

Feasibility and Acceptability of an Exercise Intervention for Childhood Cancer Patients within a Clinical Setting

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Abstract

Introduction: Physical activity (PA) is important for the development and health of children and lifelong participation is greatly encouraged. However, childhood cancer patients display significantly reduced levels of PA, both during treatment and into adulthood. As survival rates of childhood cancer are improving, it is of increased importance to reduce negative effects of treatment and late effects associated with a sedentary lifestyle. While research and implementation has been established abroad, there lacks a research community in the UK, and hence it is not surprising why PA pathways are not being developed at a similar rate. This study therefore investigates the feasibility and acceptability of a three-session exercise intervention in a clinical setting on a paediatric oncology ward in the UK.

Methods: Participants were recruited from a UK paediatric ward and were categorised into three sub-categories: patients (n=9), parent/carers (n=9) and healthcare professionals (HCP) (n=15). Patients (5-18 years) were all treated on The Kamran's Ward at the John Radcliffe Hospital (UK) and have different cancer types. Patients were also asked to complete the ASK questionnaire (pre-) to assess current PA levels and determine and set the individual exercise intensity and appropriate exercises for each of the PA sessions. A PedsQL questionnaire (pre-) to assess health-related quality of life. Perceptions, participation and support levels were obtained through semi-structured interviews. Patients then carried out three exercise taster sessions (game-based, technology-based and conditioning-based) on the ward. Heart rate (HR) and rate of perceived exertion (RPE) and fun score were noted during each session. Patients then re-completed the PedsQL and a post-intervention interview. Parents took part in two semi-structured interviews (pre- and post-) and HCP took part in one semi-structured interview to determine perceptions, advice and intervention feedback. Qualitative data was analysed using thematic analysis and PedsQL data was analysed using a paired t-test.

Results: Feasibility was determined as >50% of eligible patients participated. Acceptability was determined through the positive response from all participating groups, as well as the safe execution of sessions that were able to elicit a moderate exercise intensity (50-70% predicted HR_{max}) within a clinical setting. No adverse effects were witnessed. There was not a significant difference between pre and post PedsQL. In addition, fear and fatigue emerged as prominent barriers for patients with regards to regular PA participation.

Conclusion: This study highlights that implementation of an exercise programme on a paediatric oncology ward (UK) is feasible, accepted and safe, and should encourage future implementation and improvements to existing pathways for this population.

1 Introduction

Overall survival rates for childhood cancer have significantly improved over recent decades, which has been mostly attributed to improved diagnostic technology and treatment protocols (Robinson and Hudson, 2013; Ward et al., 2014). Whilst this is celebrated, patients must still experience the rigour of treatment and magnitude of deleterious side effects associated with treating cancer (Miller et al., 2016). Whilst there seems to be an increased awareness of survivorship, late effects of cancer and long-term morbidity and mortality are still a pressing area of research (Antwi et al., 2019; Landier et al., 2015). It has been reported that survivors of childhood cancer are ten times more likely to develop chronic health conditions compared to siblings (Nathan et al., 2008) and likely to experience lower psychological well-being (Carneiro et al., 2016; Momani et al., 2015; Wakefield et al., 2009).

Due to the side effects and late effects of treatment, it is paramount for patients and survivors to engage with life-long health-promoting behaviours, such as PA, healthy diets and limit health damaging behaviours such as smoking and illicit drug use (Ford et al., 2014; Hudson et al., 2002; Pugh and Fisher, 2017). A decreased level of PA has been reported for both patients and survivors (Weiss Kelly, 2011; Wilson et al., 2014) with few meeting 'The Centres of Disease Control and Prevention' recommendations compared with 'healthy' peers (Götte et al., 2014). Such decrease has been partly attributed to the presence of the disease itself (Winter et al., 2009), physical and psychological barriers (Götte et al., 2014; Yelton and Forbis, 2016), repeated hospitalisation (Chamorro-Viña et al., 2013) and over-protective parental attitudes (Long and Marsland, 2011; Takken et al., 2009).

Although not fully comprehensive, there has been an increase of research and literature outlining the impact of PA for paediatric patients and survivors (Braam et al., 2016; Brown et al., 2012; Huang and Ness, 2011; Mirsha et al., 2012), with preliminary results highlighting positive effects of clinical interventions (Baumann et al., 2013). Results indicate an association between increased PA and improved physical function (Morales et al., 2013; San Juan et al., 2007), quality of life (Speyer et al., 2010), and health-related fitness (Chamorro-Viña et al., 2014). While it is widely understood that PA plays a vital role in the development and health of children (Silva et al., 2018), this notion is not always best promoted within a clinical setting (Gohar et al., 2010). Rustler et al. (2017) has suggested the importance of promoting PA programmes for paediatric oncology patients during in-patient stays, while Chamorro-Viña et al. (2013) concurrently highlights the importance of increasing awareness and developing evidence-based guidelines for healthcare professionals (HCP) and families.

Whilst research developments are being made in Germany (Götte et al., 2015), Canada (Chamorro-Viña et al., 2014), Spain (Morales et al., 2018) and Italy (Kilka et al., 2018), there does not currently seem to be any research activity in the UK, looking specifically at PA guidelines and provisions for childhood cancer patients. For this reason, this study examined the current state of exercise provisions within a UK paediatric oncology ward, and perception of PA through the collection of qualitative data from semi-structured interviews of patients, parents and healthcare professionals. The study continued by assessing the feasibility and acceptability of a three-session PA intervention within a clinical setting for patients (5-18years). Participating patients participated in three sessions with different approaches to exercise (game-based, technology-based and conditioning-based). All sessions were run on the paediatric cancer ward (Kamran's Ward) at the John Radcliffe in Oxfordshire and was run by the lead investigator. Feedback was gathered from all participating patients, parents and healthcare professionals to assess acceptability and feasibility. In addition, quantitative data in the form of heart rate, RPE, ASK questionnaire and PedsQL questionnaire was collected and statistically analysed to further assess feasibility.

2 Literature Review

2.1 Epidemiology of Childhood Cancer

Between 2001 and 2015 there was 21,289 registered cases of cancer in children under the age of fifteen years in the UK, with an approximate 1,420 new registered cases per year (Public Health England, 2018). The most common cancers diagnosed in children differ considerably to the adult population. In children there is a higher prevalence of leukaemias and lymphomas, and a lower prevalence of solid epithelial cancers (Neal and Hoskin, 2012). The percentage distribution of cancer by type between 2001 and 2015 is shown in Figure 1. No other cancer type accounted for more than 5% of registrations (Public Health England, 2018). The distribution of childhood cancer by type has been consistent over the last fifty years (O'Leary et al., 2008).

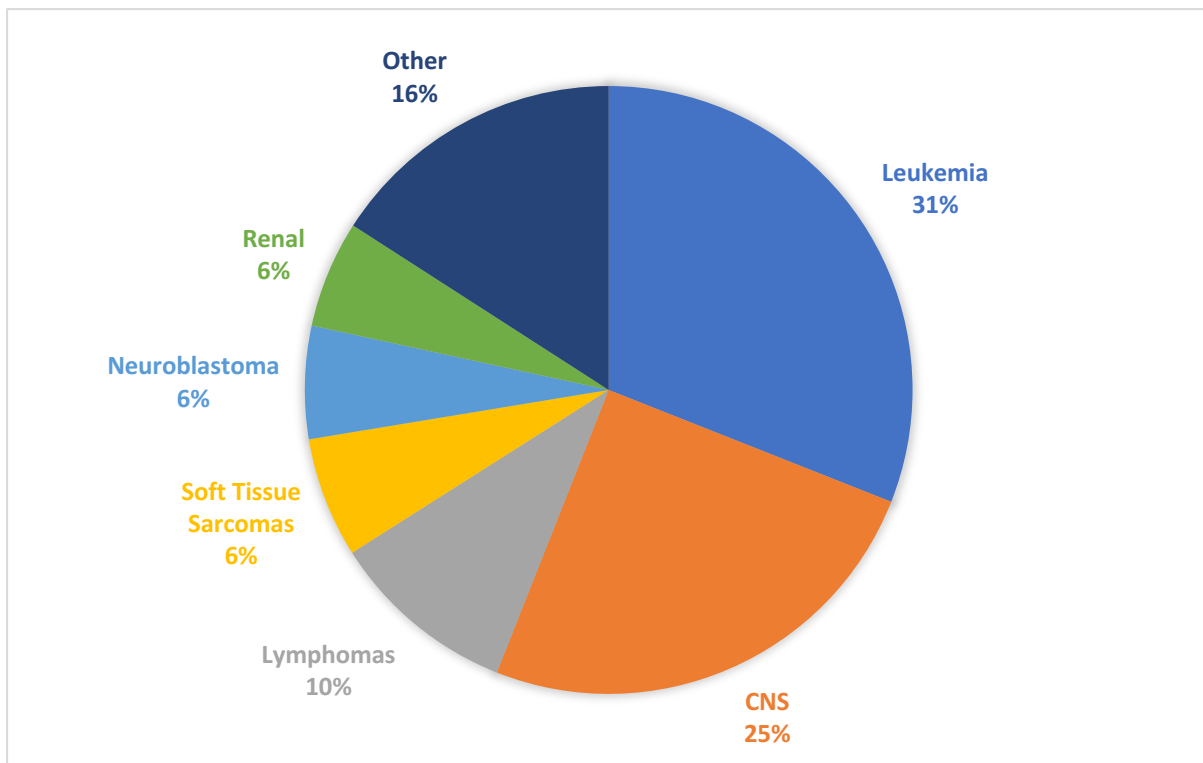


Figure 1 . Percentage distribution of childhood cancer, shown by type (Neal and Hoskin, 2012).

Childhood cancer survival rates have significantly improved from 10% fifty years ago (O'Leary et al., 2008) to 84% for those diagnosed between 2011 and 2015 (Public Health England, 2018). It has been reported that 15,000 more children have survived childhood cancer than those that would have if five-year survival rates remained at 40% which was prevalent in the 1970's (B Cancer Research UK, 2018).

2.2 Cause(s) of Childhood Cancer

Although the cause of many adult cancers is associated with behavioural and environmental factors, such as smoking, inactivity, diet, exposure to pollution and radiation, the use of addictive substances and sexual health, the cause(s) of childhood cancer is not conclusive (Weiderpass, 2010). Certain risk factors for developing childhood cancer have been investigated and thought to include pre-existing medical conditions such as Down's Syndrome, congenital abnormalities, exposure to infections such as the Epstein-Barr virus, exposure to radiation and genetics (Cancer Research UK C, 2018; Spector et al., 2015).

2.3 Diagnosis

Early diagnosis of cancer is imperative to reduce the spread of the disease and treat the malignancy whilst the disease burden is in its earliest stages (Dang-Tan and Franco, 2007). Early diagnosis is commonly associated with a reduction in mortality and morbidity (Rodrigues and Camargo, 2003). Early diagnosis and treatment of cancers is a UK government priority (Dixon-Woods et al., 2001); however, England compared to the European average, has lower rates of cancer survival (Ncin.org.uk). Such delays have been partly attributed to a later average stage of diagnosis (Ncin.org.uk, 2017). Diagnosis of childhood cancer can be more difficult to that of the adult population. Symptoms that childhood cancer patients present are often vague and insidious. Many symptoms often suggest a more common alternative diagnosis and can present very differently to that of adult malignancies (Raab and Gartner, 2009). One study noted that ten out of twenty families interviewed, reported that before their child's diagnosis was affirmed, there was some dispute with doctors over the seriousness of their child's symptoms, which contributed to a delayed diagnosis (Dixon-Woods et al., 2001). Improved awareness of childhood cancer symptoms is required to reduce time from presentation of symptoms to diagnosis (Dixon-Woods et al., 2001). Franco (2007) reviewed diagnosis delays in childhood cancer patients by calculating the mean time between first recognition of symptoms and cancer diagnosis. The mean delay times varied significantly depending on the type of malignancy. The mean time between symptom presentation and diagnosis of nephroblastoma was 2.5 weeks compared to 29.3 weeks for brain tumours. Raab and Gartner (2009) proposed that when a child presents symptoms suspicious for childhood cancer, it is important for that child to be referred to a paediatric cancer centre for further testing, which commonly included imaging and obtaining tissue for histologic review. It has been reported that the best result strongly depends on early referral

through the general practitioner. Dang-Tan and Franco (2007) expressed concerns for the UK, stating that longer delays in diagnosis may be due to an increase reliance on general practitioners to recognise cancer symptoms in children and refer patients onto paediatric oncologists or haematologists, compared to the US where insured patients can access specialists directly.

2.4 Treatment

Treatment of childhood cancer is very specific to the type and stage of the cancer. Treatments have to be individualised for each patient. The most common types of treatment include surgery, chemotherapy, radiotherapy and immunotherapy (Gabriel, 2008; Palmieri et al., 2013).

Surgery is used to remove the entire tumour and the margin resulting in an absence of cancer in the healthy tissue. Often surgery is the first stage of treatment, however depending on the size and location of the tumour, chemotherapy and radiotherapy may be required to shrink the tumour (Palmieri et al., 2013).

Chemotherapy is a cancer treatment which encompasses many medications that stop cancer cells reproducing and spreading within the body and is a common treatment in paediatric oncology. Curative chemotherapy refers to the use of medications to try to completely cure cancer. Chemotherapy can be used in combination with other treatment methods such as radiotherapy (chemoradiation) and before surgery (neo-adjuvant chemotherapy). In addition, chemotherapy can be used to reduce the risk of cancer relapse after radiotherapy or surgery (adjuvant chemotherapy) (Palmieri et al., 2013). Finally, chemotherapy can be used in conjunction with other palliative care methods to reduce unpleasant symptoms (Gabriel, 2008).

Radiotherapy uses high-energy rays to destroy cancer cells, usually administered over a number of weeks depending on the type and stage of cancer. Radiation is targeted to one area of the body; however, often the radiation can damage healthy cells around the tumour. Proton beam therapy is an advanced form of radiation that allows more precision than conventional radiotherapy, reducing side-effects and secondary malignancies (Palmieri et al., 2013).

Although not common, immunotherapy is a cancer treatment that boosts the body's immune system in order to fight cancer cells. Conventional cancer treatments are frequently used to cure cancer,

however these treatments are harmful to healthy cells and commonly result in tumours becoming drug resistance or increasing the risk of malignancy relapse. At the early stages of immunotherapy, it is thought to improve survival and quality of life (Wayne et al., 2010). Each treatment type is associated with different side effects.

2.5 Side Effects of Cancer Treatment

Cancer treatments are commonly associated with a vast range of unpleasant side effects, some of which are still experienced after treatment cessation (Coates et al., 1983; Krawczuk-Rybak, 2011). Side effects that are commonly associated with cancer treatment, more generally, include reduction in physical strength and functional capacity, fatigue, nausea, anaemia and peripheral neuropathy (Krawczuk-Rybak, 2011). Side effects of cancer treatment vary significantly depending on cancer type, treatment type, type of drug, drug doses and the patient's general health (A Cancer Research UK, 2018). The extent of each possible side effect differs from patient to patient and may change as the patient progresses through their course of treatment (A Cancer Research UK, 2018). More detailed side effects are listed in Table 1 (Durstine and Moore, 2003).

Table 1. Acute and chronic side effects of different cancer treatments (Durstine and Moore, 2003).

Treatment type	Acute side effects	Chronic side effects
<i>Surgery</i>	Pain	
	Fatigue	Pain
	Swelling	Nerve damage
	Bruising	Reduced range of motion
	Numbness	
	Reduced range of motion	
<i>Chemotherapy</i>	Fatigue	Fatigue
	Nausea	Cardiomyopathy
	Anaemia	Lung scarring
	Thrombocytopenia	Nerve damage
	Weight gain/loss	Polyneuropathy
	Nerve Damage	Reduction in bone density
	Thrombocytopenia	Endocrine problems

	Oedema/lymphedema	Infertility
	Infection and Neutropenia	Secondary malignancies
	Sleep apnoea	
<i>Radiotherapy</i>	Fatigue	Cardiac scarring
	Pain	Lung scarring
	Skin irritation	Loss of flexibility
	Pulmonary inflammation	Infertility
	Bladder inflammation	
<i>Immunotherapy</i>	Fatigue	
	Weight gain	Nerve damage
	Weight loss	Polyneuropathy
	Flu-like symptoms	Myopathy
	Nerve damage	
	Polyneuropathy	

Due to the improvement in cancer treatments and increased number of childhood survivors, late side effects should be increasingly considered. Commonly reported late side of childhood cancer include impaired growth, intellectual and pubertal development (Hjorth et al., 2015; Schwartz, 1995). The risk of other chronic health conditions is higher for childhood cancer survivors, including secondary malignancies, cardiovascular disease, severe musculoskeletal problems, reduced neurological function, renal dysfunction and endocrinopathies (Hjorth et al., 2015; Huang and Ness, 2011; Oeffinger et al., 2006). One study of 10,000 adult survivors of childhood cancer reported that 62.3% suffered from one or more chronic health conditions and 27.5% suffered from a severe and life-threatening condition (Oeffinger et al., 2006). It is therefore imperative that survivors minimise risk factors of such conditions through adopting positive and healthy lifestyle choices.

2.6 Health behaviours of childhood cancer survivors

Due to the increased risk of late side effects and secondary health conditions, it is increasingly important for survivors to engage in protective health behaviours and limit health damaging behaviours (Ford et al., 2014; Hudson et al., 2002). A number of studies have compared the engagement of health behaviours of childhood cancer survivors with non-cancer controls, with varying

results (Bauld et al., 2005; Clarke and Eiser, 2007; Emmons, 2002; Hollen and Hobbie, 1996; Hudson et al., 2002). The adoption of healthy lifestyles and its success depends on the individual health behaviour (Hudson et al., 2002).

Several studies have reported that fewer childhood cancer survivors smoke cigarettes compared to the general public (Clarke and Eiser, 2007; Emmons, 2002; Frobisher et al., 2008) and siblings (Larcombe et al., 2002). Younger survivors have displayed lower intentions to smoke in the future, yet those with lower knowledge surrounding tobacco reported greater intentions (Tyc, 2001). Similarly, fairly low rates of risky drinking habits have been reported by childhood cancer survivors (Frobisher et al., 2010) and are significantly less likely to use illicit drugs compared to the general population (Emmons, 2002; Hudson et al., 2002; Tyc, 2001). There seems to be no difference in eating healthy balanced meals, when comparing childhood survivors to non-cancer peers, with 25% in both groups not regularly eating well-balanced meals and not eating the recommended amount of fruit and vegetables (Mulhern et al., 1995). For most of these health-damaging and health-protective behaviours, survivors' habits do not differ significantly to non-cancer peers, and in fact, some health-damaging behaviours are reduced for this population, such as drug use. However, one health protective behaviour in which childhood cancer survivors do not engage in is physical activity (PA). These individuals have been shown to engage significantly less than age and gender matched controls (Alias et al., 2019; Florin et al., 2007; Murphy-Alford et al., 2019; Ness et al., 2005). To understand this pattern of sedentary behaviour, PA habits during treatment must firstly be considered.

2.7 Sedentary Behaviour during Cancer Treatment

In the past, patients were generally advised to reduce activity and rest when undergoing cancer treatment (Pinto and Trunzo, 2005). However, the prolonged periods of sedentary behaviour can precipitate decreased muscle mass and strength, impaired cardiovascular functioning, reduced range of motion (ROM), increased risk of injuries and decreased health related quality of life (HRQoL) (Pinto and Trunzo, 2005). Perceptions of PA during cancer treatment have changed dramatically over recent years and it has been widely reported that PA can reduce a number of disease and treatment-related adverse outcomes (Mishra et al., 2012). However, a reduction in activity levels are almost always seen in childhood cancer patients (Weiss-Kelly, 2011; Winter et al., 2009). One study reported that only 20% of boys and 7% of girls, during or shortly after anti-cancer treatment, met the recommended minimum 60 minutes of moderate to vigorous PA a day (Braam et al., 2015). It is important that

clinicians, researchers, young patients and their families, understand these patterns of inactivity to prescribe appropriate interventions.

A common notion that explains this reduction in PA is the presence of the disease itself and the administration and side effects of cancer treatment (Winter et al., 2009). Reported physical barriers associated with treatment effects include fatigue, nausea, dizziness, GI problems and weakness. Reported psychological barriers include bad moods, concern of injury, preference of other activities and fear of soreness (Yelton and Forbis, 2016). Young cancer patients spend a considerable amount of time in a hospital setting; if exercise is not frequently offered as part of standard care, it is unlikely children will engage with sports, exercise or PA during in-patient stays (Viña et al., 2013). Traditionally, games also provide an additional outlet for PA which are typically characterised by play which is unstructured, spontaneous and without adult involvement, for example playing in a park or playground. Children with cancer have significantly higher school absences when compared to both healthy children and those with other chronic health conditions (Vance and Eiser, 2002), which results in them missing out on these fundamental opportunities for 'play'.

Another possible factor that could contribute to increased sedentary behaviour may be due to a 'spectrum of disuse' fostered by overprotective attitudes of parents, carers and schoolteachers. Qualitative reports have suggested that overprotective and over-indulgent behaviours are often adopted by parents of childhood cancer patients (Heiney et al., 1988; Long and Marsland, 2011). Such overprotective behaviour has been linked with keeping children home from school and sports clubs and giving their children preventative medicine, all linked with a lower HRQoL (Hullmann et al., 2010).

2.8 Sedentary Behaviour after Cancer Treatment

The trend of decreased levels of PA for childhood cancer patients seems to continue after treatment cessation (Alias et al., 2019; Anti et al., 2019; Cox et al., 2009; Florin et al., 2007; Murphy-Alford et al., 2019; Stolley et al., 2010). The importance of exercise for health is paramount, but the additional benefits for lifelong PA for this population should not be overlooked. PA is important for weight control and disease prevention and an important factor to reduce the adverse late effects associated with cancer treatment (Oeffinger et al., 2006; Southern et al., 1999). Regular participation in PA is associated with a decreased risk of developing diseases such as obesity, hypertension, type II diabetes, cardiovascular disease and osteoporosis (Southern et al., 1999), which is increasingly more important

for cancer survivors to decrease the risk of life-limiting conditions and premature mortality. Whilst this notion is well understood, studies have reported that 20-52% of childhood cancer survivors are sedentary (Cox et al., 2009; Florin et al., 2007; Ness et al., 2005). An exception to this is survivors of childhood lymphoma, where 45- 80% of individuals do in fact meet recommended levels of PA (2.0 to 21.1 years after treatment) (Winter et al., 2009). Typically reported barriers include being 'too busy', 'too tired', 'not belonging to a gym' (Arroyave et al., 2008), 'fatigue', 'fear' and 'lack of appropriate facilities' (Hefferon et al., 2013; Weiss Kelly, 2011).

In addition to commonly cited barriers, there seems to be a clear lack of communication between health professionals and schools regarding a child's optimal care and rehabilitation (Roberts and Johnson, 2002). One study reported that 70% of school physical education teachers did not have the knowledge or understanding of appropriate activities for the child's rehabilitation (Robertson and Johnson, 2002). In addition, an over-cautious approach can be adopted by schools, creating an additional barrier to participation (Viña et al., 2013; Yelton and Forbis, 2016). Thoresteinsson et al. (2019) reported that children's motivation for PA involvement during the intense treatment phase for cancer were positively influenced by opportunities for PA with a classmate, group PA sessions and support from significant others. This highlights that schools and peers may play an influential role in encouraging PA for children with cancer.

2.9 The Benefits of Physical Activity for Childhood Cancer Patients

The benefits of exercise for the general population are well known, yet there seems to be limited consideration for the added benefits of exercise for childhood cancer patients and is an area of treatment that is often overlooked (Munsie et al., 2019; Ross et al., 2018). Exercise has been shown to improve both physiological and psychological health (Penedo and Dahn, 2005) in the adult population and in recent years has started to be more closely examined in paediatric populations (Huang and Ness, 2011). The extent to which exercise can affect certain acute and chronic side effects related to cancer treatment will be discussed in the following sub-sections.

2.9.1 The Effect of PA on Cancer-related Fatigue (CRF)

CRF has been reported as the most prevalent symptom for children going through cancer treatment, with those receiving chemotherapy reporting the highest prevalence (Silva et al., 2016). Children and teenagers commonly report CRF as the most persistent, stressful and anguishing symptoms of cancer treatment (Patterson et al., 2013). CRF has been recognised as a key barrier to exercise and negatively impacts PA behaviour (Ross et al., 2018). The mechanics of CRF are not well understood and it is thought that it is multi-dimensional, multifactorial and highly subjective (Barsevick et al., 2013). It is now understood that the common notion of rest and avoidance of physical effort is not the most effective at reducing CRF, yet other coping strategies are still under investigation. Moderate aerobic and resistance exercise has been shown to reduce CRF in adults (Brown et al., 2010; Dimeo, 2001; Watson and Mock, 2004) and as a result of such studies, is now currently part of the National Cancer Network Guideline for CRF (Kummer et al. 2013). The reason behind such intervention is that exercise aids normalised physical performance, thus reducing CRF (Dimeo, 2001).

Whilst such studies predominantly focus on adult populations, it was suggested that mechanisms of CRF may in fact be similar in the paediatric population (Barsevick et al., 2013; Huang and Ness, 2011). Increased PA has been longitudinally associated with lower CRF for paediatric cancer patients (Van Dijk-Lokkart et al., 2019). Table 2 summarises the research conducted on the paediatric population, with Yeh et al. (2011) and Blaauwbroek et al. (2008) reporting a significant improvement in fatigue following an exercise intervention, Rosenhagen et al. (2011) reporting a positive trend in fatigue improvement without a significant difference and Hinds et al. (2007) and Takken et al. (2009) reporting no effect on fatigue. While preliminary results suggest that PA may be of benefit for patients with CRF, further investigation is necessary to determine what type of PA is most beneficial and what frequency and duration is required to elicit changes. In addition, a number of different fatigue questionnaires were used across these studies. The validity and reliability of instruments must be considered to evaluate fatigue in young patients. Children as young as seven can describe CRF in simple terms, noticing lifestyle and activity limitations, while adolescents recognise physical fatigue and mental tiredness (Barsevick et al., 2013). This highlights the need for developmentally appropriate measures of CRF in order to make comparisons across age ranges. This point is even more relevant for childhood cancer patients as healthcare professionals work with children from birth to adulthood and the developmental range of this group is vast.

