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PHYSICAL ACTIVITY INTERVENTIONS AND ASSESSING PEOPLE WITH INTELLECTUAL DISABILITIES

Section A: What factors are important for successful physical activity interventions for adults with intellectual disabilities?
Word Count 7905

Section B: Taxonomy and Classification in Intellectual Disabilities (ID): Measuring the health status of athletes with ID using an ICD based questionnaire

Overall Word Count 7963

Overall Word Count 15868 (plus 637 additional words)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

APRIL 2021

SALOMONS INSTITUTE
CANTERBURY CHRIST CHURCH UNIVERSITY

Acknowledgments

Summary

Section A

This narrative review focuses on exploring what factors are important for successful physical activity interventions for people with intellectual disabilities with the aim to improve their physical and mental health. The analysis of eleven papers suggests that social cognitive theory-based interventions which combine personal, contextual and behavioural elements over a sustained period of time may be important factors for successful physical activity interventions for people with mild-to-severe intellectual disabilities.

Section B

This section aimed to explore a more holistic conceptualisation of people with intellectual disabilities as an alternative to an IQ-centric approach, to include physical health, which is usually compromised in PWID. Starting from a previous pilot study which developed an International Classification of Functioning, Disability and Health (ICF)-based questionnaire, this project developed the questionnaire further and tested its psychometric properties. The project suggests that the questionnaire has good discriminatory abilities and meets all the psychometric standards tested, except for internal consistency, which required more data for a statistically robust analysis. The questionnaire has the potential to be used to facilitate classification in ID sport as well as the clinical sector, supporting clinicians with a tool that can aid a more holistic understanding of clients with ID.

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Section A: Literature Review

What factors are important for successful physical activity interventions for adults with intellectual disabilities?

Word Count: 7905

April 2021

Salomons Institute of Applied Psychology

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Abstract

People with intellectual disabilities (PWID) are more vulnerable to physical and mental health problems compared to the general population. Physical activity (PA) has been shown to have beneficial effects on both mental and physical health, and PA interventions have been developed to improve the health difficulties of PWID. Still, PWID are twice as likely to be inactive compared to the general population. This review aimed to analyse what factors are important for successful PA interventions for adults with intellectual disabilities (ID). A systematic search was conducted on the databases PsychInfo, CINHAL, Assia, Medline and Sportdiscus. Eleven papers met the inclusion criteria of the study. The heterogeneity of interventions adopted made it difficult to draw general conclusions. It is suggested that social cognitive theory-based interventions that integrate personal, contextual and behavioural aspects over a sustained period of time may be important for successful PA interventions for people with mild-to-severe ID. A one-size-fits all approach is likely to be unsuccessful, and further research is needed to understand how to best support PWID in making PA accessible, across the spectrum of disability.

1. Introduction

1.1 Intellectual disabilities

An intellectual disability (ID) is currently defined as an impairment in both cognitive functioning (conceptualised as an IQ lower than 70) and adaptive functioning (expressed in ability to live independently) present before the age of 18 (World Health Orgnisation, WHO, 2018). The term used to describe this condition varies across countries, for example with the UK using the term learning disability (LD). Since ID is the term that is used internationally (Bouras & Jacobson, 2002), this terminology will be adopted for this review.

1.2 A clinical classification of disability

Approximately 1.5 million people in the UK are reported to have an ID (Office for National Statistics, 2019). For clinical classification purposes, IDs are divided into four categories according to the level of severity; 'mild', 'moderate' or 'severe' and 'profound' (Fletcher, 2001). These categories are mainly defined based on the ranges of IQ levels. Although there is great variation within each category, a person with severe and profound ID often presents with a range of profound physical conditions alongside a very low IQ (van Timmeren et al., 2017). This usually results in this population requiring greater levels of social care because of health, mobility and communication needs (Kozlovski et al., 2011). The conceptualisation of ID is a product of societal tendencies to attempt to provide an explanation to phenomena or events, making the conceptualisation of ID and its corresponding classification a social construction (Dudley-Marling, 2004). The social model of disability (Oliver, 1996) refuses this theoretical classification of ID and focuses on the experiential aspect of the disability. This model proposes the problems of exclusion and oppression experienced by PWID to be a product of how society is organised. The model suggests that individuals who are impaired are only disabled within the context of society, and therefore disability is a social construct.

1.3 ID and comorbidities

1.3.1 Mental health

The prevalence of mental health difficulties in PWID ranges from 30 to 50 percent (Cooper et al., 2007; Einfeld et al., 2011), in comparison to the general population where the likelihood of experiencing mental health problems is estimated at 25% (World Health Organisation (WHO), 2001). A recent large-scale study on the whole of the Scottish population found even higher prevalence of mental health difficulties, with a five-fold rate for PWID compared to the general population (Hughes-McCormack et al., 2017). A greater number of suicide attempts is also observed in the ID population, with a two-fold prevalence for adolescents (Fuller-Thompson et al., 2018) and three-fold for adults compared to people without ID (McConnell et al., 2016). These rates show that mental health difficulties in the ID population are a pressing issue and should not be ignored.

1.3.2 Physical health

In addition to greater mental health vulnerability, research with PWID has shown that this population also suffers from poorer physical health (LeDeR, 2017). A study on the ID population in Scotland showed that young people with ID are 54 times more likely to experience health complications compared to young people without ID (Young-Southward et al., 2018). Furthermore, another large cohort study of the Scottish population of PWID, Kinnear et al. (2018) showed that a person with ID presented on average with 11 physical health conditions and 98.7% of PWID having multimorbidity, with the most frequently observed conditions being disabling and observed across the whole of adulthood. PWID are reported to have higher prevalence of vision impairments, thyroid dysfunctions, heart conditions, epilepsy, gastrointestinal problems, cerebral palsy and diabetes (McGrother et al., 2006; Prasher & Kapadia, 2006), and these complications are already present before adulthood (Lin et al., 2009). A recent large cohort study in the UK showed that the greater prevalence of multimorbidity in PWID is associated with lifestyle factors (Tyrer et al., 2019).

1.3.3 Health inequalities and care

Health inequalities such as greater deprivation, lack of social support and lower socioeconomic status are thought to account for some of the comorbidities observed (Emerson & Hatton, 2007; Emerson, 2011; Krahn et al., 2015). The observed need to improve quality of life and access to opportunities and choice, has led the UK government to adopt strategies and policies that would ensure adequate care and support for PWID (Department of Health, 2001; Department of Health, 2010, Equality Act, 2010). Although the life expectancy for PWID has increased over the years, the physical and mental health complications still result in higher mortality and morbidity rates than the general population (LeDeR, 2018). Therefore, more attention is still required to improve and revise the healthcare of PWID. An intervention that has been commonly cited to improve health, both in the mainstream population and for those with ID, is physical activity.

1.4 Physical activity

Physical activity (PA) is defined by the WHO as "any bodily movement produced by skeletal muscles that requires energy expenditure" (WHO, 2018). PA benefits have been widely reported in the general population, with a recent systematic review of international research showing that PA is thought to be the primary prevention of over 25 chronic physical health conditions (Rhodes et al., 2017), with researchers reporting that regular PA engagement can reduce the risk of developing a wide range of chronic medical conditions by up to 30%. These benefits are observed across age, gender and ethnicity (Penedo & Dahn, 2005), making this an accessible intervention. Whilst some studies in the past suggested a dose-response relationship whereby greater engagement in PA was thought to result in greater health benefits (Janssen & LeBlanc, 2010), more recent research suggests that substantial health benefits are observed also at moderate levels of PA (Warburton & Bredin, 2017), suggesting that it is not necessary to be extremely active to observe positive health benefits, and even modest levels of PA engagement can lead to health improvements.

In addition to the physical health benefits discussed above, PA also has also a positive impact on mental health problems. A meta-analysis of 39 studies reported that PA interventions reduce

symptoms associated with a diagnosis of depression and schizophrenia (Rosenbaum et al., 2014). Positive effects of PA have also been reported on depression with a recent meta-analysis finding aerobic exercise to increase the mood for adults with major depression (Morres et al., 2018). Positive associations between anxiety and PA have also been reported in a meta-analysis by McDowell et al. (2019) on over 80,000 people, where engagement in PA improved symptoms of any type of anxiety disorder. This research therefore suggests that PA has significant benefits on mental and physical health, thereby being an intervention that can alleviate and prevent some of the health difficulties experienced by PWID.

Greater inclusion of PWID in sport through PA engagement also has the potential to address psycho-social issues such as loneliness and isolation, which may be contributing to the comorbidities (Krahn et al., 2015). PA engagement can address these issues by creating opportunities for social connections and integration in the community (Hallawell et al., 2013). This has been confirmed by a recent literature review by the European Commission, which identified cognitive benefits and social opportunities in addition to mental and physical health benefits for PWID engaging in PA (European Commission, 2018).

In the United Nations Convention on the Rights of Persons with Disabilities (The United Nations, 2006), it is stipulated that participation of people with disabilities in sport should be supported and promoted as much as possible. However, there are no guidelines to PA engagement that are specific to PWID. The current UK Chief Medical Officer's guidelines recommend adults engage in a weekly minimum of 150 minutes of moderate PA, or 75 minutes of vigorous PA or shorter duration for even more vigorous PA (Department of Health & Social Care, 2019). Despite these recommendations, PWID are reported to be twice as likely to be inactive compared to the general population (Sport England, 2016), with a study reporting only 9% of PWID engaging in the minimum amounts of PA as outlined by the guidelines (Dairo et al., 2016). Over the years, a variety of studies have been conducted to test out interventions that aim to increase PA in PWID. Understanding what

factors are important for a successful intervention is fundamental to increase PWID's participation in PA to ultimately address physical and mental health problems.

1.5 Evidence base for PA interventions for PWID

A recent systematic review by Hassan and colleagues (2019) conducted on nine randomised control trials (RCTs) aimed to explore the effectiveness of PA interventions on PWID but found inconsistent results, reporting a multicomponent health and PA programme was most likely to be successful at increasing PA levels in PWID. However, Hassan et al.'s (2019) review had some limitations that may have affected the results. Firstly, Hassan and colleagues' (2019) review was only conducted on RCTs: whilst RCTs are considered the best level of evidential designs, with their potential to show causal relationships between variables (Melnyk & Fineout-Overholt, 2015), RCTs are costly and resource intensive to run (Hariton & Locascio, 2018), and RCT interventions in the experimental context may not always be applicable in clinical practice (Roth & Fonagy, 2006). Specifically, some research has suggested that RCTs may be able to show whether an intervention is effective but are unable to explain why (Carey & Stiles, 2016), which is considered an important factor for understanding interventions (Deaton & Cartwhite, 2018). Moreover, there is a debate around the ethical aspects of RCTs (Goldstein et al., 2018), with some researchers making an ethical argument against having a control group that does not receive the intervention. Not delivering an intervention shown to be beneficial for participants, in this case PA, posits ethical questions of withholding the benefits of this intervention from the people in the control group (Kellett, 2001). To avoid these issues, some researchers often choose to use quasi-experimental designs with the ID population such as stepped-wedge designs where the intervention is delivered in a staggered way to participants, and all participants receive the intervention (Miller et al., 2020). By focusing only on RCTs, Hassan et al. (2019) may have not included other high-quality studies that explored PA interventions on PWID. Furthermore, RCTs are unable to capture experiences of participants, and this is an important element to understand why, from the perspectives of the participants, an intervention may or may not be acceptable, which provides important information on how to develop successful PA interventions for

PWID. <mark>This is in line with British Psychological Society (BPS, 2010) guidelines which highlight the need to include the service user's voice in research, which Hassan and colleagues (2019) were unable to do by only including RCTs.</mark> Finally, Hassan's et al. (2019) reviewed studies involving both child and adult participants. The inconclusiveness of the results could have been influenced by age-related variables, as different age-related reasons for PA engagement have been identified in the general population (Allender et al., 2006), which may also be applicable to the PWID. As such, conducting a review that would focus on a specific age-range of PWID, and includes quasi-experimental and qualitative studies could provide more extensive information on what may be important for successful PA interventions in PWID.

1.6 Summary, rationale and aims of this review

PWID have poorer physical and mental health compared to the general population and PA has been shown to alleviate and prevent these problems. Despite the recognised benefits of PA on health, PWID's engagement in PA is still lower than the general population. Interventions have been adopted to increase PA engagement in PWID, with different rates of success and a recent systematic review on RCT's reported inconsistent results about the effectiveness of interventions. The aim of this review was to explore what factors are important for successful PA interventions for adults with ID (AWID). Successful interventions are here conceptualised as interventions that report greater levels of PA at the end of the intervention compared to levels prior to the intervention. Building on Hassan's et al. (2019) review, this project included RCTs as well as qualitative and quasi-experimental designs, with the objective to inform future protocols for PA engagement in AWID.

2. Methods

2.1 Search Strategy

A systematic, electronic search of the literature was carried out on the 10th of September 2020, using specified research terms related to the aims of the review. The following databases were searched: PsychInfo, CINHAL, Assia, Medline and Sportdiscus and the reference lists of relevant

articles were hand searched. Figure 1 details the outcomes of the search process with a PRISMA diagram (Moher et al., 2009). The following search terms were included in the literature search: (intervention* OR treatment* OR therap*) AND (Intellectual disabilit* OR intellectual developmental disorder* OR cognitive impairment* OR intellectual impairment* OR learning disabilit* OR mental retardation OR mental handicap OR Down Syndrome) AND (Sport* OR physical activit* OR yoga* OR running* OR physical movement* OR physical exercise*) AND (successful OR effective*) NOT (child* OR infant*) NOT (older adults OR elderl* OR seniors OR aged 65+).

2.2 Inclusion and exclusion criteria

For the studies to be included in the current review, they had to meet the following inclusion criteria: studies needed to be peer-reviewed and conducted with adults (18-65). Studies needed to include programmes that were directed at increasing the PA of PWID. Finally, studies needed to be published in English for appropriate analysis to occur.
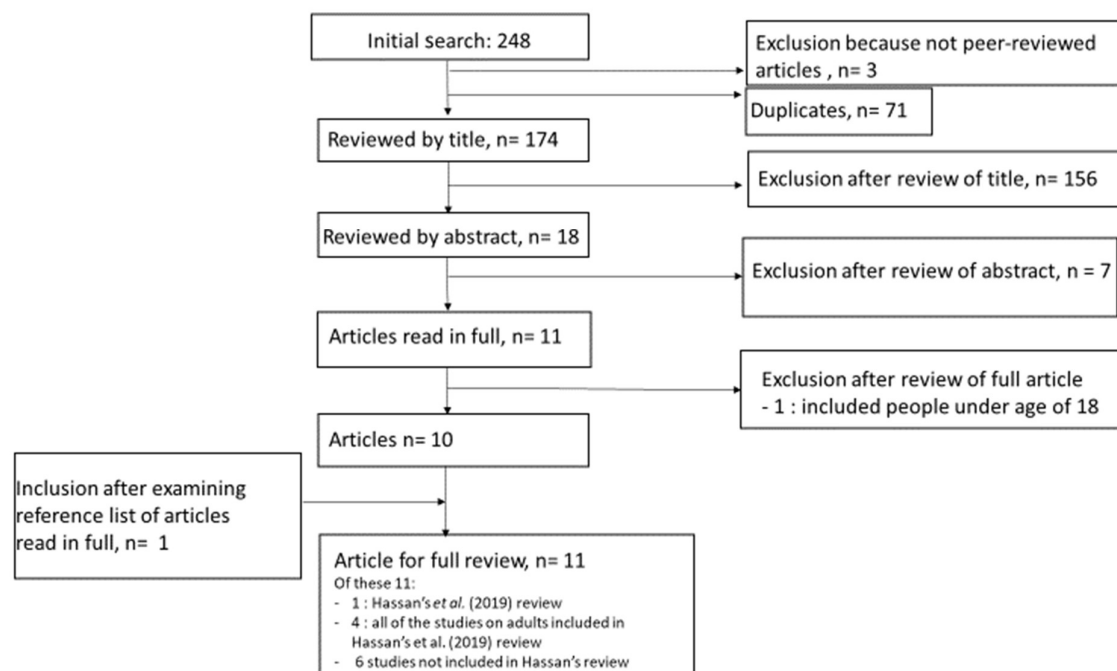
Figure 1: Review search flow through a PRISMA diagram (Moher *et al.*, 2009).

2.3 Data extraction

The initial search yielded a total of 248 studies. All duplicates of articles were removed. Subsequently, papers whose title was not relevant to the purpose of this review were removed. The abstracts of the remaining papers were read. Similarly to before, where the abstract showed that the article did not meet the inclusion criteria, the papers were removed. The remaining papers were read in full and if they did not meet the inclusion criteria they were removed. A total of ten papers met the inclusion criteria. The final papers' reference lists were hand-searched for relevant articles and this yielded one additional article. Papers were excluded either because they were not relevant to the subject of interest, were not available in English, were not peer reviewed articles, or included people under the age of 18. The hand-search of reference lists yielded one additional paper to the current review, bringing the total of papers included to 11. The final list of 11 studies included Hassan's et al., (2019) paper and all of the four RCT studies on AWID that were reviewed by Hassan ad colleagues (2019). Six new articles were included in this review: one RCT, two qualitative studies and three quasi-experimental studies. One of the qualitative studies (Matthews et al., 2016) was an evaluation of the intervention on one of the RCTs (Melville et al., 2015) included in Hassan's et al. (2019) review.

2.4 Quality appraisal

Papers were rated for their quality using standardised checklists according to the study's design, as shown in table 1. Hassan's et al. (2019) was evaluated using the AMSTAR-2 checklist for systematic reviews of RCTs (Shea et al., 2017) (see Table i, Appendix A), the two quasi-experimental studies with Joanna Briggs checklist (Moola et al., 2017) (Table ii, Appendix B), the RCT was evaluated with the Critical Appraisal Checklist (CASP) for RCTs (CASP, 2018) (Table iii, Appendix C), and the two qualitative studies with CASP for qualitative studies (CASP, 2018) (Table iv, Appendix D).

Table 1.
Studies from systematic search

Study	Design	Included in Hassan et al. (2019) review	Checklist
Hassan et al. 2019	Systematic Review of RCT	N/A	AMSTAR-2 (Shea et al., 2017)
McDermott et al. 2012	RCT	✓	CASP for RCT (CASP, 2018)
Bergstrom et al. 2013	RCT	✓	CASP for RCT (CASP, 2018)
Melville et al. 2015	RCT	✓	CASP for RCT (CASP, 2018)
Shields & Taylor 2015	RCT	✓	CASP for RCT (CASP, 2018)
Perez-Cruzado & Cuesta-Vargas 2017	RCT	x	CASP for RCT (CASP, 2018)
Marks et al. 2019	Quasi-experimental	x	Joanna Briggs (Moola et al., 2017)
Stanish et al. 2001	Quasi-experimental	x	Joanna Briggs (Moola et al., 2017)
Bodde et al. 2012	Quasi-experimental	x	Joanna Briggs (Moola et al., 2017)
Brooker et al. 2015	Qualitative	x	CASP for qualitative studies (CASP, 2018)
Matthews et al. 2016	Qualitative	x	CASP for qualitative studies (CASP, 2018)

Perez-Cruzado & Cuesta-Vargas (2017) did not include information on statistical tests and drop-out rates: authors of the study were contacted, and the information was obtained via email. The checklists' total scores were divided into quartiles and each study's quality score was rated according to where it scored in the quartile. Studies were deemed as "very poor" if they fell within the first quartile (0% - 25%), "poor" if they fell within the second quartile (26% - 50%), medium in the third quartile (51%-75%) and high in the last quartile (76% - 100%), as illustrated in Table 2. All studies rated as high quality, except for one (Perez-Cruzado & Cuesta-Vargas, 2017), which rated as poor quality.

Table 2
Studies' quality by checklist's quartile

	Checklist	Score	Quartile	Quality
Hassan et al., 2019	AMSTAR 2	12 / 13	Fourth	High
Bodde et al. 2012	Joanna Briggs Quasi-experimental	7 / 9	Fourth	High
Stanish et al. 2001	Joanna Briggs Quasi-experimental	7 / 9	Fourth	High
Marks et al. 2019	Joanna Briggs Quasi-experimental	5 / 7	Fourth	High
Perez-Cruzado & Cuesta-Vargas, 2017	CASP, RCT	4.5 / 11	Second	Poor
Brooker et al. 2015	CASP, qualitative	7.5 / 9	Fourth	High
Matthews et al., 2016	CASP, qualitative	7.5 / 9	Fourth	High

Because the Hassan's paper was deemed to be of 'high' quality, the critical evaluation of the four studies included by Hassan et al. (2019) was considered valid and the studies were not independently reviewed again in this paper.

2.5 Narrative synthesis

The current review summarises the findings relevant to AWID from Hassan et al. (2019) first: given the very high score on the AMSTAR-2 the current project does not discuss the procedure of the review itself but rather focuses on the contribution of the studies included in Hassan et al. (2019) to the research question. This paper then reviews the findings provided by the additional six studies. The review extracted information on the procedure of the intervention adopted, the type of PA analysed, PA measurement, the intervention duration, sample size and demographic, study design, data analysis and findings. The information was collated to find all factors that are important for successful PA interventions. Where barriers to PA interventions for PWID were found, these were also included as they would inform on the research question as well.

2.6 Hassan et al. (2019)'s review

This paper included a total of nine studies, five on children and four studies on PA interventions with AWID. For the purpose of this review, the findings from the adults' studies were extracted from the

results and conclusions of Hassan et al. paper (2019). Table 3 illustrated below shows the four studies

on adults included in Hassan et al. (2019).

Table 3
Summary of RCTs on adults included in Hassan et al. *(2019)*

Study	n	Intervention	Intervention length	PA type and measurement	Findings
Shields & Taylor, 2015	16	Walking	8 weeks	Walking, pedometers	No increase in PA
Melville et al., 2015	102	Personalised consultation	12 weeks	Walking, accelerometer	No increase in PA
McDermott et al., 2012	443	Health promotion	8 weeks	Walking, accelerometers	No increase in PA
Bergstrom et al., 2013	130	Multicomponent intervention based on SCT targeting PWID, carers and wider community residences	12-16 months	Walking, pedometer	Significantly higher PA levels

3. Results

3.1 Study characteristics and summary

3.1.1 Hassan et al. (2019) review

Hassan and colleagues (2019) classified interventions into unimodal, which included only a PA

component, and multimodal interventions, programmes which included a PA and also a health

component, for example workshops on healthy behaviours. All of the studies in the review were

unable to implement blinding, where participants are unaware of the group that they allocated to, but

Hassan and colleagues (2019), in their critical evaluation, recognise the difficulty of blinding

participants in this kind of study as participants would know if they are receiving a PA intervention.

Out of the four adult studies in Hassan et al. (2019), only Shields & Taylor (2015) carried out

a unimodal intervention, comparing an 8-week walking programme to a social-activities-based

intervention in sixteen adults with Down Syndrome (DS). No difference in PA levels was found in

the two groups, suggesting that an 8-week long intervention that only includes a walking programme is not sufficient to increase PA levels in adults with DS. No increase in PA was found in two other multimodal interventions included in Hassan et al. (2019) which involved a 12-week long intervention of personalised consultation programmes for participants and carers for a total of 102 participants (Melville et al., 2015) and an 8-week health promotion programme with 443 participants (McDermott et al., 2012). The only study that reported a statistically significant increase in PA activity was a 12-16-month long intervention based on Social Cognitive Theory (SCT) (Bandura, 1977) aimed to target caregivers, wider community residences and PWID (Bergstrom et al., 2013), conducted with a sample of 130 participants. Hassan and colleagues (2019) attribute the significant results to be related to the systemic approach grounded in a theoretical framework.

