SLEMAN HDSS GUIDEBOOK

Volume 2: Wave 6 (2020)

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Septi Kurnia Lestari, S.Gz., M.Med.Sc.PH., Ph.D.

Ratri Kusuma Wardani, S.Gz.

Kadharmesthan Gilang Pratama, S.Stat.

Rahayu Kia Sandi Cahaya Putri, S.Stat.

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2.   PREFACE

The Sleman Health and Demographic Surveillance System (Sleman HDSS) is an ongoing research initiative that has been conducted annually since 2015 in the Sleman Regency, located in the Special Region of Yogyakarta, Indonesia. This surveillance system is designed to monitor the continuous demographic, social, and health changes taking place within the Sleman Regency. Sleman HDSS was initiated and funded by the Faculty of Medicine, Public Health, and Nursing (FK-KMK) at Universitas Gadjah Mada (UGM), Indonesia.

In the year 2020, data collection for Wave 6 of the Sleman HDSS was conducted via telephone to ensure adherence to the Large-Scale Social Restrictions imposed by the government to control the spread of COVID-19. In addition to the change in interview methodology, the questionnaire module originally planned for Wave 6 was also modified. Furthermore, additional questionnaire modules were introduced to capture the impact of the pandemic on health, utilization of healthcare services, and economic repercussions.

This book is written to provide information to users of Sleman HDSS data regarding the changes in research methods and instruments used in Wave 6 of HDSS Sleman. Readers who wish to obtain a more comprehensive explanation of the research methods, data collection processes, modules, questionnaires, data management, and data weighting of Sleman HDSS can find them in the Sleman HDSS Guidebook Volume 1: Wave 1-5 (2015-2019). We hope that this book will assist data users in exploring Sleman HDSS data, thereby enabling the potential benefits of HDSS data to be realized by a wider audience. We extend our gratitude to all parties who have supported the compilation of this book.

Sleman, Maret 2024
Sleman HDSS Chairperson

dr. Ifta Choiriyyah, MSPH, Ph.D.
NIP. 111198412201101201

3.   SLEMAN HDSS

The Health and Demographic Surveillance System (HDSS) is a surveillance system that collects population transition data, health status, and social transition periodically within a certain period (1). In the year 2014, the Faculty of Medicine, Public Health, and Nursing at Universitas Gadjah Mada (UGM), in collaboration with the Sleman Regency government, initiated the implementation of HDSS in Sleman Regency. The vision of Sleman HDSS is to "Support scientific development in the health sector through an innovative, excellent, and high-quality, world-class research based on population data".

The Sleman HDSS conducts data collection annually, commencing with the first wave of data collection in 2015. In 2020, the sixth wave of data collection was carried out. In contrast to previous data collection methods, in 2020, interviews for the Sleman HDSS were conducted via telephone. This adjustment was made in response to the government's imposition of a Large-Scale Social Restriction (2) to control the spread of COVID-19.

Similar to face-to-face interviews, telephone interviews also require trial runs, proper question sequencing, interview guidance, and strategies for reaching out to respondents (3). The data collection for Wave 6 took place between September and November 2020. The gathered data included updates on demographics, reproductive health, infectious diseases, and atopic dermatitis in toddlers and children. Additionally, we collected data to track changes during COVID-19, including its socioeconomic impacts, healthcare service access and utilization, changes in lifestyle (such as physical activity and smoking), and mental health.

These data are expected to help in monitoring changes in demographics, social dynamics, economics, and health, both before, during, and after the COVID-19 pandemic. Furthermore, insights into the pandemic's impact can greatly contribute to the formulation of healthcare policies related to social and healthcare initiatives, particularly in the ongoing fight against the COVID-19 pandemic.

4. ETHICAL CONSIDERATIONS

ETHICAL CLEARANCE (EC)

The Sleman HDSS data collection was conducted after receiving permission from the Ethics Research Commission for Medicine and Health, Faculty of Medicine, Public Health, and Nursing at UGM, under approval number KE/FK/0586/EC/2020.

INFORMED CONSENT

Before data collection, respondents of the Sleman HDSS were requested to provide their consent to participate in the survey. Throughout the process of data collection via telephone, explanations and consent related to the research were communicated verbally or through text/chat by enumerators. Subsequently, respondents would express their willingness by responding to the enumerator's questions, thus providing verbal informed consent.

