

ORIGINAL ARTICLE

Project GYM: A randomized feasibility study investigating effect on motivation of personal trainer-led exercise in young men with hemophilia

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Funding information

Pfizer, Grant/Award Number: 34897225

Handling Editor: Johnny Mahlangu

Abstract

Introduction: Many young men with hemophilia engage in physical activity and sport but face challenges to participation because of their hemophilia. Project GYM aimed to investigate the feasibility of a hemophilia-specific fitness program led by a personal trainer (PT) and its impact on gym activity, motivation, and adherence to exercise.

Methods: This was a nonblinded, randomized feasibility study, recruiting participants aged 18 to 25 years with hemophilia A or B (all severities, \pm inhibitor) from three London hemophilia centers. All participants were given an activity tracker and free gym membership. Participants were randomized to a “gym only” or “gym and PT” arm. Participants completed questionnaires evaluating motivation to exercise, quality of life, physical activity levels, self-efficacy, and self-esteem at study start and study end.

Results: Of 142 eligible individuals, 19 agreed to participate. Participants were healthy, with mean body mass index and adiposity slightly lower than the UK average. They reported low bleed numbers and had good joint health (median Hemophilia Joint Health Score [HJHS], 0; range, 0-13). The gym and PT group had more gym attendance than the gym-only group. Seven participants increased their activity levels and nine stayed the same, with no statistical difference between groups. HJHS scores improved in 3 participants and were unchanged in 12. There was no bleeding associated with gym activity.

Conclusion: Project GYM has demonstrated the safety and feasibility of a tailored physical training program in young men with hemophilia. Increased gym attendance, with and without support from a PT, is associated with increased physical activity.

KEYWORDS

exercise, feasibility study, gym, hemophilia, personal trainer

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Essentials

- Physical activity is beneficial for people with hemophilia.
- We investigated a gym-based fitness program on motivation and adherence to exercise in people with hemophilia.
- Increased gym attendance increases physical activity.
- Gym activity, self-directed or with a personal trainer, was shown to be safe for people with hemophilia.

1 | INTRODUCTION

Life expectancy in people with hemophilia has increased since the 1950s due to advances in management and improvements in factor replacement therapy.¹ There is now concern that, as more people with hemophilia reach older age, there will be an increase in age-related disorders such as overweight, obesity, cardiovascular disease, and cancer. Research suggests that the prevalence of age-related disorders among people with hemophilia is probably at least comparable with that of the general population,²⁻⁴ though not uniformly so.^{5,6}

The UK government strategy to address cardiovascular risk factors such as inactivity, overweight, and obesity is to be “physically active including at least 150 minutes of moderate intensity activity each week, in bouts of 10 minutes or more, or 75 min of vigorous activity across a week or a mixture of moderate and vigorous activity.”⁷ Guidelines for the management of hemophilia recommend tailored physical activity focusing on bone health, muscle strengthening, coordination, physical functioning, healthy body weight, and positive self-esteem.⁸

There is no published evidence on the prevalence of sport participation or physical activity in people with hemophilia in the United Kingdom. In the UK subpopulation of the HERO study ($n = 52$ people with hemophilia and 50 parents of children with hemophilia), 23% and 12% of adults, respectively, reported swimming or cycling; the figures for children were 70% and 48%.⁹ In the SO-FIT study using HaemoQoL, 127 boys (aged 8-17) with well-controlled hemophilia self-reported good physical functioning but impairment in the domain “sports and school.”¹⁰ In one UK study ($n = 50$; 64% obese), 64% of adults with hemophilia reported sports participation, and those who did not attributed this to their physical condition (but not obesity) or fear of injury; quality-of-life scores were higher in those who participated in sports.¹¹

These studies suggest that people with hemophilia engage in physical activities and, in this respect, may not differ from the general population, but a large proportion face challenges to participation because of hemophilia. To explore these issues further, a small exploratory qualitative study was conducted in young men with hemophilia ($n = 10$), several of whom reported a sport-related injury.¹² This showed varying levels of motivation to engage in physical activity and differing levels of confidence due to perceived injury risk. It was also highlighted that physiotherapy often did not address a desire to be able to do nonrehabilitation exercise activity such as gym-based weightlifting and higher-level muscle strengthening.