Table 2. Clinical PA interventions for childhood cancer patients with fatigue as a primary outcome.

Author	Population	Intervention details	Measure	Reported Results
Blaauwbroek et al., 2008	Childhood survivors with fatigue; mixed cancers; 46 IG (29.8 ± 8.6 years) 30 CG – non-cancer controls	Home based; 10 weeks counselling (telephone) and pedometer	CIS	Fatigue improved for IG during intervention (p<0.0005) and at 36-week follow up (p<0.0005)
Hinds et al., 2007	Solid tumour (n=4) or AML (n=25) patients; 14 IG (13.08 ± 2.55 years); 15 CG (11.92 ± 3.24 years); Admitted 2-4 days chemotherapy	Hospital-based; supervised; 2/day; 30 mins cycle ergometer for 2-4 days of hospitalisation	FS-C (7-12years) FS-A (13-18 years) FS-P (Parent)	No significant change in fatigue.
Rosenhagen et al., 2011	Stem cell transplant patients. 13 IG (15.3 ± 3.7 years) 10 CG (13.6 ± 4.0 years)	Isolation phase of PBSCT treatment; in-patient; supervised. IG - 3/week – cycle ergometer (average 25 min with 0.6 watt / kg); Additional strength exercises. CG – No additional exercise therapy	Non-specific questionnaire	Fatigue improved (no significant difference) for IG.
Takken et al., 2009	ALL survivors 9 IG (9.3±3.2yr)	Home based; supervised. 12 weeks 2/week – 45 mins supervised (66->90% HR _{max}) 2/week – home-based	CIS	Improvements of 11% but not significantly different
Yeh et al., 2011	ALL patients. 12 IG (11.01 ± 3.56yr) 10 CG (12.48 ± 3.86yr)	Home-based; PA video. IG: 6wk; 3/week for 30min; aerobic PA aimed at 40-60% of HRR. CG: No additional exercise therapy	PedsQL Multidimensional fatigue scale	General fatigue score improved for IG (p=0.02) compared to CG after one month.

2.9.2 The effect of PA on the Cardiopulmonary System

Cardiorespiratory fitness, also termed ‘aerobic fitness’, ‘cardiorespiratory fitness’ and ‘maximal oxygen consumption (VO_{2max})’ is the overall capacity of the cardiovascular and respiratory systems to perform prolonged PA (Ortega et al., 2007). It has been reported that cardiovascular fitness is associated with total and abdominal adiposity, increased risk of cardiovascular disease and premature mortality (Ortega et al., 2007). Good cardiovascular fitness has been attributed to health benefits including decreased risk of cardiovascular disease, strokes, diabetes, high blood pressure and cardiopulmonary diseases (Myers et al., 2015). Cardiovascular fitness is often decreased in childhood cancer patients and survivors, and increased risk of cardiovascular disease in childhood cancer survivors are largely attributed to treatment exposure, specifically anthracycline chemotherapies and chest radiation (Armenian et al., 2018).

Thorsteinsson et al. (2017) reported significantly lower VO_{2peak} levels in childhood cancer patients compared with age-matched healthy peers (difference $19.1 \text{ mL/kg}^{-1}/\text{min}^{-1}$). Differences were also seen at 3 months (difference $21.0 \text{ mL/kg}^{-1}/\text{min}^{-1}$), 6 months (difference $21.6 \text{ mL/kg}^{-1}/\text{min}^{-1}$) and one year after treatment (difference $6.9 \text{ mL/kg}^{-1}/\text{min}^{-1}$). This reduction in VO_{2peak} is likely to limit the capacity to perform activities of daily living (ADL) without increased effort and fatigue. These reductions in cardiorespiratory fitness has been largely associated with low levels of PA and sedentary behaviour (Braam et al., 2015). Positively, cardiovascular fitness seems to be modifiable, with a number of studies reporting improvements in VO_{2peak} after various exercise interventions, displayed in Table 3. San Juan et al. (2007) saw an increase in VO_{2peak} by $6 \text{ mL/kg}^{-1}/\text{min}^{-1}$ after a 16 week exercise intervention for ALL patients (4 to 7 years). FITT (frequency, intensity, time and type) principles must be more strongly examined to determine the best training method to elicit such improvements, and researchers should consider that this may change depending on age, cancer and treatment type.

Table 3. Clinical PA interventions for childhood cancer patients with cardiorespiratory fitness as a primary outcome

Author	Population	Intervention details	Reported Results
San Juan et al., 2007	ALL (maintenance) 7 IG (5.1 ± 1.2 years)	Supervised; in-hospital 16 weeks; 3/week; resistance (one set of 8-15 repetitions of 11 exercises); aerobic (30 min at $> 70\% HR_{max}$)	Significant increase in VO_{2peak} by $6 \text{ mL/kg}^{-1}/\text{min}^{-1}$

San Juan et al., 2008	HSCT patients IG – 8 (8±4 years) CG- 7 (7±3 years) (non-cancer)	Supervised; in-hospital; 3/week; 90 mins. Aerobic – gradual increase 10 min at 50% of predicted HR _{max} to 30 min at ≥70 % HR _{max} . Resistance - 1 set of 8-15 repetitions of 11 types of exercise, 1-2-minute rest period between exercises	IG- increased aerobic capacity and strength (p<0.05).
Takken et al., 2009	ALL survivors IG – 9 6-14 years	12 weeks; Home based -2/week; Supervised – 2/week 45 mins 4/week; Aerobic – intensity increase every 4 weeks (66-77% HR _{max} , finish with >90% of HR _{max}) Resistance – included but not detailed	No change in aerobic capacity and strength
Tanir and Kuguoglu, 2012	ALL (remission) 8-12 years IG -19 CG - 21	Home-based; 12 weeks Aerobic - 3/week (30mins) Active ROM - 3/day-5/week Resistance- 3 times/day 3/week	IG- increased aerobic capacity, functional capacity and strength (p<0.05)

2.9.3 The effect of PA on the Musculoskeletal System

Skeletal muscle function defines the ability to perform muscular contractions, which generate force enabling ADL and exercise (Cardinet, 1997). Reductions in muscle function and strength have been documented in childhood cancer patients and survivors when compared to healthy siblings, (Hartman et al., 2008; Hoffman et al., 2013) with the lowest scores most prevalent in survivors on CNS tumours and bone and soft tissue sarcomas (Hartman et al., 2013). In accord with these findings Deisenroth et al. (2016) reported significant deficits in strength were observed in all muscle groups, with the lower extremities most affected. Ness et al. (2005) noted that when compared to healthy siblings, childhood cancer survivors were more likely to report performance limitations (risk ratio, 1.8 [95% CI, 1.7 to 2.0]), restricted personal care skills (risk ratio, 4.7 [CI, 3.0 to 7.2]) and routine activities (risk ratio, 4.7

[CI, 3.6 to 6.2]). These effects can also affect individuals into survivorship; Ness et al. (2005) reported that survivors are 8.5 times more likely than siblings to report musculoskeletal problems.

Another concerning factor related to inactivity is the reduction in peak bone mass which can increase the predisposition to osteopenia and osteoporosis (Wasilewski-Masker et al., 2008). In addition, it has been reported that anti-cancer drugs including methotrexate, alkylating agent and corticosteroids are associated with decreased bone mineral density (BMD) (Hovi et al., 1993). Receiving corticosteroids above the dose of 9g.m2 increases the risk of developing reduced BMD that may not recover after treatment cessation (Hovi et al., 1993). 60% of osteoporosis risk is determined by early adulthood (Gunter et al., 2012), with most of the bone mass being formed by 12 years old for girls and 14 years old for boys (Ma and Gordon, 2012). This highlights the importance of continued PA engagement for patients and interventions should not be postponed until treatment cessation.

It has been postulated that PA, especially short burst, high-impact, weight-bearing exercise, are the most important interventions at maintaining and promoting increased BMD in young survivors of ALL (Jarfelt et al., 2006). Chamorro-Viña et al. (2014) have also suggested the importance of strength training for bone health for childhood cancer patients, with specific FITT principles displayed in table 4. For patients with low BMD it is important to consider the balance of load-bearing exercises whilst reducing the risk of falls.

Table 4. FITT principles of strength training for childhood cancer patients (adapted from Chamorro-Viña et al., 2014)

F.I.T.T	Strength Training
<i>Frequency</i>	2-3/week
<i>Intensity</i>	High (50-70% of maximal voluntary contraction)
<i>Time</i>	2-3 minutes per each main muscle group (about 8-20 repetitions) Total – 20-30 mins
<i>Type</i>	Push-ups, sit-ups, pull-ups, squats, climbing, martial arts

Resistance training is safe for paediatric cancer patients and has been shown to improve muscular strength and endurance. Interventions of twelve weeks have been seen to improve 10 repetition maximum (RM) by greater than 50% for children with ALL. Other findings have been displayed in Table 5. No negative adverse effects have been reported as a result of resistance training for this population.

Table 5. Clinical PA interventions for childhood cancer patients with strength as a primary outcome

Author	Population	Intervention details	Reported Results
Chamorro-Viña et al., 2010	HSCT in isolation phase IG – 7 CG- 13 (4-16 years)	Supervised; in-hospital; 50 mins 5/week. 5/week aerobic training (50-70% of predicted HR _{max}). 2/week strength training (8-15 repetitions of 6-10 types of exercise 1-2 min rest period between exercises)	Significant Increase in strength (p<0.05)
San Juan et al., 2007	ALL (maintenance) 7 IG (5.1 +/- 1.2 years)	Supervised; in-hospital 16 weeks; 3/week; resistance (one set of 8-15 repetitions of 11 exercises); aerobic (30 min at > 70% HR _{max})	Significant increase in strength (P<0.05)
San Juan et al., 2008	HSCT patients IG – 8 (8±4 years) CG- 7 (7±3 years) (non-cancer)	Supervised; in-hospital; 3/week; 90 mins. Aerobic – gradual increase 10 min at 50% of predicted HR _{max} to 30 min at ≥70 % HR _{max} . Resistance - 1 set of 8-15 repetitions of 11 types of exercise, 1-2 minute rest period between exercises	IG- Significant increase in strength (p<0.05).
Takken et al., 2009	ALL survivors IG – 9 6-14 years	12 weeks; Home based -2/week; Supervised – 2/week 45 mins 4/week; Aerobic – intensity increase every 4 week (66-77% HR _{max} → >90% of HR _{max}) Resistance – included but not detailed	No change strength
Tanir and Kuguoglu, 2012	ALL (remission) 8-12 years IG -19 CG - 21	Home-based; 12 weeks Aerobic - 3/week (30mins) Active ROM - 3/day-5/week. Resistance- 3 times/day 3/weekk.	IG- increased aerobic strength (p<0.05)
Perondi et al., 2012	ALL IG – 6 CG – 5 (5-16 years)	Supervised; in hospital 12 weeks; 2/week; 60 mins. 10-min treadmill warm-up, 30 min of resistance training, 20 min of treadmill aerobic training, 5 min of stretching exercises. Aerobic exercise at 70% of the peak oxygen consumption. Resistance – 5 exercises; 4 sets, 6-10 reps.	Significant improvement in sub-maximal strength (p < 0.01)

2.9.4 The effect of PA on Chemotherapy-induced Peripheral Neuropathy and Gait

Chemotherapy is an effective treatment for paediatric cancer; however, certain drugs have been well known to cause microtubule destabilisation in non-cancerous cells (Gilchrist and Tanner, 2016). Those treated with taxane- platinum- and vinca alkaloid-based drugs, have been known to develop chemotherapy-induced peripheral neuropathy (CIPN) (Klecker et al., 2017). Symptoms include cold sensitivity, numbness, pain, tingling sensation, motor impairment in the hands and feet and balance impairment (Gilchrist and Tanner, 2018; Klecker et al., 2017). Kandula et al. (2018) reported that reductions in quality of life and physical functioning were associated with the total neuropathy score. CIPN is an increasingly concerning side effect from treatment, as it is a dose-limiting toxicity, therefore increasing mortality (Klecker et al., 2017). Gilchrist et al. (2009) reviewed the ped-mTNS as a measure of CIPN in twenty children (5 to 18 years) who were going through or recently received chemotherapy (<2-months) for haematological or solid tumours. It was reported that 60% reported sensory symptoms and 55% reported motor symptoms. In addition, 90% displayed deficits in muscle strength and 95% in deep tendon reflexes during a clinical examination. Gilchrist and Tanner (2016) then reported that CIPN affects gait patterns and in particular noticed that children and adolescents receiving vincristine have a slower self-selected walking velocity and tripped more frequently than age and sex matched healthy peers. Tay et al. (2017) also reported the incidence of CIPN into survivorship for 101 childhood ALL patients (4-18 years), 2.0 to 10.3 after treatment cessation. From this cohort, it was recorded that 26.7% of survivors had cTNS scores. In addition, it was reported that those with CIPN had significantly lower QoL scores in physical ($p=0.024$) and social ($p=0.039$) domains. It is for this reason that CIPN should be more strongly recognised as a late effect of chemotherapy treatment.

Although the presence of the condition is well reported, the recommendations on prevention and treatment are still significantly lacking within both policy and published literature. One study of adult cancer patients (age 56 ± 11 years, 93% female, 79% breast cancer), reported that a six week moderate exercise intervention of progressive walking and resistance exercise, resulted in a reduction of CIPN symptoms, including numbness and tingling, when compared to the control group (Kandula et al., 2018). Marchese et al. (2004), Keats and Culos-Reed (2008) and Wurz et al. (2014) reported improvements to strength and flexibility as a result of varying PA interventions within a paediatric population (Table 6). Although CIPN was not a direct measure for these studies, both strength and flexibility are indicators of CIPN and important for normal gait function, and therefore these benefits should not be overlooked for childhood cancer patients and survivors. Future studies should conclude

PA, with FITT principles in mind, the most effective method of reducing CIPN symptoms in childhood patients and survivors.

Table 6. Clinical PA interventions for childhood cancer patients with CIPN indicators as a primary outcome

Author	Population	Intervention details	Reported Results
Keats and Culos-Reed et al., 2008	Mixed cancers; survivors; 10 IG (16.2 $\pm$ 1.6 years)	Supervised; group. 16 weeks, 1/week, 90 mins. Aerobic, strength, flexibility, education	Improvement in flexibility (p<0.05)
Marchese et al., 2004	ALL (maintenance therapy) 13 IG 15 CG (4-15 years)	12 weeks; 5 sessions individualized supervised physical therapy. 4 months home-based exercise program. Stretching (held for 30 seconds /5 days a week), lower extremity strengthening (10 repetitions/3 days a week) and aerobic fitness on a daily basis	IG: Improvement ankle ROM and the knee extension strength (p<0.01). CG: $\leftrightarrow$ strength and ankle ROM
Wurz et al., 2014	Mixed cancers; Out-patient (11.88 $\pm$ 4.26 years) 4 IG 4 CG	Supervised; Community-based. 12 weeks; 2/week; 60 mins; yoga Warm-up, standing poses, group activities, supine/seated/kneeling poses, prone possess, final resting pose.	Improvement in hamstring flexibility (left, P = 0.01; right P = 0.02) $\leftrightarrow$ Ankle dorsiflexion ROM

To date, there is limited published literature that focuses on PA guidelines for patients presenting CIPN. Chamorro-Viña et al. (2014) highlighted the importance of referral to physical therapists for CIPN patients, as minimal deficits can affect one's ability to safely participate in PA. In addition, Chamorro-Viña et al. (2014) emphasised the promotion of ankle flexibility, strengthening of wrists, hands, ankles and toes and balance training. Caution should be taken to prevent falls by limiting contact sport, PA over uneven surfaces and advanced balance training. Weakness to the hands must also be considered and strength training that requires weighted devices, such as barbells, should be avoided, and instead resistance bands should be used.

2.9.5 The Effect of PA on the Immune System

It is well understood that the immune system plays a vital role in cancer treatment and recovery (Reiche et al., 2004). The effect of exercise on the immune system is not a new concept; however, there have been concerns that excessive training may suppress immune response and increase patient's susceptibility to viral infections and tumour cells (Shepard, 1999). Many studies report an inverted 'J' hypothesis in regard to exercise and immune function (Kruijsen-Jaarsma, 2013; Romeo et al., 2010) (Figure 2). It has been reported that moderate, regular exercise enhances immune function and reduces cancer susceptibility, whilst sedentariness and exhaustive exercise is thought to suppress the immune system (Kruijsen-Jaarsma, 2013). Reports show that moderate exercise inhibits tumour growth across all histologies and stages of cancer development (Hojman et al., 2013), and has been reported to reduce the risk of relapse and second malignancies (Fairley et al., 2002).

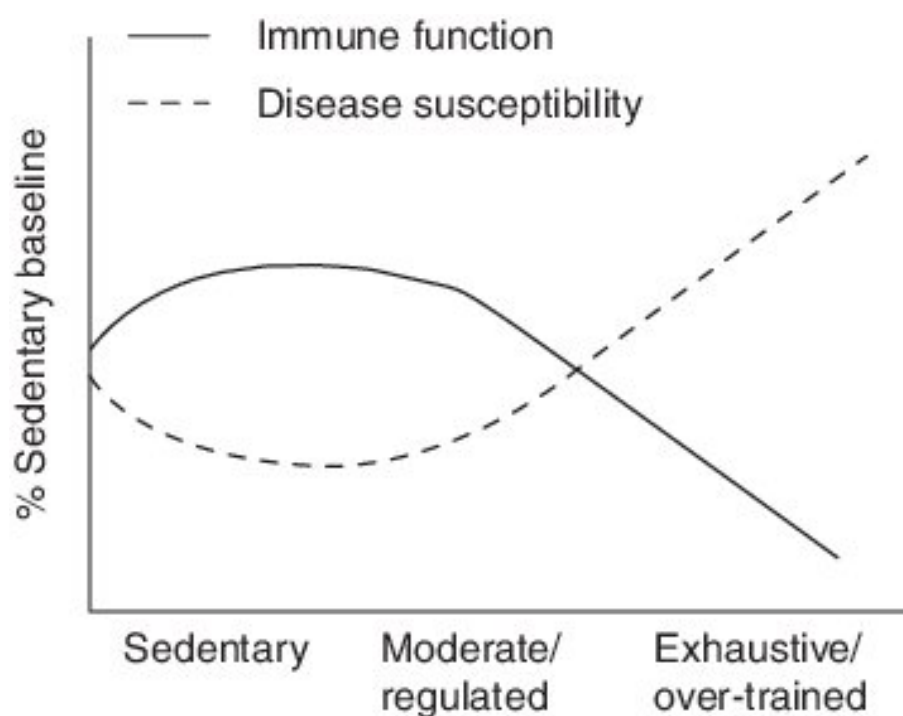


Figure 2 – Inverted 'J' hypothesis of immune response to exercise (reproduced by Romeo et al., 2010 p.391).

Following exercise, increases in Natural Killer (NK) cytotoxic activity, lymphocyte proliferation and increased number of granulocytes have been witnessed in adult cancer patients (Kruijsen-Jaarsma et al., 2013). NK cell reconstitution is critical for the success of HSCT transplants in children, and

sometimes the only curative treatment option for some paediatric malignancies. One study investigated the effect of moderate intensity exercise on NK cell recovery in children shortly after hematopoietic stem cell transplantation (HSCT) (Chamorro-Viña et al., 2016). Six children were randomised into an intervention group (IG) or control group (CG). The intervention group participated in a 10 week exercise intervention of 3 sessions per week (1 hospital-based, 2 home-based) of 60 minutes. Sessions were comprised of aerobic (50-70% predicted HR_{max}), resistance exercise and stretching. Results showed a significant increase in post-training/pre-training ratio of $CD56^{dim}$ subset ($EP = 1.27 \pm 0.07$; $CT = 0.99 \pm 0.08$; $P < .005$) of the IG group. In addition, the ratio of NK cytotoxicity was 8 times greater in the IG (Chamorro-Viña et al., 2016). Although results are preliminary and larger patient samples are needed for more conclusive evidence, these results highlight the feasibility of exercise for immunocompromised patient. It must be further examined the adjuvant therapeutic effect of moderate exercise for childhood cancer patients, and the integration of this into standard care. Further research needs to focus on the underlying mechanics of immune functions for different populations.

2.9.6 The Effect of PA on Health-related Quality of Life (HRQoL)

Assessments of HRQoL are being increasingly advocated in healthcare as a means to inform patient management and develop policy (Davies, 2009; Guyatt, 1993). It has reported that significant negative outcomes with regards to lower levels of psychological well-being, self-esteem, mood and increased anxiety, sleeping difficulties and problem behaviours have been found in childhood cancer patients (Wakefield et al., 2009). The positive relationship between HRQoL and PA levels are reported in adult literature (Anokye et al., 2012); however, only a few studies have investigated this relationship within paediatric oncology. Improvements in patients HRQoL has been reported in both a home-based (Gohar et al., 2011) and hospital-based (Speyer et al., 2010) exercise intervention for childhood cancer patients in the acute stages of treatment. In contrast, Marchese et al. (2004) reported no effect on HRQoL, following a 16 week home based intervention for children undergoing maintenance treatment for ALL. The first two of the three studied did not have a control group and therefore it is difficult to determine whether the improvements in HRQoL were in fact from the exercise programme itself or as a result of other contributing factors, such as disease recovery and maturation of participants. With this said, there does not seem to be any PA studies that report negative effects on HRQoL, and therefore its potential benefit to patients should be more strongly investigated.

HRQoL is measured subjectively using self-report questionnaires and parent proxy measures, with the 'pediatric quality of life questionnaire (PedsQL)' being the most common measure in research. However, there is not always a consistency in tools, as seen in Table 7, and therefore it is difficult to make comparisons across studies. Anthony et al. (2016) suggested the development of new HRQoL instruments to ensure content validity for childhood cancer patients. However, this may seem unnecessary due to the number of existing valid measuring tools used by clinicians and researchers, and perhaps consistency rather than development, should be targeting in future HRQoL research.

Table 7. Clinical PA interventions for childhood cancer patients with HRQoL as a primary outcome

Author	Population	Intervention details	Measure	Reported Results
Gohar et al., 2011	ALL patients; 2-weeks post diagnosis; 9 IG. (2-14years old)	Supervised; in hospital and home-based intervention. Stretching strength and aerobic training.	PedsQL 4.0	Improved HRQoL.
Keats and Culos-Reed et al., 2008	Mixed cancers; survivors; 10 IG (16.2 ±1.6 years)	Supervised; group. 16 weeks, 1/week, 90 mins. Aerobic, strength, flexibility, education.	PedsQL 4.0	Improved HRQoL.
Khodashenas et al., 2017	ALL; 10 IG (mean 8.8years); 10 CG (mean 10.1 years); 5-12 years	Supervised; IG – 12 weeks; 3/week; 60 mins; 60-85% HR _{max} . CG – No additional exercise therapy.	PedsQL 4.0	No significant different in-patient report; significant improvement in parent report (p=0.002)
Marchese et al., 2004	ALL (maintenance therapy) 13 IG 15 CG (4-15 years)	12 weeks; 5 sessions individualized supervised physical therapy. 4 months home-based exercise program. Stretching (held for 30 seconds /5 days a week), lower extremity strengthening (10 repetitions/3 days a week) and aerobic fitness on a daily basis.	PedsQL 4.0 PedsQL Cancer 3.0	No significant change in HRQoL

Müller et al., 2016	Mixed cancers; 14 IG (10.7 ± 4.3 years); Enrolled 17 months after treatment cessation	Inpatient rehabilitation; individualised. 4 week programme and home-based pedometer.	KINDL	Improvement in HRQoL after treatment p < 0.001; 12-month follow < 0.006
Rosenhagen et al., 2011	Stem cell patients; (during isolation phase of HSCT); IG 10 (15.3 ± 3.7years) 10 CG (13.6 ± 4.0yr)	Supervised; in-hospital; IG: 34,1± 94days; 3/week 50 min; cycle ergometer; strength exercises; CG: no additional exercise therapy	KINDL	Improved (trend) HRQoL
Speyer et al., 2010	Patients with mixed cancers; during hospitalisation; 30 IG (13.6 ± 2.9 years)	In hospital; supervised. 3/week; >30 mins PA	Child Health Questionnaire (CHQ)	Improved HRQoL dimensions (child and parent-proxy report)

2.9.7 The Effect of Exercise on Psychological and Psychosocial Parameters

Identifying and coping with psychological distress is an important part of survivorship care for childhood cancer patients (D'Agostino et al., 2015). An interesting finding was reported by Essen et al. (2007) that children on treatment showed levels of anxiety, depression and self-esteem similar to that of healthy children, perhaps highlighting the positive adjustment and resilience seen in childhood patients (Phipps, 2007). However, children not on treatment reported higher levels of anxiety, depression, self-esteem and psychological well-being, when compared to healthy peers. This may be due to the fact that physical and cognitive late effects may contribute to this greater level of emotional stress reported by survivors (Oancea et al., 2014). In addition, those who rated their own health as poor, reported significantly more symptoms of anxiety, depression and somatic distress (Zeltzer et al., 2009). Children have reported several strategies to cope with the psychological distress when undergoing cancer treatment; these include increasing knowledge of condition, family and friend interaction, optimism, self-esteem, personal control and sense of humour. Interestingly, one coping strategy not mentioned by patients is PA and exercise. Certainly, the effects of PA are not limited to

physiological effects alone, but additionally can increase feeling of self-esteem, control and independence, improve social interaction and decrease feelings of fear and anxiety (Dimeo et al., 1999; Penedo and Dahn, 2005). It has been reported that PA can lessen symptoms of psychological distress and improve psychosocial wellbeing in patients with chronic health conditions, including those with ischemic heart disease, (Kugler et al., 1994), chronic obstructive pulmonary disease (Emery et al., 1998) and cancer (Dimeo et al., 1999). It must therefore be more closely examined why patients are not adopting this as a way of coping with increased psychological distress to improve psychosocial wellbeing. Published research on PA for childhood cancer patients lacks psychosocial outcomes. As shown in the previous section, PA can have a positive effect on HRQoL; however, studies focus on the broad concept of HRQoL as intervention outcomes, and mostly fail to discuss individual psychosocial domains such as social functioning, self-esteem, anxiety and resilience. No detrimental psychosocial effects have been noted by such studies, and therefore further investigation must be made to conclude the effect of PA on psychological and psychosocial parameters more specifically.

