An Accessible Web-based Survey to Monitor the Mental Health of People with Mild Intellectual Disabilities and/or Low Literacy Skills during the COVID-19 Pandemic: Comparative Data Analysis

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Abstract

Background: The COVID-19 pandemic and related control measures affected the mental health of all populations. Although particular subgroups appear more vulnerable than others, they are often underrepresented in mainstream surveys because they are hard to reach and study measurements are not adapted to their literacy skills.

Objective: This study examined the impact of the COVID-19 pandemic on mental health among people with lower cognitive and literacy skills compared with people who are mainly represented in national surveys.

Methods: A repeated cross-sectional study of people with mild intellectual disabilities (MID) and/or low literacy skills and a general population sample was conducted in the Netherlands. An easy-read online survey was co-designed with, and tested among, people with MID and/or low literacy skills and conducted in three rounds within one year of the COVID-19 pandemic (T1: November-December 2020, T2: March-April 2021 and T3: September-October 2021). The survey contained questions about demographics and six aspects of mental health; feeling happy, feeling energized, stress, worry, feeling lonely, and sleeping problems.

Results: The web-based survey and adapted recruitment procedure enabled 412 persons with MID and/or low literacy skills to participate in T1, 351 in T2, and 296 in T3. They were significantly younger, had a lower level of education, and more often than not were born outside the Netherlands. The target group displayed significantly poorer mental health scores than the general population sample, and, although scores improved over time in both populations with the gradual relaxation of control measures, disproportional effects remained.

Conclusions: General disease control measures for the entire Dutch population affected people with MID and/or low literacy skills more negatively than the general population. Our study underscores the relevance of including people with MID and/or low literacy skills in public health research, as they are often overlooked in regular health data. . An accessible web-based survey particularly targeted at this population enabled us to do so, and we reached a group of respondents significantly different from regular survey participants. Results from this monitor provided a good insight into the health of people with MID and/or low literacy skills and gained knowledge for care organizations and policymakers to improve health promotion and reduce health disparities, in unexpected events such as a pandemic as well as in general.

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An Accessible Web-based Survey to Monitor the Mental Health of People with Mild Intellectual Disabilities and/or Low Literacy Skills during the COVID-19 Pandemic: Comparative Data Analysis

Koks-Leensen, M.C.J., Menko, A., Raaijmakers, F., Fransen-Kuppens, G.A.J., & Bevelander, K.E.

Abstract

Background: The COVID-19 pandemic and related control measures affected mental health of all populations. Particular subgroups are underrepresented in mainstream surveys because they are hard to reach and study measurements are not adapted to their skills. These subgroups include people with lower cognitive and literacy skills such as people with mild intellectual disability (MID), and are considered vulnerable during the COVID-19 pandemic given their low socioeconomic status, small social networks, increased risks of health problems, and difficulties understanding health-related information.

Objective: This study examined the impact of the COVID-19 pandemic on mental health among people with MID and/or low literacy skills compared with people who are mainly represented in national surveys.

Methods: A repeated cross-sectional study of people with MID and/or low literacy skills and a general population sample was conducted in the Netherlands. An easy-read online survey was co-designed with, and tested among, people with MID and/or low literacy skills and conducted in three rounds within one year of the COVID-19 pandemic (T1: November-December 2020, T2: March-April 2021 and T3: September-October 2021). The survey contained questions about demographics and six aspects of mental health; feeling happy, feeling energized, stress, worry, feeling lonely, and sleeping problems.

Results: The web-based survey and adapted recruitment procedure enabled 412 persons with MID and/or low literacy skills to participate in T1, 351 in T2, and 296 in T3. They were significantly younger, had a lower level of education, and more often than not were born outside the Netherlands, compared to the general population sample. About half of them received professional care. The target group displayed significantly poorer mental health scores than the general population sample. Percentages of people with MID and/or low literacy skills who reported more negative feelings in T1 ranged from 21% that feel lonely (very) often to 58% almost never or only sometimes feeling happy. In the general population sample this was 5% and 33%, respectively. Although scores improved over time in both populations disproportional effects remained.

Conclusions: General disease control measures for the entire Dutch population affected people with MID and/or low literacy skills more negatively than the general population sample. Our study underscores the relevance of including people with MID and/or low literacy skills in public health research, as they are often overlooked in regular health data. An accessible web-based survey particularly targeted at this population enabled us to do so, and we reached a group of respondents significantly different from regular survey participants. Results from this monitor provided insights into the health of people with MID and/or low literacy skills and gained knowledge for care organizations and policymakers to improve health promotion and reduce health disparities, in unexpected events such as a pandemic as well as in general.

Keywords: monitoring; mental health; intellectual disabilities; low literacy; COVID-19; online survey
Final word count: 5156 words

Introduction

The COVID-19 pandemic and related disease control measures affected the entire world. People were advised to adhere to strict hygiene measures and to work from home (if possible), and public places and non-essential shops were closed. In addition, social distancing and visiting restrictions were in place during lockdowns. In general, these restrictions had a major impact on daily routines, social contacts, and mental health [1-3], affecting some individuals more than others [4]. In the Netherlands, the national institute for public health and environment (RIVM) started a national longitudinal survey to monitor the impact of COVID-19 and related measures on Dutch citizens [5, 6]. The monitor is informative regarding disease control strategies and policy making [7]; however, there is an external validity bias, as participant characteristics show that a majority of participants have a high education level and are middle-aged or older and female [6, 8, 9]. Indeed, studies have demonstrated that particular subgroups are often underrepresented and excluded from mainstream surveys because general recruitment strategies are unsuitable for reaching them and study measurements are not adapted to their cognitive level or literacy skills [10-12]. These groups often comprise people with lower socioeconomic status and higher risks of health problems, and, in the case of the COVID-19 pandemic, more difficulties complying with preventive measure [13-15] given their housing or work situation.

This study examined the impact of COVID-19 and related restrictions on mental health and well-being among people with lower cognitive and literacy skills in addition to the people who are predominantly represented in the national survey. An accessible survey based on the national survey was developed, and alternative recruitment techniques were used to specifically include these underrepresented subgroups.

