- 48% reported their menstrual cycle impacts training and performance compared to 23% in females without HMB.



HMB in WGBD



**55-77% of
WGBD report
HMB**

- **HMB impacts multiple aspects of daily life including PA, social activities, and reproductive life.**
- **Musculoskeletal bleeding and joint pain.**

PA in WGBD

ORIGINAL ARTICLE

Von Willebrand disease

WILEY

Haemophilia



Sports participation and physical activity in patients with von Willebrand disease

	Type 1 (n = 474)	Type 2 (n = 301)	Type 3 (n = 23)
Age (y), mean \pm SD	40 \pm 20 [*]	38 \pm 21 [*]	29 \pm 20 [*]
Sex, female (%)	306 (64.6%) [*]	160 (53.2%) [*]	13 (56.5%) [*]
Sports participation, number (%)	334 (70.5%)	204 (68.0%)	14 (60.9%)
Physical activity per week, number (%) ^b			
0-1 h	92 (20.3%)	48 (16.7%)	7 (30.4%)
1-2 h	112 (24.7%)	76 (26.5%)	4 (17.4%)
2-4 h	129 (28.4%)	85 (29.6%)	6 (26.1%)
>4 h	121 (26.7%)	78 (27.2%)	6 (26.1%)

PA in WGBD

ORIGINAL ARTICLE

Von Willebrand disease

WILEY Haemophilia 

Sports participation and physical activity in patients with von Willebrand disease

- Large proportion participated in various types of sport.
- Type 3 VWD more limited in sports participation due to more severe bleeding symptoms and joint bleeds.
- Reasons for non-participation: Fear of bleeding, limited walking ability, limited in daily activities.
- More PA/ sport participation associated with better perception of general health status and happiness levels.

PA for people with haemophilia and inherited bleeding disorders

- Strongly recommended due to numerous health benefits.
- Access to treatment.
- Typically advised to avoid activities involving high velocity or risk of collision or impact to risk of bleeding/injury.
- Consult with a musculoskeletal specialist in planning a safe programme around PA which considers physical condition, abilities, personal preferences and available resources.

Musculoskeletal pain and exercise therapy

- Reduces perception of pain.
- Increase joint range of movement.
- Improve muscle strength to support joint health.

Musculoskeletal pain and exercise therapy

- Land or water-based exercise therapy.
- Role for analgesic therapies in combination with PA/ exercise to improve tolerance.
- Avoid/ modify activities which aggravate pain.
- Experienced multidisciplinary healthcare professionals.

PA for people with haemophilia and inherited bleeding disorders

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

PA for people with haemophilia and inherited bleeding disorders

- Musculoskeletal bleeding and joint health issues may impact PA.
- Tailored physical rehabilitation after a bleed.
- Pain and joint health.
- Muscle strength, aerobic fitness, balance.
- Bone density.

We need more detailed research regarding the physical health impact of bleeding symptoms in WGBD.

PA for people with haemophilia and inherited bleeding disorders

Considerations for PA in WGBD:

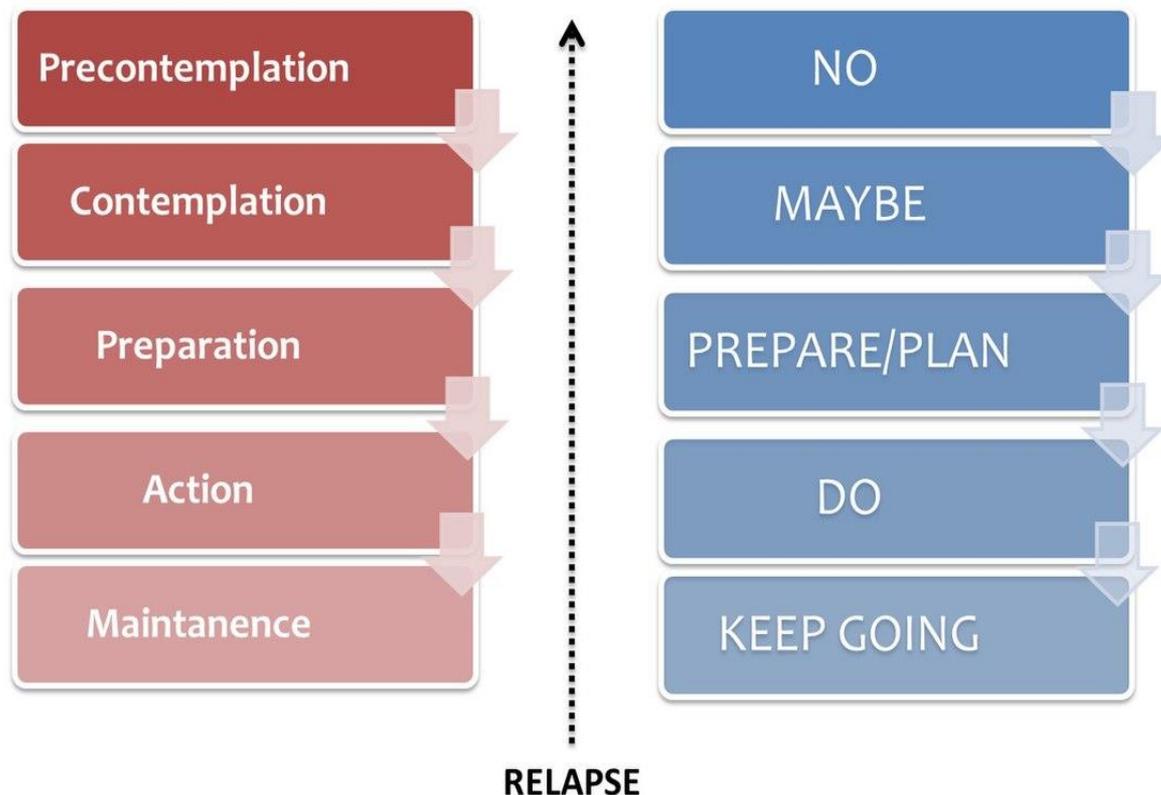
- Treatment.
- HMB, iron deficiency, anaemia.
- Pain profile.



Encouragingly, the provision of treatment and care for women with bleeding disorders has gained significant recognition as an important clinical unmet need.

Optimising PA and overcoming barriers to PA

Transtheoretical Model Stages of change





Féilthmeannacht na Seirbhíse Sláinte
Health Service Executive

Physical Activity Readiness Questionnaire (PAR-Q)

Name: _____

Date: _____ DOB: _____ Age: _____

Home Phone: _____ Work Phone: _____

Regular exercise is associated with many health benefits, yet any change of activity may increase the risk of injury. Completion of this questionnaire is a first step when planning to increase the amount of physical activity in your life.

Please read each question carefully and answer every question honestly: (Tick the appropriate answer)

1. Do you have a heart condition and should only do physical activity recommended by a physician? Y N
2. When you do physical activity, do you feel pain in your chest? Y N
3. When you were not doing physical activity, have you had chest pain in the past month? Y N
4. Do you ever lose consciousness or do you lose your balance because of dizziness? Y N
5. Do you have a joint or bone problem that may be made worse by a change in your physical activity? Y N
6. Is a physician currently prescribing medications for your blood pressure or heart condition? Y N
7. Are you pregnant? Y N
8. Do you know of any other reason you should not exercise or increase your physical activity? Y N

If you answered yes to any of the above questions, talk with your doctor BEFORE you become physically active. Tell your doctor of your intention to exercise and which questions you answered 'yes' to. If at any stage your health changes, resulting in a 'yes' answer to any of the above questions, please seek guidance from a GP.

Optimising PA and overcoming barriers to PA

- Identify barriers (e.g., time, motivation, fatigue, pain).
- Identify motivators/ facilitators (e.g., where/ how can PA be incorporated into daily activities?).
- Pick PA/ exercise/ sport you enjoy!
- Start small and gradually build exercise/ PA into routine.

Optimising PA and overcoming barriers to PA

- Aim for consistent, small and meaningful gains.
- Incorporate social aspect (family/ friends/ groups).
- N.B. For additional support or if health concerns involved, engaging in an individualised plan with experienced multidisciplinary health professionals (doctors, nurses, physiotherapists, dieticians/nutritionist, pain specialists, psychologists) is advisable.

Set SMART goals!

SMART goals

Specific

Who and what?

Measurable

By how much?

Attainable

How?

Relevant

Why?

Time-bound

When?

Let's get motivated!

Physical Activity Handout 1

'Pros' and 'cons' of being more physically active

Being physically active can help you feel better physically and mentally, but finding the motivation to engage in regular physical activity can be difficult. Writing down the 'pros' and 'cons' of being more physically active can help your motivation.

Use this form to write down the 'pros' (e.g. feeling fitter and stronger) and cons (e.g. will take time) of being more physically active.

You may find that the 'pros' of being more physically active outweigh the 'cons'!