2.10 The Current State of Physical Activity Provisions for Childhood Cancer Patients

The exploration of literature has highlighted the reduction of PA levels for both children and adolescents, both during treatment and into survivorship. The importance of exercise is well documented in literature; however, this provision is not always best promoted in a clinical setting (Gohar et al., 2010). The importance of promoting PA programmes and improving provisions for patients is paramount (Rustler et al., 2017) with the concurrent development of evidence-based guidelines (Chamorro-Viña et al., 2013). Many gaps still remain in published literature and research, and guidelines are still not conclusive. Larger sample sizes and increased study durations are needed to better understand any correlations in PA and specific cancer-related symptoms, both physiological and psychosocial. Frequency, intensity, duration and type of PA still needs closer examination to develop guidelines for healthcare professionals and researchers to better improve PA pathways for patients and families.

Most of the research, detailed in previous sections, has been carried out in Germany (Götte et al., 2015), Canada (Chamorro- Viña et al., 2014), Spain (Morales et al., 2018) and Italy (Kilka et al., 2018). Evidence-based guidelines are being developed internationally, for example the 'Pediatric Oncology Exercise Manual' (POEM) (Chamorro- Viña et al., 2014) (see additional material), with strong efforts

from other research groups, including 'Active Oncokids' in Germany (Activeoncokids.de, 2019). A previous study investigated good practice examples of PA interventions for childhood cancer patients in Germany, highlighting the feasibility, effectiveness and safe application of PA within a clinical setting (Marriott, 2018). The same study conducted a service evaluation of a paediatric oncology ward in the UK and found there to be very little PA provision or support for patients and families.

Therefore, the aim of the intervention is to determine whether an exercise intervention for paediatric oncology patients is both feasible and accepted in a hospital setting, and whether this replicates the research evidence which has been published by research groups abroad. This intervention will provide valuable evidence and information on the practical feasibility and acceptability of PA as a supportive care option within the UK, and can inform local decision-making whether long-term implementation seems possible.

3 Methods

3.1 Participants

Participants were recruited from The Kamran's Ward at the John Radcliffe Children's Hospital in Oxfordshire. Participants were divided into three groups: patients (n=9), parents/carers (n=9) and healthcare professionals (n=15).

3.1.1 Patients

Eligible patients were identified by oncology consultants and clinical psychologists working on Kamran's ward to ensure that it was appropriate for the child to be consulted with regards to health status or in the case that the patient was about to receive news that may have a detrimental impact to their psychological state.

Patient inclusion criteria

- Patients ≥ 5 years old, < 18 years old
- Paediatric oncological disease (leukaemia, lymphoma, myelodysplastic syndrome etc.) including solid tumour
- Admitted to the department for paediatric oncology in the John Radcliffe Hospital
- Regular visits to JR
- Inpatient or day-care patients
- Signed informed consent

Patient exclusion criteria

- Not meeting any of the inclusion criteria
- Parents or child not speaking English
- Benign disease
- Contraindication for physical exercise assigned by the oncologist and inability to understand and follow exercise protocol for the intervention and/or testing
- Differentiated exercise prohibition with possible later enrolment (i.e. specific body parts that should not be exercised at the time or current side effects of the medical treatment prohibiting exercise)

Table 8. Overview of patient characteristics.

Patient	Age	Sex	Cancer type	Treatment	Number of sessions completed
1	5	M	AML	Inpatient	3/3
2	5	F	Wilms tumour	Inpatient	3/3
3	7	F	ALL	Outpatient	3/3
4	7	F	ALL	Outpatient	3/3
5	13	F	Optic Pathway Ganglioglioma	Outpatient	3/3
6	15	M	Hodgkin's Lymphoma	Outpatient	3/3
7	16	M	Langerhans Cell Histiocytosis	Outpatient	1/3
8	17	M	ALL	Outpatient	1/3
9	17	M	Chondrosarcoma	Inpatient	3/3

3.1.2 Parent/carer

All parents/carers (n=9) of the participating patients also were included in the study, with their consent.

Parent/carer inclusion criteria

A parent or main carer for a participating child.

Parent/carer exclusion criteria

A parent/carer who wasn't able to speak English.

3.1.3 Healthcare Professionals

HCP included consultants, nurses, physiotherapists and clinical psychologists working within paediatric oncology (n=15). Specific distribution is shown in Figure 3.

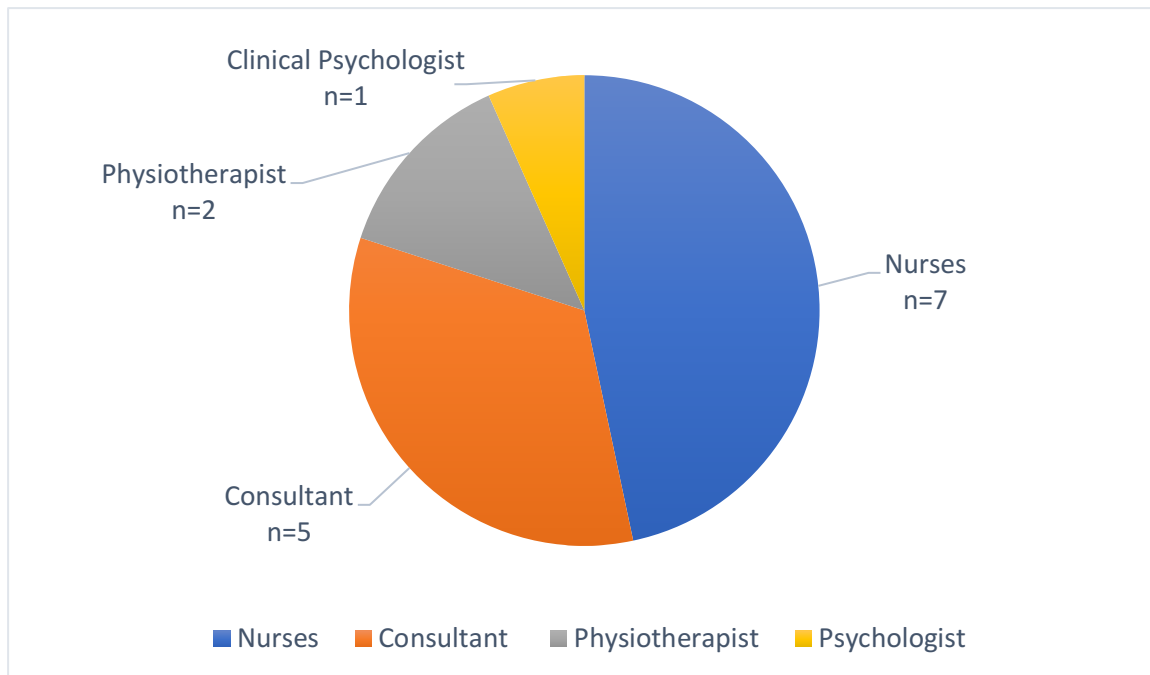


Figure 3. Number and distribution of different healthcare professionals.

HCP inclusion criteria

- Any exercise therapist supervising exercise intervention on a paediatric oncology ward
- Any oncologist or oncology nurse working on a paediatric ward
- Any physiotherapist working with children with cancer
- Any clinical psychologist working on a paediatric oncology ward
- Any researcher who has run studies in the area of exercise and paediatric oncology
- Currently working on a paediatric oncology ward or at least 1 year of experience working in the field of paediatric oncology

HCP exclusion criteria

- Any person who does not meet the inclusion criteria above

Ethical consideration

The feasibility study was performed in accordance with the Declaration of Helsinki. It was reviewed and approved by the Ethics Committee of Oxford Brookes University (DERC reference: 1218_39) and registered as a service evaluation at Oxford University Hospitals Trust.

Declaration of consent

All subjects received a group and age appropriate information sheet detailing the nature of the study (Appendix A-D). Children signed an assent form (Appendix E) with parents signing a declaration of consent, agreeing for their child to take part (Appendix F). In addition, all parents and healthcare professionals had to sign a declaration of consent for their own participation within the study. (Appendix G)

Study drop out

All subjects could terminate the study at any time.

3.2 Recruitment

For patient recruitment, potential participants were identified by staff members who were made aware and reminded of the project in weekly psycho-social team meetings, as well as regular physiotherapy meetings and other ward meetings. Oncology Consultants were consulted, particularly when identifying off-treatment patients seen in follow-up clinics; however, for all children the child's Oncology Consultant was approached by the Masters by Research student (MBR) or Clinical Psychologist within the service, to ensure that it was an appropriate time for the child to be consulted in the study, e.g. if they have just received or are about to receive bad news. Following this, staff members gained verbal consent from the parent of the child for the MBR to discuss the study in person and provide the child and parent/carer with an information sheet. Parents were encouraged to discuss the project with their child using the child information sheet. Parents were recruited once the child showed interest in the study and were given an information sheet detailing the interviews and exercise taster sessions. Staff were made aware of the project through the oncology consultant and/or clinical psychologist. Staff members were given the information sheet and MBR's email address where they can show interest in the study via email or in person.

3.3 Experimental Procedures

3.3.1 Study design

The study was conducted over 10 weeks. The study design is described in three sections, explaining the three individual groups of subjects. An overview of all subjects is shown in Figure 4.

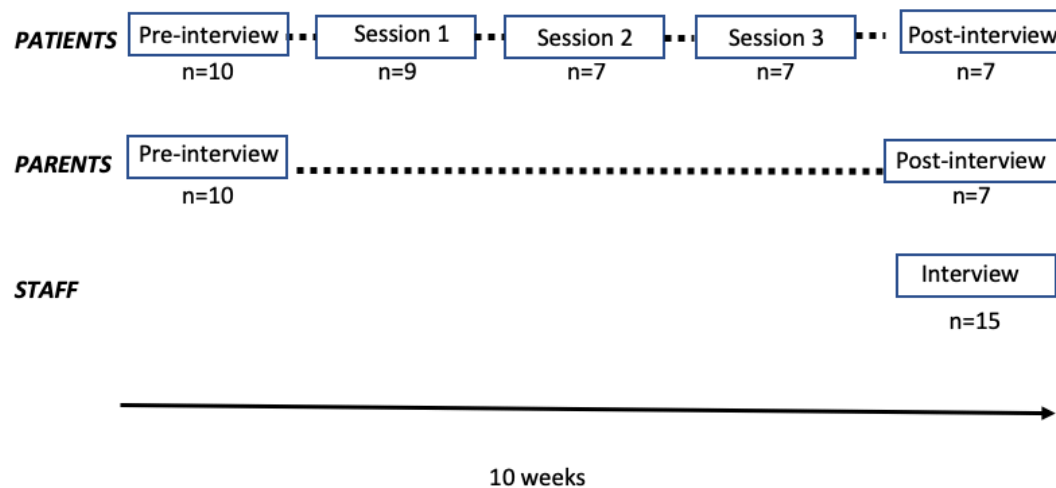


Figure 4. Schematic study design of the three subject groups across the 10-week intervention, highlighting the number of participants completing each sub-section of the study.

3.3.2 Patient intervention

Patient participation was grouped into three sub-sections: pre-intervention, intervention and post-intervention. Table 9 shows the different subcomponents to the study.

Table 9. Sub-sections of the study for patient group.

Section	Subsection	Explanation	Time commitment
<i>PRE-INTERVENTION</i>	Pre-interview	Semi-structured interview of 11 questions	5:55 - 11:34 mins
	Pre- ASK [©] questionnaire	Activity Scale for Kids questionnaire assessing current activity levels	10 mins
	Pre-PedsQL [™] questionnaire	Health-related quality of life questionnaire	10 mins
<i>INTERVENTION</i> (during the sessions HR and RPE were monitored).	Game-based session	Examples: Racket games, football, basketball, foam sword fights, target practice, animal movement game.	20-60 mins
	Technology-based session	Examples: Wii Fit, Wii Just Dance, Wii Sports, Wii Sports Island, Wii Mario and Sonic at the Olympic Games.	20-60 mins
	Conditioning session	Examples: Balance games, balance mats, strength, fine motor skills, agility games.	20-60 mins
<i>POST-INTERVENTION</i>	Post-interview	Semi-structured interview of 6 questions	4:21 – 6:17 mins
	Post-PedsQL [™] questionnaire	Health-related quality of life questionnaire	10 mins
			<i>Total = 100- 230 minutes</i>

Figure 5 shows the number of patients partaking at different parts of the intervention. Reasons for initial exclusion included patient was not interested (n=3), parent resistance (n=3) and feeling too unwell (n=1). Reasons for subjects not completing the whole intervention included unplanned infrequent visits to the JR (n=3), short duration of visits to the JR (n=1), and an unplanned change to treatment schedule (n=1).

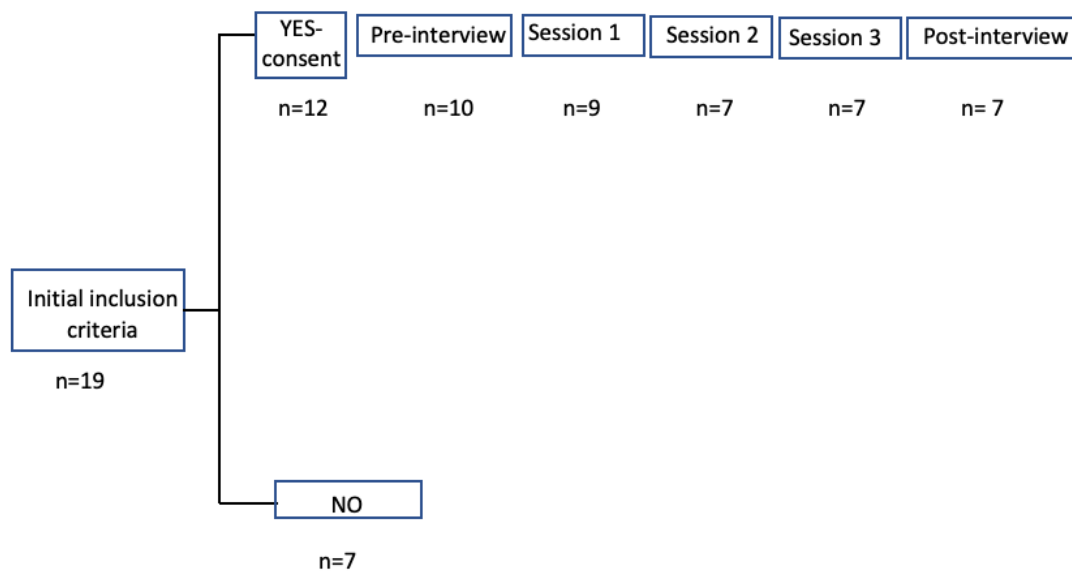


Figure 5. Schematic study design for patient inclusion/exclusion.

Pre- Interviews

Semi-structured interviews of 10 questions were asked to better understand exercise history, experience of exercise, support already received and perception of exercise for childhood cancer patients (Appendix H). Interviews were audio-recorded with permission of both patient and parent/carer for transcription purposes. Interviews followed a semi-structured form, as this allows for reciprocity between the interviewer and participants, and allows for the interviewer to conduct follow-up questions if the response is vague or off-topic (Kallio et al., 2016). During the macro-planning of the interview guidelines, the topic areas were decided as well as the chronological order of the questions.

Questionnaires

The patient completed both a PedsQL™ questionnaire and ASK[©] questionnaire prior to the intervention. The PedsQL™ (paediatric quality of life questionnaire) is a validated 23 item modular instrument that measures health-related quality of life in healthy children and adolescents, and those with chronic health conditions aged of 2-18 years (Varni et al., 2002). This questionnaire is used as an outcome measure in clinical trials, research and clinical practice. The PedsQL™ (3.0 cancer module) questionnaires were completed to assess the current status of the patient's health related quality of life to evaluate whether there was any change in terms of breaking up the children's hospital stay with regular enjoyable activities.

The Activities Scale for Kids (ASK[©]) (Young et al., 2000), a measure of PA, was completed by the patient and/or parent to assess the need for such a PA intervention. In addition, the ASK[©] questionnaire was used to determine exercise intensity for the three session intervention and to decide what activities would be most appropriate for the patient, depending on their current PA levels and functional mobility. This questionnaire has been noted to be psychometrically robust as a two-factor model, measuring both an ADL factor and play (Bagley et al., 2010). In addition, the ASK[©] focuses on a set of daily activities that are identified to be important to children and therefore seems most appropriate for a paediatric population (Bagley et al., 2010).

Exercise sessions

This study was constrained to a three session intervention. The three different types of PA sessions were chosen to allow patients to experience different types of exercise. A games-based activity was chosen to encompass a mixed approach of training through an ability and age-specific game. Typical sports or activities were adapted to suit the need of the child, for example playing badminton with a balloon to reduce the required reaction and movement speed. Secondly, a conditioning session was chosen depending on the need of the child and targeted strength or balance, for example. Thirdly, a technology-based session was chosen because of the increased access to technology that children and adolescents have in recent years and the likely increase of this into the future. The Nintendo Wii was chosen due to its increased prevalence in literature investigating the promotion of PA for children and adolescents during and after cancer treatment (Kauhanen et al., 2014; Kopp et al., 2016; Sabel et al., 2016; Speyer et al., 2010). While this research is preliminary, results indicate that PA intervention including the Nintendo Wii can increase PA levels and improve body composition.

Prior to the exercise sessions, a ward doctor or oncology consultant was consulted to ensure activity was safe for the patient, and gave verbal consent to the lead investigator. All exercise sessions were run by the lead investigator. In addition, patients answered three questions to determine how the patient was feeling and whether they had any acute issues (see Figure 15). Both heart rate (HR) and rate of perceived exertion (RPE) were measured and noted during exercise to ensure a safe level of intensity was maintained. HR was monitored on the polar OH1 Optical Heart Rate sensor. Each patient's HR_{max} was estimated using the $208 - 0.7(\text{age})$ formula, as this has been reported as a more accurate predictor of HR in children and adolescents (Mahon et al., 2010). There are limitations of these theoretical formulae, however; it would not be appropriate to put these patients through

maximal testing, and instead estimations must be used. HR% and training zones were then established. Publications have suggested that childhood cancer patients exercise at 50-70% of HR_{max} and therefore these figures have been used to determine moderate intensity (Braam et al., 2013; Kilka et al., 2018). RPE was measured using a child specific RPE scale (Ruiz et al., 2006) (Figure 6).

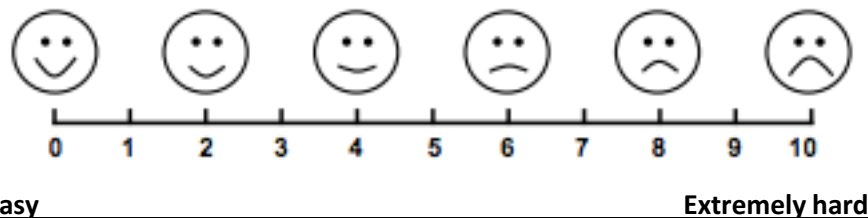


Figure 6. Adapted RPE for children (Ruiz et al., 2006).

All exercise sessions took place on Kamran's Ward, at the John Radcliffe Hospital. The specific location was determined by which room was most appropriate for the child and which space was available at the time. Locations included the playroom (n=13), empty bay (n=3), interview room (cleared of chairs and tables) (n=3), corridor (n=2), teenage room (n=1) and day care room (n=1) (Figures 7-14).



Figure 7. Photograph of Playroom



Figure 8. Photograph of Bay



Figure 9. Photograph of Interview room



Figure 10. Photograph of Corridor



Figure 11. Photograph of Teenage room



Figure 12. Photograph of Teenage room (2)



Figure 13. Photograph of Day care room



Figure 14. Photograph of Day care room (2)

All locations were cleared of trip hazards and all exercise equipment was thoroughly cleaned and inspected for any faults before each session. Sessions lasted between 20 and 60 minutes and started between 10:30 and 14:30. Duration depended on activity chosen, fatigue levels and other scheduled treatments. Patients were able to terminate sessions at any point. No adverse events were observed or recorded. Games and activities were chosen that were age and skill appropriate and aimed at increasing activity and having fun. HR was recorded throughout and noted once during the warm-up, main activity and cool down. A final RPE measurement was taken at the end of the session, in addition to four post activity questions and a score for how fun the session was, using the same scale (Figure 6). An example session is shown in Figure 15.

Exercise session: 1 28/03/2019

(empty bay)

14:00

Pre-exercise questions:

How are you feeling today?	RPE 2 "I am feeling ok today"
Do you have any acute issues?	"I feel a bit tired today and my legs feel a bit fatigued, but other than that I feel well"
Readiness	2

Warm up: (7 minutes)

Modes	Duration	Intensity	Notes/other
Mobility and aiming practice with cones/hoops and bean bags. Moving around to pick them up etc.	7 minutes	RPE 2 HR 103	

Main section (17 minutes)

Modes	Duration	Intensity	Notes/other
Badminton with balloons	10 minutes	RPE 4	Did not want to use the arm where he has his PICK line and therefore used his left arm.
Balloon kick-ups	5 minutes	RPE 4 HR 134	

Cool down (6 minutes)

Modes	Duration	Intensity	Notes/other
Trampoline bats	5 minutes	RPE 3 HR 109	

TOTAL TIME: 30 minutes**Post-exercise questions:**

How difficult?	RPE 4. "It wasn't too difficult"
How fun?	2. "It was fun, I enjoyed it"
Enjoy most?	"I enjoyed playing badminton with the balloons the most, even though I did use my weak arm".
Enjoy least?	"Umm.. I did enjoy all of it really, but if anything I would say the aiming game was my least favourite but it was still good.

Figure 15. Example session overview.

Sessions were planned to be one week apart, however; this was not always possible due to patients' individual schedules of medical and non-medical appointments and therefore there needed to be flexibility for patients to have fair access to the sessions. No two sessions were conducted within two days of each other to allow for recovery. Date, time and location of each session are shown in appendix H.

Post- Interviews

After the participants completed all three exercise sessions, they were then asked to complete a post-intervention interview of six questions (Appendix J). This was in the same semi-structured format as the first set of interviews questions and was again audio-recorded for transcription purposes.

Post- Questionnaire

A second PedsQL™ questionnaire was completed after three exercise sessions had been carried out. The rationale for completing this for a second time was that it would inform whether there was any added value beyond the usual acute enjoyment of playing/exercising. This can be considered as evaluating information to inform local decision making, and it therefore delivers relevant advice for making clinical decisions about the care/management of patients in terms of service development.

3.3.3 Parents/Carers

Pre- Interviews

Prior to their child completing any of the exercise sessions they were asked to complete a semi-structured interview of eight questions (4:10 – 12:34 minutes) (Appendix K). Interviews were audio-recorded with permission of the participant, for transcription purposes. Parents/carers were also asked to help their child complete the ASK[©] and PedsQL™ questionnaire, depending on their age and cognitive development.

Post- Interviews

After their child had completed all three sessions, parents were asked to complete a second semi-structured interview of seven questions (2:51 – 6:25 minutes) (Appendix L). Interviews were again recorded for transcription purposes. Parents/carers were also asked to help their child complete the second PedsQL™ questionnaire, if help was needed.

3.3.4 Healthcare Professionals (HCP)

Interviews

Participating HPC completed one semi-structured interview, from week 9 of the intervention. Interviews were audio-recorded, with permission, for transcription purposes. Oncologists, nurses and

clinical psychologists were asked the same series of thirteen questions (Appendix M), whilst physiotherapists were asked a different series of twelve question, more focused around physiotherapy provisions (Appendix N). Interviews lasted between 04:24 minutes and 14:44 minutes.

3.4 Equipment

Polar OH1 Optical Heart Rate Sensor (Polar Ltd., Finland) – The optical heart rate monitor which is worn around the bicep or forearm and measures HR using 6 LED sensors. The OH1 streams real-time HR onto a smart phone via the Polar App.



Sports Equipment (Youth Sports Trust, UK) – Youth Sports Trust, ‘Start To Play Balance Pack (BSL-SE1523)’ and ‘Start To Play Coordination Pack (SE1524)’. Any equipment which could not be completely disinfected was removed from the packs.





Nintendo Wii (Nintendo Co., Ltd., Japan) – Games included: Wii Sport, Wii Just Dance, Wii Sports Island, Wii Mario and Sonic at the Olympic Games and Wii Fit. Used for the technology-based session. Game depended on patients age and interests.



Protone® Balance pad– used for the conditioning element in exercise session three.



Finether Multi-use ergometer (USA) – used for both upper and lower body.



PedsQL™ questionnaire 3.0 cancer module- The PedsQL™ (paediatric quality of life questionnaire) is a validated 23 item self-report questionnaire that measures health-related quality of life in healthy children and adolescents and those with chronic health conditions. Validity and reliability have been demonstrated (Reliability ICC= 0.72 child, 0.87 parent report) (Varni et al., 2002)(Appendix O).

ASK[®] (capability) questionnaire – The Activities Scale for Kids is a self-report questionnaire for physical function and PA (reliability (ICC = 0.97)). Validity demonstrated by a correlation of 0.81 ($P < 0.0001$) with parent-reported Childhood Health Assessment Questionnaire scores (Young et al., 2000). Potential score range is 0 to 100 (high values = good function) (Young et al., 2000) (Appendix P).

