Accessible summary

- Most physical activity studies exclude individuals with severe and profound intellectual disabilities, and the reasons for these exclusions are unclear. Therefore, this study explored the practicalities of recruiting and measuring adults with intellectual disabilities, including those with severe and profound intellectual disabilities.
- Each individual and their carer or family filled in a questionnaire where they were asked about their physical activity over the previous 7 days, thereafter, they were given an accelerometer for 7 days to measure their physical activities.
- Four things were found to be important for this type of study: 1) where participants lived; 2) what was used in measuring their physical activity; 3) their reported physical activity was similar to what their family/carer reported; and 4) it was also similar to what was measured.
- The study showed that it is possible to measure physical activity irrespective of the intellectual disability severity, and that adults with intellectual disabilities can tell you about their physical activity and so can their relatives/carers without the need for expensive equipment.

Abstract

Background

Few studies have measured physical activity (PA) levels of adults with intellectual disabilities using both objective and subjective methods, but none included individuals with profound intellectual disabilities. To inform effective measurement of PA across the disability spectrum, this study explored: the feasibility of measuring PA levels using the International Physical Activity Questionnaire-short version (IPAQ-s) and a wrist-worn 7-day accelerometer; examined the level of agreement between instruments/raters; and established the recruitment rate. From the literature reviewed, no study has investigated these issues.

Materials and Methods

Two-hundred adults with intellectual disabilities from a local authority lists in UK were invited to participate. Participants were administered an accelerometer for seven days and the IPAQ-s (self and carer-reported).

Results

Twenty participants with mild to profound intellectual disabilities (20-70yrs) were recruited. The response rate was significantly different between home (16%) and residential-homes (4%): $\chi^2(1) = 7.7$, $p<.05$. All participants completed the IPAQ-s but only 15 completed 7-day accelerometer. Self and carer-reported PA had perfect agreement on IPAQ-s, and agreements between instruments using PA guidelines was substantial ($k=0.6$, $p<0.05$). However, mean moderate-vigorous PA minutes/week differed between measures at 145 and 207 from IPAQ-s and accelerometer respectively.

Conclusions

Recruitment demonstrated a need for better engagement with residential-homes. While both the IPAQ-s and accelerometers can be used to evaluate PA levels, the IPAQ-s was more acceptable and carer report was accurate, but it underestimated absolute moderate-vigorous PA levels. These findings indicate that IPAQ-s can be used to measure PA levels, including in those with profound intellectual disabilities.

1. **Introduction**

Research indicates levels of physical activity (PA[1]) are lower in adults with intellectual disabilities compared to the general population (Barnes, Howie, McDermott, & Mann, 2013; Dairo, Collett, Dawes, & Oskrochi, 2016; Phillips & Holland, 2011). However, this finding is informed by data biased towards individuals with mild-moderate intellectual disabilities. Our understanding of their low PA levels is limited by a lack of information on how it can be measured effectively, particularly in those with severe/profound intellectual disabilities. Given the predicted increase in the number of people with intellectual disabilities (Emerson, Glover, Hatton, & Wolstenholme, 2014; Harris, 2006; Holland, 2000) and the higher health care costs associated with its management (Doran et al., 2012), as well as the health disparities experienced by this group (Emerson et al., 2014; Heslop et al., 2014; Krahn, Hammond, & Turner, 2006), identifying those most at risk of physical inactivity will likely

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[1] Physical activity (PA)

lead to better outcomes at a lower cost. After all, PA benefit is higher for the least active people (World Health Organisation, 2010).

To identify those who are most at risk, it is important that PA measures can be applied across an intellectual disability spectrum. An intellectual disability is classified as mild, moderate, severe, and profound based on the extent to which an individual is unable to face the demands established by society for the individual's age group (Katz & Lazcano-ponce, 2008; Salvador-Carulla et al., 2011). Individuals with severe or profound severities may have many impairments, including limited motor functioning (Harris, 2006; Pratt & Greydanus, 2007). Consequently, being physically active is likely to be more challenging than in people with mild to moderate range of intellectual disability severity. Furthermore, evidence suggests that the severity of the intellectual disability is the most significant determinant of PA levels (Dairo et al., 2016). Therefore, to inform effective measurement of PA in this group of people, we need measures that can be used on those with mild to moderate, as well as those with severe and profound intellectual disabilities.