To date, almost all of the published literature concerning exercise in hemophilia relates to hospital-based rehabilitation,¹³ postsurgical

rehabilitation,^{14,15} or physiotherapy-led home exercise programs for specific outcomes such as balance.¹⁶ Recent reports show no additional injury or bleeding risk from sporting activity in young people with hemophilia,¹⁷ but to our knowledge no literature exists that describes nonmedicalized exercise approaches for people with hemophilia such as gym-based weight training. Younger people with hemophilia want to have the option of using gyms for their own self-identified health and fitness goals, but still identify barriers related to their hemophilia.

Personal trainers (PTs) are an increasingly common sight in gyms. They work on an individual basis with people to design strength and physical fitness programs based on identified goals and physical ability. The personalized nature of this kind of training may provide psychological reinforcement around motivation and goal attainment¹⁸ and has been shown to positively change attitudes toward exercise and increase physical activity.¹⁹ While PTs are professionally trained in health and fitness across a spectrum of physical conditions, their knowledge of rare diseases such as hemophilia would be minimal.

This study was conceived to investigate the feasibility of a PT-led fitness program on motivation and adherence to exercise for young adults with hemophilia. The aims of this study were twofold:

1. Investigate the feasibility, safety, and acceptability of a randomized, PT-led fitness program for young men with hemophilia.
2. Collect and analyze preliminary data (amount of change before and after) with the chosen outcome measures relating to motivation, adherence, self-efficacy, and physical activity.

2 | METHODS

2.1 | Study design

This was a multicenter, nonblinded, randomized feasibility study.

2.2 | Participants

Potential participants were identified from registration databases at three large hemophilia centers by physiotherapists. Inclusion criteria specified people with haemophilia A or B of any severity, aged between 18 and 25 years living within 90 minutes' travel time of the gym location and with good command of written and spoken English. If the local medical team deemed participation in this study as unsafe, participants were not included (Table 1).

TABLE 1 Study inclusion/exclusion criteria

Participant inclusion criteria	Participant exclusion criteria
Aged 18-25 years	Adults for whom the study was deemed unsuitable by their medical team
Diagnosis of hemophilia A or B – any severity	
Able to give informed consent	Limited comprehension of English (needed for safe participation)
Lives within 90 min travel to the gym study site	
Able to understand and read/write English	Travel time >90 min to gym study site

2.3 | Recruitment/enrollment

The recruitment period was for 6 months, from January to June 2018. Potential participants were mailed an information sheet and invited to contact the investigators by phone or email if they wanted to participate. Those who did not respond within 2 weeks were followed up by telephone to check if they had received the study information and if they wished to participate. Final participants were invited to a study workshop held at the gym. Written consent was taken at this point.

2.4 | Intervention

The gym location was the YMCA in Central London. Before the study commenced, the gym manager was contacted and agreed to inform all the PTs working there about the project. PTs who expressed an interest in taking part were invited to a study information, education, and training session delivered by the study team in advance of the participant workshop (Table 2). On the day of study commencement, participants were invited to attend a workshop hosted in the gym facilities. Here, they participated in the delivery of a brief education curriculum (Table 2), and a tour of the gym facilities was provided by the PTs. Baseline demographic data was collected by physiotherapists and PTs; health information was provided by each of the participants (Table 3).

