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HEALTH COMMITTEE

Working Party on the Patient Reported Indicator Surveys

Technical Standards for cycle 2 of the Patient-Reported Indicator Surveys

16th meeting of the Working Party on the Patient Reported Indicator Surveys (WP-PaRIS)

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This document contains the Technical Standards for the Second cycle of the PaRIS. Input from delegates, National Project managers, experts and stake holders has been incorporated in this version.

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This document, as well as any data and map included herein, are without prejudice to the status of or sovereignty over any territory, to the delimitation of international frontiers and boundaries and to the name of any territory, city or area.

Note by the Secretariat

1. The OECD Patient Reported Indicator Surveys (PaRIS) systematically collects standardised and harmonised patient-reported measures to assess the performance of healthcare systems, particularly for people living with chronic conditions. PaRIS employs i) a patient questionnaire collecting patient-reported outcome and experience measures in addition to sociodemographic and health behaviour characteristics; and ii) a primary care practice questionnaire collecting information regarding the characteristics of primary care practices enabling patient care.

2. The Technical Standards set out the principles underpinning PaRIS, enabling standardised data collection for cross-country comparison. They serve as the foundational reference document for three key actors: National Project Managers (NPMs), who implement PaRIS in their respective countries; International Contractor(s), who support NPMs and the Secretariat on methodological matters; and the Secretariat, which assists countries in implementing PaRIS. Building on the Technical Standards, NPMs will receive more detailed guidelines and survey operation manuals to guide the execution of the survey in a consistent and standardised manner across all participating countries.

3. A revised draft of the Technical Standards is included in this paper following the feedback received from the delegates to the Working Party on PaRIS (WP PaRIS), the various PaRIS advisory bodies and stakeholder groups as well as the Bureau members of the OECD Committee on Statistics and Statistical Policy (CSSP).

4. The Technical Standards have been improved compared to cycle 1 by incorporating the input from several sources:

- A thorough evaluation of the guidelines and manuals developed for cycle 1
- Experience built in OECD in other large scale data collections such as PISA and PIAAC
- Advice from delegates, NPMs, the PaRIS International Expert group, the PaRIS Primary Care Professional Network, and the PaRIS Patient Advisory Panel.

5. Several key decisions have been agreed upon in an ad hoc meeting of the WP PaRIS on 16 September 2025. These decisions concerned eligibility criteria, multilevel sampling structure and sampling procedures, the modes of data collection and the options to collect data centralised (using an international platform) and decentralised (using national data collection platforms). A draft of this document was discussed at the WP PaRIS meeting of 6 November 2025 (DELSA/HEA/PARIS(2025)10).

6. Subject to delegates feedback, this version is to be adopted and included as an Annex in the Terms of Reference of the Call for Tenders to recruit the International Contractor(s) for cycle 2.

7. After adoption, the Technical Standards will inform the survey operation manuals and other technical guidance documents for Field Trial (2027) and can be modified for the Main Survey data collection (2028-2029) based on the evaluation of the Field Trial.

ACTION

Delegates are invited to **ADOPT** the revised draft Technical Standards for cycle 2 of the Patient-Reported Indicator Surveys

Table of contents

Note by the Secretariat 2

1 Purpose and scope of the Technical Standards 5
1.1 Introduction 5
1.2 Balancing standards with national contexts 6

2 Purpose and scope of PaRIS 7
2.1 Purpose and scope of PaRIS 7
2.2 Measurement 8
2.3 Analytical focus 8
2.4 Scope and boundaries 8

3 Governance and planning 10
3.1 Introduction 10
3.2 Governance bodies and International Contractors 10
3.3 National Project Manager (NPM) 11
3.4 The Survey Institute 11
3.5 Timeline, training and Field Trial 12
3.6 Country Roadmap 12
3.7 Communication with the Secretariat and the International Contractor 12
3.8 Adjudication and derogations 13

4 Sampling and Data Collection 14
4.1 Purpose and principles 14
4.2 Multilevel structure and linkage 14
4.3 Target populations 15
4.4 Sampling design 17
4.5 Target sample sizes and response rate thresholds 19
4.6 Preserving the multilevel linkage 21
4.7 Reporting background characteristics of the eligible population 21

5 Recruitment and fieldwork 23
5.1 Introduction 23
5.2 Recruitment of practices 23
5.3 Recruitment of patients 24
5.4 Case management and documentation 24
5.5 Training and supervision 25
5.6 Modes of data collection 25
5.7 Centralised and decentralised data collection 26
5.8 Quality assurance in data collection 26

5.9 Response rates and minimizing bias 26
5.10 Proxy-respondents 27
5.11 Combination with other studies 27
5.12 Stakeholder engagement 27

6 Documentation and Reporting 28
6.1 Countries must provide the following to the Secretariat: 28

7 Instruments, translation and testing 29
7.1 Survey tools, translation and testing 29
7.2 Modification of questionnaires 29

8 Adjudication 30
8.1 Purpose and rationale 30
8.2 Scope 30
8.3 Adjudication process 31

9 Data protection and ethics 32
9.1 Data protection 32
9.2 Ethical approval 32

Annex A. Profile of National Project Manager 34
Rationale 34
Position 34
Key responsibilities of NPMs 34
Tasks development stage 35
Tasks Implementation Phase 35

Annex B. Quality standards and assurance criteria for PaRIS cycle 2 37

FIGURES

Figure 3.1. Governance structure of PaRIS cycle 2 11

TABLES

Table 4.1. Target numbers per country tier 19
Table 4.2. Examples of application of thresholds for minimum numbers of patients and response rates 21
Table 4.3. Example of age-sex distribution in eligible population 21

1 Purpose and scope of the Technical Standards

1.1 Introduction

8. The Technical Standards are the set of principles on which the OECD Patient-Reported Indicator Surveys (PaRIS) are based. They serve as the foundation of PaRIS quality assurance processes. The purpose of PaRIS is to generate an international dataset of a quality that allows for valid cross-national inferences to be made about patients' outcomes and experiences of healthcare. Following the procedures outlined in this document will ensure that this outcome is achieved.

9. This is a reference document aimed at National Project Managers (NPM) and their teams implementing PaRIS in the entities participating in the survey, as well as the International Contractors commissioned by the OECD to support the methodological aspects in the implementation of the second cycle of PaRIS.

10. This document lists the standards for PaRIS Cycle 2. Five goals are important in PaRIS: consistency, precision, generalisability of the data, transparency and replicability, and timeliness of the procedures. The standards identify how to achieve these goals and support participants and contractors to meet PaRIS timelines.

- **Consistency:** Equivalent data collection in all participating entities (countries/economies) is essential. Data should be collected using the same instruments that have been translated with the highest possible degree of linguistic equivalence and/or adapted as appropriate. Comparable samples of each participating country's target populations should respond under conditions that are as similar as possible. Given consistent data collection (and sufficiently high response rates), results are likely to be comparable across countries. The results should reflect differences in patients' health outcomes and care experiences and not artefacts of methodology.
- **Precision:** Processes used in PaRIS should minimise the opportunity for bias or error. Both systematic and random errors must be reduced. Higher precision leads to higher quality results, more powerful statistical analyses, and more trustworthy evidence for policy.
- **Generalisability:** PaRIS is based on samples of primary care practices and their patients. It is essential that these samples accurately represent the target populations. In addition, questionnaire materials must be developed in a way that ensures conclusions are not limited to the context in which the data were collected but hold more broadly for the intended populations across countries.
- **Transparency and replicability:** PaRIS requires comprehensive documentation of all procedures, instruments, adaptations, and data processing steps. Full transparency ensures that methodological decisions are clearly understood, while replicability guarantees that analyses can be reproduced and verified. This strengthens the credibility of results and enhances their use for policy and research.

- **Timeliness:** PaRIS is a large and complex survey. Tight timelines and budgets, as well as the number of participating countries, preclude the option of developing and monitoring local solutions to be harmonised later. Therefore, the standards specify a clear and common path along which data collection, processing and submission should progress.

11. This document strives to establish a collective agreement of mutual accountability among participating countries as well as between the International Contractors and countries. It defines each standard and identifies how each standard's quality is assured. Quality assurance refers to the processes and procedures that check that PaRIS will meet its intended goals. Implementation of all standards set out in this document is mandatory for data to be included in the analyses. Recommendations are not mandatory; however, their implementation is strongly advised, and they are explicitly identified as recommendations.