3.5 Data and Statistical Analysis

Data is presented using a mixed methods approach, with both qualitative and quantitative data in the form of quotes, figures and tables. Interviews were transcribed in a verbatim fashion and thematic analysis was carried out using the software NVivo to identify patterned meaning across the data set. Thematic analysis describes the identification, analysis and report of patterns within a data set (Braun and Clarke, 2006). The following steps were taken to analyse the interview responses: 1. familiarisation with the data, 2. coding, 3. generating initial themes, 4. reviewing themes, 5. defining themes. Such themes and patterns were used to assess whether the intervention was accepted by the three subject groups. Both the questionnaires were scored using the published scoring system

(PedsQL™ see appendix Q and R); ASK see appendix S). Significant differences in the PedsQL™ were determined using a paired T-Test (significance was determined if $p < 0.05$). Feasibility was determined if 50% of eligible participants completed all of the study subsections. Acceptability was determined from intervention feedback from all participant groups and whether future implementation would be encouraged or deterred. In addition, adverse effects, exercise intensity elicited, facilities and ward disruption were also considered to determine the safety of the intervention.

4 Results

The results section is categorised into the following sub-sections for interview results: patients-pre (sub-section 4.1), parents-pre (sub-section 4.2), patients-post (sub-section 4.3), parents-post (sub-section 4.4), healthcare professionals (sub-section 4.5) and physiotherapists (sub-section 4.6). Results are grouped by topic rather than question.

The presented pre-results are for the nine patients that participated in at least one of the three exercise sessions, and their parents/carers. Two did not fully complete the study due to a change in their treatment schedule and too little time spent on Kamran's ward to complete subsequent sessions. Post-intervention results only include the seven patients that participated in all three sessions, and their parents/carers. In addition, results are also presented for fifteen staff members that participated in the interview process. ASK and PedsQL questionnaire results will also be presented at the end of the section. All results (other than section 4.1.1) refer to the time when patients were already undergoing cancer treatment.

4.1 Patients (Pre)

4.1.1 Patient Exercise History and Perceptions

All nine patients expressed that they had all engaged with sport and exercise in PE lessons leading up to their diagnosis. Five patients had only engaged in PE, four patients were, in addition, playing at club level and one patient had then progressed up to county level sport (Figure 16).

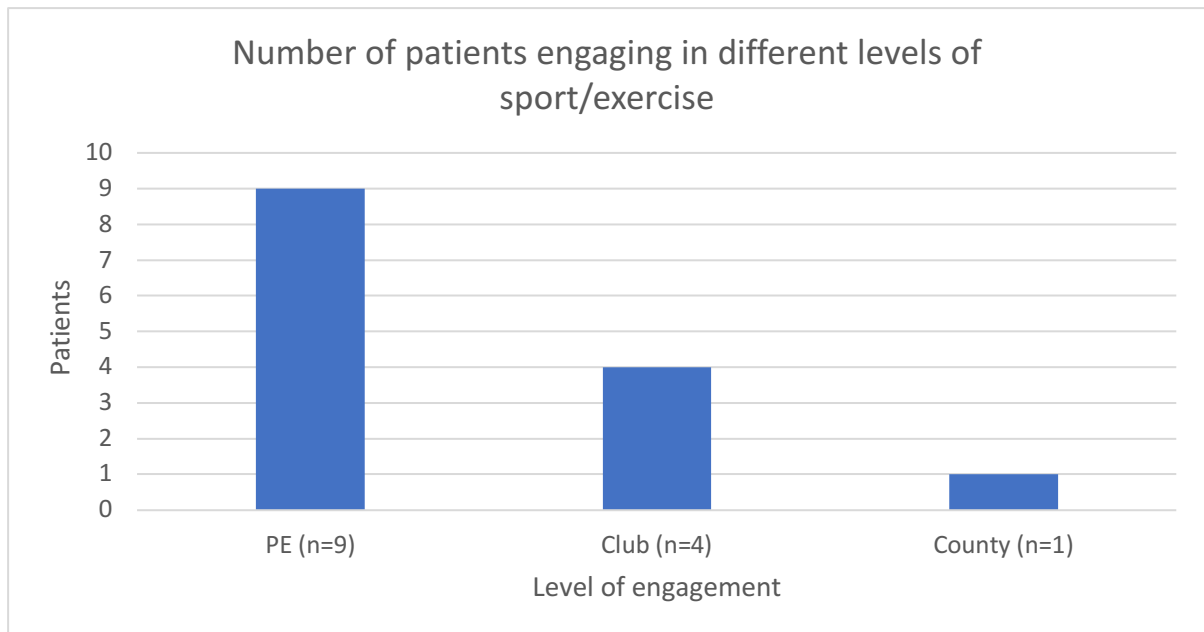


Figure 16. Number of patients engaging in different levels of sport/exercise.

Eleven different sports were cited when discussing PA, exercise and sport history (Figure 17). Football was the most referenced.

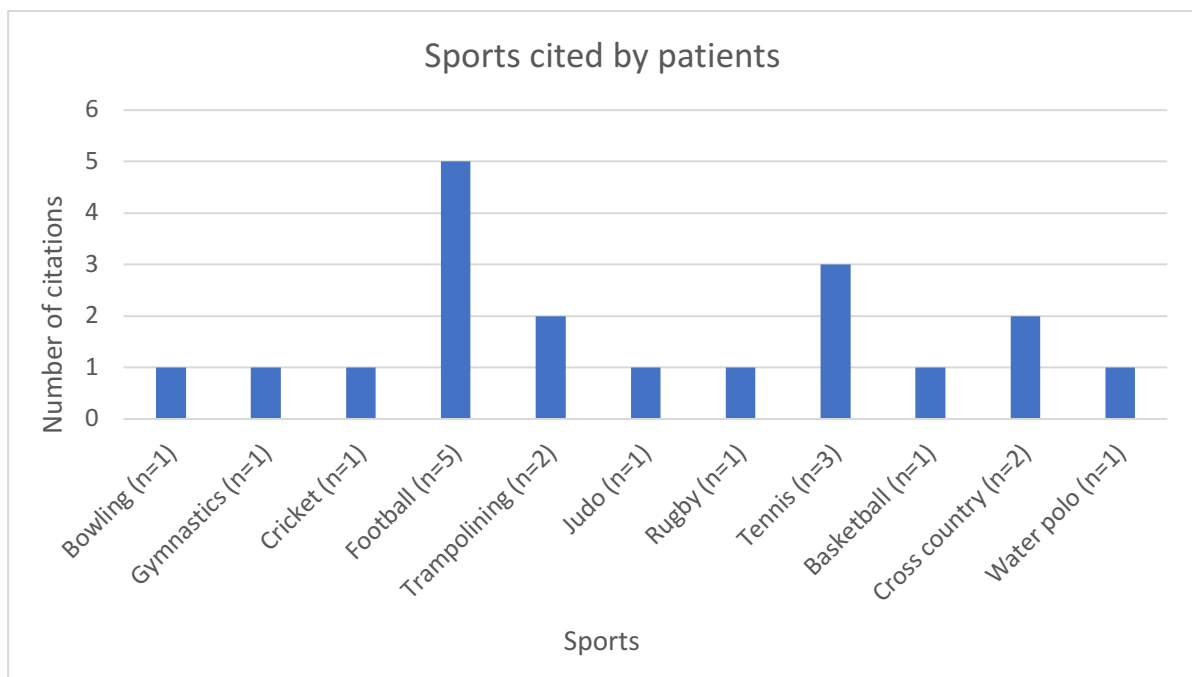


Figure 17. Sports cited by patients when asked about exercise history.

All nine patients expressed that exercise is important, with reference to both physiological and psychological impacts. No negative impacts were stated by patients.

"It keeps your body healthy and active and it is fun. I don't see why people don't do it" (Patient 9).

"Exercise is something to do and keep my mind and body active and I find it fun" (Patient 7)

"Normally you are just in a bed doing nothing unless you get out and about, enjoying yourself" (Patient 5)

"Exercise makes your muscles strong" (Patient 1)

"For me, it's because I can feel healthier and happier with myself and proud of my body as well and the social aspect of it too" (Patient 6)

Three patients expressed they engage in exercise and sport solely because they enjoy it whereas six patients expressed they engage because it is both good for their health and for enjoyment.

4.1.2 Exercise during Cancer Treatment

Patients expressed whether they were still involved in any structured or non-structured sport or exercise. Structured involvement would include participating in PE lessons, attending club training or matches and swimming lessons. Unstructured exercises would include playing, walking and cycling for leisure. Table 10 shows the current participation levels across all participants and reasons for this level of participation.

Table 10. Level of exercise involvement during cancer treatment.

Patient	Structured	Unstructured	Reasons
1	x	x	Doesn't go to school
2	x	x	Time spent in hospital
3	x	✓	Goes for walks but too unwell to attend clubs
4	✓	x	Participates in school PE lessons
5	x	x	Worried about injury
6	x	✓	Goes for walks but feels too unwell to attend clubs. Also spends a lot of time in hospital
7	x	x	Worried about injury
8	x	x	Doesn't want to, worried about injury
9	x	x	Watches team play but doesn't physically participate due to spending a lot of time in hospital, feeling sick and having a low blood count.

Only one patient is still involved in structured sport through school PE lessons. The other patients expressed there was no pattern or routine to any exercise they engaged with.

When asked, patients referenced six different side effects that they found made it more difficult or challenging to exercise during cancer treatment, these side effects are highlighted in Figure 18. Some patients cited more than one side effect.

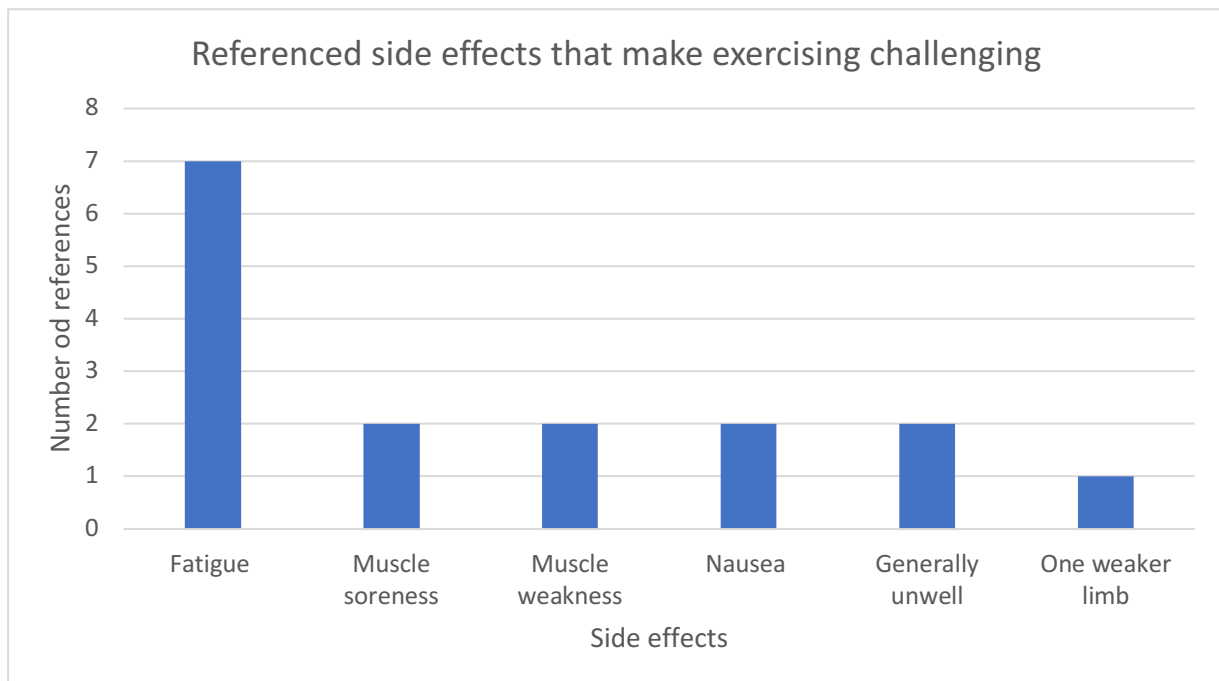


Figure 18. Side effects cited that make it more difficult to exercise.

Fatigue was the most cited side effect that patients found made exercising most difficult. Although not a side effect, and perhaps more of a barrier, one patient stated:

"... I don't think I should [exercise] because of my PIK line... I am worried I will dislodge it and that holds me back". (Patient 8)

Patients were asked whether they had participated in any sport or exercise during their time in hospital (excluding physiotherapy sessions). Eight patients expressed they had not taken part in any exercise as this had not been offered to them. One patient (5 years-old), had taken part in the hospital school PE lessons. These PE lessons are run once a week and available to those who wish to take part in the activity that is being run that day.

4.1.3 Experience of Physiotherapy

The frequency of physiotherapy sessions varied across all patients:

“Once every treatment regime” (Patient 8)

“I have only seen a physio once” (Patient 6)

“Once every time I am in, maybe twice” (Patient 7)

“It depends how I am and where I am in treatment, it is nothing regular” (Patient 5)

When asked whether they classed physiotherapy as exercise, results were mixed. The younger patients did not seem to understand the nature of the question. However, the older patients expressed mixed responses:

“Yes, I class physiotherapy as exercise” (Patient 8)

“I class physiotherapy as more of a consultancy” (patient 6)

“No, I see physiotherapy as more stretching” (patient 9)

“I see physiotherapy as somebody just checking my body, checking your body is ok. I don’t really see it like exercise. More like stretching, pre-warm up before a game”. (Patient 7)

4.1.4 Future Engagement

All nine patients expressed that they would like to take part in exercise and sports if it was offered to them when in hospital. Examples included table tennis, pool, football, running, racket sports and leisurely activities. With this said, two patients expressed that it may be dependent on other factors:

“It would depend on how I feel” (Patient 8)

“Yes, I think if it kept me occupied and keeping up your fitness levels, but I would worry how I was feeling and whether it would make me feel more ill”. (Patient 6)

4.2 Parents/Carers (Pre)

4.2.1 Exercise History and Perceptions

This sub-section section refers to parents own engagement with exercise rather than their child’s. With regards to enjoyment, participants gave very mixed results, with four parents stating they do not

enjoy sport and exercising, whilst five parents expressed that they do enjoy sport and exercise. One parent engages with exercise regularly whilst eight parents stated that they do not exercise on a regular basis. All nine parents expressed that their child's diagnosis had in fact changed their exercise habits, referencing a number of different reasons for this change (Figure 19). Parents stated:

"When I am in hospital, I stay in bed and don't exercise" (parent 1)

"It just feels like we are busier coming to the hospital and we are out of our cycle at home, out of routine" (parent 6)

"The only thing is that I used to walk on the school run which is a 15-20 minute walk there and back, but she is not up for walking that far so we now take the car every single day" (Parent 4).

"Yes, because we tend to be here almost three weeks out of five and you have to pay for the classes up front, so I haven't gone to the classes, but I intend to go back though". (Parent 9).

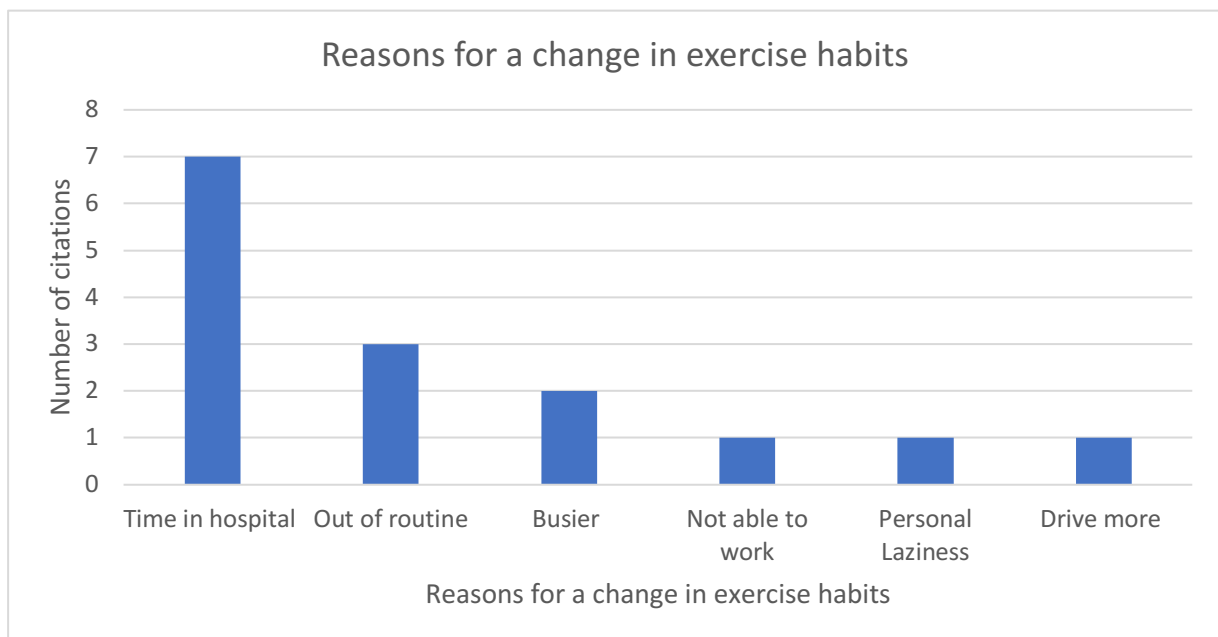


Figure 19. Reasons cited for a change in exercise habits

All nine parents stated that they did know the benefits of exercise for their child undergoing cancer treatment; however, this was their own knowledge and experience of exercise rather than any advice that had been given by ward staff. A number of different physiological and psychological benefits were cited (Figure 20).

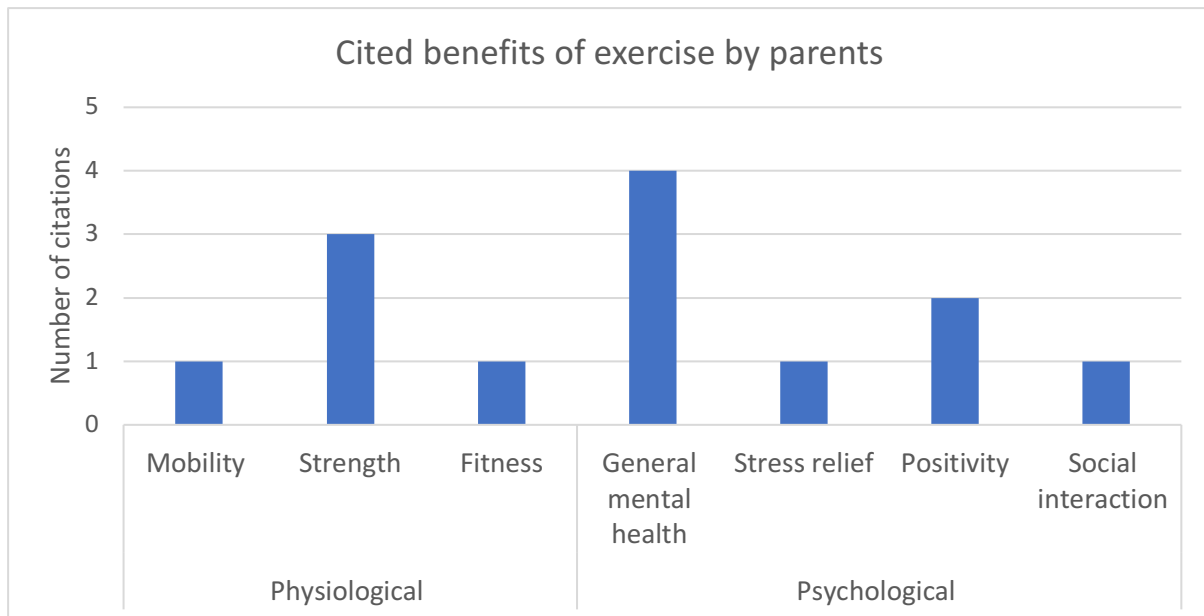


Figure 20. Benefits of exercise cited by parents.

4.2.2 Childs Exercise Experience

Parents were asked to comment on their child's experience of exercise since diagnosis. There was a mix of results. Four of nine parents commented that their child had received no exercise provisions or support:

"[Patient name] experience of exercise in the hospital... he has not really had any" (Parent 6).

"Nothing at all. When we are here, I feel like we are sat in bed doing nothing and eating lots of rubbish". (Parent 5).

Whilst five parents expressed that their child had received varying degrees of help from physiotherapists:

"By the physio we were told things that could help with her mobility. I mean she hasn't seen her in a long time because her mobility has got better and so they have less concern with her but in terms of exercising for fun there has been nothing like that for her". (Parent 4)

"Just the physio. There was an exercise bike outside, and I did say about [patient name] bringing it in (the room) but he didn't want to" (Parent 9).

4.2.3 Encouraging Exercise at Home

All nine parents stated that they do encourage their child to be active away from the hospital where possible. A number of different activities that are encouraged by parents were referenced (Figure 21).

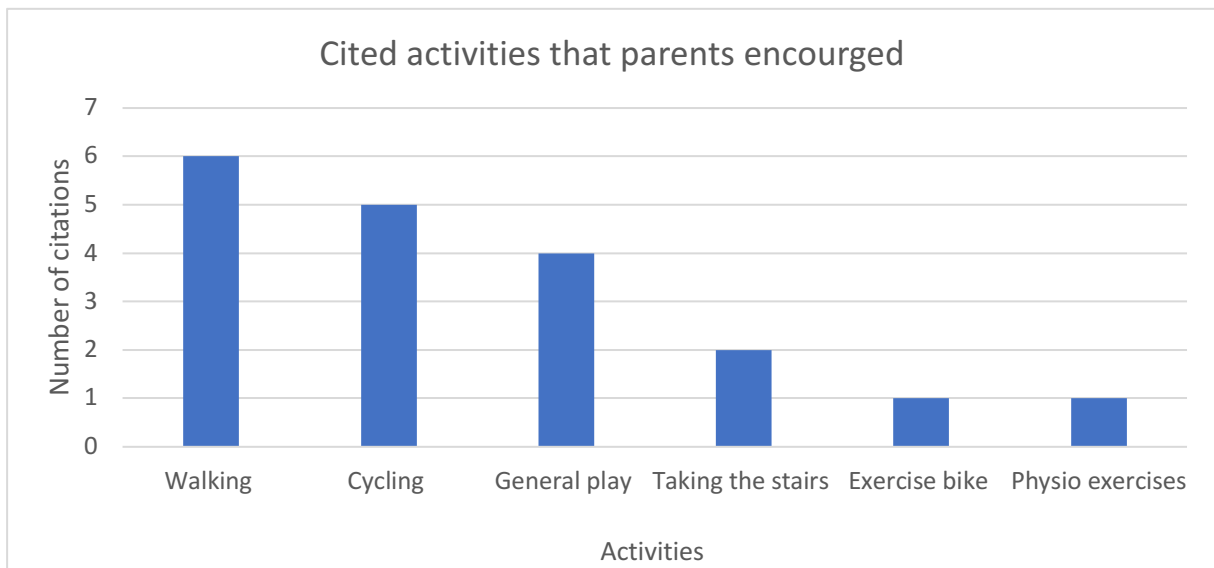


Figure 21. Activities that parents encouraged during time spent away from the hospital

4.2.4 Worries Associated with Exercise

Three parents stated they did not have any worries or concerns with their child engaging in exercise, whilst six did express a number of different worries (Figure 22). Three of the six references to injury were specifically reference to injury to the child's central line.

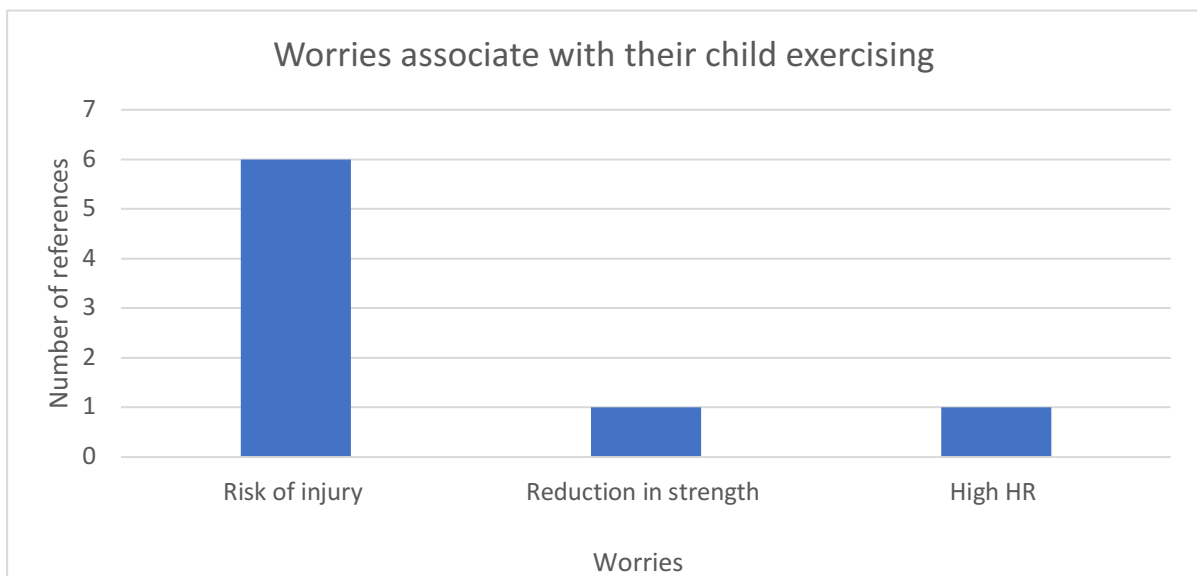


Figure 22. Cited worries associated with exercise.

4.3 Patients (Post)

4.3.1 Intervention Feedback

When asked what session each patient enjoyed most, four fell under the games-based session, two under the technology-based session and one under the conditioning session (Figure 23). There was no clear pattern of age or gender associated with patients favourite activity.