TABLE 2 Education curriculum for study participants and personal trainers

Project GYM – Curriculum	
Young men with hemophilia	Personal trainers
<ul style="list-style-type: none"> • Hemophilia and its effect on joints • How to train safely in gym/personal limits • How to use equipment safely and effectively • Principles of nutrition • How to recognize/manage bleeds versus normal physical response to exercise (such as muscle soreness) • When to seek professional help • Core program of gym-based fitness activities • Introduction to fitness opportunities available within gym 	<ul style="list-style-type: none"> • Basics of hemophilia • Psychological and sociological aspects of living with hemophilia • The effect of hemophilia on and in a family • Rationale for this study • Overview of physiotherapy assessments • Risk modification • Management and outcome assessments • Self-activation and behavioral change skills

2.5 | Randomization

Randomization (“gym only” or “gym and PT”) was completed using a sealed envelope system after consent, curriculum delivery, and questionnaire completion.

Those randomized to the PT arm were offered a 12-week tailored, PT-led fitness program. They met the PTs after randomization and were able to choose the PT with whom they wanted to train. In keeping with a real-world approach to using the service of a PT, the participants arranged their own follow-up sessions with their PT. At their first session, they agreed on goals for their program, and the PT designed a bespoke exercise program for them based on this. This enabled a highly individualized and personal program for them, based on their own identified physical needs, interests, and identified goals. As a result, no two participants did the same program. The PTs were also encouraged to contact the specialist hemophilia physiotherapist known to each participant if they felt they needed further advice or guidance. Hemophilia center physiotherapists, however, did not participate in the development of any exercise plans. Participants were allowed one face-to-face session per week for 12 weeks with their PT. They could choose to independently attend the gym as many times as they wished in addition to this. Those assigned to the gym-only arm were provided with a gym induction session and encouraged to do self-directed gym activity for 12 weeks. Both groups were advised to follow their programs for a further 12 weeks (24 weeks in total).

Participants on prophylaxis adjusted their treatment regimen, in agreement with their medical team, to allow factor administration before gym activity. All participants had free gym membership for the duration of the study, with an optional extension at study completion at a reduced price for a further 6 months.

2.6 | Measurements

The Hemophilia Joint Health Scores (HJHS) for each participant were requested from the physiotherapist at their hemophilia center. Those

TABLE 3 Participant characteristics at baseline

		All (n = 19)	PT group (n = 9)	Gym group (n = 10)
Age, y	Median	22.1	22.07	21.08
	Range	18.1-24.1	19.06-24.06	18.09-24.10
Type of hemophilia	A/B	14/5	7/2	7/3
Severity of hemophilia	Mild	4	0	4
	Moderate	3	2	1
	Severe	12	7	5
Treatment	Standard half-life factor	15	6	9
	Extended half-life factor	3	3	0
	Desmopressin	1	0	1
	Dose of factor	1500-3500 IU	2000-3500 IU	1500-3000 IU
Injection frequency	Weekly	1	1	0
	Alternate days	6	3	3
	On demand	6	1	5
	Other ^a	6	2	4
BMI, kg/m ²	Median (range)	23.4 (17.3-39.9)	23.5 (17.6-39.8)	22.3 (17.3-30.9)
	Body fat mass, %	Median (range)	20.6 (4.3-43.3)	14.8 (4.3-43.3)
Smoker		4	2	2
Hemophilia Joint Health Score (total)	Median	0	0	1
	Range	0-13	0-13	0-13
Self-reported bleeds in past 6 months ^b	Median	1	1.5	1
	Range	0-6	0-6	0-3
Comorbidity ^c	Number of participants	4	3	1
	Visited family physician in past 4 weeks	2	2	0
Ethnic background	White	12	6	6
	Black/Black British	1	0	1
	Asian	4	1	3
	Other	1	0	1

^aDaily (1), 2-3 times/week (1), every 3 days (2), weekly (1), twice monthly (1).

^bTwo participants were unable to provide an exact figure; two did not provide data.

^cMay have reported more than one comorbidity: glucose intolerance/diabetes (1), depression/anxiety (2), overweight/obesity (2), lower back pain (2), osteoarthritis (1), musculoskeletal (1), other (1).

with mild or moderate hemophilia without a recent HJHS were invited by the physiotherapist to attend this review before starting the study.

