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PaRIS Field Trial Report

Technical Report on the conduct and results of the Field Trial of the international PaRIS survey of people living with chronic conditions

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PaRIS
Patient Reported Indicator Surveys

Field Trial Report

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Abstract

As populations age and the number of people with chronic conditions increases, countries need to assess how their health systems perform with regard to the management of chronic conditions. OECD's Patient-Reported Indicator Surveys (PaRIS) initiative aims to measure outcomes and experiences of healthcare as reported by patients with chronic conditions as part of the efforts to improve quality of care. The PaRIS survey, an international survey of people living with chronic conditions who are managed in primary care, is implemented in twenty countries. Following a rigorous design and development phase, the PaRIS survey was field-tested in participating countries. This paper reports on the implementation and the results of the Field Trial. The Field Trial provided important lessons which have been used to improve the survey tools and the implementation of the Main Survey.

Supplementary material to the PaRIS Field Trial Report can be found in the following link: https://www.oecd.org/health/paris/Supplementary-Material-to-the-PaRIS-Field-Trial-Report.pdf

Executive summary

Patient Reported Indicator Surveys (PaRIS) aims to measure healthcare from the perspective of patients. The PaRIS survey is the first international survey of people living with chronic conditions who are managed in primary care, and collects Patient Reported Outcome and Experience Measures (PROMs and PREMs) to improve the quality of primary care. The PaRIS survey is carried out in three phases: the Design and Development Phase (2017-2020); the Field Trial (2021-2022); and Main Survey (2022-2023). In the design and development phase, the initial survey proposal and the draft conceptual framework were produced to develop the PaRIS questionnaires. During the subsequent Field Trial, participating countries rigorously examined the survey's design, materials, and implementation within their respective contexts. The imperative nature of the Field Trial arises from the large scale and complexity of the survey, as it provided an opportunity to pinpoint and address any potential issues in design and survey administration prior to the commencement of the Main Survey in 2023. This proactive approach ensures that the Main Survey is executed with heightened precision and efficacy, facilitating more reliable and robust results.

Eighteen countries (*Australia, Belgium, Canada, Czechia, England (United Kingdom), France, Greece, Iceland, Italy, Luxembourg, Netherlands, Norway, Portugal, Romania, Saudi Arabia, Slovenia, Spain and Wales (UK)*) participated in the Field Trial and collected data between March and November 2022. Three participating countries (Israel, Switzerland and United States) were not included in the Field Trial report, because of specific timelines.

This technical report details the conduct and results of the PaRIS Field Trial. The overall aim of this report is to provide an insight into how the participating countries conducted the Field Trial and how survey instruments (questionnaires) performed. In addition, the report provides an overview of the countries' implementation plans to see whether any adaptations were needed to ensure a successful implementation of the PaRIS Main Survey in the participating countries. Countries in this report are indicated by randomly assigned letters (from A to R) and pseudonymised results from this Field Trial are presented in this report.

Key findings and learnings from the Field Trial are as follows:

- **Countries' patient sample sizes ranged from 698 to 15,422.** The highest number of participating patients was 2,360, followed by 1,237. Overall, the sample sizes were adequate for a robust test of survey instruments. Response rates varied strongly between countries. The NPMs of participating countries critically reflected on achieved response rates and shared experiences and good practices on recruitment, engagement and communication. Several countries considerably improved their recruitment strategies to ensure higher response rates in the Main Survey.
- **A total of 10,894 patients in 18 countries completed the patient questionnaire.** In all countries, more women than men participated in the survey. The distribution of participants' age, education level and number of chronic conditions varied considerably between countries. Such differences reflect partly actual difference in populations but may in same cases also be affected by selection bias. For the Main Survey, countries will provide population statistics and the data will be weighted to a standard population to ensure international comparability.

