Routine health information system and health facility data for neglected tropical diseases

Schistosomiasis

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Abbreviations

EPIRF	epidemiological reporting form
GNARF	Global NTD Annual Reporting Form
HMIS	health management information system
ICD	International Classification of Diseases
JRF	joint reporting form
NTD	neglected tropical disease
WHO	World Health Organization

1. Introduction

Human schistosomiasis is an acute chronic parasitic disease caused by infection with the larval stages of blood flukes (trematode worms) of the genus *Schistosoma*. Estimates show that at least 254 million people required preventive treatment in 2023 *(1)*. Preventive treatment should be repeated over a number of years to reduce and prevent morbidity. Schistosomiasis transmission has been reported from 78 countries *(1)*. As of 2023, however, preventive chemotherapy for schistosomiasis, whereby people and communities are targeted for large-scale treatment, is still required in 50 endemic countries with moderate-to-high transmission.

The *WHO guideline on control and elimination of human schistosomiasis (2)* recommends that praziquantel should be made available in all health facilities and that all infected people, whatever their age, be treated. Medicines that are left over from large-scale community-based treatments should be kept in health facilities for the next treatment campaign; opened boxes can be used to treat cases in these facilities.

1.1 Approach to development of this guidance

This guidance was developed based on a template provided to health programmes by the WHO Division of Data, Analytics and Delivery for Impact. WHO disease focal points in the Global Neglected Tropical Diseases Programme provided technical content in alignment with the strategic priorities presented in *Ending the neglect to attain the Sustainable Development Goals: a road map for neglected tropical diseases 2021–2030* ("the road map") *(3)*. A drafting team comprising WHO technical officers and disease experts working on schistosomiasis at global, regional and country levels contributed to the drafting and review of initial drafts of this document. Schistosomiasis experts external to WHO reviewed the document for technical accuracy and relevance.

1.2 Declarations of interest

Declarations of interest were submitted by all contributors external to WHO for review by the secretariat. No significant interests were identified.

1.3 Objectives

This document provides guidance on the analysis and use of routine schistosomiasis data collected at the health facility. It presents core facility indicators and analysis, provides suggestions for questions on data quality as well as considerations and limitations for using the data and analysis. By the end of this document, readers should be able to use health facility data to:

- describe core schistosomiasis indicators and notable trends in its prevalence, geographical distribution and progress towards control;
- monitor the programme performance of schistosomiasis diagnosis and treatment;
- understand how to interpret changes in trends over time or by geography; and
- assess data quality and understand its implications when interpreting data

1.4 Target audience

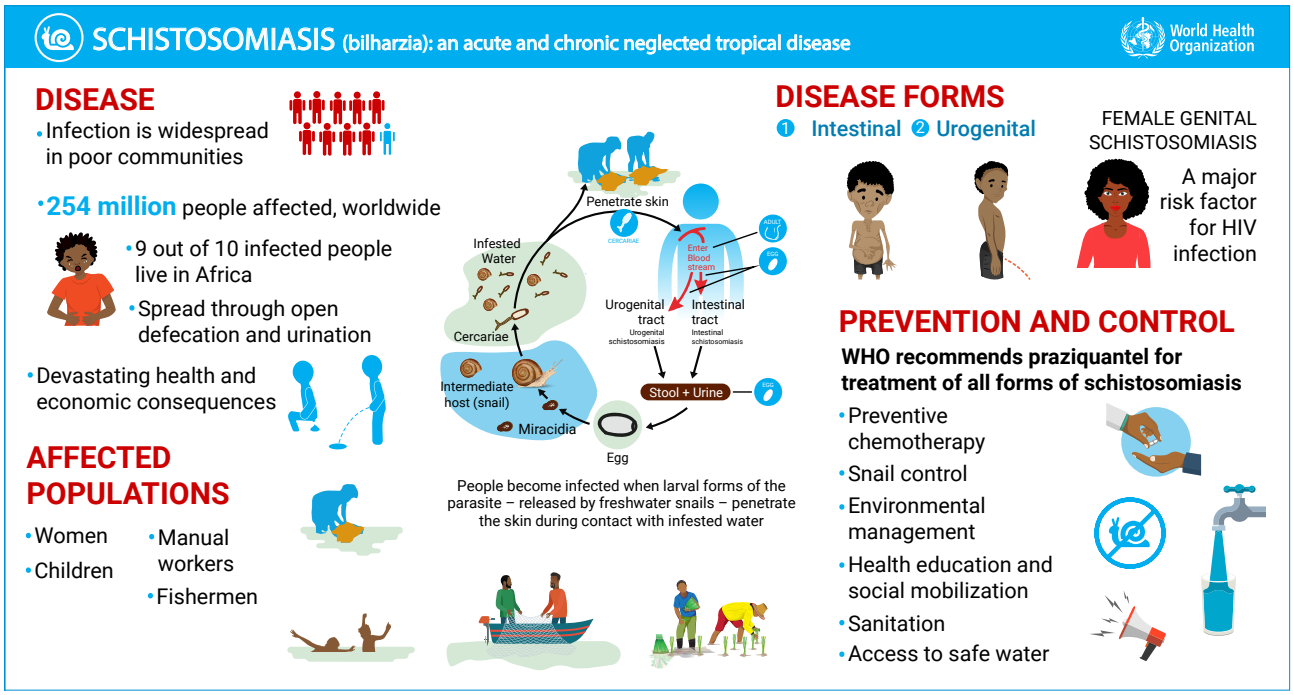
This document is relevant for different members of the health workforce working on schistosomiasis including health workers at health facilities treating schistosomiasis.

2. Human schistosomiasis

2.1 The infection and its transmission

Human schistosomiasis results from infection with the larval forms of schistosomes that are released by freshwater snails and penetrate the skin during contact with infested water. Infection is transmitted when people suffering from schistosomiasis contaminate freshwater sources with faeces or urines containing parasite eggs, which hatch in water. In the body, the larvae develop into adult schistosomes. Adult worms live in the blood vessels where the females release eggs. Some of the eggs are evacuated in the faeces or urine into the environment to continue the parasite's life cycle *(4)*. The life-cycle of human schistosomiasis is shown in Fig. 1. Others become trapped in body tissues, causing immune reactions and progressive damage to body organs. Individuals may present at health facilities with symptoms related to the consequences of infection and organ damage.

Fig. 1. Human schistosomiasis



Source: Schistosomiasis (bilharzia): an acute and chronic neglected tropical disease [WHO infographic] *(4)*.