12. This document does not describe in detail how each procedure (e.g. translation, sampling, data collection, coding) must be carried out. For these, the NPMs will receive a series of additional PaRIS survey operation manuals and guidelines to support the implementation of PaRIS in their respective countries.

13. Where standards have been fully met and the quality of the final database judged as appropriate, the data will be included in the PaRIS international database. Where standards have not been fully met or data quality is in question, an adjudication process will determine the extent to which data quality and international comparability have been affected, and whether additional analysis or evidence is required (see Section 8). Where standards are not met, data may be subject to partial exclusion from analyses and/or results may be flagged in the final report as not meeting the required standards.

1.2 Balancing standards with national contexts

14. Meeting the Technical Standards ensures the quality, cross-country comparability and policy relevance of the data. At the same time, countries vary in terms of healthcare systems, organisational structures, available resources, and legal or practical constraints. This means that in some circumstances, not all requirements can be fully met, and countries might need to consider alternative implementation options. In such cases, the OECD Secretariat and the International Contractors will work with NPMs to identify solutions that enable participation while remaining as close as possible to the agreed standards. These adaptations should always aim to minimise deviations from the common procedures, and all modifications must be fully documented.

15. Striking the right balance between international standardisation and adaptation to national circumstances is therefore an important principle of PaRIS. While consistency across countries underpins the validity of cross-national comparisons, flexibility ensures that diverse national contexts can be accommodated without compromising the integrity of the survey.

2 Purpose and scope of PaRIS

2.1 Purpose and scope of PaRIS

16. PaRIS assesses the performance of healthcare systems in delivering primary care by collecting internationally comparable indicators of patient-reported outcome and experience measures (PROMs and PREMs). PaRIS focuses on people living with chronic conditions who receive care in primary care settings and examines how healthcare delivery affects experiences of care such as co-ordination and communication as well as health outcomes such as daily functioning, well-being and quality of life from the patient perspective. By systematically measuring PROMs and PREMs and linking these data to characteristics of care delivery, PaRIS enables both cross-country comparison and within-country analysis of variation across healthcare practices. The initiative is designed to complement population-based health surveys by focusing on what happens once people are in contact with the healthcare system and by identifying concrete, actionable elements of healthcare associated with better or worse health outcomes and care experiences. PaRIS is designed to complement existing sources of health system information by focusing on what healthcare achieves for people, rather than on inputs, activity or service volumes.

Purpose

17. The purpose of PaRIS is to produce internationally comparable indicators of patient-reported outcomes and experiences of healthcare, with a particular focus on people living with chronic conditions receiving care in primary care settings. By doing so, PaRIS supports countries in assessing how healthcare delivery affects people's daily functioning, well-being and experienced health, and in identifying areas for policy and system improvement.

Policy objectives

18. PaRIS supports participating countries in pursuing four interrelated policy objectives:

- **1) Strengthening people-centred health systems**
  By systematically measuring outcomes and experiences reported by patients, PaRIS supports a shift towards health systems that are organised around people's needs, values and preferences.
- **2) Addressing information gaps in chronic care in primary care**
  PaRIS responds to long-standing gaps in internationally comparable data on outcomes and experiences of people living with chronic conditions, particularly in primary care, where most chronic care is delivered.
- **3) Supporting international benchmarking and mutual learning**
  PaRIS enables countries to compare performance with peers, identify variation in outcomes and experiences, and facilitate learning across countries facing similar challenges.
- **4) Providing actionable evidence for policy and practice improvement**
  By linking patient-reported data to characteristics of care delivery, PaRIS supports evidence-informed decision-making at policy, system and practice levels.

2.2 Measurement

19. PaRIS measures healthcare performance using two complementary types of patient-reported indicators:

- **Patient-Reported Outcome Measures (PROMs)**, which capture patients' assessments of the results of care, including physical, mental and social functioning, symptoms, pain, and well-being.
- **Patient-Reported Experience Measures (PREMs)**, which capture patients' experiences of care, including access, continuity, coordination, comprehensiveness, safety, people-centredness, communication, trust and support for self-management.

20. PaRIS indicators are internationally comparable, policy-relevant, and repeatable over time, enabling monitoring of performance and trends within and across countries.

2.3 Analytical focus

21. PaRIS focuses on people living with one or more chronic conditions who use primary care services. Analyses are designed to examine variation in patient-reported outcomes and experiences according to:

- the **number of chronic conditions**;
- the **combination (co-occurrence) of chronic conditions**, including physical and mental health conditions and their combinations;
- and **different population groups** with varying complexity of care needs.

22. The primary analytical emphasis of PaRIS is on understanding variation within the population of people with chronic conditions and on identifying care-related factors associated with better or worse outcomes and experiences. However, where relevant, comparisons with people without chronic conditions are also possible. Such analyses are enabled because the presence of a chronic condition is not a selection criterion; as a result, a proportion of the sample does not report having a chronic condition.

2.4 Scope and boundaries

23. PaRIS is **not** a general population health survey. It does not aim to measure the overall health status of the population or disease prevalence. These objectives are addressed through population-based health surveys, which provide essential contextual information on health, risk factors and access to healthcare.

24. PaRIS has a distinct and complementary scope. It focuses on people's actual experiences with healthcare and the outcomes associated with that care. Participation in PaRIS therefore requires that respondents have had contact with healthcare services. People who do not access healthcare are not included by design.

25. This boundary reflects the specific analytical purpose of PaRIS: to examine what happens once people are in contact with the healthcare system, and to identify concrete elements of care delivery that are associated with variation in patient-reported outcomes and experiences and that are amenable to policy and practice-level action.

Within-country and cross-country analysis

26. PaRIS is designed to support both cross-country comparisons and within-country analysis. Through its nested design, which links patient-reported data to the primary care practices where care is delivered, PaRIS enables analysis of:

- variation in outcomes and experiences across healthcare practices within countries;
- associations between practice-level characteristics and patient-reported results; and
- the contribution of organisational and system-level factors to observed variation.

27. By combining PaRIS data with information from national surveys and administrative data sources, countries can develop a more comprehensive understanding of health system performance, linking evidence on who accesses care with evidence on how care is experienced and what outcomes it delivers.

Focus on primary care and people with chronic conditions

28. PaRIS focuses on people living with chronic conditions and on care delivered in primary care settings. This focus reflects both the organisation of care for chronic conditions and the specific information gap PaRIS is designed to address.

29. Much of the existing patient-reported outcome measurement infrastructure is centred on specific diseases and on hospital-based care, often using condition-specific PROMs applied in specialist or acute care settings. These instruments provide essential and detailed information for clinical management and disease-specific quality improvement.

30. However, most people living with chronic conditions spend most of their time outside hospitals, receiving care in the community, and a substantial share live with multiple chronic conditions. For these individuals, outcomes and experiences are shaped not only by disease-specific treatment, but also by how well care is coordinated, continuous, people-centred and supportive of daily functioning across conditions and care settings.

31. PaRIS therefore adopts a whole-person approach, focusing on outcomes and experiences that cut across conditions rather than on disease-specific clinical endpoints. This design allows PaRIS to capture how people experience care as a whole, including the cumulative impact of managing multiple conditions over time.

32. As a result, PaRIS does not aim to replace condition-specific PROMs, for example, instruments designed for people with a particular type of cancer, cardiovascular disease or diabetes. Instead, it complements such instruments by providing a broader, cross-cutting perspective on care quality and outcomes in primary and ambulatory care. In this sense, PaRIS prioritises breadth rather than depth, enabling international comparison and system-level learning on how care is organised and delivered for people living with chronic conditions.

3 Governance and planning

3.1 Introduction

33. The Second cycle of PaRIS has three main phases: design and development (2025-2026), Field Trial (2027-2028) and Main Survey (2029-2030). During the design and development phase, PaRIS implementation guidelines and survey instruments (questionnaires) are being prepared. During the Field Trial phase, the survey design and the instruments are tested in a small sample of primary care practices and patients in the participating countries. Building on the results from the Field Trial phase and incorporating the necessary adjustments, during the Main Survey, PaRIS is fully implemented and the actual data collection for international comparison is carried out. Each phase is essential for the successful implementation of PaRIS in the countries.

