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■ **HIP**

What is the adult experience of Perthes' disease?

INITIAL FINDINGS FROM AN INTERNATIONAL WEB-BASED SURVEY

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Aims

Perthes' disease is an uncommon hip disorder with limited data on the long-term outcomes in adulthood. We partnered with community-based foundations and utilized web-based survey methodology to develop the Adult Perthes Survey, which includes demographics, childhood and adult Perthes' disease history, the University of California Los Angeles (UCLA) Activity Scale item, Short Form-36, the Hip disability and Osteoarthritis Outcome Score, and a body pain diagram. Here we investigate the following questions: 1) what is the feasibility of obtaining > 1,000 survey responses from adults who had Perthes' disease using a web-based platform?; and 2) what are the baseline characteristics and demographic composition of our sample?

Methods

The survey link was available publicly for 15 months and advertised among support groups. Of 1,505 participants who attempted the Adult Perthes survey, 1,182 completed it with a median timeframe of 11 minutes (IQR 8.633 to 14.72). Participants who dropped out were similar to those who completed the survey on several fixed variables. Participants represented 45 countries including the USA (n = 570; 48%), UK (n = 295; 25%), Australia (n = 133; 11%), and Canada (n = 46; 4%). Of the 1,182 respondents, 58% were female and the mean age was 39 years (SD 12.6).

Results

Ages at onset of Perthes' disease were < six years (n = 512; 43%), six to seven years (n = 321; 27%), eight to 11 years (n = 261; 22%), and > 11 years (n = 76; 6%), similar to the known age distribution of Perthes' disease. During childhood, 40% (n = 476) of respondents had at least one surgery. Bracing, weightbearing restriction, and absence of any treatment varied significantly between USA and non-USA respondents (p < 0.001, p = 0.002, and p < 0.001, respectively). As adults, 22% (n = 261) had at least one total hip arthroplasty, and 30% (n = 347) had any type of surgery; both more commonly reported among women (p = 0.002).

Conclusion

While there are limitations due to self-sampling, our study shows the feasibility of obtaining a large set of patient-reported data from adults who had childhood Perthes' from multiple countries.

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Introduction

Perthes' disease is an uncommon childhood hip disorder with limited information on the subsequent impact on adult function. It has typical onset between the ages of four and eight years old,[1] and can require surgery or prolonged treatment during its active phase in childhood. However, as the femoral head heals, the pain decreases and mobility returns.[2] Given the low disease incidence ranging from 0.5 to 30 per 100,000 children,[3] large samples for well-powered analysis are challenging to obtain.[4]

While some children recover and enjoy normal hip function after Perthes' disease, the disease process can also leave the femoral head and the surrounding acetabulum misshapen and incongruent.[5] Surgery in adulthood to treat progressive symptoms, such as hip-preserving procedures or total hip arthroplasty, is sometimes necessary.[6-9] After reaching adulthood, however, patients are difficult to track down and the long-term study of this population is difficult. Most long-term Perthes' disease studies focus solely on radiological outcomes, and are limited to samples of no more than 100 adults.

The advent of web surveys over the last 20 years has introduced new tools for long-term data collection. Advantages include the respondent's ability to remain anonymous, as well as the researcher's ability to track progress, survey engagement, use real-time validation, and examine timing and completion rates.[10,11] Web-based surveys have helped answer relevant and/or sensitive questions, and are gaining traction in the orthopaedic community. Recent studies include the study of opioid prescribing practices,[12,13] exploring surgical equipoise among providers,[14-16] and improving shared decision-making with patients.[17] Web-based surveys, specifically, are characterized by low cost and rapid data collection for hard-to-reach populations.[10,18,19] Further, web-based surveys can reach a substantially large, international audience.

Given the need to understand patient-reported experience of Perthes' disease, in 2019 the International Perthes Study Group initiated the Adult Perthes Survey.[20] The Survey was advertised through support networks, such as the Perthes Kids Foundation,[21] reaching a combined social network of over 20,000 members. The overall goal of the Adult Perthes Survey was to collect and evaluate a large cross-sectional sample of demographic, functional, and emotional wellbeing outcome data from adults who had Perthes' disease as children. This initial paper will investigate the feasibility of obtaining survey data from adults who had Perthes' disease as children using a web-based platform, and the composition of our collected sample with respect to baseline characteristics and self-report of childhood experience of Perthes' disease.

Methods

We obtained human subjects research approval from our institutional review board for this web-based cross-sectional survey of adults. The survey was promoted internationally among Perthes' disease support groups for English-speaking adults over the age of 18. As shown in Figure 1, means of advertisement were limited to email, virtual newsletters, Facebook, and website posts, meaning Internet access was required. Respondents were encouraged to complete the survey in one sitting. Survey participation was anonymous; however, participants could share their email address to be contacted regarding future research participation.

The Adult Perthes Survey was available to the public from 3 May 2019 through 3 August 2020 by means of a Research Electronic Data Capture (REDCap) platform. REDCap is a secure, user-friendly, web-based software platform designed to support data collection for research studies.[22,23] As shown in Figure 2, a link was available on the IPSG website to submit a preliminary consent statement, and digitally proceed through the survey. Confirming Perthes' disease diagnosis by radiograph was not feasible for this study; therefore, participants were asked to confirm their Perthes' disease diagnosis in childhood to the best of their recollection. Pre-testing was conducted with four adults from the target population prior to going live.

