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Impact of the COVID-19 Pandemic on Physical Activity and Associated Technology Use in Persons With Multiple Sclerosis: An International RIMS-SIG Mobility Survey Study

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Title. The impact of the COVID-19 pandemic on physical activity and associated technology 1 2 use in persons with multiple sclerosis: an international RIMS-SIG Mobility survey study. 3 **Abstract** 4 5 Objective. To investigate the impact of the COVID-19 pandemic on physical activity (PA) in 6 persons with multiple sclerosis (PwMS). 7 8 9 Design and Setting. A multi-centre international online survey study was conducted within 11 participating countries. Each country launched the survey using online platforms from May to 10 July 2021. 11 12 **Participants.** This was an electronic survey study targeting PwMS. 13 14 Intervention. Not applicable. 15 16 17 Outcome measures. The survey ascertained PA performance and its intensity, the nature of the activities conducted and the use of technology to support home-based physical activity before 18 and during the pandemic. 19 20 Results. 3725 respondents completed the survey. Pre-pandemic, the majority (83%) of 21 respondents reported being physically active, and this decreased to 75% during the pandemic. 22 This change was significant for moderate and high intensity activity (p<.0001). Activities 23 carried out in physiotherapy centres, gyms or pools decreased the most. Walking was the most 24 frequently performed activity pre-pandemic (27%) and increased during the pandemic (33%). 25

24% of those inactive during the pandemic had no intention of changing their PA behaviour 26 post-pandemic. 58% of the respondents did not use technology to support PA during the 27 pandemic. Of those who did use technology, wearables were most used (24%). Of those 28 currently non-active (25%) expressed a preference for an in-person format to conduct PA post-29 pandemic. 30 31 Conclusion. PA performance, especially activities at moderate and high intensities, decreased 32 during the pandemic in PwMS compared to pre-pandemic. Walking and using wearables gained 33 popularity to stay active. As we move towards an endemic-COVID-19, a call for action to 34 develop interventions focused on walking programmes, with specific emphasis on increasing 35 PA of persons with MS is proposed. 36 37 Keywords Persons with Multiple Sclerosis, COVID-19 pandemic, physical activity, 38 39 technology, walking, wearables 40 **Abbreviations** 41 42 Persons with multiple sclerosis (PwMS) Primary investigator (PI) 43 Special Interest Group for Mobility (SIG Mobility) 44 45 Rehabilitation in Multiple Sclerosis (RIMS) 46 47

Introduction

Physical activity is associated with a wide range of benefits for physical and mental outcomes and secondary disease prevention^{1,2}. For persons with multiple sclerosis (PwMS), an extensive body of literature reports evidence for the benefits of physical activity on walking³, fatigue⁴ and quality of life⁵ in PwMS. Concerningly, PwMS are less physically active compared to the general population⁶, and this may have been further reduced during the COVID-19 pandemic^{7,8}

National and local restrictions aiming to slow down the spread of COVID-19 forced many venues offering physical activity to close⁷, reducing the availability of physiotherapy and exercise services, and thus possibly decreasing the level and type of physical activity for individuals with MS. In the general population and in people living with disabilities there is emerging evidence that the Covid-19 pandemic has negatively impacted physical activity behavior⁷⁻¹¹. There is, however, a lack of knowledge regarding whether the COVID-19 pandemic has influenced physical activity in individuals with MS compared to pre-pandemic times.

Due to COVID-19 restrictions, rehabilitation services often transitioned to a virtual environment heavily reliant on technology at the beginning of the pandemic and progressed to a blended environment as restrictions were eased. Pre-pandemic, there was limited use of technology for physical activity promotion in clinical settings, despite several studies supporting technology-based interventions^{12, 13}. It is unclear how and whether technology was used by PwMS for performing physical activity during the pandemic.

The Special Interest Group for Mobility (SIG Mobility) of the Rehabilitation in Multiple 73 Sclerosis (RIMS) network launched this international survey study which aimed at investigating 74 whether and how physical activity carried out by PwMS may have changed during the COVID-75 19 pandemic. In this current paper, we describe the levels of physical activity and its intensity, 76 the nature of the activities conducted and the use of technology to support physical activity as 77 reported by PwMS before and during the COVID-19 pandemic. 78 79 **Material and Methods** 80 81 The CHERRIES reporting guideline for online surveys¹⁴ was used to inform the conduct and 82 reporting of this study. 83 84 **Design.** This was an electronic survey study targeting PwMS. Ethical approval to conduct the 85 86 study was obtained from all participating institutions, and all respondents provided their informed consent electronically prior to commencing the survey. No identifiable personal data 87 was collected from the survey. A primary investigator (PI) was identified for each country, and 88 89 a project coordinator was assigned. The PI was locally responsible for all the project phases as well as to ensure communication with the local project partners, the other PIs and the project 90 coordinator. 91 92 **Development and pre-testing.** The study was initiated by the SIG Mobility group of the RIMS. 93 Physiotherapists and researchers from eleven countries (centres/institutes/individuals) agreed 94 to participate: Australia, Belgium, Czech Republic, Ireland, Israel, Italy, Norway, Serbia, Spain, 95

Turkey and United Kingdom.