1.1. Review of Literature

PA can be measured either subjectively or objectively. Subjective methods rely on either recall or a prospective recording of PA, while objective methods measure it prospectively. For adults with intellectual disabilities, both methods can be challenging. The systematic review by Dairo et al. (Dairo et al., 2016) on PA levels of adults with intellectual disabilities showed that although several studies have used objective measures such as accelerometers (Barnes et al., 2013; Dixon-Ibarra, Lee, & Dugala, 2013; McKeon, Slevin, & Taggart, 2013; Phillips & Holland, 2011), they were limited to people with non-profound intellectual disabilities. Also, they found that in studies that used subjective measures (Barnes et al., 2013; Hawkins & Look, 2006; McKeon et al., 2013), these were not validated in intellectual

disabilities population, with the exception of the International Physical Activity Questionnaire (IPAQ[2]). Additionally, they found that despite some of the studies using both objective and subjective methods, none included participants with profound intellectual disabilities.

While objective measures of PA are generally accepted to be more accurate, subjective methods such as the IPAQ may be easier to administer clinically and in research settings (Craig et al., 2003). However, to our knowledge, only two studies have used the IPAQ within the intellectual disabilities population, with different findings (Matthews et al., 2011; McKeon et al., 2013). Furthermore, these studies were not representative of intellectual disabilities populations as one consisted only of male participants (McKeon et al., 2013) and the other was limited to participants with non-profound intellectual disabilities (Matthews et al., 2011).

From the literature reviewed, it is not clear why people with severe and profound intellectual disabilities were often excluded from PA studies, or the feasibility issues around their recruitment and measurement. Thus, the aim of the current study was to explore the feasibility of measuring PA levels in individuals across the intellectual disability spectrum.

1.2.Research questions

1) What is the response/recruitment rate of those invited to take part?

2) What are the characteristics of those who did take part (participants)?

3) Is there agreement between the wrist-worn 7-day accelerometer and the short version of the IPAQ (IPAQ-s[3])

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[2] International Physical Activity Questionnaire (IPAQ)
[3] Short version of International Physical Activity Questionnaire (IPAQ-s)

4) Is there agreement between self and carer-reported PA?

5) Do adults with intellectual disabilities find the PA measures acceptable?

2. **Methods**

This cross-sectional feasibility study was prepared and reported with reference to the 'STROBE Checklist (Knottnerus & Tugwell, 2008). Recruitment and data collection took place between January and June 2016 in Buckinghamshire, UK.

2.1. *Recruitment*

Every fifth person (n=200) on the Buckinghamshire local authority's list of adults with ID (n~1000) was identified and selected purposefully by an administrative staff to have a representative sample covering different age groups, type of residence, and both genders (Table 1). They were invited to take part by letter. This was followed by presentations by the researcher to invitees in residential-homes and at day centres, so as to increase representation from those invited with severe/profound intellectual disabilities.

(Table 1)

2.2. **Screening and eligibility**

People who indicated an interest were contacted by phone or e-mail in order to address any further questions and to screen them for suitability to participate using the eligibility criteria below:

2.2.1 Inclusion criteria

- Reside in Buckinghamshire.

2.2.2. Exclusion criteria:

- People/carers who do not understand instructions in English;

- Acute musculoskeletal injury, such as fractured limb, sprains and strains;

- Recent history (last one year) of physical violence or self- injurious behaviour;

- Unable to tolerate wearing the accelerometer;

- Acquired brain (diagnosed in adulthood) / spinal cord injuries.