The five-part web survey included sections on childhood and adult Perthes' disease history, a one-item University of California Los Angeles (UCLA) Activity Scale,[24] the Short Form-36,[25] the Hip Disability and Osteoarthritis Outcome Score (HOOS),[26,27] and a body pain diagram. The Perthes' disease-specific health history form, the data from which are presented here, was developed using expert opinion (level V evidence) and forms used by the International Perthes Study Group, and ranged from 13 to 26 questions (Supplementary Material, Hip Health History Questionnaire). Among the data collected in this form, respondents were asked which hip(s) (right/left) were affected by Perthes' disease, as well as their age at diagnosis (< six, six to seven, eight to 11, or > 11 years). Other variables included: BMI, location, comorbidities, family history, past treatment experience, and treatment in adulthood.

Statistical analysis. All participants over 18 years old who completed the Adult Perthes Survey were eligible for inclusion in this analysis. The analyses were conducted using freely available R environment (R Foundation for Statistical Computing, Austria). Post-stratification adjustments and weighting to correct for coverage error and self-selection bias were not possible due to the impossibility of identifying or contacting the sample by other means.[10] Chi-squared tests for independence were used to evaluate whether the survey completion was related to sex, country of residence, or language, and to test the relationships between other categorical variables. The logistic regression was used to test the association between the survey completion and age. Chi-squared tests for independence were also used to evaluate the relationship between sex and country of residence across Perthes' disease-specific variables. Finally, Spearman's rank-based correlations were calculated for each pair of variables and Bonferroni's correction was used for control of type I error in multiple testing. Significance was considered when $p < 0.05$. Correlations found to be significantly different from zero have numerical values of the magnitude of the Spearman's correlation.
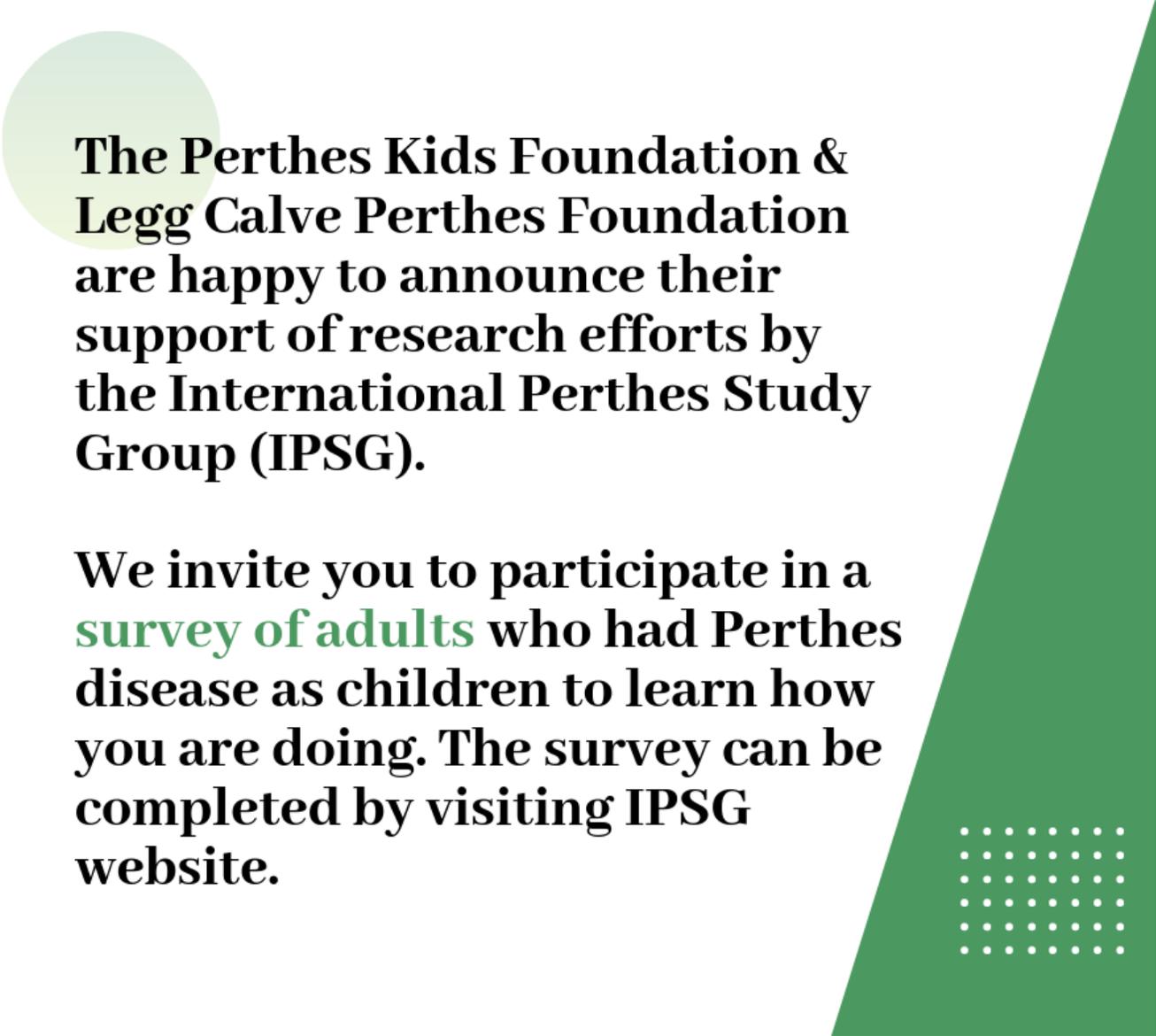
The Perthes Kids Foundation & Legg Calve Perthes Foundation are happy to announce their support of research efforts by the International Perthes Study Group (IPSG).