The respondent's identity verification, verbal informed consent, and the respondent's willingness to participate will be documented as proof of their involvement in Wave 6 data collection. This documentation will occur if the respondent agrees to have their phone conversations recorded or audio chats saved via WhatsApp. In case a respondent decline to be recorded, the interviewers will seek to confirm their identity, informed consent, and willingness to participate through text or chat. In such instances, screenshots of these interactions will serve as evidence of their participation in Wave 6 data collection. Additionally, respondents have the option to electronically sign the consent form to indicate their willingness to take part in the study.

The participants who have provided their consent to participate in this Wave 6 data collection have:

1. Understood that there is a very low level of risk associated with their participation and the responses they provide.
2. Acknowledged that the information they provide will be kept confidential, and any details related to their personal identity will not be disclosed or made public.
3. Realized that the data they provide will be used exclusively for research purposes and not for commercial gain.
4. Given permission to the researchers to use the provided data for research purposes and with the approval of the Ethics Committee of the Faculty of Medicine, Public Health, and Nursing at UGM.
5. Agreed to follow the research procedures.

6. Decided whether their interviews can be recorded or not.

The evidence of consent to participate in Wave 6 data collection includes:

1. Recorded telephone conversations.
2. Voice recordings on the WhatsApp application.
3. Electronic signatures on the informed consent document.
4. Screenshots of consent requests via text/chat on messaging applications or SMS.

PRIVACY

The Sleman HDSS maintains the confidentiality of respondents' identities and data. Data generated by the Sleman HDSS consists of processed data or data sets devoid of any information that could be used to personally identify the respondents.

SLEMAN HDSS RESEARCH METHODS

In 2020, Sleman HDSS changed its interview method from the traditional in-person format to telephone-based interviews. This adjustment was made to comply with government directives aimed at preventing the transmission of COVID-19 by reducing direct interactions and imposing social restrictions (2).

The data collection procedure via telephone was executed in accordance with the findings of a preceding feasibility study we conducted. The feasibility study employed a qualitative method with a rapid assessment approach, involving 28 participants comprising Sleman HDSS respondents, community leaders, and experts. This qualitative investigation is designed to delve into the community's perceptions of telephone-based data collection and to construct a procedural framework for the implementation of the Sleman HDSS survey through telephonic means. The study reveals that telephone-based data collection is feasible, provided that factors such as connectivity reliability, interview duration, timing, and respondent conditions are duly taken into account.

In the year 2020, the data collection process was initiated by acquiring information for the core module of the Sleman HDSS. This core module comprised demographic modules, such as Household Members (ART) and Household Member Changes (PART). Moreover, specific thematic modules were agreed upon, including Infectious Diseases (PM), Injuries, Access to Healthcare Facilities and Services (AKS), Mental Health, Reproductive Health, Maternal and Child Health, and Hirschsprung's Disease. Additionally, data collection was executed for individual panel data.

The data collection was carried out using a tablet PC, which was installed with the data collection application, e-HDSS of the Sleman HDSS. Enumerators uploaded completed questionnaires to the Sleman HDSS data server, where data managers processed them. The e-HDSS application underwent adjustments to enable the user to save the imputed data at any time during the course of interviews. In the previous version of e-HDSS, data could only be saved after completing all interview modules. Additionally, e-HDSS is equipped with a screening form. This screening form is intended to determine whether respondents contacted by telephone meet the eligibility criteria. The screening form can also record data related to migration, as well as split and merged households.

5.   SLEMAN HDSS' RESPONDENT

STUDY SUBJECTS

Sleman HDSS' respondents are household members who have resided continuously for at least six months within Sleman Regency, Daerah Istimewa Yogyakarta. The units of analysis employed in this research comprise households and individual residents. Sleman HDSS encompasses a total of 5,064 households, which are spread across 216 clusters within Sleman Regency, with 184 of these clusters situated in urban areas and the remaining 32 in rural areas. During the sixth wave, interviews were exclusively conducted with the main respondents. The main respondents were individuals, typically the household head or other family members aged 18 years or older, who possess the most comprehensive knowledge of the household's circumstances.

