User Information Guide

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

2021

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

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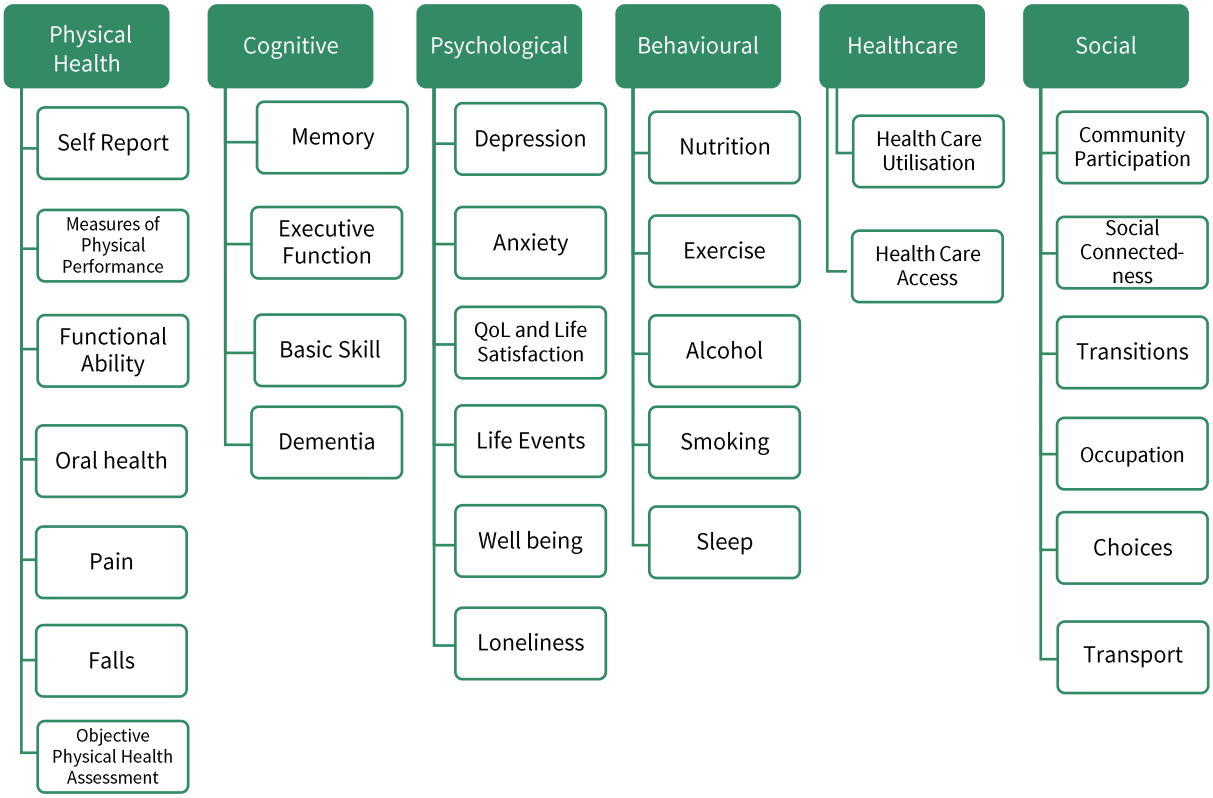
1. The IDS-TILDA study

The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) was established in 2008 with the aim to identify the principal influences on ageing in people with an intellectual disability in the Republic of Ireland aged 40 years and above. The study seeks to characterise and understand changes in ageing by examining healthy and successful ageing, determinants of health and longevity, and similarities or differences in ageing for those with and without intellectual disability using comparative data from the Irish Longitudinal Study on Ageing (TILDA) for the general population. IDS-TILDA was the first longitudinal study on ageing amongst the intellectual disability population worldwide to be implemented parallel to a study of ageing amongst the general population. The conceptual framework shown in Figure 1 illustrates the range of data collected by IDS-TILDA.

Figure 1. IDS-TILDA conceptual framework



The study is also underpinned by a set of core values including inclusion, empowerment, choice, person centeredness, best practice, promoting people with intellectual disability and making a positive impact on their lives. IDS-TILDA was developed in close cooperation with people with an intellectual disability, who have played an integral role throughout the development of the study.

Involvement of people with an intellectual disability began with the initial pilot study conducted to develop inclusive Wave 1 protocols and has continued through consultation on changes for each subsequent wave. A 'keeping in touch' strategy – for example using newsletters, cards and art competitions – is also integral to maintaining the voice of people with an intellectual disability as well as engaging people and preserving the study sample through multiple waves of data collection.