We invite you to participate in a survey of adults who had Perthes disease as children to learn how you are doing. The survey can be completed by visiting IPSG website.

Fig 1

Facebook announcement from Perthes Kids Foundation Facebook group promoting the Adult Perthes Survey

Results

The initial sample of 1,505 survey attempts was first analyzed for duplicate records based on the combination of reported background characteristics, such as email address (if provided), birth year, calculated BMI, sex, and country of residence. The remaining 1,416 records had complete initial Hip Health History data and therefore could be grouped and evaluated by Adult Perthes Survey completion status (Figure 3). The partial respondents (n = 234) dropped out by increments of 54, 113, and 67 during the UCLA (23%), the SF-36 (48%), and the HOOS (29%) sections of the survey, respectively. Of those who started the survey, 78% (n = 1,182) completed it. No relationship was observed across responses from partially complete surveys compared to fully completed surveys

with respect to sex (p = 0.903), country of residence (p = 0.295), or language (p = 0.721; all chi-squared test), which was derived from whether or not the country of residence was primarily English-speaking (Table I). Per five-year increment in age at the time of the survey, the odds of completing versus partially completing the survey was 5% higher (odds ratio (OR) 1.05 (95% confidence interval (CI) 0.99 to 1.11)). Of the 1,182 respondents with full survey responses, the median time to complete the Adult Perthes Survey was 11 minutes (IQR 8.633 to 14.72). Seven respondents took more than three hours to complete the survey, and no differences were found with respect to their functional and emotional outcomes compared to those who completed the survey in less than three hours. For the purposes of this paper,

Fig 2
International Perthes Study Group website announcement and hyperlink for public to access the Adult Perthes Survey.

Table I. Testing relationship between Adult Perthes Survey completion and sex, age, country of residence, and language (n = 1,416).

Variable	Complete respondents* (n = 1,182)	Partial respondents* (n = 234)	p-value†
Age, continuous per five-year increase (OR; 95% CI)	1.05 (0.99 to 1.11)		
Country of residence			
USA/Not USA (2 × 2 table)	570 (USA)	103 (USA)	0.365
USA/UK/Australia/Canada/Other (2 × 5 table)	-	-	0.295
Female, n	685	134	0.903
Language‡	1,054 English	203 English	0.721

*Complete respondents completed everything except for the body pain diagram; partial respondents only partially completed the survey (see Figure 3).
†Chi-squared test.
‡English includes New Zealand, Australia, Canada, UK, USA.
CI, confidence interval; OR, odds ratio.

the last section of the survey containing the pain body diagram was not included in our definition of "respondents". The final sample, which forms the basis for the present analysis, included 1,182 respondents. Of these, 77% (n = 913) included an email address to be contacted in the future.

As shown in Table II, the survey respondents resided in 45 countries including USA (n = 570; 48%), UK (n = 295; 25%), Australia (n = 133; 11%), and Canada (n = 46; 4%). More respondents from the USA were from the Southern region (n = 216; 37.9%), but the Midwest (n = 143; 25%) and Western USA (n = 119; 20.9%) were also represented. The age of survey respondents ranged from 18 to 79 years (mean 39.3 (standard deviation (SD) 12.6)), and 58% (n = 685) of respondents were female. Diagnosis of obesity was reported at a rate of 17.7% (13.3% among males and 20.9% among females) and was the most commonly

self-reported comorbid condition. Calculated BMI based on self-reported height and weight resulted in 38.7% (n = 380) of respondents with a BMI ≥ 30 kg/m^2, generally considered clinical obesity. Other frequently reported comorbidities included hypertension (n = 154; 12.9%) and hip dysplasia (n = 150; 11.8%). Written-in responses for the "other comorbidity" selection of the Hip Health History Questionnaire also emerged: arthritis (n = 33; 2.8%), spine conditions (n = 13; 1.1%), and asthma (n = 8; 0.7%). Of our sample, 15.4% (n = 182) reported a positive family history of Perthes' disease, as defined by having a blood relative with the disease. Of these variables, having at least one comorbid condition was weakly correlated with older age at time of survey (Spearman's r = 0.17) and higher BMI (Spearman's r = 0.19) (Figure 4).