Out of the four studies, only Melville et al. (2015) included people with all levels of disabilities, whereas the other studies only included people with mild-to-moderate ID, limiting the finding of the studies to be relevant for people with this level of disability. The studies differed in duration length, from 8 weeks to 12/16 months. The study with the longest intervention was also the only one that reported increased PA levels (Bergstrom et al., 2013), suggesting that duration of the intervention may also be a factor important for successful PA interventions for AWID.

In addition to the blinding bias previously discussed, all of the four studies included in Hassan et al. (2019) were deemed to be of good quality except for McDermott et al. (2012). This paper scored poorly on most of the Cochrane Risk of Bias Tool items, the tool used to rate the studies included in their review. All studies reported exhaustive information on the demographics of participants, including the level of disability. The high quality of the remaining studies increases the validity of the findings reported. Hassan and colleagues suggest the difficulty in simplifying the complexity of behaviour change techniques to the needs of PWID to be a possible explanation for the majority of negative findings. Hassan et al. (2019) identify the need to implement methodological rigour in

blinding researchers, the need to develop PA interventions grounded in theory and the need for research to explore and report possible adverse effects of PA interventions.

3.1.2 The remaining six papers

Bodde et al., 2012 adopted a unimodal intervention with an 8-week long education programme-only. Authors measured moderate-to-vigorous PA (MVPA) with accelerometers and compared PA levels at the end of the intervention with baseline values. The study found no increase in PA, suggesting that using education-only interventions may not be sufficient at increasing PA levels in PWID. Stanish et al., 2001 implemented a 10-week long video intervention where 15 PWID engaged daily in 15-minutes video aerobic dance lessons comparing a with-instructor and a without-instructor condition. Authors measured MVPA using the Software for Observing Fitness Instruction Time (SOFIT, McKenzie et al., 1991), an application which helps data collection for exercise engagement. Authors showed good engagement during the intervention (over 75% of attendance) with 60% of people participating in a 4-week-long post-intervention maintenance period. However, the authors state that over half of participants already regularly participated in PA. Moreover, the reversal design adopted (BABA) does not provide baseline values of participants PA levels, and therefore conclusions on the effectiveness of the study at increasing PA levels cannot be drawn.

Perez-Cruzado & Cuesta-Vargas conducted a small pilot study RCT with eight participants, to see whether smartphone notification reminders would increase PA levels. The authors measured PA in metabolic equivalent task (METs), a measure for energy exertion, to track whether participants engaged in PA activity. The four participants in the group that received smartphone notification reminders engaged more in PA compared to group that did not receive smartphone reminders. Whilst it would only be available to PWID with sufficient cognitive ability to use smartphones, this study suggests that technology may be a factor that can support PA engagement for PWID, similarly to how it has been shown to decrease sedentary behaviour in a recent meta-analysis in the general population (Stephenson et al., 2017). However, this was the only study that was rated of 'poor' quality, and as

such further research is needed to see whether these findings are replicable in a wider sample and a rigorous methodology.

Marks et al. (2019) conducted a multimodal, 12-week-long peer-leader intervention based on Bandura's (1977) SCT with 379 participants (Marks et al. 2019). The study involved mentors (volunteers without ID from the community), peer health coaches (PHC) (PWID), and peer participants. Mentors trained PHC in delivering a manualised health-based programme that aimed to increase health and PA levels in peers with ID. The programme was based on the transtheoretical model of behaviour change (Prochasca & DiClemente, 1983), addressing all steps of behaviour change (pre-contemplation, contemplation, preparation, action and maintenance) during the 12 weeks of intervention. Participants rated their engagement in PA to be greater at the end of the intervention compared to baseline, suggesting that an intervention involving PHC could increase PA levels in PWID.

Matthews et al. (2016) was a qualitative study that interviewed participants who took part in the Melville et al. (2015) (included in Hassan et al., 2019) personalised consultation walking programme which failed to increase PA levels. Matthews and colleagues interviewed six stake-holders and 20 participants, including carers. The study identified walking as an enjoyable activity for the majority of participants and the need to engage carers in interventions for making them successful.

Brooker et al. (2015) was a qualitative study where eleven non-compliant participants of a walking programme intervention (Brooker et al., 2015) were interviewed to identify the facilitators and barriers of a walking-based PA intervention. The following elements were considered as facilitators: health and social benefits of walking, managing emotions and being outside. However, participants considered the location of walking, the time, environmental factors and weather as barriers that prevented them to engage with the intervention. This suggests that an intervention should consider the context of where the PA takes place, the weather and time of the day when designing

programmes aimed to increase PA engagement, with the aim to make them more appealing to participants.

Table 4 provides a summary of the main findings of the remaining six papers and table vi in Appendix E provides additional details.

Table 4

Summary of remaining six papers

Study	Design	n	Intervention	Intervention length	PA type and measurement	Findings
Bodde et al., 2012	Quasi-experimental	42	Health education only	8 weeks	MVPA – accelerometer	No increase in PA from baseline
Stanish et al., 2001	Quasi-experimental (BABA)	17	Video aerobics with and without instructor	10 weeks	MVPA – Software of observing fitness instruction time (SOFIT)	Both groups engaged equally in PA
Marks et al., 2019	Quasi-experimental	379	Peer-led health and PA programme based on SCT	12 weeks	Self-report of weekly physical exercise	Increased PA from baseline
Perez-Cruzado & Cuesta-Vargas, 2017	RCT	8	Smartphone notification reminder	8 weeks	PA levels through metabolic equivalent task (METs)	Sustained engagement for PWID receiving smartphone notifications
Matthews et al., 2016	Qualitative	26	Semi-structured interviews + focus group	1-hour focus group	Walking (steps)	Walking is likeable, involvement of carers important
Brooker et al., 2015	Qualitative	11	Evaluation of walking intervention	N/A	Walking (steps)	Facilitators: social benefits, managing emotions and being outside. Barriers: safety, time of the day, weather

3.2 Methodological considerations

3.2.1 Considerations on Hassan et al. (2019)

Although this review scored 12/13 in the AMSTAR-2 checklist because of its rigorous methodology, it also presented some shortcomings. Firstly, it did not include Perez-Cruzado &

Cuesta-Vargas (2017) RCT that is included in this current review, despite it meeting the inclusion criteria for Hassan et al. (2019). Hassan et al. (2019) also did not include information on funding of the studies, which would have been important to comment on as funding sources can create conflicts of interests and biases in the findings reported (Lexchin, 2012). Finally, as mentioned in the introduction, Hassan et al. (2019)'s review was conducted on both adult and children. Since in the general population research has shown how factors that contribute to PA are partially age-related (Campbell et al., 2001), it is likely that this may also be true for the ID population, which would have affected Hassan and colleagues (2019) findings.

==3.2.2 Considerations on the remaining six papers==
3.2.2.1 Quality of the papers
According to the checklists used to evaluate the studies, none of the studies scored 100%. The paper with the lowest quality was Perez-Cruzado & Cuesta-Vargas (2017) for not reporting demographics, lack of statistical analysis reported (obtained upon email contact with the authors), and lack of reported randomisation and the lack of reported blinding procedures of researchers, which may have been biased in analysing the data. These factors and the additional small sample size as previously mentioned, yield a poor quality study which, despite reporting positive effects of smartphone notification reminders to sustain PA levels in PWID, needs replication addressing all the limitations aforementioned.

Perez-Cruzado & Cuesta-Vargas (2017) study was not the only study with poor demographical representation. Whilst only Bodde et al. (2012) and *Marks* et al. (2019) had an equal gender representation in their studies, Stanish et al. (2001) had twelve males and five females whereas Brooker et al. (2015) interviewed five females and only one male. Matthews et al. (2016) do not report at all on the demographics of the participants interviewed. Although the participants interviewed took part in a study that did report an equal representation of gender and disability (Melville et al., 2015), Matthews and colleagues (2016) did not state any demographics of the

participants they interviewed. Therefore, the personal experiences of PWID that took part in the study may have been influenced by demographic factors such as gender, disability, class or ethnicity.

Intellectual disability was also not represented across the spectrum in most of the studies. The majority of papers included people with only mild-to-moderate disability, with only Stanish et al. (2001) including the full range by having two people with severe ID. Whilst this may have been related to difficulties in recruitment of people with severe ID due to ethical issues of giving consent (Carey & Griffiths, 2017) or difficulties taking part in semi-structured interviews, which require a certain level of cognitive ability, the studies were not representative of the whole ID population, missing out on the people that have severe and profound ID.

Only Marks and colleagues (2019) include the social class and education of the participants involved, reporting a majority of white participants with a high school diploma. The other studies do not report on social class or education, making it hard to generalise findings across ethnicities and levels of education. None of the studies reported on the physical or mental health of participants, which would have been important information as it would have likely affected the participation in PA as further explored in the limitation section below.

With regards to the other quasi-experimental studies, only Bodde et al. (2012) utilised a control group (with a delayed onset design) and the other studies only had an intervention group. Including a control group would have increased the quality of the papers by increasing their validity through limiting the number of potential confounding variables (Roth & Fonagy, 2006).

Finally, it is impossible to comment on potential biases in the publications for both qualitative studies as Brooker et al., (2015) does not explain the relationship between the researcher and participants and whilst Matthews et al, (2016) state that the researchers were not directly involved in delivering the intervention, authors did not examine their role in sampling participants and how they managed participants' responses in the study. Furthermore, neither study accounted for potential

acquiescence for fear of criticising services (Merriman & Beail, 2009), social desirability and suggestibility issues (McVilly et al., 2008) or power imbalances (Patel, 2003).

3.2.2.2 Sample size

The sample size of the remaining six studies not included in Hassan and colleagues' (2019) review varied from eight to 379. Apart from Marks et al. (2019) who had 379 participants, all remaining studies had relatively small sample sizes, with Perez-Cruzado & Cuesta-Vargas (2017) having only four participants in each group. Sample size can have important generalizability implications as very small samples make it difficult to rule out confounding variables that may be specific to the participants taking part (Campbell et al., 1999). Therefore, it would be appropriate to replicate these studies in larger samples to see whether they would yield similar results.

3.2.2.3 PA type and measurement

Different types of PA were used in the interventions. The two qualitative studies (Brooker et al., 2015; Matthews et al., 2016) evaluated interventions that used walking as a form of PA, understood as steps walked. Stanish et al. (2001) and Bodde et al. (2012) used MPVA, but used two different measures to measure it, with Stanish and colleagues (2001) using SOFIT, a validated software to measure PA (Rowe et al., 1997), whereas Bodde et al. (2012) used accelerometers. Accelerometers' validity in the ID population has been questioned by a recent systematic review reporting the absence of standardised and consistent protocols for accelerometers use with PWID (Leung et al., 2017), with research suggesting that PWID may not always wear accelerometers due to discomfort (Ptomey et al., 2017), questioning the reliability of these devices as measures of PA for PWID. Marks et al. (2019) defined PA as any physical exercise, and they measured it with self-report measures of frequency of weekly PA at baseline and at the end of the intervention. Authors report increased PA levels from baseline measures, but biases in self-report measures may have occurred (van de Mortel, 2008), which would have impacted the results by not submitting truthful responses on weekly PA levels. Finally, although Perez-Cruzado and Cuesta-Vargas (2017) study was rated as poor quality,

authors used a standardised and valid measure for PA, by measuring the number of calories burned during PA using METs (Haskell et al., 2007).

3.2.2.4 Intervention duration
The interventions differed in duration. Marks et al. (2019) lasted the longest, with a total of 12 weeks, compared to the remaining studies which only lasted 8 to 10 weeks. Marks et al. (2019) was also the only study to report increased PA activity from baseline, which may have been related to the extended duration of the intervention. Due to the different cognitive abilities of PWID, which usually require longer periods for learning skills (Winnick & Porretta, 2016), longer interventions may be more successful because they allow for a greater learning period. However, none of the studies except for Stanish and colleagues (2001) included a follow-up, as explored in more detail in section 6.2.

3.2.2.5 Funding
Bodde et al. (2012), Matthews et al. (2016) and Perez-Cruzado & Cuesta-Vargas (2017) reported the bodies that funded their studies whereas Stanish et al. (2001), Marks et al. (2019), Brooker et al. (2015) did not. As such, it is not possible to rule out conflicts of interests with the funding sources for these papers.

4. Discussion

With the rationale to address physical and mental health difficulties in the ID population through PA, this study aimed to explore what factors are important for successful PA interventions with the adult population of PWID.

The search yielded a total of 11 studies, including the previous critical review by Hassan and colleagues (2019), with a total of ten of peer-evaluated studies on PA interventions in AWID. The number of papers is not large, suggesting that this field is still under-researched, highlighting the need to explore this area further.

There was great heterogeneity in the interventions, which differed in PA type, length, measure of PA and whether they were theory-based or not. The majority of the interventions were 8 weeks long.

The fact that only interventions which were at least 12 weeks long (with the exception of Melville et al., 2015) were successful at increasing PA levels for PWID may not be a coincidence. Literature on the general population reports an average need of 66 days to integrate health behaviours as habits in daily routines (Lally et al., 2010): the time needed to integrate health behaviours is likely to be longer for PWID given the cognitive load that behaviour change entails. Interventions shorter than 12 weeks may not be sufficiently long to observe behaviour changes in PA levels in PWID. Carrying out lengthy interventions can be costly, and Perez-Cruzado & Cuesta-Vargas (2017)'s paper suggests that using technology may be an effective way to sustain PA through the use of smart notifications and reminders. However, the study was rated as 'poor' according to the CASP for RCTs checklist (see Table 2) and therefore should be interpreted with caution.

This review presents preliminary evidence suggesting that, for people with mild-to-severe ID, interventions at least 12 weeks long and based on SCT (Bandura, 1977), may be necessary to observe increased levels of PA. This is in line with previous research on behaviour change (Bossink et al., 2017) proposal of designing interventions of behaviour change based on a theoretical domain approach to understand how to implement behaviour change.

The type of PA implemented in the studies ranged from walking, which was the most common, and aerobic dancing. Researchers used different tools to measure PA, including pedometers, METs, SOFIT, self-report measures and accelerometers. Walking appears to be an enjoyable type of PA for AWID, and it also presents the advantage of being relatively accessible to people and not being costly. However, it is unclear whether there are other types of PA that may be more enjoyable for AWID, as research with the general population has shown that people are more likely to practice PA if they enjoy it (Datta, 2016): further research is needed to see whether this holds true for AWID.

Out of 11 studies, only two studies of high quality (see table 2) found greater levels of PA at the end of the interventions (Bergstrom et al., 2013; Marks et al., 2019), and these were the only two studies that were designed based on psychological theory, specifically SCT (Bandura, 1977).

Although further research is needed to clarify this, it appears that an approach such as SCT, which integrates personal and environmental elements, may be key to implement behaviour change with respect to increasing PA levels in AWID, in line with the scaffolding approach of multiple types of support around one person proposed by Bossink and colleagues (2017). Bergstrom and colleagues (2013) achieve this by integrating carers and managers of the homes of PWID, whilst Marks and colleagues (2019) integrate peer leaders with the aim to provide role models and to increase PWID's confidence in overcoming personal barriers (Marks et al., 2019). The importance of involving carers and considering environmental factors in line with SCT, have also been observed in the feedback given by participants in the two qualitative studies, with Matthews et al., 2016 reporting the importance of involving carers and Brooker et al., 2015 highlighting the importance of the time of the walk, contextual factors, the weather and the location of the activity. Another study that was not able to show increases in PA but did report good engagement in PA was Stanish and colleagues' (2001) showing that video dance-aerobic lessons is a form of PA that PWID would enjoy.

The two studies that utilised an education-only approach (Bodde et al., 2012; Melville et al., 2015) demonstrated that education alone is not sufficient to increase PA levels in PWID even with personalised goals and a specialist tutor (Melville et al., 2015). This may not be surprising, as similar results have also been observed in the general population (Avis et al., 1990; Kelly & Barker, 2017) showing that knowledge alone is not sufficient to increase PA levels: this may even be more difficult for PWID where, due to their cognitive difficulties, an approach based exclusively on knowledge may not be ecologically valid. Therefore, an element of PA practice in the intervention may be necessary for programmes to achieve successful behaviour change.

It is likely that there is not a single factor that is necessary and sufficient to increase PA engagement in PWID, but rather a combination of the factors discussed above.

5. Clinical Implications

At this stage, the review is only able to inform on the development of future interventions. The heterogeneity of the interventions and the limitations of the studies reduce the confidence in drawing firm conclusions on what factors are important for successful PA interventions for AWID.

From this review, the main factor that should be considered to increase PA levels for PWID is to integrate the context by involving families, carers and services. A theory-based intervention based on a holistic approach such as SCT may be more successful because it considers the reciprocal interaction that the environment, including surrounding people, has on the learning on the individual (Bandura, 1977). An intervention that only targets the individual but does not consider the person's surroundings is likely to be unsuccessful. This suggests that carer's involvement is important to observe increased PA for PWID. This is in line with previous research that suggested that carers should be aware of behaviour change barriers for PWID so that they can be supported accordingly (Spanos et al., 2013).

In summary, those developing interventions may also want to consider; the involvement of peer leaders (Marks et al., 2019) to model behaviour change and increase social inclusion for PWID; practical elements such as intervention location, the time of the day, the weather conditions should also be taken into account as they were considered facilitators of PA by PWID (Brooker et al., 2015). In addition, it also appears important for interventions to include a practical PA element, where participants have to actively engage in PA in the intervention, rather than delivering programmes that only increase health knowledge about PA benefits (Bodde et al. 2012; Melville et al., 2015).

In terms of type of PA, the majority of studies used a walking intervention, which appears to be a popular form of exercise (Matthews et al., 2016), is also cost-effective and relatively accessible considering the frequently-observed physical health problems amongst PWID. However, aerobic-dance also appeared to be an appealing form of PA for PWID (Stanish et al., 2001), making this another type of PA that could be utilised in PA interventions. Furthermore, its delivery via video

facilitates indoor accessibility, making this type of PA weather friendly (which was one of the barriers highlighted in Brooker et al., 2015) and safe during emergencies like the COVID-19 pandemic, to which PWID have been found to be vulnerable (Courtenay & Perera, 2020). Research has shown that dancing is perceived as fun by PWID (Zitomer, 2016) and may therefore increase PWID's motivation to participate. Finally, dancing incorporates corporal elements which not only have been found to increase interaction with the surrounding environment (Fernandez-Balboa et al., 2014), but also have been shown to be more appealing for PWID rather than forms of PA that do not allow for personal expression such as walking or running (Lirola et al., 2020).

Interventions may consider using technology as a tool to help PWID engage in PA as a pilot study by Perez-Cruzado & Cuesta-Vargas (2017) suggested that smartphone notifications could support PWID in practicing PA.

6. Limitations

6.1 Mental health and physical health demographics

Mental health comorbidities can impact the effectiveness of interventions (Roth & Fonagy, 2006). As discussed in the introduction, PA has a positive impact on mental health, but this relationship is also reversed. Poor mental health has been shown to have an impact on PA levels, with people who are depressed and anxious being less likely to engage in PA (Azevedo da Silva et al., 2012). None of the studies reported on the mental health of participants: it is therefore not possible to infer whether the observed levels of PA engagement may have been linked to the mental health of people rather than the intervention itself, thereby affecting the results. Given the high prevalence of mental health conditions in PWID as outlined in the introduction, this would have been an important demographic to include in the studies as it may have constituted a confounding variable.

As discussed in the introduction, PWID experience a wide range of physical health problems. Similarly to mental health, the relationship between PA and physical health can be bidirectional, making different forms of PA inaccessible according to someone's functional ability and someone's

ability to move their body. None of the studies reports on the physical health problems of participants and this would be a salient element that could have affected the findings.

6.2 Lack of follow-up studies

None of the studies included except for Stanish et al. (2001) included a follow-up. This is an important aspect as interventions aim to implement a behaviour change that is sustained over time and not only during the duration of the intervention. Therefore, the inclusion of follow-ups in Bergstrom et al., 2013 and Marks et al., 2019, who found increased PA levels at the end of the intervention, would have contributed to the robustness of the studies and their validity (von Allmen et al., 2015) because it would have provided an estimate of the sustainability of behaviour change with regards to PA levels.

6.3 The role of motivation

Motivation, especially intrinsic motivation, driven by internal pleasure rather than external forces, has been shown to be a key factor for sustained PA adherence (Ryan et al., 1997). A recent meta-analysis has shown that intrinsic motivation was the single predictor for sustained and autonomous PA practice in adolescents (Kalajas-Tilga et al., 2020). None of the studies discussed the role of motivation. Since the purpose of the interventions is to reduce PWID's health risks by engaging in PA in the long term, studies could have explored this factor in their interventions. Whilst interventions often included a health-education component, aimed at clarifying the purpose of PA, and may have addressed internal motivators for engagement, the overall lack of success of increasing PA levels indicates that that these health-education programmes did not resonate for PWID or did not motivate participants enough to practice more PA.

A model that targets motivation is the COM-B model (Michie et al., 2011), which includes motivation in the process of behaviour change by proposing that the latter is an interacting system between three different components: opportunity, capability and motivation to change (Michie et al., 2011). The model recommends different practical approaches according to what component is targeted: acting on one or more components sets the system in action and behaviour change is

achieved. This model has been adopted by Sports England and it underpins the Mencap 'Round the World Challenge' programme (Mencap, 2019), which addresses the motivation to participate in sport by creating a fun and engaging challenge where people were rewarded miles around the world according to hours of practiced PA.

6.4 Recruitment difficulties

Recruiting PWID in research is difficult (Carey & Griffiths, 2017) and often results in small sample sizes, which can affect outcomes limiting their external validity (Faber & Fonseca, 2014). The potential lack of appeal of PA due to poor motivation to engage in sport may have made it even harder for researchers to recruit participants for these studies.

7. Other considerations: autonomy and choice

There are current guidelines for the general population to be doing PA, but people without ID still have the autonomy and choice to engage in PA and can decide what type of PA to practice according to their preferences (running, weights, walking, yoga, sport). Giving PWID autonomy and choice has been highlighted as a necessary and important (Department of Health, 2010). The freedom that the general population exercises over their PA engagement raises the ethical question whether interventions that aim to change the behaviours of PWID by engaging them with a specific type of PA at a given time may be in contrast with values of choice and autonomy advocated. An alternative approach that would favour a person-centred view is social prescribing, which is already being adopted in the NHS and is set out to be used more widely by 2023/24 (NHS, 2019). Social prescribing aims to provide a personalised, meaningful and holistic approach to health and wellbeing, referring people to localised non-clinical services to support their health, with programmes set out to support people's involvement with physical activity (Public Health England, 2019). Utilising social prescribing as a more common source of support for PWID may help PWID to find more enjoyable and individually tailored physical exercise activities.