For recruitment of the original study sample at Wave 1, the Health Research Board (HRB) supported use of the National Intellectual Disability Database (NIDD) to anonymously recruit adults with an intellectual disability aged 40 years and above in the Republic of Ireland. The final Wave 1 sample of 753 demographically and geographically representative of the target population within the NIDD, equating to 8.9% of the total eligible population at the time. The sample was 45% male and 55% female; aged 41 to 90 years (mean age 54.7 years); 24% had a mild ID, 46% moderate ID, 24% severe ID, and 5% profound ID (with 5% unverified). Around 40% lived in 52-week residential care centres, with a further 5.3% in other residential centres (i.e. 45.3% in 'institutional' or 'congregated' residential care settings); around one-third (34.1%) lived in community group homes with other individuals with intellectual disability; 5% lived independently or semi-independently; and 11% lived at home with their families (McCarron et al., 2011).

The retention rate for Wave 2 of IDS-TILDA was 94%, with a final sample of 708 completing at least one element of the study. At Wave 3, a surviving sample of 609 participants equated to 80.9% of the original Wave 1 sample. Of the 144 participants lost to the study by Wave 3, 105 had died and 39 had withdrawn.

To maintain adequate statistical power and ensure the representativeness of the study, additional recruitment was planned for Wave 4. As in Wave 1, HRB supported use of NIDD to anonymously recruit sufficient numbers of new participants to restore the sample to its Wave 1 size and representativeness. A targeted recruitment drive successfully addressed underrepresented groupings including in the 40-49-year-old category. A final representative sample of 739 individuals was achieved for Wave 4 with 135 new participants in the new 40-49-year-old cohort.

Table 1. Demographic profiles of IDS-TILDA Wave 4 sample and COVID-19 survey sample

	Wave 4 Participants % (n)
Gender	
Male	46.5 (344)
Female	53.5 (395)
Age	
< 50 years	18.3 (135)
50-64 years	55.1 (407)
65+ years	26.7 (197)
Level of Intellectual Disability[1]	
Mild	29.6 (204)
Moderate	42.5 (293)
Severe-Profound	27.9 (192)
Aetiology of Intellectual Disability	
Down syndrome	19.6 (145)
Other aetiology/Unknown	80.4 (594)
Residence Type	
Independent/Family	17.3 (126)
Community Group Home	49.0 (358)
Residential Care	33.8 (246)
Total	100.0 (739)

The first three waves of IDS-TILDA were reported in 2011 (McCarron et al., 2011), 2014 (Burke, McCallion, & McCarron, 2014) and 2017 (McCarron, Haigh, & McCallion, 2017). This established the study as a global leader in research on ageing among people with intellectual disability, contributing to policy and service development in Ireland, and supporting the establishment in

[1] 50 participants had an unverified level of intellectual disability

2018 of the Trinity Centre for Ageing and Intellectual Disability (TCAID) at Trinity College Dublin (TCD)[2]. The planned fourth wave of the longitudinal study was interrupted in March 2020 by the outbreak of COVID-19 while data collection was ongoing. Adapting to the emerging crisis, and following ethical approval, the IDS-TILDA study resumed data collection in May 2020 using remote interviewing and with the addition of a survey of the impact of COVID-19 among IDS-TILDA participants.

1.1 Wave 4 COVID-19 Survey

When the COVID-19 pandemic emerged and Ireland went into its first lockdown in March 2020, the ongoing data collection for Wave 4 of IDS-TILDA was suspended. A unique opportunity emerged at this time to examine how COVID-19 affected the lives of people with an intellectual disability who are getting older.

Given the emerging scale and seriousness of the COVID-19 crisis, and the lack of knowledge at that time about its potential impact among people with intellectual disability, there was an urgency to disseminate knowledge about how the virus and its associated public health measures was impacting people with an intellectual disability in Ireland. The first IDS-TILDA COVID-19 survey was developed to assess rates of symptoms and testing, morbidity and treatment, stress and anxiety associated with the pandemic, and any positive outcomes experienced by individuals during the lockdown period. Data were collected between May and September 2020, when Ireland experienced its first wave of infection and first lockdown measures. These data were supplemented with health data from the main IDS-TILDA study, to explore associations with disease morbidity and other health and well-being outcomes, to consider potential predictors of symptoms and COVID positivity and of differences in people's lives, before and during COVID-19 restrictions.