2.2 Epidemiology

Schistosomiasis is prevalent in tropical and subtropical areas, especially in communities without access to safe drinking-water and adequate sanitation. It is estimated that at least 90% of those requiring treatment for schistosomiasis live in Africa; the remaining infections occur mainly in the Mediterranean region and in South-East Asia *(5)*.

There are two major forms of schistosomiasis – intestinal and urogenital – caused by five main species of blood fluke *(6)*, as shown in Table 1.

Table 1. Parasite species and geographical distribution of human schistosomiasis

Schistosomiasis form	Species	Geographical distribution
Intestinal schistosomiasis	*Schistosoma mansoni*	Africa, Brazil, Caribbean, Middle East, Suriname, Venezuela (Bolivarian Republic of)
	Schistosoma japonicum	China, Indonesia, Philippines
	Schistosoma mekongi	Several districts of Cambodia and Lao People's Democratic Republic
	Schistosoma guineensis and related *S. intercalatum*	Rainforest areas of central Africa
Urogenital schistosomiasis	*Schistosoma haematobium*	Africa, Corsica (France), Middle East

Source: *Schistosomiasis* [WHO factsheet] *(6)*.

Schistosomiasis mostly affects poor and rural communities, with little access to clean water and proper sanitation, particularly agricultural and fishing populations. Women doing domestic chores in infected water, such as washing clothes, are also at risk and can develop female genital schistosomiasis *(7)*. Inadequate hygiene and contact with snail infested water make people especially children vulnerable to infection.

Migration to urban areas and population movements are introducing the disease to new areas. Increasing population size and the corresponding needs for power and water often result in development schemes, and environmental modifications facilitate transmission.

With the rise in eco-tourism and travel to remote areas, increasing numbers of tourists are contracting schistosomiasis. At times, tourists present severe acute infection and unusual problems including paralysis.

Urogenital schistosomiasis is also considered to be a risk factor for HIV infection, especially in women *(8)*.

2.3 Symptoms

Intestinal schistosomiasis can result in abdominal pain, diarrhoea and blood in the stool. Liver enlargement is common in advanced cases and is frequently associated with an accumulation of fluid in the peritoneal cavity and hypertension of the abdominal blood vessels. In such cases, there may also be enlargement of the spleen.

The classic sign of urogenital schistosomiasis is haematuria (blood in urine). Kidney damage and fibrosis of the bladder and ureter are sometimes diagnosed in advanced cases. Bladder cancer is another possible complication in the later stages. In women, urogenital schistosomiasis may present with genital lesions, vaginal bleeding, pain during sexual intercourse and nodules in the vulva. In men, urogenital schistosomiasis can induce pathology of the seminal vesicles, prostate and other organs. This disease may also have other long-term irreversible consequences, including primary and secondary infertility.

The economic and health effects of schistosomiasis are considerable and the disease disables more than it kills. In children, schistosomiasis can cause anaemia, stunting and a reduced ability to learn, although the effects are usually reversible with treatment. Chronic schistosomiasis may affect people's ability to work and, in some cases, can result in death. The number of deaths due to schistosomiasis is difficult to estimate due to underreporting because of hidden pathologies such as liver and kidney failure, bladder cancer and ectopic pregnancies due to female genital schistosomiasis.

Deaths due to schistosomiasis are currently estimated at 14 366 globally in 2021 *(9)*. However, these figures are likely underestimated.

2.4 Diagnosis

Schistosomiasis is diagnosed through the detection of parasite eggs in stool or urine specimens. Antibodies and/or antigens detected in blood or urine samples are also indications of infection.

For urogenital schistosomiasis, a filtration technique using nylon, paper or polycarbonate filters is the standard diagnostic technique. Children infected with *S. haematobium* almost always have microscopic blood in their urine which can be detected by chemical reagent strips.

The eggs of intestinal schistosomiasis can be detected in faecal specimens through direct faecal smear or a technique using methylene blue (or green malachite)-stained cellophane soaked in glycerin or glass slides, known as the Kato–Katz technique for intestinal schistosomiasis. In *S. mansoni* transmission areas, the circulating cathodic antigen test can also be used.

In low-resource settings, diagnosis could be based on the presence of blood in urine (questionnaire), or visual observation of blood in urine for urogenital schistosomiasis, or observation or reporting of blood in stool or bloody diarrhoea for intestinal schistosomiasis.

For people living in non-endemic or low-transmission areas, serological and immunological tests may be useful in showing exposure to infection and the need for thorough examination, treatment and follow-up. Morbidity due to schistosomiasis can also be assessed using imaging techniques X-ray, magnetic resonance imaging (MRI) and ultrasound, which can put on evidence calcification of the bladder wall, polyps and masses in the bladder, hydronephrosis in urogenital schistosomiasis or hepatosplenomegaly, liver fibrosis or portal vein dilatation in intestinal schistosomiasis.

Colposcopy is used for observation of the specific vaginal and cervical lesions due to female genital schistosomiasis.

2.5 Treatment

Praziquantel is the medicine of choice for treatment against all the causative species of human schistosomiasis *(2, 6)*. It is safe, effective and can be administered by non-medical persons trained to determine dosage (in a single dose at dosage of 40 mg/kg body weight). The dosage is determined also using a tablet pole. Children aged under 5 years or below 94 cm in height can be treated individually by medical personnel using the paediatric formulation of praziquantel, if available, or crushed regular praziquantel *(10)* (Table 2).

Individuals may experience a range of adverse effects after receiving treatment, including dizziness, headache, nausea, cramps and abdominal colic. These reactions are usually light and resolved within 24 hours. Food is recommended to be taken within 2 hours before medicines are taken.

Table 2. Summary dosage table according to height and weight

Body weight (kg)	Height (cm)	Number of tablets
10–14.9	94–1091	1
15–22.4	110–124	1.5
22.5–29.9	125–137	2
30–37.4	138–149	2.5
37.5–44.9	150–159	3
45–59.9	160–177	4
≥ 60	≥ 178	5

Source: From *WHO guideline on control and elimination of human schistosomiasis (2) and Report of a meeting to review the results of studies on the treatment of schistosomiasis in preschool-age children (10).*

2.6 Prevention and control

The control of schistosomiasis is based on large-scale treatment of at-risk population groups, increased access to safe water, improved sanitation, hygiene education and behavioural change, snail control and environmental management.

