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Run, walk, cheer or volunteer: a patient and public involvement survey

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ABSTRACT

Background Children with chronic diseases have been reported to participate in less regular physical activity (PA) than peers without chronic diseases; and less than recommended in guidelines. Sheffield Children's Foundation Trust (SCFT) is an Active Hospitals pilot site, exploring options to facilitate PA for all children. One option is collaboration with Junior Parkrun: a free, weekly 2 km running event for children. The team investigated whether Junior Parkrun was of interest to guardians of children attending SCFT to increase PA.

Aims This patient and public involvement survey assessed perceptions of PA for children attending SCFT according to their accompanying guardians. This will inform a possible collaboration between SCFT and Junior Parkrun.

Methods A three-part, 14-question survey was developed, including demographics (age, ethnicity, postcode); perceptions of PA (barriers and facilitators); PA behaviours self-reported on Likert scales; and perceptions of Junior Parkrun. Guardians were asked whether they and their child would be interested in attending Junior Parkrun with SCFT staff support. This was distributed to guardians of children attending outpatient appointments.

Results 126 guardians responded. The average age of child was 10 years 10 months. 29.1% of guardians supported daily PA for their child. Almost half of respondents reported their child would be interested in attending Junior Parkrun. Of those not interested, the most common reason was travel.

Conclusion The findings highlighted PA barriers perceived by guardians, and identified that almost half of respondents would be interested in attending Junior Parkrun. A collaboration between Junior Parkrun and SCFT could be explored.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Children with chronic disease tend to participate in less regular physical activity (PA) than their peers and may fall short of PA guidelines.
⇒ Common barriers to exercise include expense, travel and accessibility.
⇒ Having a social and inclusive form of regular exercise is considered important for this patient group.
⇒ A collaboration between a children's hospital and Junior Parkrun has not previously been investigated and this project aimed to explore whether this might be a feasible option for children with chronic diseases to be physically active.

WHAT THIS STUDY ADDS

⇒ Less than half of guardians agreed or strongly agreed that their child's health condition was a barrier to PA.
⇒ Time, cost and travel are common barriers to regular activity participation as perceived by guardians of patients at Sheffield Children's Foundation Trust (SCFT).
⇒ 49.5% of respondents would be interested in participating in Junior Parkrun but travel is the main barrier.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The findings justify exploring a collaboration between SCFT and Junior Parkrun which may lead the way for other organisations to improve access to regular PA for children with chronic diseases.

INTRODUCTION

National and international guidelines recommend children between 1 and 5 years of age are physically active for 3 hours/day, and those aged 5–18 are active for 1 hour/day to achieve health benefits.[1–3] Children with long-term health conditions may not meet guidelines. For example, less than 40% of children with type 1 diabetes and juvenile idiopathic arthritis (JIA) exercise sufficiently,[4] and more than half of paediatric cancer survivors do not meet exercise guidelines.[5] Physical activity (PA) has benefits in many health conditions, such as better control of asthma, increased school attendance for patients with JIA[6] and improved insulin sensitivity in diabetes.[7]

Previous interventions targeting children's PA have shown mixed results. A marketing campaign in the USA aiming to increase youth PA demonstrated positive effects on PA levels on self-reported measures.[8] However, a Cochrane review evaluated PA interventions in schools and found little effect, with large heterogeneity in the studies.[9] These studies were not specific to children with chronic disease, and regular PA events which are accessible to all children could support independent activity away from health services.

In a cross-sectional study by Arakelyan *et al*, characteristics of 12195 children with

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and without disabilities were compared.[10] Those with a disability were less frequently involved in community PA. Their recommendations included improving availability of community support and ensuring financially viable options; clinicians could signpost to nearby services with social and physical benefits. Willis *et al* conducted a qualitative study at a Norwegian rehabilitation facility to investigate the views of children with disabilities and their parents (n=75) on a PA intervention.[11] They used realist evaluation[12] to review the context, mechanisms and outcomes of their intervention which consisted of a 19-day schedule including social involvement, cultural and PA. 'Choice, fun, friends, specialised health professionals, and time' were the mechanisms used to engage these children in a 'safe, social, learning-based and family-centred' context. Another qualitative study by Willis *et al* was based on the views of staff at the same Norwegian rehabilitation centre, as well as service providers (n=20) and identified important factors for an intervention to foster PA behaviours in children with disabilities.[13] 'Support and relationships', 'interpersonal interactions' and 'services, systems and policies' were reported most frequently when qualitatively investigating activity participation. Parental views on PA can influence PA behaviours among children with chronic disease, and can be prohibitive if the parent believes PA may be harmful.[14] Junior Parkrun could provide some of these identified needs by being a safe social environment which whole families can attend. Junior Parkrun is a free, weekly, community-based 2 km running event aiming to promote participation in PA among children 4–14 years and their families.[15]