Another consideration to be made is how society is preventing PWID in doing PA due to environmental constraints. Shared knowledge and technology could be applied to change the environment to overcome physical barriers that PWID may encounter. Whilst it is true that for some people the inactivity levels are due to physical health constraints, PWID can compete at high levels of sport, even if they have physical health difficulties (https://www.virtus.sport/). Changing the narrative from what PWID are unable to do to what they can achieve could instil hope and motivation, at least for PWID who have an insight and cognitive understanding of their disability (Brooks et al., 2001) and provide inspiring role models (Hallawell et al., 2013).

Finally, although the review focused on PA as a strategy to address physical and mental health difficulties in PWID, PA should not be considered as a substitute for other interventions, and it acknowledges that different forms of PA than the ones adopted by the reviewed studies should be considered for PWID who have severely restricted mobility.

8. Future research

The current review highlighted that further research is needed to implement longer, larger and multicomponent studies which are not exclusively targeted at PWID but also staff and carers. This review also suggests that it is unlikely that a single, one-off study would be able to achieve increased and sustained PA levels in PWID and that a one-size-fits-all approach is likely to be unsuccessful given the spectrum of presentations for PWID. Research could explore ways of making PA more appealing and fun for PWID, following the Sport England model targeting the motivation of participants, in a similar way that Mencap did in the 'Round the World' Challenge.

Studies should also try to explore what form of PA may be suitable for people with severe ID and PMID: given the WHO definition of PA as "any bodily movement produced by skeletal muscles that requires energy expenditure" (WHO, 2018), it is likely that PA is still accessible for this population, such as in the form of play, and is likely be very different from that for people with mild or moderate

ID. Finally, more research is needed around motivational factors for PWID, to understand how to engage PWID at an internal level, in order for PWID to enjoy PA and sustain exercise levels autonomously where possible. Finally, research is needed to observe whether and how larger programmes of work, national initiatives such as Sport England, and social prescribing may impact on PA levels in PWID.

9. Conclusions

This review aimed to explore what factors are important for successful PA interventions for adults with ID. Due to the diversity of interventions in terms of PA style, length of intervention, demographic information and sample sizes, it is difficult to draw solid conclusions on what these factors may be. However, it is suggested that social cognitive theory-based interventions that aim to integrate personal, contextual and behavioural aspects integrated over a sustained period of time may be important to have successful PA interventions for AWID who have a mild-to-moderate level of ID. A one-size-fit all approach is likely to be unsuccessful and further larger-scale research which links to national initiatives and integrates social prescribing is needed to understand how to best support AWID in making PA accessible, across the spectrum of disability.

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Section B: Empirical Paper

Taxonomy and Classification in Intellectual Disabilities (ID): Measuring the health status of athletes with ID using an ICD based questionnaire

Word Count: 7963

April 2021

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Abstract

The current conceptualisation of intellectual disabilities (ID) primarily based on IQ does not capture the complex nature of people with ID (PWID), which calls for a more ecologically valid understanding of PWID. The International Classification of Functioning, Disability and Health (ICF) offers an alternative standardised taxonomy of ID based on a comprehensive view of health and disability by focusing on the functional aspect of health and impairment. PWID present with a significant prevalence of physical health problems and this makes physical health a salient aspect to include in a revisited taxonomy of ID. This project built upon a previous pilot study which developed an ICF-health based questionnaire (ICF-35), with the aim of developing the questionnaire further. In this study, sixty-seven elite athletes were administered the questionnaire (ICF-37) to test its psychometric properties. Combined data sets were then used to analyse the discriminatory abilities of ICF-37 using performance as a dependent variable to test the questionnaire's sensitivity. The results showed that ICF-37 meets the psychometric standards tested and demonstrated good discriminatory abilities. A bigger sample was required for a robust analysis on internal consistency. The ICF-37 has the potential to contribute to a revisited taxonomy of ID which includes physical health. It also has the potential to be used in sporting classification to allow for greater inclusion of athletes and fairer competition, as well as the clinical sector, to facilitate more holistic client formulations.

1. Introduction

1.1 The current classification of intellectual disability: a health condition perspective

Intellectual disabilities (ID) are currently classified as health problems under the International Classification of Diseases and Related Health Problems, Eleventh Revision (ICD-11) (WHO, 2020), which codes them as a health disorder. Specifically, according to ICD-11, ID is diagnosed if a person meets the following criteria: IQ below 70 and impaired social functioning; both need to be present before the age of 18. ICD-11 is widely used by many World Health Organisation (WHO) countries to direct governmental healthcare policies. As such, the medical conceptualisation of ID, with its inclusion in ICD-11, has important implications for health care access (Bertelli et al., 2016). The characteristics of ID vary greatly along a spectrum, and the ICD classifies ID into four different categories according to IQ levels: mild (50 – 69), moderate (35 – 49), severe (20 – 34) and profound (less than 20). However, this medical stance has long been criticised because, by focusing primarily on IQ, it does not provide an ecologically valid representation of people across the spectrum (Greenspan et al., 2015). One of the key examples where this classification is unable to describe the population is for people with Down Syndrome (DS), who have very specific metabolic and sensory characteristics associated with their genotype (Carvalho & Vasconcelos, 2011). A recent Scottish study by O'Leary and colleagues (2018) reported one of the most salient observations to be the physical health differences between PWID with and without DS, with people with DS having greater prevalence of physical health problems than people without, supporting the argument that the current health approach lacks in comprehensiveness due to its inability to capture the complexity and richness of the ID population (Barnes & Mercer, 2011).

The argument for a revision of the current conceptualisation of ID has been raised by clinicians (Whitaker, 2008; Leyin, 2010), who urge to reconsider a classification based on discrete categories as it lacks ecological validity (Leyin, 2010). Whitaker (2008) also raised concerns around the validity of the tests used to capture IQ, highlighting the accuracy shortcomings, reliability limitations,

observed tendency of the population's IQ to increase as a whole (Flynn, 1987) and the lack of consistency in IQ scores across tests (Whitaker, 2008). If IQ scores are one of the three criteria to give a diagnosis of ID and the tests used to measure IQ are not valid, this suggests that the whole approach to classification of ID requires revision.

Furthermore, criticism has also been raised towards the weakness of the current conceptualisation of adaptive behaviour (AB) for lacking a universally accepted definition, and the concept being predominantly defined by the assessment scales used to measure adaptive behaviour (Price et al., 2018). Price and colleagues (2018) also highlight the poor ecological validity of AB measurement tools for not distinguishing behaviours across ages and for being deeply rooted in a Westernised understanding of what is expected and accepted from the social functioning of an individual. The argument for a revised view of the conceptualisation of ID is further strengthened by recent research showing IQ to be a weak predictor of AB (Ardvisson & Granlund, 2018), and issues have been raised on the problems of an arbitrary age of onset (BPS, 2000).

1.2 The revision of an ID taxonomy that includes physical health

One of the key aspects that appears to be overlooked in the current classification of ID is physical health, since over 95% of people with ID present physical health and sensory difficulties (Cooper et al., 2015). A recent large-cohort study in Scotland by Kinnear and colleagues (2018) confirmed that physical health is a pressing issue in this population, showing that the average number of physical health conditions was over 11 per individual, and that over 98.7% of participants with PWID experienced two or more physical health and/or sensory issues. In some cases, the roots of these physical health issues appear to be generated and maintained to an extent by the problems associated with the disability or social context created by the ID itself (Emerson & Baines, 2011), and that social contexts aggravates the difficulties that are associated with the ID alone. Roberston and colleagues (2010) conducted a large systematic review on health checks on over 5,000 PWID across a range of countries and concluded that the poor health conditions of PWID are often avoidable. This is in line

with the so-called diagnostic overshadowing phenomenon where health symptoms (either physical or mental) are overlooked because they are attributed to the ID, which is a phenomenon that has been reported to often occur in the ID population (Bhaumik & Alexander, 2020; Javaid et al., 2019). These physical health problems are thought to contribute and maintain health inequalities experienced by PWID (Shefer et al., 2014), which led to the White Paper 'Valuing People Now' (Department of Health, 2009), calling for a reduction in marginalisation by increasing opportunities of inclusion for PWID.

Despite the government's call for addressing these issues, a recent English study by Hosking and colleagues (2016) on a large cohort of over 16000 participants showed that PWID have three-to-four times higher mortality rates than the general population. In addition to diagnostic overshadowing, the evidence suggests a link between the prevalence of physical health problems and IQ. Kreitler and colleagues (2013) have explained this theoretically, suggesting that early-life hormones which are responsible for cognition also play a major role for physical health and body size. Further evidence for a link has been illustrated in Kinnear et al., (2018) study which showed that, as congenital problems increase, so does severity of ID, supporting the theoretical need to include physical health in a revisited taxonomy of ID.

1.3 A holistic conceptualisation of ID: The International Classification of Functioning, Disability & Health

A revised, more comprehensive classification of ID than the current one proposed by the ICD should be based on a scientific and systematic basis (Nakken & Vlaskamp, 2007). The WHO themselves have recognised the shortcoming of the medical ICD approach, and so introduced the International Classification of Functioning, Disability and Health (ICF, WHO, 2001), which is based on a standardised taxonomy and has been validated in 71 countries (Kostanjsek, 2011). This framework was formulated to provide a more comprehensive understanding of a person's functioning to support people clinically and to inform policy making processes. The ICF thereby includes factors that are

not captured in the ICD classification, and provides a holistic view of health and disability which focuses on an individual's ability to function in their life and in society. To understand the health of an individual, the ICF combines elements of 'Body Functions & Structure' (anatomy and physiology) with 'activities' and 'participation' (understood as limitations in a person's active life). It therefore looks at the functional aspect of health and impairment. The ICF also takes into consideration the role of context, defined as environmental and personal factors, in creating and maintaining the disability. By introducing the concept of contextual factors and their impact on the health condition of the individual, the ICF incorporates principles of the social model of disability (Oliver, 1996). This model of disability does not aim to classify ID but explains the experience of PWID in society. The social model of disability rejects the view that locates the problems associated with the disability within the person, but rather in how society is structured and organised. This model proposes that society, with its barriers, creates the discrimination and exclusion that PWID experience. By including environmental factors, the ICF is able to integrate some of the concepts of the social model in its taxonomy. These concepts relate to the health condition of the person, as depicted in Figure 1.

Moreover, the ICF areas are all rated according to the degree of difficulty, which increases the sensitivity of this approach. By acknowledging that anyone can suffer from health difficulties and consequently experience some level of disability, the ICF proposes a person-centred approach and more ecologically valid understanding of ID. Moreover, the ICF has been widely used with the ID population (Arvidsson et al., 2015; Vale et al., 2017), and with its wide adoption in 191 countries, it constitutes an optimal framework to redefine the current classification of ID.

With the aim to make the ICF more accessible for clinical use, Core Sets specific to different health conditions were developed, to include categories that would most commonly apply to the very specific condition of the Core Set. Some of these pre-existing Core Sets include conditions of musculoskeletal, cardiopulmonary and neurological health as well as cerebral palsy in children and younger adults.
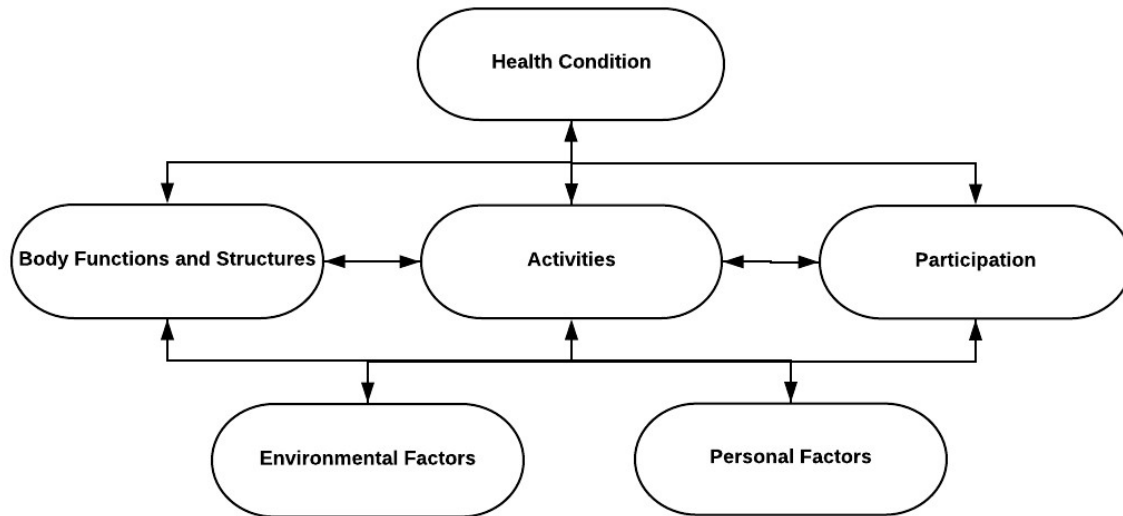
Figure 1. The ICF model of disability – retrieved from
https://www.who.int/classifications/icf/icfbeginnersguide.pdf?ua=1

1.4 The development of the International Classification of Functioning-based questionnaire, ICF-35

In line with the theoretical need to include physical health in the revised conceptualisation of ID, Lemmey and colleagues (2021) developed an ICF-based questionnaire that would capture physical health difficulties in PWID. This questionnaire, which will be referred to as ICF-35, was developed through a Delphi study with an expert panel (see section 2.4.1 in the methods section for more details on ICF-35 development). This generated a 35-item questionnaire which was translated in Finnish, Spanish, German, French and Chinese with the help of the WHO tool (http://www.icf-core-sets.org/en/page0.php) to have additional supporting material for participants from those nationalities or spoke those languages. Lemmey and colleagues (2021) piloted the questionnaire in the specific context of applied sport for PWID interviewing non-elite, elite athletes with ID and athletes with and without DS. The ICF-35 provided to be a valuable tool to capture functional health in PWID, however, it was a pilot study conducted on a small sample size which required replication in a wider sample to further evaluate its psychometric properties.

1.5 Summary and current project

Research has called for a revision of the current classification of ID due to the lack of ecological validity, over-reliance on IQ, and lack of attention to multi-morbidity in the current ICD-based taxonomy. In clinical settings, clients receive support with the aim to optimise their daily functioning, from a psychological and/or physical perspective. In order to support PWID in reaching their optimal functioning, it is necessary to understand their overall functional needs. The current classification of ID which is heavily based on IQ, is able to provide only a limited picture of PWID's functional needs: the integration of a physical health component with the cognitive one and AB would provide a more holistic and ecologically valid understanding of a person's impairment in the context of their functioning in life and society.

The need to integrate physical health in the ID taxonomy has been already proposed by previous researchers (Nakken & Vlaskamp, 2007), given the extensive evidence showing a significant prevalence of physical health problems in PWID. With the need for a revisited scientific and systematic taxonomy of ID which would focus on the overall functioning of individuals to include both cognitive and physical needs, the ICF, with its established validity, has been selected as a tool to guide the development of a new questionnaire, the ICF-35, to capture physical and sensory functional impairments in PWID (Lemmey et al., 2021). The current project aimed to further develop ICF-35 and enhance its psychometric properties.

1.5.1 Athletes with ID

Similarly to Lemmey et al., (2021), this study will be conducted in the very specific context of sport for PWID. This population was selected for the following reasons: firstly, a rigorous taxonomic theory is already used in Para-sport as a classification system with ICF as a foundation model (Tweedy et al., 2018): the further development of the questionnaire will contribute to a new approach to classification in elite sport increasing inclusion. In the Paralympics there is currently only one class

for athletes with ID and, as such, all athletes have to compete in the same class, independently of the level of disability. This results in the exclusion of athletes who have greater functional impairments, such as athletes with DS (O'Leary et al., 2018) from accessing the highest sporting competitions. Shortcomings in classification are observed also within Virtus[1], the international sports federation for athletes with ID, as only the most functionally able athletes come through to international competition, not representing the diversity of the impairment group. This then unintentionally excludes from international competition DS athletes who are more functionally compromised.

The development of the questionnaire will support the implementation of a second competition class for athletes with ID who are more functionally impaired in Virtus, facilitating increased inclusion and fairer competition. Secondly, the sporting population is a unique group that self-selects those with less comorbidity, providing a higher ceiling and therefore increased sensitivity than selecting a sample from the mainstream ID population. Finally, classification in Paralympic sports provides a naturalistic experimental context that allows for generalization leading to practical application of research findings and increased sporting opportunities for athletes with ID.

1.5.2 A functional-health classification – the role of performance

Within the context of sport, classification is important to allow for fair competition and greater motivation to participate in sport (Tweedy & Vanlandewijck, 2011). Having a fair classification system in sport addresses issues of exclusion and increases opportunities for PWID in the context of sport, in line with government initiatives such as Valuing People Now that have highlighted the need to increase participation and reduce marginalisation for PWID (Department of Health, 2009).

The aim of classification in Para sport is to minimise the impact of the impairments on the outcome of competition. Studies have been unable to find correlations between sporting performance and IQ scores in PWID (Van Biesen et al., 2016; Gilderthorp et al., 2018), suggesting that IQ is not a valid criterion to capture athlete's functional abilities. In line with the theoretical arguments of

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[1] Virtus changed its name in October 2019 from its original name, INAS. When the study was conducted the rebranding had not occurred yet, so all the appended forms have the old INAS logo.

needing to take a more holistic approach to the assessment of PWID, including assessment of their physical and sensory functioning, research by Gilderthorp and colleagues (2018) has shown that health status is a predictor of sports performance. The current project investigates this further by collecting performance data to explore the discriminatory abilities of the refined version of the ICF-35, the ICF-37, to see whether it can be used as a classification tool which is able to discriminate between athlete's level of sports performance based on their functional health status, as measured by the ICF-37, and therefore to group more functionally impaired athletes together (DS and non-DS) to compete fairly together. Before this wider question can be answered, the psychometric and discriminatory powers of the questionnaire must be established.

Although tested out on a very specific sporting population, this project addresses important inclusion issues and has the scope to be applied to clinical practice by developing a useful tool of overall functional ability/disability, to be used in addition to IQ and adaptive behaviour.

1.6 Research questions and hypotheses

The project was divided into two phases. Phase 1: established psychometric properties of ICF-37; Phase 2: test ICF-37's discriminative powers. The two phases had the following research questions:

1.6.1 Phase 1:

Question 1.   Does ICF-37 meet psychometric standards of internal consistency, rater consistency, construct validity and convergent validity?

1.6.2 Phase 2:

Question 2.   Is there a difference between the ICF scores for DS athletes and non-DS athletes with ID?

The following hypothesis and questions are aimed to further test the discriminative powers of the ICF-37 to see if it can be used as a classification tool to group more functionally impaired athletes together. The relationship between ICF-37 scores and athletic performance will be investigated, as it has been shown that poorer physical health is associated with poorer sporting performance (Gilderthorpe et al., 2018).

Hypothesis 1. Higher scores of the ICF-37 will be related to poorer athletic performance.

Question 3. Do non-DS athletes with ICF-35 scores equal-to or higher-than DS athletes, perform worse than non-DS athletes with ICF-35 scores lower than DS athletes?

Question 4.   Is ICF-37 better at predicting performance than IQ?

2.Methods

2.1 Design

The current study adopted a naturalistic cross-sectional, between-subjects design across three groups, displaying different levels of sporting performance: sub-elite ID athletes, ID athletes competing for Virtus (elite) and athletes with DS. It utilised three datasets to answer the research questions and test the hypothesis. The first dataset Dataset-2018, was the pre-existing database of elite and non-elite athletes who had completed ICF-35 in Lemmey and colleague's (2021) study. Dataset-GG was a new dataset, which consisted of new data collected from interviews at the Virtus Global Games 2019 in Australia. Dataset-2020 was a database that combined both Dataset-GG and Dataset-2018.

2.2 Participants

2.2.1 Phase 1 - Global Games

The participants of phase 1 included the athletes who were administered the ICF-37 at the Global Games (GG), the world's biggest elite sports event for athletes with ID. To be included in the dataset,

athletes needed to be a Virtus accredited athlete: as such, they already had their diagnosis of ID verified by Virtus. Athletes also needed to be at least 18 years-old and be able to consent to participate in the research. Athletes were also required to be accompanied by a coach, a carer or family member with good knowledge of their medical history that would act as a supporter in case athletes needed help in answering the questionnaire. In this paper, these people accompanying the athletes will be referred to as supporters. Either the athlete and/or the supporter was required to speak English to ensure that they gave informed consent and to answer the questionnaire. Where English was not known, translators were used and there was access to the translated forms of the ICF-37. Additionally, athletes had to compete in an individual sport (i.e. not team sports) where there is an interval score, e.g. time, so that a measure of individual performance could be collated. A total of 67 athletes completed the ICF-37 questionnaire for Phase 1. Table 1 summarises the inclusion criteria of Dataset-GG and the inclusion criteria that were used in Dataset-2018 for Lemmey et al.'s study (2021).

Table 1.
Inclusion criteria for the datasets

	Dataset-2018	Dataset-GG
Age 18 or older	✓	✓
Able to provide informed consent	✓	✓
ID diagnosis with standardised measure of IQ below 75	✓	✓
Accompanied by a person that has good knowledge of medical history – where English is not spoken translators were used	✓	✓
Competed in individual sports (performance data collected)	x	✓
Virtus elite athletes	✓	✓
Included non-elite athletes	✓	x
Included people with DS diagnosis	✓	x
Competed in team sports	✓	x

2.2.2. Phase 2

Phase 2 utilised Dataset-2020, which combined Dataset-GG with the pre-existing dataset, Dataset-2018, from Lemmey et al., (2021). The Dataset-2018 included a total 102 athletes. All participants in the Dataset-2018 had provided informed written consent for their data to be used for research purposes in line with the Virtus consent process for eligibility, and therefore could be included in this study. All Dataset-2018 data were anonymised, with personally identifiable information removed. Dataset-2018 includes athletes that competed at either elite (26) or non-elite (19) levels and also included athletes with DS diagnosis (N = 32).

The ICF-37 differed from the ICF-35 with the addition of two additional items around digestion and weight, but all other items remained the same. Since this Dataset-2020 included athletes who completed two different versions of the questionnaire (ICF-35 for athletes in Dataset-2018, and ICF-37 Dataset-GG athletes from the Global games), to run analyses on Dataset-2020, the athletes' questionnaire scores needed to be comparable. To do this, ICF-37 scores of athletes that competed in the GG were converted to ICF-35 scores by subtracting the scores from the two new questions in the questionnaire. When analyses were carried out on questionnaire scores of the Dataset-2020, they were referring to ICF-35 scores of 169 athletes.

Table 3 in the results section illustrate the demographics of Dataset-GG and Dataset-2020 participants respectively.

2.3 Ethics

The current study received approval from the University's Ethics Committee panel in July 2019 (Appendix F). In order to make sure that the study would have the minimum impact on the sporting performance, interviews were scheduled around a time that would suit athletes best. The ICF-35 version of the questionnaire developed by Lemmey et al. (2021) had not elicited any distressing reactions by athletes being interviewed. However, to minimise the likelihood of athletes experiencing

any distress, access to support was made available by coaches, carers and team sport psychologists. Prior to administering the questionnaire, athletes were read the information sheets of the study (Appendix G) and the supporters were also given an information sheet to read (Appendix H). They were asked if they had any questions and if not, and still wished to participate, athletes were asked to sign a consent form (Appendix I). Both information sheet and consent form for this project had been adapted from the ones used in previous research (Lemmey et al., 2021) and approved by the ethics committee panel. Finally, athletes were asked more than once throughout the interview if they still wished to continue with the questionnaire, to ensure that the willingness to take part in the study did not change since signing the consent form.