34. The NPMs are responsible for the implementation of PaRIS in their respective countries (see section 3.3 for more about the roles and tasks of NPMs). To document how PaRIS is (planned to be) implemented in the country, the NPMs draft a country roadmap (see section 3.6) which details how PaRIS Technical Standards, survey operation manuals and guidelines are employed in the country and how the implementation is planned. In addition, the NPMs also draft plans for sampling, translation and adaptation, and data protection impact assessment which detail each of these implementation points for their respective country. The work of the NPM and the collaboration with the Secretariat and the international contractor(s) in a timely manner will be crucial in ensuring international standards are met within the national context.

3.2 Governance bodies and International Contractors

35. The governance of PaRIS Cycle 2 is shared between the Secretariat and the OECD countries. At the highest level, the OECD Health Committee is the body under which PaRIS is mandated (Figure 3.1). It approves the overall direction of the survey. The Working Party on the Patient Reported Indicator Surveys (WP-PaRIS), a subsidiary body under the Health Committee, steers the project on a technical level[1]. The WP-PaRIS is composed of delegates from the OECD member countries and non-member participating countries and must approve all major decisions on survey design, implementation and reporting. In this way, countries have full ownership of the work and play a central role in steering it.

36. The Secretariat is responsible for developing and enforcing Technical Standards, monitoring compliance, and overseeing quality assurance. It also conducts data adjudication and considers requests for derogations.

37. The Secretariat works in close collaboration with International Contractors, who support technical aspects including translation of the PaRIS questionnaires, data collection platforms, verification services,

[1] All mandates for official OECD bodies can be found in the bodies guide: https://oecdgroups.oecd.org/Bodies/ListByNameView.aspx?book=true

and technical support. International Contractors also conduct cross-country quality control, data integration, and weighting, with specific tasks being delegated to NPMs.

Figure 3.1. Governance structure of PaRIS cycle 2



Note: Four types of relations among the various actors exist: 1. Formal responsibility for appointing country representatives and National Project Managers (indicated by white arrows); 2. Formal reporting responsibility (indicated by green arrows); 3. Technical support (indicated by yellow arrow); 4. Advisory role (indicated by grey arrows). The Secretariat will facilitate the interactions between all parties.
Source: Authors.

3.3 National Project Manager (NPM)

38. Each participating country must appoint an NPM, who serves a focal point to the Secretariat and the International contractors. The NPM is responsible for the preparation and implementation of PaRIS in their respective country and can work with an NPM team in their country. The NPMs prepare essential documents such as the Country Roadmap, the Sampling Plan, the Translation and Adaptation Plan, the Fieldwork Quality Control Plan, and the Data Protection Impact Assessment. The NPM also coordinates the production of fieldwork reports and the weighting and estimation report.

39. The NPM will in many cases be affiliated with the Survey Institute (see 3.4).

40. A detailed task profile for the NPM is included in Annex A.

3.4 The Survey Institute

41. Countries are expected to partner with an organisation with proven experience in large-scale surveys in their country (hereinafter the Survey Institute) to implement the survey. The Survey Institute should have expertise in (probability) sampling, respondent recruitment, mixed-mode data collection, case management, data security, and quality control. In most cases, the NPM will be employed with the Survey Institute. Subcontracting is permitted, but the NPM must retain overall accountability.

42. Survey Institutes can be either governmental institutes, independent research institutes, universities, or other public or private service providers.

3.5 Timeline, training and Field Trial

43. To ensure smooth progress, NPMs must attend international NPM meetings and training sessions. They must also respect the PaRIS timeline, which includes submission of all planning documents, a Field Trial (unless waived for country-specific reasons), and the timely delivery of data and reports. Only after the Field Trial has been cleared can a country proceed to the Main Survey.

44. A Field Trial is mandatory. The Field Trial or elements of it can be waived if the participating country has participated in cycle 1 and can demonstrate that all elements of the survey execution have already been tested sufficiently during cycle 1. Cognitive testing of survey instruments should be conducted in all cases. There are no mandatory sample sizes for Field Trials, this will be decided together with participating countries on a case-by-case basis.

3.6 Country Roadmap

45. A Country Roadmap (CRM) is a national implementation plan developed by each country participating in PaRIS. This document serves as comprehensive and detailed action plans that outline all the necessary steps for the successful implementation of PaRIS within a specific national context. Building on the template provided by the Secretariat, NPMs will prepare the country roadmaps for their respective countries. The first version of the CRM applies to the Field Trial. Based on Field Trial results, the CRM may be updated to apply to the Main Survey.

46. The CRM details:

- who does what and when;
- how the Technical Standards and Survey Operation Manuals are translated into national contexts, including sampling, recruitment, reach out, modes of data collection and stakeholder engagement;
- eventual deviations from the Technical Standards and why these are necessary and what expected consequences of these deviations are.

47. CRMs will be created in several iterations with the support of the International Contractors and will follow a strict template (provided by the Secretariat).

48. Data collection can only start after that the Secretariat has approved the CRM. To give enough time for the review and revision process (when deemed necessary), the NPM will share the final version of the country roadmap, for approval, at least 4 weeks before the data collection starts. The details regarding the iterative development process and interim deadlines for review and approval of each section will be further detailed in the respective guidelines, to be provided by the Secretariat. Timely and thorough review and revision of the country roadmaps will minimise the risk of excluding the country's data from the final analysis or be flagged in the report for not fulfilling the standards; this will guarantee data quality for international comparability.

49. All instructions in the following sections regarding sampling and data collection apply to the Field Trial as well as the Main Survey unless otherwise indicated.

3.7 Communication with the Secretariat and the International Contractor

50. Each country will designate the NPM as the single point of contact for all communication about technical issues. Queries from the Secretariat or the International Contractors will be answered within agreed periods. Additionally, each country must designate a delegate to the WP-PaRIS who can speak on behalf of the country. The delegate can be the NPM or another official from the country. If not the same person, the NPM and the delegate should ensure all materials and decisions are communicated accordingly.

3.8 Adjudication and derogations

51. Inclusion of national data in the international database and analyses depends on adherence to these Technical Standards.

52. An adjudication process will be used to decide on inclusion and exclusion of data and on decisions on including disclaimers on specific countries. During the adjudication process, the data from each participant will be evaluated against all standards jointly. This process includes considering factors beyond the control of the NPM, such as a national strike or pandemic. Where agreement between NPMs and the international contractors cannot be reached, the Secretariat will adjudicate and make a final decision.

53. See Section 8 for a detailed explanation.

4 Sampling and Data Collection

4.1 Purpose and principles

54. The sampling and data collection procedures for PaRIS are designed to ensure the production of high-quality, reliable, and internationally comparable data on the outcomes and experiences of people living with chronic conditions, who are managed in primary care. The methodology must ensure that results are representative of the target populations in each participating country and enable valid cross-country comparisons.

55. Key principles guiding the sampling and data collection for PaRIS include:

- **Probability-based sampling** of both primary care practices and patients to ensure representativeness of the target population.
- **Transparency and accountability** in all sampling and recruitment procedures.
- **Adaptability to national contexts** while maintaining strict adherence to standards.
- **Consistency across countries** to enable valid international comparisons.
- **Inclusivity** by ensuring that people with chronic conditions are appropriately represented in the survey.
- **A multilevel design** that links data from patients and their corresponding primary care practices to enable analysis at both levels.

56. To improve efficiency and minimise respondent burden, NPMs should actively coordinate, and where feasible work jointly, with national statistical agencies to align survey activities (including sampling, recruitment, etc.) and avoid duplication at the national level.

4.2 Multilevel structure and linkage

57. PaRIS employs a multilevel survey design, where patients are nested within primary care practices, which are nested in countries. This design is essential for understanding how characteristics of primary care practices relate to the outcomes and experiences of patients living with chronic conditions.

58. Maintaining the linkage between patients and their primary care practices is an essential requirement of PaRIS. All data collection processes must ensure that:

- All patient's data are linked to the practice-level data of the practice where they receive care.
- The multilevel structure is preserved in the final datasets to enable appropriate statistical analyses (e.g., multilevel modelling).

4.3 Target populations

Primary Care Practices

59. A primary care practice is an organisational unit responsible for the delivery of first-contact, continuous and co-ordinated primary care services to a defined patient population and must be involved in the management of chronic conditions (for example, through regular check-ups, long-term prescribing and co-ordination of care).

60. A primary care practice may operate from one or multiple physical locations (sites) and may consist of one or more healthcare professionals working together. The defining feature of a primary care practice is the existence of organisational arrangements and patient management, rather than a single physical site or building.