The road map sets out global targets for 2030 and milestones to prevent, control, eliminate and eradicate a diverse set of diseases, including schistosomiasis *(3)*. The target is to eliminate schistosomiasis as a public health problem in all endemic countries and interrupt its transmission (absence of infection in humans) in selected countries.

The WHO strategy for schistosomiasis control focuses on reducing disease through periodic, targeted treatment with praziquantel involving large-scale treatment (preventive chemotherapy) of affected populations and regular treatment of all at-risk groups *(11)*. In a few countries, where there is low transmission, the aim should be interruption of transmission.

The following groups are targeted for preventive chemotherapy treatment:

- preschool-aged children;
- school-aged children;
- adults considered to be at risk in endemic areas and people with occupations involving contact with infected water, such as fishermen, farmers, irrigation workers and women whose domestic tasks bring them in contact with infested water; and
- entire communities living in highly endemic areas.

WHO recommends treatment of infected preschool aged children based on diagnostic and clinical judgment and their inclusion in large-scale treatment using paediatric praziquantel. The frequency of treatment is determined by the prevalence of infection in school-aged children. In high-transmission areas, treatment may have to be repeated once every year for several years. Monitoring is essential to determine the impact of control interventions *(12)*.

The aim is to reduce disease morbidity and transmission towards the elimination of the disease as a public health problem. Periodic treatment of at-risk populations will cure mild symptoms and prevent infected people from developing severe, late-stage chronic disease. Praziquantel is the recommended treatment against all forms of schistosomiasis. It is effective, safe and low-cost. Even though re-infection may occur

after treatment, the risk of developing severe disease is diminished and even reversed when treatment is initiated and repeated in childhood.

Schistosomiasis has been successfully controlled over the past 40 years in several countries. Over the past 10 years, treatment campaigns have been scaled up in a number of sub-Saharan countries, where most of those at risk live. These campaigns have resulted in the decrease of prevalence and intensity of schistosomiasis in school-aged children by almost 60% *(13)*.

2.7 WHO response

WHO's work to eliminate schistosomiasis is part of an integrated approach to controlling neglected tropical diseases (NTDs). Although medically diverse, NTDs share features that allow them to persist in conditions of poverty, where they cluster and frequently overlap.

WHO coordinates the strategy of preventive chemotherapy. Working with partners and the private sector, the Organization has advocated for increased access to praziquantel and resources to implement preventive chemotherapy. Each year, Merck provides up to 250 million tablets for preventive chemotherapy treatment of schistosomiasis through its partnership with WHO. This aims to treat a minimum of 100 million school-aged children annually. National authorities are required to complement this donation by procuring additional praziquantel for treatment of all at-risk groups including adults, and for treatment of patients presenting at health facilities for clinical care.

3. About schistosomiasis data

Data on population-based treatments are collected to measure the progress being made towards achieving the targets set by World Health Assembly resolutions to reach at least 75% all school-aged children who are at risk of morbidity from schistosomiasis and soil-transmitted helminthiases. Of the 78 countries considered endemic for schistosomiasis, only 50 countries have populations requiring preventive chemotherapy. The total number of people in need of preventive chemotherapy globally in 2023 was 254 million, of which 135 million were school-aged children *(1)*. Data reported in 2022 from 33 countries for treatment of school-aged children and from 20 countries for treatment of adults show that 90 million people received preventive chemotherapy for schistosomiasis globally, which is equivalent to 56% global coverage for school-aged children and 12% for adults at risk *(1)*. However, these reports do not presently include data from clinical settings and health facility-based interventions for schistosomiasis. Additionally, the role of health facilities in the prevention, diagnosis, control, and elimination of schistosomiasis is poorly documented.

3.1 Importance of health facility data on schistosomiasis

Health facilities can play a vital role in the control and elimination of schistosomiasis. WHO recommends that *"... health facilities provide access to treatment with praziquantel to control morbidity due to schistosomiasis in all individuals regardless of age, including infected pregnant excluding the first trimester, lactating women and pre-SAC [preschool-aged children] aged < 2 years" (2)*. Additionally in low prevalence settings, the majority of the population is uninfected and the few infected individuals mainly carry light-intensity infections. In such settings, health facilities enable passive surveillance through the collection and reporting of information on testing, treatment and reporting of cases.

Health facility data on schistosomiasis are therefore important for understanding:

- presentation at clinical examination as a marker related to access to early detection;
- schistosomiasis-derived morbidity and mortality in endemic countries;
- trends for schistosomiasis indicators in treatment centres;
- access to diagnostics, including polymerase chain reaction (PCR); and
- utilization of anthelminthics in clinical settings.

3.2 Data collection and reporting

Schistosomiasis data should be reported to WHO in accordance with data management and coordination mechanisms established at the national level for NTD programmes. National data for schistosomiasis are formally reported to WHO by Member States through the following channels:

- Countries submit their data using the epidemiological reporting form (EPIRF) and the joint reporting form (JRF) for preventive chemotherapy outcomes of community-based interventions.
- Countries that are not implementing preventive chemotherapy submit their data using the Global NTD Annual Reporting Form (GNARF), from clinical treatments in health facilities.

Additionally, as part of passive surveillance activities, schistosomiasis data on the number of patients seen by clinicians should be included in the monthly report summaries from health facilities to the national levels.

Schistosomiasis data that are formally reported to WHO are disseminated and visualized through the following publicly-accessible platforms:

- NTD road map tracker,
- NTD country profiles,
- WHO Global Health Observatory, and
- WHO regional data visualization platforms, such the AFRO/EPSEN portal *(14)* and the dashboard for NTDs in the WHO Regional Office for the Western Pacific *(15)*.

3.3 WHO-recommended case definitions

The definitions of a suspected, probable and confirmed case of schistosomiasis are provided in Table 3.

Table 3. Case definitions of schistosomiasis

Suspected	**Urogenital schistosomiasis in endemic areas:** not applicable **Urogenital schistosomiasis in non-endemic areas:** A person with visible haematuria, or with positive reagent strip for haematuria, and possibly infective water-contact **Intestinal schistosomiasis in endemic areas:** A person with non-specific abdominal symptoms, blood in stool, hepato(spleno)megaly **Intestinal schistosomiasis in non-endemic areas:** A person with non-specific abdominal symptoms, blood in stool, hepato(spleno)megaly and possibly infective water-contact
Probable	Not applicable
Confirmed	**Urogenital schistosomiasis in endemic areas:** A person with visible haematuria, or with positive reagent strip for haematuria, or with eggs of *S. haematobium* in urine (microscope). **Urogenital schistosomiasis in non-endemic areas:** A person with eggs of *S. haematobium* in urine (microscope). **Intestinal schistosomiasis in endemic areas:** A person with eggs of *S. mansoni, S. japonicum, S. mekongi* or *S. intercalatum* in stools (microscope). **Intestinal schistosomiasis in non-endemic areas:** A person with eggs of *S. mansoni, S. japonicum, S. mekongi* or (possibly) *S. intercalatum* in stools (microscope); a person with a positive reaction to immunoblot test.