NUMBER OF SLEMAN HDSS' RESPONDENTS

The initial in-scope population for Wave 6 (respondents who could be interviewed in the previous wave or who could not be interviewed but had not yet withdrawn from the study) was 5,070. After a nested study following data collection for Sleman HDSS Wave 5, six participants withdrew from all Sleman HDSS-related studies, reducing the in-scope population to 5,064. In Wave 6, a total of 1,674 households completed the household module interview, with 1,525 main respondents also completing the individual module interview.

Among the 3,390 households that failed to be interviewed, the main reasons for non-interview were inactive phone numbers (48.1%) and because HDSS Sleman did not have the respondent's phone number (28.1%). The strategies employed to minimize non-interview rates included contacting respondents at least three times at different times, contacting other family members, requesting assistance from community leaders to inform the respondent, and requesting the

respondent's phone number from community leaders (Figure 1). A total of 490 phone numbers were obtained from community leaders. Of these numbers, 12 did not belong to HDSS Sleman respondents, but the individuals associated with them were willing to participate as new respondents.
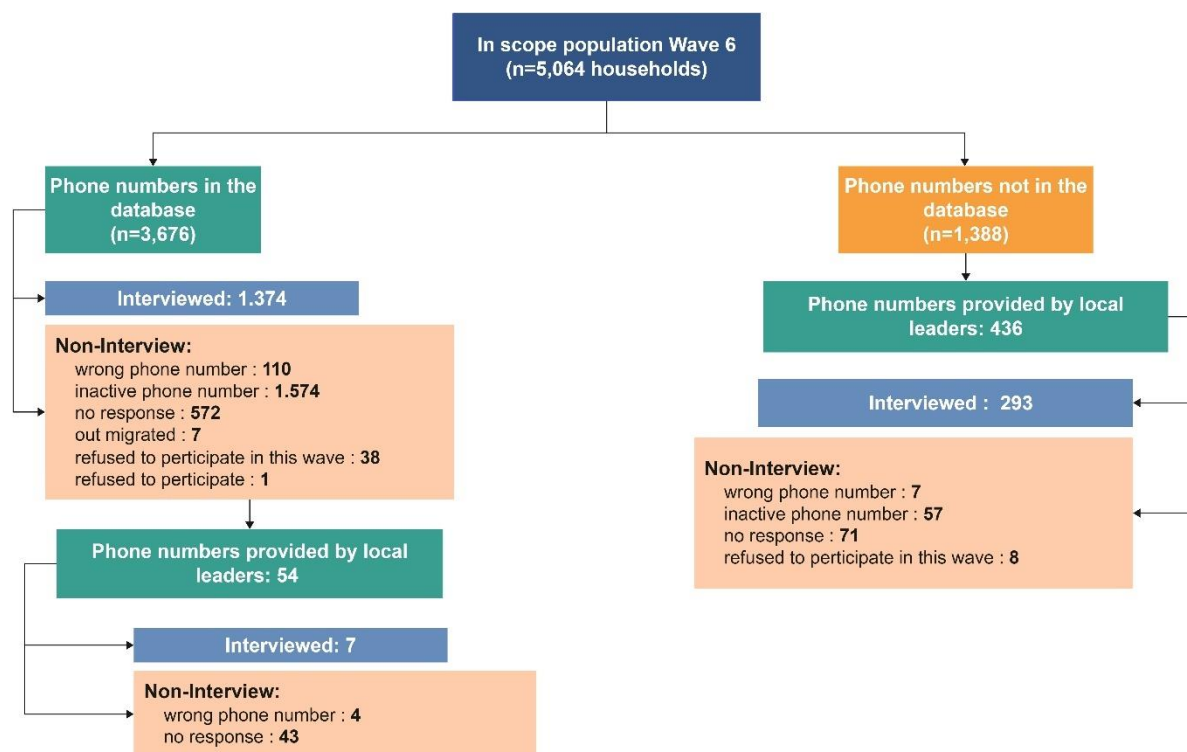
Figure 1. The total count of interviewees successfully engaged and the count of unsuccessful engagements, including the reasons for unsuccessful contacts in Wave 6.