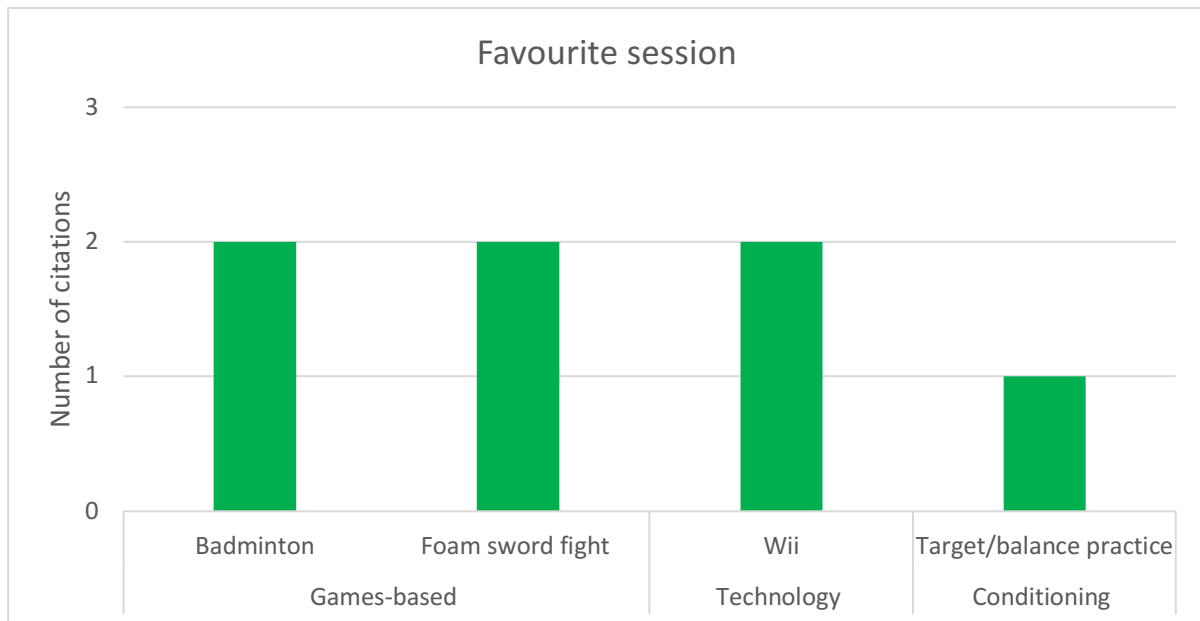


Figure 23. Patients favourite session

When asked why they enjoyed participating, the following reasons were referenced (Figure 24).

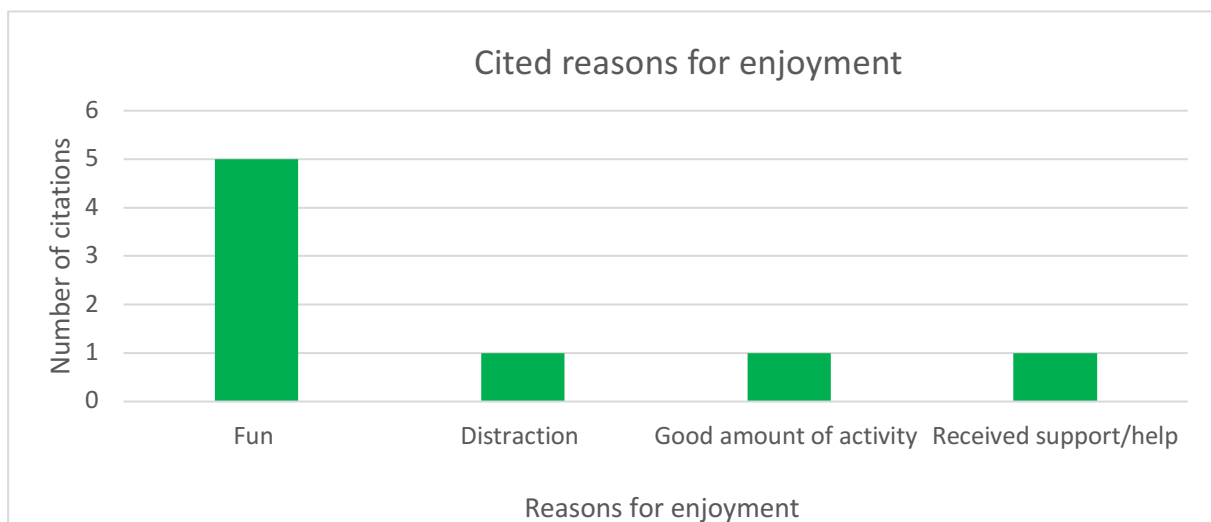


Figure 24. – Reasons for enjoyment

All patients were asked what they did not enjoy during the sessions. All nine patients expressed that there was not anything they did not enjoy and liked it all.

“No I loved everything” (Patient 2)

“No I enjoyed all of it” (Patient 5)

4.3.2 Change in perception

Patients were asked whether their perception of exercise has changed at all since participating in the sessions. Only three of the older patients understood this question. From the three clear responses, all three patients expressed their perception had changed, quoting:

“I have always loved it but not always been able to do it, because we have always been in here and never seen the space like you have and used the space to be able to do something, instead of seeing it like a big playing field, just using what you have got”. (Patient 5)

“I think I am shocked at how many calories you can burn” (Patient 6)

“Its made me realise there are a lot more ways of moving, like boxing on the Wii” (Patient 9).

4.3.3 Future Engagement

All seven patients expressed that they would like a similar intervention to be offered on a regular basis. Patients were asked whether there are any other games or activities that would like to be offered. Four patients did not state any specific game or activity. Other recommendations included rugby, basketball, boxing, trampolining and hula-hooping.

4.4 Parents/Carers (Post)

4.4.1 Intervention Feedback

All seven parents expressed that they felt like their child enjoyed participating in the exercise sessions. With regards to psychological impact for patients, a number of different ones were referenced by parents (Figure 25). All impacts referenced were positive.

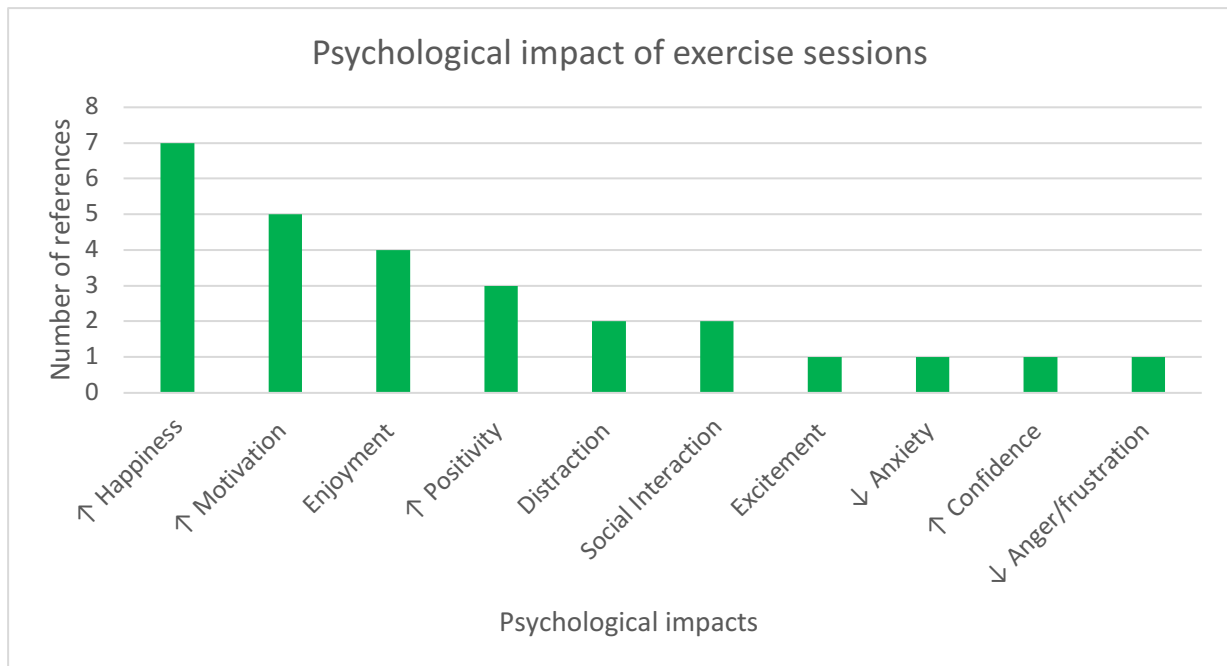


Figure 25. Number of references to difficult psychological impacts

All seven parents expressed that they did not have any concerns regarding the delivery of exercise sessions or the impact this may have had on their child’s well-being.

4.4.2 Change in Perception

Three parents expressed no change in perception of exercise, whilst four parents expressed a change, for example:

“I didn’t think he would be able to do any exercise at all. Including today when he was having his chemo or after it” (Patient 6).

4.4.3 Future Provision

All seven parents expressed that they would like to see a similar intervention run on the ward on a regular basis for patients to be able to engage with.

“Yes, I really do, absolutely. It was a lot more fun so she was a lot more willing to do it.” (Parent 3)

“Yes. 100%. It gives them motivation and a reason to get out of the bed.” (Parent 5)

4.5 Healthcare Professionals (Consultants, Nurses and Clinical Psychologists)

4.5.1 Exercise History

Staff were asked if they exercised regularly. A follow up question of “how many times a week?” and “what types of exercise do you do?” were asked to determine whether staff recognised what exercising regularly meant in terms of frequency and duration, and whether they engaged more with sport, exercise or exercise for travel. All thirteen staff members stated that they did exercise regularly with responses varying between three times a week to everyday (Figure 26).

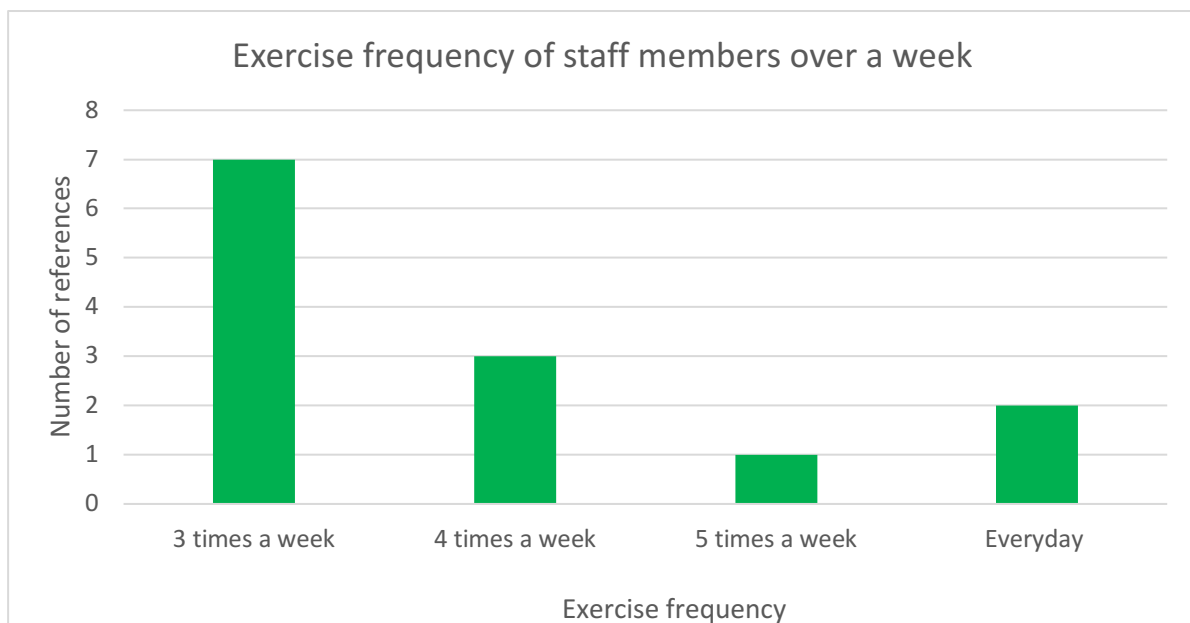


Figure 26. Exercise frequency of staff members over a week.

Staff referenced a number of different exercises that they typically engage in (Figure 27). All cited PA and sports are included in the figure.

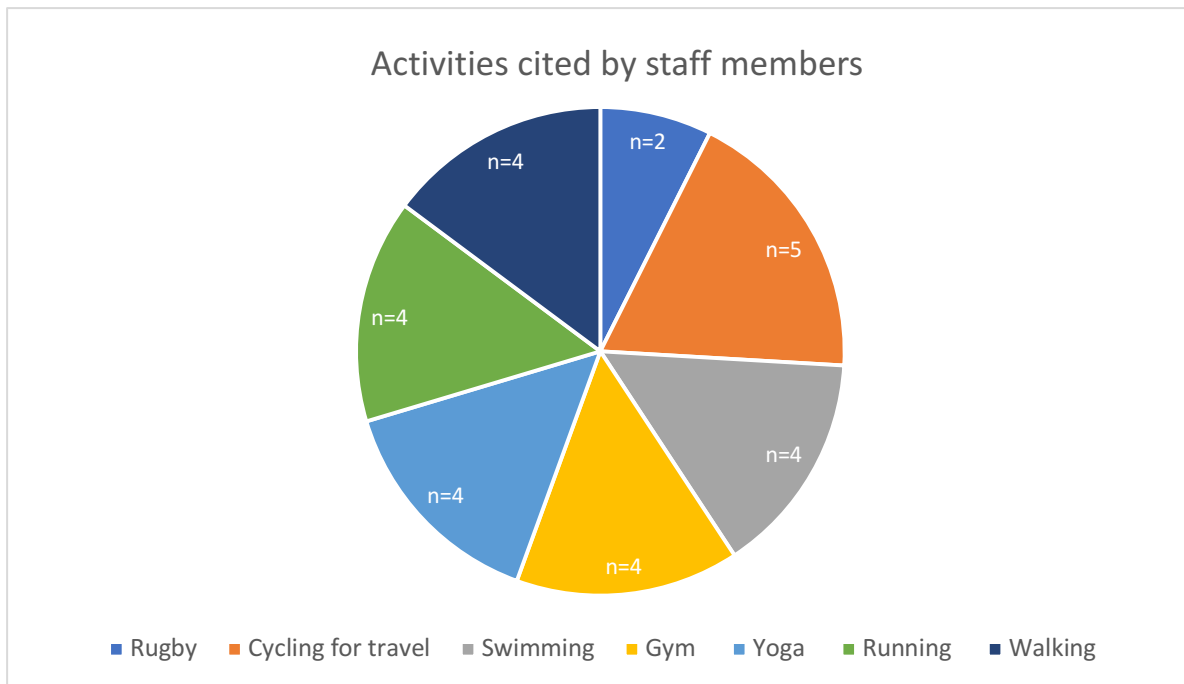


Figure 27. Activities cited by staff members

Only one member of staff reported receiving formal training on exercise for health in Medical School. It must be noted that this training took place in Canada. The remaining twelve staff members reported receiving **no** formal training on exercise. Two members of staff (1 consultant and 1 nurse) made reference to carrying out their own research on the topic, with one reference to ‘Moving Medicine’, an online tool aimed at starting a conversation with patients about PA (Moving Medicine, 2019).

4.5.2 Perceptions of exercise

Perceptions of exercising during treatment varied with the key themes including:

“It is vitally important and a really missing part of what we do. Children get into a sick role very quickly and get inactive, especially if they are advent from all of the technology that allows them to have tablets, and they get very bed bound, and I think it is something we could massively improve on.” (Consultant)

“Very important but quite difficult to get them motivated to do anything, and I guess probably quite low on the list of priorities” (Nurse)

“We know it is good for their overall health, but a lot of them are against the physio... I think sometimes the children see the physio as just another appointment...” (Nurse)

Other key themes included: adjusting expectations, barriers to exercise and limited abilities. Seventeen different benefits of exercise were referenced by staff. These have been grouped into general benefits, psychological benefits and physiological benefits. The most referenced benefit was general well-being (n=10) and the most referenced group was psychological benefits (Figure 28).

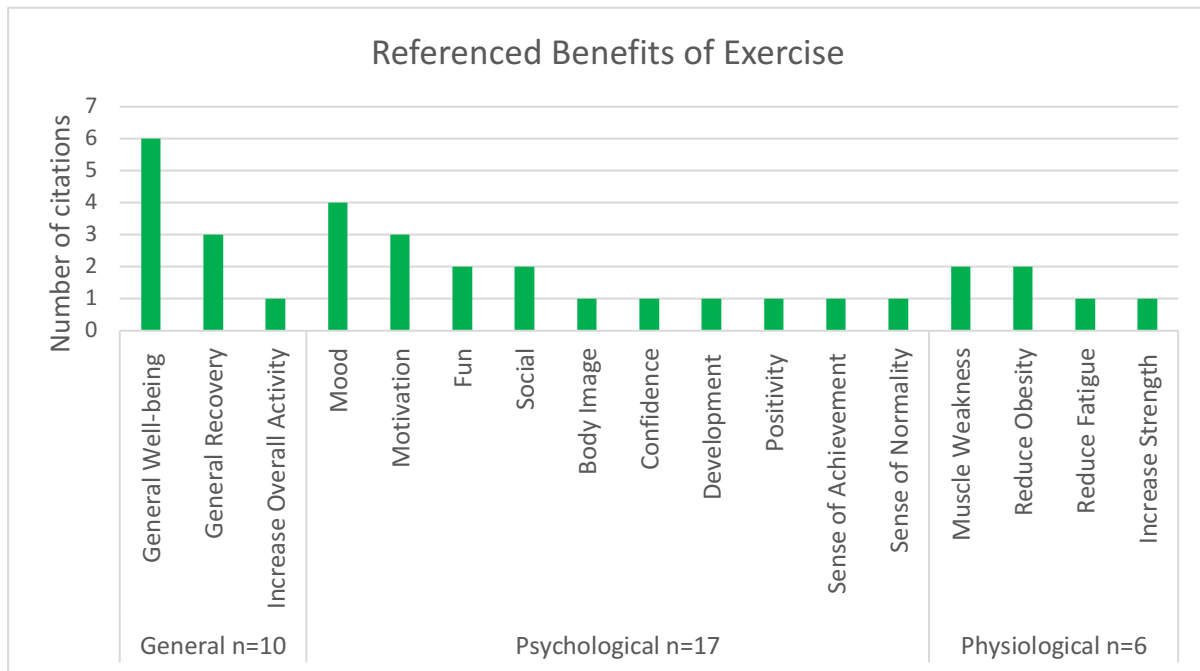


Figure 28. Referenced benefits of exercise

4.5.3 Exercise advice and encouragement

Staff members are grouped into categories for this question, to see if there is any difference in advice across different health professionals. Advice is also grouped into three groups: regular advice, irregular advice and no advice. Results are presented in Table 11. Numbers refer to the number of staff who reported that level of advice.

Table 11. Different levels of exercise advice given by different health professionals.

	Regular advice	Irregular advice	No advice
<i>Consultants</i>	n= 2	n= 2	n= 1
<i>Nurses</i>	n= 0	n= 4	n=3
<i>Clinical psychologist</i>			n=1

It is clear that there are no guidelines or advice on how to encourage patients to be active on the ward. Patients are likely to be receiving different levels of advice and encouragement with PA.

"...I guess if we are busy it is not something I actively communicate" (Nurse)

"That is harder because I don't think they have much access to it" (Consultant)

"I haven't specifically... I guess it's because I'm not really sure what exercise would be good for them" (Clinical Psychologist)

"I try, yes. Even if they are attached to fluids and they are not neutropenic then they can have a walk around and take the pump with them" (Nurse)

"I encourage them to go walking and if they have the exercise bike, we encourage them to use it but there isn't much else they can do" (Nurse)

"On the whole, yes. But probably more in terms of referring them to the physio and then letting the physio do the actual encouragement" (Consultant)

4.5.4 Intervention feedback

All thirteen staff members expressed they did not have concerns regarding the implementation of an exercise intervention on the ward. There were three references to not having a lot of space:

"No, maybe space. But that is not really a concern, it is more of a challenge you will need to overcome" (Nurse)

There were also three reference to the patient being checked by the medical team before engaging in any exercise:

"I assume there would be some criteria and that the medical team would check that they were fit to do the exercise and whether there were any medical risks then I would say no, but I am not concerned with the principle" (Consultant)

HCP expressed that the exercise sessions which were carried out on the ward, fit in with the daily routine of the hospital:

"No, it didn't interfere with anything I was doing, at all" (Consultant)

"...It hasn't been disruptive, and I am sure that if it became part of standard therapy, even the sickest children could be encouraged to move more" (Consultant)

“I think you have been really considerate of when the children have other things due and taken considerate times” (Nurse)

Participants did not report any disruption as a result of the exercise sessions.

Staff were asked whether they had seen any change in the emotional state of patients and parents after they had completed an exercise session. Responses varied when discussing whether any change in patient mood was witnessed by staff (Table 12). All changes referenced were positive and no negative changes were witnessed.

Table 12. Change in mood (positive) witnessed by staff, grouped into different healthcare professionals.

	Consultant	Nurse	Clinical Psychologist
<i>Change witnessed</i>	n=0	n=5	n=0
<i>Change not witnessed</i>	n=5	n=2	n=1

Referenced changes include increased happiness (n=4), increased energy (n=2), chattier (n=1), and increased engagement (n=1). Those who did not notice any change stated:

“No, but that is not because there hasn’t been any change, but they haven’t necessarily been my patients.” (Nurse)

“Not particularly, but this has raised an important point... there is a different consultant on every week and different nurses every day, and maybe people are not aware of when they are doing the exercise, or not have worked with children who have engaged, so it is hard to know if they have benefitted from it” (Consultant)

A similar response was given regarding any change in parent mood (Table 13). All changes observed were positive with no negative changes referenced by staff.

Table 13. Change in mood (positive) witnessed by staff, grouped into different healthcare professionals

	Consultant	Nurse	Clinical Psychologist
<i>Change witnessed</i>	n=0	n=5	n=0
<i>Change not witnessed</i>	n=5	n=2	n=1

Referenced changes include enjoying the break (n=3), increased happiness (n=2) and chattier (n=1).

"I think sometimes, whether it is an abuse of the system, I think some of them enjoy the break. They are stuck in the cubicles with the patients, I think it is good for them to get a bit of exercise but also gives the parents 5 or 10 minutes to have a break themselves. I think that can only be beneficial." (Nurse)

4.5.5 Future provision

All thirteen participants expressed a positive response to implementing an exercise programme on the ward on a regular basis:

"I think it would be really good to get all of the children up... it would be good to get them into a routine of doing something every day" (Nurse)

"I think that it's really good because it will give people the motivation to engage with exercise because sometimes I think you need an external person to motivate you to do those things... I guess it's also acknowledging that it is sometimes helpful to push people to do things and sometimes it's knowing when to back off and not be too pushy." (Clinical Psychologist).

The frequency of how often these sessions should be offered was also discussed with the general response being:

"Ideally we should be able to provide this every day because people are not in for the whole week. We are trying to offer an equal service to every one of our patients and actually if its only on every Friday then it is totally unfair on those who cannot access that" (Consultant).

4.6 Physiotherapists

4.6.1 Physiotherapy Provisions

Physiotherapists reported that physiotherapy sessions for the patients are very individual and it is dependent on the patient's individual needs.

“It is completely dependent on what the current need is for the child... it might be 2-3 times a day... the less intense spectrum, you have the ones on Kamran’s Day Care that are still undergoing treatment, but we are only touching base checking they are returning to usual activities and that might be once a month that we check in with them”

Both physiotherapists gave a wide range of different activities that patients may take part in. These included: treadmill, exercise bike, plinth work, palates, parallel bars, gym ball activities, range of movement, balance exercises, walking exercises and games, re-conditioning endurance programmes. Physiotherapists reported that there was no standard set of equipment, and instead equipment was tailored to the physiotherapy session most appropriate for the patient. Referenced equipment included parallel bars, plinths, mats, balls, gym balls, hoops, weights and exercise bikes.

“There is no standard set. This is because the children are such different ages, and what they need varies so much, so in the vincristine type ALL patients, it might just be teaching them some stretches which does not require any equipment”

“Nothing lives on the ward permanently and that is mostly because of storage”

Holistic exercise is included in physiotherapy sessions; however, it is dependent on patient needs.

“With the littles ones it is very much more holistic than specific, and we try to incorporate play where possible... I would say it is pretty holistic for most of our patients because they rarely have one need and we try to keep it functional...”

Although some parameters of fitness may be measured and recorded, there is no set protocol or formal assessment for this. Another key theme emerged from the data set that there is no funding for the physiotherapists to continue to see patients after treatment cessation.

“The vincristine patients there should be a baseline one done at the start of treatment, but the other chemotherapies and other treatments might just be early on in treatment”.

“There is no set protocol of when we test or see them and after treatment, we do not see them. There is no funding for that”.

4.6.2 Exercise education for patients

Physiotherapists reported that patients are educated about the benefits of staying active during treatment.

“We do it individually. So, when they come in, we try to catch them and talk to them about some of the side effects they are likely to come across. They also get a leaflet on “How physiotherapy can help my child... If they are more active, we have less to do with them. If they really struggle, they will see us quite often”.

Both physiotherapists made reference to a leaflet which gives parents information on “How physiotherapy can help my child”.

One physiotherapist reported that over-protection for parents can be an issue during treatment; however, it seems to depend on the individual family and their perception and attitudes towards exercise and PA.

4.6.3 Intervention feedback

One physiotherapist could not comment on whether there has been any change witnessed after the patients had completed an exercise session as part of this study, as they had not been around the patients after any of the sessions. The second physiotherapist reported that:

“I would say the patients have enjoyed the sessions and they have come to you wanting more... It looks like they are having lots of fun. So, somebody like [patient name], being full of energy would not meet my criteria but that does not mean that he should miss out on exercise”.