Ages at onset of Perthes' disease were grouped based on current clinical practice guidelines, with
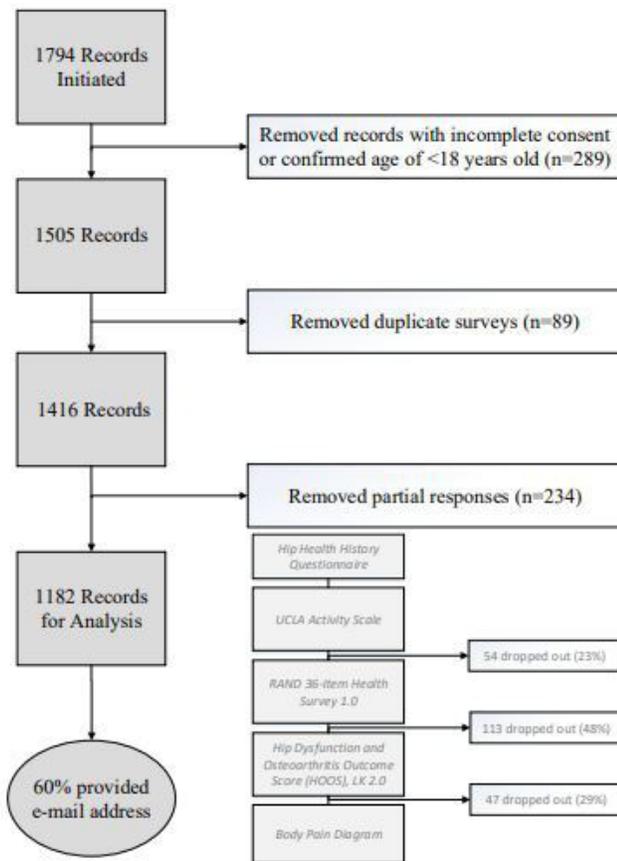
Fig 3

Adult Perthes Survey enrolment, completion, and retention diagram. UCLA, University of California Los Angeles.

43.3% (n = 512) of the sample experiencing onset prior to age six (n = 324 (47%) females and n = 188 (37.8%) males). Respondents whose disease onset was from ages six to seven made up 27% (n = 321), onset at ages eight to 11 were 22% (n = 261), and onset over 11 years old were 6.4% (n = 76) of the sample. As shown in Table III, females in our sample had younger age at onset (p = 0.007, chi-squared test). Bilaterally affected survey respondents made up 15.8% (n = 185) of the sample, and occurred equally in males and females (p = 0.487, chi-squared test). As children, 59.7% (n = 706) of respondents reported no surgery for Perthes' disease; the other 40.3% (n = 476) had at least one surgery before the age of 18. Total number of surgeries in childhood was similar between men and women (p = 0.489, chi-squared test), and was negatively correlated with current age (Spearman's r = -0.27). Other commonly reported childhood treatment for Perthes' disease included: activity restrictions (n = 753; 63.7%), use of a walking device such as a walker, crutches, or a wheelchair (n = 640; 54.1%), restrictions regarding weightbearing (n = 560; 47.4%), physical therapy (n = 481; 40.7%), abduction bracing (n = 395; 33%), and casting

(n = 346; 29.3%). Upon detailed review, traction treatment emerged as an "other" treatment (n = 68; 5.8%), almost at the same rate as having no treatment at all (n = 75; 6.3%) (Table IV). Figure 4 shows the moderately positive relationships between childhood reports of physical therapy, weightbearing restrictions, activity restrictions, and use of walking devices in this sample. Activity restriction (p = 0.037), walking devices (p = 0.024), weightbearing restrictions (p = 0.002), and abduction bracing (p < 0.001; all chi-squared test) were more frequently reported among respondents residing in the USA compared to other countries. Respondents from the USA were also significantly less likely to report not having any treatment, compared to other countries (p < 0.001, chi-squared test). There was no difference by country for those who reported physical therapy (p = 0.566), surgery (p = 0.412), and casting (p = 0.553; all chi-squared test) as treatments for Perthes' disease.

After the age of 18, 347 (29.3%) respondents reported experiencing at least one surgical event (Table V), which was more common for females (p = 0.002, chi-squared test). For both females (n = 172; 25.1%) and males (n = 89; 17.9%) in our sample, the most common surgical treatment in adulthood was total hip arthroplasty (THA), as reported by 261 (22.1%) survey respondents at the time of survey. Of these, 14 (5.4%) reported complications of THA, such as loosening, revision surgery, or equipment failure. Use of physical therapy in adulthood was noted by 173 (14.6%), which included 47 males (9.5%) and 126 females (18.4%). Upon review of the "other" descriptive responses, 41 respondents mentioned steroid injection as an additional means of treatment in adulthood (3.5%). Steroid injection (p = 0.005), hip arthroplasty (p = 0.004), physical therapy (p < 0.001), and arthroscopy (p = 0.014; all chi-squared test) were significantly more widely reported among females compared to males. Regardless of current surgical status, both male (n = 213; 42.9%) and female (n = 333; 48.6%) respondents anticipated future surgery or revision surgery at a similar rate (p = 0.843, chi-squared test), which correlated weakly with the number of surgeries reported in childhood (Spearman's r = 0.18) and negatively with current age (Spearman's r = -0.22).