Participants completed baseline study questionnaires (Table 4) that focused on assessment of readiness to change (the Stages of Change questionnaire),^{20,21} degree of self-efficacy for management of their chronic disease (the Self-Efficacy to Manage Chronic Disease Scale [SEMCD]),²² generic health-related quality of life (EQ-5D),²³ type and intensity of physical activity in daily life (the International Physical Activity Questionnaire [IPAQ]),²⁴ and a measure of self-esteem (Rosenberg's Self-Esteem Scale).²⁵

All participants were issued a Fitbit Versa 2 activity tracker and instructed on how to connect to the "Fitabase" data collection system

and how to upload their activity data. The consent form included permission for the study team to access activity data (step count and heart rate) for the duration of the study. To minimize any potentials bias, participants were only informed they could keep the Fitbit after they completed all the study procedures and had been assigned to their randomized group.

At 6 months, participants were invited to a follow-up workshop, completing the same questionnaires as at baseline. Follow-up HJHS assessments were also requested. All participants were contacted for an interview with one of the study team, either face to face or over the phone, to discuss their experience of the study and whether they had maintained any changes in activity.

TABLE 4 Questionnaires used in the study

Stages of change	Assesses readiness to change behaviour through a series of characteristic stages (precontemplation, contemplation, preparation, action, maintenance, and relapse) toward adopting and maintaining a new habit.
Self-Efficacy to Manage Chronic Disease Scale	Assesses self-efficacy for managing chronic disease using six items on a visual analogue scale (VAS; 0–10). Higher scores indicate higher self-efficacy.
International Physical Activity Questionnaire (IPAQ) – short form	Assesses the types and intensity of physical activity and sitting time that people do in their daily lives. The IPAQ short form has seven questions to self-report physical activity in the preceding seven days. The score is calculated by multiplying the time and level of activity; higher scores indicate greater activity.
Rosenberg's Self-Esteem Scale	Consists of five positively and five negatively worded statements, that individuals score using a 4-point scale, from strongly agree to strongly disagree. Scores range from 0 to 30; scores below 15 suggest low self-esteem.
EQ-5D-5L	Standardized generic instrument that comprises five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression, which together can be used to calculate a respondent's health status. A visual analog scale (where 0 is worst and 100 is best health status) is also included. Higher scores represent higher health.

A telephone call was made at 12 months to ascertain if any gym activity continued.

2.7 | Feasibility outcomes

These were identified as:

1. Recruitment rate (how many were eligible and ability to recruit planned number [$n = 20$] in time period) and follow-up rate (how many were successfully followed up at 6 and 12 months).
2. Acceptability of study procedures, chosen outcome measures, and randomization (assessed through post-study interviews).
3. Safety of intervention (assessed by number of recorded bleeds, for any reason) and any other adverse events (such as injury).

2.8 | Statistical methods

Data are presented as descriptive, with median and range data, and interquartile range where appropriate. Statistical analysis was done using SPSS (version 25; IBM, Armonk, NY, USA). Interviews were recorded and transcribed verbatim; transcripts were coded and analyzed thematically.

2.9 | Sample size

Because this was designed as a feasibility study, there was no need to achieve a desired power to detect any effect. The study

aimed to see if this could be done in the way it was conceived and delivered.

The study was approved by the Ethics Committee and Health Research Authority in accordance with local governance and legal requirements (IRAS project ID: 241384; REC reference 18/WA/0179). The study was registered with the Research and Development Office of the Royal Free Hospital, London, UK.

3 | RESULTS

3.1 | Demographic data

Participant demographic data are presented in Table 3. Nineteen participants were recruited, with a median age of 22.1 (18.1–24.1) years. Fourteen had a diagnosis of hemophilia A, 12 had severe hemophilia, 3 were moderate, and 4 were mild. Participants were from diverse racial backgrounds, with median body mass index and adiposity (23.4 [17.3–39.9] and 20.6 [4.3–43.3], respectively). Joint health was good: 13 participants had HJHS scores of between 0 and 3, two scored 7 and 8, and three participants had scores of 12 and 13.