- **The median time taken for patients to complete the online questionnaire ranged from 24 to 33 minutes between countries.** Completion time appears to be related to patient age (older patients need more time) and number of chronic conditions (people reporting chronic conditions need more time). The drop-out rate was 8% on average, with only a few countries exhibiting higher rates. Contrary to initial assumptions, the length of the questionnaire doesn't emerge as a significant factor influencing dropout rates. In instances where higher dropout rates were observed, it was often attributed to specific circumstances such as the integration of additional surveys or the absence of alternative survey formats (e.g., paper-based options) rather than the questionnaire's length itself. This suggests that factors beyond mere survey length play a more prominent role in dropout rates across various countries. Although all questions have been critically assessed, the questionnaire has not been shortened significantly for the Main Survey.
- **From 118 questions for patients, there were only three questions with 10% or more missing answers.** These were questions on household income and the number of children and adults in the household. There was a large variation in the percentage of missing answers on these questions between countries, which suggests that these questions are more sensitive or more difficult to answer in some countries than in others. Therefore, translations and localisations of these questions were critically reviewed in all countries and adapted where needed.
- In most countries, **the majority of patient questionnaires were administered online**, except in two countries where the patient questionnaire was administered exclusively by telephone interview and in one country where more participants completed the questionnaire on paper. Six countries offered only online administration of the questionnaire. Most of these countries had relatively high drop-out rates (people who started to fill out the questionnaire but did not complete it). This underlines the need to offer patients an alternative way of participating in the survey, and to not rely exclusively on online administration. While offering alternatives for online administration was strongly advised, not all countries were able to implement this recommendation due to the associated additional costs and logistical challenges inherent in paper-and-pencil survey administration.
- **Regarding the performance of the internationally validated PROMs (PROMIS Global – Physical and Mental health scales, and WHO-5 Wellbeing Index), confirmatory factor analyses revealed that the scales performed well** when the data from all countries were combined.
- **All (multiple item) PROMs included in the patient questionnaire could be assessed reliably at patient level,** except for two sets of two questions that we combined to explore their scalability. These sets of questions (on fatigue and sleeping problems) had not been designed to form a scale.
- **In total, 540 primary care practices in 17 countries completed the practice questionnaire.** The characteristics of the participating practices varied considerably from country to country. This included the degree of urbanisation of their location and practice type.
- **The median completion time for the practice questionnaire was around 20 minutes in each country**. There was substantial variation in the time it took respondents to complete the questionnaire, but this does not appear to be a cause for concern. Longer completion times were likely caused by respondents leaving the online survey open and completing it between other activities during their daily work. Given the very low dropout rate (<5%) there was no reason to shorten the questionnaire for the Main Survey.
- **From the total set of 58 (single) questions in the practice questionnaire, there were only three questions with 10% or more missing responses.** These questions were related to the acute response to the COVID-19 pandemic (e.g., testing, vaccination) and will not be part of the Main Survey questionnaire because they were not considered relevant in the long term given changed circumstances. These questions have been replaced with long-COVID questions. There were also four questions to which at least 10% of the respondents answered they were ‘not sure’

of the answer. For two of these questions, on the practice's clinical information system and a question on reviewing indicators to monitor patient care, the relatively high percentage of 'not sure' answers is most likely to be a good reflection of the actual situation. A question on the use of patient care plans, was not well understood, and was therefore revised for the Main Survey. Furthermore, changes were made to questions on the use of patient care plans and on the type of chronic conditions for which care was provided, as these questions appeared to be unclear or multi-interpretable.

- **Most data were collected centrally via the online platform provided by the consortium. In general, the experiences with this tool were positive.** The same holds for the sampling guidelines and other tools to support the sampling process.

The Field Trial provided valuable lessons for the Main Survey. Based on the results the surveys tools have been revised and survey administration procedures have been improved. As countries improve their plans for implementing the Main Survey, the international study design is becoming more robust for international comparison. Further results from the first cycle of the PaRIS survey will provide insight into where countries stand in providing high-quality care from the patients' perspectives. Future cycles will help improve the quality of primary care for people with chronic conditions and make health systems more people centred.

Points saillants

L'enquête PaRIS est la première enquête internationale sur les personnes atteintes de maladies chroniques prises en charge en soins de santé primaires, et recueille les mesures des résultats et de l'expérience rapportés par les patients (PROMs et PREMs) afin d'améliorer la qualité des soins de premier recours. L'enquête PaRIS se déroule en trois phases : la phase de conception et de développement (2017-2020), l'essai sur le terrain (2021-2022) et l'enquête principale (2022-2023). Au cours de la phase de conception et de développement, la proposition d'enquête initiale et le projet de cadre conceptuel ont été produits pour élaborer les questionnaires PaRIS. Au cours de l'essai sur le terrain qui a suivi, les pays participants ont examiné rigoureusement la conception, le matériel et la mise en œuvre de l'enquête dans leurs contextes respectifs. La nécessité d'un essai sur le terrain découle de la grande échelle et de la complexité de l'enquête, et il a permis de mettre en évidence et de résoudre tous les problèmes potentiels liés à la conception et à l'administration de l'enquête avant le début de l'enquête principale en 2023. Cette approche proactive a permis que l'enquête principale soit exécutée avec une précision et une efficacité accrue, rendant les résultats plus fiables et plus robustes.