Discussion
Acquiring a large amount of long-term follow-up data for a uncommon condition is challenging in a hospital setting, as children typically transition to adult care, making outcomes research unattainable.[28,29] The longitudinal data we have for Perthes' disease patients is limited regarding patient-reported outcomes. In this section, we discuss the response to our research questions: what is the feasibility of obtaining survey data from adults who had Perthes' disease as children using a web-based

Table II. Sociodemographic distribution of characteristics of Adult Perthes Survey respondents (n = 1,182).

Variable	Mean by sex (SD)		
	Male (n = 497)	Female (n = 685)	Total
Age at time of survey, yrs	40.7 (13)	38.2 (12.3)	39.3 (12.6)
BMI at time of survey, kg/m²*	29 (6.9)	30 (8.0)	29.6 (7.6)

Variable	Frequencies by sex, n (%)		
	Male	Female	Total
BMI ≥ 30 kg/m² (clinically obese)*	147 (35.6)	233 (40.9)	380 (38.7)
Country of residence			
USA	253 (51)	317 (46.3)	570 (48.2)
UK	110 (22.1)	185 (27)	295 (25)
Australia	54 (10.9)	79 (11.6)	133 (11.2)
Canada	17 (3.4)	29 (4.2)	46 (3.9)
Other	63 (13.5)	75 (10.9)	138 (11.7)
Region of residence in USA based on ZIP code (n = 555)†			
Northeast†	32 (12.6)	43 (13.5)	75 (13.1)
Midwest‡	52 (20.5)	91 (28.7)	143 (25)
South§	99 (39.13)	117 (36.9)	216 (37.9)
West¶	65 (25.7)	54 (17)	119 (20.9)
Other	0	2 (0.6)	2 (0.3)
Comorbid conditions ever diagnosed (yes)			
Obesity	66 (13.3)	143 (20.9)	209 (17.7)
Hypertension	68 (13.7)	86 (12.6)	154 (13)
Hip dysplasia	38 (7.6)	102 (14.9)	140 (11.8)
Genetic disorder	18 (3.6)	34 (5)	52 (4.4)
Diabetes	20 (4)	24 (3.4)	43 (3.6)
Arthritis/fibromyalgia	4 (0.8)	29 (4.2)	33 (2.8)
Bleeding/clotting disorder	6 (1.2)	24 (3.5)	30 (2.5)
Spine condition	1 (0.2)	12 (1.8)	13 (1.1)
Asthma	2 (0.4)	6 (0.9)	8 (0.7)
Other	36 (7.2)	70 (10.2)	106 (9)
Family history of Perthes' disease (yes, related by blood)	63 (12.7)	119 (17.4)	182 (15.4)

*There are a total of 200 missing values; the percentages are out of the non-missing.
†New York, Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont, New England, New Jersey, Pennsylvania, Delaware, Maryland, District of Columbia.
‡Iowa, Kansas, Missouri, Nebraska, North Dakota, South Dakota, Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin.
§Texas, Florida, Georgia, North Carolina, Virginia, Tennessee, Maryland, South Carolina, Alabama, Louisiana, Kentucky, Oklahoma, Arkansas, Mississippi, West Virginia.
¶Arizona, Colorado, Utah, Nevada, New Mexico, Idaho, Montana, Wyoming, Mountain, California, Washington, Oregon, Hawaii, Alaska, Pacific.

platform?; and what is the composition of our collected sample with respect to baseline characteristics and self-reported experience of Perthes' disease from childhood?

Our sample included English-speaking populations with reliable Internet access. Cognitive ability and health literacy were not evaluated prior to survey administration, which could impact individual responses. The surveys were not validated for a web-based means of administration,[30] which may have introduced mode effect bias.[10] When asked to reflect and self-report on childhood experiences, the responses are subject to recall and reporting bias. However, children with chronic disease may be accustomed to this line of questioning as they transition into adult care.[31] The volunteers were not random; although we are unable to access this selection bias due to the absence of a sampling frame,[32] the aim of

the second question was simply to describe our sample of adults who had Perthes' disease as children.