4.6.4 Future provisions

Both physiotherapists had a positive response to an exercise programme being offered regularly on the ward, in addition to physiotherapy.

“I think that’s very good and as well some kids as well can be quite unwell with their platelets and haemoglobin as well so I guess that will be factored in as well so providing that would be factored in then I think that would be terrific”.

4.7 ASK questionnaire

The ASK questionnaire was carried out pre-intervention to assess PA levels. Data is presented for all nine individuals that completed the pre-intervention ASK questionnaire. Patients had a range between 7.5 and 99.2, highlighting a wide range of activity and ability. Results are then broken down into different sub-section. The results of this questionnaire are presented in Table 14.

Table 14. ASK questionnaire results (Pre-intervention)

Patient ID	ASK30 Summary Score	Degree of assistance to complete ASK	Inside Aid	Outside Aid	Personal Care	Dressing	Other Skills	Loco- motion	Play	Standing Skills	Transfers
1	93.3	Some help with most answers	None	None	91.7	87.5	87.5	100.0	87.5	90.0	100.0
2	95.8	Some help with most answers	None	None	91.7	100.0	93.8	96.4	87.5	95.0	100.0
3	7.5	Some help with most answers	Yes	Yes	16.7	12.5	12.5	3.6	0.0	5.0	5.0
4	99.2	Some help with most answers	None	None	100.0	100.0	93.8	100.0	100.0	100.0	100.0
5	55.8	Some help with most answers	Yes	Cane	75.0	56.3	56.3	50.0	37.5	50.0	65.0
6	90.8	None	None	None	100.0	75.0	87.5	92.9	62.5	100.0	100.0
7	73.3	None	None	Help of parent	91.7	100.0	56.3	67.9	25.0	55.0	100.0
8	95.0	None	None	None	91.7	100.0	100.0	100.0	62.5	90.0	100.0
9	80.8	None	None	None	100.0	93.8	93.8	82.1	37.5	95.0	50.0
Mean	76.9				84.3	80.6	75.7	77.0	55.6	75.6	80.0
SD	29.4				26.5	29.6	28.7	32.5	33.1	32.4	33.8

4.8 PedsQL questionnaire

Data is presented for the seven patients that completed all three exercise sessions and PedsQL both pre- and post-intervention. The PedsQL has eight different dimensions. The results are grouped into total score, physiological score (pain and hurt, nausea), psychosocial (anxiety about procedures, treatment anxiety, worry, perceived physical appearance and communication) and cognitive for both pre and post assessment. A higher score indicates a higher health-related quality of life. No significant difference was seen across either the total score or subsections ($p>0.05$). Patient scores are highlighted in Table 15.

Patient	Total (PRE)	Total (POST)	Physiological (PRE)	Physiological (POST)	Psychosocial (PRE)	Psychosocial (POST)	Cognitive (PRE)	Cognitive (POST)
1	85	89	100	70	97	100	56	13
2	63	65	51	51	60	63	100	100
3	34	49	33	45	32	53	50	37.5
4	84	30	49	55	97	23	94	13
5	52	37	50	39	53	35	50	40
6	54	56	51	54	60	62	30	35
7	80	79	71	115	82	82	90	85
Mean	64.6	57.9	57.9	61.3	68.7	59.7	67.1	46.2
SD	19.3	21.5	21.6	25.6	24.2	26.3	27.1	33.8
<i>T-Test score from pre-post</i>	<i>p=0.46</i>		<i>p=0.70</i>		<i>p=0.47</i>		<i>p=0.12</i>	

Table 15. PedsQL scores (pre- and post- intervention)

The range was between 34 and 89, and due to the small sample size, results must be analysed with caution.

4.9 RPE and HR Measurements

Data is presented for the seven patients that completed all three exercise sessions. RPE was recorded at three different points of the exercise session, during the warm-up, main activity and cool down, using a scale from 0-10 (shown in methods section, figure 6). A score of 2-4 would indicate low intensity, 4-6 moderate intensity and 7+ high intensity exercise. A fun score was also recorded at the end of the session, using the same scale (Figure 6). The lower number indicated more fun. RPE scores are highlighted in table 16.

Table 16. RPE scores and HR across three sessions.

Patient	Session	WU RPE (0-10)	MS RPE (0-10)	CD RPE (0-10)	Overall RPE (0-10)	Fun Scale (0-10)
1	1	3	5	2	4	0
	2	3	5	3	4	0
	3	3	5	3	5	0
2	1	2	4	2	4	0
	2	2	4	2	4	0
	3	2	4	2	4	0
3	1	3	5	4	5	0
	2	3	5	3	6	0
	3	3	5	3	5	0
4	1	3	5	2	5	0
	2	2	5	2	5	2
	3	3	5	2	4	0
5	1	2	4	3	4	0
	2	3	4	3	4	0
	3	2	5	3	5	0
6	1	2	4	2	4	0
	2	3	4	3	5	2
	3	3	5	2	5	2
7	1	3	5	4	6	0
	2	4	6	4	6	2
	3	4	5	3	6	2

WU= Warm up ; MS = Main section; CD = Cool-down

Session 1 = Games-based Session 2 = Technology-based Session 3 = Conditioning-based

HR was monitored during the whole session, with an average HR and HRpeak being calculated from patients HR trace (Table 17). Missing HR figures are as a result of the HR sensor not picking up the

patients HR continuously during the sessions. This is likely to be as a result of the sensor not properly fitting the younger children, the patient moving the arm strap or a dropped connection between the sensor and IOS app.

Table 17. Patients HR data and exercise intensity as a percent of estimated HRmax.

Patient	Predicted HRmax (bpm)	Session	Total duration (mins)	HR average (bpm)	% of HRmax	HRpeak (bpm)	% of HRpeak
1	205	1	35	138	67%	141	69%
		2	30	133	65%	157	77%
		3	50	-		-	
2	205	1	35	120	59%	141	69%
		2	50	-		-	
		3	20	101	49%	133	65%
3	203	1	35	-		-	
		2	45	121	60%	140	69%
		3	45	-		-	
4	203	1	35	-		-	
		2	35	133	66%	140	69%
		3	45	-		-	
5	199	1	30	126	63%	153	77%
		2	35	109	55%	129	65%
		3	35	-		-	
6	197	1	35	129	66%	151	77%
		2	30	120	61%	136	69%
		3	45	119	60%	144	73%
7	196	1	45	116	59%	133	68%
		2	60	-		-	
		3	30	-		-	

HR <50% HRmax (Low Intensity) HR 50-70% HRmax (Moderate Intensity) HR>70% HRmax (High Intensity)

Session 1 = Games-based Session 2 = Technology-based Session 3= Conditioning-based

4.10 Feasibility and acceptability

Feasibility has been established as 58% of those who fit the initial criteria and consented to the study (>50%). Acceptability has been established as all participating patients enjoyed the sessions and would like a similar intervention to be run on a regular basis on the ward. This feedback was mirrored by all participating parents and staff members.

5 Discussion

5.1 Patients (Pre)

Patient engagement with PA

There is an apparent disparity between patient's engagement with PA from pre-diagnosis to during cancer treatment. Although this is not unexpected (Weiss-Kelly, 2011; Winter et al., 2009), these patterns of behaviour must be better understood to increase patient PA and improve PA provisions within a healthcare setting. Results show that all patients understand the physiological and psychological benefits associated with PA and exercise; however, eight of the nine patients expressed they had no regular PA routine, mirroring the trend found by other researchers (Braam et al., 2015; Weiss-Kelly, 2011; Winter et al., 2009). This finding highlights the need for PA provisions to be more closely investigated, as current provisions do not seem to be promoting regular PA participation.

Inactivity is not only something that is prevalent during treatment (Alias et al., 2019; Braam et al., 2015), but is commonly seen after treatment cessation (Antwi et al., 2019; Cox et al., 2009). Antwi et al. (2019) concluded through a meta-analysis of sixteen studies that survivors of childhood cancer display significantly lower levels of PA and fitness compared to non-cancer controls; with others reporting up to 52% of survivors leading sedentary lifestyles (Cox et al., 2009). This has been partly attributed to physical limitations and medical comorbidities (Antwi et al., 2019). It is these figures that may be even more worrying, as it demonstrates that physical inactivity is not just an acute effect of treatment, and instead likely to effect long-term health. Although not investigated in this study, it is likely that PA habits during treatment are likely to affect post-treatment PA levels. It has been noted that a broad range of PA during childhood and adolescence can positively affect lifelong participation in PA (Skille and Solbakken et al., 2014).

Patient barriers to PA

Barriers to PA is a common construct across most populations, and one that is maybe more relevant to cancer patients. Barriers can be grouped into physical, psychological and organisational barriers. Main barriers referenced in this study included fatigue (n=7), nausea (n=2), muscle weakness (n=2), muscle soreness (n=2), one weaker limb (n=1) and feeling generally unwell (n=2) with reference to 'fear of injury'. The barrier of 'fear' and 'worry' has been mirrored by Ross et al. (2018), who reported that although 94% of respondents recognised the benefits of exercise, 50% of on-treatment patients

and 12% of off-treatment patients believed that “their cancer diagnosis makes it unsafe to exercise regularly” (p. 2180). In addition to this, it has been reported that on-treatment patients are more likely than off-treatment patients to report more than one barrier relating to physical complaints (Ross et al., 2018). A number of barriers have been referenced in other studies (Arroyave et al., 2008; Götte et al., 2014; Yelton and Forbis, 2016) and should be more closely examined to improve participation levels. In addition, regular exercise could in fact improve the physical side effects associated with cancer treatment, such as fatigue and weakness (Brown et al., 2012), and should therefore be better encouraged. Adolescent cancer survivors prefer face-to-face contact with HCP to overcome barriers and engage in lifestyle interventions (Touyz et al., 2019).

Patient perceptions of physiotherapy

For many of these patients, physiotherapy is perhaps the only form of structured exercise that children regularly engage with, but surprisingly physiotherapy was not mentioned when patients were asked to discuss their current involvement in PA. Patients perception of physiotherapy is important to determine whether they are likely to positively engage. Interestingly, there was a mixed response from patients with some deeming physiotherapy as exercise, whilst others classified physiotherapy as an ‘extra consultation appointment’, or regarding it to be more ‘stretching related’. However, the data set was too small to be able to identify whether there was any significant correlation between perceptions and age or sex of patients. Although focused on children with cerebral palsy (12.2 ± 2.5 years), Chong et al. (2012) reported that with an increase of patient age, there was a decreased belief that physiotherapy could improve their own condition. Although this information is not directly transferable to paediatric cancer patients, it does open up the research area to how childhood cancer patients perceive physiotherapy, and how positive association can be reinforced to improve engagement.

5.2 Parents/Carers (Pre)

Parents own engagement with PA

It is not surprising that families have to adapt when a child is diagnosed with a chronic and life-threatening illness. There are a number of new stresses and demands, including repeated hospitalisation, alterations in parent-child relationships, parental occupations and sibling care, ultimately leading to a change in routine for families (McCubbin et al., 2004). It is therefore not unexpected that all nine parents interviewed expressed that their exercise habits had been affected

as a result of their child's diagnosis, with only one parent still managing to engage regularly with exercise. This decreased level of activity coupled with impaired physical and social function (Halliday et al., 2017), often seen in parents of childhood cancer patients, can lead to reduced physical and mental health of individuals. A previous study has reported mental health benefits of a pedometer-based exercise intervention for oncology parents as a holistic approach to improving psychological health (Halliday et al., 2017). Although separate interventions may not be feasible for parents within a clinical setting, it does seem important for HCP to encourage regular PA for patients and parents alike, in order to promote healthy lifestyle behaviours for both patient and family.

Leading on from the findings of Halliday et al. (2017), the development of smartphone apps for activity tracking seem beneficial for parents to monitor PA levels when engagement in more structured exercise proves difficult. Asimakopoulos et al. (2017) reported increased self-efficacy and motivation from activity trackers and smartphone applications, have been proven to be accurately track daily step count (Case et al., 2015). The use of such technology could be used to track health behaviours, increase PA levels and motivate parents to walk and move more, even during time in hospital.

Parental encouragement of PA

Looking past parents own interaction with PA, it is important to recognise that parents and carers play an important role in supporting and encouraging their child to remain active where possible (Takken et al., 2009). It is reported that parents can act as powerful role models, and parental encouragement can have an effect on a child's exercise behaviour (Sánchez-Miguel et al., 2013). It is reported that parents of childhood cancer patients can adopt an over-cautious attitude with regards to their child (Chamorro-Viña et al., 2013). Takken et al. (2009) also reported that parents may restrict their child's daily activity, which may be seen for years after treatment cessation. Such discouragement towards PA is likely to cause detrimental effects to a child's recovery and increase the risk of comorbidities associated with a sedentary lifestyle (Brown et al., 2012). Positively, in this study, all parents reported encouraging PA at home with the most cited activities being 'walking, cycling and general play'. Only three patients reported engaging in any structured or unstructured PA, posing the question 'does such parental encouragement in fact translate into the execution of activities?'

Whilst all participating parents of this study may claim to encourage PA, it should be noted that the possibility of over-reporting and the potential for bias could be a factor in these results. Previous studies have investigated the use of subjective measures, and concluded that substantial differences can be seen between subjective and objective measures of PA (Haskell et al., 2012; Steene-

Johannessen et al., 2016). Whilst objective measures, for example the use of an accelerator-based device, may yield more accurate results (Steene-Johannessen et al., 2016), they lack key information, such as activity type, location or context, and therefore future studies should consider the use of multi-model measurements.

It should not be assumed that this trend of PA encouragement is the same across all oncology families being treated on the ward. Reasons for initial voluntary exclusion included feeling too unwell (n=1), patient disinterest (n=3) and parent resistance (n=3). In the case of parent resistance, the true reasons behind not encouraging their child to take part is not fully understood and may mirror the topics raised by Takken et al. (2009). It would seem reasonable to assume that it may be this group of parents, and patients that need to be targeted in future studies to better understand this reluctant behaviour to engage with PA, and whether this is typically patient, or parent led. It would also be interesting to conclude whether there is a significant difference in PA engagement between groups of parents with differing perceptions of PA. These findings could facilitate the development of different educational tools to change negative perceptions of parents.

5.3 Healthcare Professionals (Pre)

HCP perceptions of PA and subsequent advice

All staff that were interviewed strongly understood the benefits of PA with seventeen different benefits being cited. The importance of keeping active was also highlighted by staff, and all healthcare professionals (HCP) reported to exercise regularly. However, results of this study highlight a disparity of advice and encouragement given by all HCP interviewed, with only two giving regular advice on PA and twelve giving irregular or no advice. This finding is interesting as it has been previously suggested that physicians that are regularly active are more likely to prescribe exercise to patients (Green et al., 2018), suggesting that more HCP in this study would have been giving patients advice on this topic. This trend has been reported elsewhere, with Painter et al. (2004) concluding that 72% of dieticians, nurses and social workers felt it was not their responsibility to advice and encourage patients regarding PA. From staff responses in this study, it was not clear whether this lack of encouragement is because of this reason or due to the fact that all but one HCP reported receiving no formal training regarding PA and exercise (the one nurse who did received training in Canada). This lack of undergraduate training at medical school has been regarded as a key barrier for physicians to prescribe PA to patients (Green et al., 2018). Dunlop and Murray (2013) also suggested that UK

students tend to underestimate the risks associated with physical inactivity compared with other lifestyle behaviours, and over half did not feel confident in giving patients PA advice. This lack of education coupled with a clear lack of official guidelines for HCP seem to explain the lack of advice they give to childhood cancer patients. This trend does not seem to be apparent only at the JR, but instead a more global issue with other studies reporting the same trend (Gohar et al., 2010; Götte et al., 2014; Keats et al., 2007). Chamorro-Viña et al. (2013) recognised the importance of enhancing awareness among HCP and families and promoting evidence-based exercise programmes. Since then, guidelines for PA and exercise have been developed and published, for example the 'Pediatric Oncology Exercise Manual (POEM)' developed by Chamorro-Viña and colleagues (2014) and the 'Keeping Active During and After Treatment' booklet by The Children's Cancer and Leukaemia Group (2017) (see additional material). However, it does not seem that such material is currently distributed or followed in the UK health setting, and work should be made on improving and distributing such guidelines and education to give HCP more confidence in giving PA advice to patients.

5.4 Physiotherapy (Pre)

Physiotherapy provisions during treatment

Undoubtably, physiotherapy is an important aspect of care for cancer patients, as mobility is likely to be affected to some extent (NICE, 2005). Paediatric cancer care is much individualised due to the number of cancers, treatments and prognosis (Imbach et al., 2014), and therefore it would not be suitable for one physiotherapy programme to fit all patients. Such notion was strongly reported by both physiotherapists, highlighting that frequency, duration, location and exercises varied greatly depending on the need of the patient. Physiotherapists also highlighted a range of activities and equipment available to patients, with both specific and holistic exercises being referenced and an additional small gym facility at the JR (external to ward). However, it is concerning that there is no exercise equipment that lives permanently on the ward, meaning that children are unable to spontaneously engage with exercise, and instead are more reliant on physio involvement.

Frequency of sessions varied greatly, patients and parents expressed a lack of regularity to physiotherapy sessions and physiotherapists stating, that some patients may not have mobility problems great enough to warrant regular contact with physiotherapists. This trend does not only seem to be unique to this hospital trust, and it has been reported elsewhere that physiotherapy, as a basic PA support is not offered to all patients, and that only those with severe enough functional

disabilities are referred (Gohar et al., 2010). Gohar et al. (2010) did not document the reasons why referrals were made, but did raise an important point that physicians' examinations may not be sensitive enough to detect more subtle deficits in neuroskeletal and neuromuscular health. Although the exact reasons may not have been reported yet, findings of this study highlighted that some patients may only 'touch in' with a physiotherapist once a month, posing the question whether childhood provisions must be more closely examined in terms of fair access to PA. It is also morally questionable that some patients may be prioritised in the sense of support with healthy living and physical literacy. It is unlikely that children undergoing treatment would be able to meet the recommended amount of PA for healthy children, but it has been suggested that frequencies as low as two sessions per week can elicit improvements in cardiorespiratory fitness in less fit individuals (Takken et al., 2009; Wenger and Bell, 1986). Although for some patients this may be achievable with their current physiotherapy sessions, for others it is still a long way off their monthly 'check-ins'.

While it seems true that many institutions still adopt this traditional care paradigm of only engaging patients after impairment or disability, Lanni et al. (2014) reported positive effects of implementing an exercise and wellness rehabilitation programme for adult cancer patients. Patients had consultations with physical therapists before the disruption of functionality, shifting focus on sustaining wellness through education and support. Reports highlighted an increase in patient proactiveness regarding their health and wellbeing. As a result of positive patient experience and staff who supported physical therapy into cancer care, the programme was adapted as a standard of care in both an inpatient and outpatient setting. Although this programme focused in the adult population, this approach to care also seems important for adolescent and child wellbeing.

Physiotherapy's role in patient monitoring

Cancer patients are likely to experience a decline in physical capacity, physical function and muscle strength (Thorsteinsson et al., 2017). There are a lot of parameters of fitness that physiotherapists can informally measure to assess this decline; however, in this study it was reported that there is "little formal standardised testing" with no formal assessment or re-assessment for patients being treated on Kamran's Ward. While this does not mean that physiotherapists do not know where patients need physiotherapy support, this finding would suggest that the significance of such decline is not accurately measured or monitored. It could be argued that by formally assessing patients regularly, it could take away from patient's physical treatment time with the physiotherapist, especially for those who do not regularly have physiotherapy appointments. However, it has been reported that regular assessment of physical parameters (pre-diagnosis, 3 month post diagnosis, 6 month post diagnosis

and 1 year after treatment cessation) is safe and feasible and that patients can in fact perform comprehensive physiological testing (VO_{peak} , sit-to stand, timed-up-and-go, balance and grip strength) during and after treatment for cancer (Thorsteinsson et al., 2017). In addition to this, the MOON test is a measure of motor performance for cancer patients aged 6-17 years (Götte et al., 2013). The measure has been reported as feasible for various cancers including bone cancer patients, amputees, patients with low health status, and is possible whilst attached to an infusion stand. The test consists of eight subtests, shown in Table 18.

Table 18. Eight parameters of the MOON test

Test	Measures
<i>Inserting pins</i>	Hand-eye coordination
<i>Static stand</i>	Body posture and balance
<i>Reaction</i>	Speed/Reaction time
<i>Target throw</i>	Coordination of upper extremities
<i>Stand and reach</i>	Flexibility
<i>Medicine ball throw</i>	Muscular explosive strength of upper body
<i>Sit-to-stand</i>	Muscular endurance of lower body
<i>Hand grip dynamometer</i>	Handgrip strength

Monitoring in such a method may give HCP a better understanding of patient's physical function, areas to focus physical treatment and may increase the perceived importance of early rehabilitation as a means to preserve physical function and pre-diagnosis habits.

Physiotherapy provisions after treatment

PA is likewise important after treatment cessation to control late effects associated with cancer treatment (Oeffinger et al., 2006). Regular engagement has been associated with improved well-being and survivorship of childhood cancer patients (Antwi et al., 2019). PA has been concluded to have a strong protective effect on all-cause mortality, and increased levels have been concluded to reduce mortality by 20-30% (Schmid and Leitzmann, 2014). Although well understood by physiotherapists in this study, unfortunately it has been noted that there is no funding to see patients after treatment finishes. It is unknown whether this is localised to this one NHS hospital trust or a more national problem. This is a worrying finding as it needs to be questioned what support patients receive with regards to reintegration back into regular PA and forming healthy habits around exercise. Peterson and Darling (2019) suggested that adult survivors should be monitored throughout their life for

functional loss, while Ness and Gurney (2007) highlighted the importance of community-based health promotion programmes for survivors. Physiotherapists and HCP must work with survivors to establish personal programmes, set goals and track progress to improve survivorship. Resources and information for post-cancer PA must be developed and made accessible to patients coming to the end of treatment. This study did not investigate the PA levels of patients' post-treatment and future studies should determine PA levels for patients treated in the UK.

5.5 ASK Questionnaire

The overall averages for the ASK questionnaire for this study were lower (76.9 ± 29.4), compared to the average scores for 'healthy' children, reported in literature (93.12 ± 6.45) (Plint et al., 2003). The ASK questionnaire highlighted that across all seven sub-categories, the lowest average was reported for the sub-category 'play' (average 55.6 ± 33.1). As previously discussed, 'play' is typically unstructured, spontaneous and without adult involvement (Vance and Eiser, 2002). It is likely for patients to experience increased hospitalisation and increased dependence on parental figures, and therefore it is not surprising that patients report the lowest values for this section. Play and PA are closely associated, and all children should engage in unstructured, semi-structured and structured play to best promote physical literacy, motor skill proficiency, health-related fitness, development and fun (Barreiro and Howard, 2017). For such reasons, it would be beneficial for patients to have the opportunity to 'play' whilst in hospital, whether this is facilitated by a physiotherapist or an exercise therapist or through patients having sports equipment to engage with in a more spontaneous manner. In addition, standing skills (75.6 ± 32.4) and locomotion (77.0 ± 32.5) was also in the bottom four sub-categories, highlighting that children may have more difficulty with such activities over other sub-categories including dressing and personal care. This not only highlights the decline of physical function for paediatric patients which has been similarly concluded by others (Peterson and Darling, 2018), but also expresses the need for better PA provisions. For the five youngest patients in the study, it was noted that parents helped with the completion of the questionnaire and is questionable whether this may affect the validity of results. However, Young et al. (2000) reported a strong concordance between child and parent report and concluded that the questionnaire is generalisable for parental completion for children with cognitive limitations.

5.6 PedsQL Questionnaire

PedsQL scores varied between all participants (pre average 64.4 ± 19.3 , post average 57.9 ± 21.5 , range 34-89), which was expected due to the lack of control of cancer types, stage of cancer, stage of treatment and health status, along with other multiple variables that may affect HRQoL (Momani et al., 2015). Varni et al. (2002) reported average PedsQL scores for oncology samples ($n=219$) being 72.2 and healthy samples ($n=401$) of children being 83.0. For this study mean PedsQL (pre and post intervention) were below both averages found by Varni et al. (2002). No significant difference between pre and post intervention was found; however, failure to find a significant difference may be as a result of other psychological and physiological factors, and this should not be fully attributed to this study alone. Although possible, it would be unlikely to see any significant change in HRQoL after only three sessions of PA. This however does raise two important question 'How much PA is required to see a change in HRQoL in paediatric patients with cancer?' and 'would this vary depending on whether psychological and physiological dimensions being assessed independently?'

When discussing perceptions of exercise with all participant groups, both psychological and physiological benefits were cited. Interestingly, staff cited seventeen psychological, six physiological and ten general benefits. Parents cited eight psychological and five physiological benefits, and patients cited seven psychological, six physiological and two general benefits of exercise. In all participant groups psychological effects were the most cited, perhaps implicating the added importance of psychological health in this population. For such reasons, future studies may focus on whether psychological or physiological quality of life is more affected with regular engagement in PA.

5.7 HR, RPE and Fun Scores

HR

HR was one measure used to determine exercise intensity. Previous literature has recommended that childhood cancer patients exercise at 50-70% age predicated HR_{max} (Kilka et al., 2018; San Juan et al., 2007; San Juan et al., 2008). In addition, Hartman et al. (2009) reported the safe execution of short bursts of high intensity exercise, twice daily. Out of the twelve sessions where HR was reordered, the average HR was between 50-70% of predicted HR_{max} for eleven sessions. HR_{peak} as a percentage of predicted HR_{max} was between 50-70% for eight sessions and >70% for four sessions. It has been

advised that for anaemic patients, HR at rest and with execution will be higher, as a result of decreased efficiency of the blood ability to carry oxygen; for these patients monitoring both HR and RPE concurrently seems most appropriate. In addition, for younger patients, where the HR monitor strap did not fit properly, the main investigator was more reliant on RPE and observation to determine exercise intensity.

