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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 Peer-reviewed author version

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

26 24% of those inactive during the pandemic had no intention of changing their PA behaviour 27 post-pandemic. 58% of the respondents did not use technology to support PA during the 28 pandemic. Of those who did use technology, wearables were most used (24%). Of those 29 currently non-active (25%) expressed a preference for an in-person format to conduct PA post-30 pandemic.

31

32 Conclusion. PA performance, especially activities at moderate and high intensities, decreased 33 during the pandemic in PwMS compared to pre-pandemic. Walking and using wearables gained 34 popularity to stay active. As we move towards an endemic-COVID-19, a call for action to 35 develop interventions focused on walking programmes, with specific emphasis on increasing 36 PA of persons with MS is proposed.

37

38 Keywords Persons with Multiple Sclerosis, COVID-19 pandemic, physical activity,

39 technology, walking, wearables

40

41 Abbreviations

42 Persons with multiple sclerosis (PwMS)

43 Primary investigator (PI)

44 Special Interest Group for Mobility (SIG Mobility)

45 Rehabilitation in Multiple Sclerosis (RIMS)

46

48 Introduction

49

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}.

56

National and local restrictions aiming to slow down the spread of COVID-19 forced many 57 venues offering physical activity to close⁷, reducing the availability of physiotherapy and 58 exercise services, and thus possibly decreasing the level and type of physical activity for 59 individuals with MS. In the general population and in people living with disabilities there is 60 emerging evidence that the Covid-19 pandemic has negatively impacted physical activity 61 behavior⁷⁻¹¹. There is, however, a lack of knowledge regarding whether the COVID-19 62 pandemic has influenced physical activity in individuals with MS compared to pre-pandemic 63 times. 64

65

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
Sclerosis (RIMS) network launched this international survey study which aimed at investigating
whether and how physical activity carried out by PwMS may have changed during the COVID19 pandemic. In this current paper, we describe the levels of physical activity and its intensity,
the nature of the activities conducted and the use of technology to support physical activity as
reported by PwMS before and during the COVID-19 pandemic.

79

80 Material and Methods

81

The CHERRIES reporting guideline for online surveys¹⁴ was used to inform the conduct and reporting of this study.

84

Design. This was an electronic survey study targeting PwMS. Ethical approval to conduct the study was obtained from all participating institutions, and all respondents provided their informed consent electronically prior to commencing the survey. No identifiable personal data was collected from the survey. A primary investigator (PI) was identified for each country, and 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 coordinator.

92

Development and pre-testing. The study was initiated by the SIG Mobility group of the RIMS.
Physiotherapists and researchers from eleven countries (centres/institutes/individuals) agreed
to participate: Australia, Belgium, Czech Republic, Ireland, Israel, Italy, Norway, Serbia, Spain,
Turkey and United Kingdom.

Development. A small working group of PI's drafted the first version of the survey based on 98 previous work⁸ and extensive expertise. File sharing on Google Drive and regular discussion 99 meetings with the project PIs enabled shared online working. During January and February 100 101 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 102 for usability and clarity. The surveys were then translated into the national language of the 103 participating countries and transferred into an online survey platform. The following platforms 104 were used across the 11 countries: Survey Monkey, Qualtrics, Google Forms, Corporater 105 106 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 107 level. 108

109 The final survey consisted of 74 questions, and took approximately 30 minutes to complete. 110 Response options included multiple choice and open-ended answers. The latter was not the case 111 in Norway due to their ethics requirements. The complete survey as well as the coding 112 methodology of the variables applied can be found as Supplementary Table 1. This paper 113 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.

Perceived positive and negative aspects of home-based physical activity using
technology.

124

125 The following explanations were provided to define physical activity and intensity in the 126 survey.

Physical activity. 'Physical activity includes activities you do at work, as part of your house and garden work, to get from place to place, and in your space time for recreation, exercise or sport. It also includes rehabilitation or exercise led by your physiotherapist in person or using technology, doing a home programme provided by a physiotherapist or other professional. It also includes activities such as walking, gardening, sports, fitness classes, going to the gym, Pilates, yoga, home exercises and dance. It also includes active travel such as cycling or walking to work'.

Intensity. Light - you can do this activity and sing a song, moderate - you can do this activity
and have a conversation but not sing, strenuous - you can only utter a few words while doing
this activity.

137

Recruitment. For each country, the PI was responsible for sending the online surveys to their respective recruitment channels, and for collating responses. The recruitment channels comprised of local MS centres and hospitals (through websites, social media and direct mailing to neurologists), national MS registries, physiotherapy MS associations, neurologists and networks involved in MS research or clinical care, as well as the PI's or national MS organisations professional social media (LinkedIn, Facebook, Instagram, Twitter).

144

Data collection. Each country launched the survey for a total duration of 6 weeks from May to
July 2021. PIs' had the possibility of sending a reminder every 2 weeks if it was feasible within
their respective recruitment channels.

148

149 Statistical analysis

Survey questions which involved perceived ratings are reported as the percentage proportion ofthe responses.

152

The McNemar test was applied to determine whether significant differences exist between the proportion of respondents taking part in physical activity before the pandemic and at the time of completing the survey (during the pandemic). The Chi-square test was applied to determine whether significant differences exist in proportions of responders on: physical activity intensity (light, moderate and high) across time and physical activity type across the 16 listed physical activities across time. All analyses were conducted using the statistical software JMP Pro 15 (SAS Institute Inc., Cary, NC), with a significance level of alpha set at 0.05.