2.3. *Ethical considerations and consent procedures*

Ethical approval was sought from and granted by the University Research Ethics Committee (no.150967). The study was conducted in line with the declaration of Helsinki. Participants were provided with space and time in their own home to consent to participate in the study and consent obtained primarily, from each individual participant. Where a person lacked the capacity to consent, in line with the Mental Capacity Act (UK government Department of Health, 2005), a proxy decision-maker (staff /carer or next of kin) was identified, who must have known the participant for at least six months.

2.4. *Data collection and Materials*

Information on age range, sex, and type of residence was obtained from social care records of all invitees. For participants, we obtained consent as described in section 2.3. Additionally, we collected information on their age, race, employment status, and mobility. We then assessed the intellectual disability severity by administering the Leicestershire Intellectual Disability tool to the participants or their carer/relative. The severity was categorised by the total score of the tool based on the ICD-10 criteria for mild, moderate, severe, and profound intellectual disabilities (Tyrer et al., 2008). Thereafter, we assessed participants' PA as described below.

2.4.2. *Physical activity assessment*

The participant and their carer/relative received an accelerometer during a home visit by the researcher. The accelerometer models used were Axivity AX3 or GENEActiv. They were shown how to wear the accelerometer on their wrist (left or right depending on preference) during all waking hours for seven consecutive days, with instructions on how to contact the researcher in case of discomfort or equipment malfunction. They also received copies of the IPAQ-s, in which we included pictures of PA and time for ease of understanding (**International Physical Activity Questionnaire**, 2002; Lee, Macfarlane, Lam, & Stewart, 2011). They were instructed that on the 8th day, they and or their carers would complete the questionnaire and return it with the accelerometer in a stamped self-addressed envelope.

2.5. *Data analysis*

Data from Axivity and GENEActiv accelerometers were downloaded directly onto a laptop using software from https://github.com/digitalinteraction/openmovement/blob/master/Downloads/AX3/AX3 -GUI-29-beta.zip, and from http://www.geneactiv.org/resources-support/downloads-software/ respectively. The Axivity data were also converted by the same software, but the GENEActiv data were converted by means of an in-house custom written program into how much time a participant spends in sedentary, light, moderate- or vigorous-intensity physical activity (MVPA[4]) using PA cut-points based on the Eslinger study (Esliger et al., 2011). Similar cut-points have been used in previous intellectual disabilities studies (Dixon-Ibarra et al., 2013; Phillips & Holland, 2011). As this is a feasibility study, we included all accelerometer data in the descriptive analysis. For both PA methods, minutes of MVPA intensity were used to

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[4] Moderate- or vigorous-intensity physical activity (MVPA)

estimate the percentage of participants meeting the physical activity guidelines (PAG[5]) established by the UK Chief Medical Officer (Chief Medical Officer, 2011).

A flow chart of the recruitment process was reported (see Figure 1). Descriptive and frequency statistics were used to summarise the characteristics of participants. Groups (age, race, and residence) were compared using a non-parametric statistics, the one sample Goodness-of-Fit Chi square test. Cohen's kappa coefficient (Cohen, 1960) was used to measure inter-rater agreement and the agreement between the two PA measures. Also, a Bland-Altman plot was used to visualise the level of agreement between the two measures (Bland & Altman, 2010).

(Figure 1)

3. **Results**

3.1. *Response and recruitment rates*

The response rate (Table 1) for those living in a residential-home was significantly lower compared to those living at home (X^2 (1) = 7.7, p <0.05). However, there was no statistically significant difference between: the number of participants living at home and those in a residential-home; the different age groups; and the sexes. The recruitment flow is presented in Figure 1.

(Table 2)

3.2. *Characteristics of participants*

Participants were 20 adults with mild to profound intellectual disabilities (profound (n=5), severe (n=7), moderate (n=4), and mild (n=4)) with a mean age of 50 (16) years (22 – 70). A

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[5] Physical activity guidelines (PAG)

summary of participants' characteristics is found in Table 2 Fewer participants were active compared to those inactive (Table 3), accelerometer and IPAQ-s data indicated 6/16 (38%) and 8/20 (40%) respectively.