Sheffield Children's Foundation Trust (SCFT) is an Active Hospitals pilot site considering collaboration with Junior Parkrun to meet the needs of its patients. Prior to collaboration, guardians' views about Junior Parkrun are needed. The aim of this patient and public involvement study was to understand guardians' beliefs on PA and whether Junior Parkrun might be a feasible way to support PA for SCFT patients. Additionally, this survey sought to understand some of the barriers to attending Junior Parkrun. Ajzen's theory of planned behaviour[16] postulates that behaviour can be determined by perceptions of the behaviour, perceived norms and perceived control over that behaviour. This theory was used in the development of the survey to cover perceptions held by guardians of patients and how this might influence PA behaviours. To the best of the authors' knowledge, there is no existing research on perceptions of guardians of children with chronic disease on Junior Parkrun.

METHODS

Sampling

This was a single-centre convenience sample survey. Families attending SCFT outpatient clinics between February and April 2022 were invited to complete a self-reported survey. Every effort was made to include a variety of clinics, times and trust locations.

Inclusion criteria

- Any guardian of an outpatient attending SCFT who consented to participating.

Exclusion criteria

- Anyone who did not wish to participate.
- Any family attending that did not speak English, with no interpreter present.

Consent

Consent was given by guardians of children attending clinics as part of the survey. It was explained that not taking part would not affect care.

Design

This was a patient and public involvement survey. Participants were given a QR code to the survey, or provided with a device by the researcher. Anonymity was maintained in the survey. This was explained to the participants.

Participants

Guardians of any patient attending outpatient appointments were invited. SCFT normally cares for patients aged under 18, but occasionally care is extended for continuity. There were no exclusions for disease or health status. Data on type of illness were not collected.

Survey

The survey was a 10 min, three-part online survey in English. It was informed by research outlining the key barriers and enabling factors for children with chronic diseases and their guardians for engaging in PA.[13 17 18] The first section included basic sociodemographic information such as age, ethnicity and postcode.

The second section focused on the guardian's perceptions of their child's current engagement in PA and beliefs and attitudes towards PA (using the theory of planned behaviour[16]). Respondents were asked to rate on a scale of never/rarely, about once a month, one to two times a week, most days, or daily, how often they supported their child's PA, for example, playing outside with their child or providing transport. On a scale of strongly disagree, somewhat disagree, neither agree nor disagree, somewhat agree or strongly agree, respondents were asked about their child's current PA, for example, going out of their way to enrol their child in sports, taking them to places for PA and using their behaviour to support their child's PA. On the same scale, they were asked about potential barriers, such as whether they felt they had the ability, skills, opportunity, time, financial means, transport and access to support PA. These options were based on common barriers identified in the literature.[18]

The third section explored awareness and acceptability of Junior Parkrun to improve PA (using the theoretical framework of acceptability[19]). Guardians were asked if they were aware of Junior Parkrun and if so, whether there was one near to them, and if they and their child would be interested in Junior Parkrun supported by presence of SCFT staff. If yes, how frequently they might

Table 1 Age as reported by guardians

Age (years)	Frequency
1	0
2	0
3	3
4	1
5	6
6	7
7	10
8	7
9	10
10	5
11	13
12	13
13	5
14	12
15	8
16	8
17	4
18	0
19	1
Not answered	13
Total	126

Table 2 Ethnicity as reported by guardians

Ethnicity	Frequency
English, Welsh, Scottish, Northern Irish or British	73
Irish	0
Gypsy or Irish Traveller	0
Any other white background	4
White and black Caribbean	2
White and black African	0
White and Asian	2
Any other mixed or multiple ethnic background	4
Indian	4
Pakistani	13
Bangladeshi	1
Chinese	0
Any other Asian background	0
African	4
Caribbean	1
Any other black, African or Caribbean background	1
Arab	3
Any other ethnic group	2
Not answered	12
Total	126

attend, and if no, why not (from a list of common barriers to select from, or 'other' with an open box).

Data analysis

Data were inputted into Qualtrics for descriptive analysis. Means and SDs were calculated for questions on a Likert scale. Characteristics of the group who indicated they would be interested in Junior Parkrun were compared with the group who indicated they would not be interested, using 'Statskingdom.com'.[20] The two-sample Mann-Whitney U test was applied, with significance level set to 0.05. The percentage of guardians reporting that they supported daily PA for their child was compared with available literature on children meeting daily PA guidelines in a similar region,[21] using the one-sample proportion test and significance level set to 0.05.