From a total Wave 4 sample of 739 participants, 710 completed the COVID-19 survey, a response rate of 96.1%. The demographic profile of the COVID-19 survey is provided in Table 2.

[2] https://www.tcd.ie/tcaid/

Table 2. Demographic profile of IDS-TILDA Wave 4 COVID-19 survey sample

	COVID-19 Participants % (n)
Gender	
Male	46.8 (332)
Female	53.2 (378)
Age	
< 50 years	18.7 (133)
50-64 years	55.1 (391)
65+ years	26.2 (186)
Level of Intellectual Disability[3]	
Mild	29.7 (196)
Moderate	41.8 (276)
Severe-Profound	28.5 (188)
Aetiology of Intellectual Disability	
Down syndrome	19.6 (139)
Other aetiology/Unknown	80.4 (571)
Residence Type	
Independent/Family	17.4 (122)
Community Group Home	49.6 (348)
Residential Care	33.0 (231)
Total	100.0 (710)

[3] 50 participants had an unverified level of intellectual disability

The initial findings from this representative sample of older adults with intellectual disability in Ireland were launched in December 2020 (McCarron et al., 2020)[4]. It is hoped that the publication and availability of data through HRB Open Research will further contribute to our understanding of the impact of COVID-19 on this population, and of the impact of public health measures implemented to combat spread of the virus.

As part of the open publication process, the authors of this study have decided to make the data used in the study publicly available. The data from the original study is anonymised to make the data publicly available for future use. The details of the anonymisation process and rules used for anonymisation are described in the section below. The data set is saved as 'Wave4 Covid 19 phase1 data' in the ISSDA website. This is a subset of the Wave 4 dataset, used in the paper, entitled *'The impact of COVID-19 on older adults with an intellectual disability during the first wave of the pandemic in Ireland'* from the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA). All variables in the dataset are created based on CAPI, PIQ and Covid-19 questionnaire (Available in ISSDA website). Of note, the dataset does not comprise any personal identifiers such as name, address, or ID numbers. Any potentially identifiable data on its own, or in combination with others are either top coded, grouped or dropped completely. The resulting dataset has 17 partially or completely anonymised variables with 739 rows.

The dataset is available in SPSS version 26. All variables in the dataset were created using R Studio Version 1.4.1103.

2. Data anonymisation process

Both IDS-TILDA and the COVID-19 survey added to the fourth wave of IDS-TILDA collect sensitive information from a small representative sample of a relatively small population group, when compared to the size of the general ageing Irish population. IDS-TILDA information is often used by people who work within the intellectual disability (ID) sector, many of whom know the ID population well. Thus, for someone in such a position, it may be possible to determine the identity of a participant based on a few pieces of information viewed together. As such, it has always been the highest priority of IDS-TILDA to ensure that the participants' information remain protected and, by extension, access to the data is strictly controlled.

In order to make the data available, while making sure that the identities of the IDS-TILDA participants remain protected, an extensive data de-identification process was undertaken during which a number of variables had to be excluded from the COVID-19 dataset due to personal identification concerns.

[4] https://idstilda.tcd.ie/assets/docs/wave4idstildareport.pdf

Only the variables that were used in the paper, entitled *'The impact of COVID-19 on older adults with an intellectual disability during the first wave of the pandemic in Ireland'*, are considered for release and hence, for anonymisation. The details of the variables included and excluded from the list of original variables used in the paper's analyses are given in the Excel file "List of variables used in original study".

As per McGrath and Hanan (2016), variable cell sizes of 20 or more ensure that data are sufficiently anonymised. This criterion was used as the basis of the anonymisation process that was carried out over several rounds of data analysis.

At each round the variables were assessed on a case-by-case basis. The variables which may lead to the potential identification of the participants, e.g. types of respondents, were omitted from the first round of anonymisation. Subsequently, each variable was summarised into category frequencies, where each frequency was compared to the cut-off of 20. Each variable was also cross tabulated with specific demographic variables, namely gender, age, ID aetiology, ID level and residence type, and the resulting cell counts were compared to the cut-off of 20. Variables that did not meet the criteria were either removed or considered for regrouping, combination with other variables, top coding, or bottom coding. These steps formed part of consecutive rounds of data anonymisation. The only numerical variable that was used in the paper's analyses could not be made available due to the nature of the question and that releasing this variable would almost certainly lead to personal identification due to very few observations being captured for it.