In the Netherlands, approximately 19% of the adult population (ie, 2.5 million adults) have limited reading, writing, or numeracy skills [16]. These limitations have various causes such as a low level of educational attainment, migrant background, parents' level of education and literacy, or low information processing skills [17]. The latter plays an important role in people with a mild intellectual disability (MID), who experience considerable limitations in both intellectual functioning and adaptive behavior and often need support in their daily life [18]. It is estimated that 4 to 8% of the Dutch population have an MID [19]. People with lower literacy skills or MID often have limited work and income, poor health, and small social networks [20-24]. In general, studies have shown that people with low education and/or health literacy, and people without social support, stable income, daily routine, and access to services, are more at risk of mental health problems such as anxiety, general distress, and loneliness, arising from the COVID-19 pandemic [1, 3, 5, 14, 25, 26]. It is therefore likely that the COVID-19 pandemic has had a higher impact on the mental health of people with MID and/or low literacy skills compared with the general population. However, during the first months of the pandemic, very limited knowledge was available about the impact on this subpopulation, and our study was set up to provide both these essential insights and practical recommendations for policy makers and care providers.

During the ongoing COVID-19 pandemic, studies on mental health specifically aimed at people with (mild) intellectual disabilities (ID) showed negative impact as a result of social isolation or lack of social support, the rapid changes in COVID-19 measures and difficulty understanding these measures, difficulty assessing services, and/or disruption of their daily routine [27-29]. Two European surveys among people with ID found that more than half reported stress or anxiety [30, 31] or felt more anxious than usual because of the virus and subsequent lockdown [31]. A US survey found that 41% of the participants with ID experienced more mental health problems or symptoms since the pandemic; worry and stress were most mentioned [32]. Similarly, people with low health literacy suffered more from anxiety disorders, depression, and sleeping disorders during the COVID-19 pandemic than people showing sufficient health literacy [14]. Altogether, these studies – primarily conducted during the first lockdown period(s) – showed a great impact on the mental health of people with MID and/or low literacy skills, which contributed to an increase in pre-existing inequalities in health and well-being [24, 33].

The current underrepresentation in national surveillance and surveys of people with low literacy skills and/or MID, and the consequent lack of information about them, adds to existing health disparities. To better understand the impact of the COVID-19 pandemic, specific factors driving this impact, and specific needs of persons with MID and/or low literacy skills, more information is urgently needed. Knowledge acquired through monitoring population health in its local context can provide a basis for government and health organizations to develop appropriate strategies to reduce this impact accordingly. Additionally, the course of the pandemic and its ever-changing disease control strategies over time are important aspects regarding the context in which people were affected. During the rapidly changing situation and regulations in the pandemic (e.g., when vaccinations were offered or restrictions were lifted), a dynamic impact on mental health was expected, and more insight is needed into how people responded to this unpredictable course.

This study is the first to examine the impact of the COVID-19 pandemic on people with MID and/or low literacy skills in direct comparison with the general population and over the course of the pandemic at three different time points. A unique survey study was set up that complemented RIVM's national survey. This study developed an accessible version of the online survey together with representatives of the target population and used suitable techniques to reach people with MID and/or low literacy skills.

Methods

Study design

A repeated cross-sectional study of people with MID and/or low literacy skills and a general population sample was conducted during the COVID-19 pandemic in the Netherlands. Inclusion criteria were people with reading and writing difficulties, 16 years or older, living in the Netherlands, and completion of the survey. No exclusion criteria were used. A control question to assess participants on literacy skills or intellectual ability was not included, as this was expected to be too sensitive for the participants. For reasons of comparison, the same survey was presented to a panel used to represent the general Dutch population.

The survey was administered three times in a one-year period between November 2020 and November 2021. The first survey (T1) was distributed during a nationwide second lockdown (November–December 2020), the second survey (T2) was administered after the second lockdown and when the Dutch vaccination program had started (April–May 2021), and the third survey (T3) was distributed after the summer when most COVID-19 restrictions had been lifted (September–October 2021). Figure 1 shows the timeline and the severity of the COVID-pandemic in the Netherlands by means of excess mortality rates.

[Figure 1 about here]

Study population and recruitment

The surveys were disseminated via organizations working with people with MID and/or low literacy skills, such as advocacy organizations, care facilities for people with MID, language education organizations and libraries supporting and educating illiterates, social workplaces, the Dutch national expertise center for health differences ‘Pharos’, Special Olympics, and a website offering accessible online information and programs for people with limited digital and/or literacy skills (www.steffie.nl). The surveys were open for between 4 and 6 weeks, giving organizations time to distribute them within their network. Support was available to allow people who were anxious or unable to complete the survey independently to participate in this study. At the end of each survey, participants were asked to participate in future research, resulting in a panel to contact directly for consecutive survey rounds.

Our easy-read survey was also distributed within the same time period to two panels of Municipal Health Service (MHS) (in Dutch: GGD) Gelderland-Zuid (approx. n=2500) and Gelderland-Midden (approx. n=7000). Each MHS has a panel consisting of residents in its service area who are regularly asked to complete health surveys. There is a known bias to these panels, as they generally consist of older, more highly educated members, with an overrepresentation of females [34]. We particularly used these panels in our study to obtain comparative data from a representation of the Dutch population and because these panels were also invited to participate in the national RIVM survey.

All participants received the same survey . Participation was voluntary and participants could stop completing the survey at any time. Completion of a prior survey was not obligatory to participate in a latter round. Data were obtained anonymously, and therefore matching between surveys and paired within-group analysis over time was not possible.