96

Development. A small working group of PI's drafted the first version of the survey based on previous work⁸ and extensive expertise. File sharing on Google Drive and regular discussion meetings with the project PIs enabled shared online working. During January and February 2021 input from all project partners were accounted for to improve the content and focus of the survey. The English-language version of the survey was piloted with PwMS in four countries for usability and clarity. The surveys were then translated into the national language of the participating countries and transferred into an online survey platform. The following platforms were used across the 11 countries: Survey Monkey, Qualtrics, Google Forms, Corporater Surveyor, Eusurvey, onlinesurveys.ac.uk and RedCap. Additional pilots were conducted by all project PIs to explore usability and technical functionality of the individual platforms at country level.

The final survey consisted of 74 questions, and took approximately 30 minutes to complete. Response options included multiple choice and open-ended answers. The latter was not the case in Norway due to their ethics requirements. The complete survey as well as the coding methodology of the variables applied can be found as Supplementary Table 1. This paper reports on the following information which were collected in the survey:

- Descriptive information such as country of participation, age, gender, years since diagnosis, patient determined disease steps scale and local restrictions due to pandemic aimed at slowing the spread of COVID-19.
- Self-reported physical activity participation which included type and intensity of physical activity; type of technology used to perform physical activity both prior to COVID-19 and at the time of the survey, i.e. during the pandemic.
- Intention to change physical activity participation and preferred mode of performing physical activity once restrictions are removed.

122	- Perceived positive and negative aspects of home-based physical activity using
123	technology.
124	
125	The following explanations were provided to define physical activity and intensity in the
126	survey.
127	Physical activity. 'Physical activity includes activities you do at work, as part of your house
128	and garden work, to get from place to place, and in your space time for recreation, exercise or
129	sport. It also includes rehabilitation or exercise led by your physiotherapist in person or using
130	technology, doing a home programme provided by a physiotherapist or other professional. It
131	also includes activities such as walking, gardening, sports, fitness classes, going to the gym,
132	Pilates, yoga, home exercises and dance. It also includes active travel such as cycling or walking
133	to work'.
134	Intensity. Light - you can do this activity and sing a song, moderate - you can do this activity
135	and have a conversation but not sing, strenuous - you can only utter a few words while doing
136	this activity.
137	
138	Recruitment. For each country, the PI was responsible for sending the online surveys to their
139	respective recruitment channels, and for collating responses. The recruitment channels
140	comprised of local MS centres and hospitals (through websites, social media and direct mailing
141	to neurologists), national MS registries, physiotherapy MS associations, neurologists and
142	networks involved in MS research or clinical care, as well as the PI's or national MS
143	organisations professional social media (LinkedIn, Facebook, Instagram, Twitter).

145	Data collection . Each country launched the survey for a total duration of 6 weeks from May to
146	July 2021. PIs' had the possibility of sending a reminder every 2 weeks if it was feasible within
147	their respective recruitment channels.
148	
149	Statistical analysis
150	Survey questions which involved perceived ratings are reported as the percentage proportion of
151	the responses.
152	
153	The McNemar test was applied to determine whether significant differences exist between the
154	proportion of respondents taking part in physical activity before the pandemic and at the time
155	of completing the survey (during the pandemic). The Chi-square test was applied to determine
156	whether significant differences exist in proportions of responders on: physical activity intensity
157	(light, moderate and high) across time and physical activity type across the 16 listed physical
158	activities across time. All analyses were conducted using the statistical software JMP Pro 15
159	(SAS Institute Inc., Cary, NC), with a significance level of alpha set at 0.05.
160	
161	