Dix-huit pays (Arabie saoudite, Australie, Belgique, Canada, Angleterre (Royaume-Uni), Espagne, France, Grèce, Islande, Italie, Luxembourg, Norvège, Pays-Bas, Portugal, République tchèque, Roumanie, Slovénie et Pays de Galles (Royaume-Uni)) ont participé à l'essai sur le terrain et ont collecté des données entre mars et novembre 2022. Trois pays participants (Israël, Suisse et États-Unis) n'ont pas été inclus dans le rapport de l'essai sur le terrain, en raison de calendriers spécifiques.

Le présent rapport technique détaille la conduite et les résultats de l'essai sur le terrain de l'enquête PaRIS. L'objectif général est ici de donner un aperçu de la manière dont les pays participants ont mené l'essai sur le terrain et des performances des instruments d'enquête (questionnaires). En outre, le rapport rend compte des plans de mise en œuvre des pays afin de déterminer si des adaptations étaient nécessaires pour garantir une mise en œuvre réussie de l'enquête principale PaRIS dans les pays participants. Dans ce rapport, les pays sont désignés par des lettres attribuées de manière aléatoire (de A à R) et les résultats sont pseudonymisés.

Les principaux résultats et enseignements de cet essai sur le terrain sont les suivants :

- **La taille des échantillons de patients des pays varie de 668 à 15 422.** Parmi les personnes échantillonnées, le nombre maximal de patients ayant donné leur accord pour répondre à l'enquête était de 2 360 dans un pays, suivi de 1 237 dans un autre pays. Dans l'ensemble, la taille des échantillons était suffisante pour permettre un test solide des instruments d'enquête. Les taux de réponse ont fortement varié d'un pays à l'autre. Les Chefs de projet nationaux des pays participants ont mené une réflexion critique sur les taux de réponse obtenus et ont partagé leurs expériences et bonnes pratiques en matière de recrutement, d'engagement et de communication. Plusieurs pays ont considérablement amélioré leurs stratégies de recrutement afin de garantir des taux de réponse plus élevés lors de l'enquête principale.

- **Au total, 10 894 patients de 18 pays ont répondu au questionnaire**. Dans tous les pays, les femmes ont été plus nombreuses que les hommes à participer à l'enquête. La répartition par âge, niveau d'éducation et par nombre de maladies chroniques varie considérablement d'un pays à l'autre. Ces différences reflètent en partie les différences réelles entre les populations, mais peuvent aussi, dans certains cas, être influencées par un biais de sélection. Pour l'enquête principale, les pays fourniront des statistiques démographiques et les données seront pondérées en fonction d'une population standard afin de garantir la comparabilité internationale.
- **Le temps médian nécessaire aux patients pour remplir le questionnaire en ligne varie de 24 à 33 minutes d'un pays à l'autre.** Le temps de remplissage semble être lié à l'âge du patient (les patients plus âgés ont besoin de plus de temps) et au nombre de maladies chroniques (les personnes déclarant des maladies chroniques ont besoin de plus de temps). Le taux d'abandon était faible (8 % en moyenne, seuls quelques pays affichant des taux plus élevés). Contrairement aux hypothèses initiales, la longueur du questionnaire n'apparaît pas comme un facteur significatif influençant les taux d'abandon. Dans les cas où des taux d'abandon plus élevés ont été observés, ils ont souvent été attribués à des circonstances spécifiques telles que l'intégration d'enquêtes supplémentaires ou l'absence de formats d'enquête alternatifs (par exemple, des options sur papier) plutôt qu'à la longueur du questionnaire lui-même. Cela suggère que des facteurs autres que la simple longueur de l'enquête jouent un rôle plus important dans les taux d'abandon dans divers pays. Bien que toutes les questions aient fait l'objet d'une évaluation critique, le questionnaire n'a pas été raccourci de manière significative pour l'enquête principale.
- **Sur les 118 questions posées aux patients, seules trois questions comportaient 10 % ou plus de réponses manquantes.** Il s'agissait de questions sur le revenu du ménage et sur le nombre d'enfants et d'adultes dans le ménage. Le pourcentage de réponses manquantes à ces questions varie considérablement d'un pays à l'autre, ce qui suggère que ces questions sont plus délicates ou plus difficiles à répondre dans certains contextes. C'est pourquoi les traductions de ces questions, prenant en compte les langues locales et les différences culturelles, ont fait l'objet d'un examen critique dans tous les pays et ont été adaptées le cas échéant.
- **Dans la plupart des pays, la majorité des questionnaires destinés aux patients ont été administrés en ligne**, sauf dans deux pays où le questionnaire destiné aux patients a été administré exclusivement par entretien téléphonique et dans un pays où davantage de participants ont rempli le questionnaire sur papier. Six pays n'ont proposé que l'administration en ligne du questionnaire. La plupart de ces pays ont enregistré des taux d'abandon relativement élevés (des personnes qui ont commencé à remplir le questionnaire mais ne l'ont pas terminé). Bien qu'il soit fortement conseillé de proposer des alternatives pour l'administration en ligne, tous les pays n'ont pas été en mesure de mettre en œuvre cette recommandation en raison des coûts supplémentaires associés et des défis logistiques inhérents à l'administration des enquêtes papier-crayon.
- En ce qui concerne les performances des PROM validés au niveau international (PROMIS Global - échelles de santé physique et mentale, et indice de bien-être OMS-5), les analyses factorielles confirmatoires ont révélé que les échelles fonctionnaient raisonnablement bien lorsque les données de tous les pays étaient combinées.
- Tous les PROM (à items multiples) inclus dans le questionnaire destiné aux patients ont pu être évalués de manière fiable au niveau du patient, à l'exception de deux séries de deux questions qui furent combinées pour étudier leur capacité à évoluer. Ces séries de questions (sur la fatigue et les problèmes de sommeil) n'avaient pas été conçues pour former une échelle.
- Au total, 540 cabinets de soins primaires dans 17 pays ont rempli le questionnaire. Les caractéristiques des cabinets participants varient considérablement d'un pays à l'autre. Il s'agissait notamment du degré d'urbanisation de leur lieu d'implantation et du type de cabinet tels qu'un