Online survey development

RIVM’s Dutch national survey on preventive measures and behavior, and the impact of COVID-19 formed the basis of this monitor, but was adapted to provide an easy-read version for this study [6]. The national survey consisted of more than a hundred questions – for example, about participants’ well-being, trust in the government, adherence to COVID-19 measures, risk of COVID-19 infection, and understanding of COVID-19 information. Over time, new topics such as willingness to receive COVID vaccinations or vaccine hesitancy were added to the survey. We adjusted the national survey in three steps to create an easy-read version, by (1) shortening the survey selecting only a limited number of relevant topics, (2) reducing the number of response categories, and (3) adjusting the language level. This procedure was based on literature insights [35] and carried out in collaboration with professionals (eg, researchers (n=2), care providers (n=3), and policy makers (n=2) working with people with MID and/or low literacy skills regarding health-related issues) and, in addition, with two experiential experts with MID or low literacy skills trained to advise, and experienced in advising, research projects. To shorten the survey (1), we discussed, prioritized, and selected the most relevant topics in light of a) our research objective to measure mental health, b) relevance to the target population, and c) the target population's cognitive capacity to answer the questions. The number of response categories was reduced (2), in terms of Likert-scale options [36, 37], by verifying distinctiveness between answering categories and checking the relevance of categories [38]. During the final step, abstract concepts, time references, and the language level were adjusted (3) [39].

The easy-read survey consisted of 40 to 60 questions, depending on the answers given to previous questions. The survey was pilot-tested with people with MID and/or low literacy skills (n=6) using the Think Aloud methodology in cognitive interviews [40]. We used these methods to verify the intended constructions of the questions and to assess the language level and the fit of the questions and response categories. Next, a web-based version of the survey was created in an online platform (called 'I co-research') designed with and for people with MID (www.ikonderzoekmee.nl). The platform has a clear layout, the possibility to enlarge font size, icons that can be added to answering options, and a speech-to-text and text-to-speech function. Additional pilot tests were carried out in which we observed participants (n=4–7 each wave) while they were completing the survey to evaluate and improve the usability of the platform. The observations were followed by retrospective interviews. The tests resulted in minor adjustments to the questions, the response categories, and the online platform. This procedure resulted into a final short easy-read online survey.

These same steps were followed to modify and revise the survey for the second and third rounds. After each survey round, the findings were discussed in 4–5 focus groups with either people with MID and/or low literacy, or with care and support professionals and policy makers concerned with these subgroups. On the one hand, this led to a quick dissemination of our findings accompanied by solutions or practical tips to put into practice. On the other hand, these group discussions provided input for the consecutive survey rounds, in which questions that became less relevant over time (eg, adherence to specific measures, difficulty coping with changes in specific daily activities) were replaced by new questions, for example about vaccination.

Measures

The easy-read survey consisted of 40–60 questions. We report the measures that were used for this specific study only (also see Appendix).

Demographics and contextual factors

Similar to the national survey, an extensive section on demographics was included, such as age, sex, educational level, country of birth and living situation were. Furthermore, contextual factors known to have a potential influence on mental well-being were selected from the national survey and included, such as health status (eg. rating of physical health, experienced COVID-19 infection), having social contacts, and socioeconomic status (eg. work status and cessation of main activities because of COVID-19). [24,25]. To fit our target group's everyday experience work status included paid work, volunteer work, school and/or daycare. In addition to the national survey, receiving professional care was included as this is an important characteristic describing support needs of our target population, as well as survey completion methods (alone or with help) about which the panel for people with MID and/or low literacy skills was asked. See supplemental material for all questions in the easy-read questionnaire.

Mental health

To gain a better understanding of the impact of the COVID-19 pandemic on mental health, a final set of six outcome measures regarding mental health was defined. The Dutch national survey incorporated a mix of newly developed and existing validated scales or items in their wellbeing module including the five-item Mental Health Inventory [41], loneliness (6-item De Jong Gierveld Loneliness Scale [42]), life satisfaction, resilience, positive and negative effects experienced due to COVID-19 pandemic and emotional response (i.e. how much worry, stress or fear people experience) to monitor various aspects of mental health during COVID-19 [6]. Most relevant items for our target group and research aim were selected from this set, in the first developmental step of item generation. Consecutively, response format was evaluated. For reasons of uniformity, response options were adapted to a similar 4-point Likert scale in this series of questions. All questions had to be revised in accordance with the language level and understanding of the target group and we ensured to avoid overlapping concepts. These steps resulted in the following six questions: 'Did you feel happy / full of energy / worried / stressed / lonely in the last couple of days?', and 'Did you have problems falling asleep in the last couple of days?'. The outcomes were measured on a 4-point Likert scale: 1=Yes, very often; 2=Yes, often; 3=Yes, sometimes; 4=No, almost never [See supplemental material] .

Statistical analyses

Mental health was measured at three time points over a one-year period among people with MID and/or low literacy skills (referred to as target panel) and the MHS panels. First, we calculated the frequencies and the median of the descriptive and contextual measures at each time point for the target panel and the MHS panels. To assess differences between panels, in each round Pearson Chi-square tests were conducted for nominal or ordinal variables, and nonparametric t-tests were performed for age. Second, we calculated the differences in frequencies of mental health scores using Pearson Chi-square tests between survey rounds within each panel and between panels for each survey round. Third, we analyzed the impact of the group differences on mental health using linear regression analyses, while controlling for sex and age-related differences. Given the large number of participants in each round and the multitude of comparisons made in analysis, differences and associations were considered statistically significant if *P* values were smaller than 0.01 [43]. Statistical analyses were conducted in SPSS version 25.0 (Armonk, NY: IBM Corp.).

Ethical considerations

The study was reviewed by the Medical Research Ethics Committee of Radboud University Medical Center, who ruled that this study was not subjected to the Medical Research Involving Human Subjects Act, and was therefore exempted from formal ethical review (2020-7033) We conducted the study in accordance with GDPR en Standard Operating Procedures of our research center.

All participants received the survey after they were fully informed, in plain language, about the purpose of this study. All participants provided online written informed consent regarding participation and use of data for this study and for future purposes before filling out each questionnaire. Per survey, 20 vouchers of €50 were raffled among people with MID and/or low literacy skills, motivating participation.

Contact information used for the purpose of this raffle and/or future research were obtained and saved in a separate environment, so survey data could be obtained anonymously. Therefore matching between surveys and paired within-group analysis over time was not possible.

Results

Participant characteristics

Our online survey and adapted recruitment procedure enabled 412 persons with MID and/or low literacy skills to participate in T1, 351 in T2, and 296 in T3. Background and contextual characteristics per survey round for the target panel and the MHS panels are displayed in Table 1. Over the three time periods, 47–53% of participants with MID and/or low literacy were female, with a median age ranging from 42 to 44 years, and more than 70% reporting no or a low education level. The majority (73–86%) were born in the Netherlands, 50–63% received professional care, and 23–32% reported living in a residential setting. About half of the respondents in each round reported (very) good physical health.