(Table 3)

3.3. *Level of agreement between the two physical activity measures*

The mean values between accelerometers and the IPAQ-s differed (Table 4), but they had a substantial agreement in identifying participants who achieved PAG, $k= 0.61$ $p<0.05$ (Table 3). Also, the Bland-Altman plots (see Figure 2) shows no heteroscedasicity demonstrating that variation between measures is not influenced by PA levels.

(Figure 2)

3.4. *The level of agreement between self and carer-reported physical activity*

Seven of the participants were able to recall PA over the previous seven days using the IPAQ-s, with an almost equal number of carers overestimating as underestimating PA minutes/week, but there was a perfect agreement ($k=1$, $p<0.05$) between self and carer recall of PA in identifying participants who achieved PAG.

(Table 4)

3.5. *Acceptability of physical activity measures*

All the 20 participants completed the IPAQ-s while for the accelerometer; although 17 participants wore it for seven days, only 15 had a complete seven days data. All 10 participants living at home had seven days' accelerometer data, though their intellectual disabilities ranged from mild to profound. In contrast, the five participants with

no/incomplete accelerometer data lived in a residential-home. Reasons for not wearing the accelerometer included statements from participants of: "too heavy" and "uncomfortable". Overall, there were two cases of reported 'adverse reaction' to the Axivity, due to irritation caused by the strap. Consequently, we changed the sensors to GENEActiv. Therefore, 8 out of 17 received Axivity whilst the rest (9 participants) received the GENEActiv.

4. **Discussions and conclusion**

4.1.   Discussion

We experienced greater difficulty in recruiting people from residential-homes compared to those living at home, which is important for understanding the lack of data on individuals with profound intellectual disabilities.   However, we found that both accelerometers and the IPAQ-s could be used to measure PA across the intellectual disability spectrum. Participants' recall of PA over the previous seven days was as good as that of their carers in determining whether they were active/inactive. Likewise, a substantial agreement was found between the accelerometer and IPAQ-s, when the outcome is whether an individual is active/inactive as determined by the PAG. However, the minute by minute measurement of PA by IPAQ-s tended to underestimate MVPA in comparison to the accelerometer.

4.1.1.   Research engagement

Only 5 out of 76 invitees living in residential-homes initially responded to the research invitation, with only two positive responses. The reasons for this are not fully understood, but the reluctance of carers to give consent by proxy could be a contributing factor (Dairo,

Collett, & Dawes, 2017). Evidence of proxy respondent's willingness in intellectual disabilities population is limited, but studies in other spheres, such as end of life care, found the responsibility for proxy-decision may leave carers stressed and uncomfortable (Arora, Cummings, & Crome, 2016). Similarly, an older adult study found that informal caregivers were reluctant to proxy response, especially if they consider the risk to be high (Dubois et al., 2011). Unfortunately, these factors might have contributed to carers excluding individuals from research studies. Improving participation in research in this population might require changes to the current ethical application procedures and committees, either for them to have representation from the boards of residential-home providers or for researchers to be able to apply and have permission granted by a board of residential-homes. An example of a board of residential-homes granting permission was found in a recent study that used diaries to measure motor activation of individuals with profound intellectual disabilities from the Netherlands (van Der Putten, Bossink, Frans, Houwen, & Vlaskamp, 2017).

4.1.2. Demography

The response rate was higher among individuals living at home compared to those in residential-homes, with half of those recruited living at home despite the fact that they made up just a little more than a third of the those invited. Notably, the local authority area where we recruited from has a higher proportion of adults with intellectual disabilities living in registered-care than the national average (MacDonnell, 2014). While age was not significantly different between participants and non-participants, the trend was an increasing number of participants with increasing age. This warrants further investigation with an appropriately powered study. It is also likely that race is a factor as all the participants were white. Information from the local authority suggests that invitees have different ethnicities

with approximately 12% -18% of Buckinghamshire intellectual disabilities population from Asian origins (MacDonnell, 2014).

