DATA SHARING STANDARDS (DSS)

1. DATA STRUCTURE

1.1. File format

- Preferred file formats (e.g., CSV, Excel, SPSS, Stata)
- Preferred unit of analysis: each record in the dataset must represent a unique visit per woman (i.e., the file should be in <u>long format</u>). **If the dataset is in a <u>wide format</u> (i.e. one record contains information about multiple visits per woman, please provide details on how this dataset could be converted into a long format)**.

1.2. Data dictionary

Please share a data dictionary to facilitate the harmonization of the dataset. This data dictionary should contain all variable names, descriptions, and value labels.

1.3. Data anonymization

All datasets should be anonymized before sharing with the WHO Gestational Weight Gain (GWG) Steering Committee. That is, **no personally identifiable information, such as name and exact geo-coordinates, should be included in the datasets shared**.

1.4. Mandatory variables

NAME OF THE VARIABLE	DESCRIPTION	TYPE	OBSERVATIONS
Pre-pregnancy weight	in kg, measured before/close to the conception or self-reported or measured in the first trimester (up to 13+0 weeks), preferably with an accompanying variable describing how it was obtained	Continuous, up to 2 decimals	Pre-pregnancy weight measurement method: type of assessment used to measure maternal weight (i.e., measured by study staff, maternal report, based on chart review, or multiple methods)

Maternal height	in cm, measured in the first pregnancy trimester, or measured during pregnancy or after delivery, with the date or gestational age at the measurement or abstracted from medical records (if available, include the date or gestational age at the measurement) or self-reported, preferably with an accompanying variable describing how it was obtained	Continuous, no decimals	
Gestational weight	In kg, measured during pregnancy, and at least one measurement in each trimester. All the available weight measurements are welcome	Continuous, up to 2 decimals	Weight measurement method: type of assessment used to measure maternal weight (i.e., measured by study staff, maternal report, based on chart review, or multiple methods)
Gestational age	**Ideal:** dates of weight measurements (and any other date of data collection), dates of ultrasounds, gestational age at ultrasounds, and date of delivery	Dates in DD/MM/YYYY format	If gestational ages provided are already calculated (according to the acceptable rules), the measurement must be in days (integer variable)
	Acceptable: dates of weight measurements (and any other date of data collection), gestational age at birth/delivery estimated by ultrasound performed before 24+0 weeks		
	Possible: dates of weight measurements (and any other date of data collection) and gestational age at birth estimated by the last menstrual period (LMP) date confirmed by an ultrasound performed before 24+0 weeks		
	Possible: dates of weight measurements (and any other date of data collection) and LMP date confirmed by an ultrasound performed before 24+0 weeks.		
Maternal age	**Ideal:** maternal date of birth and date of delivery	Dates in DD/MM/YYYY format	
	Possible: In years, at delivery.	Continuous, up to 1 decimal	

Date of delivery or gestational age at delivery	**Ideal:** dates of weight measurements (and any other date of data collection), dates of ultrasounds, gestational age at ultrasounds, and date of delivery	Dates in DD/MM/YYYY format	If gestational age already calculated is provided (according to the acceptable rules), the measurement must be in days (integer variable)
	Acceptable: dates of weight measurements (and any other date of data collection), gestational age at birth/delivery estimated by ultrasound performed before 24+0 weeks		
	Possible: dates of weight measurements (and any other date of data collection) and gestational age at birth estimated by the last menstrual period (LMP) date confirmed by an ultrasound performed before 24+0 weeks		
	Possible: dates of weight measurements (and any other date of data collection) and LMP date confirmed by an ultrasound performed before 24+0 weeks.		
Birth weight	In grams, measured at the study or obtained from medical records, preferably with an accompanying variable describing how it was obtained	Continuous, no decimals	
Sex of the newborn	Male/female/unknown, evaluated by the study researcher or obtained from medical records, preferably with an accompanying variable describing how it was obtained	Categorical	

1.5. Additional variables

The list of important variables that interest the project and **should be shared if available** are described below.