3.2 | Recruitment and retention

Participant identification, recruitment, and retention for the study are detailed in Figure 1. Nineteen participants were recruited, compared to the original aim of 20. HJHS data were unavailable for 15 participants (78.9%) at 6-month follow-up. Outcome measure data were not available for two participants (10.5%) at 6 months, as they

did not attend the follow-up workshop or return questionnaires by post. Only 10 participants (52.6%) agreed to an interview at 6 months, five over the telephone and five face to face. At 12 months, only seven (36.8%) agreed to a follow-up phone call.

3.3 | Attendance rates

Participants who were randomized to the 12-week PT-led fitness program visited the gym more frequently (median visits, 16; range, 3-83) than those with gym membership only (median visits, 3; range, 3-41).

3.4 | Activity levels

Physical activity levels (reported via IPAQ) showed that in the PT group, activity level increased in five participants, with no change in five. In the non-PT group, there was an increase in activity level for four participants, with no change for three.

At 12 months, seven participants reported that they were still attending a gym, with two individuals continuing to pay for a PT.

3.5 | Fitbit

Fitbit activity data were available for 17 of 19 participants at 6-month follow-up. Participants did not synchronize their data regularly with the Fitabase system; therefore, quality of the overall data was poor. Across the group, median total steps per day was 7937 (range, 4287-17 182). Data on heart rate were consistently poor, with multiple missing data points, so we are unable to include it here.

3.6 | Joint health in study

The HJHS remained unchanged at 6-month follow up for 63.2% of participants ($n = 12$), with a decreased total score in 15.8% ($n = 3$; range, 1-3 points improvement). It did not increase in any participant. There were no follow-up HJHS data available for four participants.

3.7 | Adverse events

At baseline, participants were asked to estimate how many bleeds (all bleeds) they recalled having in the preceding 6-month period. A total of 78.9% ($n = 15$) reported bleeds (range, 1-3), with 21.1% ($n = 4$) reporting zero bleeds.

Self-reported bleed data were available for only 17 participants (84.2%) at the 6-month follow up. Of these, 68.8% ($n = 11$; seven participants in the PT group and four in the gym-only group) reported bleeding episodes (median, 2; range, 1-5), with 37.5% reporting no bleeds ($n = 6$; three in the PT group and three in the gym-only group). The follow-up interviews revealed that none of

the reported bleeds were gym related (one shoulder injury, one low back pain, one "ankle problem," one wrist injury, and one trauma related to a wall-climbing injury).²⁶ Comparing bleeding rate before and after the intervention, 37.5% ($n = 6$) reported fewer bleeds (range, 1-5), 37.5% ($n = 6$) reported an increase in bleed rate (range, 1-4), and 25% ($n = 4$) reported no change. Of those reporting an increase in bleed rate, one had moderate hemophilia; of those reporting decreased or no change in bleed rate, five had severe hemophilia, one had moderate hemophilia, and four had mild hemophilia. None reported this increase as being associated with being part of the study.

3.8 | Outcome measures

Results are shown in Table 5.

In the PT group, the median change in the SEMCD from baseline to study end (six months) was 41 (range 19–60) and 54 (range 25–60), compared to the non-PT group which was 53 at baseline (range 25–60) and 49.5 (range 43–60) at study end.

For the EQ-5D-5L index score, the PT group had a median change from baseline to post-study of 0.74 to 0.82 compared with a slight decrease of 0.84 to 0.79 for the non-PT group.

Self-esteem score in the PT group had a median change from baseline to post-study of 23 (range, 12-30) to 24 (range, 13-30), with a slightly larger change found in the non-PT group of 22 at baseline (range 14-28) and 26 (range, 18-30) at study end.