Table 1. Distribution of demographic and contextual characteristics (health and socioeconomic status, social contacts and target group specific characteristics) per survey round, by target panel and MHS panels

	T1 target panel n, (%) n=412	**T1 MHS panels n, (%) n=2930**	**T2 target panel n, (%) n=351**	**T2 MHS panels n, (%) n=3213**	**T3 target panel n, (%) n=296**	**T3 MHS panels n, (%) n=3162**
Age, median (IQR,y)	**42, 27-57[a]**	**53, 41-64**	**44, 30-57 [a]**	**58, 45-71**	**42, 28-54 [a]**	**59, 46-72**
Sex[b]						
Female	**218 (53.2)[c]**	**1,832 (62.5)**	185 (52.7)[d]	1.865 (58.0)	**138 (46.6)[a]**	**1.766 (55.9)**
Educational level[a]						
No – Basic	**91 (22.1)**	**12 (0.4)**	**63 (17.9)**	**17 (0.5)**	**85 (27.7)**	**25 (0.8)**
Low	**201 (48.8)**	**361 (12.3)**	**190 (54.1)**	**477 (14.8)**	**139 (47.0)**	**515 (16.3)**
Middle	**53 (12.9)**	**769 (26.2)**	**64 (18.2)**	**811 (25.2)**	**45 (15.2)**	**790 (25.0)**
High	**27 (6.6)**	**1730 (59.0)**	**8 (2.3)**	**1848 (57.5)**	**12 (4.1)**	**1785 (56.5)**
Other[e]	**39 (9.5)**	**56 (1.9)**	**25 (7.1)**	**59 (1.8)**	**17 (5.7)**	**46 (1.5)**
Born in the Netherlands	**299 (72.6)[a]**	**2790 (95.2)**	**295 (84.0)[a]**	**3.073 (95.6)**	**253 (85.5)[a]**	**3.023 (95.6)**
Living situation[a]						
Alone	**101 (24.5)**	**388 (13.2)**	**123 (35.0)**	**495 (15.4)**	**88 (29.7)**	**516 (16.3)**
With family	**209 (50.7)**	**2525 (86.2)**	**149 (42.5)**	**2708 (84.4)**	**112 (37.8)**	**2636 (83.4)**
In residential setting	**93 (22.6)**	**6 (0.2)**	**79 (22.5)**	**6 (0.2)**	**94 (31.8)**	**3 (0.1)**
(Very) Good physical health	**217 (52.7)[a]**	**2326 (79.4)**	**164 (46.7)[a]**	**2478 (77.1)**	**170 (57.5)[a]**	**2435 (77.0)**
COVID-19 infection	-	-	61 (17.4)[q]	461 (14.3)	45 (15.2)[r]	364 (14.7)
Daily activities[f]						
Paid work	**145 (35.2)[a]**	**1.920 (65.5)**	**133 (37.9)[a]**	**1.628 (50.7)**	**117 (39.5)[g]**	**1.528 (48.3)**
Volunteer work	92 (22.3)[h]	748 (25.5)	74 (21.1)[i]	652 (20.3)	62 (20.9)[j]	738 (23.3)
School	**100 (24.3)[a]**	**154 (5.3)**	**42 (12.0)[a]**	**87 (2.7)**	**47 (15.9)[a]**	**73 (2.3)**

Daycare	**121 (29.4)[a]**	**43 (1.5)**	**103 (29.3)[a]**	**32 (1.0)**	**103 (34.8)[a]**	**30 (0.9)**
Other (sport/hobby/care/other)	197 (47.8)[k]	1558 (53.2)	179 (51.0)[l]	1760 (54.8)	176 (59.5)[m]	1668 (52.8)
none	32 (7.8)[n]	351 (12.0)	**19 (5.4)[a]**	**379 (11.8)**	**9 (3.0)[a]**	**373 (11.8)**
Daily activity changed[o]						
Reduced or stopped	**125 (30.3)[a]**	**385 (13.1)**	**98 (27.9)[a]**	**538 (16.7)**	**67 (22.6)[a]**	**229 (7.2)**
Nothing to do (bored)	-	-	**18 (5.1)[a]**	**54 (1.7)**	**19 (6.4)[a]**	**49 (1.5)**
Social contacts						
No one I can talk to	**42 (10.2)[a]**	**188 (6.4)**	**45 (12.8)[a]**	**134 (4.2)**	20 (6.8)[p]	135 (4.3)
No one who can help me	**59 (14.3)[a]**	**103 (3.5)**	**34 (9.7)[a]**	**88 (2.7)**	**24 (8.1) [a]**	**79 (2.5)**
Receives professional care	**204 (49.5)[a]**	**96 (3.3)**	**216 (61.5)[a]**	**92 (2.9)**	**184 (62.2)[a]**	**105 (3.3)**
Survey completion						
Alone	187 (45.4)		202 (57.5)		169 (57.1)	
With help	223 (54.2)		147 (41.9)		127 (42.9)	

Category totals do not always add up to 100%, as some categories (I don't know, I don't want to answer) and item non-response are not shown. Percentages are based on presented variable totals per category.

[a] Value for target panel is significantly different from regional panel, with P<.001

[b] Less than 1% indicated their sex as 'other'.

[c] Value for target panel is significantly different from regional panel, with P=.001

[d] Value for target panel is not significantly different from regional panel, P=.15

[e] Answer category 'other' is chosen by respondents when it does not fit any of the provided options. This may be because they do not know their education level, do not recognize their education from the option list, or followed education in a country other than the Netherlands.

[f] Respondents could provide multiple answers; category total can therefore add up to than 100%.