SLEMAN HDSS' QUESTIONNAIRE MODULES

Tabel 1. Sleman HDSS' questionnaire modules in Wave 1-6

Module Name	HDSS 1 (2015)	HDSS 2 (2016)	HDSS 3 (2017)	HDSS 4 (2018)	HDSS 5 (2019)	HDSS 6 (2020)
Household-Level Modul						
Updates on Demographic Data	-	Yes	Yes	Yes	Yes	Yes
Birth Event	Yes	Yes	Yes	Yes	Yes	Yes
Death Event	Yes	-	-	-	-	Yes
Reproductive Health	-	Yes	-	Yes	Yes	Yes
Child Health	-	Yes	-	Yes	Yes	Yes
Communicable Disease	-	Yes	Yes	Yes	Yes	Yes
Individual-Level Modul						
Non-communicable disease	-	Yes	Yes (ver.2)	-	Yes	Yes
Healthcare Access and Utilization	-	Yes	-	-	Yes	Yes

Module Name	HDSS 1 (2015)	HDSS 2 (2016)	HDSS 3 (2017)	HDSS 4 (2018)	HDSS 5 (2019)	HDSS 6 (2020)
COVID-19 Impacts on the Social Economy	-	-	-	-	-	Yes
Physical activity	-	-	-	Yes	-	Yes
Tobacco consumption	-	-	Yes	Yes	-	Yes
Mental health	-	-	-	-	Yes	Yes

The questionnaire employed in each wave is available for download from the Sleman HDSS website. The list of data variables collected by the Sleman HDSS is available in the Sleman HDSS codebook, which can be downloaded from the Sleman HDSS website (Table 1).

6. ADJUSTMENTS MADE IN WAVE 6'S INTERVIEW MODULES

The modules used for data collection during Wave 6 were fewer than initially intended. This adjustment was made because it was highly likely that respondents would be unwilling to engage in lengthy telephone interviews. The choice of modules or questions for Wave 6 was based on their relevance to the pandemic situation. Demographic modules, such as registering new respondents, updating data for existing ones, and recording births, deaths, and migrations, were still used due to the significant impact of the pandemic on population dynamics.

Questions regarding the health history among household members are limited to cases of dengue fever. In the reproductive health module, we only inquire about parity. These questions are intended for newly enrolled female respondents within the reproductive age range of 15 to 49 years. Data on the health of infants and young children only consists of anthropometric measurements taken at birth for newly enrolled household members aged 0 to 59 months, including measurements such as height, weight, and head circumference (Module Code: KAI). Furthermore, a set of questions about atopic dermatitis in children aged 2 months to 13 years (Module Code: PK) is included. These questions are a part of a nested study within the Sleman HDSS, titled "Exploring Risk Factors and Levels of Knowledge, Attitude, and Behaviour of Mothers Towards Atopic Dermatitis Incidence in Children (A Study on Mothers with Children Aged 2 Months to 12 Years in the Sleman HDSS Survey Population) ", overseen by Dr. dr. Niken Trisnowati, M.Sc., Sp.KK.

In Wave 6, there were plans to collect data from individual panel members. However, due to difficulties in contacting these individual respondents, it was decided that only the main respondents would be interviewed using the individual panel questionnaire. The questions within this questionnaire were also adjusted accordingly. It is important to note that these questionnaire

inquiries were not intended to update the data obtained during the interviews with individual panel members in Waves 3 and 4. The purpose of the individual panel questionnaire used in Wave 6 was to assess the impact of the pandemic on healthy lifestyles, mental health, healthcare utilization, and economic conditions, and to gather information regarding the respondents' history of infectious diseases.

The non-communicable disease (Module Code: PTM) module for the individual panel includes inquiries regarding the status of non-communicable diseases such as hypertension, diabetes, stroke, cardiac conditions, cancer, and asthma/chronic obstructive pulmonary disease (COPD). PTM questions are aimed at determining whether individuals have previously been diagnosed with these conditions and whether they have taken medication or received other treatments in the past two weeks and the preceding 12 months. This module has been adapted from the Chronic Conditions and Health Services Coverage Module originally employed by the Study on Global Ageing and Adult Health (SAGE) (4).

The module on Access and Utilization of Health Services (Module Code: AKS) comprises questions related to the respondents' medical history, their primary healthcare providers, methods of payment, and reasons for not seeking medical care. This module has been adapted from the questionnaire used in the 2013 Indonesia Basic Health Research Survey (RISKESDAS) (5). There have been some slight changes to the AKS module in this wave. In this iteration, individual respondents are asked about their access to and use of healthcare services during the COVID-19 pandemic, whereas in previous modules, these questions focused on the past 12 months (Waves 2 and 3). Additionally, to explore the use of telemedicine (remote healthcare) and traditional healing practices, researchers have added questions about the use of online healthcare consultations and alternative medical treatments.