61. A primary care practice, as defined for the purposes of this study, does not necessarily correspond to a single legal entity or a single physical building. Practices may be embedded within larger organisations or may operate across multiple physical locations, provided they share responsibility for patient care.

62. *Example 1:* a large primary care organisation or chain may operate primary care practices in different cities or neighbourhoods. In such cases, each primary care practice should be considered a separate primary care practice if care is delivered by distinct teams with their own organisation of day-to-day clinical work, even if they belong to the same legal entity.

63. *Example 2:* A group of primary care professionals (e.g., general practitioner/family doctor, nurse, midwife, physiotherapist, nutritionist) operating across multiple buildings may be considered one practice if it functions as a single clinical unit serving a shared patient population.

64. *Example 3*: two or more general practitioners/family doctors operating in the same site, but have distinct clinical information systems, have their own organisation of day-to-day work, and do not share a patient population or practice staff may be considered different primary care practices.

65. In cases where the boundaries between one or more primary care practices are unclear, the final determination of what constitutes a practice for the purposes of this study will be made jointly by the Secretariat and the NPM. Such decision will be guided by the questions and their relevant subdomains in the PaRIS primary care practice questionnaire.

Examples of eligible practices:

- General practices (GP) or family medicine practices
- Group practices or health centres in the primary care settings where patients receive continuous chronic care management
- Practices that serve as the first point of contact and provide continuity of care for patients with chronic conditions

Examples of non-eligible practices:

- Specialist outpatient clinics (e.g. cardiology, oncology, dermatology)
- Pharmacies
- Diagnostic centres that only perform tests or screenings
- Urgent care or walk-in centres providing episodic treatment without follow-up
- Healthcare professionals, practices, and establishments that focus exclusively on a specific condition, organ system, or episodic/one-off care.
- Single-service providers (e.g. vaccination-only centres, dialysis units)

- Paramedical practices limited to one category of health problems (e.g. dental clinics, physiotherapy practices, speech therapy centres)
- Intramural settings such as nursing homes, long-term care facilities, rehabilitation centres, or other residential care institutions

66. The unit of participation is the primary care practice as an organisation unit, not individual healthcare professionals. Data collection concerns the characteristics of the practice and how care is organised. NPM should prepare a detailed description of the care units considered as primary care practices – including their original names in the native language and their main characteristics –in the Country Roadmap.

Patients

67. The patient population consists of individuals aged 45 years and over who have had a contact with the participating primary care practice within the 12 months preceding the moment of sampling. This contact can be in-person, online, by telephone for any reason including administrative purposes (e.g. repeated prescription, medical certificate).

68. To ensure that participating patients have a significant attachment to the practice:

- The patient is expected to receive ongoing or continuous care from the practice or is supposed to be under such care if needed.
- In some health systems this means that the patient is formally listed or registered with the practice.
- Patients who only have one-off or incidental contacts (e.g. a tourist or visitor receiving care during travel, or someone attending once for an urgent issue without follow-up) or a second opinion are not eligible.

69. Institutionalised patients (e.g. nursing homes, long-term hospitals) should not be excluded if they meet all other eligibility criteria. institutionalised individuals are eligible ***only if*** they are still on the practice list / receive chronic care management from the practice. For example, a might continue receiving care from their usual primary care professional for chronic care management after moving to a nursery home. However, samples should not be drawn in such institutional settings.

70. The size and characteristics of institutionalised populations vary substantially across countries. On this basis, decisions on the inclusion or exclusion of institutionalised patients may be made on a case-by-case basis at country level. Any such decision must be clearly documented and justified by the NPM, including an assessment of implications for representativeness and international comparability.

71. Eligibility is not conditioned on diagnosis; chronic condition status is measured via the questionnaire and used analytically.

Patients under 45 years

72. **Recommendation:** include a supplementary sample of patients between 18 and 44 years old in the data collection.

73. While the PaRIS target population is aged 45 years and older, country delegates may choose to draw an additional sample of younger patients (under 45 years). Including this younger group can provide insights into the experiences and outcomes of younger adults, for example those living with early-onset chronic conditions, or to allow further comparisons across age groups. Such an additional sample is optional and outside the mandatory international design. However, given the many younger people who live with chronic conditions, it is encouraged to include such supplementary samples.

74. While minors often live with chronic conditions and this deserves policy attention, it is not advised to include minors in the survey as the questionnaires were only designed for adults and making them suitable for minors would require substantial revision.

75. Patients under 45 do not count for the sampling targets (see sample size requirements).

4.4 Sampling design

76. It is recommended to sample patients and primary care practices independently based on the registers/lists, where possible. Such sampling approach must ensure that the linkage between the patient and their primary care practice can be established afterwards.

77. When the lists are not available or such independent sampling approach is not possible, sampling takes place on two levels; first primary care practices will be sampled, then patients in these practices.

Sampling of primary care practices

78. NPMs must establish a probability-based sampling frame of eligible primary care practices, this should be a complete, deduplicated list with identifiers and stratifiers ensuring that each practice has a known, non-zero probability of selection.

79. The stratifiers should include at least practice type (categories based on common types in the country, for example solo/group) and geographical region (granularity based on possibilities, e.g. province, region). Other examples of stratifiers are urbanicity, size of the population, and ownership (such as public/private). The exact list will be specified in the Country Roadmap.

80. **Recommendation**: Sampling frames may be constructed using national registers, administrative data, or other reliable sources.

81. The sampling of practices must:

- Reflect the diversity of primary care settings in the country, such as solo/group or public/private.
- Meet the PaRIS target sample size and be sufficient in size to produce robust national estimates and enable multilevel analyses.

82. Because there are significant differences in relevant stratifiers for practices between countries, the relevant and feasible stratifiers will be determined in accordance with each country.

83. Sample size requirements for primary care practices in the Main Survey will be determined by the Secretariat, based on statistical power calculations, anticipated response rates, and the need for valid cross-country comparisons.

84. Sample size requirements for practices in the Field Trial will be determined jointly by the Secretariat and the participating country.

85. Practices that have been included in the Field Trial remain eligible for inclusion in the Main Survey, provided that a new patient sample is drawn. Patients who participated in the Field Trial must not be included again in the Main Survey.

86. Practices not selected in the Main Survey but volunteering to participate without invitation may be included in the sample. However, such practices do not count towards the sampling targets and must be flagged in the databases as *volunteering practices.*

87. If certain categories of practices that meet the eligibility criteria are nevertheless excluded from the sampling frame, for example because their data are not accessible or they are part of a supplemental healthcare network not eligible for public reimbursement, this must be explicitly documented and explained in the CRM.

Sampling of patients

88. Patients must be sampled using probability-based methods that ensure each eligible patient has a known, non-zero chance of selection. Countries may implement two alternative approaches, depending on their national data infrastructure:

Option 1: Direct sampling from national or regional registers (preferred approach)

89. This approach is preferred as it is more efficient, minimizes burden on practices, and reduces the risk of bias.

- In countries with comprehensive national registers (e.g., health insurance databases), patients can be sampled directly from these databases. It is required that such registries enable a link between patients and participating practices.
- The corresponding primary care practices must complete the practice questionnaire, but do not need to facilitate patient sampling. Instead, sampling of patients is done directly within patients linked to the participating practice through the registry.
- The number of completed patient questionnaires linked to primary care practices should meet the sample size targets for both patients and primary care practices and be representative of the diversity of the population/primary care practice in the country.

90. When patients are sampled directly, it is possible that their primary care practice is not responding to the practice questionnaire. In such cases, the practice has missing values in the data, but patients can still be linked to that same practice. Eventually, some basic information that is available in the data can be included about the practice, such as practice type or geographical location.

Option 2: Sampling through primary care practices

- In countries without national registers, or where these are not accessible, patients must be sampled within participating primary care practices using random sampling methods.
- To do so, practices should be able to provide a complete list with eligible patients to serve as sampling frame, ideally by age and sex on practice level.
- Patient privacy, ethical standards, and applicable legal requirements must be fully respected. Where practices are unable to share identifiable patient lists due to legal, ethical, or privacy constraints, alternative approaches must be used that ensure equivalent protection of personal health information.
- In such cases, participating practices may conduct patient recruitment themselves, following detailed instructions provided by the NPMs to ensure random or systematic selection, minimise selection bias, and reduce practice workload.
- Sampling never takes place on-site (such as in the waiting rooms or through links/QR codes in the practice) as this will create a bias towards more frequent attenders.
- Practice staff must not influence in any way which patients are selected. However, they may review the generated sample lists to request the removal of specific individuals only for compelling reasons, such as:
  - The patient is in a palliative stage of care.
  - Participation would be too burdensome or inappropriate (e.g., severe cognitive impairment, recent bereavement).