[g] Value for target panel is significantly different from regional panel, with P=.005

[h] Value for target panel is not significantly different from regional panel, P=.16

[i] Value for target panel is not significantly different from regional panel, P=.73

[j] Value for target panel is not significantly different from regional panel, P=.38

[k] Value for target panel is not significantly different from regional panel, P=.04

[l] Value for target panel is not significantly different from regional panel, P=.18

[m] Value for target panel is not significantly different from regional panel, P=.03

[n] Value for target panel is not significantly different from regional panel, P=.01

[o] This variable is constructed concerning the daily activities of paid work, volunteer work, and daycare.

[p] Value for target panel is not significantly different from regional panel, P=.02

[q] Value for target panel is not significantly different from regional panel, P=.12

[r] Value for target panel is not significantly different from regional panel, P=.72

In T1 2930 MHS panel members completed our survey, while in T2 3213 and in T3 3162 panel members participated. On the MHS panels over the three survey rounds, 56–63% of participants were female, with a median age ranging from 53 to 59, and 13–17% had no or a low education level (ie, more than 70% had a middle or higher education). They were born mainly in the Netherlands (96%), only 3% received professional care, and less than 1% lived in a residential setting. In addition, 77–80% reported having (very) good physical health.

Altogether, this suggests that we successfully included a representation of our target population, i.e., people with MID and/or low literacy skills. In addition, the characteristics of the MHS panels resemble the characteristics of the national sample, which is often used to represent the general Dutch population [9, 34].

Mental health

The analyses on the distribution of frequencies of mental health scores within the target panel show no differences between survey rounds T1 and T2. There are significant differences between T1 and T3 for feelings of happiness, energy, worries, stress, and loneliness among people with MID and/or low literacy skills (Figure 2), and between T2 and T3 for these aspects except for worry and feeling lonely; the percentage of people reporting positive feelings ‘often’ or ‘almost always’ increased and the percentage of people reporting negative feelings ‘often’ or ‘almost always’ decreased over time. There were no differences observed for sleeping problems.

On the MHS panels, there were significant differences between each survey round T1–T2–T3 for feelings of happiness, energy, and stress. For worries and loneliness, significant differences are observed only between T3 and the two previous rounds. The direction of the differences is similar to that observed in the target panels. Similar to the target panels, the MHS panels did not report differences in sleeping problems.

The analyses between the different panels within survey rounds show that the percentage of the target panel reporting negative feelings on mental health outcomes is significantly higher compared with the MHS panels, especially within T1 and T2. For example, looking at the six outcome measures within T1, the percentages of people who reported more negative feelings range from 21% (85/408) feeling lonely (very) often to 58% (238/408) almost never or only sometimes feeling happy. The MHS panels show a different and more positive distribution on all outcome measures. The percentages of people that reported more negative feelings on the MHS panels range from 5% (160/2904) feeling lonely (very) often to 33% (941/2918) almost never or only sometimes feeling happy. See Figure 2 for more details on the distribution of all mental health outcomes for the target panel and the MHS panels.
[Figure 2 about here]

Impact of literacy skills on mental health

Regression analyses adjusted for age and sex by using them as covariates show that the differences found between the two panels exist for almost all mental health outcomes in each survey round, except feelings of stress in T3 (p=.069). In addition, the differences between the panels during T1 (age and sex-adjusted B ranging from -0.376 to 0.525) are larger than observed in T3 (age and sex-adjusted B ranging from -0.257 to 0.509), except for sleeping problems.

See Table 2 for details for all time periods and outcome measures.

Table 2. Results for each survey round with panel as independent variable, mental health measures as dependent variables, and sex and age as covariates

	T1		T2		T3	
	b(CI 95%)	*P* value	b (CI 95%)	*P* value	b (CI 95%)	*P* value
Happiness						
Panel	**-0.386 (-0.464 to -0.287)**	**<.001**	**-0.385 (-0.481 to -0.288)**	**<.001**	**-0.257 (-0.362 to -0.152)**	**<.001**
Sex	-0.037 (-0.096 to 0.022)	.22	-0.092 (-0.151 to -0.034)	.002	-0.065 (-0.122 to -0.07)	.03
Age	0.000 (-0.002 to 0.002)	.75	0.000 (-0.002 to 0.002)	.86	0.000 (-0.002 to0 .002)	.77
Energy						
Panel	**-0.156 (- 0.249 to -0.063)**	**.001**	**-0.243 (-0.340 to -0.145)**	**<.001**	**-0.143 (-0.249 to -0.037)**	**0.008**
Sex	-0.039 (-0.102 to -0.023)	.22	-0.080 (-0.139 to -0.021)	.008	-0.058 (-0.117 to 0.000)	.05
Age	0.004 (0.002 to 0.006)	<.001	0.003 (0.001 to0.005)	.003	0.004 (0.002 to 0.006)	<.001
Worries						
Panel	**0.328 (0.246 to 0.409)**	**<.001**	**0.324 (0.255 to 0.429)**	**<.001**	**0.227 (0.135 to 0.319)**	**<.001**
Sex	0.158 (0.104 to 0.213)	<.001	0.217 (0.165 to 0.270)	<.001	0.181 (0.131 to 0.232)	<.001
Age	0.000 (-0.001 to 0.002)	.60	-0.002 (-0.004 to 0.000)	.02	-0.002 (-0.003 to 0.000)	.06
Stress						
Panel	**0.274 (0.195 to 0.353)**	**<.001**	**0.199 (0.117 to 0.281)**	**<.001**	0.081 (-0.168 to 0.006)	.07
Sex	0.158 (0.105 to 0.211)	<.001	0.189 (0.140 to 0.239)	<.001	0.195 (0.147 to 0.243)	<.001
Age	-0.010 (-0.012 to -0.008)	<.001	-0.012 (-0.014 to - 0.011)	<.001	-0.013 (-0.014 to -0.011)	<.001
Sleeping problems						
Panel	**0.525 (0.439 to 0.611)**	**<.001**	**0.518 (0.427 to 0.609)**	**<.001**	**0.509 (0.411 to 0.606)**	**<.001**
Sex	0.220 (0.163 to 0.278)	<.001	0.296 (0.241 to 0.351)	<.001	0.240 (0.187 to 0.294)	<.001
Age	0.003 (0.001 to 0.005)	.002	0.000 (-0.002 to 0.002)	.90	0.002 (0.000 to 0.003)	.09
Loneliness						
Panel	**0.479 (0.409 to0.549)**	**<.001**	**0.461 (0.387 to0.535)**	**<.001**	**0.297 (0.229 to 0.365)**	**<.001**
Sex	0.095 (0.049 to 0.142)	<.001	0.161 (0.116 to 0.206)	<.001	0.071 (0.034 to 0.109)	<.001
Age	-0.001 (-0.003 to 0.000)	.10	-0.002 (-0.004 to -0.001)	.002	-0.002 (-0.003 to 0.000)	.01