cabinet individuel, un cabinet de groupe avec ou sans une patientèle non partagée ou un cabinet pluridisciplinaire.

- Le temps médian pour remplir le questionnaire était d'environ 20 minutes dans l'ensemble des pays. Le temps nécessaire aux répondants pour remplir le questionnaire a varié considérablement entre les pays, mais cela ne semble pas être une source d'inquiétude. Les temps de réponse plus longs sont probablement dus au fait que les répondants ont laissé l'enquête en ligne ouverte et l'ont remplie entre deux activités au cours de leur travail quotidien. Compte tenu du très faible taux d'abandon (inférieur à 5%), il n'y avait aucune raison de raccourcir le questionnaire pour l'enquête principale.
- Sur l'ensemble des 58 questions (uniques) du questionnaire, seules trois questions comportaient 10 % ou plus de réponses manquantes. Ces questions étaient liées à la pandémie COVID-19 et ne feront pas partie de l'enquête principale. Il y avait également quatre questions auxquelles au moins 10 % des personnes interrogées ont répondu qu'elles n'étaient pas sûres de la réponse. Pour deux de ces questions, portant sur le système d'information clinique du cabinet et sur l'examen des indicateurs de suivi des soins aux patients, le pourcentage relativement élevé de réponses "incertaines" reflète très probablement la situation réelle. La quatrième question, sur l'utilisation des plans de soins des patients, n'a pas été bien comprise et etait donc révisée pour l'enquête principale. En outre, des changements ont été apportés aux questions sur l'utilisation des plans de soins des patients et sur le type de maladies chroniques pour lesquelles des soins ont été fournis, car ces questions semblaient peu claires ou susceptibles d'interprétations multiples.
- La plupart des données ont été collectées de manière centralisée via la plateforme en ligne fournie par le consortium. En général, les expériences avec cet outil ont été positives. Il en va de même pour les lignes directrices sur l'échantillonnage et les autres outils destinés à soutenir le processus d'échantillonnage.

Au total, l'essai sur le terrain a permis de tirer des enseignements précieux pour l'enquête principale. Sur la base des résultats, les outils d'enquête ont été révisés et les procédures d'administration de l'enquête ont été améliorées. L'amélioration des plans de mise en œuvre de l'enquête principale rend plus robustes les comparaisons internationales. Les résultats du premier cycle de l'enquête PaRIS permettront de savoir dans quelle mesure les pays dispensent des soins de haute qualité du point de vue des patients. Les prochains cycles contribueront à améliorer la qualité des soins de santé primaires pour les personnes atteintes de maladies chroniques et de centrer davantage les systèmes de santé sur la personne.