NAME OF THE VARIABLE	DESCRIPTION	TYPE
General variables		
Mother ID		char
Country/Territory	Country where the data collection occurred	char
City	City where the data collection occurred	char
Location	Whether the data was collected in a urban/rural context	char
Study type	Indication of prospective cohort, retrospective cohort/administrative data, clinical trial	char
Intervention assignment	If an intervention study, whether the participant was assigned as intervention or control arm. Please provide details if control arms received placebo or standard care	char
Date of study enrolment	Date of the study enrolment or baseline visit	date in DD/MM/YYYY format
Visit date	Date of follow-up visit	date in DD/MM/YYYY format
Socio-demographic variables		
Maternal race/ethnicity	Race/ethnicity of the mother	char
Maternal education (years)	Number of maternal schooling years	integer
Maternal occupation	Type of occupation that the mother was engaged in prior to or during pregnancy	char
Wealth index	An aggregate index of wealth, typically based on characteristics of the household. Description for each study should be sent.	float, with at least one decimal
Family income (monthly)	Monthly family income	float, with at least one decimal
Family Income Currency Unit	Unit for Monthly family income for ex. 'Taka', 'Rupees', 'Dollar' etc.	char
Marital status	Maternal marital status during pregnancy	char
Partner's education	Number of the partner's schooling years	integer
Partner's occupation	Type of occupation that the partner was engaged in prior to or during pregnancy	char
Family violence	Please inform the instrument used	integer
Social support during pregnancy	Please inform the instrument used	integer
Maternal variables		
Date of last menstrual period	Date of the last menstrual period	date in DD/MM/YYYY format
Date of delivery	Date when the infant was born	date in DD/MM/YYYY format

Type of delivery	Whether the delivery was spontaneous vaginal delivery, assisted, or cesarean	char
Type of C-section	Emergency vs. elective	integer
Parity	No. of previous births	integer
Gravidity	Number of pregnancies including the current pregnancy	integer
Smoking status (Pre-pregnancy)	Maternal smoking status before pregnancy (previous year)	integer
Smoking amount (Pre-pregnancy)	Maternal smoking amount before pregnancy	char
Smoking status during pregnancy	Maternal smoking status during pregnancy - if available, separated by trimester	integer
Smoking amount during pregnancy	Maternal smoking amount during pregnancy - if available, separated by trimester	char
Alcohol status during pregnancy	Maternal alcohol intake during pregnancy - if available, separated by trimester	integer
Alcohol amount during pregnancy	Maternal alcohol amount during pregnancy - if available, separated by trimester	char
Physical activity during pregnancy	Maternal physical activity during pregnancy - if available, separated by trimester	integer
Physical activity frequency during pregnancy	Maternal physical activity frequency during pregnancy - if available, separated by trimester	char
Iron-Folic Acid supplementation	Did the participant receive IFA supplementation during pregnancy?	integer
IFA supplementation duration (Days)	Number of days the participant consumed IFA	integer
Maternal hemoglobin (g/dL)	Maternal hemoglobin status	float, with at least one decimal
Date of maternal hemoglobin collection	Date of the maternal hemoglobin exam	date in DD/MM/YYYY format
History of spontaneous fetal loss	Miscarriage and stillbirth (not abortion)	integer
History of miscarriage	Whether the mother has previously had a miscarriage, defined as the spontaneous loss of a fetus prior to 20 weeks gestation	integer
History of preterm birth	Whether the mother has had a previous preterm birth (defined as birth <37+0 weeks GA)	integer
History of stillbirth	Whether the mother has had a previous stillbirth and, if available, the gestational age of this occurrence.	integer
History of induced abortion	Whether the mother has had a previous induced abortion	integer
Preexisting maternal conditions		
Maternal hypertension	Pre-existing hypertension (SBP >=140 OR DBP>=90) or reported as Hypertensive, or on medication to control blood pressure	integer
Maternal diabetes	Pre-existing diabetes mellitus	integer

Maternal thyroid illness	Pre-existing thyroid disorders	integer
Maternal HIV status	Maternal HIV status	integer
Maternal eating disorders	Pre-existing eating disorders and instruments used to assess those	integer
Maternal bariatric surgery	Whether the mother underwent bariatric surgery and the date of the procedure	integer
Maternal cardiovascular diseases	Pre-existing cardiovascular diseases	integer
Complications during the current pregnancy		
Maternal gestational diabetes	Maternal clinically diagnosed with GDM, definition and parameters used to characterize GDM (e.g., glucose tolerance test)	integer
GDM Diagnosis Date		date in DD/MM/YYYY format
Maternal systolic blood pressure (mmHg)	Systolic blood pressure during pregnancy (average of two readings)	float, with at least one decimal
Maternal diastolic blood pressure (mmHg)	Diastolic blood pressure during pregnancy (average of two readings)	float, with at least one decimal
Date(s) of blood pressure collection		date in DD/MM/YYYY format
Maternal proteinuria	Proteinuria during pregnancy as measured by dipstick test or any other method.	integer
Maternal Preeclampsia	Maternal clinically diagnosed with pre-eclampsia (HBP and protein in urine), define definition used)	integer
Preeclampsia Diagnosis Date		date in DD/MM/YYYY format
Maternal Hypertension	Maternal hypertension during pregnancy based on SBP and DBP	integer
Maternal Hypertension Diagnosis Date		date in DD/MM/YYYY format
Chronic Hypertension	Maternal hypertension before 20 weeks based on SBP >=140 or DBP >=90 or on the use of medication to control blood pressure	integer
Maternal depression in pregnancy	Please inform the instrument used	integer
Maternal depression Diagnosis Date		date in DD/MM/YYYY format
Maternal stress during pregnancy	Please inform the instrument used	integer
Maternal quality of sleep during pregnancy	Please inform the instrument used	integer
Maternal hookworm infection (*Necator Americanus*)	Egg count test result of ≥ 1	integer
Ascaris sp. Infection	Egg count test result of ≥ 1	integer
Trichurus sp. Infection	Egg count test result of ≥ 1	integer
Maternal malaria	Maternal malaria during pregnancy, define criteria use	integer