91. NPMs shall log and code all exclusions, with a reason provided for each excluded case. The NPMs should record these exclusions in the fieldwork documentation.

92. If certain categories of patients that meet the eligibility criteria are nevertheless systematically excluded from the sampling frame, for example because their data are not accessible, this must be explicitly documented and explained in the CRM.

93. NPMs shall ensure that the participating practices remain representative of the diversity of primary care practice in their respective country.

4.5 Target sample sizes and response rate thresholds

General principle

94. Two distinct requirements apply to sample design and data inclusion:

- a) minimum numbers of valid responses (**absolute numbers**); and
- b) minimum and target response rates (**percentages**).

95. Minimum numbers of valid responses ensure sufficient statistical power and cross-country comparability. Response rate thresholds serve to safeguard data quality and reduce the risk of non-response bias. These requirements apply independently and meeting one requirement does not imply that the other has been met. Both conditions shall be satisfied for inclusion in the analytical dataset.

Minimum number of practices

96. The minimum number of primary care practices with valid linked patient data required per country depends on:

- the total number of eligible primary care practices available;
- the need to support stratification (e.g. solo/group, urban/rural, public/private); and
- the objective of producing robust and comparable country-level estimates.

97. Table 4.1 specifies the minimum number of practices required by country tier.

Practices shall be counted towards the required minimum only if they meet the patient-level requirements specified in the following sections.

Table 4.1. Target numbers per country tier

Country tier	Number of eligible practices in the country	Minimum number of practices required	Minimum number of patients required
1	<100	50% of population (practice-level census)	50 × number of practices
2	101–1000	100	5 000
3	1001–5000	150	7 500
4	5001 or more	200	10 000

Minimum number of patients per practice

98. For each participating practice there should be a minimum of **50 completed and valid patient questionnaires** that can be linked to that practice. This means that the minimum number of valid patient responses required at **country level** is calculated as:

- (Minimum number of practices required) × 50

99. Practices with fewer than 50 valid patient responses shall not count towards the required number of practices.

100. Patient questionnaires without a valid linked practice response shall not count towards the required patient sample size. Such cases may be retained for supplementary analyses (e.g. assessment of non-response bias), subject to Secretariat guidance.

Response rate thresholds (percentages)

101. Response rates refer to **the proportion of invited units** (practices or patients) that provide a valid response.

Target practice response rate

102. "Practice response rate" refers to the proportion of invited practices that participate in the survey, defined as practices that both complete the practice questionnaire and allow patients registered with them to be sampled for the patient survey (if approval from the practice is needed). NPMs shall aim to achieve a practice response rate of **at least 50%**. This target shall be reflected in the national recruitment strategy and country roadmap.

103. The minimum acceptable practice response rate is **10%**. Countries failing to meet this threshold may be excluded from the main analytical dataset and/or from cross country comparative analyses, or included in reports with methodological disclaimers regarding representativeness, subject to review by the Secretariat. Replacement practices may be used, provided that:

- the replacement procedure is specified in advance in the national sampling plan;
- the procedure preserves the probabilistic nature of the sample; and
- full documentation is provided to the Secretariat.

Target patient response rate

104. "Patient response rate" refers to the proportion of invited patients that completed at least 90% of the patient questionnaire. NPMs shall aim to achieve a patient response rate of **at least 50% within practices**. This target shall be reflected in the national recruitment strategy and country roadmap. The minimum acceptable patient response rate is **20%**. Practices failing to meet this threshold may be excluded from the main analytical dataset and/or from cross country comparative analyses, or included in reports with methodological disclaimers regarding representativeness, subject to review by Secretariat.

105. Replacements could be used under the same conditions as for replacement practices.

The two requirements combined

106. Table 4.2 provides fictional examples of four practices to clarify the application of the dual patient-level requirements set out in the sections above.

107. Both of the following conditions must be met for a practice to qualify for inclusion in the analytical dataset:

- a) at least 50 completed and valid patient questionnaires; and
- b) a patient response rate of at least 20% within the practice.

Table 4.2. Examples of application of thresholds for minimum numbers of patients and response rates

Practice	Patients invited	Completed questionnaires	Response rate	= 50 completed questionnaires?	= 20% response rate?	Eligible for inclusion?
A	120	60	50%	Yes	Yes	**Yes**
B	80	10	12.5%	No	No	**No**
C	40	20	50%	No	Yes	**No**
D	500	60	12%	Yes	No	**No**

4.6 Preserving the multilevel linkage

108. Regardless of the sampling approach, the link between patient and practice data must be maintained to allow multilevel analysis of the final dataset. NPMs must ensure that:

- Each patient record is associated with the correct practice identifier.
- No data processing or anonymisation step breaks the linkage between levels.
- The final dataset enables multilevel analyses (e.g., patients nested within practices, practices nested within countries).

4.7 Reporting background characteristics of the eligible population

109. For the calculation of an international standard population, it is necessary to know the age and sex distribution as well as the total number of inhabitants in the eligible patient population in each country. Table 4.3 shows an example of how this distribution could look like.

Table 4.3. Example of age-sex distribution in eligible population

		% of patients in eligible population
Sex	Men	45%
	Women	55%
	other	<0.1%
Age	45-54 years	25%
	55 – 64 years	28%
	65 – 74 years	27%
	75+ years	20%

110. As the eligible PaRIS population differs from the general population, in several countries the age-sex distribution of the eligible population may not be readily available. In this case, there are the following alternatives to calculate a proxy for the age-sex distributions of the eligible population, the order is from most to least desirable:

- 1: Calculating the age-sex distribution of the total **sampling universe**[2]
- 2: Calculating the age-sex distribution of the total **sampling frame**

[2] Sampling universe refers to the full population of interest to which survey results are intended to be generalised (i.e. all individuals meeting the eligibility criteria in the target population during the reference period). The sampling frame is the operational list or database from which eligible individuals can be identified and selected. The sample comprises the individuals selected and invited to participate, and respondents are those who provided usable survey data.

- 3: Calculating the age-sex distribution of the **sample** (to do this, sex and age of non-responders must also be recorded)
- 4: **modelling** the age-sex distribution of the sampling universe or sampling frame by combining population statistics and statistics about primary care contacts from representative sources.
- 5: Calculating the age-sex distribution of the valid **responders**

111. The last option is the least desirable option; it does not enable the calculation of a national standard population and is of little value in the calculation of the international standard population. Moreover, sample representativeness cannot be assessed against a more comprehensive reference population, such as the target population or the sampling frame.

5 Recruitment and fieldwork

5.1 Introduction

112. Recruitment and fieldwork are critical phases and must be carried out in a way that secures sufficient participation while ensuring comparability across countries. The quality of the final dataset depends heavily on the ability to engage primary care practices and patients, and to document every step of the recruitment, reach out and data collection process.

5.2 Recruitment of practices

113. The recruitment of practices should be based on a comprehensive strategy that combines different forms of engagement, including:

- endorsement by relevant authorities and opinion leaders;
- outreach through professional organisations and practice champions;
- personalised contacts, follow-up and reminders by email, telephone, postal or in person, and the provision of clear and accessible information about the study;
- incentives (financial or non-financial) may be used where national legislation allows, but even in such cases they should not replace the need for direct and personalised engagement.

114. To support recruitment, NPMs will prepare a package of communication materials that includes advance letters, frequently asked questions, explanations of expected workload, and data privacy notices. The templates in English will be provided by the Secretariat. Practices should also have access to an escalation channel if they need additional information before deciding whether to participate.

115. **Recommendation:** It is advisable to create a national website with this information with accessible contact information.

116. Burden on practices in terms of time, energy and resources should be as minimal as possible. Wherever possible, NPMs should rely on national registers for sampling patients, use automated extraction of patient lists, and centralise mailing services. This ensures that practice staff are not asked to carry out time-consuming tasks that may hinder their willingness to participate.