4.1.3. Concurrent validity

Our results suggest that the IPAQ-s was more acceptable than the accelerometer, which is consistent with findings from a follow-on study where only 3 out of 11 adults with intellectual disabilities that accepted IPAQ-s agreed to wear an accelerometer (Dairo et al., 2017). We also found that the IPAQ-s underestimated the absolute MVPA, and whilst this contrasts with previous studies of the general population (Lee et al., 2011), it is consistent with a previous study in intellectual disabilities (Matthews et al., 2011). In spite of the difference in the estimate of the PA levels between the IPAQ-s and accelerometer, the substantial agreement between the two in identifying those who were active/inactive, is good enough to indicate that the IPAQ-s could be used both clinically and for research in this population to determine those who are active/inactive. However, we would recommend a bigger study to investigate the reliability of the difference in PA minutes/week between the two instruments.

4.1.4. Inter-rater agreement

The Cohen's Kappa shows a perfect agreement between the carer and the self- reported IPAQ-s in identifying participants who are active/inactive. The strength of inter-rater reliability coefficients like Cohen's Kappa is that it is a gauge of the quality and the clinical value of observations characterising an individual (Kottner, 2009; Shrout, 1998). In this study, the significant kappa statistics show that both self and carer recall of PA can reliably

identify those who are active/inactive. This suggests that carers' recall of PA is accurate. There is no other study in this population to compare our findings with, but factors influencing concurrence can be gleaned from proxy response studies. Those studies have found that concurrence between participants and their proxy is enhanced when the proxy knows the person well and has regular contact (J. Magaziner, Bassett, Hebel, & Gruber-Baldini, 1996); when the proxy respondent is asked to recall the actual behaviour; and when the variables of interest are observable (Jay Magaziner, Zimmerman, Gruber-Baldini, Hebel, & Fox, 1997). In our study, the proxies were family/carers who were asked to recall PA behaviour and had known participants for at least six months. This may explain the perfect agreement between raters observed in this sample.

4.2. *Limitations*

There was a higher response from individuals living at home, and able to consent. Although, these factors suggest that our sample is skewed towards those with family support, and more able; therefore, likely to be more active, it has highlighted that it is difficult to engage with people in residential-homes. Another limitation is that we excluded individuals where either they or their carers/relatives were not fluent in the English language, due to time and resource constrictions. While none of the contact/response from the research invitation raised any issues relating to language, it is possible that the exclusion criteria which were part of the invitation letter may have excluded such individuals.

Finally, the accelerometer cut-points that were used in this study were based on the validation study in a normal population (Esliger et al., 2011). To our knowledge, only one study has investigated activity cut-points in individuals with intellectual disabilities, but it was a small study consisting only people with Down syndrome and they did not report cut-points for sedentary behaviour or for light PA (Agiovlasitis et al., 2011).

*4.3.   **Conclusion***

It is possible to measure PA levels using both accelerometers and IPAQ-s in adults with intellectual disabilities across the intellectual disability spectrum, but there was a poor response from residential-homes and consequently, a low recruitment rate. Participants were more likely to be living at home, therefore, greater access is required to improve research engagement in adults with intellectual disabilities living in residential-homes.