The "Socioeconomic Impact of the Pandemic" module (Module Code: DSE) has been developed to assess the socioeconomic circumstances of individual respondents during the COVID-19 pandemic. This module seeks information regarding changes in employment status, the influence on personal finances or income sources, adjustments in spending habits, the receipt of any aid, and the specific type and form of assistance received. The questions within this module have been adapted from the demographic and social survey questionnaire on the impact of COVID-19 provided by Statistics Indonesia (6).

The module on physical activity (Module Code: f) and tobacco usage (Module Code: g) is adapted from the World Health Organization's Stepwise Approach to Chronic Disease Risk Factor Surveillance (7). To monitor changes in physical activity and tobacco use during the

COVID-19 pandemic, researchers included questions about changes in physical activity and tobacco usage during the pandemic (8).

Questions related to mental health originate from the Self Rating Questionnaire 20(SRQ 20), a mental health screening tool developed by the World Health Organization (9). This questionnaire was also utilized in the 2019 survey (Wave 5). In 2020 (Wave 6), three additional questions about the history of therapy (medication use and counselling) were introduced.

Verbal Autopsy interviews were not conducted in Wave 6. The collection of Verbal Autopsy data for mortality events between Wave 5 (2019) and Wave 6 (2020) will be incorporated into Wave 7.

7.   GENERATED VARIABLES

In addition to the "raw variables" (variables directly obtained from the questionnaire), the Sleman HDSS dataset also includes generated variables. These generated variables are the outcomes of processing several original variables following established standards. The generated variables in the Sleman HDSS Wave 6 dataset, along with their explanations, are as follows:

PHYSICAL ACTIVITY LEVEL

Variable name in dataset: phyact
Physical activity level is measured using the GPAQ V2 questionnaire (7). Collected data are stored as the following variables: f1, f2, f3a, f3b, f4, f5, f6a, f6b, f7, f8, f9a, f9b, f10, f11, f12a, f12b, f13, f14, f15a, and f15b. These data are then processed according to the GPAQ manual (27). During this process, additional variables are generated, namely: p1, p2, p3a, p3b, p4, p5, p6a, p6b, p7, p8, p9a, p9b, p10, p11, p12a, p12b, p13, p14, p15a, p15b, ptotal, ptotalday, phyact, and metsedent. The final outcome of this entire process is the "phyact" variable, which categorizes individuals into three levels of physical activity:

1. High: Individuals achieving a minimum of 3000 MET-minutes/week through a combination of walking, moderate or vigorous-intensity activities, or accumulating 1500 MET-minutes/week from vigorous-intensity activity within at least three days.
2. Moderate: Individuals achieving a minimum of 600 MET-minutes/week through a combination of walking, moderate or vigorous-intensity activities, or engaging in moderate activities for at least 30 minutes each on five or more days.

3. Low: Individuals who engage in no activity or some activity but do not meet the criteria for the previous two categories.

CARDIOVASCULAR DISEASE

Variable Name in the Dataset: pjk_w6

The criteria for cardiovascular disease involves respondents who have self-reported a diagnosis of coronary heart disease (ptm10a) and have consumed medication or received treatment in the last 12 months (ptm10c).

CANCER

Variable Name in the Dataset: cancer_w6

The criteria for cancer encompass respondents who have self-reported a diagnosis of cancer (ptm13a) and have consumed medication or received treatment in the last 12 months (ptm13c).

STROKE

Variable Name in the Dataset: stroke_w6

The criteria for stroke pertain to respondents who have self-reported a diagnosis of stroke (ptm06a) and have consumed medication or received treatment in the last 12 months (ptm06c).

CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

Variable Name in the Dataset: ppok_w6

The criteria for COPD encompass respondents who have self-reported a diagnosis of COPD (ptm35) and have taken medication and received treatment within the last 12 months (ptm35b).

HYPERTENSION

Variable Name in the Dataset: hiper_w6

The criteria for hypertension pertain to respondents who have self-reported a diagnosis of hypertension (ptm02a).