Patient and public involvement

Guardians of patients were invited to respond to gauge perspectives of Junior Parkrun and explore facilitators and barriers. Their responses will guide service development, research and policy planning to improve access to regular PA for this patient demographic. Findings will be reported to the communications team and quality and governance team at SCFT for further dissemination.

Equality, diversity and inclusion statement

This patient and public involvement survey investigated perceptions of guardians of children attending SCFT outpatient appointments. As a National Health Service setting, this is a 'universal service'.[22] Volunteers read questions to patients who had difficulty with reading. Interpreters assisted with the survey where they were already in attendance for the appointment.

RESULTS

Demographics

There were 126 respondents in total, but not all answered every question. Children's ages ranged from 3 to 19 (mean 10 years 10 months, SD 3.75 years- see table 1). Ethnicity data are shown in table 2. Children were attending a range of outpatient clinics, including respiratory, gastroenterology, metabolic bone, trauma and oncology.

PA beliefs and behaviours

Participants were given statements and asked to rate on a 5-point Likert scale, the degree to which they agreed or disagreed (1=strongly disagree, 5=strongly agree—figure 1). 68% agreed or strongly agreed they go out of their way to support PA for their child and 60% reported frequently exercising with their child. 82% reported taking their child to places where they can be active, meanwhile 12% reported they never or rarely drive or provide transport for their child's PA.

Children aged 5–18 should be physically active for at least 1 hour everyday according to guidelines.[1] 29% of guardians agreed or strongly agreed that they encouraged daily PA. This was significantly lower

#	Question	Strongly disagree		Somewhat disagree		Neither agree nor disagree		Somewhat agree		Strongly agree		Total
1	I go out of my way to enroll my child in sports and other activities that get him/her to be physically active eg., after school programs.	5.83%	6	7.77%	8	18.45%	19	32.04%	33	35.92%	37	103
2	I often take my child to places where he/she can be active (e.g., parks, playground, sport games or practices).	4.85%	5	2.91%	3	10.68%	11	32.04%	33	49.51%	51	103
3	I often watch my child participate in sporting activities (e.g., watch your child perform at a football game or a dance recital).	14.56%	15	13.59%	14	21.36%	22	16.50%	17	33.98%	35	103
4	I often organise family outings that involve physical activity (e.g., going for a walk or a bike ride, going ice skating).	2.91%	3	3.88%	4	17.48%	18	29.13%	30	46.60%	48	103
5	I frequently exercise or do something active with my child.	6.80%	7	13.59%	14	19.42%	20	30.10%	31	30.10%	31	103
6	I use my behaviour to encourage my child to be physically active.	8.74%	9	6.80%	7	18.45%	19	25.24%	26	40.78%	42	103

Figure 1 Responses to questions on a Likert scale (1=strongly disagree, 5=strongly agree).

(0.0013) than existing literature which found 43% of children in a similar region were meeting daily PA.[21]

Barriers to PA

44.1% of guardians agreed or strongly agreed that their child's health condition was a barrier to PA (figure 2). Other barriers identified were time (13% of respondents) and finances (12% of respondents).

Facilitators to PA

77.2% agreed or strongly agreed they had access to what they need to support their child's PA. 86.3% and 85.4% of respondents agreed or strongly agreed that they had the ability or capability to support their child's PA, respectively (see figure 2). 80.6% agreed or strongly agreed that they had skill to support their child's PA and 81.4% agreed they had opportunity to do this. 85.2% felt they could transport their child to their activity.

Awareness and acceptability of Junior Parkrun

45.6% of respondents were unaware of Junior Parkrun and 73.3% were unaware if there was a Junior Parkrun near to them, which may be a barrier. Respondents were asked if their child would be interested in attending Junior Parkrun in Sheffield, supported by SCFT staff—49.5% responded 'yes'. There was no significant difference in age of children whose guardians responded they would, or would not, be interested in participating. Time was considered a significantly higher barrier to PA by the people who were not interested in Junior Parkrun than those who were (figure 3).