2.4 Materials

2.4.1 IQ scores

All athletes interviewed at the GG had already provided official documents evidencing IQ scores to Virtus, who will have verified their eligibility as an ID athlete. IQ scores of athletes included in the Dataset-2018 who were non-Virtus athletes were tested using the WASI-II with a Full-Scale IQ provided by the Vocabulary and Matrix Reasoning subtests (Lemmey et al, 2021).

2.4.2 The ICF-health based questionnaire

2.4.2.1 The development of ICF-35

ICF-35 was developed using the Delphi method to assess the reported presence of physical health problems in people with ID (Lemmey et al., 2021). An expert panel was consulted to select which codes in the original ICF questionnaire on body functions would be relevant for athletes with ID. The first steps of the procedure implemented to develop ICF Core Sets (Selb et al., 2015) was adopted. A total of 35 questions on physical health were included in ICF-35.

2.4.2.2 ICF-37

This study aimed at further developing ICF-35. Two questions on digestive functioning were added as a result of feedback from athletes and supporters that participated in Lemmey et al.'s research (2021), as these were thought to be common issues not included in ICF-35. The new questionnaire,

ICF-37, had a total of 37 questions (Appendix J). Questions were clustered around topics of senses and pain; heart, lungs and immune system; digestion; movement and ability. Individuals were asked to rate whether they experienced a specific health problem, where they answered yes, they were asked to rate how much of a problem it was to them, using a visual scale that ranged from "no problem", which was scored as 0, "mild problem" scored as 1, "moderate problem" scored as 2, "severe problem" scored as 3 and "complete problem", scored as 4 (see Appendix K for adapted visual scale). The range of possible scores was 0-148. Similarly, to Lemmey et al.'s (2021) study, translated versions of the official ICF questionnaire (available from the WHO online tool http://www.icf-core-sets.org/en/page0.php) in Finnish, Chinese, French and Spanish were used alongside the ICF-37 in case athletes/supporters who spoke those languages needed clarifications on the questions.

2.4.3 Post Questionnaire Interview

The Post ICF-health interview was administered following the completion of the ICF-37 following the same protocol as Lemmey et al., (2021). The purpose was to gain feedback on the interview questions and the participant's experience of the interview (Appendix L).

2.5 Recruitment strategy

2.5.1 Global Games

The Virtus GG is a world-wide sporting competition held every four years for elite athletes with ID. Given the size of the event, and to ensure familiarisation with the research for potential participants and coaches prior to the event, the recruitment process began a few months before the GG. Information about the study was made available on the GG website by promoting it with a video made by the researchers (https://www.youtube.com/watch?v=FSXtmovIVUA#action=share). This video included both audio and subtitles: it introduced the researchers, discussed the purpose of the study and showed important sections from example research interviews with two elite athletes (one

in the UK who spoke English, and one in Hong Kong who spoke Cantonese) who had capacity to give consent to be part of the video. This was done to provide a visual and concrete example of what athletes could expect should they wish to participate in the study. All participating countries' head coaches or team managers were contacted via email informing them of the purpose of the current project and asked to get in touch if any athlete expressed an interest to take part (Appendix M). Once the interest to participate in the project was received, the time and place for the interview was agreed together with the athletes and coach/parent or carer to suit the athlete's schedule.

Three countries, France, Czech Republic and Hong Kong had scheduled a training camp the week before the start of the Games. Researchers attended the training camp as this made it possible to interview many athletes prior to the Games themselves, and therefore interfere less with the competition schedule. Athletes were also recruited at the competitions within the GG schedule by approaching coaches or managers with the information about the study (see Appendix M). Coaches and/or managers then asked which athletes would be willing to participate and organised a rota for their participation.

2.6 Procedure

2.6.1 Phase 1: Global Games administration of questionnaire

Three researchers carried out the interviews at the GG. One is the author of this project (Researcher 1) and the others (Researcher 2 and Researcher 3) had developed ICF-35. Researchers 2 and 3 trained Researcher 1 in delivering the questionnaire. Athletes were interviewed in private rooms where possible, and always with a supporter. All coaches spoke English, so they acted as translators for athletes whose first language was not English. One of the researchers spoke French and Spanish, so they used this language to communicate with athletes whose first language was either French or Spanish. Finally, original copies of the ICF questionnaire in Finnish, Chinese, German, French and

Spanish were available as a reference to the ICF-37 for athletes or coaches who spoke these languages, to help them understand any medical terminology in the questionnaire.

Following completion of the information sheet (Appendix G) and consent form (Appendix I), the ICF-37 was administered as outlined in the section 2.4.2 using the visual scale to rate any functional problems identified. After the completion of ICF-37, participants were asked to complete the post-interview questionnaire (see Appendix L). The whole interview process ranged from approximately 30 minutes to one hour.

2.6.2 Phase 2: Combining new and pre-existing data

Phase 2 did not involve additional interviews. Data from Dataset-GG and Dataset-2018 were combined to establish a larger dataset, Dataset-2020 (see Table 3).

2.6.2.1 Performance calculation procedure

GG performance data was collected from the results that are publicly available via the GG website. A standardised performance score (SPS) was obtained by comparing each athlete's performance to the corresponding world record in that event. The world records were obtained from the Virtus Website, in the World Records section updated to December 2019. For timed events such as swimming, rowing, cycling, and running, the SPS was calculated using the formula adopted by Gilderthorp and colleagues (2018). Table 2 illustrates the calculation procedure and interpretation of SPS percentages.

Table 2
Performance values calculation

Event	Calculation	Percentage	Meaning
Swimming, rowing, cycling, running	SPS = (AR / WR) x 100	< 100 %	New WR
		= 100 %	Same as previous WR
		> 100 %	Worse than previous WR
Javelin, shotput, hammer, discus	SPS = (WR / AR) x 100	< 100 %	New WR
		= 100 %	Same as previous WR
		> 100 %	Worse than previous WR

==2.6.3 Physical health problems==

==The prevalence of physical health problems was calculated by searching which individual questions in the questionnaire were most frequently reported to be problematic for participants. The first five most common questions on physical health problems for participants were reported. Moreover, prevalence for wearing assistive devices and which devices was also calculated. A comparison between Dataset-2018 and Dataset-GG was made to see differences in the datasets.==

2.7 Data Analysis

All data analyses were carried out using the SPSS statistical analysis software, version 23 (IBM Corp, 2015). The only two databases that were used for analyses were Dataset-GG and Dataset-2020: Dataset-2018 was only used to draw together the data with the new GG data, and its data had already been presented by Lemmey et al., (2021). Table 3 shows which dataset was used for which analysis according to the research question.

Table 3
Research Question with corresponding analysis and dataset

Question/Hypothesis	Analysis	Statistical test	Dataset, ICF score
Q 1. Does ICf-37 meet psychometric standards?	Internal consistency	Cronbach's alpha	Dataset-GG, ICF-37 vs Dataset-2018, ICF-35
	Rater consistency	Kruskal-Wallis test	Dataset-GG, ICF-37
	Construct validity	Exploratory Factor Analysis	Dataset-2020, ICF-35
	Convergent validity	Correlation	Dataset-2020, ICF-35
Q 2. Is there a difference between the ICF-35 scores for DS athletes and non-DS athletes?		Mann-Whitney U test	Dataset-2020, ICF-35
H 1. Higher scores of the ICF-37 will be related to poorer athletic performance		Correlation between ICF-37 scores and performance	Dataset-GG, ICF-37

| Q 3. Do non-DS athletes with ICF-35 scores equal-to or higher-than DS athletes, perform worse than non-DS athletes with ICF-35 scores lower than DS athletes? | Mann-Whitney U test | Dataset-GG, ICF-35 |
| Q 4. Is ICF-37 better at predicting performance than IQ? | Multiple Hierarchical Regression | Dataset-GG, ICF-37 |

2.7.1   Question 1: does ICF-37 meet psychometric standards?

Where possible, results will also be compared between ICF-35 to ICF-37.

2.7.1.1 Internal consistency

Internal consistency was analysed using Cronbach's alpha. To see if internal consistency improved with the newer version of the questionnaire, Cronbach's alpha of the new ICF-37 (Dataset-GG) was compared with the Cronbach's alpha from the ICF-35 from Dataset-2018. Item analysis was carried out to observe whether internal consistency would be higher by eliminating any questions of the questionnaire (Field, 2018).

2.7.1.2 Rater Consistency

Rater consistency was analysed by comparing questionnaire scores across the three different raters with Kruskal -Wallis test. This was be done using Dataset-GG because sufficient data was available from three different raters for ICF-37 but not ICF-35, so rater consistency could not be compared between the two questionnaires.

2.7.1.3 Construct validity

Construct validity was calculated to see whether the questionnaire is measuring the construct it's set out to measure (functional health status). Exploratory factor analysis was chosen as the method to calculate construct validity as it allows to estimate underlying factors (Field, 2018). Originally it was expected to recruit sufficient numbers to carry out a robust exploratory factor analysis but due to COVID-19 this was not possible. Comrey and Lee (1992) define sample sizes lower than 100 as not

sufficiently robust for a factor analysis. Therefore, the analysis was carried out on the ICF-35 Dataset-2020 as it had a greater sample size than the Dataset-GG. The factor analysis was carried using 'direct oblimin' oblique rotation as factors are expected to be related to each other (Field, 2018). The anti-image matrix was scanned for questions with values lower than 0.5 and re-run without them.

2.7.1.4 Convergent validity

Convergent validity measures whether two measures of constructs that theoretically should be related, are effectively related. This was calculated by correlating IQ scores and ICF-35 scores, as previous research has demonstrated a relationship between level of ID and prevalence of health issues (Wraw et al., 2015). Here, the data from all 169 participants (and therefore Dataset-2020, ICF-35 scores) was used as a bigger sample was needed.

2.7.2 Question 2. Is there a difference between the ICF scores for DS athletes and non-DS athletes?

The Dataset-2018 and ICF-35 scores were used for this analysis as no DS athletes were interviewed at the GG. Due to the non-normal distribution of ICF-35 scores, the non-parametric test Mann-Whitney U test was chosen.

2.7.3 Hypothesis 1. Higher scores of the ICF-37 will be related to poorer athletic performance.

Performance data was collected for the Dataset-GG and the ICF-37 were used. A correlation analysis was performed.

2.7.4 Question 3. Do non-DS athletes with ICF-35 scores equal-to or higher-than DS athletes, perform worse than non-DS athletes with ICF-35 scores lower than DS athletes?

This question aimed to see whether there was a difference in performance for athletes that presented with similar physical and or sensory impairments to DS athletes. Since the comparison was with DS athletes for which only Daset-2018, ICF-35 scores were available, these were used for the analysis. The average ICf-35 scores for DS were calculated. Non-DS athletes were divided into athletes with questionnaire scores equal-to or higher-than DS athletes in on group and non-DS athletes with lower

questionnaire scores than DS athletes in the other group. The performance data of these two groups were analysed for significant difference using a Mann-Whitney U test.

2.7.5   Question 4. Is ICF-37 better at predicting performance than IQ?

Multiple hierarchical regression was used to answer this question.

3.   Results

3.1 Participants
The table 4 below shows the demographics of participants by database.

Table 4
Participants' demographics

		Dataset-2018	Dataset-GG	Dataset-2020
Sample Size		102	67	169
Age (*mean, SD*)		26.02 (± 8.40)	24.69 (± 6.05)	25.49 (±7.57)
Gender	Female (*n*)	39 (38.25%)	25 (37.3%)	64 (37.9%)
	Male (*n*)	63 (62.65%)	42 (62.7%)	105 (62.1%)
Ethnicity	Asian (*n*)	5 (4.9%)	3 (4.5%)	8 (4.7%)
	Black (*n*)	5 (4.9%)	5 (7.5%)	10 (5.9%)
	Black African (*n*)	1 (1.0%)	2 (3.0%)	3 (1.8%)
	Black British (*n*)	2 (2.0%)	0 (0.0%)	2 (1.2%)
	Black Caribbean (*n*)	0 (0.0%)	2 (3.0%)	2 (1.2%)
	Brazilian (*n*)	0 (0.0%)	7 (10.5%)	7 (4.1%)
	British-Indian (*n*)	1 (1.0)	0 (0%)	1 (0.6%)
	Caribbean (*n*)	2 (2.0%)	0 (0.0%)	2 (1.2%)
	Indian (*n*)	0 (0.0%)	2 (3.0%)	2 (1.2%)
	Mixed (*n*)	2 (2.0%)	11 (16.4%)	13 (7.7%)
	White American (*n*)	2 (2.0%)	3 (4.5%)	5 (3.0%)
	White Australian (*n*)	13 (12.8%)	17 (25.4%)	30 (17.8%)
	White European (*n*)	69 (40.8%)	15 (22.3%)	84 (49.7%)
Nationality	France (*n*)	8 (7.8%)	22 (32.8%)	30 (17.8%)
	Brazil (*n*)	0 (0%)	7 (10.4%)	7 (4.1%)
	Australia (*n*)	19 (18.6%)	17 (25.4%)	36 (21.3%)
	Hong Kong (*n*)	8 (7.8%)	3 (4.5%)	11 (6.5%)
	Portugal (*n*)	0 (0.0%)	2 (3.0%)	2 (1.2%)
	Spain (*n*)	0 (0.0%)	1 (1.5%)	1 (0.6%)
	Czech Republic (*n*)	1 (1.0%)	2 (3.0%)	3 (1.8%)
	Finland (*n*)	0 (0.0%)	1 (1.5%)	1 (0.6%)
	India (*n*)	0 (0.0%)	2 (3.0%)	2 (1.2%)
	New Zealand (*n*)	0 (0.0%)	1 (1.5%)	1 (0.6%)
	Iceland (*n*)	0 (0.0%)	1 (1.5%)	1 (0.6%)
	Denmark (*n*)	0 (0.0%)	2 (3.0%)	2 (1.2%)

	USA (*n*)	2 (2.0%)	3 (3.0%)	5 (3.0%)
	Thailand (*n*)	0 (0.0%)	3 (3.0%)	3 (1.8%)
	UK (*n*)	61 (59.8%)	0 (0.0%)	61 (36.1%)
	Belgium (*n*)	2 (2.0%)	0 (0.0%)	2 (1.2%)
	Germany (*n*)	1 (1.0%)	0 (0.0%)	1 (0.6%)
Sport	Athletics (*n*)	14 (13.7%)	37 (55.2%)	51 (30.2%)
	Basketball (*n*)	14 (13.7%)	0 (0.0%)	14 (8.3%)
	Boccia (*n*)	2 (2.0%)	0 (0.0%)	2 (1.2%)
	Cricket (*n*)	11 (10.8%)	0 (0.0%)	11 (6.5%)
	Cycling (*n*)	1 (1.0%)	5 (7.5%)	6 (3.6%)
	Equestrian (*n*)	2 (1.2%)	0 (0.0%)	2 (1.2%)
	Football (*n*)	1 (1.0%)	0 (0.0%)	1 (0.6%)
	Netball (*n*)	3 (2.9%)	0 (0.0%)	3 (1.8%)
	Power lifting (*n*)	1 (1.0%)	0 (0.0%)	1 (0.6%)
	Swimming (*n*)	35 (34.3)	22 (32.8%)	57 (33.7%)
	Rowing (*n*)	0 (0.0%)	3 (4.5%)	3 (1.8%)
	Table tennis (*n*)	7 (6.9%)	0 (0.0%)	7 (4.1%)
	Tennis (*n*)	9 (8.8%)	0 (0.0%)	9 (5.3%)
	Ten pin bowling (*n*)	2 (2.0%)	0 (0.0%)	2 (1.2%)
Years competing	In current sport (*mean, SD*)	11.34 (± 7.09)	9.05 (± 5.42)	10.48 (± 6.58)
	In all sports (*mean, SD*)	11.87 (± 7.26)	12.21 (± 7.38)	12.00 (± 7.29)
Other Diagnoses	Epilepsy (*n*)	6 (5.9%)	8 (11.9%)	14 (8.3%)
	Autism (*n*)	31 (30.4%)	18 (26.9%)	49 (29.0%)
	Cerebral Palsy (*n*)	3 (2.9%)	2 (3.0%)	5 (3.0%)
Athlete Group	Down Syndrome (*n*)	32 (31.4%)	0 (0.0%)	32 (18.9%)
	Elite non-DS (*n*)	44 (43.1%)	67 (100%)	111 (65.7%)
	Non-elite non-DS (*n*)	26 (25.5%)	0 (0.0%)	26 (15.4%)

3.2 ICF-37 Descriptive statistics

The average of the ICF-37 scores was 8.04 (± 8.03), with a minimum score 0 and a maximum score 46, out of a possible range of 148. ICF-37 yielded similar scores to Lemmey et al. (2021) ICF-35 (mean 8.49± 7.92) which was slightly higher due to the inclusion of DS athletes who would have scored higher due to greater physical health problems.

The distribution of scores for gender showed positive skewness (1.97 ± 0.46 for females and 1.47 ± 0.37 for males) and kurtosis (3.96 ± 0.92 for females and 2.53 ± 7.17 for males), indicating that they were not normally distributed, similarly to Lemmey et al., (2021) Dataset-2018. This was confirmed by the Shapiro-Wilk test, which suggested that the ICF-37 scores were not normally

distributed across gender (p < 0.05) and sport (p < 0.05). There was no significant difference in ICF-37 scores across male and females ($U = 2923.5$, $p = 0.156$).

3.3 Physical health problems

Thirty-nine percent of the elite athletes interviewed at the GG needed assistive devices, with 32.8% wearing glasses 1.5% hearing aid and 1.5% orthotics. Dataset-GG yielded slightly lower rates of assistive devices use compared to Dataset-2018 which showed 60% of participants to make use of devices and almost 50% of athletes reporting to wear glasses. The most common health problems other than sight have been included in table 5 for Dataset-GG and table 6 for Dataset-2018. The observed greater prevalence of health problems in Dataset-2018 is not surprising as this dataset also included non-elite athletes and athletes with DS, who are known to have a greater number of health problems (Kinnear et al., 2018). For the same reasons, there is a greater prevalence of muscle tone problems in Dataset-2018, which is in line with research on people with DS and muscle tone (Dey et al., 2013).

Table 5.
Prevalence of health problems Dataset-GG

Health problem	Prevalence (%)
Energy and drive	31.3
Maintaining health body weight	26.9
Sensations of pain	25.4
Immune system	20.9
Complex voluntary movement	16.7

Table 6.
Prevalence of health problems Dataset-2018

Health problem	Prevalence (%)
Sensations of pain	31.4
Maintaining healthy body weight	29.4
Muscle tone	28.4
Complex voluntary movement	27.5
Energy and drive	24.5

3.4 Question 1. Does the ICF-37 meet psychometric standards of internal consistency, rater consistency, construct validity and convergent validity?

3.4.1 Internal consistency

ICF-37 conveyed a 'good' internal consistency with a Cronbach's α= 0.81 (Field, 2018) which was higher than the previous ICF-35, which yielded a Cronbach's α of 0.75 (Lemmey et al., 2021). Further analysis showed that ICF-37 Cronbach's α's value was not improved by removing any items. This suggested that no questions should be taken out of the questionnaire to improve its internal consistency.

3.4.2 Rater consistency

Researcher 1 interviewed 51 athletes (76.1%), Researcher 2 interviewed 10 athletes (14.9%) and Researcher 3 interviewed 6 athletes (9.0%). ICF-37 scores did not differ significantly across researchers $\chi_2(2) = 4.819$, $p > 0.05$, showing good rater consistency (see Figure 2). Outliers observed may be an artefact due to the greater number of people seen by Researcher 1.
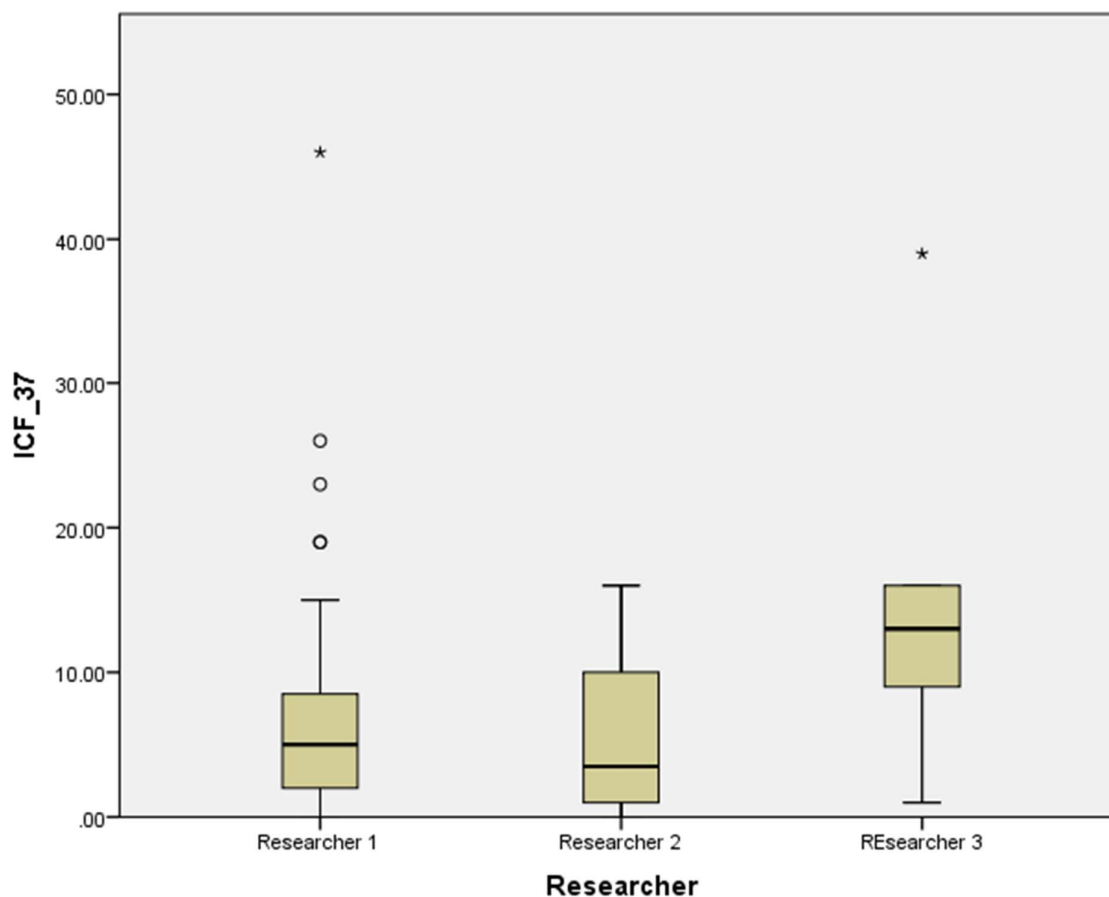
Figure 2: Boxplot showingICF-37 scores by researcher

3.4.3 Construct validity – Factor analysis
The results, as illustrated in appendix N, confirmed that the current sample size is not sufficient for a

robust factor analysis.