3.9 | Acceptability

At the 6-month follow-up, only 10 participants (52.6%) agreed to be interviewed about their views and opinions on their experience of the study, and as such only a limited evaluation is possible here. Participants reported that the measures chosen were acceptable in terms of time to complete and assessment type. Activity monitoring via Fitbit was acceptable, even though there was low adherence to uploading data. Reasons for poor adherence to wearing/using the Fitbit included losing it and remembering to charge it. One preferred a different device as it was part of his health insurance plan. All reported they were happy to be randomly assigned and understood its purpose. One participant randomly assigned to PT failed to contact the PT, stating that he was "happy just to have access to the gym to do his own thing." Fifty percent of this group ($n = 5$) were happy with the gym location. Reasons given by participants for the gym location being problematic included living too far away to travel and trying to get there after work.

4 | DISCUSSION

Although exercise is broadly recommended for people with hemophilia, private gym-based exercise activity has yet to be fully

FIGURE 1 Recruitment and retention of participants in study. HJHS, Hemophilia Joint Health Score

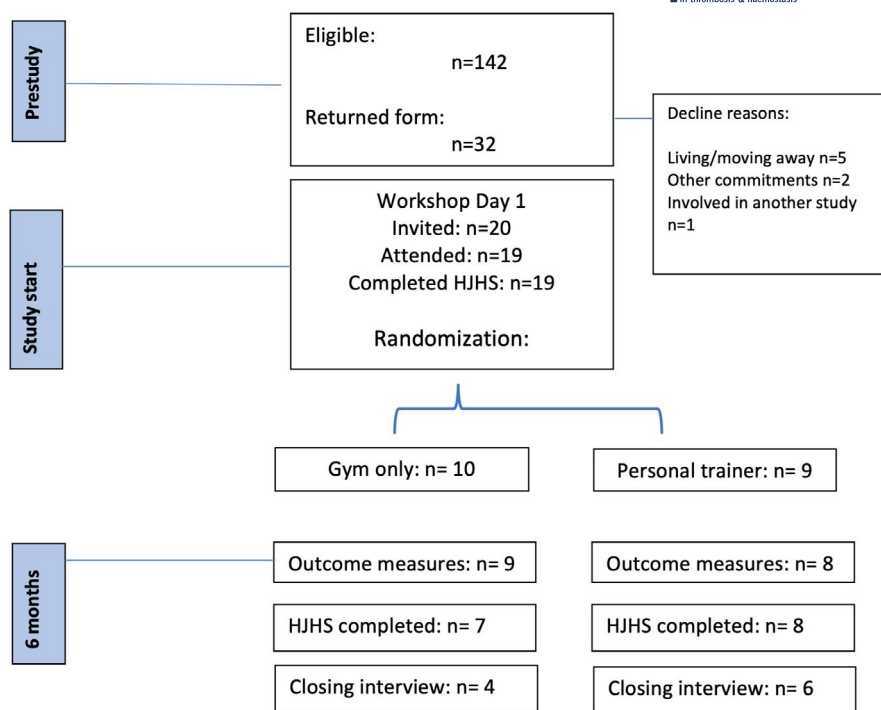


TABLE 5 Global changes in efficacy end points

Measure	Statistic	PT group		Gym-only group	
		Prestudy [n = 10]	Post-study (6 months) [n = 10]	Prestudy [n = 9]	Post-study (6 months) [n = 7]
Stages of change	Change in grouping (start vs end)	Precontemplation (0) Contemplation (1) Preparation (3) Action (3) Maintenance (3)	Precontemplation (0) Contemplation (0) Preparation (0) Action (1) Maintenance (9)	Precontemplation (0) Contemplation (0) Preparation (1) Action (0) Maintenance (8)	Precontemplation (0) Contemplation (0) Preparation (0) Action (0) Maintenance (7)
International Physical Activity Questionnaire (IPAQ)	Change in score (start vs end)	Low (2) Moderate (3) High (5)	Low (0) Moderate (2) High (8)	Low (2) Moderate (4) High (3)	Low (0) Moderate (2) High (5)
Self-efficacy	Change in score (start vs end)	Median = 41 Range = 19-60	Median = 54 Range = 25-60	Median = 53 Range = 25-60	Median = 49.5 Range = 43-60
EQ-5D index score	Change in score (start vs end)	Median = 0.74 Range = 0.41-1.00	Median = 0.82 Range = 0.51-1.00	Median = 0.84 Range = 0.69-1.00	Median = 0.79 Range = 0.62-1.00
EQ-5D VAS	Change in score (start vs end)	Median = 72.5 Range = 15-97	Median = 80 Range = 45-98	Median = 75 Range = 40-100	Median = 80 Range = 55-96
Self-esteem	Change in score (start vs end)	Total score Median = 23 Range = 12-30	Median = 24 Range = 13-30	Total score Median = 22 Range = 14-28	Median = 26 Range = 18-30

investigated. To our knowledge, this is the first time such an approach has been attempted. As such, response and adherence to self-structured exercise (as opposed to hospital-based rehabilitation or prescribed home exercises) remains unknown. This feasibility study demonstrates that self-directed and PT-supported gym activity is safe, that joint health (HJHS) was not negatively affected, and that PT-led activity encourages increased participation.