117. A minimum typical contact strategy for primary care practices would look as follows:

- Contact day 0: Pre-notification letter / email from professional organisation endorsing the study
- Contact day 1: Initial recruitment email/letter from the NPM introducing the study, estimated time investment, a link to the survey, and next steps
- Contact day 3: Follow-up telephone call to emphasise importance of participation to improve quality of care, reinforce confidentiality and privacy, and provide further information. This should be done only to those practices that have not yet responded to the survey,

- Contact day 7: Follow up SMS/email to mention declining window for participation, reinforce the importance of participation and support recruitment. If possible, this should be sent only to those practices that have not yet participated in the survey.
- Contact day 14: Reminder if necessary, by either phone call, SMS or letter / email

118. A census approach to the recruitment of practices is not permitted, as it is likely to result in low response rates and does not allow for the use of personalised, high-impact recruitment approaches (for example, individual letters or telephone contact). An exception may be made for countries with fewer than 100 eligible primary care practices, subject to agreement with the Secretariat, and should be appropriately documented.

5.3 Recruitment of patients

119. Patients must be recruited in a way that guarantees transparency, voluntary participation, and informed consent. Contact with patients should be made using multiple channels, such as paper letters or invitations via email and SMS.

120. A minimum typical contact strategy for patients would look as follows:

- Contact day 0: Pre-notification letter / email from professional organisation and/or patient organisation endorsing the study
- Contact day 1: Initial recruitment email/letter introducing the study, estimated time burden, voluntary participation, include link to the survey, and next steps
- Contact day 3: Follow-up telephone call, to those that have not yet participated, to emphasise importance of participation to improve quality of care, reinforce confidentiality and privacy, and provide further information about the next steps including alternative modes of data collection (paper and/or telephone)
- Contact day 7: Follow up SMS/email, to those who have not yet participated, to mention declining window for participation, reinforce the importance of participation

121. **Recommendation:** If possible, the national primary care professional organisation's and/or national patient organisation's endorsements of this study should be explicitly mentioned.

122. Alternatives such as paper questionnaires and telephone support must be available to ensure inclusiveness. Clear eligibility confirmation procedures must be in place, and all information materials should make explicit the purpose of the survey, the voluntary nature of participation, and the safeguards for data protection.

123. Patients can never be recruited on-site in the waiting room or with an online link/QR code put at the waiting rooms or by primary care practice staff (see also section 4.4).

5.4 Case management and documentation

124. Every country must operate a national Case Management System (CMS) that tracks each contact with practices and patients. The CMS should allow for real-time monitoring of recruitment, participation and follow-up, and must record the outcome of each contact using a harmonised set of disposition codes. These codes, which were tested and applied in Cycle 1, distinguish between categories such as complete, partial, refusal, ineligible, and unknown eligibility. Maintaining this documentation in a consistent manner is essential for transparency and for conducting subsequent analyses of response rates and non-response bias.

125. For data that are collected centralised via the international survey platform, contacts will be tracked with the International Contractor's CMS. In countries that collect data decentralised (See also 5.7), NPMs send reports every two weeks during the recruitment period and data collection to the International Contractor.

5.5 Training and supervision

126. The Secretariat and the International Contractor will provide training to NPMs regarding the implementation of PaRIS in their respective countries. All staff involved in fieldwork, including helpdesk staff and interviewers for telephone follow-up, must receive training before the start of data collection. During fieldwork, NPMs must implement continuous supervision mechanisms, including back-checks, call monitoring, and review of paradata.

127. NPMs should intervene promptly when problems arise, and corrective actions must be documented. This ensures that standards are adhered to throughout the entire period of fieldwork, and that deviations are identified and addressed quickly.

5.6 Modes of data collection

128. PaRIS has two questionnaires: one for the participating patients (PaRIS Patient Questionnaire) and one for the primary care practices (PaRIS Primary Care Practice Questionnaire). The primary mode of data collection for PaRIS is online.

129. When countries conduct decentralised data collection through their national platforms (see also 5.7): NPMs must implement an online survey system that is:

- Accessible via computers and mobile devices.
- Designed according to user-friendly and inclusive standards.

130. The Secretariat will provide countries that opt for centralised data collection access to an online survey system.

131. For patients who are unable or unwilling to complete the survey online, a paper-based questionnaire and / or telephone survey must be offered as an alternative.

132. Where necessary, Computer Assisted Telephone Interviewing (CATI) may be used to ensure inclusivity. For all telephone surveys:

- Specifically adapted versions of the questionnaire must be developed to account for mode effects (e.g., simplified skip patterns, interviewer scripts).
- These adaptations must be reviewed and approved by the Secretariat to ensure consistency.

133. Countries that can demonstrate that telephone surveying is the most appropriate option in their context may, subject to approval, use it as the primary mode of data collection, provided that full comparability with other data collection modes is ensured in terms of questionnaire design, sampling procedures, and data quality standards, and must clearly specify how response rates are recorded and calculated.

134. Countries that use telephone surveying besides other modes of data collection must test this in the Field Trial.

5.7 Centralised and decentralised data collection

135. PaRIS allows for both centralised and decentralised modes of data collection.

- **Centralised data collection:** In this approach, the International Contractor provides a common survey platform for all participating countries. Patients receive their survey ID, log in to the platform, and complete the questionnaire online. The data are stored directly and securely on the contractor's central server, regardless of the country of the respondent. This ensures maximum uniformity in data handling, security, and processing.
- **Decentralised data collection:** In this approach, participating countries use their own online survey systems to administer the questionnaire, collect responses, and manage the initial database. Once data collection is completed, the national database is transferred in full to the International Contractor for processing and integration into the international database. Whenever data are collected on paper or by telephone, this is a decentralised mode of data collection.

136. Both approaches are acceptable within PaRIS, but the choice of mode may have implications for the security measures and timeliness of the data. Clear documentation of the chosen approach is therefore required. Decentralised platforms must meet a set of criteria that will be provided by the International Contractor. To avoid problems with merging the data to the central database and ensure good quality of data, NPMs shall provide a dummy dataset and have this approved before data collection starts.

5.8 Quality assurance in data collection

137. NPMs must implement robust quality assurance procedures based on the quality assessment criteria in line with the OECD Statistical Quality Framework (Annex B), as well as the following process-related criteria:

- A practice sampling frame approved by National Statistics Institute or other national data authority or verified with statistics of such an institute.
- Pre-testing and cognitive testing of instruments, including all modes of data collection.
- Comprehensive training for all personnel supporting practices and data collection.
- Clear communication materials for practices and patients, including Frequently Asked Questions (FAQs) and support channels.
- Monitoring of fieldwork progress, response rates, and data quality in real time.
- Verification procedures for sampling and data collection processes.

138. NPMs will receive detailed instructions and manuals for these procedures through the International Contractors.

5.9 Response rates and minimizing bias

139. Countries shall strive to achieve **response rate targets** for the Main Survey for both primary care practices and patients (See section 4.5). Strategies to maximise participation include:

- Clear communication and engagement with practices and patients at an early stage.
- Creation of a national steering group that includes relevant stakeholders such as national medical organisations and patient organisations.
- Follow-up reminders and outreach.
- Provision of accessible survey materials.
- Monitoring of response rates and proactive intervention to address issues.
- (financial) incentives

140. NPMs shall submit and log:

- Achieved response rates at both levels.
- Documented reasons for exclusions from patient lists.

5.10 Proxy-respondents

141. In cases where patients are unable to complete the questionnaire themselves, the use of a proxy respondent is permitted. A proxy respondent should typically be someone close to the patient, such as a spouse, family member or an informal caregiver. At the end of the questionnaire, there is a specific question that asks whether it was completed by the patient or by a proxy respondent.

5.11 Combination with other studies

142. At the time of completion, respondents, whether practices or patients, should only be asked to fill out the PaRIS questionnaires. It is not permitted to combine the PaRIS questionnaire with other studies or survey instruments. Nevertheless, PaRIS allows countries to add a few questions to detail some aspects at their national context. Such additional national questions must be in the approved final version of the questionnaire and will be placed in a standard location in the questionnaire for which a place holder will be included in the source questionnaire.

143. NPMs should communicate all suggested changes to the PaRIS questionnaires to the International Contractor or the Secretariat and await approval from the Secretariat.

144. Using sampling frames from other (national) data collection infrastructures is possible as long as questionnaires are not combined.

5.12 Stakeholder engagement

145. NPMs should support implementation by structured, active stakeholder engagement, not limited to one-way information provision. Evidence from the PaRIS Field Trial and associated OECD analyses shows that stronger engagement improves feasibility (especially participant recruitment), increases patient participation, and strengthens the relevance, ownership and downstream use of results.