2.1 List of original variables considered for anonymisation

The first round of anonymisation saw a large number of the variables used in the paper's analyses removed from consideration as they either contained the participants' personal information or did not meet the minimum cell size cut-off of 20. This section contains the details of all remaining original variables considered for anonymisation. The details of the excluded variables are given in the Excel file named "List of variables used in original study". The list of variables considered for anonymisation is given in Table 3.

Table 3: List of original variables considered for anonymisation

No.	Variable name	Categories	Label	Description
1.	W4_gender	1 = "Male" 2 = "Female"	Gender of Wave 4 participants.	The variable is created based on question NP1 from the PIQ and questions CS_GenderConf and CS_Gender_4 from Section 1: Cover Screen & Demographics (CS) of CAPI.

No.	Variable name	Categories	Label	Description
2.	W4_age_cat	1 = “40-49” 2 = ”50-64” 3 = “65+”	A categorical variable for age of participants at Wave 4.	The variable is created based on question NP2 from the PIQ and questions CS_DOBConf_4 and CS_DOB_4 Section 1: Cover Screen & Demographics (CS) of CAPI.
3.	W4_residence	1 = “Independent / Family” 2 = “Community group home” 3 = “Residential Care”	A categorical variable for residence types of participants at Wave 4.	The variable is created based on the questions CS_TypeConf_4, CS_ToR_4, CS_ToR_2B_4, CS_1c_4 and CS_1c_oth_4 Section 1: Cover Screen & Demographics (CS) of CAPI.
4.	W4_BMI_3cat	1 = “Underweight” 2 = “Normal” 3 = “Overweight/Obese”	Self-reported BMI coded to 3 categories.	Self-reported weight, question 3 in the PIQ, and height, question 4 in the PIQ, were used to calculate BMI that was then grouped according to the BMI scale.
5.	W4_smoking	1 = “Never smoked” 2 = “Previously smoked but not currently” 3 = ”Currently smoking”	A pre-existing variable for Smoking status of the participants.	The variable is created based on the variables BH_1_4 and BH_2_4 from Section 11: Behavioural Health (BH) of the CAPI.
6.	W4_GDS	1 = “GD no depression” 2 = “GD depression”	A categorical variable representing self-reported depressive symptomology according to the Glasgow Depression Scale.	This variable is created based on question MH_11_4 and its subsections in Section 10: Mental Health (MH) of the CAPI.
7.	W4_GAS	1 = “GA no anxiety” 2 = “GA anxiety”	A categorical variable representing self-reported symptoms of anxiety according to the Glasgow Anxiety Scale.	This variable is created based on question MH_12_4 and its subsections in Section 10: Mental Health (MH) of the CAPI.

No.	Variable name	Categories	Label	Description
8.	W4_GDS_carer	1= “GD no depression” 2= “GD depression”	Carer supplement to Glasgow Depression Scale.	This variable is created based on question MH_11A_4 and its subsections in Section 10: Mental Health (MH) of the CAPI.
9.	W4_heart_high_cholesterol_allwave_prevalence	1 = “Does not have condition” 2 = ”Prevalence”	History of high cholesterol across all waves.	First, a Wave 4 high cholesterol prevalence variable was created using questions PH_310A_4, PH_310XO_8, PH_310Y_08_4, PH_310_08_4, and PH_310YB_08_4 in Section 9: Physical Health (PH) of the CAPI. Then, the history of high cholesterol variable was created by counting high cholesterol as present if the participant reported ever having high cholesterol in any of the IDS-TILDA waves (1 – 4).
10.	W4_heart_hypertension_allwave_prevalence	1 = “Does not have condition” 2 = ”Prevalence”	History of hypertension across all waves.	First, a Wave 4 hypertension prevalence variable was created using questions PH_310A_4, PH_310XO_1, PH_310Y_01_4, PH_310_01_4, and PH_310YB_01_4 in Section 9: Physical Health (PH) of the CAPI. Then, the history of hypertension variable was created by counting hypertension as present if the participant reported ever having hypertension in any of the IDS-TILDA waves (1 – 4).
11.	W4_heart_diabetes_allwave_prevalence	1 = “Does not have condition” 2 = ”Prevalence”	History of diabetes across all waves.	First, a Wave 4 diabetes prevalence variable was created using questions PH_310A_4, PH_310XO_5, PH_310Y_05_4, PH_310_05_4, and PH_310YB_05_4 in Section 9: Physical Health (PH) of the CAPI. Then, the history of diabetes variable was created