3.4 Other key WHO-recommended definitions for data management

The International Classification of Diseases (ICD) provides the main basis for comparability of statistics on causes of mortality and morbidity between places and over time. ICD allows the systematic recording, analysis, interpretation and comparison of mortality and morbidity data collected in different countries or regions and at different times. It also ensures semantic interoperability and reusability of recorded data for the different use cases beyond mere health statistics, including decision support, resource allocation, reimbursement, guidelines and more. The latest (eleventh) version of the ICD (ICD-11) *(16)* was adopted by the Seventy-second World Health Assembly in 2019 and came into effect on 1 January 2022. Schistosomiasis is included in ICD-11, under code F186 (Table 4).

Table 4. Schistosomiasis: ICD-11 general code 1F86

Data codes for clinical diagnosis	
1F86.0	Schistosomiasis due to *Schistosoma haematobium*
1F86.1	Schistosomiasis due to *Schistosoma mansoni*
1F86.2	Schistosomiasis due to *Schistosoma japonicum*
1F86.3	Other schistosomiases
1F86.4	Cercarial dermatitis
1F86.5	Schistosomal pneumonitis
1F86.Z	Schistosomiasis due to unspecified or unknown *Schistosoma* species

Data code for main manifestations	
1F86.0	Schistosomiasis due to *Schistosoma haematobium* Schistosomiasis of bladder haematochyluria in schistosomiasis genitourinary tract schistosomiasis Schistosomiasis due to *Schistosoma haematobium* [urinary schistosomiasis]
1F86.1	Schistosomiasis due to *Schistosoma mansoni*
1F86.2	Schistosomiasis due to *Schistosoma japonicum*
1F86.3	Other schistosomiases Schistosomiasis bovi
1F86.Z	Schistosomiasis due to unspecified or unknown *Schistosoma* species
0A08.6	Special screening examination for other protozoal diseases or helminthiases Schistosomiasis screening
1F86.Z	Hepatosplenic schistosomiasis
1F86.1	Pneumonia in schistosomiasis due to *Schistosoma mansoni*
1F86.Z	Fibrosis of spleen in schistosomiasis
1F86.Z	Granuloma of brain due to schistosomiasis
DA26.00	Oesophageal varices with bleeding Oesophageal varices with bleeding in schistosomiasis
1F86.Z	Disorders of kidney or ureter in schistosomiasis [bilharziasis]
DA26.01	Oesophageal varices without bleeding Oesophageal varices without bleeding in schistosomiasis
8801.0	Pulmonary arterial hypertension Pulmonary arterial hypertension associated with schistosomiasis

Table 4. *contd.*

Data code for additional manifestations (to add into data reporting system, if desired)	
1D04.0	Parasitic intracerebral granuloma
3B81.9	Fibrosis of spleen: glomerular diseases
GB40	Nephritic syndrome
GB41	Nephrotic syndrome
GB42	Persistent proteinuria or albuminuria
GB42.0	Albuminuria, Grade A2
GB42.1	Albuminuria, Grade A3
GB42.Y	Other specified persistent proteinuria or albuminuria
GB42.Z	Persistent proteinuria or albuminuria, unspecified
GB4Y	Other specified glomerular diseases
GB4Z	Glomerular diseases, unspecified

Disease stage (to add into data reporting system, if desired)	
XT5R	Acute
XT8W	Chronic

Source: ICD-11 *(16)*.

4. Data quality

One of the challenges to interpreting health facility data is that responsibility for data recording, entry, cleaning and management. Unlike special studies or surveys, there are often limited resources available for entering and cleaning routine data, impacting the quality and usability of routine monitoring data. Systems and protocols have therefore been established to enhance good data collection, reporting data analysis and use at the facilitates. However, as for all data sources, any analysis must consider whether the results are affected by data quality issues.

The WHO data quality review toolkit *(17)* and the preventive chemotherapy field manual *(18)* provide guidance for defining measures of data quality, conducting a desk review to assess data quality and conducting data verification of routine facility data systems. The five key domains used for periodic assessments of data quality are summarized below.

4.1 Completeness of data

The completeness of the data is assessed by measuring whether all the entities which are supposed to report actually do so. This applies to health-facility reporting to districts and to districts reporting to the regional or provincial levels.

4.2 Timeliness of data

The timeliness of data is assessed by measuring whether the entities that submitted reports did so before a predefined deadline.

4.3 Consistency of data

4.3.1 Internal consistency

The internal consistency of reported data relates to the coherence of the data being evaluated. Internal consistency metrics examine: (i) coherence between the same data items at different points in time; (ii) coherence between related data items; and (iii) comparison of data in source documents and in national databases.

4.3.2 External consistency

The external consistency of reported data refers to the agreement with other sources of schistosomiasis data such as surveys. The level of agreement between two sources of data measuring the same health indicator is assessed. Both sources of data usually compared are data flowing through the health management information system (HMIS) or the programme-specific information system and data from a periodic population-based survey. The HMIS can also be compared to pharmacy records or other types of data to ensure that the two sources fall within a similar range.

4.4 External comparisons of population data

External comparisons of population data review to reviews of the denominator data used to calculate rates for performance indicators. Population data serve as the denominator in the calculation of a rate or proportion and provide important information on coverage. This data quality measurement compares two different sources of population estimates (for which the values are calculated differently) in order to ascertain the level of congruence between the two. If both population estimates are discrepant, the coverage estimates for a given indicator can be very different even though the programmatic result (i.e. the number of events) is the same. The higher the level of consistency between denominators from different sources, the more likely it is that the values represent the true population value.

5. Indicators

5.1 Core indicators

Table 5 outlines the recommended minimum core indicators, definitions, disaggregation and data sources for schistosomiasis data collection, reporting and surveillance. These indicators enable monitoring and evaluation that support programme management, and country reporting on the road map indicators 2021–2030 *(12)*.