3.4.4 Convergent validity
A Spearman's Rho test was run as data was non-parametric. Dataset-2020 was used to calculate

convergent validity as this allowed for a bigger and more varied sample since it included participants

with DS and non-elite athletes. There was a statistically significant negative correlation between IQ

and questionnaire scores ($r_s(8)$ = -.217, p = .006). As such, as IQ scores decrease, scores in the ICF

questionnaire increase. This suggests that participants who had lower IQ scores also have greater

physical health problems.

3.5 Phase 2

Unless otherwise stated, the ICF scores data in phase 2 will be referring to ICF-35 scores, as some of the participants in this phase completed the first version of the questionnaire. Figure 3 shows the distribution of ICF-35 ICF scores of Dataset-2020 according to athlete group (DS, elite (Virtus), non-

elite).
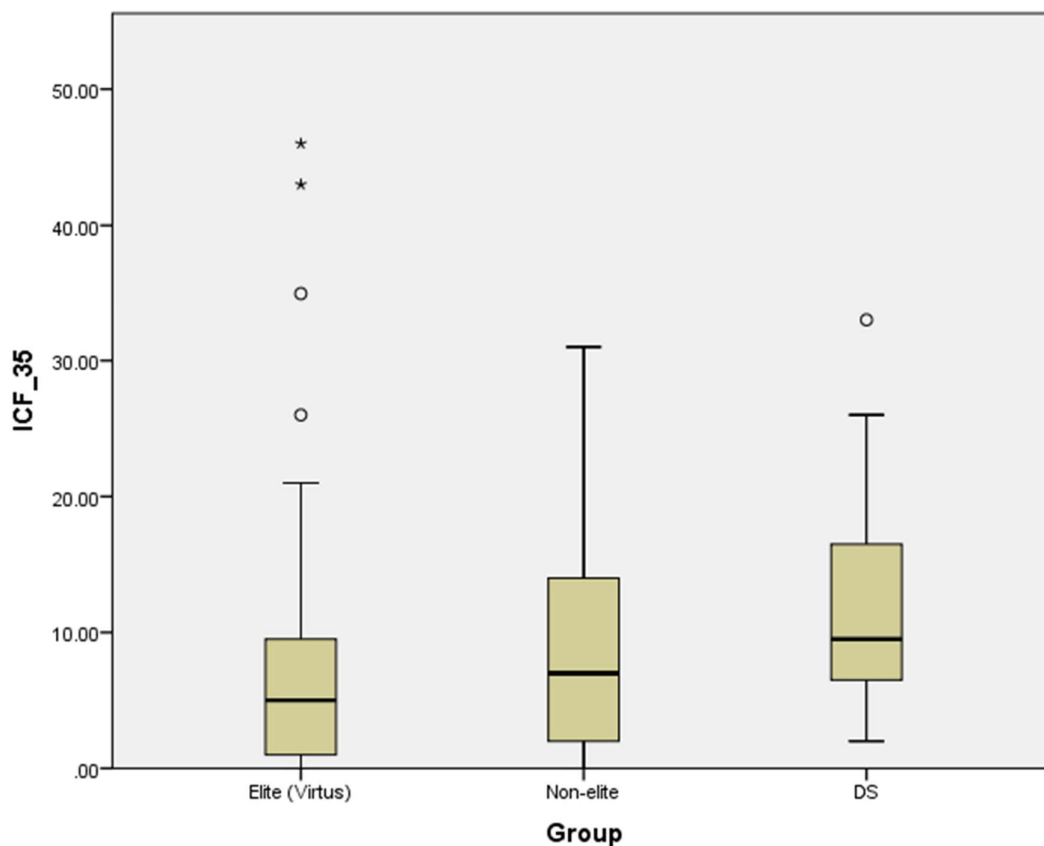
Figure 3: Boxplot showing Dataset 2020 ICF-35 scores according to group

3.5.1 Question 2 - Is there a difference between the ICF scores for DS athletes and non-DS athletes?

There were 32 athletes with DS in Dataset-2020 (see Table 3). There was a statistical significance in ICF-35 scores between the 32 DS participants (11.72 ± 7.49) and the 137 non-DS participants (7.18 ± 7.93), (U= 1265, p= 0.000) (Figure 4), suggesting that athletes with DS had poorer physical health, which supports previous research (O'Leary et al., 2018).
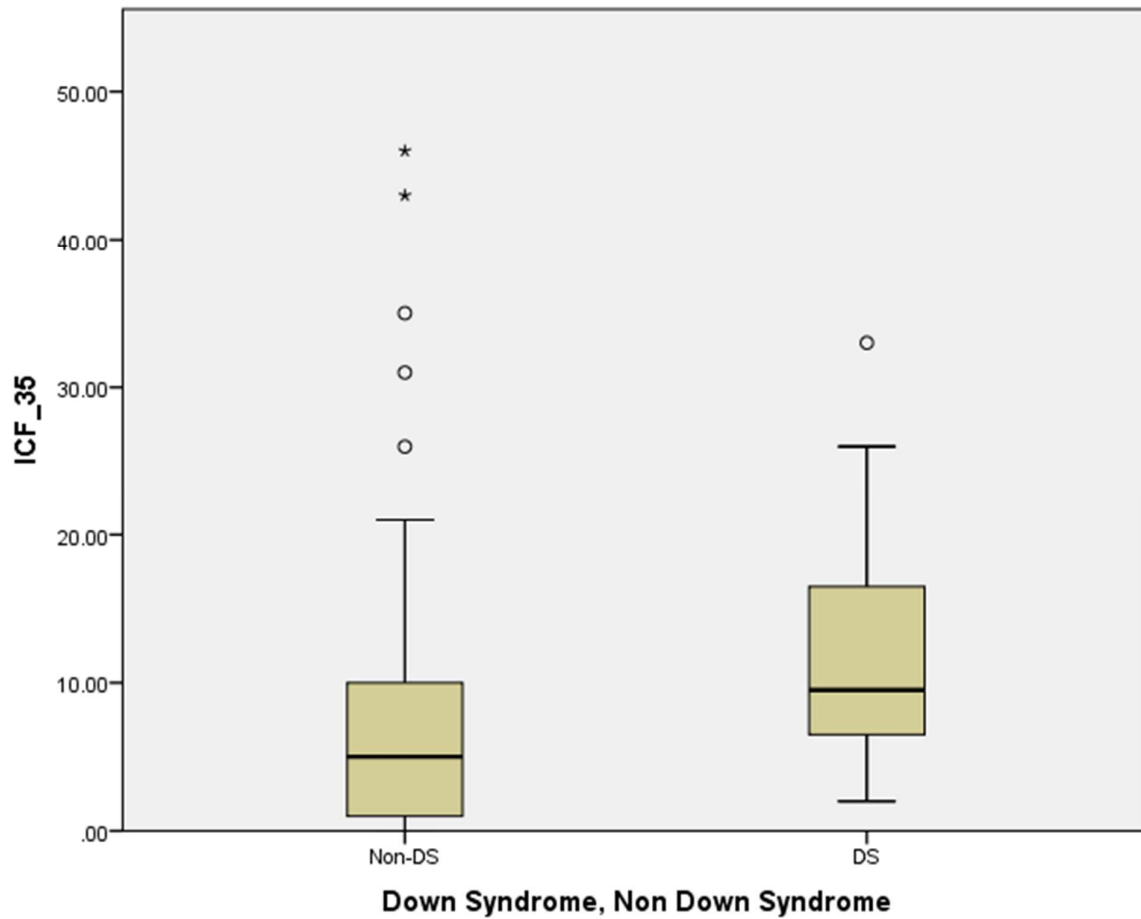
Figure 4: Boxplot of Down Syndrome scores and ICF-35 scores.

The next analysis is in response to the hypothesis 1.

Figure 5 illustrates the variability in performance. Two athletes broke the world records at the GG. The mean performance was 118.50% (±17.57%), with a minimum of 96.86% and a maximum of 193.84%.
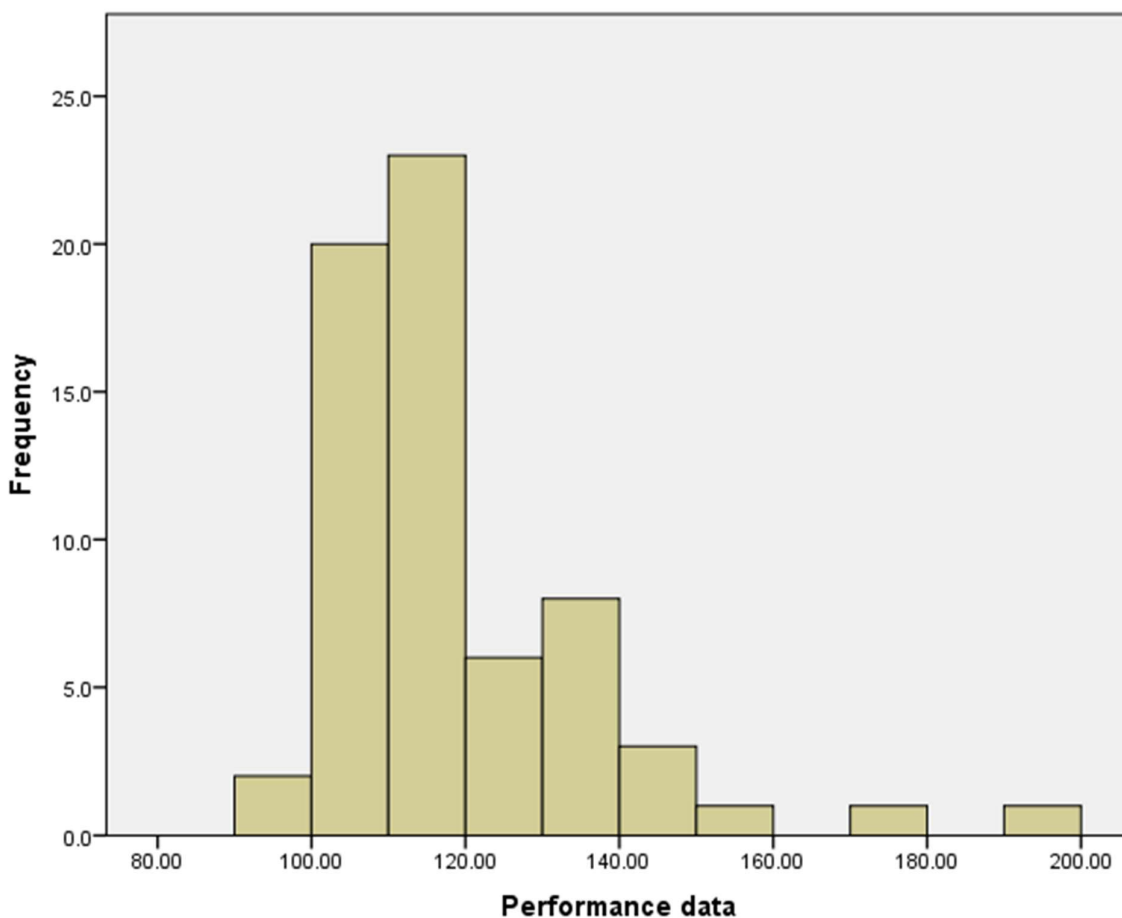
Figure 5: Histogram showing the performance variability. <mark>For timed sports: standardised performance score (SPS) = (AR / WR) x 100, for throwing sports: SPS = SPS = (WR / AR) x 100</mark>

3.5.2 Hypothesis 1 - Higher scores of the ICF-37 will be related to poorer athletic performance

There was a significant negative correlation between ICF-37 scores and sports performance, $r = 0.33$, $p = 0.007$, replicating previous research showing that health status is a predictor of performance (Gilderthorp et al., 2018).

3.5.3 Question 3. Do non-DS athletes with ICF-35 scores equal-to or higher-than DS athletes, perform worse than non-DS athletes with ICF-35 scores lower than DS athletes?

Athletes who present with similar <mark>level of</mark> physical health difficulties <mark>or impairment</mark> as athletes with DS are expected to have similar functional abilities and therefore perform at a similar level to athletes with DS. In line with the rationale outlined in the introduction for a need to group more functionally

challenged ID athletes with DS athletes to have a fairer competition, this research question explored whether ICF-health based questionnaire can be used to group non-DS athletes at a similar functional level to athletes with DS. The mean ICF-35 score of DS athletes was 12 which was used as a reference point to compare groups. The performance scores between non-DS athletes with SPS < 12 were compared to the non-DS athletes with SPS >12. A non-parametric test was used as data was not normally distributed. A statistical difference in SPS (%) was observed between athletes who scored higher than DS participants (128.02% ± 5.82) and athletes who scored lower than DS participants (114.42 ± 1.53), U= 220, p= 0.035, (see Figure 6), showing that using a cut off score of 12 the ICF-35 discriminated between higher and lower sports performance. This suggests that physical health as captured by ICF-35 has potential to classify athletes according to their functional ability, which may predict sporting performance.
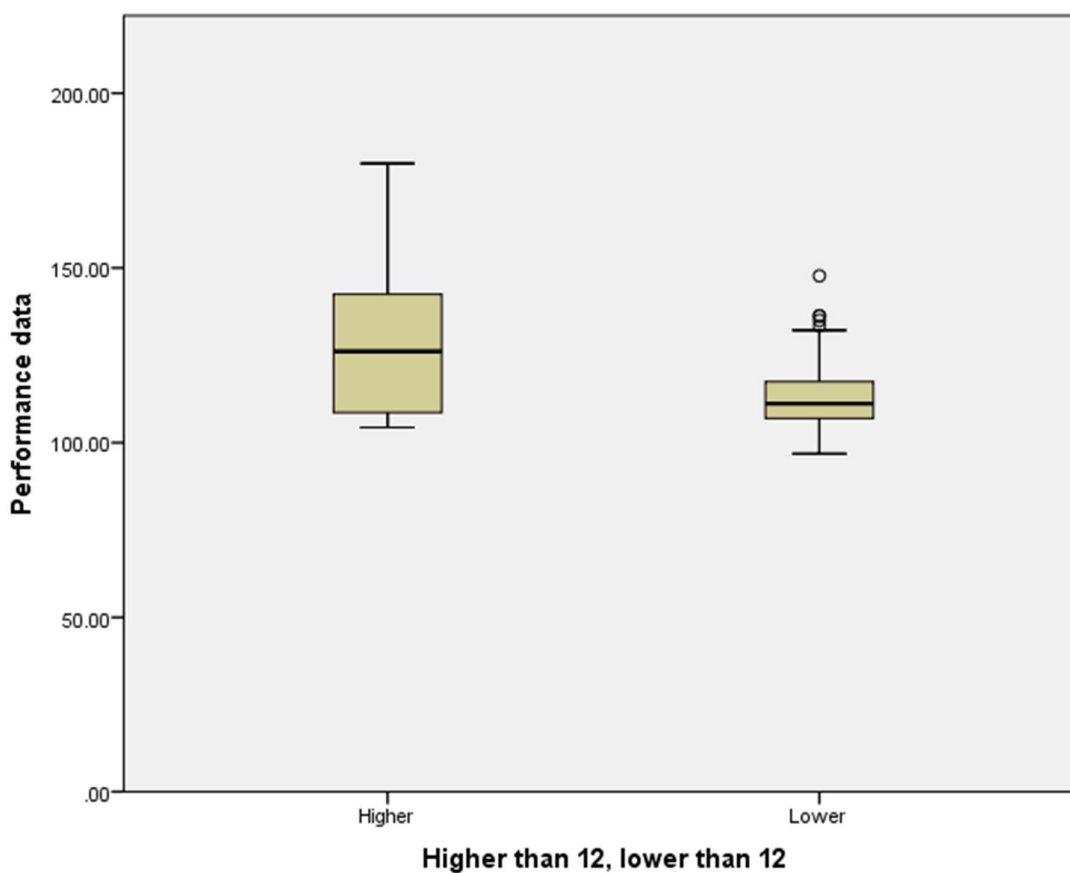
Figure 6: Boxplot showing performance for non-DS athletes with scores higher and lower than 12, outliers excluded.

3.5.4 Question 4 - Is ICF-37 better at predicting performance than IQ?

A multiple hierarchical regression was carried out to predict performance based on individual's IQ and ICF-37 scores. The highest correlation observed was between performance and ICF-37 scores, which was significant at 0.01 level ($r = 0.332$, $p = 0.003$), showing that functional physical health status as captured by the questionnaire, is correlated to wider functional abilities, in this case, performance. As expected, there was no significant correlation between IQ and performance ($p = -0.072$). The results indicated that the model explained 11.1% of variance and that the model was a significant predictor of athletic performance, $F (2,62) = 3.855$, $p = 0.03$. IQ did not contribute significantly to the model ($B = -0.03$, $p = 0.90$), whereas ICF-37 scores did ($B = 0.68$, $p < 0.05$), suggesting that IQ is not a good predictor of sports performance, but functional health status is.

3.6 Post-questionnaire results

Ninety-one percent of athletes thought that the length of the questionnaire was 'just right' and six-percent judged it to be 'long but OK'. This suggests that the carrying out the questionnaire is not an uncomfortable process for individuals. Feedback on the difficulty of the questionnaire showed that the majority understood either all of the questions (79.1%) or most of them (13.4%), and everyone was able to answer them with the help of the supporter present, suggesting that athletes were able to complete the questionnaire. No further suggestions to include additional items on physical health were made by either athletes or coaches were made.

4. Discussion

The sports-related aim of this project was to explore if ICF-35/37 could be used as a classification tool to group more functionally impaired athletes together (DS and non-DS) to compete fairly in a parasports context. This question has a wider taxonomic relevance in terms of questioning if there are better ways in which to define and assess the capability of PWID.

The project utilised data from a pre-existing dataset (Dataset-2018) of elite, non-elite and DS athletes with ID who had completed the first version of the ICF-health based questionnaire, ICF-35. The project consisted of two phases: the first phase involved data collection by interviewing elite, non-DS athletes with ICF-37, the more recent version of ICF-35, and capturing their performance scores. The data from this phase (Dataset-GG) was used to test out the psychometric properties of ICF-37. The second phase drew together Dataset-2018 with Dataset-GG to form Dataset-2020 to test the discriminative powers of the questionnaire.

In line with Kinnear et al.'s (2018) study, the current findings showed a greater prevalence of physical health problems for athletes with DS compared to athletes without DS, suggesting that ICF-37 is able to capture health differences across these two populations. The most common physical health problem captured by the ICF-37 questionnaire, was problems with vision, with almost half of participants reporting problems with their sight. This is in line with the research by Woodhouse and colleagues (2004) that showed that athletes with ID presented with greater prevalence of vision problems for PWID compared to the general population.

From the psychometric analyses, the internal consistency yielded a slightly higher Cronbach's alpha compared to the first version by Lemmey et al. (2021), which may be linked to the presence of two additional questions, as number of items in a scale is related to Cronbach's alpha values (Field, 2018). The Cronbach's alpha value falls within the 'good' category (Fields, 2018), indicating that ICF-37 is effectively measuring physical health. Raters had similar scores across participants, suggesting that there was a consistency in scoring between the researchers. The unforeseen smaller sample size than initially hoped for, due to the arrest of data collection because of the COVID-19 pandemic, did not allow for a robust factor analysis to be conducted, and therefore this project was unable to provide answers towards the construct validity of ICF-37 at this stage. Further data needs to be collected to achieve this. The literature has shown a correlation between IQ scores and physical health (Wraw et al., 2015), and the findings of this project support these results, showing that athletes

who have lower IQ also presented with worse physical health as captured by the ICF-37, suggesting that the questionnaire has good construct validity.

To examine the discriminatory abilities of ICF-37, one of the aims of this project was to explore whether there was a difference between the ICF scores for DS athletes and non-DS athletes. The findings showed that athletes with DS had higher ICF scores than athletes without DS, suggesting that the latter have less physical health problems, which corresponds to previous research (O'Leary et al., 2018). As such, the ICF-37 appears to be able to capture physical health differences between PWID with and without DS, suggesting that it has good discriminatory abilities.

The project also aimed to test the hypothesis that higher ICF-37 scores will be related to poorer athletic performance and that the questionnaire could be used to group non-DS athletes who have similar functional levels to athletes with DS. The questionnaire was able to differentiate between athletes with similar functional abilities to DS athletes and athletes with better functional abilities to DS athletes suggesting that the ICF-37 has good discriminatory abilities between the two groups. Finally, a multiple regression analysis showed that ICF-37 was better at predicting performance compared to IQ, which replicates previous findings by Gilderthorp and colleagues (2018). As such, athletes that score high on the ICF-37 (and therefore greater physical health problems), are predicted to perform worse than athletes who score lower than them. This, in addition to the lack of association between performance and IQ, suggests that, within the domain of sport, physical health would be a better criterion to classify athletes' competition class.

Further work on a larger sample is required to investigate the construct validity of the questionnaire and inter-intra-rater reliability, but these results suggest that the ICF-37 shows good internal consistency, construct and discriminatory ability as a measure of functional health for PWID. This project suggested ICF-35/37 shows potential as a way of classifying ID athletes according to their functional abilities to allow for fair competition in sport and greater inclusion. The ICF-37 has the potential to be used as a sport classification tool and sets the ground for introducing a second competing class in the Paralympics for athletes with greater functional impairments, such as athletes

with DS. The results suggests that ICF35/37 merits further investigation for use by Virtus, to introduce an additional competition class combining athletes with more significant impairments, as assessed in this way with, allowing athletes with similar functioning abilities to athletes with DS to compete in the same class.

4.1 Clinical implications

The association between physical health and wider functional capacity supports the argument for a need to include health problems to have a true understanding of the impairments faced by PLWD. This has concrete practical implications in para-sport classification, making ICF-37 a potential tool that sets the groundwork for classification based on an individual's functioning abilities. In the Paralympics, this work would translate into the introduction of a second competing class for athletes with ID to recognise their performing abilities, just as it does with other competing classes for athletes without ID. In Virtus, this work provides evidence for the need to shift from a classification based on DS diagnosis to a classification based on performance and functional ability, allowing for greater inclusion and fairer sporting competition.

Although this research has been conducted in the very specific context of sport, the very fact that even elite athletes, who are to be expected to have better health than the rest of PWID, reported a high prevalence of physical health problems, further highlights the salience of physical health problems for PWID. ICF-37 has the potential to be used clinically as a tool to capture physical health status and facilitate the care of PWID by shedding light on the functional abilities of individuals and how to optimise them. The ICF-37, being able to inform on the functional ability of the individual, would provide a more holistic understanding of clients in the clinical setting, informing healthcare professionals of the health difficulties and their associated impact on the people that they work with. Furthermore, it would help clinical psychologists to have a more in-depth understanding of the physical health of service users, supporting them in understanding how physical health problems are impacting on the service users' wellbeing, enriching the formulation process. A more enriched

<mark>formulation could then inform treatment plans to address service users' needs, for example by guiding positive behaviour support plans.</mark> The ICF-37 could also be used as a tool with PWID and carers as a part of a functional assessment of behaviour, <mark>to have an in-depth understanding of the difficulties of clients</mark>. Furthermore, an ecologically valid taxonomy of ID that includes physical health, with the ICF-37 in a clinical setting, has the potential to reduce diagnostic overshadowing, provide improved care for PWID and avoid PWID's exclusion from appropriate services.