LIST 'PROS'	LIST 'CONS'

Get ahead of potential obstacles!

Physical Activity Handout 2

Overcoming obstacles to being more physically active

Being physically active makes you feel better physically and mentally, but finding the motivation to engage in regular physical activity can be difficult. It can be beneficial to anticipate the obstacles or barriers that you may encounter to being more physically active. To help motivate you, write down below the obstacles that might stop you from being physically active, and in the other column write down some possible solutions to overcome those obstacles.

OBSTACLES I MAY ENCOUNTER	POSSIBLE SOLUTIONS
<i>E.g. I don't like walking on my own</i>	<i>Arrange to meet up with a friend who regularly exercises for a 'walk and talk' catch up!</i>

Safety!

- » Warm-up of gentle range of motion movements.
- » Stretch after physical activity.
- » Gradually building up activity.
- » Drink enough water.
- » Avoid alcohol.
- » Do not eat a large meal 2 hours before undertaking physical activity.
- » Avoid exercising late at night as this can keep you awake.
- » Don't undertake physical activity if you feel sick.

Safety!

- » Listen to your body – monitor your level of fatigue, breathing and physical discomfort.
- » To warm up- start the activity slowly, increasing your intensity slowly.
- » To cool-down–decrease your pace at the end of your session.
- » Stretch the muscles you were using if possible at the end of the session.
- » Wear comfortable footwear and loose fitting clothing.

Useful PA and exercise resources

- <https://www.hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/heal/heal-docs/lets-get-active-guidelines.pdf>

The Get Active Challenge

Start by setting realistic goals for physical activity during the next 2 weeks.

Keep a record of what activity you do each day. For example, if you walk for 15 minutes and garden for 20 minutes fill in your record like this:

Day	Activity	Minutes	Total
Monday	walking	15	
Tuesday	gardening	20	
Wednesday			

Week 1

Goal:

Day	Activity	Minutes	Total
Monday			
Tuesday			
Wednesday			
Thursday			

Useful PA and exercise resources

- <https://www.getirelandactive.ie/?page=Home>

Get Ireland Active

Ireland is an island full of sport, recreation and adventure. With Get Ireland Active, discovering where is made easy. Explore thousands of opportunities, from casual to competitive, and find what suits you best.

Get Ireland Active will guide you and help you to take control of your own activity journey. All in one place, explore countless trails, clubs, facilities and public places across the country.

Get active your way!

Useful PA and exercise resources

- <https://www.hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/heal/heal-docs/lets-get-active-leaflet.pdf>
- <https://www.hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/heal/heal-docs/lets-get-active-poster.pdf>
- <https://healthyworkplace.ie/areas/wellbeing-areas/physical-activity/other-physical-activity-resources/>
- <https://www.hse.ie/eng/about/who/healthwellbeing/>