The relationship with the Perthes Kids Foundation was a key modifying factor for this, and for future survey methods in the orthopaedic community. We observed increases in survey participation when periodic advertising stimulus (such as email blasts and e-newsletters) from the Perthes Kids Foundation activated their membership network (Figure 5). With 60% (n = 706) of respondents including their email address for future research opportunities, we suspect the degree of motivation and interest among participants was high. We observed that lower respondent engagement (i.e. survey dropout) was more likely with younger age, but overall survey completion was high (n = 1,182; 78%). Compared to complex surgeon-based recruitment protocols and
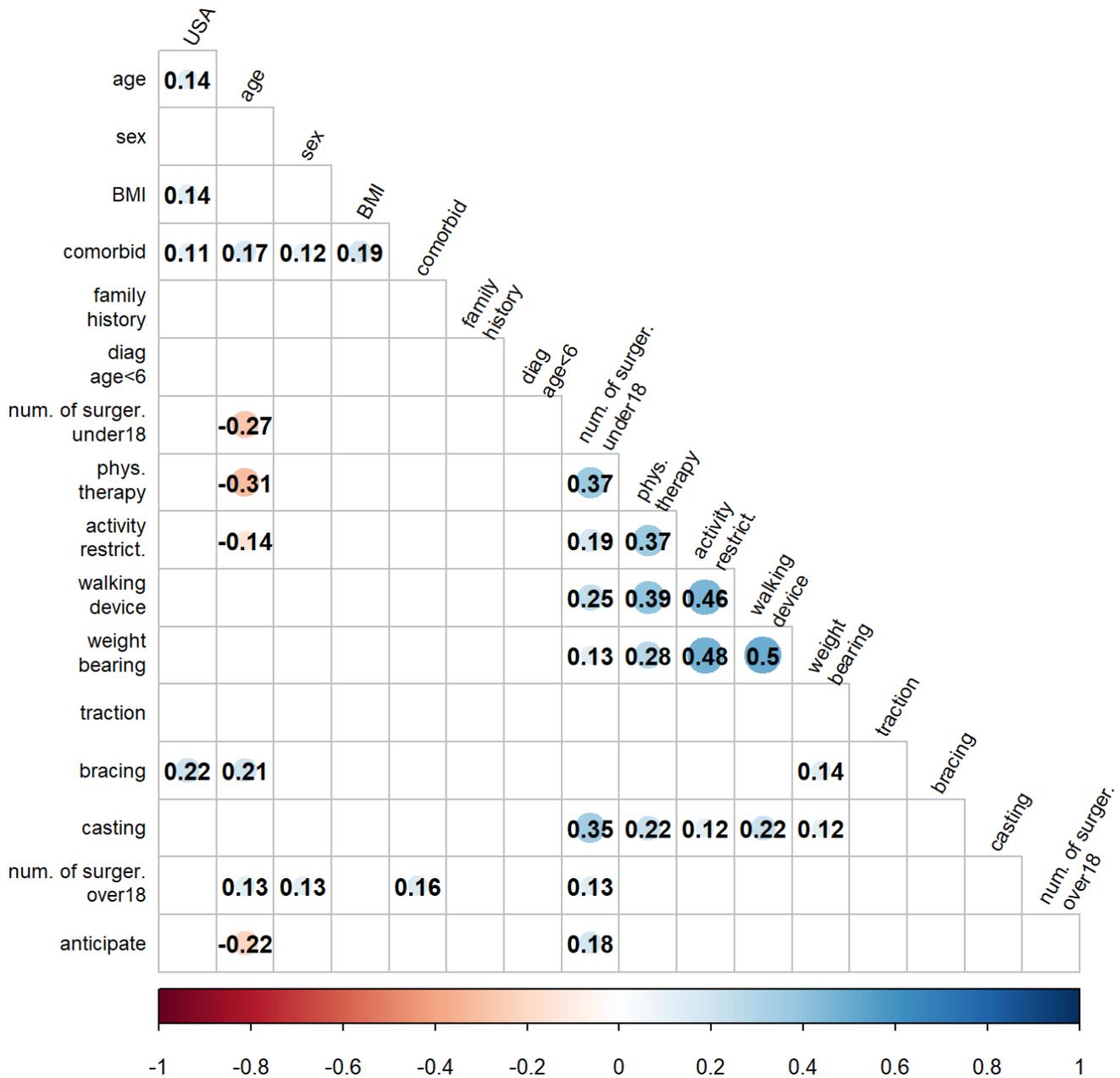
Fig 4

Spearman's rank-based correlation matrix of demographic and hip-specific data reported in the Adult Perthes Survey.

expensive registry programmes, the Adult Perthes Survey quickly and cheaply obtained quality self-report data for scientific analysis. Additionally, respondents represented multiple countries and a wide age range (18 to 79 years). Our web-based approach also provided substantial data from a subset of adults who were not seen in the hospital and did not undergo any surgical procedures in childhood (706; 60% of respondents), as well as females, who are three to four times less commonly affected with Perthes' disease (n = 685; 58% of respondents).

Similar to other demographic reports of Perthes' disease in children,[33–35] 30% of our adult sample was clinically obese. Potential weight gain is a common concern among families during the active stages of disease. Our calculated BMI results also demonstrate that while nearly 38.7% (n = 380) of our sample were clinically obese, the report of clinically diagnosed obesity was almost half of that (n = 209; 17.7%), suggesting that undiagnosed obesity may continue to be a threat into adulthood and well after Perthes' disease has healed.

With 1,182 surveys completed, 685 females in our sample represent 58% (n = 685) of respondents. A recent review estimated that 18.6% of Perthes' disease cases across representative study samples were female,

Table III. Childhood experience of Perthes' disease by sex (n = 1,182).