Health equity for people with hemophilia is intrinsically associated with access to prophylaxis – allowing normal mobility and participation in work, school, and family life without restriction.²⁷ This normalization of lifestyle also normalizes the risk of trauma associated with an active lifestyle. This applies to the cohort in this study whereby the overall benefit of being physically active outweighs risk of inactivity associated with hemophilia.

Recent reviews of exercise for people with hemophilia have been broadly encouraging with regard to its safety as an intervention. Poor-quality studies and lack of reporting of methods and findings mean that care must still be taken with such recommendations.^{28,29} However, as shown in our findings, safety in participation with gym-based exercise programs was demonstrated. It is noteworthy that none of the studies included in these two reviews used private gym facilities – they were either home exercise programs or physiotherapy rehabilitation facilities. It remains that exercise in people with hemophilia is heavily medicalized even when not associated with an acute clinical episode. In contrast, recent findings from a Dutch cohort suggest that nonmedicalized sports participation appears to be a safe activity in young people with good joint health receiving adequate prophylaxis.¹⁷

Being physically active as a child predicts increased participation in physical activity in adulthood,³⁰ with activity that has been supported by parents, peers, and teachers enhancing self-awareness and confidence in activity as an adult.³¹ For many adults with hemophilia, normal participation in activity and school-based sports were limited or prohibited due to fears of bleeding.³² It is unclear if some legacy of this message remains in the lives of younger men with hemophilia, so it remains important to engage and encourage normal lifestyle and physical activities with peers.

The outcome measurements used were based on themes identified in the preliminary work for this project. However, only one subset within the EQ-5D showed any significant change. This may reflect the low participant numbers, the chosen measure being inappropriate, or the amount of physical activity undertaken being insufficient to elicit significant change in measures. The IPAQ also highlighted that many of the participants had already reported high levels of baseline activity. We acknowledge that this may present with a selection bias of people with a more positive view of exercise in general and more willing to participate in studies such as this, so care should be taken with the findings.

This study did not record baseline activity data, and while all participants registered and agreed for data to be used from Fitbit, many failed to upload their movement data. Although a recent study reported that people with hemophilia were accepting of wearing a Fitbit,³³ adherence with wearable technology in our study cohort was poor, being negatively influenced by forgetting to charge and wear it. It is noted that user experiences of activity trackers are more positive when used alongside personal goal setting,³⁴ and changes to longer-term behavior may not succeed with such techniques.³⁵