Results 162 163 **Descriptive information on the responders** 164 In total, data was collected from 11 countries, with a total of 3725 responses which completed 165 the survey: (Australia n= 91, Belgium n= 26, Czech Republic n= 264, Ireland n= 153, Israel n= 166 52, Italy= 585, Norway = 2218, Serbia n= 27, Spain n= 230, Turkey n= 35, UK n= 44). 167 168 Figure 1 shows the percentage distribution of age, the number of years since diagnosis, and the 169 170 patient determined disease steps scale across the responders. In total, 70% of respondents were female, reflecting the normal distribution of gender in MS¹⁵. Of the total responders, 72% had 171 no local restrictions due to pandemic aimed at slowing the spread of COVID-19 at the time of 172 completing the survey. 173 174 175 _____ 176 Insert Figure 1 177 _____ 178 Physical activity 179 Overall, the proportion of responders conducting physical activity at the time of completing the 180 survey was significantly decreased compared to the proportion of responders conducting 181 physical activity before the pandemic; 75% during the pandemic as compared to 83% pre-182 pandemic (p<0.001). 183 184 Intensity of physical activity performance pre-pandemic compared to post-pandemic 185 significantly differed (X²(2, 10421)=36.22, p<0.0001). The proportions of responders 186

conducting physical activity at light intensity did not change over time (Pre 10.9%, During 10.5%). However the proportion of responders conducting physical activity at moderate and high intensity decreased at the time of answering the survey compared to pre-pandemic times (moderate: Pre 35.5%, During 27.98%; high: Pre 9.23%, During 5.99%).

The contingency model revealed significant changes (increase or decrease) within the sixteen activities reported (X²(15, 10561)=379.27, p<0.0001). Respondents reported changes in four of the sixteen listed activities, these were: home exercise programmes, exercises in the gym, exercises in water and walking. The changes reflect proportions of respondents changing their activities at the time of completing the survey compared to pre-pandemic times. As seen in Figure 2, There was a 3% increase in respondents participating in physiotherapy home exercise programmes, 6% increase of walking, 7% decrease in exercise in the gym (strength and aerobic exercises), and 3% decrease in exercise in water (e.g. swimming or aqua aerobics).

Insert Figure 2

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Reasons to start a new activity or increase physical activity level

The most frequently reported reasons to start a new activity or increase level of physical activity were: more awareness of the public health message to go for a walk and stay active (14%); more time to exercise as there was no travelling to work (6%); more time for physical activity as less time was spent socialising or shopping (6%); more structure and routine in the day (6%); more family and friends support for physical activity (5%).

Reasons to stop or do less physical activity levels
The most frequently reported reasons to stop or do less physical activity were: closed venues
(12%); restrictions preventing going to the venue (9%); restrictions preventing exercising in
groups (7%); fear of contracting COVID-19 (7%); worsening of MS symptoms (6%); less
motivation to exercise (5%); classes were cancelled by the organiser (5%).
Plans to change physical activity post-pandemic
Of the 75% (n=2,756) that were active at the time of survey completion during the pandemic,
44% reported not wanting to change physical activity after restrictions were to be removed,
while 33% did want to change physical activity, 22% reported they were unsure if they wanted
to make changes when restrictions were lifted. These respondents (of the 75% that were active)
had the following preferences to conduct physical activity after COVID-19 pandemic: 31% in-
person, 3% remote, 25% mix, 26% no preferences and 15% did not know.
Of the 25% (n=928) that were active pre-pandemic but not at the time of survey completion
during the pandemic, 24% reported not wanting to change their physical activity after
restrictions were removed, while 31% did want to make changes, and 44% were unsure. These
respondents had the following preferences to conduct physical activity after COVID-19
pandemic: 44% in-person, 2% remote, 14% mix, 19% no preferences and 21% did not know of
their preferences.
Use of technology
Table 1 provides an overview of the technology used to perform physical activity pre-pandemic
and at the time of survey completion, by respondents who were physically active. Table 2 shows
the perceived rating of performing home based physical activity using technology.

237 238 239 Insert Table 1 and 2 240 241 242 **Discussion** 243 244 245 This relatively large international survey study focused in the MS population, found that 83% of respondents reported being physically active pre-pandemic, and this decreased significantly 246 to 75% during the COVID-19 pandemic. Not surprisingly, activities carried out in the 247 physiotherapy centres, gyms, or pools decreased the most. Walking was the most frequently 248 performed activity pre-pandemic and increased during the pandemic. Concerningly, 31% of 249 those inactive during the pandemic had no intention of changing their physical activity 250 behaviour once restrictions due to the pandemic were lifted, (while 42% were unsure). Two 251 thirds of the respondents (66%) did not use technology aimed to support physical activity during 252 253 the pandemic. For those who used technology, wearables were the most common device used. Those currently non-active had a preference for an in-person format for physical activity post-254 pandemic. 255 256 Many of our respondents reported being physically active, however, previous studies (pre-257 pandemic)^{16, 17} indicate that most PwMS are not reaching sufficient levels of physical activity 258 for mental and physical health benefits¹⁸. Thus, our findings of a reduction of physical activity 259 during the pandemic is now of even greater concern. 260

There is a significant body of evidence of the benefits of physical activity for PwMS for physical and mental health, symptoms and secondary disease prevention^{4, 19, 20}. Therefore, it is concerning that there was a significant reduction of number of people who were physically active during the pandemic. The MS clinical research community needs to turn their attention to re-engaging those persons that ceased being active, in addition to engaging those that were not active at either time point.