**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**

References

- Atiq, F., Mauser-Bunschoten, E. P., Eikenboom, J., van Galen, K. P. M., Meijer, K., de Meris, J., Cnossen, M. H., Beckers, E. A. M., Laros-van Gorkom, B. A. P., Nieuwenhuizen, L., van der Bom, J. G., Fijnvandraat, K., & Leebeek, F. W. G. (2019). Sports participation and physical activity in patients with von Willebrand disease [Article]. *Haemophilia*, 25(1), 101-108. <https://doi.org/10.1111/hae.13629>
- Bruinvels, G., Burden, R., Brown, N., Richards, T., & Pedlar, C. (2016). The Prevalence and Impact of Heavy Menstrual Bleeding (Menorrhagia) in Elite and Non-Elite Athletes. *PLoS ONE*, 11(2), e0149881. <https://doi.org/10.1371/journal.pone.0149881>.
- Bull FC, Al-Ansari SS, Biddle S, Borodulin K, Buman MP, Cardon G, Carty C, Chaput JP, Chastin S, Chou R, Dempsey PC, DiPietro L, Ekelund U, Firth J, Friedenreich CM, Garcia L, Gichu M, Jago R, Katzmarzyk PT, Lambert E, Leitzmann M, Milton K, Ortega FB, Ranasinghe C, Stamatakis E, Tiedemann A, Troiano RP, van der Ploeg HP, Wari V, Willumsen JF. World Health Organization 2020 guidelines on physical activity and sedentary behaviour. *Br J Sports Med*. 2020 Dec;54(24):1451-1462. doi: 10.1136/bjsports-2020-102955. PMID: 33239350; PMCID: PMC7719906.
- Fraser, I. S., Mansour, D., Breymann, C., Hoffman, C., Mezzacasa, A., & Petraglia, F. (2015). Prevalence of heavy menstrual bleeding and experiences of affected women in a European patient survey. *Int J Gynaecol Obstet*, 128(3), 196-200. <https://doi.org/10.1016/j.ijgo.2014.09.027>
- Hallberg L, Hogdahl AM, Nilsson L, Rybo G. Menstrual blood loss-a population study. Variation at different ages and attempts to define normality. *Acta Obstet Gynecol Scand*. 1966;45(3):320-51. 2.
- Healthy Ireland. (2019). *Healthy Ireland Summary Report 2019*. I. MRBI. Available from: <https://assets.gov.ie/41141/e5d6fea3a59a4720b081893e11fe299e.pdf> (Accessed 27th November)
- Healthy Ireland. (2019). *Healthy Ireland Summary Report 2019*. I. Ipsos. Available from: <https://www.gov.ie/pdf/?file=https://assets.gov.ie/241111/e31b2aaa-a8d7-411d-8b62-02cca079c741.pdf#page=null> (Accessed 27th November)
- Hennegan, J., Winkler, I. T., Bobel, C., Keiser, D., Hampton, J., Larsson, G., Chandra-Mouli, V., Plesons, M., & Mahon, T. (2021). Menstrual health: a definition for policy, practice, and research. *Sex Reprod Health Matters*, 29(1), 1911618. <https://doi.org/10.1080/26410397.2021.1911618>
- Higham JM, Shaw RW. Clinical associations with objective menstrual blood volume. *Eur J Obstet Gynecol Reprod Biol*. 1999;82(1):73-6. 3.

References

- Khair, K., Pollard, D., Steadman, L., Jenner, K., & Chaplin, S. (2022). The views of women with bleeding disorders: Results from the Cinderella study. *Haemophilia*, 28(2), 316-325. <https://doi.org/https://doi.org/10.1111/hae.14514>
- National Collaborating Centre for Women's and Children's Health. Heavy menstrual bleeding clinical guideline (2007) Available from: <https://www.nice.org.uk/guidance/ng88/evidence/full-guideline-pdf-4782291810> (Accessed 27th November)
- Noone, D., Skouw-Rasmussen, N., Lavin, M., van Galen, K. P. M., & Kadir, R. A. (2019). Barriers and challenges faced by women with congenital bleeding disorders in Europe: Results of a patient survey conducted by the European Haemophilia Consortium. *Haemophilia*, 25(3), 468-474. <https://doi.org/10.1111/hae.13722>
- Piercy KL, Troiano RP, Ballard RM, Carlson SA, Fulton JE, Galuska DA, George SM, Olson RD. The Physical Activity Guidelines for Americans. *JAMA*. 2018 Nov 20;320(19):2020-2028. doi: 10.1001/jama.2018.14854. PMID: 30418471; PMCID: PMC9582631.
- Riebe, D., Ehrman, J. K., Liguori, G., & Magal, M. (2018). *ACSM's guidelines for exercise testing and prescription (Tenth edition.)*. Wolters Kluwer.
- Srivastava, A., Santagostino, E., Dougall, A., Kitchen, S., Sutherland, M., Pipe, S. W., Carcao, M., Mahlangu, J., Ragni, M. V., Windyga, J., Llinás, A., Goddard, N. J., Mohan, R., Poonnoose, P. M., Feldman, B. M., Lewis, S. Z., van den Berg, H. M., Pierce, G. F., the, W. F. H. G. f. t. M. o. H. p., & co, a. (2020). WFH Guidelines for the Management of Hemophilia, 3rd edition [<https://doi.org/10.1111/hae.14046>]. *Haemophilia*, 26(S6), 1-158. <https://doi.org/https://doi.org/10.1111/hae.14046>
- UK Chief Medical Officers' Physical Activity Guidelines (2019) Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/832868/uk-chief-medical-officers-physical-activity-guidelines.pdf (Accessed 27th November)
- van Galen, K., Lavin, M., Skouw-Rasmussen, N., Fischer, K., Noone, D., Pollard, D., Mauser-Bunschoten, E., Khair, K., Gomez, K., van Loon, E., Bagot, C. N., Elfvinge, P., d'Oiron, R., & Abdul-Kadir, R. (2021). European principles of care for women and girls with inherited bleeding disorders. *Haemophilia*, 27(5), 837-847. <https://doi.org/10.1111/hae.14379>