160

162	Results
163	
164	Descriptive information on the responders
165	In total, data was collected from 11 countries, with a total of 3725 responses which completed
166	the survey: (Australia n= 91, Belgium n= 26, Czech Republic n= 264, Ireland n= 153, Israel n=
167	52, Italy= 585, Norway = 2218, Serbia n= 27, Spain n= 230, Turkey n= 35, UK n= 44).
168	
169	Figure 1 shows the percentage distribution of age, the number of years since diagnosis, and the
170	patient determined disease steps scale across the responders. In total, 70% of respondents were
171	female, reflecting the normal distribution of gender in MS ¹⁵ . Of the total responders, 72% had
172	no local restrictions due to pandemic aimed at slowing the spread of COVID-19 at the time of
173	completing the survey.
174	
175	
176	Insert Figure 1
177	
178	
179	Physical activity
180	Overall, the proportion of responders conducting physical activity at the time of completing the
181	survey was significantly decreased compared to the proportion of responders conducting
182	physical activity before the pandemic; 75% during the pandemic as compared to 83% pre-
183	pandemic (p<0.001).
184	
185	Intensity of physical activity performance pre-pandemic compared to post-pandemic

186 significantly differed ($X^2(2, 10421)=36.22$, p<0.0001). The proportions of responders

187 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
189 high intensity decreased at the time of answering the survey compared to pre-pandemic times
190 (moderate: Pre 35.5%, During 27.98%; high: Pre 9.23%, During 5.99%).

191

The contingency model revealed significant changes (increase or decrease) within the sixteen 192 activities reported (X²(15, 10561)=379.27, p<0.0001). Respondents reported changes in four 193 of the sixteen listed activities, these were: home exercise programmes, exercises in the gym, 194 195 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 196 Figure 2, There was a 3% increase in respondents participating in physiotherapy home exercise 197 programmes, 6% increase of walking, 7% decrease in exercise in the gym (strength and aerobic 198 exercises), and 3% decrease in exercise in water (e.g. swimming or aqua aerobics). 199 200

202 Insert Figure 2

203 -----

204

201

205 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%).

212 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%).

217

218 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% inperson, 3% remote, 25% mix, 26% no preferences and 15% did not know.

225

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.

232

233 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.

243 Discussion

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 (prepandemic)^{16, 17} indicate that most PwMS are not reaching sufficient levels of physical activity for mental and physical health benefits¹⁸. Thus, our findings of a reduction of physical activity during the pandemic is now of even greater concern.

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.

268

There seems to be an opportunity to get people more physically active through engaging in 269 270 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, 271 kinetics and kinematics, following physiotherapy²¹ and exercise³. However, our initial scoping 272 search found no studies that solely evaluate walking programmes with a focus on increasing 273 physical activity and meeting the exercise guidelines^{18, 22, 23}. We found only a few studies 274 included walking activity in various forms, but those focused on reducing perceived fatigue^{24,} 275 ²⁵, cardiovascular parameters²⁴ and quality of life²⁶ in MS, while other included walking as an 276 aerobic activity in exercise interventions and programmes²⁷⁻²⁹. 277

278

These data suggest that PwMS could potentially favour walking programmes, and as such, 279 paying attention to the impairments underlying walking restrictions in addition to addressing 280 walking as an activity is essential. For example, addressing drop foot or impaired balance by 281 using assistive devices may be important prior to increasing walking distance or intensity³⁰. 282 Addressing these factors will be an essential element of any sustainable programme 283 development in the fluctuating restrictions and uncertainties with COVID-19 becoming 284 endemic in society. We note that fear of contracting COVID-19 was reported as a barrier for 285 physical activity participation, as well as, lack of access to venues and indoor group activities. 286

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.

290

The format of any future physical activity programme is also an important consideration. Our 291 results suggest that purely technology-based, or remote interventions are not favoured by most 292 PwMS. Those PwMS that continued to be physically active during the pandemic preferred a 293 blended approach, and those persons that were physically inactive preferred an in-person 294 295 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 296 evidence of their use to sustain physical activity behaviour is largely growing³³, thus they can 297 298 be a valuable addition to walking programmes.

299

300 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 301 large number of video based resources were developed and widely circulated³⁴⁻³⁶, however only 302 303 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 304 during any future intervention developments to ensure the resources health care professionals 305 306 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. 307

308

309 Strengths and Limitations

Noteworthy are a few methodological considerations. The first is that data was collected within 311 a multicentre setting in order to increase sample size. We noted that those countries using 312 registers or MS societies were the ones who were the most successful in recruiting a bigger 313 sample of patients, and thus we recommend future survey studies to consider this recruitment 314 channel. We acknowledge the variation in number of respondents between countries as well as 315 the high proportion of respondents from Norway. However, Supplementary Table 2 shows that 316 the change in physical activity behaviour of the Norwegian respondents was not markedly 317 different from that seen in the other countries, hence it is unlikely that the high proportion of 318 319 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 320 factors other than the restrictions which aimed at reducing the spread of COVID-19 may have 321 influenced physical activity behaviour. The analysis of the association between stopping and 322 reducing physical activity participation and factors such as disease severity, restrictions aimed 323 at reducing the spread of COVID-19 and fear of contracting COVID-19 is explored within the 324 project's working group, and will be reported elsewhere^{38,39}. 325

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328 Conclusion
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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

336	activity. These interventions have an enormous potential to address the concerns of PwMS in			
337	terms of fear of contracting COVID-19 and are not reliant on a venue. Including wearable			
338	technologies as part of these interventions can be considered for PwMS who are keen to use			
339	them.			
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- 455
- 456 List of Figures and tables.

- **Figure 1.** Percentage distribution of age, years of diagnosis and patient determined disease
- 458 steps scale across the responders.
- **Figure 2.** Percentage distribution of physical activity conducted pre- and during the
- 461 pandemic.