There seems to be an opportunity to get people more physically active through engaging in activities of walking, as this was the most frequently performed activity pre- and during the pandemic. There are studies that focus on improving walking outcomes such as speed, distance, kinetics and kinematics, following physiotherapy²¹ and exercise³. However, our initial scoping search found no studies that solely evaluate walking programmes with a focus on increasing physical activity and meeting the exercise guidelines^{18, 22, 23}. We found only a few studies included walking activity in various forms, but those focused on reducing perceived fatigue^{24, 25}, cardiovascular parameters²⁴ and quality of life²⁶ in MS, while other included walking as an aerobic activity in exercise interventions and programmes²⁷⁻²⁹.

These data suggest that PwMS could potentially favour walking programmes, and as such, paying attention to the impairments underlying walking restrictions in addition to addressing walking as an activity is essential. For example, addressing drop foot or impaired balance by using assistive devices may be important prior to increasing walking distance or intensity³⁰. Addressing these factors will be an essential element of any sustainable programme development in the fluctuating restrictions and uncertainties with COVID-19 becoming endemic in society. We note that fear of contracting COVID-19 was reported as a barrier for physical activity participation, as well as, lack of access to venues and indoor group activities.

As we focus on developing interventions to reverse the inactivity during the pandemic, these data suggest that combining education, information-provision and behaviour change techniques with the relevant physical activity will be important.

The format of any future physical activity programme is also an important consideration. Our results suggest that purely technology-based, or remote interventions are not favoured by most PwMS. Those PwMS that continued to be physically active during the pandemic preferred a blended approach, and those persons that were physically inactive preferred an in-person approach. Wearables were the most frequently used technology to support physical activity. Wearables are highly sensitive in detection of gait disturbances and fatigue in PwMS^{31, 32} and evidence of their use to sustain physical activity behaviour is largely growing³³, thus they can be a valuable addition to walking programmes.

We noticed a mismatch between what PwMS were doing (in terms of physical activity) with what the research and clinical community made available during the pandemic. For example, a large number of video based resources were developed and widely circulated³⁴⁻³⁶, however only 3% of respondents in our sample used them during the pandemic. Similarly, usage of physiotherapy exercise platforms was minimal, highlighting the need to collaborate with PwMS during any future intervention developments to ensure the resources health care professionals provide are in line with the preferences of the end users. The LEAP-MS study is an example of good practice in public patient involvement in intervention and trial design³⁷.

Strengths and Limitations

Noteworthy are a few methodological considerations. The first is that data was collected within a multicentre setting in order to increase sample size. We noted that those countries using registers or MS societies were the ones who were the most successful in recruiting a bigger sample of patients, and thus we recommend future survey studies to consider this recruitment channel. We acknowledge the variation in number of respondents between countries as well as the high proportion of respondents from Norway. However, Supplementary Table 2 shows that the change in physical activity behaviour of the Norwegian respondents was not markedly different from that seen in the other countries, hence it is unlikely that the high proportion of Norwegian respondents has skewed the data of this international sample. Noteworthy, is that the survey was conducted during the pandemic (May – July 2021). We argue that additional factors other than the restrictions which aimed at reducing the spread of COVID-19 may have influenced physical activity behaviour. The analysis of the association between stopping and reducing physical activity participation and factors such as disease severity, restrictions aimed at reducing the spread of COVID-19 and fear of contracting COVID-19 is explored within the project's working group, and will be reported elsewhere 38,39.

Conclusion

In PwMS, physical activity performance, especially at moderate and high intensities, decreased during the pandemic compared to pre-pandemic. PwMS who were active during the pandemic expressed the preference for delivery of physical activity in a hybrid form once the pandemic restrictions ended, while inactive PwMS preferred an in-person form of physical activity. The most frequent type of physical activity was walking. We propose a call for action to develop interventions that include walking programmes with specific emphasis on increasing physical

activity. These interventions have an enormous potential to address the concerns of PwMS in terms of fear of contracting COVID-19 and are not reliant on a venue. Including wearable technologies as part of these interventions can be considered for PwMS who are keen to use them.

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List of Figures and tables.

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461	pandemic.
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