A subsequent question was if not interested in Junior Parkrun, what the reason was, with six options, and an open box for 'other'. Perceived barriers to Junior Parkrun agreed with most frequently were 'it is too far for me to travel' (17), 'it doesn't interest my child' (12), 'other' (9), 'we have other commitments on Sunday mornings' (8), 'my child is too young/old' (2) and 'it doesn't interest me' (2). 35 participants

#	Question	Strongly disagree		Somewhat disagree		Neither agree nor disagree		Somewhat agree		Strongly agree		Total
1	I have the ability to support my child's physical activity	1.96%	2	3.92%	4	7.84%	8	26.47%	27	59.80%	61	102
2	I am capable of supporting my child's physical activity	1.94%	2	3.88%	4	8.74%	9	19.42%	20	66.02%	68	103
3	I have enough skill to support my child's physical activity	1.94%	2	4.85%	5	12.62%	13	26.21%	27	54.37%	56	103
4	I will have an opportunity to support my child's physical activity	1.96%	2	6.86%	7	9.80%	10	30.39%	31	50.98%	52	102
5	There is enough time to support my child's physical activity	3.92%	4	8.82%	9	16.67%	17	36.27%	37	34.31%	35	102
6	I have the financial means to support my child's physical activity	2.94%	3	8.82%	9	12.75%	13	31.37%	32	44.12%	45	102
7	I can transport my child to support their physical activity	0.99%	1	3.96%	4	9.90%	10	27.72%	28	57.43%	58	101
8	I have access to what I need to support my child's physical activity	1.98%	2	4.95%	5	15.84%	16	28.71%	29	48.51%	49	101
9	My child's health condition is a barrier to him/her participating in physical activity	26.47%	27	8.82%	9	20.59%	21	19.61%	20	24.51%	25	102

Figure 2 Responses to questions on a Likert scale (1=strongly disagree, 5=strongly agree).

said they would be interested in volunteering at Junior Parkrun events.

DISCUSSION

Children with chronic diseases may fall short of PA guidelines

PA guidelines recommend children aged 5–18 should be physically active for at least 1 hour everyday.[1] Children with chronic health conditions, including asthma and diabetes, should partake in regular PA.[6 23] However, our findings showed only 29.1% of guardians surveyed supported daily PA for their children, despite the majority of respondents reporting that they go out of their way to support PA. SCFT is based in Sheffield, South Yorkshire. A previous study identified South Yorkshire as a 'high need' area for promotion of children's PA.[21] They reported 42% of all children in these areas were meeting PA guidelines.[21] This is significantly higher (p=0.0013) than the percentage of guardians in our study who reported daily PA for their children. Existing literature also suggests that children with disabilities engage in less PA than children without disabilities.[24]

In the current study, potential barriers were identified. 19.4% did not agree that they had the opportunity to support their child's PA (ie, responded strongly disagree, somewhat disagree or neither agree nor disagree). 29.4%, 24.5% and 14.9% did not agree that they have the time, financial means or transport options to support their child's PA, respectively. Parents may perceive more barriers to supporting children's PA than other health behaviours which might be because more active involvement and time is required.[25] Time constraints due to work may be difficult to address.[25] A systematic review investigated views of parents of young people with disabilities and described some commonly perceived obstacles[17]; these included absence of opportunities for those with disabilities, time restraint, lack of professional input, inadequate equipment and insufficient skills from parents. Columna *et al* suggested further research should investigate interventions which remove these barriers.[17] Future research might evaluate if Junior Parkrun could overcome these barriers.

44.1% of guardians agreed or strongly agreed that a barrier to participation was their child's health condition. We do not have details of medical conditions but existing literature demonstrates that individualised PA can benefit a range of common chronic childhood illnesses, including asthma, type 2 diabetes and some paediatric cancers.[6] Future research might evaluate if support from SCFT staff at Junior Parkrun may provide expertise and confidence to enable children with chronic disease to participate.

Interest in Junior Parkrun but lack of awareness

45.6% of guardians were not aware of Parkrun, and 73.3% were not aware if there was a Junior Parkrun local to them. Importantly, 49.5% would be interested in attending Junior Parkrun, and of those 46% would be interested in attending every week.

These responses indicate the need for Sheffield Junior Parkrun marketing. Increasing awareness of Junior

Parkrun through healthcare settings might support PA for patients. Shields and Synnot (2016) conducted a qualitative study involving young people with disabilities, parents and staff (n=63) in focus groups to ascertain their perceptions on PA.[18] Among the recommendations were: financial support for parents and implementing PA in which children with chronic disease can participate according to their choice. Among policy recommendations was 'develop partnerships between the sport and disability sectors, local government, and schools'.[18] Options of inclusivity and social support were identified as important factors for exercise participation for young people with disabilities.[18] With almost half of respondents to this study expressing interest in participating, Junior Parkrun should be explored as an option to include these young people.

Travel was the most common barrier to Junior Parkrun

The most reported barriers to Parkrun were travel, lacking interest and competing interests. 11.7% of guardians reported they never or rarely drive or provide transport for their child to be active.