While there was agreement between accelerometers and the IPAQ-s in identifying those that were active, the IPAQ-s seems to underestimate PA levels. However, it was more acceptable as a PA measure.   We also found a perfect agreement between the carer and self-report of PA in identifying those that were active/inactive, signifying that carers can accurately report PA. These are important findings and could inform the design and intervention of future PA studies. We suggest, based on our findings that the IPAQ-s can be used to evaluate PA levels for health in this population. We recommend that future studies could examine factors affecting/promoting research engagement by residential-homes and other factors such as choice of PA measure, age, and race that may impact on research engagement in this population.
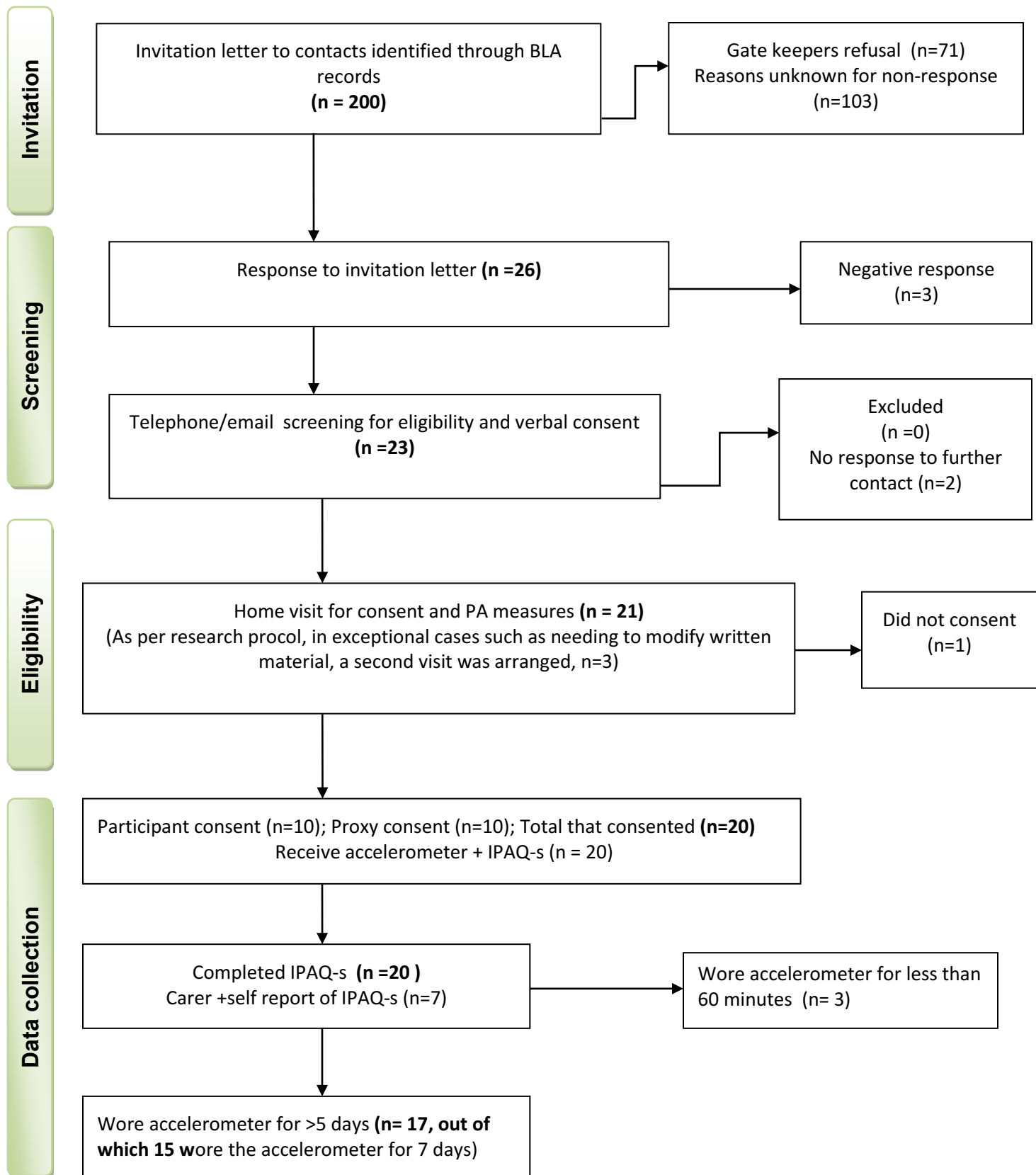
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Figure 1. Study flow diagram

Figure 2. Physical activity levels measured by accelerometer and IPAQ-s (n=15)*

Figure 1: Study flow diagram

Invitation

Invitation letter to contacts identified through BLA records
(n = 200)

→ Gate keepers refusal (n=71)
Reasons unknown for non-response (n=103)

Screening

Response to invitation letter **(n =26)**

→ Negative response (n=3)

Telephone/email screening for eligibility and verbal consent **(n =23)**

→ Excluded (n =0)
No response to further contact (n=2)