Maternal malaria diagnosis method	Method used to diagnose maternal malaria during pregnancy	char
Maternal malaria diagnosis date		date in DD/MM/YYYY format
Maternal diarrhea	Maternal experience with diarrhea during pregnancy, define criteria used	integer
Maternal nausea/vomiting	Maternal nausea/vomiting, defined measurement window and criteria used	integer
Other complications and intercurrences	Other complications such as hyperemesis gravidarium, anorexia, bulimia, with the instrument used to assess those	integer
Nutrition-related variables		
Household food security during pregnancy	Please inform the instrument used - if available, separated by trimester	integer
Dietary diversity during pregnancy	Variable definitions possible.	integer
Dietary intake during pregnancy per day	As assessed by 24-hour recall or food frequency questionnaire - please inform instrument used and if available, separate by trimester	integer
Quality of the diet	Please inform the instrument used - if available, separated by trimester; the gestational age/date of evaluation	integer
Dietary counseling during pregnancy	Please inform whether the individual received any type of dietary counseling during pregnancy, the type and frequency of counseling received	integer
Perinatal outcomes		
Vital status	Categorical variable that identifies whether the pregnancy under observation resulted in live birth/stillbirth	integer
Singleton/twin birth	Whether pregnancy resulted in single or multiple births	integer
Neonatal death	Death within the first 28 days from birth	integer
Physiological Fetal Loss		integer
Miscarriage	Spontaneous loss of a fetus prior to 20 weeks gestation	integer
Abortion	Induced abortion	integer
Postnatal variables		
Length/height (cm)	Length or height of the infant at follow-up	float, with at least one decimal
Weight (kg)	Weight of the infant at follow-up	float, with at least one decimal
Date of the follow-up for the infant		date in DD/MM/YYYY format
Maternal weight (kg)	Weight of the mother at follow-up	float, with at least one decimal
Date of the follow-up for the mother		date in DD/MM/YYYY format

2. DATA SHARING PROCESS

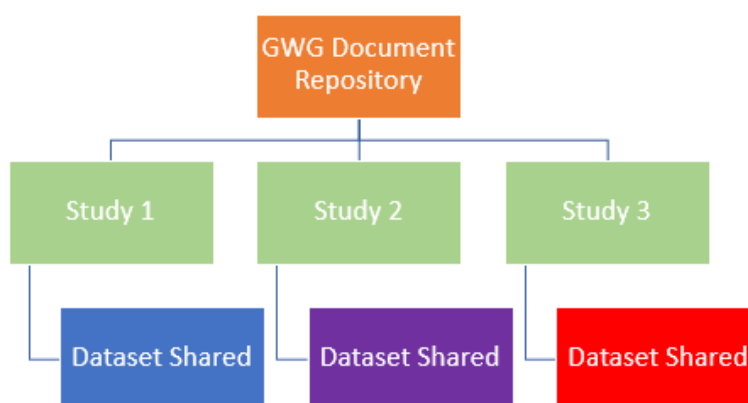### 2.1. Information security and privacy policy

Information security at WHO is based on the ISO 27001 standard. WHO has formal and comprehensive information security policies with respective implementation guidelines. Policies cover information security, access to information and systems, cloud computing, application security, information classification, and related security standards. As international civil servants, all WHO staff must adhere to confidentiality as detailed in Staff Regulation 1.6. For more details on WHO's five core data principles, please visit https://www.who.int/data/principles. WHO's data policy can be found here https://www.who.int/about/policies/publishing/data-policy

In its mission to uphold member states' trust in data, WHO ensures that all data shared with the organization are securely and confidentially stored. WHO also upholds the highest data protection standards and respect for human rights, including the right to privacy, about any personal data and data aggregates of groups of individuals in WHO-controlled data sets. Before sharing any datasets with the organization, we require member States and non-State actors who share data to confirm that the data have been collected following applicable national laws, including data protection laws to protect the confidentiality of identifiable persons.