146. NPMs conduct a stakeholder mapping/analysis for their country and detail its outcomes in the country roadmap. Based on the outcomes of the stakeholder exercise, NPMs should establish (or repurpose) a national PaRIS stakeholder advisory group with a clear mandate. Such an advisory board should include at minimum representatives from primary care professionals and their organisations and patients with lived experiences and their representatives.

147. Where relevant, NPMs may also invite representatives from other areas, including in the field of data/IT and survey operations, communication experts, data privacy experts, local authorities, academics, payers and insurers.

148. The stakeholder group should engage in the full cycle of PaRIS, from design, implementation to interpretation of findings and dissemination. The group may advise on any relevant topics, to be decided by the NPM of the country, including reach out to practices and patients, inclusion of disadvantaged groups, and identifying priority areas for national and international analyses.

149. NPMs may decide on the mode of meetings (in person, online or hybrid), as well as the frequency of them as relevant for their country context.

6 Documentation and Reporting

6.1 Countries must provide the following to the Secretariat:

- Contact details of the NPM (name, surname, affiliation, function) (provided by the signing authority in the Participation Agreement). Any changes to the NPMs should be communicated timely to the Secretariat and the International Contractor.
- A Country Roadmap for the Field Trial following the template provided by the Secretariat
- A revised Country Roadmap for the Main Survey, when needed
- Before the data collection is conducted, for countries that opt for decentralised data collection: a dummy dataset (Field Trial and Main Survey)
- Before data collection is conducted, a Sampling Report detailing design, sources, methods, and any eventual deviations (Field Trial and Main Survey) following the template provided by the Secretariat
- A Fieldwork Report describing data collection procedures, challenges, response rates, and exclusions (Field Trial and Main Survey) including a weighting and estimation report following the template provided by the Secretariat
- Questionnaire Adaptation Spreadsheet documenting any changes, additions or deletion (Field Trial and Main Survey) following the template provided by the Secretariat
- Final cleaned datasets, preserving the multilevel structure, according to the PaRIS data specifications.
- Paradata documenting for survey participant, starting and ending time, dropouts, completion time, etc.

150. All documentation must ensure transparency, traceability, and reproducibility of the survey process.

151. The Secretariat and the International Contractor will provide detailed manuals, templates and instructions to countries for all these materials.

7 Instruments, translation and testing

7.1 Survey tools, translation and testing

152. The PaRIS patient questionnaire is primarily delivered online using a mobile-responsive design, but paper and telephone modes are available where needed. The primary care practice questionnaire is also mainly online, though other modes may be offered to ensure inclusiveness. All mode adaptations must be documented and shown to maintain equivalence.

153. Translation must follow the TRAP-D method, which involves translation, reconciliation, adjudication, pre-testing, and documentation. A detailed guideline will be provided by the Secretariat, and this process will be conducted in collaboration with the International Contractor.

154. The translation process will take place in close collaboration with the International Contractor. The country must provide one professional translator and one expert on the content of the questionnaires, which could also be the NPM. **Recommendation:** the NPM can serve as content-expert in this process.

155. NPMs must keep a Questionnaire Adaptation Spreadsheet (QAS) where all changes are logged and justified. Adaptations are allowed only for cultural or linguistic reasons and must be verified independently. A QAS will be provided by the International Contractor.

156. Before the Main Survey, each NPM must conduct cognitive testing to ensure that instruments are clear and function properly in all modes for different patient groups and practices. The Field Trial serves as a further check of measurement properties, and its results must be reviewed and approved before moving to the Main Survey. The International contractor will provide detailed guidelines for cognitive testing.

7.2 Modification of questionnaires

157. It is not allowed to modify an approved questionnaire in any way. This also applies to all introductions to questions, clarifications, response options, order of items, order of response categories and labelling, layout, etc. All items and answering categories should be included unless the removal of an item has been explicitly agreed upon with the Secretariat.

158. NPMs may include a maximum of five country- or region-specific questions to the questionnaires. The questions should be included in the final approved version.

159. It is not allowed to combine the questionnaire with other survey instruments or items.

8 Adjudication

8.1 Purpose and rationale

160. Adjudication is the formal process through which each participating country's implementation of PaRIS is assessed against the Technical Standards and its approved National Roadmap.

The purpose of adjudication is to:

- ensure compliance with the agreed methodological and operational requirements;
- safeguard cross-country comparability and data quality;
- document and transparently evaluate any deviations from the standards; and
- determine the eligibility of data for inclusion in the international database and reporting.

161. Adjudication focuses on overall adherence to the Technical Standards and approved Country Roadmaps. It does not reassess individual operational decisions unless these have implications for data quality or comparability.

8.2 Scope

162. Adjudication covers the full national implementation of the survey, including all elements set out in these Technical Standards and the approved National Roadmap.

163. The assessment is based on:

- the delivered national datasets;
- the completed Sampling Report submitted by the NPM;
- other required implementation documentation; and
- the approved National Roadmap, including any formally agreed derogations.

164. The Sampling Report constitutes a key component of the adjudication process. It provides the technical basis for assessing compliance with sampling requirements, including the definition of the target population, sampling frame construction, selection procedures, response rates, weighting procedures and any deviations from the prescribed design.

165. Where formal derogations or approved adaptations have been granted in advance by the Secretariat, these will be considered, and compliance will be assessed against the standards as modified by any formally approved derogations.

166. Adjudication takes place after the delivery of national data and accompanying documentation. However, potential issues are anticipated and mitigated throughout implementation through:

- review and approval of National Roadmaps;
- ongoing monitoring of implementation;
- analysis of Field Trial data and documentation; and

- technical dialogue between the NPM, the international contractor and the Secretariat.

These steps aim to minimise the risk of major non-compliance at the adjudication stage.

8.3 Adjudication process

167. The adjudication process consists of the following steps:

1. Initial technical review

168. Following data delivery, the International Contractors conduct a systematic assessment of each country's implementation against:

- the Technical Standards;
- the approved National Roadmap (including any formally agreed derogations); and
- the Sampling Report and accompanying technical documentation.

169. The Contractors prepare a structured adjudication report identifying:

- areas of compliance;
- minor deviations;
- significant deviations with potential impact on data quality or comparability; and
- recommended corrective actions, where applicable.

2. Dialogue with the National Project Manager

170. The draft adjudication findings are shared with the NPM for factual verification and clarification. NPMs may provide additional documentation, including clarification or revision of elements contained in the Sampling Report.

3.Resolution of disagreements

171. If the International Contractors and the NPM do not reach agreement on specific adjudication findings, the matter will be referred to the Secretariat. The Secretariat will review the documentation and makes a final decision.

4. Final adjudication decision

172. The Secretariat confirms the final adjudication outcome, including:

- whether the national data meet the requirements for inclusion in the international database;
- whether limitations must be documented; and/or
- whether specific exclusions or caveats are required.

9 Data protection and ethics

9.1 Data protection

173. Participation in the survey is voluntary, and all participants must receive clear information about the purpose of the survey, the data being collected, confidentiality, the third-party use of de-identified data, and their right to withdraw at any time. NPMs must complete a Data Protection Impact Assessment (DPIA) and comply with national and international privacy regulations[3].

174. All personal identifiers must be pseudonymised, with linkage keys kept securely at national level. Identifiable data shall never be transmitted to the Secretariat or the International Contractors. The International Contractor will provide each country with a unique set of artificial identifiers (Survey-IDs). The NPM provides each survey participant with a survey-ID.

175. All survey data must be encrypted during transfer and storage, with role-based access and audit logs in place. Retention and destruction of data must follow national regulations and OECD requirements. Ethics approvals must be secured where necessary, and staff must be trained in ethical conduct and confidentiality.

176. Online systems must meet strict security standards, in line with national and international legislation. Paper questionnaires must be numbered, tracked, and stored securely.

177. Survey participants will enter their survey-ID within a secure on-line portal, will provide informed consent; and, subject to their consent, will complete the survey on-line and the de-identified data will be saved in the survey data centre. Where NPMs collect data directly from survey respondents (for example on paper), NPMs will de-identify the data by removing all personal contact information and attaching a survey-ID to each case before securely transferring the data to the survey data centre.

178. The OECD data protection rules as described in ANNEX XII to the Staff Regulations apply to all data collection, processing and storage of PaRIS data[4].