No.	Variable name	Categories	Label	Description
				by counting diabetes as present if the participant reported ever having diabetes in any of the IDS-TILDA waves (1 – 4).
12.	W4_heart_heart_attack_allwave_prevalence	1 = “Does not have condition” 2 = ”Prevalence”	History of heart attack across all waves.	First, a Wave 4 heart attack prevalence variable was created using questions PH_310A_4, PH_310XO_3, and PH_310_03_4 in Section 9: Physical Health (PH) of the CAPI. Then, the history of heart attack variable was created by counting heart attack as present if the participant reported ever having a heart attack in any of the IDS-TILDA waves (1 – 4).
13.	W4_heart_stroke_allwave_prevalence	1 = “Does not have condition” 2 = ”Prevalence”	History of stroke across all waves.	First, a Wave 4 stroke prevalence variable was created using questions PH_310A_4, PH_310XO_6, and PH_310_06_4 in Section 9: Physical Health (PH) of the CAPI. Then, the history of stroke variable was created by counting stroke as present if the participant reported ever having a stroke in any of the IDS-TILDA waves (1 – 4).
14.	W4_other_asthma_allwave_prevalence	1 = “Does not have condition” 2 = ”Prevalence”	History of asthma across all waves.	First, a Wave 4 asthma prevalence variable was created using questions PH_350A_4, PH_350XO_1, PH_350Y_01_4, PH_350_01_4, and PH_350YB_01_4 in Section 9: Physical Health (PH) of the CAPI. Then, the history of asthma variable was created by counting asthma as present if the participant reported ever

No.	Variable name	Categories	Label	Description
				having asthma in any of the IDS-TILDA waves (1 – 4).
15.	W4_other_arthritis_allwave_prevalence	1 = “Does not have condition” 2 = ”Prevalence”	History of arthritis across all waves.	First, a Wave 4 arthritis prevalence variable was created using questions PH_350A_4, PH_350XO_18, and PH_350_18_4 in Section 9: Physical Health (PH) of the CAPI. Then, the history of arthritis variable was created by counting arthritis as present if the participant reported ever having arthritis in any of the IDS-TILDA waves (1 – 4).
16.	W4_other_epilepsy_allwave_prevalence	1 = “Does not have condition” 2 = ”Prevalence”	History of epilepsy across all waves.	First, a Wave 4 epilepsy prevalence variable was created using questions PH_350A_4, PH_350XO_20, and PH_350_20_4 in Section 9: Physical Health (PH) of the CAPI. Then, the history of epilepsy variable was created by counting epilepsy as present if the participant reported ever having epilepsy in any of the IDS-TILDA waves (1 – 4).
17.	W4_other_dementia_allwave_prevalence	1 = “Does not have condition” 2 = ”Prevalence”	History of dementia across all waves.	First, a Wave 4 dementia prevalence variable was created using questions PH_350A_4, PH_350XO_23, and PH_350_23_4 in Section 9: Physical Health (PH) of the CAPI. Then, the history of dementia variable was created by counting dementia as present if the participant reported ever having dementia in any of the IDS-TILDA waves (1 – 4).

No.	Variable name	Categories	Label	Description
18.	W4_other_chronic_kidney_disease_allwave_prevalence	1 = “Does not have condition” 2 = ”Prevalence”	History of chronic kidney disease (CKD) across all waves.	First, a Wave 4 CKD prevalence variable was created using questions PH_350A_4, PH_350XO_24, and PH_350_24_4.x in Section 9: Physical Health (PH) of the CAPI. Then, the history of CKD variable was created by counting CKD as present if the participant reported ever having CKD in any of the IDS-TILDA waves (1 – 4).
19.	W4_tilda_cvd_allwave	1 = “Does not have condition” 2 = ”Prevalence”	History of CVD (angina, heart attack, hypertension, congestive heart failure (CHF), stroke, TIA, abnormal heart rhythm, heart murmur, stent) across all waves.	**Angina**: A Wave 4 Angina prevalence variable was created using questions PH_310A_4, PH_310XO_2, PH_310Y_02_4, PH_310_02_4, and PH_310YB_02_4 in Section 9: Physical Health (PH) of the CAPI. **Heart attack**: see variable no. 12. **Hypertension**: see variable no. 10. **CHF**: A Wave 4 CHF prevalence variable was created using questions PH_310A_4, PH_310XO_4, PH_310Y_04_4, PH_310_04_4, and PH_310Y_04B_4 in Section 9: Physical Health (PH) of the CAPI. **Stroke**: see variable no. 13. **TIA**: A Wave 4 TIA prevalence variable was created using questions PH_310A_4, PH_310XO_7, and PH_310_07_4 in Section 9: Physical Health (PH) of the CAPI.