Eligibility

Home visit for consent and PA measures **(n = 21)**
(As per research procol, in exceptional cases such as needing to modify written material, a second visit was arranged, n=3)

→ Did not consent (n=1)

Data collection

Participant consent (n=10); Proxy consent (n=10); Total that consented **(n=20)**
Receive accelerometer + IPAQ-s (n = 20)

Completed IPAQ-s **(n =20)**
Carer +self report of IPAQ-s (n=7)

→ Wore accelerometer for less than 60 minutes (n= 3)

Wore accelerometer for >5 days **(n= 17, out of which 15 w**ore the accelerometer for 7 days)

Key: BLA, Buckinghamshire local authority; PA, physical activity; IPAQ-s, International Physical Activity Questionnaire-Short version.

Figure 2: Physical activity (PA) levels measured by accelerometer and IPAQ-s (n=15)*
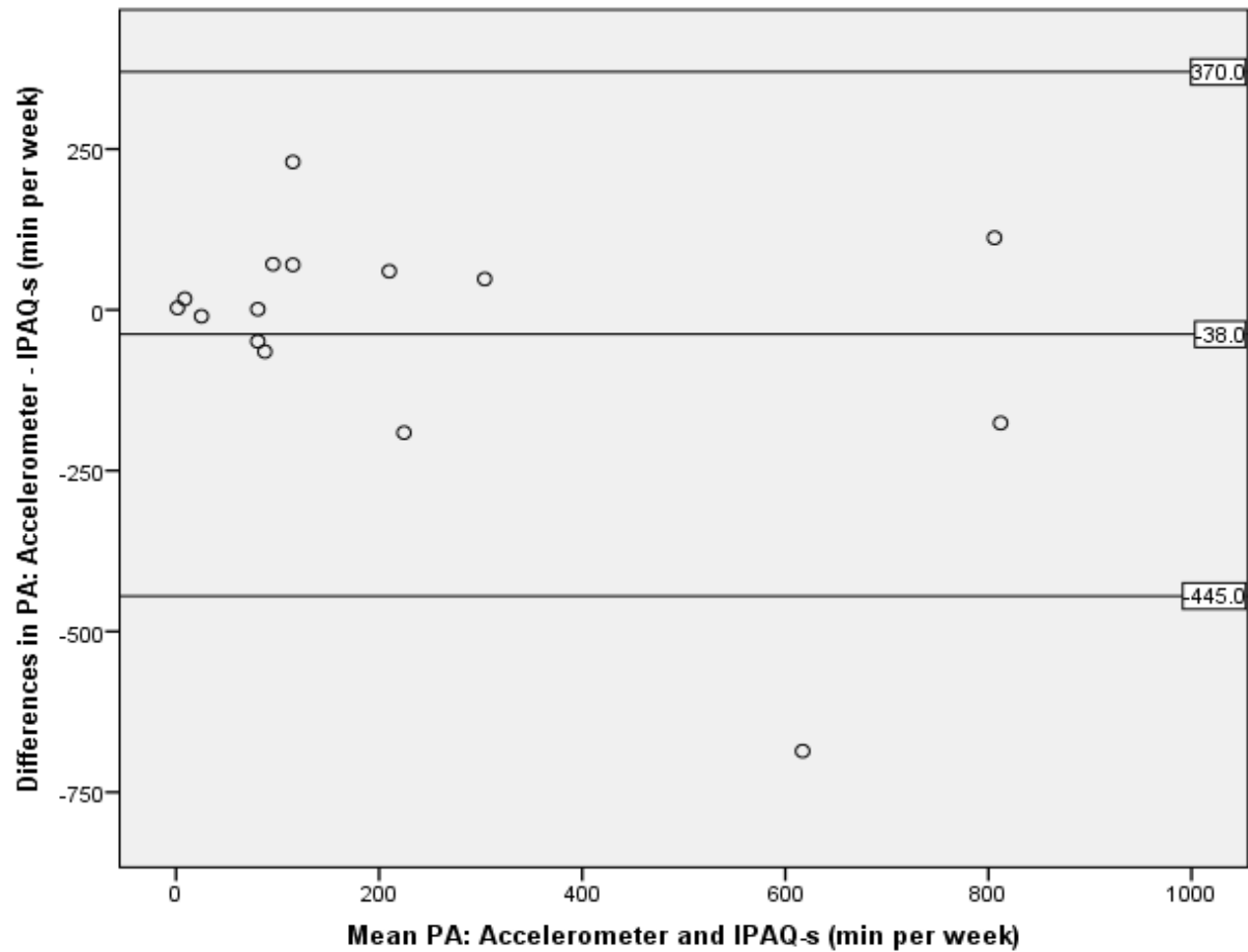
Notes: IPAQ-s: International Physical Activity Questionnaire -short version
*one incomplete data and an outlier data were excluded.