Variable	Frequencies by sex, n (%)		p-value*	Total
	Male (n = 497)	Female (n = 685)		
% bilateral	73 (14.7)	112 (16.4)	0.487	185 (15.6)
Age at onset of disease, yrs			0.007	
Before turning 6	188 (37.8)	324 (47.3)		512 (43.3)
Between 6 and 7	141 (28.4)	180 (26.3)		321 (27.2)
Between 8 and 11	131 (26.4)	130 (19)		261 (22.1)
After turning 11	33 (6.6)	43 (6.3)		76 (6.4)
Total surgeries in childhood†			0.489	
0	307 (61.8)	399 (58.2)		706 (59.7)
1	61 (12.3)	79 (11.5)		140 (11.8)
2	71 (14.3)	99 (14.4)		170 (14.4)
3	30 (6)	56 (8.2)		86 (7.3)
4	13 (2.6)	21 (3.1)		34 (2.9)
5+ surgeries	15 (3)	31 (4.5)		46 (3.9)

*Chi-squared test.
†Participants who reported treatment with surgery in Table IV did not necessarily report similarly in response to the item in Table III.

Table IV. Childhood treatment experience of Perthes' disease by country of residence (n = 1,182).

Treatment type	Frequencies by country of residence, n (%)		p-value†	Total
	USA* (n = 570)	Non-USA* (n = 610)		
No treatment	18 (3.2)	57 (9.3)	< 0.001	75 (6.3)
Activity restrictions‡	381 (66.8)	371 (60.8)	0.037	753 (63.7)
Walking device (walker, wheelchair, crutches)	329 (57.7)	311 (51)	0.024	640 (54.1)
Weightbearing restrictions	298 (52.3)	262 (43)	0.002	560 (47.4)
Physical therapy	227 (39.8)	254 (41.6)	0.566	481 (40.7)
Surgery on either hip§	223 (39.1)	254 (41.6)	0.412	477 (40.4)
Bracing	252 (44.2)	143 (23.4)	< 0.001	395 (33.4)
Casting	162 (28.4)	184 (30.2)	0.553	346 (29.3)
Traction	23 (4)	45 (7.4)	0.020	68 (5.8)
Other	20 (3.5)	28 (4.6)	0.428	48 (4.1)

*Two participants did not report their country of residence.
†Chi-squared test.
‡Of two participants who did not report country of residence, one did report about activity restrictions, therefore the total is 753.
§Participants who reported at least one surgery in Table III did not necessarily indicate they were treated with surgery in Table IV.

ranging from 10% to 32%.[3] Females in our sample reported earlier onset (47.3% before age six) compared to males (37.8% before age six); these findings are unique and should be further explored in probability samples. More females than males reported obesity (n = 143; 21%), hip dysplasia (n = 102; 15%), and arthritis (n = 29; 4%) in our sample (13%, 8%, and 1%, respectively). Additionally, residual hip treatment in adulthood varied by sex with females reporting a significantly higher rate of THAs (n = 172; 25%), use of physical therapy (n = 126,18%), and steroid injection (n = 33; 5%) compared to males: 18%, 10%, and 2%, respectively. Several studies have reported sex discrepancies in outcomes of LCPD.[36,37] However, many of these studies are not controlled and therefore inconclusive. Controlling for treatment arm and lateral pillar classification, Herring et al[38] demonstrated that females were more likely to have worse radiological outcomes compared to males by the time they were skeletally mature (p = 0.0034), which was modified by chronological age of onset above (p = 0.004) or below (p = 0.77) the age of eight, and bone age of onset above (p = 0.03) or below (p = 0.86) six years.[38] Developmentally, females also arrive at skeletal maturity faster than males. Our results support the need for further studies to understand the factors impacting outcomes of Perthes' disease by sex.

The Adult Perthes Survey revealed interesting differences between USA and non-USA respondents regarding treatments received during childhood. Activity restriction, walking device usage, weightbearing restrictions, and abduction bracing were significantly more frequently reported among USA compared to other countries. Indeed, abduction bracing in our sample was weakly positively correlated with living in the USA (Spearman's r = 0.22) and with increasing current age (Spearman's r = 0.21). Furthermore, respondents from the USA were also significantly less likely to report not having any treatment, compared to other countries. However, equal

Table V. Adulthood treatments reported in the Adult Perthes Survey by sex (n = 1,182).

	Frequencies by sex, n (%)			
Variable	Male (n = 497)	Female (n = 685)	p-value*	Total
Total surgeries in adulthood			0.002	
0	384 (77.3)	451 (65.8)		835 (70.6)
1	75 (15.1)	147 (21.5)		222 (18.8)
2	20 (4)	44 (6.4)		64 (5.4)
3	8 (1.6)	21 (3.1)		29 (2.5)
4	5 (1)	10 (1.5)		15 (1.3)
5+ surgeries	5 (1)	12 (1.7)		17 (1.4)
Adult treatment on Perthes' hip(s)				
Total hip arthroplasty	89 (17.9)	172 (25.1)	0.004	261 (22.1)
Physical therapy	47 (9.5)	126 (18.4)	< 0.001	173 (14.6)
Arthroscopy	17 (3.4)	47 (6.9)	0.014	64 (5.4)
Steroid injection	8 (1.6)	33 (4.8)	0.005	41 (3.5)
Resurfacing	9 (1.8)	22 (3.2)	0.193	31 (2.6)
Periacetabular osteotomy	8 (1.6)	18 (2.6)	0.329	26 (2.2)
Surgical hip dislocation	2 (0.4)	12 (1.8)	0.065	14 (1.2)
Other	5 (1)	14 (2)	0.244	19 (1.6)
Unknown surgery	19 (3.8)	47 (6.9)	0.034	66 (5.6)
Anticipating future surgery or revision (yes)	213 (42.9)	333 (48.6)	0.843	546 (46.2)
Complications of total hip arthroplasty reported (yes)	7 (7.9)	7 (4.1)	0.317	14 (5.4)