No.	Variable name	Categories	Label	Description
				Abnormal heart rhythm: A Wave 4 abnormal heart rhythm prevalence variable was created using questions PH_310A_4, PH_310XO_12, PH_310Y_12_4, PH_310_12_4, and PH_310YB_12_4 in Section 9: Physical Health (PH) of the CAPI. **Heart murmur**: A Wave 4 heart murmur prevalence variable was created using questions PH_310A_4, PH_310XO_9, PH_310Y_09_4, PH_310_09_4, and PH_310_09_4 in Section 9: Physical Health (PH) of the CAPI. **Stent**: A Wave 4 stent prevalence variable was created using questions PH_321_4 and PH_321b_4 in Section 9: Physical Health (PH) of the CAPI. Then, the history of CVD variable was created by counting CVD as present if the participant reported ever having any of the above conditions in any of the IDS-TILDA waves (1 – 4).
20.	CO_1_4	1 = "Yes" 2 = "No" 3 = "Don't know" 4 = "Refused to answer"	Do you/did you have any symptoms of COVID-19?	This variable is created based on question 1 of the 'Covid-19 phase 1 questionnaire'.
21.	CO_2_4	1 = "Yes, and testing completed" 2 = "No, not invited for testing" 3 = "Invited but did not consent for testing"	Have you been tested for COVID-19?	This variable is created based on question 2 of the 'Covid-19 phase 1 questionnaire'.

No.	Variable name	Categories	Label	Description
		4 = ”Invited and testing commenced but not completed” 98 = ”Don’t know” 99 = ”Refused to answer”		
22.	CO_2i_4	1 = ”Once” 2 = ”Twice” 3 = ”Three times” 4 = ”More than three times” 6 = ”Not applicable” 98 = ”Don’t know” 99 = ”Refused to answer”	If you were tested, how many times were you tested?	This variable is created based on the follow up question to question 2 of the ‘Covid-19 phase 1 questionnaire’.
23.	CO_3_4	1 = ”Yes” 2 = ”No” 3 = ”Not applicable” 4 = ”Refused to answer”	Did you need to move from your usual home due to the COVID-19 crisis?	The variable is created based on question 3 of the ‘Covid-19 phase 1 questionnaire’.
24.	CO_8_4	1 = ”Yes” 2 = ”No” 98 = ”Don’t know” 99 = ”Refused to answer”	Did you feel stressed/anxious about COVID-19?	The variable is created based on question 8 of the ‘Covid-19 phase 1 questionnaire’.
25.	CO_8a_04_4	0 = ”No” 1 = ”Yes“	If you did feel stressed/anxious about COVID-19, what was the reason? - Isolation	The variable is created based on question 8a of the ‘Covid-19 phase 1 questionnaire’.
26.	CO_8a_05_4	0 = ”No” 1 = ”Yes“	If you did feel stressed/anxious about COVID-19, what was the reason? - Feeling lonely	The variable is created based on question 8a of the ‘Covid-19 phase 1 questionnaire’.

No.	Variable name	Categories	Label	Description
27.	CO_8a_06_4	0 = ”No” 1 = ”Yes“	If you did feel stressed/anxious about COVID-19, what was the reason? - Not being able to do usual activities	The variable is created based on question 8a of the ‘Covid-19 phase 1 questionnaire’.
28.	CO_8a_07_4	0 = ”No” 1 = ”Yes“	If you did feel stressed/anxious about COVID-19, what was the reason? - Not seeing friends	The variable is created based on question 8a of the ‘Covid-19 phase 1 questionnaire’.
29.	CO_8a_08_4	0 = ”No” 1 = ”Yes“	If you did feel stressed/anxious about COVID-19, what was the reason? - Not seeing family	The variable is created based on question 8a of the ‘Covid-19 phase 1 questionnaire’.
30.	CO_8a_09_4	0 = ”No” 1 = ”Yes“	If you did feel stressed/anxious about COVID-19, what was the reason? - Change in staff	The variable is created based on question 8a of the ‘Covid-19 phase 1 questionnaire’.
31.	CO_8a_10_4	0 = ”No” 1 = ”Yes“	If you did feel stressed/anxious about COVID-19, what was the reason? - Not being in My/His/Her own room or home	The variable is created based on the question 8a of ‘Covid-19 phase 1 questionnaire’.
32.	CO_9_4	1 = ”Yes” 2 = ”No” 98 = ”Don’t know” 99 = ”Refused to answer”	Were there any good things about the COVID-19 period?	The variable is created based on question 9 of the ‘Covid-19 phase 1 questionnaire’.