2.2. Repository details

All the microdata sets that will be shared will be housed in a WHO-managed SharePoint environment. SharePoint is an online, secure document repository developed and maintained by Microsoft. This document repository is private and compliant with General Data Protection Regulation (GDPR).

There are three levels in the Gestational Weight Gain (GWG) Repository. The first two levels (orange and green) are only accessible to the WHO steering committee. WHO staff not working on

the GWG project nor other researchers that supply data to the project will get access to these levels.

The third level (blue, purple, and red) is only accessible to the study's principal investigator (PI) or data provider supplying data to the GWG project. Data providers or PI will only have access to folders related to the study shared. They will not be able to get access to that folder in other studies. For example, the data provider given access to the blue folder will not get access to the purple or red folders even though they are on the same level.
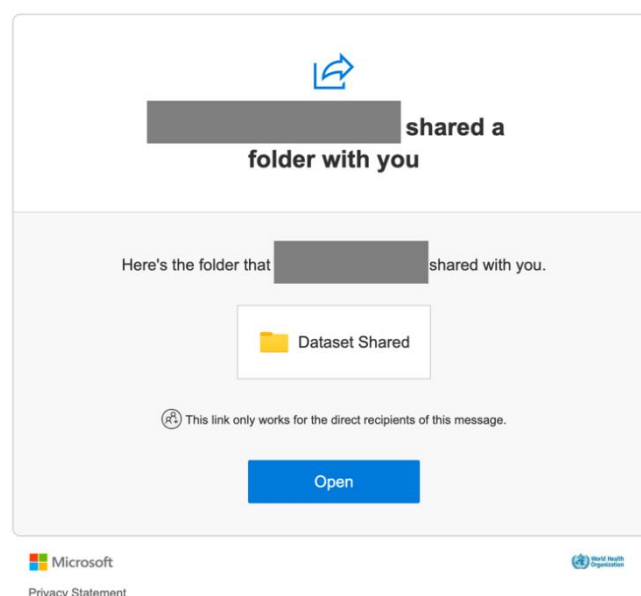
2.3. Data upload

Stage 1: Signing data agreement

After a study (dataset) has met the eligibility criteria, the data provider will complete a data sharing agreement that permits the WHO steering committee to use the microdata for the purpose of developing the GWG standards. The data agreement will contain the corresponding data providers' names, affiliations, and e-mails and a confirmation that the data has been collected following applicable national laws, including data protection laws and ethical standards.
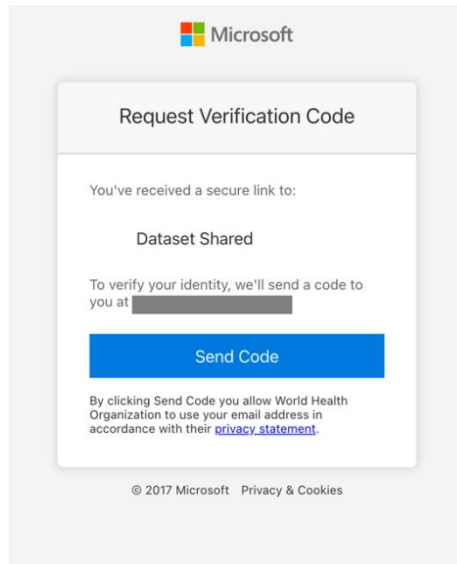
Stage 2: Shared folder invitation