Table 5. Schistosomiasis minimum core indicators

Core indicator	Definition	Numerator	Denominator	Factor indicator type	Formula/ calculation (if applicable)	Disaggregation numerator
Number of schistosomiasis cases reported (ICD-11 code: 1F86)	Number of schistosomiasis cases reported by age and sex	Number of schistosomiasis cases reported in the reporting period	1	Number		By diagnostic method By case classification (suspected or clinically confirmed or laboratory confirmed) By age group (years): < 1, 1–4, 5–14, 15–24, 25–49, 50–64, ≥ 65, unknown By sex By residency status (autochthonous, imported) By species By administrative unit(s)
Annual reported schistosomiasis incidence	Annual schistosomiasis incidence rate by age and sex	Number of new schistosomiasis cases reported in the reporting period	Estimated population living in the area	per 100,000 population	Number of new cases of schistosomiasis reported in a year/ Population living in the area × 100 000 population	By age group (years): < 1, 1–4, 5–14, 15–24, 25–49, 50–64, ≥ 65, unknown By sex
Schistosomiasis prevalence	Estimated schistosomiasis site surveyed prevalence by age and sex	Number of schistosomiasis cases detected during the site survey	Number of people tested	Percentage	Number of schistosomiasis cases detected during the site survey / Number of people tested × 100	By age group (years): < 1, 1–4, 5–14, 15–24, 25–49, 50–64, ≥ 65, unknown By sex By administrative unit(s)
Schistosomiasis prevalence	Estimated schistosomiasis site surveyed prevalence by age and sex	Number of schistosomiasis cases detected during the site survey	Number of people tested	Percentage	Number of schistosomiasis cases detected during the site survey / Number of people tested × 100	By intensity class (urinary, light: < 50 epg/10 mL of urine, heavy: ≥ 50 epg per 10 mL of urine), intestinal schistosomiasis (light: 1–99 epg, moderate: 100–399 epg, heavy: ≥ 400 epg)
Number of deaths reported attributable to schistosomiasis	Number of deaths reported attributable to schistosomiasis by age and sex	Number of deaths reported attributable to schistosomiasis	1	Number		By age group (years): < 1, 1–4, 5–14, 15–24, 25–49, 50–64, ≥ 65, unknown By sex By administrative unit(s)
Total number of people requiring PC interventions/ MDA against schistosomiasis	Number of people requiring PC/ MDA against schistosomiasis	Number of people requiring PC/ MDA against schistosomiasis	1	Number		By age group (years): < 1, 1–4, 5–14, 15–24, 25–49, 50–64, ≥ 65, unknown By sex By administrative unit(s)

Table 5. *contd.*

Core indicator	Definition	Numerator	Denominator	Factor indicator type	Formula/ calculation (if applicable)	Disaggregation numerator
Number of schistosomiasis cases receiving clinical treatment	Number of schistosomiasis cases receiving clinical treatment	Number of schistosomiasis cases treated	1	Number		By age group (less than 1y, 1 -4y, 5-14y, 15-24y, 25-49y, 50-64y, 65+ years, unknown) By gender By case classification (suspected, clinically confirmed or laboratory confirmed) By treatment By administrative unit(s)
Proportion of people presenting haematuria, either visible haematuria reported by the patient or micro-haematuria detected by a positive dipstick	Proportion of people presenting haematuria, either visible haematuria reported by the patient or micro-haematuria detected by a positive dipstick	Number of individuals reporting visible haematuria or with positive dipstick for micro-haematuria	Number of individuals screened	Percentage	Number of individuals reporting visible haematuria or with positive dipstick for micro-haematuria / Number of individuals screened × 100	By age group (years): < 1, 1–4, 5–14, 15–24, 25–49, 50–64, ≥ 65, unknown By gender By administrative unit(s)

Epg: eggs per gram; MDA: mass drug administration; PC: preventive chemotherapy.

5.2 Additional indicators

Additional indicators for schistosomiasis are provided in Table 6.

Table 6. Additional schistosomiasis indicators

Indicator	Definition	Numerator	Denominator	Factor indicator type	Formula/ calculation (if applicable)	Disaggregation numerator
Prevalence of high intensity infection of any schistosome species	Prevalence of high intensity infection of any schistosome species	Number of individuals with heavy intensity infection	Number of individuals providing a specimen	Percentage	Number of individuals with high intensity infection / Number of individuals providing a specimen × 100	By age group (years): < 1, 1–4, 5–14, 15–24, 25–49, 50–64, ≥ 65, unknown By sex By administrative unit(s)
Urogenital schistosomiasis urinary lesions prevalence	Prevalence of lesions in the urinary tract	Number of people assessed by ultrasound having schistosomiasis lesions in the urinary tract	Number of people examined for schistosomiasis by ultrasound	Percentage	Number of people assessed by ultrasound having schistosomiasis lesions in the urinary tract / Number of people examined by ultrasound × 100	By age group (years): < 1, 1–4, 5–14, 15–24, 25–49, 50–64, ≥ 65, unknown By sex By type of lesion (masses, hydronephrosis) By location of lesion (bladder, kidney, ureter) By administrative unit(s)
Urogenital schistosomiasis genital lesions prevalence	Prevalence of genital manifestations of schistosomiasis	Number of genital schistosomiasis cases detected during the survey	Number of people tested for schistosomiasis	Percentage	Number of genital schistosomiasis cases detected during the survey / Number of people tested × 100	By age group (years): < 1, 1–4, 5–14, 15–24, 25–49, 50–64, ≥ 65, unknown By sex By testing method (clinical examination, colposcopy, ultrasound of pelvic organs) By administrative unit(s)
Intestinal schistosomiasis clinical abnormalities prevalence	Prevalence of blood in stool (including persistent bloody diarrhoea)	Number of people having blood in stool/ persistent bloody diarrhoea	Number of people tested for schistosomiasis	Percentage	Number of people having blood in stool/persistent bloody diarrhoea / Number of people tested × 100	By age group (years): < 1, 1–4, 5–14, 15–24, 25–49, 50–64, ≥ 65, unknown By sex By testing method (reagent strips, FOBT, visual observation) By administrative unit(s)