3 Description of variables included in the dataset

The variables listed in Table went through further rounds of anonymisation. As some of these variables again failed to meet the minimum cell-size cut-off of 20, especially after cross-tabulation,

recoded versions of the variables were derived after regrouping of categories, combination with other variables, top coding, or bottom coding. The variables that went through this recoding process are called 'derived variables' and are listed in Table **5**5 in Section 3.2. The remaining variables are henceforth referred to as 'original variables' and they are listed in Table in Section 3.1.

3.1 Original variables

This section contains the list of original variables being made available with/without minor changes as part of the anonymisation process. Table Table includes the names of the variables, the categories of the variables, descriptions of the variables, names of the original variables used in the paper and the actions taken on the original variables so that they could be made available in the dataset.

Table 4: List of original variables included in dataset

Variable name	Variable categories	Description	Original variable used	Action taken on the original variable
Gender	0 = "Female" 1 = "Male"	Gender category.	W4_gender	• Category values are recoded as 0 and 1.
W4_heart_CVD_allwave_prevalence	0 = "No" 1 = "Yes"	History of CVD (angina, heart attack, hypertension, congestive heart failure, stroke, TIA, abnormal heart rhythm, heart murmur, stent).	W4_CVD_allwave_prevalence	• Category values are recoded as 0 and 1.
W4_heart_diabetes_allwave_prevalence_recode	0 = "No" 1 = "Yes" 98 = "Missing value"	Does the participant have a history of Diabetes across four waves? (Yes/No)	W4_heart_diabetes_allwave_prevalence	• Category values are recoded as 0 and 1. • Missing values are coded.
CO_1_4_recode	0 = "No" 1 = "Yes" 98 = "Missing value"	Did the participant have any symptoms of COVID-19? (Yes/No)	CO_1_4	• The original variable is grouped into two categories, Yes/No. • Category values are recoded as 0 and 1. • Missing values are coded.

Variable name	Variable categories	Description	Original variable used	Action taken on the original variable
CO_3_4_recode	0 = "No" 1 = "Yes" 98 = "Missing value"	Did the participant need to move from their usual home due to the COVID-19 crisis? (Yes/No)	CO_3_4	• The original variable is grouped into two categories, Yes/No. • Category values are recoded as 0 and 1. • Missing values are coded.
CO_8_4_recode	0 = "No" 1 = "Yes" 98 = "Missing value"	Did the participant feel stressed/anxious about COVID-19? (Yes/No)	CO_8_4	• The original variable is grouped into two categories, Yes/No. • Category values are recoded as 0 and 1 • Missing values are coded.
CO_9_4_recode	0 = "No" 1 = "Yes" 98 = "Missing value"	Were there any good things about the COVID-19 period? (Yes/No)	CO_9_4	• The original variable is grouped into two categories, Yes/No. • Category values are recoded as 0 and 1. • Missing values are coded.

3.2 Derived variables

The details of the new variables created, the categories of the new variables, the original variables used, and the actions taken on the original variables are summarised in Table 5.

Table 5: Description of derived variables

Variable name	Variable categories	Description	Original variable used	Action taken on the original variable
W4_age_new	1 = "40+"	Age of participants.	W4_age_cat	• Age is **recoded** into one category.
Residence_new	1 = "Community based residence"	Residence type	W4_residence	**Regrouped categories of** 'W4_residence':

Variable name	Variable categories	Description	Original variable used	Action taken on the original variable
	2 = “Residential services”			• Independent/family & Community group home grouped into Community based residence. • Residential care as residential services (i.e. non-community based).
BMI_Obese	0 = “No” 1 = “Yes”	Is the participant overweight/obese? (Yes/No)	W4_BMI_3cat	**Bottom coded** underweight and normal categories of the original variable.
Co_testing	0 = “No” 1 = “Yes” 98 = “Missing value”	Did the participant get tested for Covid-19? (Yes/No)	CO_2_4	**Regrouped** • ‘Yes, and testing completed’ named as **‘Yes’**. • ‘No, not invited for testing’, ‘Invited but did not consent to testing’ and ‘Invited and testing commenced but not completed’ named as **‘No’**.
Co_test_freq	1 = “Once” 2 = “More than once” 98 = “Missing value” 99 = ”Irrelevant”	If the participant get tested for Covid-19, how many times did they get tested?	CO_2i_4	• **Regrouped** Options ‘Twice’, ‘Three times’ and ‘More than three times’ grouped into ‘**more than once**’. • Missing values and irrelevant observations are coded (see next bullet). • The variable ‘CO_2i_4’ is a sub- variable of ‘CO_2_4’. The participants who are in the ‘No’ category of ‘Co_testing’ are labelled as irrelevant in ‘Co_test_freq’.