Gym attendance was higher for the PT group, and at 12 months, more participants in that group reported they were still attending the gym, suggesting that the involvement of the PT positively influenced attendance. A sustained change in behavior such as choosing to attend a gym regularly is a complex process involving an individual's capability, opportunity, and motivation. Personal reflection and reappraising one's own expectations for gym attendance are powerful drivers for behavior change, with confidence in ability and skill acquisition of gym activity having a positive influence on motivation.²⁸ Although we did not specifically aim to include behavior

change techniques in the design of this project, it is clear from the number of gym attendances as well as data from interviews that those in the PT group felt more confident in activity and did more of it because they had regular support. Further work should aim to base interventions in behavior change techniques to investigate the value of this approach further. It may also be useful in future studies to ascertain if working with a PT helps positively manage any body image issues an individual may have. It is noteworthy that the YMCA is active in the non-body shaming movement, and participants commented that they felt welcome at the gym.

The authors acknowledge there were many limitations with this study. As a feasibility design, the study was not designed to provide statistical power, so no clinical recommendations or generalizations can be made from this data. The cohort included here are representative of those registered in hemophilia centers in London. Although we included all severities of hemophilia, further work may want to establish barriers and facilitators to this type of gym-based exercise within each severity level. We believe that the outcome measures chosen for use here were acceptable to participants and may have value in larger studies. Although we did not set out to do so here, future researchers should consider if measures may have more clinical utility if chosen to identify relationships between general physical activity and more formalized exercise. The data capture from the Fitbit was poor, and although the small group interviewed at 6 months reported acceptability of it, it was clear that using and wearing it habitually did not occur. Further studies should address behavioral change requirements and personal beliefs for using such equipment as well as pragmatic applicability of wearable technology for study quality. The Central London location of the gym may have been a barrier to participants; future studies need to consider the potential "facilitator effect" of using geographically local gyms, and if any personal trainer can be involved without training or support from clinical teams if necessary. A follow-up period of 6 months for collecting outcome measures appears to be acceptable, with only two participants lost to follow-up at this point. However, the loss to follow-up for interview at 6 months was more substantial, so care must be taken with the feedback given by those who did get interviewed, as it may not be representative of the group. Further research will need to consider how medium- to long-term effects of exercise and activity interventions can be monitored. The study protocol used here requires further refinement and review before proceeding to a larger study, and it is hoped that the reporting of this feasibility study can inform the design and implementation of further similar studies.

5 | CONCLUSIONS

This study demonstrates the safety and feasibility of a gym-based exercise intervention for young men with hemophilia. To our knowledge, this is the first study investigating a nonmedical gym environment and PTs in people with hemophilia. Participants training with PTs had more gym attendance and felt better supported than

those in the gym-only group. This highlights the need to further understand support needs in future studies. Behavior change theory and techniques should be included when investigating gym-based activity for young men with hemophilia. Consideration should be given as to whether a randomized controlled trial approach is the best way to evaluate this type of intervention in this cohort, given the relatively small numbers and the high degree of variability and behavior of potential participants involved.

ACKNOWLEDGMENTS

We express our thanks to the young men and personal trainers for their participation in this study, the physiotherapists (Vishal Patel at the Royal London Hospital, Stephen Classey at St Thomas' Hospital, London) for identifying and obtaining consent from participants. Thanks also to Matt Boyton for statistical support. Project GYM was conducted by Haemnet in association with the YMCA Club, London.

RELATIONSHIP DISCLOSURE

This study was undertaken by Haemnet with funding from a Pfizer Inc. investigator-initiated research grant (award number 34897225). Pfizer had no involvement in the protocol design or identification of study objectives and no influence or contribution on reporting the findings.

AUTHOR CONTRIBUTIONS

PML, MH, and KK designed the study, collected and analyzed the data, and wrote the first draft of the paper. All authors critically reviewed revisions of the manuscript and agreed its final version.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

How to cite this article: McLaughlin P, Holland M, Dodgson S, Khair K. Project GYM: A randomized feasibility study investigating effect on motivation of personal trainer-led exercise in young men with hemophilia. *Res Pract Thromb Haemost.* 2021;5:e12613. <https://doi.org/10.1002/rth2.12613>