Upon submission of the data agreement, the corresponding data provider(s) will receive an e-mail invitation from a member of the WHO steering committee inviting the data provider to their specific data folder. The data provider will have to click "Open" to proceed to the next stage.
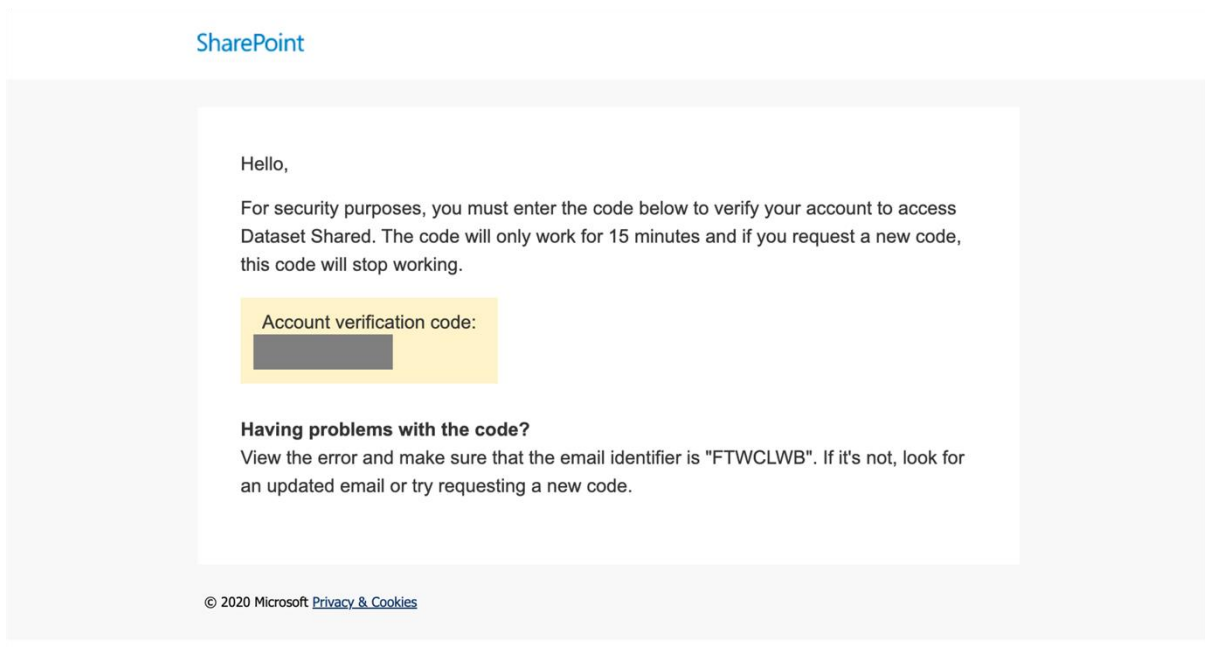
Stage 3: *Requesting a verification link*

Clicking "Open" in Stage 2 will navigate the data provider to a webpage where they can request a verification code to access the Shared Folder.
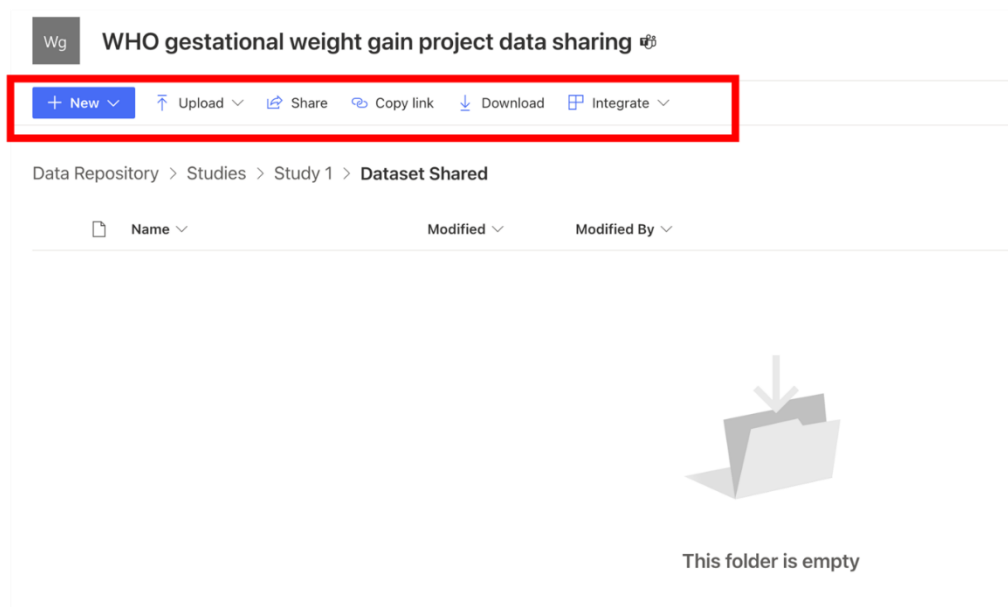

After clicking "Send Code", the data provider will receive an e-mail from no-reply@notify.microsoft.com with a verification code. That e-mail will resemble the image below:

The verification codes are time-bound and will only work for 15 minutes. The data provider must request a new code every time you sign into the folder.

Stage 4: *Uploading a dataset*

Once the data provider has access to the folder, they can upload your dataset by selecting "Upload" and selecting the file from the location from their local machine.

For any additional questions and queries, please contact globalgwg@who.int.