RPE

For RPE all patient expressed RPE between 2-4 for the warm-up and cool-down and 4-6 for the main activity. These figures showed that the warm-up and cool-down were low intensity whilst the main activity was performed at a moderate intensity. The overall RPE for the whole session was reported between 4-6, again indicating a moderate intensity. No RPE values above 6 were reported by patients, indicated that a high intensity was not reached. With both the HR and RPE data, the results indicate that it is feasible to conduct exercise sessions with limited space and equipment, within a clinical setting and reach a moderate exercise intensity. It is this intensity which has been reported to provoke improvements in health-related fitness (HRF) and more specifically cardiorespiratory fitness, strength and physical function in paediatric cancer patients (Chamorro-Viña et al., 2014).

Fun

Patients also gave a score on the fun scale, scores between zero (n=16) and two (n=5), were recorded, for every session, highlighting the greatest levels of fun. Fun is an important goal for PA and a lack of fun has been considered a critical reason why children and teenagers stop participating (Garn and Cothran, 2006; Visek et al., 2015). Five dimensions of PA have been reported to alter children's attractiveness to PA: a) liking of vigorous exercise, b) fun experienced through activity, c) perceived importance of PA, d) peer acceptance of game, e) fun of physical exertion (Butt et al., 2011). Visek et al. (2015) also highlighted the effect of 'barriers to fun' and how these can affect individual PA involvement. Aiming to increase fun and reduce such individual barriers within activities may not only prevent boredom for patients but is more likely to promote long-term PA participation (Aldiss et al., 2009). Takken et al. (2009) also raised the point that increased fun may increase compliance to an exercise programme and this relationship should be more closely examined in future studies.

5.8 Patients (Post)

Patient intervention feedback

All seven patients expressed that they enjoyed the sessions with five references to 'fun', one reference to 'distraction' and one reference to 'support/help'. The importance of fun has already been discussed above and may positively affect future engagement in similar studies. Secondly, distraction is another positive response and with regards to exercise has been associated with an anti-depressant effect (Craft, 2005). In addition, all patients stated that they would like similar interventions to be offered on a regular basis, again highlighting the acceptability from patients and the potential for future studies or implementation. There was a distribution between the three types of sessions and patients favourite session with four preferring the games-based session, two preferring the technology-based session and one enjoying the conditioning-based session. Such findings would suggest that exercise sessions should be individualised for each patient to match preference to increase enjoyment and fun (Butt et al., 2011), and to control an intervention to one type of exercise may not best promote PA. This may be a critical reason why significant differences may not have always been found in other paediatric exercise studies where exercise programmes have been more restricted in terms of exercise or game choice for participants. In addition to this, diversified participation should not be overlooked for cancer patients as a means to best promote motor skill development and physical literacy, especially in younger patients (Mostafavifar et al., 2012). While the implementation of a regular exercise programme within a healthcare setting seems a beneficial way to support patients and increase PA. The continuation of exercise at home is important and is also an area worthy of investigation. It is important for patients to not solely engage with structured and instructor-led PA and instead regularly engage in PA at home, in order to elicit the benefits discussed previously. For this to happen, it seems important to educate parents, schoolteachers and coaches to encourage and support safe and appropriate PA at home and school. The use of technology also seems beneficial to promote, for example 'Change 4 Life' 10 minute shake up games and videos (NHS.uk, 2019), which could be further developed to promote inclusivity of childhood diseases.

5.9 Parents/Carers (Post)

Parent intervention feedback

Similarly, all parents expressed that their child enjoyed the sessions, with nine different positive psychological impacts being referenced, the greatest referenced impact being an "increase in

happiness" (n=7). Happiness has been previously associated with longevity in health populations (Veenhoven, 2007), and although not well investigated within an oncology population, there is increasing interest in using happiness as an index for quality of life (Tay et al., 2014). This is a promising finding because it may indicate that regular engagement in a similar intervention could improve psychological well-being over time. No negative impacts were referenced highlighting the acceptability from parents. Three parents reported a change in perception surrounding exercise, with reference to use of space and the manageability of exercise. It is interesting that such a short intervention could change perception, and future interventions should perhaps include more parental involvement to provoke parental encouragement that Sánchez-Miguel et al. (2013) highlighted the importance of.

5.10 Healthcare Professionals (Post)

HCP intervention feedback

All HCPs gave positive response to implementation of regular exercise sessions conducted on the ward, highlighting acceptability of staff. Staff gave mixed responses in terms of frequency of such provision. Although provisions were mixed, the general response was 'every(week)day if possible'. Children on the ward have individualised treatment which can vary considerably and change regularly. If this provision was not offered regularly, some children would not be able to engage and therefore it is questionable whether this is promoting fair access to care.

No HCP reported concerns about the intervention; however, there was reference to checking regularly with the medical team and the lack of space on the ward. Regularly engaging with all HCPs highlights the importance of a multi-disciplinary communication strategy approach within the healthcare setting (Kilka et al., 2018). With regards to space, this was a considerable challenge during both this intervention and looking forward. It has been suggested that ideal facilities for such interventions would include a 100m² sports hall with the addition of a 30m² fitness room gym. (Marriott, 2018). This recommendation is unattainable at The John Radcliffe Hospital, with no designated space on the ward for such activities. It is not impossible to conduct exercise sessions with limited space, which has been demonstrated both in the study and a previous study that investigated good practice examples of paediatric exercise interventions in Germany for paediatric cancer patients (Marriott, 2018). The exercise therapist running the sessions should be flexible with exercise ideas and able to adapt to the space available at that time, for example jumping activities may be chosen over running activities if

space is limited. Likewise, sessions on the Nintendo Wii also relies on small amounts of space, and televisions can be moved on portable stands. In addition, all staff expressed that the intervention fit in with the daily routine of the ward and was not disruptive, highlighting the study's feasibility. It is important to consider other HCPs work on the ward and children's treatment routine as they are likely to have numerous appointments. The therapist running the sessions must take special consideration of this point and check when is a suitable time for the child and family involved.

Witnessing change(s) in patients and parents

A positive change in patient and parent mood was witnessed by five nurses out of the thirteen participating HCP. It is interesting that only nurses witnessed this change, and may be because nurses have a lot of contact with patients over the day. In addition to this, one consultant highlighted that staffing rotas often change, resulting in patients having contact with many different HCPs.

"...this has raised an important point... there is a different consultant on every week and different nurses every day and maybe people are not aware of when they are doing the exercise or not have worked with children who have engaged so it is hard to know if they have benefitted from it."

This again highlights the importance of including all HCP into the conversation regarding exercise. It is for this reason that all HCP that interact with patients and families should be educated about PA, as it may be nurses, psychologists or play therapists that in fact spend more face to face time with patients and may have more time to convey such important information.

5.11 Physiotherapists (Post)

Physiotherapists intervention feedback

One physiotherapist noticed a positive change in patients and expressed "they have come to you wanting more". This type of response in patients is an important observation, as it gives an indication of patient's future participation if such intervention was implemented. While this may be true, it is important to not only focus on those already engaged, and also consider uninterested patients in any future implementation. Also, it was noted that patients were able to take part who would normally meet the requirements for physiotherapist involvement. For patients, this can have enormous benefits and promotes fair access to PA for patients, if implemented long-term. Although patients may

not have severe mobility problems at a given time in treatment PA can help to prevent further loss in physical performance (Antwi et al., 2019), and improve other areas of physiological and psychological health.

In addition, both physiotherapists gave a positive response to the idea of offering a similar intervention on a regular basis for patients, and did not report any concerns over the intervention. Only two physiotherapists were included in this study, making it difficult to be able to determine more general perceptions and opinions of the physiotherapy department at the JR. There did not seem to be any resistance from either physiotherapist, during the length of the study or in the intervention feedback. This can be seen as promising for any future implementation or a multi-disciplinary approach, however longer duration interventions must be carried out to better determine this relationship.

5.12 Multi-disciplinary Approach

Although in this study, physiotherapists and other HCP have been discussed separately, the need to consider a multi-disciplinary approach is important. In many healthcare systems, a multidisciplinary approach is adopted, and a central part of cancer care is important to encourage positive change in care management (Soukup et al., 2018). With regards to the promotion of PA it is unfair to expect physiotherapists to take sole responsibility in encouraging patients to be more active. It is important to change this attitude and instead all HCPs must play a role in supporting patients.

*‘...(I refer) them to the physio and then let the physio’s do the actual encouragement’
(Consultant)’*

In addition, a previous study investigating good practice examples of exercise interventions for paediatric cancer patients in Germany (Marriott, 2018) reported that it is exercise professionals, often with a degree in Sport (& Exercise) Science, that deliver this provision. Standal et al. (2018) also reported the specialised contribution of sport pedagogues in adapted PA programmes in Norway. Knowledge of appropriate and safe adaptation, strength and conditioning, principles of training and game delivery is imperative for adapted PA interventions. Standal et al. (2018) also highlighted the need to “focus on the capacity, on the opportunities rather than the limitations” of patients, which is an important attitude to adopt when working with children with cancer.

As discussed above, the importance of including consultants, nurses and clinical psychologists alike is paramount due to the range of individuals involved within a child's care, spending varying degrees of time with families. If we only rely on one individual within a patient's care-team to deliver and promote this information, it is likely to result in a lack of continuity for the patient and likely to reduce both patients and parents perceived importance of PA. Kilka et al. (2018) reported that for safe and effective PA programmes a multifactorial approach is necessary, with input from cardiology, pulmonology, orthopaedics, psychology, sports medicine and exercise oncology specialists. Education and engagement in organisations such as Moving Medicine (2019), for example, may give HCP the knowledge and confidence to prescribe and encourage PA. 'Moving Medicine' is an online resource which give evidence-based practical advice to clinicians and encouraging conversations with patients surrounding increasing PA, enforcing the ideology that a conversation as little as 3-5 minutes with a physician can positively impact PA levels (Calfas et al., 1996). One study has reported that healthcare professionals must correct misconceptions about PA and advocate regular PA with the aim of enhancing physical and psychological well-being for patients (Li et al., 2013). HCP should utilise recourses such as 'Moving Medicine' more frequently to improve education within this multi-disciplinary approach.

As previously mentioned, parents additionally play a vital role in PA promotion away from a clinical setting, and should also be included in this approach. All parents stated that they knew the benefits of exercise with both physiological and psychological benefits referenced. It was reported across all parents that this knowledge was as a result of their own personal experience rather than any information or education received since their child's cancer diagnosis. Takken et al. (2009) and Winter et al. (2009) reported that parents of childhood cancer patients should be better educated on the benefits of exercise. Keats et al. (2006) combined educational sessions and a group exercise session for patients. Adherence of the intervention was high (81.5%) and significant improvements in QOL, fatigue and physical fitness were reported. Li et al. (2013) also found that combining education with adventure-based training was effective at promoting regular PA in survivors of childhood cancer and increasing self-efficacy. Booklets such as 'Keeping Active During and After Treatment' published by the Children's Cancer and Leukaemia Group (2017), should also be distributed to patients at the beginning of treatment, and families should be encouraged to follow the presented advice. Education for all involved in a child's cancer care seems an important place to start for promotion of PA; however, to increase the actual execution of PA it has been recommended for patients to have regular contact with an exercise therapist who can educate, encourage and run exercise sessions for patients (Götte et al., 2014).

German models have demonstrated that regular exercise interventions for childhood cancer patients are possible with a varying degree of infrastructure, hospital facilities, equipment, staffing and funding (Marriott, 2018). However, perhaps less transferrable from international models is staffing and funding due to differences in the healthcare systems. For these reasons, regular funding for implementation must be strongly considered if the current care model is to be adapted to include regular physical therapy by a trained exercise therapist.

5.13 Feasibility and Acceptability

Both feasibility and acceptability have been established. Over 50% of eligible patients took part in the study and only positive responses were given from all patients, parents, HCPs and physiotherapists regarding the study and future implementation on a regular basis. No adverse effects were witnessed, highlighting the ability to safely deliver exercise interventions within a healthcare setting and find space within an already limited environment. These results mirror the findings of a systematic review of PA interventions for children during the intense phase of treatment (Grimshaw et al., 2016). There is evidence that these interventions were accepted by both patients and parents, safe and successfully implemented (Grimshaw et al., 2016). The positive results from this study and previous studies highlights the possibility for long-term implementation of exercise therapy within this ward, and highlighting the need for future studies looking at PA provision of paediatric cancer patients and families.

Future studies should focus on concluding:

- The effect of PA and different dimension of HRQoL
- The relationship between diversified PA programmes and physiological and psychological well-being of childhood cancer patients
- The importance of fun within PA for children with cancer
- Perceptions of unengaged patient and parents and PA
- Parental involvement and encouragement of PA
- Post-treatment access to PA provisions and physical rehabilitation for patients
- The use of new technologies in long-term implementation outpatient rehabilitation.

Recommendations with regards to policy are to develop PA guidelines for paediatric oncology patients and better disseminate these within a healthcare setting. With regards to development of practice, it

is important to adopt a stronger multidisciplinary approach to PA and regular encouragement of PA from all HCPs. In addition, regular supervised PA interventions within a clinical setting should be strongly considered to increase PA levels for childhood patients during treatment.

5.14 Study Limitations

This study has some limitations. Firstly, the number of participants was small and heterogenous (e.g. diagnosis, age), leading to questions regarding generalisability. Secondly, it is unlikely to see any significant changes to psychological well-being after only three PA sessions and more sessions over a longer duration of time would be beneficial to assess this relationship. Thirdly, the ASK questionnaire is validated for children between the ages of 5-15 years (Young et al., 2000); however, for this study all participants (5-17 years) completed this questionnaire. This is due to the fact that there does not seem to be an evidence-based measure that encompasses children up to 18 years old and there is a need for the development of validated tools for older adolescents. In addition, some patients required more help from parents when completing both the ASK and PedsQL questionnaire, questioning the validity of results. However, this is somewhat unavoidable because of patients' different levels of cognitive development, mostly associated with age.

The use of self-reported data and qualitative-based questions does highlight for the potential of recall bias and over-reporting. In addition, it must be noted that the deliverer of the intervention was also the one conducting the interviews and evaluating the response, which could have resulted in some degree of both researcher and participant response bias. Although not a possibility for this study, future studies should consider employing different researchers for the different stages of the research process.

Furthermore, there were inconsistencies with the timing between the exercise sessions. The timing of each PA session varied between patients and between sessions. This was somewhat unavoidable due to the unpredictable nature of childhood cancer, with particular consideration of treatment protocols and day to day variability of side effects. Inconsistencies in patient health and patient's dedication to other medical and non-medical appointments must be considered for either future studies or long-term implementation.

Monitoring of HR was inconsistent, mostly attributed to the arm strap not fitting all patients, especially the younger patients. A more reliable or individualised method should be considered for future research or implementation.

6 Conclusion

The potential importance of PA for childhood cancer patients, during and after treatment, has been well-established through existing literature. However, the need for better education, evidence-based guidelines and implementation needs further exploration and development. Although the number of participants, exercise sessions and data collected for this study were limited, the results seem paramount for further development for a better PA pathway for children and adolescents in the UK. Both feasibility and acceptability have been established and only positive responses were made by all participants. While it is imperative to consider the environment, this study has suggested it is possible to elicit moderate intensity levels with limited space and equipment within a clinical setting with no specific designated exercise space. A longer intervention would be needed to better determine whether there is a significant impact on patient QoL as a significant difference in PedsQL was not concluded in this three-session study. The positive impacts stated by all participant groups and the absence of adverse effects and disruption highlights the potential for future implementation of PA programmes in the UK.

While the potential for improving provisions seems encouraging, this does not exist without further investigative efforts to improve the current PA pathway. It has been concluded that there is not a consistent level of PA support and advice for patients, with some receiving far greater than others. This gap needs to be reduced to promote fair access to care, encourage healthy habits and reduce physiological and psychological deficits associated with a sedentary lifestyle. To improve this, it would seem necessary to adopt a more multi-disciplinary approach. While all participant groups recognised benefits of exercise, it is strongly questionable whether this transcribes into the physical execution of PA, with preliminary results suggesting it does not. For this reason, education of all HCPs, parents and patients' needs to be more closely examined to improve perceptions and decrease fear and misconceptions of PA which have been reported to affect participation. HCP should utilise the 'Moving Medicine' online resource, as well as the evidence-based recommendations published in the 'POEM' (2014) (see additional material). The educational booklet published by the 'Children's Cancer and Leukaemia Group' (2017) (see additional material) should be distributed to all patients and families as an educational tool.

While research is vitally important, next steps should also focus on the implementation of exercise therapy on the ward. This study highlights that it is feasible, accepted and safe to implement an exercise programme onto the paediatric oncology ward at The John Radcliffe Hospital, and future

implementation is supported and encouraged by patients, parents and HCP alike. HCP support ranges from staff nurse to consultant paediatric and adolescent oncologist (Deputy Divisional Medical Director) who are eager to implement regular exercise therapy into standard care for paediatric oncology patients. In addition, during this project, a collaboration with 'Moving Medicine' has been established to develop specific paediatric oncology exercise recommendations, which should also encourage future implementation and improvements to existing pathways for this population.

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Appendix

(A) CHILD INFORMATION SHEET

Hayley is doing a project. She wants to ask children who have been on Kamran's ward whether they have been able to do any sports or exercise during their time in hospital and whether playing games and sport is something they would like to be able to do when they are in hospital. This is because our team would like to think about how we can help children and their families in the future.

We are wondering if you would be ok to answer a few questions about what you think.

Hayley will ask you some questions about how your exercise experience during your time in hospital. This would be for up to 20 minutes. You will then be offered three exercise sessions where you can try out different games and sports. Each session will last 30- 45 minutes and you can choose what you would like and not like to do. Hayley will then ask you whether you enjoyed the sessions, what you liked the most and least and whether this is something that you would like to do in the future when you stay in hospital. This will take around 20 minutes.

When Hayley has finished speaking to different children and their families from Kamran's ward, she will write a report for her University and for the hospital.

Hayley will audio record the interview with you and your parent/ carer, which will then be typed up.

Hayley will also make sure that what you say in the interview is private. However, if you say something that makes Hayley worried about you or someone else being safe then she may need to speak to someone else about it.

You can say no to doing this project and no one will mind. You can also change your mind at any time.

If you would like to take part in the project and speak to Hayley, tell someone in your family so that they can arrange for her to come and speak to you 😊

(B) ADOLSCENT INFORMATION SHEET

Title of Study: **Feasibility and Acceptability of an Exercise Intervention for Childhood Cancer Patients.**

I would like to invite you to take part in a project. Before you decide whether you would like to take part, you need to understand why the project is being done and what it would involve you doing.

What is the purpose of the project?

It is well understood that regular exercise is important for physical and mental wellbeing. It is very common that whilst receiving cancer treatment, you are likely to be less active than you had been before your diagnosis. This is likely due to the side effects associated with cancer treatment or the amount of time spent in hospital. Exercise has been shown to reduce cancer related fatigue (tiredness), increase bone density and prevent muscle weakness in such populations during intensive treatment.

The thoughts and idea of patients receiving treatment on Kamran's Ward are really important for us to be able to improve the care of future patients on the ward.

Do we have to take part?

It is entirely up to you whether you would like to take part. You would be free to change your mind at any time and you do not need to tell us why. Nobody will think any differently of you if you decide that don't want to take part.

What will happen next?

If you would like to take part, Hayley will ask you some questions about how your exercise experience during your time in hospital. This interview would last approximately 20 minutes. You will then be offered to participate in three exercise taster sessions where you can try out different games and sports. Each session will last approximately 30-45 minutes. After the three sessions Hayley would like to speak to you again to see what you thought about the sessions, this will take about 20 minutes and be similar to the first interview, just with some different questions.

When Hayley has finished speaking to different children and their families from Kamran's ward, she will write a report for her University and for the hospital. If you would like to take part, speak to Hayley or somebody in your family who can speak to Hayley about arranging a time for her to speak with you.

Will taking part in the project be kept confidential?

Hayley will also make sure that what you say in the interview is private. However, if you say something that makes Hayley worried about you or someone else being safe then she may need to speak to someone else about it.

What will happen to the results of the research project?

The findings of the report will be submitted to Oxford Brookes University as part of a piece of university work. The findings will also be presented to the Kamran's ward where there will an opportunity for you to attend a short presentation that will discuss the findings. You will not be identified by name in the report or presentation.

Who is organising the research?

The project is being conducted by Hayley who is a Master's student at Oxford Brookes University. The project is being supervised by the lead of sport and coaching sciences at Oxford Brookes University.

What if there is a problem?

If you have a concern about any aspect of this project, please speak to Hayley or somebody in your family who will be able to pass your questions onto Hayley.

Thank you for reading.

Hayley Marriott, MSc by Research Student
Contact: 18009463@brookes.ac.uk

Supervised by: Dr Peter Wright
Contact: pwright@brookes.ac.uk

(C) PARENT/CARER INFORMATION SHEET

Title of Study: **Feasibility and Acceptability of an Exercise Intervention for Childhood Cancer Patients.**

Dear Parent/ Carer,

I would like to invite you and your child to take part in a project. Before you decide whether you wish to take part, you need to understand why the project is being done and what it would involve for you and your child. Please take the time to read the following information carefully.

What is the purpose of the project?

It is well understood that regular exercise is important for physical and psychological wellbeing. It is very common that whilst receiving cancer treatment, you are likely to be less active than you had been prior to diagnosis. This is likely due to the side effects associated with cancer treatment or the amount of time spent in hospital. Exercise has been shown to reduce cancer related fatigue increase bone density and prevent muscle weakness in such populations during intensive treatment. To increase physical activity during cancer treatment, current physical activity advice and support that patients receive as part of standard care must be firstly assessed. The thoughts and perception of patients and parents are crucial to determine the acceptability of implementing an exercise intervention within the ward as a pilot study in the future and any implementation as a standard therapy.

Do we have to take part?

It is entirely up to you and your child whether you take part. You would be free to withdraw at any time, without giving a reason. This will not impact on you or your child's involvement with the service.

What will happen next?

We would encourage you to speak to your child about the project and depending on their age you may wish to read through the modified information sheet for children. Please make them aware that this is not part of their treatment or involvement with the service, and that there is no pressure to be involved. Should you both wish to take part, you will both be required to take part in an interview. Firstly, your child will be interviewed for 20 minutes, and will be structured only around their experience with exercise. Your prompting and support may be beneficial. You will then be interviewed for approximately 20 minutes to talk about how your perceptions of exercise during cancer treatment. Your child will then be offered three exercise taster sessions, these will include a game-based session, Wii session and a conditioning session. After the three sessions you and your child (in separate interviews) will be asked your thoughts surrounding the taster sessions. This final interview will take approximately 20 minutes. The interviews will be audio taped for transcription purposes.

Will taking part in the project be kept confidential?

All of the information collected will be kept confidentially, however limits to this confidentiality do apply. If the MSc by research student is concerned about the safety and wellbeing of you, your child, or anyone else mentioned during the interview they may have to break confidentiality and discuss this with someone else in the team in line with duty of care.

You and your child's anonymity will be preserved at all times. If you withdraw from the project, all the information and tape recordings collected from you, to date, will be destroyed and your name removed from all the project files.

What will happen to the results of the research project?

The findings of the report will be submitted to Oxford Brookes University as part of an MSc by research thesis. The findings will also be presented to the Kamran's ward where there will an opportunity for you to attend a short presentation that will discuss the findings. You or your child will not be identified by name in the report or presentation. Any identifiable information will be changed to preserve your anonymity. Permission will be requested to use direct quotations. Findings will be presented as a summary of all participants' feedback to give an overall picture of people's experiences. Audio recordings will not be included in the report or presentation.

Who is organising the research?

The project is being conducted by an MSc by Research student at Oxford Brookes University. The project is being supervised by the lead of sport and coaching sciences at Oxford Brookes University.

What if there is a problem?

If you have a concern about any aspect of this project, please contact me on the email address below and I will do their best to answer your questions. If you remain unhappy and wish to speak to someone else, you may contact the MSc by research supervisor (please find all contact details at the bottom of this document).

Should you both wish to discuss further, or make arrangements for the interview, please contact me via email or telephone.

Yours sincerely,

Hayley Marriott, MSc by Research Student
Contact: 18009463@brookes.ac.uk

Supervised by: Dr Peter Wright
Contact: pwright@brookes.ac.uk

(D) ADULT INFORMATION SHEET (MEMBER OF STAFF)

Study title

Acceptability of an exercise intervention for childhood cancer patients.

Invitation paragraph

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

The background and the aim of the study should be given here. You should say how long the study will run and outline the overall design of the study.

It is well understood that regular exercise is important for physical and psychological wellbeing. It is very common that whilst receiving cancer treatment, you are likely to be less active than you had been prior to diagnosis. This is likely due to the side effects associated with cancer treatment or the amount of time spent in hospital. Exercise has been shown to reduce cancer related fatigue increase bone density and prevent proximal muscle weakness in such populations during intensive treatment. To increase physical activity during cancer treatment, current physical activity advice and support that patients receive as part of standard care must be firstly assessed. The thoughts and perception of staff are crucial to determine the acceptability of implementing an exercise intervention within the ward as a pilot study in the future and any implementation as a standard therapy.

Why have I been invited to participate?

You have been asked to participate in the study as you are a member of staff working on Kamran's Ward at the John Radcliffe Hospital and your feedback matters.

Do I have to take part?

It is up to you to decide whether or not to take part in this research study. If you do decide to take part you will be given this information sheet and be asked to give your consent. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

Whether you participate or not does not have any impact on your professional development.

What will happen to me if I take part?

If you decide to take part in the study, you will be asked to take part in a short interview (up to 30 minutes) where you are going to be asked questions about current exercise offers on the ward and your perceptions of regular exercise for childhood cancer patients. The interviews will be audio recorded, with your permission.

What are the possible disadvantages and risks of taking part?

The interview will take up to 30 minutes to complete. However, will be carried out at a time convenient for you. There are no other associated disadvantages or risks.