There is existing research in the adult population on the inclusivity and accessibility of Parkrun for those with chronic diseases in a project called PROVE ('parkrun: running or volunteering for everyone').[26] 15 people including patients, carers or specialists involved in chronic health conditions were interviewed based on their experience of PROVE. Parkrun was considered to be inclusive but there is more to be done to ensure accessibility for everyone, such as logistics, policies and resources to support people with long-term health conditions.[26] A qualitative follow-up study (n=11) evaluated the impact of PROVE and made recommendations for similar projects; one of these recommendations was to realise the target population and ensure efficient ways to reach them.[27]

Junior Parkrun has many locations. Travel is a barrier which, without implementing more locations or liaising with transport operators, is not easily resolved. Although offering support from SCFT staff at Junior Parkrun may be viable, there need to be ways to engage children in events closer to them. Maybe by starting in one location and then communicating this effectively, with signposting to find a closer Parkrun, this barrier can be reduced.

Clinical implications

This patient and public involvement survey supports previous literature that children with chronic disease may fall short of PA guidelines. We have identified that, according to their guardians, Junior Parkrun with support from healthcare staff interests almost 50% of

	Would you and your child be interested in attending a junior parkrun in Sheffield, supported by staff from Sheffield Children's NHS Foundation Trust?		
	Responded "Yes"	Responded "No"	Significance level alpha=0.05
	Average response on Likert scale (standard deviation)	Average response on Likert scale (standard deviation)	
My child's health condition is a barrier to him/her participating in physical activity	2.84 (1.43)	3.31 (1.59)	p=0.095 Not statistically significant
There is enough time to support my child's physical activity	3.61 (1.22)	4.14 (0.94)	p=0.028 Statistically significant
I have the financial means to support my child's physical activity	3.92 (1.24)	4.16 (0.95)	p=0.5 Not statistically significant
I can transport my child to support their physical activity	4.19 (1.02)	4.53 (0.73)	p=0.09 Not statistically significant
What is your child's age?	9.9 (3.7) years	11.06 (3.79) years	p=0.12 Not statistically significant

Figure 3 Average responses to questions on a Likert scale, according to whether participants were or were not interested in attending Junior Parkrun (1=strongly disagree, 2=somewhat disagree, 3=neither agree nor disagree, 4=somewhat agree, 5=strongly agree).

respondents. We have further highlighted some beliefs held by guardians of children with health conditions, their PA participation and barriers.

As an Active Hospitals pilot site, SCFT is seeking ways to improve access to PA for children with chronic diseases. Findings of the current patient and public involvement survey justify collaboration with Junior Parkrun, with further research to evaluate its efficacy.

Strengths

To the best of the authors' knowledge, this patient and public involvement survey is the first to assess feasibility of collaboration between a hospital trust and Junior Parkrun. This study has identified some common barriers to PA among guardians of patients attending SCFT. The survey was based on suggestions from previous research. It is important for people who access health services to have a say in how services are delivered, influencing interventions to meet the needs of the population. This survey is the first step in a collaborative intervention design. We have identified that Junior Parkrun may provide a meaningful opportunity for children with chronic disease to participate in regular PA.

Limitations

This patient and public involvement survey was conducted in Sheffield, England, which is a high-income country, so findings may not be generalisable to other countries. The survey was not validated and cannot be considered reliable. As a convenience-based sample, results are susceptible to selection bias; some participants did not complete the whole survey. It may be argued that the waiting room is not an appropriate setting to consider questions carefully. The survey recruited 126 participants and, as an observational survey at one site, limits generalisability. Being quantitative, we cannot perform a more detailed analysis of participants' views. Responses represent views of guardians rather than children. This might limit the extent to which Junior Parkrun can be recommended.

CONCLUSION

This patient and public involvement survey gauged perspectives of guardians of children with chronic diseases on PA, including current activity participation, awareness of Junior Parkrun and perceived barriers and facilitators to participation. 126 guardians of children attending SCFT outpatient departments responded and almost half expressed interest in participating in Junior Parkrun. Child's health condition was not regarded as a barrier to PA by more than half of respondents. These results provide a foundation to start addressing PA needs of patients of SCFT and further exploration of a collaboration with Junior Parkrun.

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Contributors All authors had a significant role in developing this survey, gaining and interpreting the data and writing it up for publication. DR is the guarantor.

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Competing interests Both AR and DR have previously participated in Parkrun but did not deliver the survey to participants to minimise influence.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval Approval for this survey was gained from the Quality and Governance Team at SCFT. It was agreed by Sheffield Children's Foundation Trust Clinical Audit and Effectiveness Board (Audit number: SE1678).

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Deidentified data are available upon reasonable request from roshan.gunasekera1@nhs.net.

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