Discussion

Principal findings

This is the first study to monitor the mental health and well-being of people with MID and/or low literacy skills and a general population sample over the course of one year during the COVID-19 pandemic. With our adapted online survey co-designed with representatives from our target population, we were able to reach subgroups that are usually underrepresented in surveys. Our study showed that feelings of happiness, energy, worries, stress, and loneliness improved in both populations over the course of the pandemic. However, the COVID-19 pandemic and related restrictions impacted the mental health of people with MID and/or low literacy skills considerably more than the general population.

In general, our findings show that, during the second lockdown in the Netherlands (i.e., the first survey round), people with MID, low literacy skills, and the general population sample reported poorer mental well-being than when all restrictions were lifted and the COVID-19 infections became less severe one year later (i.e., third survey round). These findings are in line with research on people in vulnerable positions [1] as well as the general population who experienced fewer negative feelings over the course of the COVID-19 pandemic [5]. Previous literature has shown that the impact on mental health and well-being was correlated to the stringency of disease control measures [25, 44]. For example, the closure of social offices, workplaces, and daycare activities negatively influenced daily structure and social interactions [29-31, 45, 46], thereby increasing stress and anxiety [47], and quarantines and social isolation were found to have a (long-term) effect on loneliness, fear, and boredom [27, 28, 48]. During relaxations of these measures the decline in mental health was partly restored [44]. Although our study was not designed to prove any causation between stringency of disease control measures and mental health impact, findings show a similar pattern of decreasing worries, stress, and loneliness whereas feelings of happiness and energy increased over time. Notably, this was also the case in our general population sample [1, 3, 5, 14, 25, 26], however, the pandemic disproportionately impacted people with MID and/or low literacy skills reporting more negative mental health outcomes in all survey rounds..

Qualitative studies among people with MID show that in particular long-term social restrictions had an extensive impact on their daily life by limiting the social connections and work activities [27, 29]. Our target population reported these limitations in daytime activities to a greater extent than the general population sample. Interviews by Voermans et al. [29] provide more in depth assessment of the consequences of these limitations for people with MID, showing major impact in terms of social isolation, difficulties coping with negative thoughts, struggles with autonomy in society, stigmatization, lack of routine and purpose, boredom and lower self-worth. As awareness is raised about the significant value of meaningful social contacts and daytime activities, professionals and policymakers should provide tailored policies considerate of both health risks and risks of social isolation. Societal participation initiatives should be organized and sustained for people with MID and/or low literacy, both during and outside a pandemic.

Besides the disruptive impact of disease control measures on the target population's daily routines and social contacts, the high levels of confusion and uncertainty that resulted from the rapidly changing measures as well as fear and loss of control may have played a role in their reduced mental health [32], in periods of both stringent measures and relaxation of control measures [14]. Additionally, people with lower health literacy skills are known to have less resilience, affecting their feelings of anxiety, stress, or worries [49, 50], thereby putting them at greater risk of mental health problems. Ongoing support should be provided to enhance resources of resilience and coping strategies in people with MID and/or low literacy skills, from either formal or informal caregivers.

Our findings highlight the need to prioritize the mental health consequences of the pandemic and the disease control measures for people with MID and/or low literacy skills [1, 51, 52]. More than half of the respondents in our sample received support from formal and informal caregivers, who are an important source of support. Studies have shown detrimental effects on the mental health of these caregivers as well [28, 53]. Therefore, we suggest tailoring generic disease control measures to specific situations of vulnerable groups and their support system instead of widely implementing measures such as social distancing, visiting restrictions, and closing schools or daycare facilities – for example, by developing strategies to maintain social inclusion during pandemic challenges through a combination of supportive carers, assisted digital communication technologies, and/or safe, socially distanced activities [54, 55]. Hence, engaging vulnerable groups and their support system in policy making and decision making is essential in the tailoring process [56].

This study underscores the relevance of including people with MID and/or low literacy skills in health research and therefore endorses other calls to action currently made in practice and science [57]. Health information systems are crucial for providing data for policy making and decision making, but the underrepresentation of people with MID and/or low literacy skills in health data may lead to biased policy decisions with adverse and detrimental effects on existing health disparities [13, 33]. Previous research has suggested that, to reduce disparities and guide policy, researchers should assess the distribution of health among specified groups and compare it with the health distribution for the entire population [58], as was done in our study. Collecting information about people with MID and/or low literacy skills should become a routine in demographic and public health data collection. We have shown that, by co-designing an adjusted survey and using an accessible online platform and specific recruitment procedures, it is possible to collect information among people with MID and/or low literacy skills, even during lockdown periods. For example, the sample characteristics showed that participants differed compared with the general population in educational level, country of birth, and daily activities. With our adjusted approach to data collection, we were quickly able to obtain relevant information about people with MID and/or low literacy skills and disseminate our findings and recommendations based on those, thereby facilitating policy makers to guide disease control measures and health promotion activities addressing the immediate and longer-term health needs of people with MID and/or low literacy skills, or other vulnerable populations.