Table 1

Demographics Summary of Participants and their Response and Recruitment Rates

Descriptor	Age groups				Type of residence		Sex	
	18-29	30-44	45-59	60+	Lives at home[a]	Residential-home[b]	Male	Female
Invited, n (%)	50 (25)	50 (25)	50 (25)	50 (25)	76 (38)	124 (62)	100 (50)	100 (50)
Response rate, n (%)	U	U	U	U	12 (16)*	5 (4)*	8 (8)	9 (9)
Home visits, n	3	5	6	7	10	11[c]	10	11
Recruitment rate, n (%)	3 (6)	4 (8)	6 (12)	7 (14)	10 (13)	10 (8)	10 (10)	10 (10)

Notes:

U (information not available); response rate (those that responded to the study invitation over the recruitment period of six months); recruitment rate (those that consented to participate in the study over the recruitment period of six months).

[a]Lives at home with family/alone.

[b]Residential-homes (this includes registered care homes and supported living accommodation).

[c]Interested individuals increased from an initial 5 to 11 following presentation at residential-homes by the researcher.

*Significant difference between those living at home and those living in a residential-home ($p < 0.05$).

Table 2
Summary of Participants' Characteristics, n=20

		Frequency	Percent
Sex	Female	10	50.0
	Male	10	50.0
Race	White	20	100.0
Residence	Alone	2	10.0
	With family	8	40.0
	Registered care	8	40.0
	Supported living	2	10.0
Level of Intellectual Disability	Mild	4	20.0
	Moderate	4	20.0
	Profound	5	25.0
	Severe	7	35.0
Employment	No	19	95.0
	Yes	1	5.0
Mobility	Assistance	2	10.0
	Independent	18	90.0
Mobility Aids	Walker	1	5.0
	Nil	17	85.0
	Wheelchair for >15 mins walk	1	5.0
	Walking Stick	1	5.0
Consent obtained from	Participant	10	50.0
	Participant and a proxy respondent	10	50.0

Table 3

Participants who Achieved Physical Activity Guidelines (PAG) with Accelerometer Compared with the IPAQ-s, n=16*

		Participants who achieved PAG with IPAQ-s (moderate and vigorous PA min/week) and walking min/week		
		Active	Not-active	Total
Participants who achieved PAG with accelerometer (moderate and vigorous PA min/week)	Active	5	1	6
	Not-active	2	8	10
	Total	7	9	16

Notes: IPAQ-s, International Physical Activity Questionnaire-short version; PA, physical activity

*one incomplete data was excluded from the analysis

Table 4

Descriptive Statistics of Minutes per week of Physical Activity as Measured by Accelerometers and the IPAQ-s

	N	Minimum (Minutes)	Maximum (Minutes)	Mean	Std. Deviation
IPAQ-s (MVPA)	20	0	960	144.5	257.8
Accelerometer[a] (MV PA)	17	3	862	207.1	240.8
IPAQ-s (MVPA and Walking)	20	0	1200	269.0	372.3

Notes: IPAQ-s: International Physical Activity Questionnaire -short version
MVPA: moderate- or vigorous-intensity physical activity
[a]Two participants had less than seven days data