4.2 Limitations

One of the main limitations of this project was the sample size as it was not sufficient to carry out a factor analysis in a robust manner (Field, 2018).

Furthermore, it was not possible to test some of the psychometric properties of questionnaires such as test-retest reliability or inter-rater reliability as it as it felt unethical to interview participants again especially in such as short amount of time and during sporting competitions.

Another limitation was having to revert on occasions to the earlier version ICF-35 of the questionnaire, in order to reach sufficient power for the analysis. This meant that it was not possible to establish to what extent ICF-37 contributes to the discriminative powers of the questionnaire.

4.3 Future directions

Future research should continue to collect data by assessing more elite athletes using ICF-37 in order to have a greater sample size to run a robust factor analysis and further explore its discriminative powers. Once this is accomplished, this data could be used to conduct an ROC analysis to facilitate sporting classification into competing categories by determining a cut-off point that would distinguish higher-competing from lower-competing athletes. The questionnaire should also be used with PWID who are not athletes, in order to define the full range of health limitations that may have not been captured in the athlete population. With the confirmed internal validity of ICF-37, the questionnaire could be trialled in clinical practice to explore how clients and clinicians may perceive this tool, with

the aim to provide a more holistic understanding of PWID.It could also be used as the starting point of a formal WHO process for an ID specific Core Set.

5. Conclusions

This project suggests that ICF-37 is a promising instrument to assess functional health in PWID. The findings show that ICF-37 is able to distinguish between physical health problems even within the population of elite athletes with ID, which are expected to have fewer health difficulties than the rest of the ID population, thereby suggesting good discriminatory ability of the questionnaire. Future research is needed to increase the sample size to ascertain the construct validity of the questionnaire and confirm its ability to contribute to a revisited taxonomy of ID that includes physical health. Once this is established, the ICF-37 has the potential to be used in the sports classification system to differentiate athletes based on their functional health status and allow for fairer sporting competition and greater inclusion. In the clinical sector, the ICF-37 has the potential to be used in clinical practice to inform health professionals' understanding of their clients and facilitate their care.

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Section C. Part A appendices

Appendix A: Systematic review evaluation

Table i. Evaluation of systematic reviews of RCTs using AMSTAR 2 (Shea et al., 2017)

Study	Hassan et al. 2019
1. Did the research questions and inclusion criteria for the review include the components of PICO?	Yes – authors included all four elements (population, intervention, control group and outcome) in the report
2. Did the report of the review contain an explicit statement that the review methods were established prior to the conduct of the review and did the report justify any significant deviations from the protocol?	Yes – authors state that they followed the PROSPERO protocol
3. Did the review authors explain their selection of the study designs for inclusion in the review?	Yes – authors explain why they included only RCTs
4. Did the review authors use a comprehensive literature search strategy?	Yes – authors included comprehensive search strategy, justified publication restrictions, searched for reference lists of included studies, conducted the search within 24 months of completion of the review, contacted authors where information was missing
5. Did the review authors perform study selection in duplicate?	Yes – two reviewers independently agreed on selection of eligible studies and achieved consensus on which studies to include
6. Did the review authors perform data extraction in duplicate?	Yes - at least two reviewers achieved consensus on which data to extract from included studies
7. Did the review authors provide a list of excluded studies and justify exclusions?	Yes – authors list the studies that were not included and justify their exclusion because consensus was not agreed
8. Did the review authors describe the included studies in adequate detail?	Yes – authors described PICO elements in detail and described study's setting
9. Did the review authors use a satisfactory technique for assessing the risk of bias in individual studies that were included in the review?	Yes- authors used the Cochrane Collaboration Risk of Bias Tool (Higgins et al., 2011)
10. Did the review authors report on the sources of funding for the studies included in the review?	No
11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	No meta-analysis conducted – authors also provide explanation for not conducting meta-analysis (heterogeneity)
12. If meta-analysis was performed, did the review authors assess the potential impact of risk of bias in individual studies on the results of the meta-analysis or other evidence synthesis?	No meta-analysis conducted
13. Did the review authors account for risk of bias in individual studies when interpreting/discussing the results of the review?	Yes – authors discussed the of unconcealed allocation, lack of blinding of patients, allocation sequence, selection of results and how these impacted on the studies
14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	Yes – authors explain heterogeneity due to the variability of interventions and time points across trials
15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	No meta-analysis conducted

16. Did the authors report and potential sources of conflict of interest, including any funding they received for conducting the review?	Yes – authors reported no competing interests

Appendix B: Quasi-experimental studies evaluation

Table ii.

Evaluation of quasi-experimental studies using Joanna Briggs Institute checklist (Moola et al., 2017)

Study	1 (Bodde et al., 2012)	2 (Stanish et al., 2001)	3 (Marks et al., 2019)
Is it clear in the study what is the 'cause' and what is the 'effect'?	Yes – there is clear temporal relationship and which variable is being manipulated	Yes – there is clear temporal relationship and which variable is being manipulated	Yes - there is clear temporal relationship and which variable is being manipulated
Were the participants included in any comparison similar?	Partial – both groups were adults with LD. Unclear about differences in age, ethnicity, gender and social class	Yes – subjects were their own control	Yes – this was a pre-post-test design without control group
Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	Yes	Yes	N/A
Was there a control group?	Yes- delayed onset control group	No- checklist advises to score 'no' if control group is not independent	No
Were there multiple measurements of the outcome both pre and post the intervention/exposure?	Yes - multiple measures to observe the outcome	No – reversal design does not allow for pre-intervention measurement	Yes - multiple measures to observe the outcome
Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	No – no follow-up completed	Yes – follow-up included	Partial – follow-up was only on peer health coaches' knowledge. No follow-up on Peer participants
Were the outcomes of participants included in any comparisons measured in the same way?	Yes	Yes	N/A
Were outcomes measured in a reliable way?	Partial – more recent research questioned reliability of ActiGraph accelerometers for adults with ID due to poor compliance (Ptomey *et al.*, 2017)	Yes - modified version of System for Observing Fitness Instruction Time (SOFIT) (McKenzie, Sallis & Nader, 1991)	Partial - unclear whether there were biases as peer health coaches collected health knowledge and health behaviours data for peers with ID
Was appropriate statistical analysis used?	Yes	Yes	Yes

Appendix C: RCT evaluation

Table iii.

Evaluation of studies using CASP RCT checklist (Singh, 2013)

Study	Perez-Cruzado & Cuesta-Vargas, 2017
Did the trial address a clearly focused issue? • population • intervention • comparator • outcomes considered	Partial – there was a clear focused issue. However, no information was given on participant's demographics
Assignment of patients to treatment randomised? • How is this carried out • Allocation concealed to patients and researchers	Can't tell – information not included in the paper
Were all of the patients who entered the trial properly accounted for at its conclusion?	Yes
Patients, health workers and study personnel 'blind' to treatment?	Can't tell – information not included in the paper
Were groups similar at start of the trial? • Age, sex, social class	Can't tell – information not included in the paper
Were groups treated equally?	Yes
How large was the treatment effect? • What outcomes were measured • Is the primary outcome clearly specified • What results were found for each outcome	Can't tell – small sample size and no power analysis to determine whether this small sample would have been able to predict significant differences
How precise was the estimate of the treatment effect?	Can't tell – see above
Can results be applied to local population? • Patients representative of population • How do they differ	No – very small sample
Were all clinically important outcomes considered? • There is other information that should be there • Does this affect your decision	Yes – the use of smartphones could be an effective way to maintain PA for people with LD
Are the benefits worth the harms and costs?	No costs nor harms reported in the study

Appendix D: Qualitative studies evaluation

Table iv.

Evaluation of qualitative studies using CASP qualitative checklist (Singh, 2013)

Study	Brooker et al., 2015	Matthews et al., 2016
Clear statement of aims? • What is the goal • Why is it important • Its relevance	Yes – relevance, context and aims all clearly stated	Yes – relevance, context and aims all clearly stated
Qualitative methodology appropriate? • Does research seek to interpret or illuminate the actions or subjective experiences of participants • Is qualitative research the right methodology for aims of research	Yes – study aims to explore the subjective experiences of participants	Yes – study aims to investigate subjective experiences of participants and stakeholders (process evaluation)
Design appropriate for aims? • Design justified	Yes	Yes
Recruitment strategy appropriate? • Participant selection explained • Explanation why participants were most appropriate • Discussions around recruitment	Yes – participant selection explained, appropriateness of participants explained and discussion around recruitment	No – researchers interview some of the participants that took part in an RCT on PA intervention (Melville et al., 2015) where the recruitment was appropriate. However, no description on the recruitment for these participants provided
Did data collection address the research issue? • Setting justified • Clear data collection • Methods justified • Explicit methods • If methods modified, explanation for how and why • Form of data clear • Data saturation discussed	Yes – setting, data collection, methods justified and clear. Data analysis conducted to be more truthful to content on interview with less extraction of themes to remain more faithful to participants contents in interviews, therefore no data saturation discussed	Yes
Relationship between researcher and participants explained? • Has researcher examined their own role, biases and influence in formulating research question and sampling • How researcher responded to events during the study	No – this is not mentioned	Yes – conducted by two researchers that were not directly involved in delivering the intervention

Ethical issues considered? • Showed how research was explained to participants • Has researcher discussed issues raised by the study • Approval from ethics committee	Yes – ethics approval, researchers demonstrated to have thought about potential stressors of the study for participants by conducting interviews in 'safe and comfortable settings for informants should they require debriefing'.	Partial – not mentioned in the methods but talked about ethical issues of 'freedom of choice' in the discussion
Rigorous data analysis? • In-depth description of analysis • If thematic analysis was used, clear how categories were derived from data • Explanation of how data presented was selected from original sample to demonstrate analysis process • Is there sufficient data to support findings • Is contradictory data accounted for • Analysis of role of researcher?	Partial – methodology of thematic analysis explained by researcher to be 'less rigorous' and more 'descriptive' because of the LD of participants in order to remain more faithful 'to the informant responses'.	Yes – interview transcripts analysed following process evaluation guidelines (Moore , 2015; WHO, 2001; Steckler, 2002).
Clear statement of findings? • Are findings explicit • Adequate discussion for and against the arguments • Credibility discussed • Findings discussed in relation to original research question	Yes – findings are explicit and there has been adequate discussion for and against arguments. Limitations are considered and findings are discussed in relation to original question.	Yes – findings are explicit and there has been adequate discussion for and against arguments. Limitations are considered and findings are discussed in relation to original question.

Table v

Study description

Author, Location	N	Age	Sample Characteristics	Design	Intervention - Procedure	Outcome Measures	Analysis
Hassan et al. 2019	666	18-83	Adults with ID	Review of RCTs	Review of RCTs	N / A	Quality appraisal through Cochrane Risk of Bias Tool
Bodde et al., 2012, USA	42	19-62	Adults with ID, equally divided by gender	Quasi-experimental	8-week long educational intervention	P.A. knowledge through: Nutrition Activity Knowledge Scale (NAKS) (Illingworth et al., 2003) and the Physical Activity Recommendations Assessment (PARA). P.A. measured through ActiGraph dual-axis accelerometers.	Paired independent samples t-tests for knowledge tests. Wilcoxon signed-rank and Mann-Whitney U for physical activity participation
Stanish et al., 2001, USA	17	42.6 (range 30-60)	5 females, 12 males. 15 with mild ID and 2 with severe ID (classified according to American Psychiatric Association, 1994)	Quasi experimental (Single subject reversal) (B-A-B-A)	10-week intervention with promotion of exercise through either video only (aerobic dance) or video and live exercise leader. At the end of intervention, the final reversal of the video-only condition was 4 weeks of duration where participants were told that they video would still be played at the regular time.	Moderate to Vigorous PA (MPVA) measured through modified version of System for Observing Fitness Instruction Time (SOFIT) (McKenzie, Sallis & Nader, 1991)	Data graphed for visual analysis (Parsonson & Baers, 1990):

Marks et al., 2019, USA	379	Peer health coaches 35.5 (13.9), Peer participants 41.2 (16.1)	33 Peer health coaches with LD; 35 mentors/staff, 311 peer participants- peers with IDD	Quasi-experimental	Phase 1: training of peer health coaches and mentors. Phase 2: 12 weeks of 30min lessons led by peer leader coaches to peers with ID on health message and related activity.	Self-efficacy, promoting healthy lifestyles, health knowledge, health behaviours, PA, social support, process evaluation	Repeated measures ANOVA	Peer health coaches improved PA Knowledge. Mentors greater self-efficacy. Social support and Total Health Behaviour increased for peer participants. Peer participants had the greatest improvements after the 12- week program with exercise, drinking more water, and greater PA
Perez-Cruzado & Cuesta-Vargas, 2017, Spain	8	N/A	Mild LD	RCT	After receiving a PA + education intervention, participants were divided into two groups: smartphone intervention and no intervention. The smartphone intervention delivered advice and reminders every 2 days. The intervention lasted for 12 weeks.	PA measured with metabolic equivalent of task (METs) (Jetté et al., 1990)	Not included in the published paper. Upon contact with the authors, it resulted that Mann-Whitney U test was used	Increased PA engagement for the smartphone intervention
Matthews et al., 2016, UK	20 PWID, 6 stakeholders	N/A	Adults with LD	Qualitative	Semi-structured interviews and focused group	N/A	Process evaluation guidelines (Moore et al., 2015; WHO, 2001; Steckler, 2002).	Likeability of walking intervention. Positive impact carer participation.

| Brooker et al., 2015, Australia | 11 | 30- 59 | 5 PWID (4 females, 1 male) who expressed interest in the program but did not take part. 6 community-based volunteers | Qualitative | Walk and talk programme: walk at least once a week for 30min with a local volunteer | N/A | Thematic analysis | Barriers: safety, time of the day, weather condition. Facilitators: being in contact with nature, health and social benefits, managing emotions |

Appendices Part B
Appendix F: ethics approval
Salomons Institute for Applied Psychology

Canterbury
Christ Church
University

Lorena Tussis
Trainee Clinical Psychologist   **27 February 2020**
Canterbury Christ Church University   Direct line 01227 927094

                                                    E-mail   margie.callanan@canterbury,ac.uk

                                                    Our Ref   V:\075\Ethics\2019-20

Dear Lorena

Taxonomy and classification in intellectual disabilities (ID): inferences from an ICF-health- based questionnaire on athletes with ID[2].

Outcome: Full Approval

Thank you for addressing the points raised by the Ethics Panel so thoroughly, we are pleased to offer you approval for your proposed study.

We look forward to receiving a short report on progress and outcome on completion of the research, in order to complete our file. The report should be the same one that is provided to your participants. Please note that any changes of substance to the research will need to be notified to us so that we can ensure continued appropriate ethical process.

We wish you well with your study and hope that you enjoy carrying it out.

Yours sincerely,

Professor Margie Callanan
Chair of the Salomons Ethics Panel
Cc   Jan Burns
School of Psychology, Politics and Sociology
Faculty of Social and Applied Sciences

Canterbury Christ Church University
1 Meadow Road Tunbridge Wells Kent TN1 2YG (UK)
Tel +44 (0)1227 927166   www.canterbury.ac.uk

Registered Company No: 4793659 A Company limited by guarantee

Professor Rama Thirunamachandran, Vice-Chancellor and Principal

Registered Charity No: 1098136

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[2] This was the original title of the project when it was approved by the Ethics Panel

Appendix G: Information sheet for athletes

Canterbury Christ Church University

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Information about the research
Physical health in athletes with intellectual disabilities

Hi! My name's Lorena Tussis**. I'm a trainee clinical psychologist.**

I'm studying **at the Salomons Centre, part of Canterbury Christ Church University.**

Are you 18 years old, or older?

I would like to invite you **to take part in a research study.**
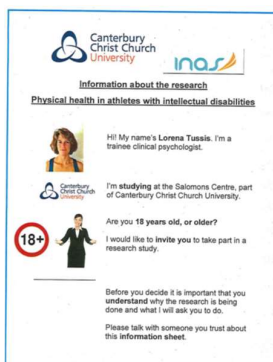
Before you decide it is important that you understand **why the research is being done and what I will ask you to do.**

Please talk with someone you trust about this information sheet**.**

Why are we doing this study?

I'm doing research **with** INAS**, the International Sports Federation for Persons with Intellectual Disability, and** Canterbury Christ Church University**. They are paying for the research.**

We want to get more people with intellectual disabilities to take part in sport**.**

We think that physical health **is important. We think it might be stopping some people with intellectual disabilities taking part in sports.**

Why have I been invited?

I am going to be talking with people with intellectual disabilities that compete at all sorts of different sporting events**.**

I am going to aim to talk to 100 people!

Do I have to take part?

You do not have to **talk to me!**

If you agree to take part, I will ask you to sign a consent form**. That means that you agree to take part in the study.**

You can change your mind **at any time. No one will think badly of you if you do this. If you change your mind we would not use what you say in the study.**

What will happen to me if I take part?

You can talk to me with someone that you trust**, like your coach, a family member or friend.**

I would ask you questions **about your physical health.**
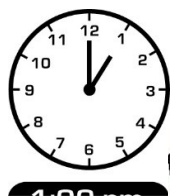
We would talk for about 30 minutes**.**

I would write down **your answers on a computer.**

It could be quite tiring **answering lots of questions. But you can ask for a break if you are feeling tired.**

I will be asking you questions about your physical health. This could feel difficult **or** embarrassing**. You do not need to answer all the questions. But you can talk about it if you want to.**

Other people have taken part in a project like this before. They found it OK**.**

What could be good about taking part?

We cannot promise that the study will help you**.**

But we hope that this study will help people with intellectual disabilities and physical health disabilities to take part **in all sport events.**

Will anyone know I have taken part?

I would keep what you say anonymous. **This means that we would not use your name, and no one would know that you took part.**

But it's not a secret! You can tell people that you have taken part, if you want to!

I would keep what you say safe**. It will be kept on a laptop. A password is needed to open the laptop.**

Only myself and my supervisor will look at what you say.

We will keep what you say for ten years**. After that we will delete all of the information.**

What will happen to what I say?

We will let you know **what we found out. We will do this by putting information on the INAS website.**

We hope to let other people know what we find. We will do this by writing a paper which could be printed **or be put on the** internet**.**

This paper would talk about everyone together**. No one reading the paper will be able to tell that you took part, unless you tell them.**

What if there is a problem?

If you are unhappy about any aspect of this study, you can speak to me and I will do my best to answer your questions.

Email: lt343@canterbury.ac.uk
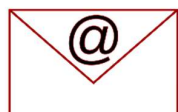
**You can leave a message for me on a 24-hour voicemail phone line:
(00 44) 1227 927070.
Please say that the message is for me (Lorena Tussis) and leave a contact number so that I can get back to you.**

**If you are still unhappy and wish to complain you can contact:
Doctor Fergal Jones Research Director**

Salomons Centre for Applied Psychology, 1 Meadow Road, Tunbridge Wells, Kent TN1 2YG.

Email: fergal.jones@canterbury.ac.uk

Tel: (00 44) 01227 927110

My Address
2 High Street
Newton
NW1 1PG
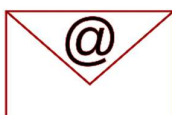
Appendix H: Information sheet for coaches/carers/family

Physical health in athletes with intellectual disabilities: Information about the research for people attending with participants

Hello. My name is Lorena Tussis and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study alongside the person you know who is an athlete with an intellectual disability (ID). Before you decide it is important that you understand why the research is being done and what it would involve for you.

Please feel free to talk to others about the study if you wish. Please also **read the information sheet for athletes** for further details.

What is the purpose of the study?
The purpose of the study is to **explore physical and sensory abilities in athletes with ID**. The reason for this is that, currently, there is only one competing class for athletes with ID at elite levels. This means that athletes with additional physical and/or sensory disabilities are often unable to compete at this level. We are working towards developing an additional competing class for athletes with ID, and hope that the information that we obtain in this research will be a step towards this goal.

Why have I been invited?
We will be interviewing athletes with intellectual disabilities about any physical and sensory difficulties that they experience. We are asking for someone who has a good relationship with the athlete and knows them and their medical history well to join the interview and **help answer questions**. It is therefore also **important that you speak English**. You could be the athlete's coach, a family member or a friend.

Do I have to take part?
It is up to you to decide to join the study. If the athlete you know agrees to take part I will ask them to sign a consent form.

What will happen to me if I take part?
If you and the athlete agree to take part I will come and meet you both at this event, at a time that suits you. I will talk over the research with both of you and ensure that you both want to continue with the interview. The interview itself will be based on the International Classification of Functioning, Disability and Health developed by the World Health Organisation.

The full interview will last up to **30 minutes**. I will use a laptop to record the answers to the interview. At the end I will also ask for some feedback on how you both found the interview.

What will I have to do?
I will be addressing questions to the athlete. However, as some of the questions will be quite specific, it will be valuable to have you there to **help answer** and, if necessary, **translate** questions. We will talk at the beginning of the interview about how we will manage this.

Who has reviewed the study?
All research is looked at by an independent group of people, called a Research Ethics Committee, to protect the interests of people who take part. This study has been reviewed and given favourable opinion by the Salomons Campus Ethics Panel.

Further information and contact details
If you would like to take part, or have any questions, please come and find me at this event! You can also send me an email:

Email: lt343@canterbury.ac.uk

You can leave a message for me on a 24-hour voicemail phone line at (00 44) 1227 927070. Please say that the message is for me (Lorena Tussis) and leave a contact number so that I can get back to you.

You can also find out more about the background to the research through the following sources:
- Information on the ICF: http://www.who.int/classifications/icf/en/
- Details on current classification of athletes with ID:
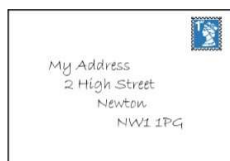 http://www.inas.org/member-services/eligibility-and-classification

Complaints
If you are unhappy about any aspect of this study, you can speak to me and I will do my best to answer your questions [(00 44) 1227 927070].

If you are still unhappy and wish to complain you can contact:
Doctor Fergal Jones, Research Director

Salomons Centre for Applied Psychology, 1 Meadow Road, Tunbridge Wells, Kent TN1 2YG.

Email: Fergal.Jones@canterbury.ac.uk

Tel: (00 44) 01227 927110

Appendix I: Consent form

![Canterbury Christ Church University logo] ![Inas logo - For para-athletes with an intellectual disability]

Consent form
Research with athletes with intellectual disabilities

Researcher: Lorena Tussis
Your unique number:

		Please initial box if you agree
	I have read, or I have had read to me, the information sheet **for the above study (dated 12/03/2019 v7)**	
	I understand **the information sheet for the above study (dated 12/03/2019 v7)**	

	I know why **you are doing this study.** **You have asked me if I have any** questions**.** **I have had any questions** answered	
	I want to **take part**	
	I know that it's OK to stop **at any time**	
	I know that this information will be about what I'm great at **and** what I'm not so good at	
	I agree **to take part in this study**	

_____   _____ _____
Name of Participant   **Date**   **Signature**

_____   _____ _____
Researcher   **Date**   **Signature**

Canterbury Christ Church University

The ICF-based Questionnaire

PART ONE
I'm going to start by asking some questions about you. You can ask your parent/carer/coach for help to answer the questions, if you need to.

i. **What is your gender?**
   Male/Female/Other
   [if hesitation: *Would you say you are a man, a woman, or something else?*]

ii. **What is your date of birth?**

iii. **What is your nationality?**

iv. **What is your ethnic group/background?**
   [if hesitation: *"Sometimes people are unsure about this question".* Use a famous person or, if you're happy to, yourself as an example]

v. **How many years have you been competing as an athlete (in any sport)?**

vi. **How many years have you been competing in this sport?**

vii. **Do you compete in any other sports?**

viii. **Do you have any problems with your health at the moment?**
[If yes] What are your main problems at the moment?

ix. **Are you taking any medication, either prescribed or over the counter?**

   [If yes] What are they?

x. **Do you use any assistive device, such as glasses, hearing aid, wheelchair etc?**

   [If yes] What are they?