Table 6. *contd.*

Indicator	Definition	Numerator	Denominator	Factor indicator type	Formula/ calculation (if applicable)	Disaggregation numerator
Intestinal schistosomiasis ultrasound abnormalities prevalence	Prevalence of lesions in the liver, spleen and portal veins, presence of ascites.	Number of people having lesions in the liver, spleen, portal veins and/or ascites	Number of people examined by ultrasound	Percentage	Number of people having lesions in the liver, spleen, portal veins and/or ascites / Number of people examined by ultrasound × 100	By age group (years): < 1, 1–4, 5–14, 15–24, 25–49, 50–64, ≥ 65, unknown By sex By type of lesion (PPF, etc.) By administrative unit(s)
Number of people treated using schistosomiasis test and treat strategy	Number of people treated using schistosomiasis test and treat strategy	Number of people treated using schistosomiasis test and treat strategy	1	Number		By age group (years): < 1, 1–4, 5–14, 15–24, 25–49, 50–64, ≥ 65, unknown By gender By treatment By administrative unit(s)
Number of health workers trained on FGS	Number of health workers trained on FGS	Number of health workers trained on FGS	1	Number		By administrative unit(s)

FGS: female genital schistosomiasis; FOBT: faecal occult blood test; PPF: periportal fibrosis.

6. Core analyses

The recommended core analyses and considerations in their interpretation are summarized below. Before interpreting trends in data, it is essential to investigate data quality issues. If any sudden changes in trends arise, first check data to make sure there has not been any error in data entry (see section 4 for recommended data quality indicators to guide interpretation).

6.1 Purpose

The purpose of the core analyses are:

- to assess the quality of the data in order to guide the analysis of indicators;
- to identify the weaknesses in data quality, including data collection, entry, storage, completeness, timeliness and consistency; and
- to identify the health facilities with data quality issues.

6.2 Analysis and interpretation

The formulas for calculation are explained in the tables above. The data should be computed to report on the following:

- total number of individuals diagnosed, by *Schistosoma* species and clinical manifestations/ complications;
- total number of people treated in health facilities and during mass drug administration campaigns;
- data by age group;
- data by sex;
- trends in incidence; and
- trends in prevalence.

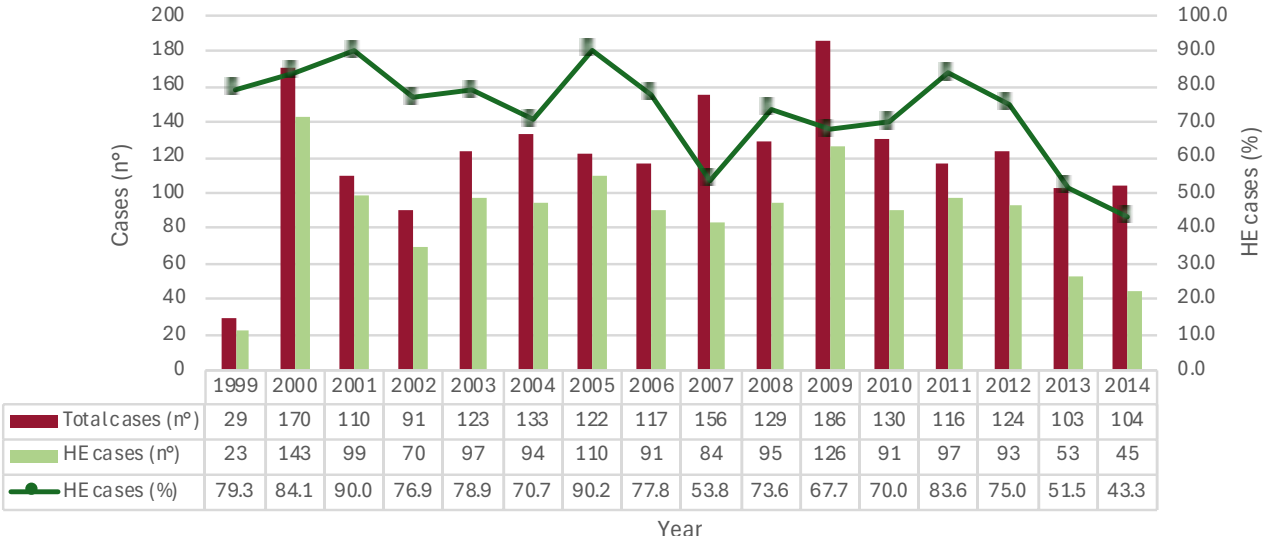
Examples of analysis and presentation of health facility data are provided in Tables 7–12 and Figs. 2–3.

Table 7. Number of intestinal schistosomiasis cases per sanitary district and per year as determined by direct smear at health centre level in Burundi

SD name	Zone	2011	2012	2013	2014	2015
Bubanza	ZNI	99	78	36	143	63
Rwibaga	ZNI	103	14	0	2	6
Bururi	ZNI	8	1	2	14	22
Matana	ZNI	32	9	21	19	20
Cankuzo	ZNI	10	1	0	2	0
Murore	ZNI	1	18	4	0	0
Mabayi	ZNI	64	74	38	30	53
Gitega	ZNI	27	17	24	55	31
Kibuye	ZNI	0	1	5	1	2
Mutaho	ZNI	13	2	3	6	1
Ryansoro	ZNI	4	0	3	4	2
Buhiga	ZNI	0	2	0	2	0
Nyabikere	ZNI	0	4	0	0	1
Kayanza	ZNI	6	6	8	7	69
Musema	ZNI	5	7	2	31	8
Gahombo	ZNI	30	25	18	6	15
Mukenke	ZNI	13	4	4	5	0
Vumbi	ZNI	27	26	26	26	1
Makamba	ZNI	238	267	249	270	195
Muramvya	ZNI	0	19	3	103	2
Kiganda	ZNI	0	5	6	3	15
Muyinga	ZNI	28	17	8	19	31
Gashoho	ZNI	38	9	1	0	0
Giteranyi	ZNI	0	22	152	7	12
Kibumbu	ZNI	10	2	40	4	19
Fota	ZNI	0	0	0	0	0
Ngozi	ZNI	5	1	0	32	0
Kiremba	ZNI	9	97	3	34	0
Buye	ZNI	0	0	0	0	0
Rutana	ZNI	12	30	15	5	2
Gihofi	ZNI	15	68	72	16	13
Butezi	ZNI	9	4	0	5	2
Kinyinya	ZNI	69	25	99	125	103
Ruyigi	ZNI	1	1	6	2	1
Mpanda	ZI	585	397	307	121	118
Zone Nord	ZI	493	483	215	118	50
Zone Centre	ZI	504	9	70	22	36
Zone Sud	ZI	145	24	23	11	39
Kabezi	ZI	115	47	56	174	82
Isale	ZI	210	156	71	346	53
Rumonge	ZI	189	136	374	213	351
Cibitoke	ZI	883	996	901	296	169
Kirundo	ZI	10	21	9	12	3
Busoni	ZI	23	23	103	15	4
Nyanza-Lac	ZI	247	315	255	263	149

SD: sanitary district; ZI: zone of intervention, targeted for MDA with PZQ; ZNI: zone of non-intervention, not targeted for MDA with PZQ.
Source: Bizimana et al., 2020 *(19)*.