Limitations of the study

Executing a repeated cross-sectional survey among people with MID and/or low literacy skills, during a pandemic, is fraught with challenges. Therefore, our study has some limitations. First, we did not collect longitudinal data because we wanted to lower the threshold for participation by choosing an anonymous design. In addition, people were not obliged to complete all three surveys. As a result, it was impossible to track individual participants over time. Second, inevitably, the validated questions had to be revised to include people with MID and/or low literacy skills in our survey. However, we tested the questions in cognitive interviews, and the project team worked as inclusively as possible together with the target population in order to create a valid survey to obtain reliable data. Most participants were able to complete the online survey themselves (53%), and support was arranged for the remaining group of respondents (47%). This should encourage future researchers to consider easy-read online surveys among people with MID and/or low literacy skills, as long as they are closely involved in designing and testing these surveys. Third, our study started after the onset of the COVID-19 pandemic and lacks a baseline measurement of mental health before the pandemic. Therefore, it remains indecisive as to whether people with MID and/or low literacy skills experienced greater mental health problems than prior to the COVID-19 pandemic. Fourth, we relied mostly on organizations in our network (eg, health care organizations, public libraries with special literacy programs, and so forth) to contact and recruit people with MID and/or low literacy skills. Besides the possible sampling bias that this may have caused, we could not track how many people were approached to take part in the survey. Therefore, we were unable to report information about response rates. Fifth, as the survey was conducted online, those without access to the internet or sufficient digital literacy skills may have been excluded. Lastly, there was also a bias in our general population sample. Although the sample was not representative of the Dutch general population in age, sex, and educational level, it allowed us to contextualize our findings and gain a deeper understanding of the pitfalls of people with MID and/or low literacy compared with the general population sample, while controlling for differences in sex and age. We were able to do so, due to the use of the exact same easy-read questionnaire in both groups to prevent survey bias. An open-ended question about MHS-panel respondents' experience with this type of questionnaire at T3 revealed that the majority of participants appreciated this approach given that a broader population was enabled to participate. Although this may indicate that easy-read questionnaires can be used for broader purposes and other populations, rather than being aimed specifically at people with low literacy skills alone, this single question does not provide sufficient information regarding a broad survey approach and more research is required.

Conclusion

In conclusion, our study enabled insight into the impact of the COVID-19 pandemic and related control measures on the mental health of people with MID and/or low literacy skills. General disease control measures for the entire Dutch population had a more negative impact on people with MID and/or low literacy skills than on the general population. Although mental health improved over the course of the pandemic in both populations as measures were gradually lifted and COVID-19 became less severe, the disproportional effect remained. Professionals should be aware of this and provide attention to the needs of people with MID and/or low literacy in research, practice and policy by tailoring measures considerate of physical, social and mental health effects, and providing support to overcome consequential effects.

This study underscores the relevance of including people with MID and/or low literacy in public health research, as they are often overlooked in regular health data. An accessible and structural web-based monitor for people with MID and/or low literacy skills enabled us to do so and provides better knowledge for care providers and policy makers to react to unexpected events such as a pandemic. To prevent existing health disparities from growing even further, greater account should be taken of the impact of control measures on people who are relatively more vulnerable.

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Data availability

Data will be available for verification for at least 15 years. The datasets generated and analyzed during this study are available in the DANS Easy repository [Citation of DOI]. *DOI to be added when received.*

Authors' contributions

MKL, FR, and GFK participated in the study conception and design. AM and MKL conducted literature search and coordinated survey development and recruitment. KB, AM, and MKL performed survey development, AM was involved in survey programming, and KB enabled survey application on the online platform. AM, FR, and MKL contributed to acquisition of the data. AM accessed and verified the data, and KB, AM, and MKL analyzed the data and plotted the tables and figures. AM and MKL drafted the manuscript. All authors participated in interpreting the data and study findings, critically reviewed and contributed to the revision of the manuscript, and approved the final version submitted.

Conflicts of interest

The authors declare that they have no conflicts of interest.

Abbreviations

ID: Intellectual disabilities

MID: Mild intellectual disabilities

MHS: Municipal Health Service

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Figures

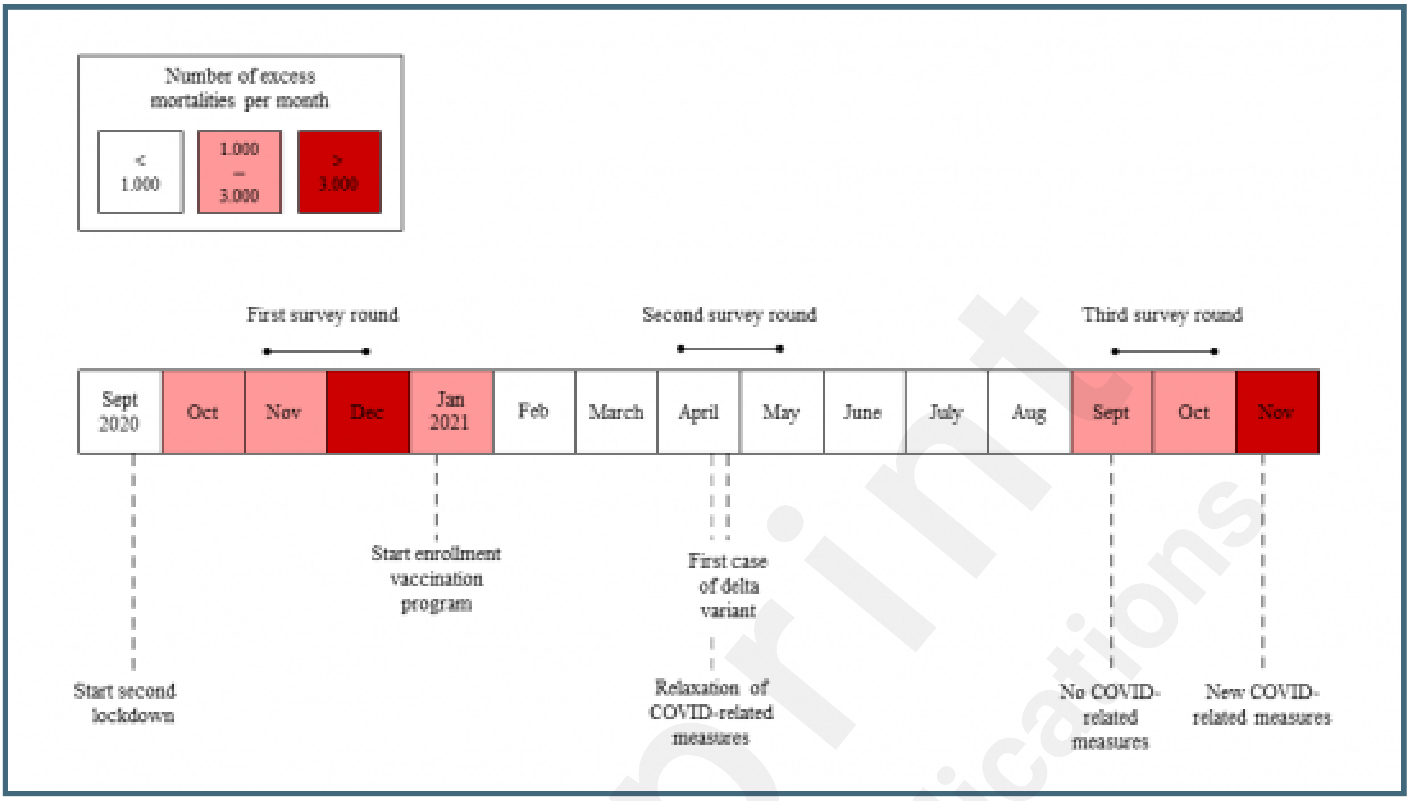
Figure 1. Time line COVID-19 measures, COVID-19 mortality cases, and timing of survey periods.