   Can you play sport when wearing your [insert device]?

xi. **Do you have Downs Syndrome?**

   [If yes] Do you know which type?

   Trisomy 21 (nondisjunction) / Translocation /

   Mosaicism / Don't know

PART TWO
Now I'm going to ask you some questions about your physical health.

These questions are taken from a tool made by the World Health Organisation. So some of the language that's used is a bit difficult or confusing. I can give you more information to help you answer the question if you need it, just ask! Your parent/coach/carer can also help to answer the questions. They might also have a different opinion on the answers! If

they do, is it alright if they say, and then we can have a chat together about it?

You might not see these things as much of a problem. Or you might not think that they affect your day-to-day life very much. So it might be useful when answering the questions to think about someone else around your age that you know without the problem, to see if there is any difference.

This section is quite long. Please let me know if you'd like to stop or have a break.

Q1a Do you have problems with consciousness?
This means problems with being aware, alert and awake.
This includes loss of consciousness, such as blackouts, or fainting
[Including: functions of the state, continuity and quality of consciousness]

Q1b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete
[always illustrate this question using the scale at the end]

Q2a Do you have problems with energy and drive?
This includes things like your energy level, motivation, appetite, craving (including craving for substances, like alcohol), and impulse control
[Problems with the physiological and psychological mechanisms that cause the individual to move towards satisfying specific needs and general goals in a persistent manner.]

Q2b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

<u>Now I'm going to ask you some questions about SENSES AND PAIN</u>

Please answer this question for how you see without glasses, if you wear them

Q3a. Do you have problems with seeing things?

[Problems with sensing the presence of light and/or seeing form, size, shape and colour.

Including: impairments such as myopia (short-sightedness), hypermetropia (long-sightedness), astigmatism, hemianopia (blindness over half the field of vision), colour-blindness, tunnel vision, central and peripheral scotoma (a partial loss of vision or blind spot in an otherwise normal visual field), diplopia (double vision), night blindness and impaired adaptability to light]

Q3b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q4a. Do you have problems with the structures adjoining the eye?
This means problems with the structures in and around the eye that help you to see, such as the muscles in the eye, and the eyelid.

[Including: external muscles of the eye, including <u>voluntary and tracking movements and fixation of the eye</u>, lachrymal glands, accommodation, pupillary reflex; impairments such as in nystagmus (constant uncontrolled movement of the eyes), xerophthalmia (abnormally dry eyes) and ptosis (drooping or falling of the upper eyelid).]

Q4b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q5a. Do you have problems related to your eyes and adjoining structures?
This means sensations of tired, dry and itching eyes and related feelings.

[Including: feelings of pressure behind the eye, of something in the eye when there is nothing there, eye strain, burning in the eye; eye irritation]

Q5b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Please answer this question for hearing without the use of, for example, a hearing aid, if you use one.
Q6a. Do you have problems with hearing sounds?
[Problems relating to sensing the presence of sounds and telling the different location, pitch, loudness and quality of sounds.
Including: auditory discrimination, localisation of sound source, lateralization of sound, speech discrimination; impairments such as deafness, hearing impairment and hearing loss.]

Q6b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q7a. Do you have problems with the vestibular system?
This means problems with position, balance and movement.
[Related to functions of the inner ear. Including: problems with position and positional sense; problems with balance of the body and movement]

Q7b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q8a. Do you have problems related to hearing and vestibular function?
This means sensations of dizziness, falling, tinnitus (ringing in ears) and vertigo (feels like you or everything around you is spinning – enough to affect your balance).
[Including: sensations of ringing in ears, irritation in ear, pressure in the ears, nausea associated with dizziness or vertigo.]

Q8b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q9a. Do you have problems with proprioceptive function?

This means problems with sensing the relative position of body parts, without looking. For example, being able to reach out for a pen without looking, rather than having to stop, look, and direct your hand to grab the pen.

[Including: statesthesia (also known as joint position sense: the ability to know where your joints are when you have your eyes closed) and kinaesthesia (awareness of position, weight, tension and movement)]

Q9b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q10a. Do you have problems related to touch?
This means problems with sensing surfaces and their texture or quality. For example, being able to tell what this table feels like.

[Including: problems with touching, feeling of touch; impairments such as numbness, anaesthesia (temporary loss of sensation), tingling, paraesthesia ('pins and needles') and hyperaesthesia (excessive physical sensitivity, especially of the skin)]

Q10b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q11a. Do you have problems related to sensing temperature, vibration, and pressure?
For example: knowing what's a good temperature for the shower; feeling when your phone vibrates; feeling when someone touches your arm.

[Including: sensitivity to temperature, vibration, shaking or oscillation (swaying), superficial (slight) pressure, deep pressure, burning sensation or sensitivity to an unpleasant or harmful stimulus]

Q11b   If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q12a. Do you have sensations of pain?

This includes problems such as muscle pain, inability to feel pain, and being much more sensitive to pain than other people

[Unpleasant feelings indicating potential or actual damage to some body structure.

Including: myalgia (muscle pain), analgesia (inability to feel pain) and hyperalgesia (abnormally heightened sensitivity to pain), sensations of generalized or localized pain in one or more body part, pain in an area of skin, stabbing pain, burning pain, dull pain, aching pain]

Q12b   If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Now I'm going to ask you some questions about your HEART, LUNGS AND IMMUNE SYSTEM

Q13a. Do you have problems with your heart?
[Problems with the heart pumping blood around the body. Including: problems with heart rate and rhythm; the heart muscles; the heart valves; impairments such as tachycardia (abnormally high heart rate), bradycardia (abnormally slow heart rate) and irregular heart beat

and as in heart failure, cardiomyopathy (chronic disease of the heart muscle), myocarditis (inflammation and damage of the heart muscle) and coronary insufficiency (insufficient blood flow through one or more arteries in the heart)]

Q13b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q14a. Do you have problems with your blood vessels?
This means problems with moving blood around the body.
[Including: problems with the arteries, capillaries and veins (the tubes that transport blood around the body); constriction (tightening) or dilatation (widening) of blood vessels; valves of veins; impairments such as in blockage or constriction of arteries; atherosclerosis (a disease of the arteries in which fatty material is left on their inner wall), arteriosclerosis (the thickening and hardening of the walls of the arteries),

thromboembolism (obstruction of a blood vessel by a blood clot) and varicose veins (swollen and enlarged veins)]

Q14b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q15a. Do you have problems with blood pressure?
[This is what doctors look at when they put a cuff around your arm.
This means problems with keeping up a steady flow of blood around your body.
Including: problems with maintaining blood pressure; increased and decreased blood pressure; impairments such as in hypotension (abnormally low blood pressure), hypertension (abnormally high blood pressure) and postural hypotension (a drop in blood pressure after standing for at least one minute)]

Q15b   If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q16a. Do you have problems with your immune system?
This means problems related to protecting the body against things like infections.
This includes allergic reactions.
[Allergic reactions = e.g. anaphylactic shock from peanuts, NOT an intolerance e.g. to dairy.
Including: problems with the immune response (specific and non-specific); hypersensitivity reactions; lymphatic vessels and nodes; cell-mediated immunity, antibody-mediated immunity; response to immunization;
impairments such as in autoimmunity (abnormal immune response to a normal body part), lymphadenitis (inflammation of the lymph nodes) and lymphoedema (localized fluid retention and tissue swelling caused by a compromised lymphatic system)]

Q16b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q17a. Do you have problems with breathing?
[Problems with inhaling air into the lungs, the exchange of gases between air and blood, and exhaling air.
Including: problems with respiration rate, rhythm and depth; impairments such as <u>apnoea</u> (temporarily stopping breathing, especially during sleep), hyperventilation, irregular respiration, paradoxical respiration (breathing in which all or part of the chest wall moves in during inhalation and out during exhalation) and bronchial spasm (sudden constriction of the muscles in the walls of the bronchioles) and as in pulmonary emphysema (a condition in which the air sacs of the lungs are damaged and enlarged, causing breathlessness.)]

Q18b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q18a. Do you have problems with the muscles involved in breathing?
[Including: problems with the thoracic respiratory muscles; diaphragm; accessory respiratory muscles]

Q18b   If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q19a. Do you have additional breathing issues?
This means additional problems related to breathing, such as coughing, sneezing, yawning and mouth breathing

Q19b   If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q20a. Do you have problems with exercise tolerance?
This means issues related to breathing and your heart which allow you to exercise for a long time.
This includes: your body's ability to take in and use oxygen to do well in sport, and if you get tired or lose strength easily

Q20b   If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q21a. Do you have problems with sensations related to your heart and breathing?
This means sensations such as missing a heart beat, feelings of very quick or irregular heartbeat, and shortness of breath.
[Including: sensations of tightness of chest, palpitations, dyspnoea (shortness of breath or breathlessness), air hunger, choking, gagging and wheezing]

Q21b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Now I'm going to ask you some questions about your DIGESTION. These questions might feel a bit more sensitive

QX Do you have problems with going to the toilet?
This includes problems with constipation and diarrhoea. [includes: consistency of stool, frequency of defecation; incontinence; flatulence; impairments such as constipation, diarrhoea, watery stool and anal sphincter incompetence or incontinence]

QXb If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

QY Do you have problems with uncomfortable sensations with digestion?
This means uncomfortable feelings from eating and drinking. It includes feeling sick/nauseous, feeling bloated, getting stomach cramps, and heartburn.
[includes: fullness of stomach, globus feeling (painless sensation of a lump in the throat and may be described as a foreign body sensation, a tightening or choking feeling), spasm of stomach, gas in stomach. Exclusions: sensation of pain)

QYb If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q22a Do you have problems with keeping a healthy body weight?
[This includes: maintenance of acceptable Body Mass Index (BMI); impairments such as underweight, cachexia (weakness and wasting of the body due to severe chronic illness), wasting, overweight, emaciation (being abnormally thin or weak) and such as in primary and secondary obesity]

Q22b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Now I'm going to ask you some questions about MOVEMENT AND MOBILITY

Q23a. Do you have problems with moving your joints?
This includes problems such as in hypermobility of joints (like your wrist moving back too far), frozen joints, and arthritis
[This means problems with the range and ease of movement of a joint.
This includes: problems with the mobility of a single or several joints; mobility of joints in general.
joints include: vertebral (spine), shoulder, elbow, wrist, hip, knee, ankle, small joints of hands and feet]

Q23b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

 Q24a. Do you have problems with the stability of joints?
This means problems with the muscles and ligaments around your joints, that might mean that your joints dislocate, or you get a lot of injuries to your joints.
[This includes: problems with the stability of a single joint, several joints, and joints in general; impairments such as in unstable shoulder joints, dislocation of a joint, dislocation of shoulder and hip]

Q24b   If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q25a. Do you have problems with the mobility of bones?

This means problems with the range of movement, and how easy it is to move, your shoulder blade, pelvis, and bones in the wrist and foot
[Including: impairments such as frozen scapula and frozen pelvis]

Q25b   If yes, how much of a problem is this?
Mild Moderate   Severe   Complete
Q26a. Do you have problems with muscle power?
Examples of muscular power include throwing a punch, jumping over a hurdle, or swinging a bat.
This includes muscle weakness and muscle paralysis
[This means problems related to the force generated by the contraction of a muscle or muscle groups.
Including: problems associated with the power of specific muscles and muscle groups, muscles of one limb, one side of the body, the lower half of the body, all limbs, the trunk and the body as a whole;
impairments such as weakness of small muscles in feet and hands, monoplegia (paralysis restricted to one limb or region of the body), hemiplegia (paralysis of one side of the body), paraplegia (complete or incomplete paralysis affecting the legs and possibly also the trunk, but not the arms), quadriplegia (partial or total loss of use of all four limbs and torso)]

Q26b   If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q27a. Do you have problems with muscle tone?
If you have high muscle tone, this means that your muscles are tight and tense, even when you're not doing anything. If you have low muscle tone, you don't have enough tension in your muscles when you're resting, and muscles might feel 'floppy'.
[For example[3], if you had high muscle tone, you would have to concentrate very hard to reach out to grab a drink. It would take a lot of effort, and your movement might be jerky. If you have low muscle tone, you might need to use a bit extra

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[3] http://www.ot-mom-learning-activities.com/muscle-tone.html

momentum a grab a drink, maybe by flinging your arm out! You might then use too much oomph at first (to overcome the lack of "tension" in your muscles) with the result that the drink sloshes out!

Muscle tone means problems related to the tension present in the resting muscles and the resistance offered when trying to move the muscles.

This includes muscle spasticity (tight or stiff muscles and an inability to control those muscles)

Including: problems associated with the tension of isolated muscles and muscle groups, muscles of one limb, one side of the body and the lower half of the body, muscles of all limbs, muscles of the trunk, and all muscles of the body; impairments such as hypotonia (decreased muscle tone), hypertonia (increased muscle tone)]

Q27b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q28a. Do you have problems with muscle endurance?
This means problems related to your muscles keeping going without getting tired, like in doing sit ups, lifting weights, or in running or swimming.
[Including: problems associated with sustaining muscle contraction for isolated muscles and muscle groups, and all muscles of the body; impairments such as in myasthenia gravis (a rare long-term condition that causes certain muscles in the body to become weak)]
Q28b   If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q29a. Do you have problems related to motor reflexes?
This means problems with your muscles working automatically, without you thinking about it, in reaction to something. For example: reacting when you touch something hot.
[Including: problems with stretch motor reflex, automatic local joint reflex, reflexes generated by unpleasant stimuli and other

external stimuli; withdrawal reflex, biceps (upper arm) reflex, radius (forearm) reflex, quadriceps (thigh) reflex, patellar (knee) reflex, ankle reflex]

Q29b   If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q30a. Do you have problems related to involuntary movement <u>reactions</u>?
For example: when you step into the road and notice a car is coming, and you're able to jump back without thinking about it; or when you lose your balance and have to right yourself so you don't fall over.
[This means problems with involuntary contractions of large muscles or the whole body induced by body position, balance and threatening stimuli.
Including: problems with postural reactions, righting reactions, body adjustment reactions, balance reactions, supporting reactions, defensive reactions]

Q30b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q31a. Do you have problems related to control of voluntary movement?
This means problems with control over and <u>coordination</u> of voluntary movements.
This includes hand-eye coordination
[Including: problems of control of simple voluntary movements and of complex voluntary movements, coordination of voluntary movements, supportive functions of arm or leg, right left motor coordination, eye foot coordination; impairments such as control and coordination problems, e.g. dysdiadochokinesia (impaired ability to perform rapid, alternating movements)]

Q31b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q31c. Do you have problems related to control of complex voluntary movements?
This means problems with control over and coordination of <u>complex</u> voluntary movements. This is sometimes called fine motor control. For example, movements of the hands and fingers, like when holding a pen or doing up buttons.
Q31d If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q32a. Do you have problems related to involuntary movement?
This includes tremors, tics (like twitching or making a noise without meaning to) or other unusual movements
[This means problems with unintentional, non- or semi-purposive involuntary contractions of a muscle or group of muscles.
Including: involuntary contractions of muscles; impairments such as mannerisms, stereotypies (repetitive or ritualistic movement, posture, or utterance), motor perseveration (uncontrolled repetition or continuation of a response), chorea (involuntary jerky movements), athetosis (involuntary writhing movements), vocal tics, dystonic movements (involuntary muscle contractions that cause slow repetitive movements or abnormal postures) and dyskinesia (involuntary muscle movements)]

Q32b   If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Q33a. Do you have problems related to gait pattern?
This means problems with movements when you walk or run.
[Including: walking patterns and running patterns; impairments such as spastic gait (walking stifly, dragging the feet), hemiplegic gait (gait resulting from weakness/paralysis on one side of the body), paraplegic gait (gait resulting from weakness/paralysis in the lower limbs), asymmetric gait (limbs move together), limping and stiff gait pattern]

Q33b   If yes, how much of a problem is this?

Mild Moderate   Severe   Complete

Q34a. Do you have sensations related to muscles and movement functions?
This includes sensations of muscle stiffness and tightness of muscles, muscle spasm or constriction, and heaviness of muscles.

Q34b If yes, how much of a problem is this?
Mild Moderate   Severe   Complete

Appendix K: Visual scale

100% — **COMPLETE problem (total)**

90% —

80% —

70% — **SEVERE problem (high, extreme)**

60% —

50% —

40% — **MODERATE problem (medium, fair)**

30% —

20% —

10% — **MILD problem (slight, low)**

0% — **NO problem**
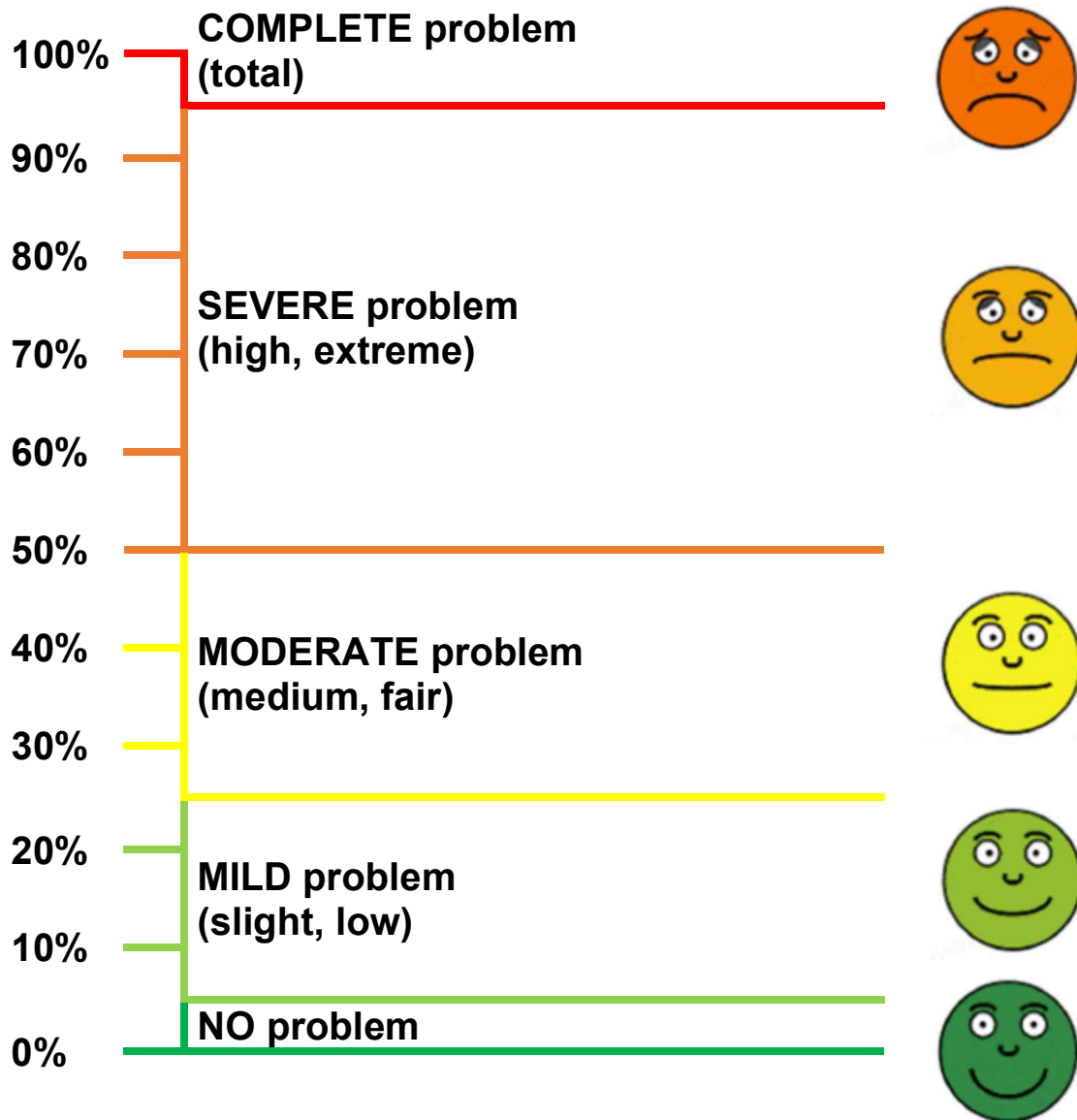
Post-interview questionnaire

1. Do you have a diagnosis of epilepsy?

Yes   No   Don't know

2. Do you have a diagnosis of Autism, Asperger's Syndrome or Autism Spectrum Disorder (ASD)?

Yes   No   Don't know

3. Do you have a diagnosis of Cerebral Palsy?

[This is a lifelong condition that affects movement and co-ordination]

Yes   No   Don't know

4. What did you think about the length of the ICF interview?

Too long
Long, but OK
Just right
Too short

5. Did you understand the questions that were asked?

Yes, all of them
Yes, most of them
Yes, some of them
No
If No, which ones?

6. Did you think the questions applied to you?

Yes   No

Is there anything that could have been explained more? If so what?

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                                                                    e
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up today?

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Any other comments?

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Appendix M: Manager and coaches' information about research for recruitment prior to GG

INAS II2 Eligibility Research Project:
Information about the research for team managers

Hello. My name is Lorena Tussis and I am a trainee clinical psychologist at Canterbury Christ Church University and I am working collaboratively with INAS, under the direction of Prof Jan Burns. I would like your help in recruiting athletes with intellectual disabilities (ID) to take part in a research study. Before you decide to help it is important that you understand why the research is being done and what we are asking of you.

Please feel free to talk to others about the study if you wish. Please also **read the information sheet for athletes for further details.**

What is the purpose of the study?
The purpose of the study is to explore physical and sensory abilities in athletes with ID and how this, alongside their intellectual disabilities, leads to their overall level of functional impairment. The reason for this is that, currently, there is only one competing class for athletes with ID in INAS competitions. This means that all athletes with ID must compete together with level of impairment not being considered. We are developing an additional

competing class for athletes with ID, and this research will help us develop the method by which athletes can access the II2 class for more significant impairments.

Why have I been contacted?
The research involves individual athletes, and somebody who knows them well, participating in a research interview. We are hoping to interview athletes with intellectual disabilities at the INAS Global games in October. As a team manager we would be very grateful for your support to interview athletes from your team.

Why should I help out?
The membership of INAS mandated the INAS Board to develop additional competition classes. To do this we need to establish an evidence-based approach to eligibility for those classes. We have established II2 for athletes with 'significant impairments'. However, this is only open to athletes with Down Syndrome (Trisomy) at the moment as their genetic condition means they will always have significant impairments due to additional health and physiological factors. However, we need to include other athletes who fall into this category and to do this we need to complete the research to establish the eligibility system. The faster we can complete the research, the faster we can fully establish this class and offer fairer competition and increased opportunities for more athletes.