What are the possible benefits of taking part?

By taking part in the study, you will be helping to improve knowledge regarding current exercise support for childhood cancer patients and general perceptions on exercise for this population. This information will help to develop a proposed plan for any future pilot studies.

Will what I say in this study be kept confidential?

All information that is collected will be kept strictly confidential. Your privacy and anonymity will be ensured in the collection, publication and storage of research material.

What should I do if I want to take part?

If you would like to take part in the study, please contact Hayley Marriott (18009463@brookes.ac.uk) who can schedule an interview at a convenient time for you.

What will happen to the results of the research study?

The information gathered will be used for a thesis for a MSc by Research. A copy of the findings will be supplied to participants on request. Requests should be made to 18009463@brookes.ac.uk.

Who is organising and funding the research?

Hayley Marriott, (MSc by Research student in the faculty of Health and Life Sciences at Oxford Brookes University).
Dr Peter Wright (project supervisor).

Who has reviewed the study?

The research has been approved by the University Research Ethics Committee, Oxford Brookes University.

Contact for Further Information

Hayley Marriott (18009463@brookes.ac.uk)

Dr Peter Wright, project supervisor (pwright@brookes.ac.uk)

If you have any concerns about the way in which the study has been conducted, they should contact the Chair of the University Research Ethics Committee on ethics@brookes.ac.uk.

Thank you

Thank you for taking time to read the information sheet.

(E) CHILD ASSENT FORM

Title of Study: **Feasibility and acceptability of an exercise intervention for childhood cancer patients**

Name of researcher: **Hayley Marriott (MSc by Research Student)**

Please tick the box if you agree:

I have read the information sheet and have had the opportunity to ask questions about the study

☐

It is OK to talk to Hayley and participate in the exercise taster sessions

☐

It is OK for Hayley to write a report for her University about the things we talk about

☐

It is ok for my words to be used in the report

☐

I understand that I can stop taking part in the study at any time and this will not affect my care in hospital in any way

☐

Signed:

Full name of participant:

Date:.....

Full name of Researcher.....

Signed:.....

Date:.....

(F) PARENT/CARER CONSENT FORM FOR RESEARCH INVOLVING CHILDREN AND YOUNG PEOPLE

Title of Study: **Acceptability of an exercise intervention for childhood cancer patients**

Name of researcher: **Hayley Marriott (MSc by Research student)**

PART 1: MY CHILDS INVOLVEMENT

(Form to be signed by person with parental responsibility for child or young person under 16 years).

I have read the information sheet and I have had the opportunity to discuss it/raise any questions with the MSc by research student, (Hayley Marriott) and I understand the contents.

Based on the information I have received, I give my permission for the child for whom I am responsible to be involved in this research.

I understand that their two interviews will last up to 20 minutes each. My child will be given the opportunity to have breaks should they need.

I agree to the interview to be audio taped for the purposes of transcription (this audio will be stored securely and deleted when the research has been submitted and completed in September 2019).

I give my permission that my child whom I am responsible to participate in the three exercise taster sessions and understand that they can stop the session at any time.

I understand that any information my child provides is confidential, and that no information they disclose will lead to the identification of them or any other individual in the reports on the project.

All of the information collected will be kept confidentially

I understand that if the MSc by research student is concerned about the safety and wellbeing of me, my child, or anyone else mentioned during the interview they may have to break confidentiality and discuss this with someone else in the team in line with duty of care.

I give my permission for the MSc by Research student to submit an anonymised account of their work with the child or young person for whom I am responsible to Oxford Brookes University.

I understand that I can withdraw my permission at any time and that this will not affect the service that my child receives.

Full name of child (PRINTED):

Full name of person with parental responsibility:

Signed:

Date:

PART 2. MY INVOLVEMENT AS A PARENT/CARER

I have read the information sheet and I have had the opportunity to discuss it, raise any questions with the MSc by Research student and I understand the contents.

I understand that my two interviews will last up to 20 minutes each.

I agree to the interview to be audio taped for the purposes of transcription (this audio will be stored securely and deleted after transcribing)

I understand that any information I provide is confidential, and that no information that I disclose will lead to the identification of myself or any other individual in the reports on the project.

I give my permission for the MSc by Research student to submit an anonymised account of their work to Oxford Brookes University.

I understand that I can withdraw my permission at any time and that this will not affect the service that either me or my child receives.

Full name (PRINTED):

Signed:

Date:

(G) ADULT CONSENT FORM (ADOLESCENTS, PARENTS, STAFF)

Full title of Project: Feasibility and acceptability of an exercise intervention for childhood cancer patients.

Miss Hayley Marriott, MSc by Research Student 18009463@brookes.ac.uk
Dr Peter Wright, Project Supervisor pwright@brookes.ac.uk

Please initial box

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.

☐

3. I agree to take part in the above study.

☐

Please initial box

4. I agree to the interview being audio recorded

Yes

No

☐☐

5. I agree to the use of anonymised quotes when reporting the findings

☐☐

I agree that an anonymised data set, gathered for this study may be stored in a specialist data centre/repository relevant to this subject area for future research

☐☐

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

(H) DATE, TIME AND LOCATION OF EXERCISE SESSIONS

Patient	Session	Date	Time	Location
1	1	28 March 2019	11:45	Playroom
	2	16 April 2019	11:30	Playroom
	3	24 April 2019	11:15	Playroom
2	1	17 April 2019	10:30	Bay
	2	24 April 2019	11:45	Interview room
	3	08 May 2019	12:00	Playroom
3	1	23 April 2019	12:45	Empty bay
	2	03 May 2019	11:20	Playroom
	3	08 May 2019	13:15	Playroom
4	1	06 May 2019	11:00	Playroom
	2	09 May 2019	12:15	Playroom
	3	15 May 2019	12:15	Playroom
5	1	18 April 2019	13:30	Playroom
	2	03 May 2019	12:10	Teenage room
	3	10 May 2019	11:45	Playroom
6	1	11 April 2019	13:30	Interview room
	2	15 April 2019	13:50	Playroom
	3	18 April 2019	02:30	Day care
7	1	04 April 2019	12:30	Corridor
	2			
	3			
8	1	28 March 2019	13:00	Bay
	2			
	3			
9	1	23 April 2019	13:40	Interview room
	2	30 April 2019	02:30	Playroom
	3	03 May 2019	11:30	Playroom

(I) PATIENT PRE-INTERVENTION INTERVIEW QUESTIONS

1. What is your exercise and sport history?
(this will include which sports they have played, to what level and what sports they have enjoyed most)
2. What are your main side effects from treatment?
(side effects associated with cancer treatment and treatment stage)
3. Are you still involved in any exercise/sports? If not, why do they think that you are not?
4. Have you taken part in any PA, exercise or sports during your time in hospital?
(excluding physiotherapy)
5. How often do you see the physiotherapist on the ward?
6. Do you class physiotherapy as exercise?
7. Would you like to take part in any exercise or sports during you time in hospital?
If so, what sports or games would you like to do?
8. Why do you think that PA/exercise is important?
9. Do you exercise because you enjoy it or because it is good for you?

(J) PATIENT PRE-INTERVENTION INTERVIEW

1. Is there anything you would like to do that was not already included?
2. What did you enjoy the most (what session) and why?
3. Is there anything you did not enjoy?
4. Has your perception of PA/exercise changed?
5. Would you like exercise like this to be offered to you every week?
6. Any other comments?

(K) PARENT PRE-INTERVENTION INTERVIEW

1. Do you enjoy sport and exercise regularly?
(The individual will be asked how many times a week and what type of exercise if not already specified?)
2. Has your child's diagnosis affected your PA/exercise habits? And in what way?
3. What is your child's exercise history?
(What types of sports/activities, how many times a week? Their enjoyment?)
4. What is your child's experience of PA/exercise during their hospital visits/stays?
5. Do you know how PA/exercise can benefit your child during and after cancer treatment?
6. Do you encourage PA/exercise and sport during the child's time away from the hospital? What types of things do you do or encourage?
7. Do you have any worries associated with PA, sport and activities for your child?

(Further questions if overprotection seems to be a theme within their answer)

8. What would be the greatest concern/reason for you to avoid letting your child exercise or participate in sport?

(L) PARENT POST-INTERVENTION INTERVIEW

1. Do you feel your child enjoyed the PA/exercise sessions?
2. Do you feel that the exercise has had any impact on your child's emotional state?
3. Are there any concerns you have over the exercise sessions?
4. Has your perception of exercise for your child changed?
5. Would you like to see something like this regularly provided by the NHS, in addition to physiotherapy?
6. Do you have any additional suggestions of other activities that should be offered?
7. Any other comments?

(M) HEALTHCARE PROFESSIONAL INTERVIEW QUESTIONS

1. Do you exercise regularly? How many times a week? What do you do?
2. What are your perceptions of PA/exercising during treatment?
3. Have you received any training on the benefits of PA/exercise during and after childhood cancer treatment, if so what is the extent of this training?
4. Do you give patients and parents any PA/exercise advice? If so, what kind of advice?
5. Do you encourage patients to be active on the ward?
6. Do you have any concerns regarding implementing an exercise intervention on the ward?
7. What do you think about the idea of offering PA/exercise programmes on the ward on a regular basis?
8. How frequently do you think this provision should be?
9. Did the exercise sessions fit in with the daily routine of the hospital? If not, what did it interfere with?
10. Have you noticed any change in the emotional state of the children after the sessions?
11. Have you noticed any changed in the parents after the exercise sessions?
12. What potential benefit can you see for the children?
13. Any additional comments/suggestions?

(N) PHYSIOTHERAPIST INTERVIEW QUESTIONS

1. What is the frequency and duration of typical physio sessions for childhood cancer patients?
2. What types of PA/exercise do patients have access to?
3. What equipment do you typically use? Is this a standard set of equipment?
4. Is there any exercise equipment on the ward that patients can use during their time in hospital?
5. Is there holistic exercise incorporated into physio sessions?
6. Are patients educated about the benefits of staying active during and after treatment?
(How? By who? When?)
7. Do you find that overprotection is a common occurrence in parents?
8. Are parameters of fitness measured, recorded and monitored during a patient's course of treatment? If not, do you think this would be beneficial?
9. Have you noticed any change in the patients physical and emotional state/attitude after the exercise sessions (time since last seen)?
10. What do you think about the idea of offering exercise programmes on the ward on a regular basis?
11. What potential benefit can you see for the children?
12. Any additional comments/suggestions?

ID# _____
Date: _____

PedsQLTM

Cancer Module

Version 3.0 - English (United Kingdom)

CHILD REPORT (ages 8-12)

DIRECTIONS

Children with cancer sometimes have special problems. Please tell us **how much of a problem** each one has been for you over the **PAST MONTH** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

Over the **PAST MONTH**, how much of a **problem** has this been for you...

PAIN AND HURT (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I ache or hurt in my joints and/or muscles	0	1	2	3	4
2. I hurt a lot	0	1	2	3	4

NAUSEA (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I become sick to my stomach when I have medical treatments	0	1	2	3	4
2. Food does not taste very good to me	0	1	2	3	4
3. I become sick to my stomach when I think about medical treatments	0	1	2	3	4
4. I feel too sick to my stomach to eat	0	1	2	3	4
5. Some foods and smells make me feel sick to my stomach	0	1	2	3	4

ANXIETY ABOUT THE PROCEDURES (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Needles (i.e. injections, blood tests, intravenous drips) hurt me	0	1	2	3	4
2. I get scared when I have to have blood tests	0	1	2	3	4
3. I get scared about having needles (i.e. injections, blood tests, intravenous drips)	0	1	2	3	4

TREATMENT ANXIETY (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I get scared when I am waiting to see the doctor	0	1	2	3	4
2. I get scared when I have to go to the doctor	0	1	2	3	4
3. I get scared when I have to go to the hospital	0	1	2	3	4

WORRY (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I worry about side effects from medical treatments	0	1	2	3	4
2. I worry about whether or not my medical treatments are working	0	1	2	3	4
3. I worry that my cancer will come back or relapse	0	1	2	3	4

COGNITIVE PROBLEMS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard for me to figure out what to do when something bothers me	0	1	2	3	4
2. I have trouble solving maths problems	0	1	2	3	4
3. I have trouble writing school papers or reports	0	1	2	3	4
4. It is hard for me to pay attention to things	0	1	2	3	4
5. It is hard for me to remember what I read	0	1	2	3	4

Over the ***PAST MONTH***, how much of a ***problem*** has this been for you...

PERCEIVED PHYSICAL APPEARANCE (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I feel I am not good-looking	0	1	2	3	4
2. I don't like other people to see my scars	0	1	2	3	4
3. I am embarrassed when others see my body	0	1	2	3	4

COMMUNICATION (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard for me to tell the doctors and nurses how I feel	0	1	2	3	4
2. It is hard for me to ask the doctors and nurses questions	0	1	2	3	4
3. It is hard for me to explain my illness to other people	0	1	2	3	4

(P) Example of ASK Questionnaire

**full questionnaire in additional material.*

INSTRUCTIONS

This is a new booklet that asks you how often you think you could have done activities on your own last week. Try to remember the things you thought about doing at home, at school, and when you were with your friends. Record your answer by putting an X in the most correct box. Even if you never had a chance to do an activity last week, or had no reason to do one of the activities, you still must pick a box. Imagine how hard it would have been to do it last week, and pick the best box.

It is important that you answer all questions.

What do the answers mean?

<u>Answers</u>	<u>Meaning</u>
☐ with no problem	I could have done it with no pain, or difficulty, or extra time
☐ with little problem	I could have done it with a little pain, or difficulty, or extra time
☐ with a moderate problem	I could have done it with a medium amount of pain, or difficulty, or extra time
☐ with a big problem	I could have done it with a lot of pain, or difficulty, or extra time
☐ I could not	I could not have done it at all

Example:

Last week, Terry's mum dressed him on 3 days, because it would have been very painful for him to do. He dressed himself on the other 4 days because he didn't have any pain. So, over the week he had some bad days and some good days.

One of Terry's answers looked like this:

I think I could have fastened my clothes by myself . . .
(fastened means doing up buttons & zips)

- ☐ with no problem
- ☐ with a little problem
- ☒ with a moderate problem
- ☐ with a big problem
- ☐ I could not



Last Week . . .

1 I think I could have put toothpaste on my toothbrush then brushed my teeth by myself . . .

- ☐ with no problem
- ☐ with a little problem
- ☐ with a moderate problem
- ☐ with a big problem
- ☐ I could not

2 I think I could have used the toilet at home by myself . . .
(includes getting on and off the toilet)

- ☐ with no problem
- ☐ with a little problem
- ☐ with a moderate problem
- ☐ with a big problem
- ☐ I could not

3 I think I could have washed my whole body by myself . . .

- ☐ with no problem
- ☐ with a little problem
- ☐ with a moderate problem
- ☐ with a big problem
- ☐ I could not

4 I think I could have put my shirt on by myself . . .

- ☐ with no problem
- ☐ with a little problem
- ☐ with a moderate problem
- ☐ with a big problem
- ☐ I could not



(Q) PEDSQL SCORING FOR 5-7 YEAR OLDS

PedsQL™ 3.0 Cancer Module



The **Child and Parent Reports** of the **PedsQL™ 3.0 Cancer Module** for Young Children (ages 5-7), are composed of 26 items comprising 8 dimensions.

DESCRIPTION OF THE CANCER MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	2	1-2	1-2	Higher scores indicate lower problems.
Nausea	5	1-5	1-5	
Procedural Anxiety	3	1-3	1-3	
Treatment Anxiety	3	1-3	1-3	
Worry	3	1-3	1-3	
Cognitive Problems	4	1-4	1-4	
Perceived Physical Appearance	3	1-3	1-3	
Communication	3	1-3	1-3	

SCORING OF DIMENSIONS:

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
Scoring Procedure	<u>Step 1: Transform Score</u> Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. <u>Step 2: Calculate Scores by Dimensions</u> - If more than 50% of the items in the scale are missing, the scale scores should not be computed, - Mean score = Sum of the items over the number of items answered. <u>Total Score:</u> Sum of all the items over the number of items answered on all the Scales.
Interpretation and Analysis of Missing Data	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed. If 50% or more items are completed: Impute the mean of the completed items in a scale.

(R) PEDSQL SCORING FOR 8-18 YEAR OLDS

PedsQL TM 3.0 Cancer Module



The **Child and Parent Reports** of the **PedsQL TM 3.0 Cancer Module** for:

- Children (ages 8-12),
- Teens (ages 13-18),
- Young Adults (ages 18-25),

and the **Adult Report** (ages over 26)

are composed of 27 items comprising 8 dimensions.

DESCRIPTION OF THE CANCER MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	2	1-2	1-2	Higher scores indicate lower problems.
Nausea	5	1-5	1-5	
Procedural Anxiety	3	1-3	1-3	
Treatment Anxiety	3	1-3	1-3	
Worry	3	1-3	1-3	
Cognitive Problems	5	1-5	1-5	
Perceived Physical Appearance	3	1-3	1-3	
Communication	3	1-3	1-3	

SCORING OF DIMENSIONS:

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
Scoring Procedure	<u>Step 1: Transform Score</u> Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. <u>Step 2: Calculate Scores by Dimensions</u> • If more than 50% of the items in the scale are missing, the scale scores should not be computed, • Mean score = Sum of the items over the number of items answered. <u>Total Score:</u> Sum of all the items over the number of items answered on all the Scales.
Interpretation and Analysis of Missing Data	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed. If 50% or more items are completed: Impute the mean of the completed items in a scale.

(S) ASK QUESTIONNAIRE SCORING

SECTION 5: HOW TO ADMINISTER AND SCORE THE *ASK*®

The *ASK*® is intended to assess physical disability and to monitor functional change. It comes in two versions, one that measures what the child 'does do' in the child's usual environment (termed performance), and the other measures what the child thinks he or she 'can do' (termed capability). One or both versions may be administered to either a single child or a group of children. Children under the supervision of their parents may complete both versions, although those under nine years of age may require a parent to read the questions for them. Because a clinician need not (and should not) assist the child, the process is relatively inexpensive.

Note: the *ASK*® is intended for five to 15 year old children with a broad range of musculoskeletal disorders, ranging from muscular dystrophy to osteogenesis imperfecta. Although it may be applied to other very similar groups, the validity of the measure in these groups is unknown.

Environment for Administration

It is recommended that the assessment be sent home (either by mail in advance of the patient's clinic appointment or with the child following an appointment). It is believed that the accuracy of scores will be greater if the assessment is filled out in the environment where most daily activities take place.

Standardized Instructions

In order to make administration as consistent as possible, it is recommended that each child and parent be given a concise set of instructions. These instructions will vary slightly depending on whether one or both versions of the *ASK*® are being administered. Sample instruction cards that may be photocopied and included with the questionnaires are shown in Appendix II. Because all of the questions inquire about disability experienced 'last week', children should be encouraged to identify 'last week' and any special events in that week with the assistance of a calendar and their parents prior to completing the *ASK*®. Because of this referenced time period, the child must complete the assessment within one day but is allowed to take as many breaks as needed. Finally, children do not always have the same meanings for words as one might expect; thus, a white card should be inserted into each questionnaire to explain the meaning of the response options more clearly. Sample response option cards are included in Appendix III.

Time to Complete

The *ASK*® takes approximately 30 minutes to complete the first time, but it may take as little as 10 minutes to complete on subsequent administrations.

Aggregation of Items to Generate Summary Scores

Each of the 30 activity items is answered using a five point ordinal scale. On this scale, 4 points are allotted for the first response option ('with no problem' on the *ASK*®*c* and 'all of the time' on the *ASK*®*p*), 3 points for the second option, 2 points for the third option, 1 point for the fourth option and 0 points for the fifth option ('I could not' on the *ASK*®*c* and 'none of the time' on the *ASK*®*p*). Because the *ASK*®*c* inquires about perceived abilities, all children should be able to answer all of the questions. However, the *ASK*®*p* inquires about frequency of actual performance. Therefore, some items may not be applicable and the sixth response option (included only for activities that have the potential to be not applicable) should be selected. This

sixth response option does not contribute any points to the summary scale's numerator or denominator.

The 30 activity items (or however many were complete, less those that were not applicable) may be aggregated into a single summary score for performance and a single summary score for capability. This is achieved by averaging the responses then multiplying by 25 in order to convert the score to a 0 to 100 range, where high scores are indicative of a favorable outcome. There are also 6 information items asked on the questionnaire (e.g., assistive devices, degree of assistance), but these are not used in the aggregation process.

Summary Score = Average of all completed items x 25

(where items are scored on a 0 to 4 scale,
with 4 scored for best function)

Equivalent Alternative

Summary Score = $\frac{\text{Sum of all completed items} \times 25}{\text{Maximum possible score for those items}}$

Example 1: All items are applicable and are answered.

$$\begin{aligned} &= \frac{\text{Item 1} + \text{Item 2} + \dots + \text{Item 30}}{30} \times 25 \\ &= \frac{4 + 3 + \dots + 0}{30} \times 25 = \frac{86}{120} \times 25 \\ &= 71.6 \end{aligned}$$

If questions are not answered or are marked "not applicable" they are not included in either the numerator or denominator.

Example 2: Items 6 and 7 were marked not applicable.

$$\begin{aligned} &= \frac{\Sigma \text{Items 1 to 6} + \Sigma \text{Items 9 to 30}}{28} \times 25 \\ &= \frac{18 + 62}{28} \times 25 = \frac{80}{28} \times 25 \\ &= 71.4 \end{aligned}$$

These summary scores may be calculated by using an *ASK*® hand scoring sheet, or a computer spreadsheet can be used to enter and calculate summary scores when groups of children are being assessed.

NOTE: When data are to be manually entered into an excel spreadsheet, specifically the one provided by the developers of the *ASK*®, the raw values entered should be 1 for the first response option, 2 for the second, 3 for the third, 4 for the fourth, 5 for the fifth and 6 for the not-

applicable option, if present. This is necessary to keep the data entry process simple. Asking data entry clerks to reverse the scoring to 0, 1, 2, 3, 4 results in a high possibility of data entry errors. The excel spreadsheet is designed to work with raw scores in this format.

Eventually, it may be possible to use more sophisticated computer software to calculate norm referenced summary scores that are normally distributed. However, a stable Rasch model based on large numbers of subjects is required as a precursor to this last method, and sufficient data is not yet available.³

Interpreting Scores

This summary score gives a clinician a single numeric value that indicates a child's level of physical disability. How this number is used depends on whether or not a clinician is interested in assessing a child's physical disability status (how he or she is doing now), measuring change (how the child differs from the last time he or she completed the *ASK*®), or identifying specific areas in which therapy might be most effective (what items have the greatest discrepancy between capability and performance). It also depends in part on if a clinician is evaluating one child or a large group of children.

Assessment of Physical Disability Status

The *ASK*® expresses disability status as a summary score that lies between 0 and 100, where 0 indicates extreme disability. The numeric score may be compared to any one of several standards. Scores may be compared to data from children with a variety of musculoskeletal disorders collected at the Hospital for Sick Children (see Table 3), or to the clinician's own data collected from other children in the same clinical facility. When using the *ASK*® with a group of children, it is most time efficient to review the distribution of the summary scores as an indicator of the group's overall level of physical functioning, than to plot the scores to see if there are some children in the group who are doing much better or much worse than their peers.

Table 3: *ASK*® Summary Data from HSC Study of 200 Children

<i>ASK</i> ® performance		<i>ASK</i> ® capability	
Minimum Score	2	Minimum Score	12
Maximum Score	100	Maximum Score	100
25th percentile	42	25th percentile	58
50th percentile	72.5	50th percentile	83
75th percentile	90	75th percentile	94
Mean	66.1	Mean	74.7
Standard Deviation	26.96	Standard Deviation	23.69

Note: diagnoses include arthritis, fractures, muscular dystrophy, osteogenesis imperfecta, spina bifida, etc.

The mean *ASK*® scores for non-disabled children has not yet been determined. It is hypothesized that non-disabled children may not be as cognizant of their physical function as their disabled

³ If you decide to use the *ASK*® and were willing to share your data with us, your data would contribute to the reference sample (provided the ages and diagnostic groups were appropriate) thus enabling us to work towards norm referenced scores sooner.

peers. Since it is the limitations that make the activities salient and memorable, those without limitations may report 100% functioning without careful consideration of the questions. We expect that scores below 95 are indicative of disability, whereas scores between 95 and 100 may be questionable and may warrant further investigation. In all cases, serial measures over time are much more informative than a single score taken at one point in time.

Monitoring Change

The most important standard of comparison is the data from the same child collected earlier. For example, a series of measures may be collected to look at the natural progression of the disease or at the pattern of recovery after treatment. Since the assessment is self-report and may be administered through the mail, there is little cost associated with additional measurement points. The resulting data may be converted into summary scores. Summary scores for two key points in time may be subtracted to derive a change score, or multiple points may be plotted and analyzed by repeated measures analysis of variance to determine if there has been a statistically significant change during the time period. As described above, changes on individual items may be of interest to those evaluating small numbers of children. As with any assessment, however, it is important to determine whether the change is greater than that expected due to chance alone. Since the *ASK*® is highly reliable, changes of five points or more are indicative of significant change. The clinical importance of this degree of change is up to the individual clinician to determine.

Identifying Discrepancies Between Capability and Performance

If both the *ASK*®*p* and *ASK*®*c* are administered, the clinician may fill out the hand scoring sheets to determine if there is a discrepancy in what the child does do versus what the child thinks he or she is capable of doing. Identifying key activities in which there is a capability-performance discrepancy may provide insight into where to focus further clinical assessment. For example, if the child reports he or she can climb stairs but doesn't, a clinician may want to explore the environment in which he or she needs to climb stairs as part of the clinical assessment. In this respect the *ASK*® is intended to be an efficient data collection mechanism to evaluate therapy and to augment (not replace) traditional clinical assessment skills.

This type of analysis is primarily intended for application to data from individual children. It is too time consuming to examine individual item discrepancies for large groups of subjects.