Figure 2: Distribution of mental health for target group and MHS panels at three different time periods.
Note: Number of excess mortalities indicates the severity of the Covid-19 waves. Data derived from Centraal Bureau voor Statistiek. Gezondheid in coronatijd. Den Haag: CBS; 2022 [Available from https://www.cbs.nl/nl-nl/visualisaties/welvaart-in-coronatijd/gezondheid-in-coronatijd]

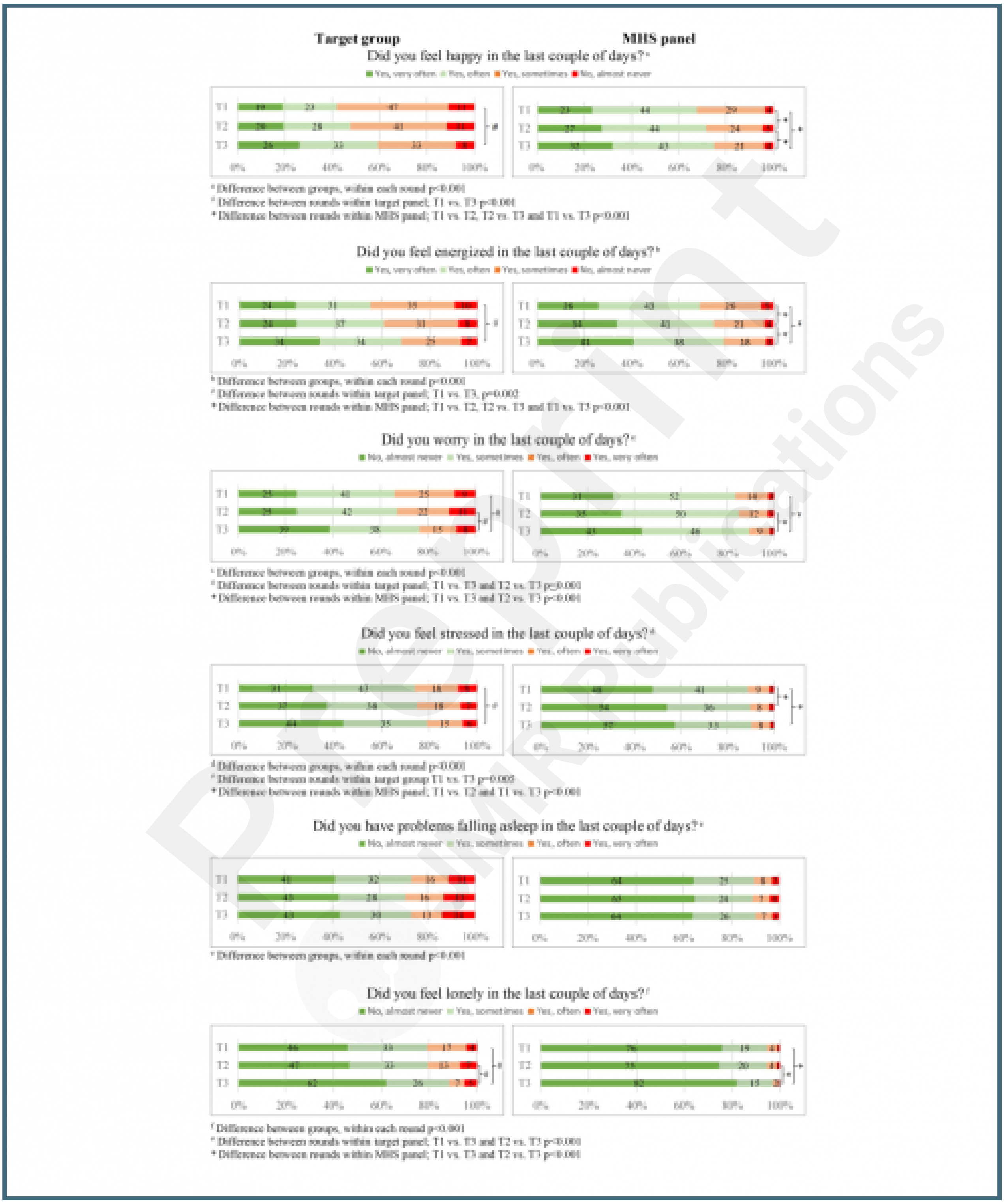
Supplementary Files

Figures

Time line of COVID-19 measures, COVID-19 mortality cases, and timing of survey periods.



Distribution of mental health for target group and MHS panels at three different time periods Note: Number of excess mortalities indicates the severity of the Covid-19 waves - Data derived from Centraal Bureau voor Statistiek. Gezondheid in coronatijd. Den Haag: CBS; 2022 [Available from https://www.cbs.nl/nl-nl/visualisaties/welvaart-in-coronatijd/gezondheid-in-coronatijd].



Multimedia Appendixes

Untitled.
URL: http://asset.jmir.pub/assets/9c24f5c68486a57fa497a9e8d0ce6e5c.docx