What does the research involve?
An interview with one of three trained researchers to complete a standard health questionnaire. The researcher will record the answers and the interview should take about 30-40 mins. The athlete must be accompanied by someone who knows them well, so they can assist in helping the athlete answer the questions as accurately as they can. This may be a coach or other support team member, or a family member. The questionnaire is in English, we will have some parts of it available in other languages and some of the researchers and volunteer helpers have other languages, but at this stage we really need the accompanying person or an additional person who has good English.

Which athletes need to be involved?
At this point we need athletes who meet the following criteria
1. They do not have Down Syndrome
2. They are competing in either
   a. Swimming
   b. Cycling
   c. Athletics
   d. Rowing

What will I have to do?
1. **Before the Global Games**
   a. Please let the athletes competing at the global games know about the research. We are attaching an information sheet for the athletes for this purpose. Please feel free to distribute this information as widely as possible. Unfortunately, we can only provide this in English, so please ask people to explain it in your language.
   b. If you know that you have athletes who want to take part please can you complete form A attached and return to either Lorena (l.tussis343@canterbury.ac.uk) or Jan (jan.burns@inas.org). We will then contact you to make arrangements in advance of the Global Games.

2. **At the Global Games**
   We will confirm arrangements with you, including the time and place we will be carrying out the interviews and address any scheduling issues. <u>It is very important that somebody attends with the athlete who knows them well, and so can help them to answer the questions. Also, somebody who has a good understanding of English. This may be the same person or an additional person.</u> We are expecting that we will be carrying out the interviews close to where the athletes will be and so disrupt their schedule as little as possible.

3. **After the event**
   You won't need to do anything else after the event. However, once we have enough data and completed the analysis we will be providing a report to INAS on how to further develop class II2.

Who has reviewed the study?
All research is looked at by an independent group of people, called a Research Ethics Committee, to protect the interests of people who take part. This study has been reviewed and passed by Canterbury Christ Church University, Salomons Institute Ethics Panel.

Who is funding the study?
The study will be funded jointly by INAS and Canterbury Christ Church University.

Further information and contact details
If you would like to take part, or have any questions, please get in touch!

Lorena Tussis
Email: lt343@canterbury.ac.uk

You can leave a message for me on a 24-hour voicemail phone line at (+44) 0333 011 7070. Please say that the message is for me (Lorena Tussis) and leave a contact number so that I can get back to you.

Prof Jan Burns
Email: jan.burns@canterbury.ac.uk

Appendix N - Factor Analysis

The factor analysis did not meet the <mark>Kaiser</mark>'s rule of all communalities being above 0.7 (Field, 20017)

and due to its small sample it was not possible to rely on the Scree plot (Figure i) to identify underlying

factors (Stevens, 2002). The pattern matrix (Table iii) did not show clear factor loadings, which was

confirmed by the factor correlation matrix (see Table iv).

The analysis was re-run excluding the questions that yielded correlation coefficients smaller than 0.5

in the anti-image correlation matrix (Field, 2018). The following six questions with respective

correlation coefficient were removed:

- Do you have problems with proprioceptive function (0.473)

- Do you have problems with breathing (0.393)

- Do you have problems with muscle endurance (0.494)

- Do you have problems with involuntary movement reactions (0.491)

- Do you have problems with control of voluntary movement (0.497)

- Do you have sensations related to muscles and movement functions (0.465)

The new KMO value was still significant but decreased to 0.549, which was expected as some

questions that would have accounted for the variability were removed (Field, 2018).

Table *i* below illustrates how many factors explain the total variance observed, suggesting that there

might be twelve underlying factors.

Table *i*

Total variance explained

Factor	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings[a]
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total
1	3.249	11.202	11.202	2.699	9.307	9.307	1.371
2	2.206	7.607	18.809	1.694	5.842	15.149	1.339
3	1.876	6.470	25.279	1.336	4.605	19.755	1.513
4	1.653	5.702	30.981	1.154	3.980	23.735	1.168
5	1.573	5.425	36.406	1.020	3.518	27.253	1.395
6	1.452	5.007	41.413	.906	3.125	30.378	1.137
7	1.325	4.571	45.983	.772	2.662	33.040	1.209
8	1.259	4.342	50.325	.714	2.462	35.502	1.145
9	1.167	4.025	54.350	.634	2.187	37.689	1.162
10	1.130	3.897	58.248	.561	1.935	39.625	1.133
11	1.080	3.724	61.972	.545	1.879	41.504	1.132
12	1.065	3.673	65.645	.469	1.617	43.120	1.036
13	.971	3.349	68.994				
14	.883	3.044	72.038				
15	.829	2.860	74.898				
16	.783	2.700	77.598				
17	.769	2.653	80.250				
18	.690	2.378	82.628				
19	.639	2.204	84.833				
20	.587	2.026	86.858				
21	.573	1.975	88.834				
22	.522	1.799	90.633				
23	.494	1.704	92.336				
24	.468	1.614	93.951				
25	.436	1.504	95.454				
26	.395	1.362	96.816				
27	.353	1.217	98.033				
28	.324	1.119	99.152				
29	.246	.848	100.000				

Extraction Method: Principal Axis Factoring.

Keiser's rule states that for all twelve factors to be valid, in factor analysis on less than 30 variables, all their communalities should be above 0.7 (Field, 2018), which is not the case for the data collected

in this project (see Table ii). Moreover, the scree plot (Figure *i*) is not a reliable criterion for factor

selection since the sample size is smaller than 200 (Stevens, 2002).

Table *ii*

Communalities

|	Initial	Extraction
Do you have problems with consciousness?	.243	.503
Do you have problems with energy and drive?	.273	.383
Do you have problems with seeing things?	.308	.382
Do you have problems with the structures adjoining the eye?	.222	.223
Do you have problems related to your eyes and adjoining structures?	.248	.360
Do you have problems with hearing sounds?	.239	.350
Do you have probems with the vestibular system?	.351	.733
Do you have problems relaeted to hearing and vestibular function?	.352	.462
Do you have probolems related to touch?	.340	.366
Do you have problems relaeted to sensing temperature, vibration and pressure?	.321	.434
Do you have sensations of pain?	.316	.365
Do you have problems with your heart?	.190	.222
Do you have problem with your blood vessels?	.405	.688
Do you have problems with blood pressure?	.187	.178
Do you have problems with your immune system?	.368	.484
Do you have problems with the muscles involved in breathing?	.341	.557
Do you have additional breathing issues?	.178	.242
Do you have problems with exercise tolerance?	.333	.441
Do you have problems with sensations related to your heart and breathing?	.298	.383
Do you have problems with keeping a healthy body weight?	.239	.258
Do you have problems with moving your joints?	.249	.512
Do you have problems with the stability of your joints?	.382	.568
Do you have problems with the mobility of bones?	.286	.422
Do you have problems with muscle power?	.419	.697
Do you have problems with muscle tone?	.244	.311
Do you have problems related to motor reflexes?	.314	.496
Do you have problems related to control of complex voluntary movements?	.312	.550
Do you have problems related to involuntary movement?	.321	.426
Do you have problems relaeted to gait pattern?	.370	.509

Extraction Method: Principal Axis Factoring.
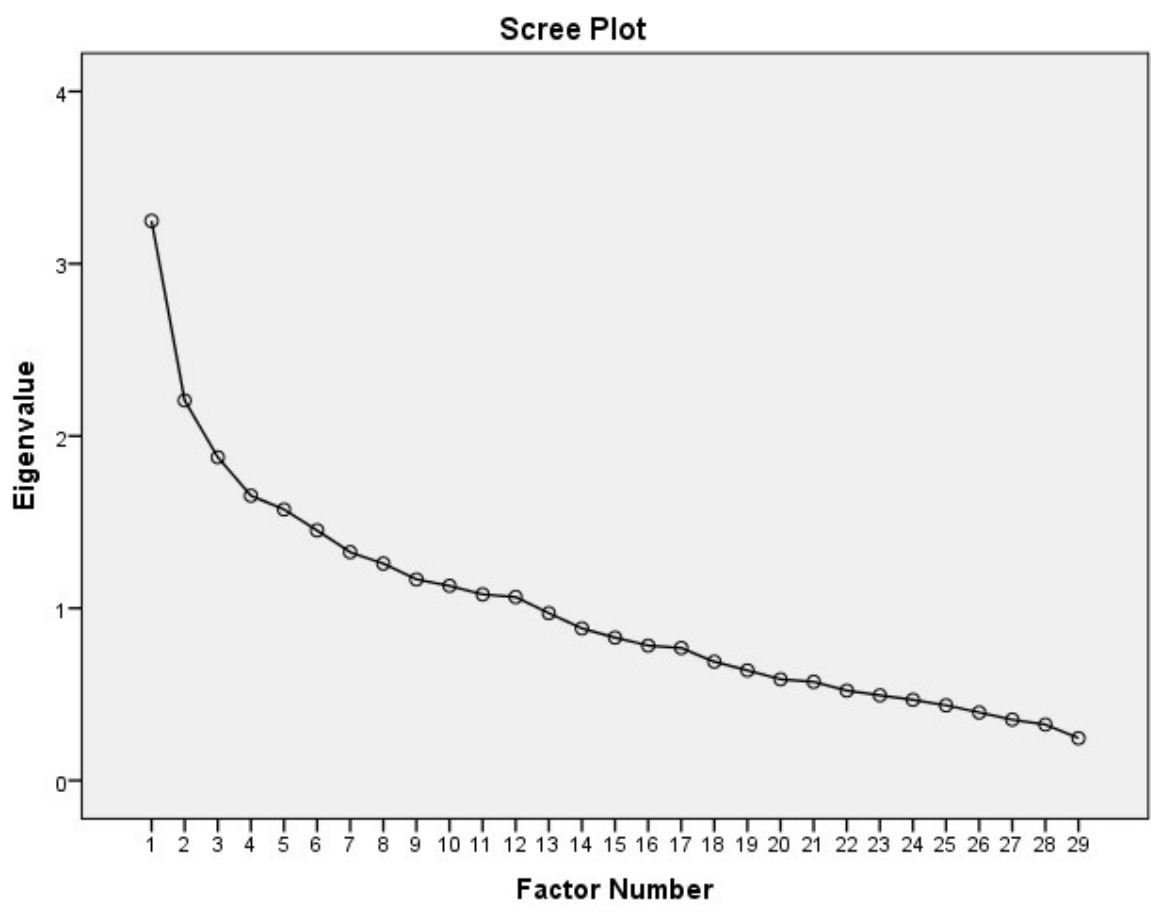
Figure i. Scree Plot

Field (2018) recommends using the pattern matrix (Table *iii*) to interpret factor loadings.

Table *iii*
Pattern matrix

	Factor											
	1	2	3	4	5	6	7	8	9	10	11	12
Do you have problems with your immune system?	.572											
Do you have problems related to involuntary movement?	.351					.339						
Do you have problems with blood pressure?	.340											
Do you have sensations of pain?	.336											
Do you have problem with your blood vessels?		.729										
Do you have problems with the stability of your joints?		.568										
Do you have probems with the vestibular system?			.861									
Do you have problems relaeted to gait pattern?			.463						-.349			
Do you have problems with the structures adjoining the eye?												
Do you have problems with the muscles involved in breathing?				.762								
Do you have problems relaeted to sensing temperature, vibration and pressure?				.401					.372			
Do you have problems with seeing things?				.334							.302	
Do you have problems with muscle power?					-.762							
Do you have problems with the mobility of bones?					-.510							
Do you have problems with muscle tone?												
Do you have problems with consciousness?						.711						
Do you have problems with energy and drive?						.497						
Do you have problems with hearing sounds?							.588					
Do you have problems relaeted to hearing and vestibular function?	-.352						.403					
Do you have problems related to control of complex voluntary movements?								.728				
Do you have problems related to motor reflexes?									.606			
Do you have probolems related to touch?					-.308				.438			
Do you have problems related to your eyes and adjoining structures?										.552		
Do you have additional breathing issues?										.334		
Do you have problems with keeping a healthy body weight?												
Do you have problems with moving your joints?											.702	
Do you have problems with sensations related to your heart and breathing?											.380	
Do you have problems with exercise tolerance?												.464
Do you have problems with your heart?												.413

Extraction Method: Principal Axis Factoring.
Rotation Method: Oblimin with Kaiser Normalization.

From the pattern matrix, at this stage, there are no clear factor loadings, confirmed by the factor correlation matrix (Table iv) does not show any good correlations between the factors.

Table *iv*
Factor correlation matrix

Factor	1	2	3	4	5	6	7	8	9	10	11	12
1	1.000	.080	-.027	.085	-.093	.172	.107	-.007	.072	.173	.148	.106
2	.080	1.000	.036	.033	-.001	.053	.090	.015	-.021	.132	.163	-.021
3	-.027	.036	1.000	.032	-.198	.022	.205	.221	.087	.047	.119	.132
4	.085	.033	.032	1.000	-.015	-.028	.093	.168	.014	-.003	.023	.141
5	-.093	-.001	-.198	-.015	1.000	-.132	-.049	-.163	-.097	.004	-.042	-.080
6	.172	.053	.022	-.028	-.132	1.000	.122	-.019	.014	.072	-.018	.049
7	.107	.090	.205	.093	-.049	.122	1.000	.077	-.072	.170	.117	.108
8	-.007	.015	.221	.168	-.163	-.019	.077	1.000	.072	.015	.112	.031
9	.072	-.021	.087	.014	-.097	.014	-.072	.072	1.000	.089	-.080	.112
10	.173	.132	.047	-.003	.004	.072	.170	.015	.089	1.000	.141	.045
11	.148	.163	.119	.023	-.042	-.018	.117	.112	-.080	.141	1.000	-.067
12	.106	-.021	.132	.141	-.080	.049	.108	.031	.112	.045	-.067	1.000

Extraction Method: Principal Axis Factoring.

Rotation Method: Oblimin with Kaiser Normalization.

Appendix O – Salomons Ethics Panel letter report

To the Chair of Salomons Ethics panel,

This is a brief report on the Major Research Project 'Taxonomy and Classification in Intellectual Disabilities (ID): Measuring the health status of athletes with ID using an ICD based questionnaire', which was initially titled as 'Taxonomy and classification in intellectual disabilities (ID): inferences from an ICF-health- based questionnaire on athletes with ID'.

The project aimed to explore the current conceptualisation of intellectual disability (ID), questioning an IQ-centred classification to consider a more holistic taxonomy that includes physical health. The project further developed and tested the psychometric properties of a pre-existing health-based questionnaire that was built on the International Classification of Functioning, Disability and Health (ICF) classification in a previous pilot study (Lemmey et al., 2021). The project involved two phases. The first phase was based on data-collection by interviewing athletes at different sporting events. Due to COVID-19, the data collection was limited to one single sporting event, the Global Games, which were held in Australia in October 2019. A total of sixty-seven elite athletes were interviewed using the final questionnaire (ICF-37). The second phase combined the data from the pilot study and the newly-collected data to analyse the discriminatory abilities of ICF-37 using performance as a variable to test the questionnaire's sensitivity. The ICF-37 met all psychometric standards tested, except for internal consistency as more participants are needed for a robust analysis. The ICF-37 also showed to have good discriminatory abilities. Participants' feedback of the experience of being interviewed with the ICF-37 was positive. This questionnaire has the potential to contribute to a revisited taxonomy of ID to include physical health which, if adopted in the clinical sector, would facilitate a more holistic understanding of clients. It also has the potential to be used in sporting classification allowing for greater inclusion of athletes and fairer competition.

Yours sincerely,

Lorena Tussis

Trainee Clinical Psychologist

Reference:

Lemmey, S., Burns, J., & Jones, F. (2021). Developing additional competition classes for athletes with intellectual impairments: Conceptual approach and efficacy of an ICF derived measure. *Journal of Sports Sciences, ahead-of-print*(ahead-of-print), 1-10. https://10.1080/02640414.2021.1881302

Appendix P – End of Study Report for Participants

Physical health in athletes with intellectual disabilities research: our results!

Thank you for taking part in my study!

The research was with **VIRTUS**, the International Sports Federation for Persons with Intellectual Disabilities, and **Canterbury Christ Church University**
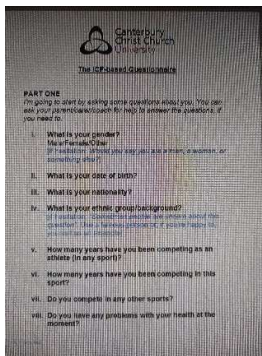
Why did we do this study?

We want to get more people with intellectual disabilities to take part in **sport**.

We think that **physical health** is important. We think it might be stopping some people with intellectual disabilities taking part in sports.

What did we do?

We talked to **69 athletes!**

We asked athletes to do a **physical health questionnaire.**

What did we find?

The questionnaire showed that different athletes had different **physical health** problems.

Athletes with better physical health do better in **sport competitions** than athletes with poorer physical health.

We hope that this research will allow for more athletes with physical health problems to **compete in sport**!

With this research more athletes can enter **ll2 class**!

What will happen next?

We hope to let other people know what we find. We will do this by writing a paper which could be **printed** or be put on the **internet**.

This paper would talk about **everyone together**. No one reading the paper will be able to tell that you took part, unless you tell them.

Thank you so much for taking part. Good luck in your next sport competition!

Lorena Tussis
Trainee Clinical Psychologist

Supervised by Jan Burns, Professor of Clinical Psychology
and by
Suzie Lemmey, Doctor in Clinical Psychology

Appendix Q - MRP Confirmation Form
CONFIRMATION FORM FOR MRP

In submitting my Major Research Project to the CCCU institutional repository and the British Library EThOS service, I confirm that I have checked that my thesis:

1) does not contain any copyrighted or confidential material (such as copies of measures or complete interview transcripts in appendices),
2) that any blacked-out information cannot be found through the search function and
3) that I have securely deleted all personally identifiable data collected during this MRP and have only retained anonymous data. This includes deleting identifiable data off an online survey host, if one was employed. I also confirm that I will store the anonymous research data securely and erase it 10 years after the completion of the study.*

SIGNED: _LC._   Author

NAME (PRINTED): Lorena Tussis   Author

Date: 16.04.2021

*Occasionally, at the time of MRP submission, a study may still be collecting data in order to improve the chances of publication. If that is the case, please instead confirm that you will follow the data storage and retention procedures specified in your approved ethics application.

Appendix R – Author guidelines for chosen journal

The chosen journal for publication of this dissertation is the Journal of Adapted Physical

Activity Quarterly.

Below are the author guidelines for publication in this journal (available at

https://journals.humankinetics.com/view/journals/apaq/apaq-overview.xml?tab_body=null-

7643)

Authorship Guidelines

The Journals Division at Human Kinetics adheres to the criteria for authorship as outlined by the International Committee of Medical Journal Editors*:

Each author should have participated sufficiently in the work to take public responsibility for the content. Authorship credit should be based only on substantial contributions to:

a. Conception and design, or analysis and interpretation of data; and
b. Drafting the article or revising it critically for important intellectual content; and
c. Final approval of the version to be published.

Conditions a, b, and c must all be met. Individuals who do not meet the above criteria may be listed in the acknowledgments section of the manuscript. *Uniform requirements for manuscripts submitted to biomedical journals. (1991). *New England Journal of Medicine*, 324, 424–428.

Open Access

Human Kinetics is pleased to allow our authors the option of having their articles published Open Access. In order for an article to be published Open Access, authors must complete and return the Request for Open Access form and provide payment for this option. To learn more and request Open Access, click here.

Manuscript Guidelines

As outlined in the *Adapted Physical Activity Quarterly* (*APAQ*) Mission, the journal accepts five major types of papers: Viewpoint, Review, Original Research, Brief Research Note, and Application. Occasionally, *APAQ* may present papers related to a specific theme; to read more about special issues, download the guidelines here.

Cover Letters. Authors must submit a separate cover letter that lists (a) the title of the manuscript, (b) the date of submission, and (c) the full names of all the authors and their institutional or corporate affiliations, as well as (d) the corresponding author's e-mail address. In addition to this essential information, a cover letter should be composed as described on pp. 230–231 of the *Publication Manual of the APA* (7th ed., 2020) and should include clear statements pertaining to potential fragmented publication, authorship, and other ethical considerations.

More specifically, the cover letter should include the following statements:

- "This manuscript represents results of original work that have not been published elsewhere (except as an abstract in conference proceedings). This manuscript has not and will not be submitted for publication elsewhere until a decision is made regarding its acceptability for publication in *APAQ*. If accepted for publication, it will not be published elsewhere."
- "Furthermore, if there are any perceived financial conflicts of interest related to the research reported in the manuscript, I/we (the author/s) have disclosed it in the Author's Notes."
- "All authors acknowledge ethical responsibility for the content of the manuscript and will accept the consequences of any ethical violation."
- "This research is not part of a larger study."

If the study *is* part of a larger study, authors must follow the guidelines specified in the *Publication Manual of the American Psychological Association* (pp. 17–20 of 7th ed.).

Editorial Decisions. Submissions that are rejected (i.e., that do not receive a minor- or major-revision decision and invitation to resubmit) should not be resubmitted to *APAQ* per the *Publication Manual of the APA* (7th ed., 2020, p. 381), which reads that any manuscript "that has been rejected by a journal may not be revised and resubmitted to that same journal."

<p align="center">Preparing and Reporting Guideline</p>

ViewpointsAPAQ will publish well-informed viewpoints relevant to adapted physical activity (APA) integrating the body of knowledge in a relevant area. Exchanging and debating ideas is central to the future of APA. *APAQ* welcomes the exchange and debate of ideas related to key issues in our field.

Different types of papers might qualify as Viewpoint. In general, Viewpoints are a subset of articles that reflect a particular position adopted by a person or a group. A Viewpoint is an articulated organized perspective about a particular topic or issue associated with APA. It is a scholarly view on a topic of importance in APA. A Viewpoint must be clearly expressed and demonstrate a thorough and broad understanding of the literature and practices in the field. The opinion expressed must be cogently presented and lead to insights and possibly new and interesting perspectives. *APAQ* will expect a Viewpoint paper to stimulate discussion among the APA community that will result in advancing our knowledge and understanding of contemporary issues, as well as practice, in APA.

While the subjective nature of Viewpoint manuscripts should be taken into account, high scholarly standards for relevance, documentation, organization, and content pertain. The author must establish a context for why the manuscript is justified and must point toward the implications or consequences that might follow from the opinions expressed in the article.

General Criteria

- The article addresses a serious challenge facing the APA community.
- The article significantly adds to or enhances our understanding of challenges and/or issues on the subject in question.
- A good case for the Viewpoint is made.

Writing

- The context for the article is made in the introduction and a logical case is made for the expression of the Viewpoint.

- The purpose of the Viewpoint is clear and well articulated. The Viewpoint is cogently argued.
- The Viewpoint is based on a thorough understanding of the present body of knowledge and/or practices.
- As needed, the literature is thoroughly reviewed, appraised, and well-integrated.
- Historical background is thoroughly reviewed, where appropriate.
- Key concepts and terms are well explained.
- The manuscript is logically organized, well written, and easy to follow.
- The parts of the manuscript are well integrated and coherent and the conclusions follow.
- Contrasting viewpoints or counter-arguments are considered.
- The perceived benefits and limitations of the position advocated are clearly stated.
- The number of references is appropriate and their selection is judicious.