Variable name	Variable categories	Description	Original variable used	Action taken on the original variable
Other_health_conditions	0 = “No” 1 = “Yes” 98 = “Missing value”	History of Asthma, Arthritis, Epilepsy, Dementia and CKD across all waves.	W4_other_arthritis_allwave_prevalence W4_other_asthma_allwave_prevalence W4_other_dementia_allwave_prevalence W4_other_epilepsy_allwave_prevalence W4_other_chronic_kidney_disease_allwave_prevalence	• Variables combined • Participant who has a history of Asthma/Arthritis/Epilepsy/Dementia/CKD is considered to be in the Yes category of ‘Other_health_conditions’ and in the ’No’ category otherwise. • Missing values are coded.
Co_stress_loneliness	0 = “No” 1 = “Yes” 98 = “Missing value” 99 = “Irrelevant”	If the participant felt stressed/anxious about Covid-19, what was the reason? Loneliness (Yes/No)	CO_8a_04_4 CO_8a_05_4 CO_8a_07_4 CO_8a_08_4	• Variables combined. • Missing values and irrelevant observations are coded (see next bullet). • The variables CO_8a_04_4, CO_8a_05_4, CO_8a_07_4 and CO_8a_08_4 are sub-variables of ‘CO_8_4’. Participants who marked ‘No’ in ‘CO_8_4’ are considered as irrelevant in ‘Co_stress_loneliness’.
Co_stress_changeroutine	0 = “No” 1 = “Yes” 98 = “Missing value” 99 = “Irrelevant”	If the participant felt stressed/anxious about Covid-19, what was the reason? Change in routine (Yes/No)	CO_8a_06_4 CO_8a_09_4 CO_8a_10_4	• Variables combined. • Missing values and irrelevant observations are coded (see next bullet). • The variables CO_8a_06_4, CO_8a_09_4, and CO_8a_10_4 are sub-variables of ‘CO_8_4’. Participants who marked ‘No’ in ‘CO_8_4’ are considered as irrelevant in

Variable name	Variable categories	Description	Original variable used	Action taken on the original variable
				'Co_stress_ changeroutine'.
Smoking	0 = "No" 1 = "Yes"	Has the study participant ever smoked? (Yes/No)	W4_smoking	• **Regrouped** 'Previously smoked but not currently' and 'Currently smoking' named as 'Yes' and 'Never smoked' named as 'No'.
Mental_health_ disorder	0 = "No" 1 = "Yes" 98 = "Missing value"	Does the participant show any of symptoms of mental health disorder? (Yes/No)	W4_GDS_carer W4_GAS W4_GDS	• Combined W4_GDS, W4_GAS and W4_GDS_carer.Participants who were scored as 'Yes' in any of 'W4_GDS_carer', 'W4_GAS' or 'W4_GDS' are counted as having a Mental_health_disorder. • Missing values are coded.

4 Final list of variables included in the dataset

Table 6 includes the final list of variables that are available, in the order that they appear in the SPSS file 'Wave 4 Covid-19 Phase1 data'. An indication of whether the variable is original or derived is provided next to each variable in the table.

Table 6: Final list of variables that are included in the dataset

No.	Included variable	Original/Derived
1.	Gender	Original
2.	W4_age_new	Derived
3.	Residence_new	Derived
4.	BMI_Obese	Derived
5.	Smoking	Derived
6.	Mental_health_disorder	Derived
7.	W4_heart_CVD_allwave_prevalence	Original
8.	W4_heart_diabetes_allwave_prevalence_recode	Original
9.	Other_health_condition	Derived
10.	CO_1_4_recode	Original

No.	Included variable	Original/Derived
11.	CO_3_4_recode	Original
12.	CO_8_4_recode	Original
13.	CO_9_4_recode	Original
14.	Co_testing	Derived
15.	Co_test_freq	Derived
16.	Co_stress_loneliness	Derived
17.	Co_stress_changeroutine	Derived

5 Disclaimer

There can be errors or inaccuracies in the dataset and documentation. The errors will be corrected in future upgrades. We request you to contact the IDS-TILDA Project Manager via email, **HAIGHM@tcd.ie**, in the event of any errors or if you have any queries.

6 References

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