Fig. 2. Evolution of the total number of cases of schistosomiasis and cases of hepatosplenic (HE) form recorded for a period of 16 years in a hospital of Brazil, 1999–2014



	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Total cases (nº)	29	170	110	91	123	133	122	117	156	129	186	130	116	124	103	104
HE cases (nº)	23	143	99	70	97	94	110	91	84	95	126	91	97	93	53	45
HE cases (%)	79.3	84.1	90.0	76.9	78.9	70.7	90.2	77.8	53.8	73.6	67.7	70.0	83.6	75.0	51.5	43.3

Source: Barbosa et al., 2016 *(20)*.

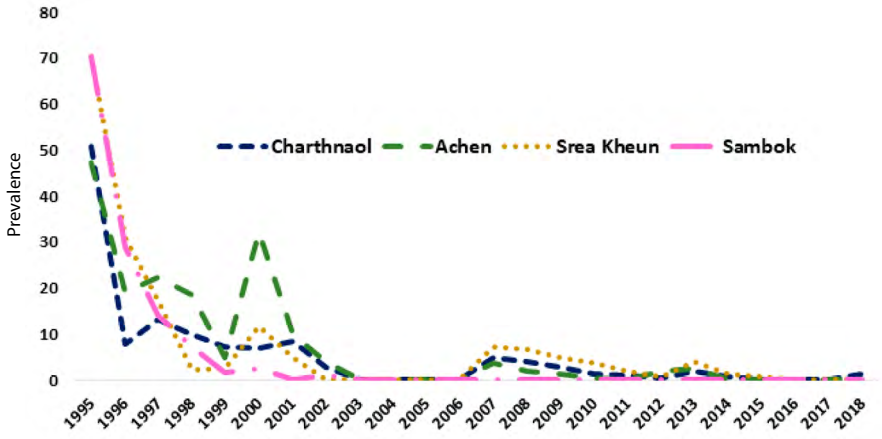
Table 8. Number of deaths due to schistosomiasis registered in the death information system of the Ministry of Health, by federal unit of residence in Brazil, 1999–2013

Region/Federation Unit	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	Total
North Region	**10**	**7**	**1**	**5**	**3**	**5**	**1**	**7**	**1**	**5**	**3**	**0**	**0**	**0**	**3**	**51**
Rondônia	7	4	1	4	3	5	1	0	1	2	0	0	0	0	3	31
Acre	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	1
Pará	0	2	0	0	0	0	0	4	0	3	3	0	0	0	0	12
Tocantins	3	1	0	1	0	0	0	2	0	0	0	0	0	0	0	7
Northeast Region	**289**	**323**	**385**	**394**	**315**	**328**	**345**	**370**	**358**	**365**	**324**	**327**	**366**	**309**	**297**	**5095**
Maranhão	4	5	11	2	7	2	12	11	6	8	8	1	3	6	10	96
Piauí	0	0	0	1	1	0	0	1	1	1	0	2	1	0	1	9
Ceará	5	7	8	7	2	9	5	2	4	2	12	3	2	2	2	72
Rio Grande do Norte	5	2	3	5	4	7	5	5	2	3	4	3	3	5	4	60
Paraíba	8	8	7	9	18	14	17	14	16	11	15	14	23	4	15	193
Pernambuco	135	158	136	141	176	202	192	205	205	206	153	196	174	158	141	2578
Alagoas	75	93	165	193	62	47	54	52	68	49	54	28	62	52	49	1103
Sergipe	10	8	11	3	10	13	18	11	13	20	18	20	25	21	15	216
Bahia	47	42	44	33	35	34	42	69	43	65	60	60	73	61	60	768
Southeast Region	**134**	**138**	**178**	**157**	**134**	**176**	**154**	**168**	**164**	**157**	**160**	**175**	**169**	**167**	**152**	**2383**
Minas Gerais	34	43	52	65	46	56	62	61	58	60	49	66	59	77	69	857
Espírito Santo	13	9	9	8	9	9	7	12	13	12	10	15	14	18	8	166
Rio de Janeiro	11	13	16	22	12	13	11	15	19	17	14	17	13	10	11	214
São Paulo	76	73	101	62	67	98	74	80	74	68	87	77	83	62	64	1146
South Region	**5**	**5**	**5**	**4**	**5**	**4**	**6**	**1**	**3**	**8**	**4**	**4**	**2**	**3**	**3**	**62**
Paraná	4	3	4	4	4	4	6	1	3	7	4	4	1	3	3	55
Santa Catarina	0	1	1	0	0	0	0	0	0	1	0	0	1	0	0	4
Rio Grande do Sul	1	1	0	0	1	0	0	0	0	0	0	0	0	0	0	3
Midwest Region	**8**	**11**	**14**	**8**	**7**	**6**	**8**	**8**	**8**	**6**	**7**	**8**	**9**	**9**	**13**	**130**
Mato Grosso do Sul	1	1	0	1	0	3	0	0	0	1	0	1	1	1	1	11
Mato Grosso	1	5	6	1	1	0	1	3	1	0	2	2	2	0	2	27
Goiás	3	2	5	2	5	0	3	1	2	2	2	1	4	5	4	41
Distrito Federal	3	3	3	4	1	3	4	4	5	3	3	4	2	3	6	51
Total	**446**	**484**	**583**	**568**	**464**	**519**	**514**	**554**	**534**	**541**	**498**	**514**	**546**	**488**	**468**	**7721**

Source: Barbosa et al., 2016 *(20)*.

Analysis of prevalence trend

Fig. 3. Prevalence of schistosomiasis by Kato Katz from 1995 to 2019 in four sites in Cambodia



Source: Khieu et al., 2019 *(21)*.