179. Further specifications of data protection and privacy will be included in the Participation Agreement, which will be signed by the participating country and the Secretariat.

9.2 Ethical approval

180. The interests and wellbeing of both patients and practice staff are at the forefront of PaRIS. At each stage of the research design, careful consideration has been given to ensure that the study presents a minimal risk to potential participants' mental or physical well-being. This includes the questionnaire design (respondent focus, tailored questions and minimising burden), invitation letters and leaflets (explaining how

[3] See for an explanation https://gdpr.eu/data-protection-impact-assessment-template/ for countries that are under the GDPR, a DPIA is mandatory and it is highly recommended for other countries.

[4] https://www.oecd.org/content/dam/oecd/en/about/data-protection/Decision-of-the-SG-on-Personal-Data-Protection.pdf

contact details have been obtained, how data will be used and confidentiality) and participation methods (designed to maximise inclusiveness).

181. In many countries ethical review or data governance approval process may be needed ahead of approaching participants or any data collection activity. Ethical review processes vary by country but generally involve an independent committee assessing the ethics, quality, methods, informed consent information and researcher capabilities of a project against the accepted national guidelines. Informed consent can in most cases be obtained by including it as the first question.

182. NPMs are responsible for identifying the ethical requirements within their countries and to explore the procedures that should be followed to obtain approval, or a statement of no objection, for implementation of the survey from a local research ethics committee. More specifically NPM should:

- Identify whether ethical approval is required in their country, and if it is required, they will need to:
  - Identify the appropriate ethical approval body
  - Identify the timings for the ethics application, considerations include lead-in times, the calendar for ethics committee meetings and time taken for approval
  - Evaluate these timings against the PaRIS survey timetable to understand any conflicts
  - Understand the evaluation criteria and review the proposed PaRIS processes and documents for the country to determine whether any modifications are required
  - Identify the relevant documents that need to be submitted as part of the application and
  - Prepare the documents for application with the support of the International Contractor

183. **Recommendation:** Ethical approval procedures are a notorious source of delay and should therefore be started as early as possible. The Secretariat will provide a guide to NPMs to support ethical approvals.

Annex A. Profile of National Project Manager

Rationale

Each participating country will appoint an NPM to take responsibility for implementing PaRIS at the national level. The NPM has overall responsibility for ensuring that all required tasks are carried out on schedule and in accordance with the specified international Technical Standards. A well-qualified NPM will facilitate the conduct of PaRIS.

To improve efficiency and minimise respondent burden, National Project Managers (NPMs) should actively coordinate, and where feasible work jointly, with national statistical agencies to align survey activities and avoid duplication at the national level.

Position

The position of NPM will ideally involve a full-time contract under stable conditions, to ensure continuity of activities over time. The NPM must be able to commit a significant amount of his/her time to PaRIS. If the NPM does not work full time on PaRIS, there should be significant supporting staff in key positions such as operations and data management.

Key responsibilities of NPMs

The tasks and responsibilities outlined below may be carried out by an individual NPM or by a NPM team working under their supervision. For reasons of readability the term NPM is used, rather than team. The NPM should:

- Be a mid- to senior-level professional with strong knowledge of the national primary care system,
- Have a well-established and relevant professional network in primary care,
- Have a solid understanding of and experience with survey research.
- Possess excellent oral and written communication skills in the local language, as well as in English.
- Have demonstrated management and leadership skills to effectively coordinate activities at the national level and liaise with international partners.

In the first cycle, many participating countries appointed a NPM as delegate to the WP PaRIS. This is not necessary, and these roles can be fulfilled by different persons, as long as there is effective and regular communication between the two.

Tasks development stage

Communication and collaboration with the Secretariat, the International Contractor, and the WP-PaRIS delegate

- NPMs maintain regular, day-to-day communication with the Contractor, the Secretariat, and the national WP-PaRIS delegate.
- Promptly raise issues of national concern or questions related to the project development with the International Contractor or the Secretariat.

National stakeholder engagement

- Lead communications with and engagement of the public, stakeholders, and survey respondents (patients and primary care professionals). Actively search for the input and advice of relevant stakeholders regarding implementation of the survey, recruitment and communications about the survey.

Survey instrument development

- Oversee the translation, adaptation, and verification of the survey instrument.
- Organise cognitive testing of PaRIS questionnaires at the national level and reporting the results following PaRIS Technical Standards.
- Identify large minority populations in their country and their languages needs. Oversee the translation, adaptation and cognitive testing in minority languages, where needed.
- Design and/or manage the inclusion of any nationally specific questions in the survey.

Preparation for survey implementation

- Provide information on national implementation requirements, including but not limited to: ethics approvals, relevant legislation, health system structures, registries of primary care practices, language requirements, and cultural sensitivities.
- Ensure compliance with all national requirements for research ethics, data privacy, and data security.
- Lead sampling design for the Field Trial and Main Survey, in accordance with PaRIS Technical Standards (e.g. exploring sampling frames such as physician registries, association lists, and existing national surveys).
- Identify national service providers for elements of the implementation where needed (e.g. translation, sampling, mailing, printing of questionnaires, data entry, etc.)

Tasks Implementation Phase

Communication and collaboration with the Secretariat and the International Contractor

- Maintain regular communication with the Secretariat and International Contractor.
- Raise any national issues or questions related to project implementation in a timely manner.
- Participate in NPM meetings to share experiences, results, challenges, and solutions with the International Contractor, the Secretariat, and fellow NPMs.

National stakeholder engagement

- Work with the OECD Secretariat to develop communication and engagement strategies for the public, stakeholders, and survey respondents.
- Implement national engagement and communication plans, including the production and distribution of printed survey materials.

Implementation of Field Trial and Main Survey

- Ensure all national requirements for ethics approval, data privacy, and security are met.
- Attend training sessions, and organise trainings at the national level, where needed, for the Field Trial and Main Survey.
- Recruit primary care practices to participate in the survey.
- Adhere to PaRIS Technical Standards and guidelines for key activities such as sampling, translation/adaptation of materials, survey operations, data analysis, and use of the IT platform.
- Timely signal to the Secretariat if any requirement as put in the Technical Standards and guidelines cannot be met.
- Ensure the sampling frame meets quality standards; monitor the selection process and report on representativeness and potential sources of non-response bias.
- If data collection is decentralised: adopt, test, and provide staff training on the IT platform used for survey delivery.
- Monitor data collection, report quality control statistics, and alert the International Contractor to issues; implement proposed solutions.
- Assist the International Contractor in identifying and correcting statistical anomalies in Field Trial and Main Survey data.
- Manage data entry for paper-and-pencil data collection.

Reporting

- Review and comment on international technical and analytical reports.
- Review and comment on draft country note created by the Secretariat.
- Prepare national survey result reports, where applicable.
- Report on findings from results of national analyses and/or nationally specific questions added to PaRIS.

Annex B. Quality standards and assurance criteria for PaRIS cycle 2

This annex defines quality standards and assurance criteria for PaRIS Cycle 2 data, aligned with the OECD Statistical Quality Framework[5]. The criteria are designed for a posteriori assessment of data quality at national and international levels.

1. Relevance

- ✓ Target population coverage for primary care practices consistent with PaRIS Cycle 2 definitions
- ✓ Target population coverage for patients consistent with PaRIS Cycle 2 definitions

2. Accuracy

- ✓ Practice response rate ≥10%.
- ✓ Patient response rate ≥20%.
- ✓ Sampling design (detailing sampling frame), weights provided.
- ✓ Non-response documented and adjusted or justified.

3. Timeliness

- ✓ Data submitted within the agreed submission window.
- ✓ Reference periods clearly specified.

4. Punctuality

- ✓ Submission received by the agreed deadline or approved extension.
- ✓ Any delays documented and justified.

5. Accessibility (for decentralised data collections,)

- ✓ Data submitted in approved PaRIS technical formats.
- ✓ Variable names, labels, and coding fully aligned with the PaRIS data dictionary.

5 https://unstats.un.org/unsd/energy/Workshops/Annex%20Ia%20OECD%20Statistical%20Quality%20Framework.pdf

- ✓ No undocumented country-specific variables in core datasets.

8. Credibility / Transparency

- ✓ Methods for sampling, weighting, and adjustments transparently documented.
- ✓ Deviations from standard instruments or protocols documented.
- ✓ Revisions between submissions logged and justified.
- ✓ Ethical approval and data protection compliance confirmed (where needed).