DIABETES MELLITUS

Variable Name in the Dataset: dm_w6

The criteria for diabetes mellitus involve respondents who have self-reported a diagnosis of diabetes mellitus (ptm04a)

MENTAL HEALTH

The individual mental health module utilized the Self Reporting Questionnaire 20 (SRQ 20) developed by the World Health Organization (WHO) (9). It consists of 20 questions addressed to selected respondents. The aim is to assess the respondent's mental health problems during the past month. This instrument validity in Indonesian setting has been tested and it has been used in The Basic Health Research (RISKESDAS) Indonesia. A study In Indonesia reported that with a cut-off point of 5/6, SRQ had a positive predictive value of 60% and a negative predictive value of 92% (12). If a subject answers "Yes" to six or more questions out of the 20, they are considered to have emotional, mental disorder, or distress that may lead to mental problems (11). The generated variable representing mental health status is "mental".

In addition to the total score, subscale scores can be calculated for specific symptoms, such as symptoms of depression. These symptoms are indicated by answering "Yes" to all the following questions (variable name: **depresi**):

1. srq06: Does [NAME]'s hands shaking?
2. srq09: Does [NAME] feel unhappy?
3. srq10: Does [NAME] cry more than usual?
4. srq14: Is [NAME] unable to play a useful part in life?
5. srq15: Has [NAME] lost interest in things?
6. srq16: Does [NAME] feel that she/he is a worthless person?
7. srq17: Does [NAME] has the thought of ending his/her life been on [NAME] mind?

Symptoms of anxiety: answer "Yes" to all the following questions (**variable name: cemas**):

1. srq03: Does [NAME] sleep badly?
2. srq04: Is [NAME] easily frightened?
3. srq05: Does [NAME] feel nervous, tense, or worried?

Somatic symptoms: answer "Yes" to all the following questions (**variable name: somatik**):

1. srq01: Does [NAME] often have headaches?
2. srq02: Is [NAME] appetite, poor?
3. srq07: Is [NAME] digestion, poor?
4. srq019: Does [NAME] has uncomfortable feelings in his/her in stomach?

Cognitive symptoms: answer "Yes" to all the following questions (**variable name: kognitif**):

1. srq08: Does [NAME] have trouble thinking clearly?
2. srq12: Does [NAME] find it difficult to make decisions?
3. srq13: Is [NAME] daily work suffering?

Symptoms of decreased energy: answer "Yes" to all the following questions (**variable name: energi**):

1. srq08: Does [NAME] have trouble thinking clearly?
2. srq11: Does [NAME] find it difficult to enjoy your daily activities?
3. srq12: Does [NAME] find it difficult to make decisions?
4. srq13: Is [NAME] daily work suffering?
5. srq18: Does [NAME] feel tired all the time?
6. srq20: Is [NAME] easily tired?

8.   SLEMAN HDSS DATA RELEASE

Every year, Sleman HDSS releases a dataset that includes compiled data from the first wave up to the latest wave. Each dataset is assigned a release number, indicating its version. The data undergo continuous cleaning and synchronization between waves. Therefore, it is recommended that data users always utilize the latest version and include the corresponding release number in their publications.

The release number of the Sleman HDSS dataset (Table 2) consists of three digits, with the following explanations:

1. The first digit indicates a significant change in the dataset, such as the addition of the latest data or data corrections that result in a change in the sample size.
2. The second digit represents a data change that does not affect the sample size.
3. The third digit indicates a minor change, such as adding a new variable.

Table 2. Sleman HDSS dataset version list

Version Number	Date of Release
1-0-0	24 November 2017
2-0-0	29 December 2017
3-0-0	02 July 2018

Version Number	Date of Release
3-1-0	11 February 2019
5-0-0	13 June 2017
5-1-0	15 Mei 2017
6-0-0	19 December 2017
7-0-0	12 December 2018
8-0-0	26 February 2019
9-0-0	30 December 2020
9-1-0	02 January 2020
9-1-1	09 March 2020
10-0-0	10 December 2020
10-1-0	22 April 2021
10-1-1	07 Juli 2021

9.   FURTHER INFORMATION SOURCES

For a more comprehensive understanding of research methodologies, data collection procedures, modules, questionnaires, data management, data weighting, and the instruments utilized in the data collection of Sleman HDSS, please consult the following literatures:

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