Analysis of intensity of infection trend, and incidence trend

Table 9. Total number of cases and incidence rate per 100 000 population by age group and gender in Ecuador, 2011–2021

	Women			Men		
Age [years]	**Cases [n]**	**Frequency**	**Incidence rate per 1 00 000 population**	**Cases [n]**	**Frequency**	**Incidence rate per 1 00 000 population**
< 1	2	0.7	6.08 [6.08 to 6.08]	NA	0.0	NA
1 to 4	2	0.7	1.54 [1.54 to 1.54]	7	2.7	3.39 [2.93 to 3.85]
5 to 9	7	2.4	2.15 [1.39 to 2.9]	9	3.5	1.72 [1.34 to 2.11]
10 to 14	12	4.1	3.03 [2.17 to 3.89]	8	3.1	3.27 [1.33 to 5.21]
15 to 19	11	3.7	2.06 [1.82 to 2.3]	1	0.4	1.37 [NA to NA]
20 to 24	16	5.4	2.81 [2.4 to 3.22]	9	3.5	2.14 [1.81 to 2.47]
25 to 29	24	8.1	4.55 [3.73 to 5.37]	15	5.9	2.83 [2.41 to 3.26]
30 to 34	30	10.1	4.41 [4.06 to 4.75]	18	7.1	4.46 [3.62 to 5.3]
35 to 39	38	12.8	7.49 [6.57 to 8.42]	32	12.5	6.78 [5.78 to 7.79]
40 to 44	34	11.5	8.59 [7.32 to 9.86]	27	10.6	8.41 [7.55 to 9.27]
45 to 49	26	8.8	7.33 [6.15 to 8.51]	19	7.5	6.69 [5.6 to 7.79]
50 to 54	28	9.5	8.14 [7.11 to 9.17]	24	9.4	9.61 [8.25 to 10.98]
55 to 59	25	8.4	7.78 [6.27 to 9.3]	32	12.5	12.01 [10.43 to 13.59]
60 to 64	13	4.4	6.28 [5.69 to 6.88]	19	7.5	8.77 [7.73 to 9.8]
65 to 69	14	4.7	8.52 [7.63 to 9.41]	10	3.9	7.71 [7.03 to 8.38]
70 to 74	7	2.4	9.71 [7.67 to 11.75]	15	5.9	16.18 [13.2 to 19.15]
75 to 79	1	0.3	10.21 [NA to NA]	6	2.4	21.12 [11.09 to 31.14]
> 80	6	2.0	12.11 [10.2 to 14.03]	4	1.6	9.09 [9.09 to 9.09]
Total	**296**	**100**	**5.27 [4.92 to 5.61]**	**255**	**100**	**5.66 [5.31 to 6.01]**

Source: Vásconez-González et al., 2023 *(22)*.

Table 10. Annual distribution of schistosomiasis in Saudi Arabia, 2014–2020

Year	Total population	Number of examined	Positive, n (%)	Negative, n (%)	Incidence 100 000 population	*p* Value	OR (95% CI)
2014	28 309 273	787 699	117 (0.0148)	787 582 (98.6)	0.413	<0.001	1.41 (0.98–2.03)[ns]
2015	29 816 382	781 366	159 (0.0203)	781 207 (97.97)	0.533		1.93 (1.36–2.74) ***
2016	30 954 198	726 216	119 (0.0164)	726 097 (98.36)	0.384		1.56 (1.08–2.23) **
2017	30 977 355	593 011	103 (0.0174)	592 908 (98.26)	0.332		1.65 (1.14–2.38) **
2018	30 196 281	587 608	96 (0.0163)	587 512 (98.37)	0.318		1.55 (1.07–2.25) *
2019	30 063 799	525 301	47 (0.0089)	525 254 (99.11)	0.156		0.85 (0.56–1.29)[ns]
2020	31 552 510	370 280	39 (0.0105)	370 241 (98.95)	0.123		Reference
Total	–	**4 371 481**	**680 (0.0155)**	**4 370 801 (98.45)**	**2.155**		–

* p value < 0.05; ** p value < 0.01; *** p value < 0.001; and ns not significant.

Source: Zrieq et al., 2023 *(23)*.

Table 11. Type of schistosomiasis by region in Saudi Arabia, 2014–2020

	Type of schistosomiasis		Total, n (%, out of all positive cases)	
Regions	**Urinary, n (%)**	**Intestinal, n (%)**		***p* Value**
Mecca	22 (3.2)	398 (58.5)	420 (61.7)	<0.001
Medinah	11 (1.6)	40 (5.9)	51 (7.5)	
Aseer	27 (4.0)	20 (3.0)	47 (7.0)	
Jazan	69 (10.1)	1 (0.15)	70 (10.3)	
Najran	2 (0.29)	1 (0.15)	3 (0.4)	
Al-Bahah	3 (0.44)	80 (11.8)	83 (12.2)	
Eastern region	5 (0.74)	1 (0.15)	6 (0.9)	
Total	**139 (20.4)**	**541 (79.6)**	**680 (100)**	

Source: Zrieq et al., 2023 *(23)*.

Table 12. Gender distribution of schistosomiasis by region in Saudi Arabia, 2014–2020

	Gender		Total n (%, out of all positive cases)	
Regions	**Male, n (%)**	**Female, n (%)**		***p* Value**
Mecca	371 (54.5)	49 (7.2)	420 (61.7)	<0.001
Medinah	44 (6.5)	7 (1.0)	51 (7.5)	
Aseer	42 (6.2)	5 (0.7)	47 (7.0)	
Jazan	52 (7.6)	18 (2.6)	70 (10.3)	
Najran	3 (0.44)	0	3 (0.4)	
Al-Bahah	68 (10)	15 (2.2)	83 (12.2)	
Eastern region	4 (0.59)	2 (0.3)	6 (0.9)	
Total	**584 (85.9)**	**96 (14.1)**	**680 (100)**	

Source: Zrieq et al., 2023 *(23)*.

6.3 Use of the data

Routine health facility data should be incorporated and mainstreamed into the passive surveillance of the national health information system. Such mainstreaming will enable schistosomiasis data to be linked and incorporated into broader information systems as appropriate in the context of the country for civil deaths registers, early warning systems, severe adverse events monitoring, logistics and supply chain systems.

Additionally, this data should be interpreted along with complementary data obtained from sentinel and sporadic surveys, vector control, water and sanitation activities. Information obtained from the health facilities should therefore be regularly and extensively used to inform programme management, target resources and implement interventions against schistosomiasis at district and national levels.

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