*Chi-squared test.
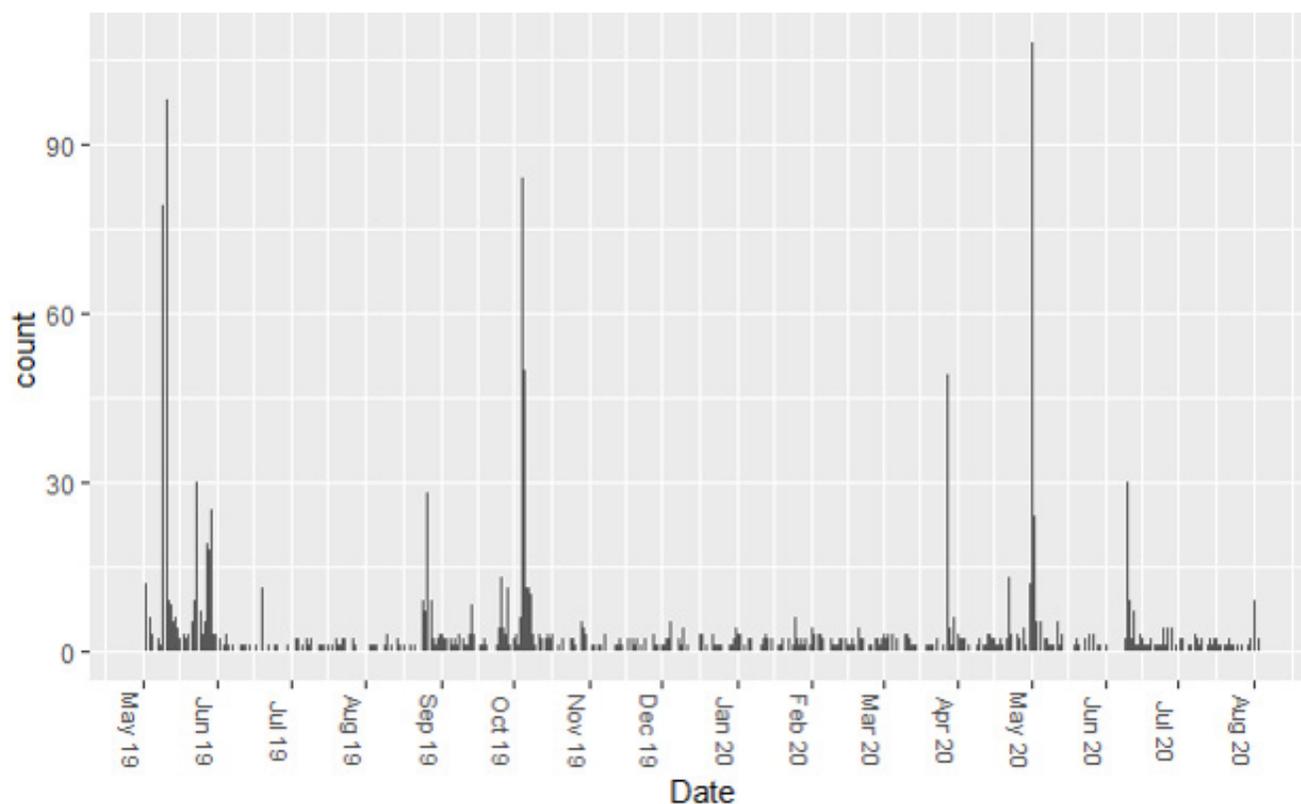
Fig 5

Chronological survey response frequency from May 2019 to August 2020.

rates of childhood surgery, casting, and physical therapy were reported globally. While the distribution of age of onset was similar to distribution in the incident Perthes' disease population, less than half (n = 476; 40.3%) of the sample reported having at least one surgical event prior to the age of 18. Information about the type of surgery in

childhood was not collected, but may be a future source of inquiry. After the age of 18, only 29% (n = 347) of our adult sample had at least one surgical event, the majority of which were THAs (n = 261; 22.1%). Future analysis stratifying those who had a THA is planned.

In conclusion, our study shows the feasibility of quickly obtaining a large set of patient-reported data from multiple countries for those who experience a rare disease. While we expect limitations due to self-selected sampling, further analysis of our large dataset specializing in functional outcomes in adulthood will be another step forward in understanding the long-term outcomes of Perthes'.

Take home message
- This study shows the feasibility of quickly obtaining a large set of patient-reported data from multiple countries (> 1,100) of those who experience a rare orthopaedic disease.
- Pain levels reported in this study were higher than the normative population.
- Further analysis of our large dataset will be a step forward in understanding the long-term outcomes of Perthes' disease in adults.

Supplementary material
Hip Health History Questionnaire

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