Abbreviations

CFI	Comparative Fit Index
eHEALS	e-Health Literacy Scale
MCBS	Medicare Current Beneficiary Survey
NPM	National Project Managers
OECD	Organisation for Economic Co-operation and Development
PaRIS	Patient Reported Indicator Surveys
PaRIS-PP	PaRIS Patient Advisory Panel
PREMs	Patient Reported Experience Measures
PROMs	Patient Reported Outcome Measures
P3CEQ	Person-Centred Coordinated Care Experiences Questionnaire
RMSEA	Root Mean Squared Error of Approximation
SRMR	Standardised Root Mean Squared Error
TLI	Tucker Lewis incremental fit Index
TRAPD	Translation-Review-Adjudication-Pretest-Documentation
WHO	World Health Organisation
WP-PaRIS	Working Party for PaRIS

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1. The PaRIS survey: an introduction

1. Health systems collect vast amounts of data on various dimensions such as spending on healthcare, access to care, and quality of care. However, little information is available about how health systems perform from the perspective of people living with chronic conditions.

2. In 2017, OECD Health Ministers provided directions for the future work of the OECD on improving the collection and use of patient-reported measures to improve the performance of health systems[1]. OECD Member States joined efforts to develop and implement the first international survey of patient-reported outcome and experience measures (PROMs and PREMs) of people living with chronic conditions who are managed in primary care (PaRIS survey). An international consortium, the PaRIS-SUR consortium[2], has been tasked by the OECD to provide technical assistance for the development and implementation of the PaRIS survey.

3. The ultimate goal of the PaRIS survey is to help countries to make their health systems more centred to the needs of people living with chronic conditions, by collecting patient-reported data on quality and performance from the patient perspective and conducting cross-country comparative analyses. Therefore, core elements of the PaRIS survey are the international standardisation of instruments and procedures for sampling and data collection, to facilitate international comparison and cross-country learning.

4. As primary care plays a pivotal role in the management of chronic conditions, the PaRIS survey is being implemented in primary care settings. Data are collected with a survey among primary care service users aged 45 years or older, with or without chronic conditions. An additional survey is conducted among their primary care providers. Because of the nested study design, the survey allows analysis of patient-reported outcomes and care experiences in relation to characteristics of and care provided by primary care professionals within and across countries.

5. The PaRIS survey is being rolled out in three phases: Design and Development Phase (2017-2020); Field Trial (2021-2022); and Main Survey (2022-2023). In the Design and Development Phase, the OECD Secretariat formed a Task Force including international experts, and representatives from patient and healthcare professional organisations. During this phase, the initial survey proposal and design were prepared, as well as the draft conceptual framework to develop the PaRIS questionnaires. In the Field Trial, participating countries tested survey design and materials as well as the implementation of the PaRIS survey in countries' contexts. Currently, the Main Survey is rolled out in participating countries.

6. Twenty countries (Australia, Belgium, Canada, Czechia, France, Greece, Iceland, Israel, Italy, Luxembourg, Netherlands, Norway, Portugal, Romania, Saudi Arabia, Slovenia, Spain, Switzerland, Wales

[1] https://www.oecd.org/health/ministerial-2017/ministerial-statement-2017.pdf

[2] A consortium of five highly qualified and experienced international partners: NIVEL, Ipsos, University of Exeter, Avedis Donabedian Institute and Optimedis A.G has been identified through a tendering process to assist the Secretariat and the countries with the development and implementation of the PaRIS survey. NIVEL is the consortium leader and is the Contractor of the project.

(United Kingdom), United States) are currently implementing the survey. OECD's Health Committee[3] and the Working Party for PaRIS (WP-PaRIS)[4] oversee the design, development, and implementation of the project (de Boer et al., 2022[1]). Key stakeholders, namely patients and primary care professionals, participated in the design, development and implementation of the PaRIS survey (Kendir et al., 2023[2]).

7. All participating countries appointed a national coordination team (National Project Managers, NPMs) to implement the PaRIS survey. Based on the international PaRIS study protocol (de Boer et al., 2022[1]), NPMs developed implementation plans (so-called country roadmaps) for the Field Trial. Furthermore, NPMs led the translation process and cognitive testing of the survey instruments for use in the Field Trial in their countries. The consortium provided guidance and supportive materials to help NPMs in the development and implementation of the PaRIS survey in their respective countries.

8. This Technical Report details the conduct and results of the Field Trial. The overall goal of this report is to provide insight in how participating countries conducted the Field Trial and how survey instruments (questionnaires) performed. In addition, the report provides an overview of countries' implementation plans to see whether any adaptations are needed to ensure successful implementation of the PaRIS Main Survey in participating countries.

9. The report proceeds as follows. Chapter 1 provides background information about the PaRIS survey: the conceptual framework, research questions and the study design of the Field Trial. In Chapter 2. the sampling procedures, response rates, and data collection methods for the primary care practice and patient questionnaires are discussed, as well as an overview of the characteristics of the participating primary care practices and patients. Chapter 2. provides more detailed information on how the Field Trial was conducted. Chapter 3. presents paradata. Chapters 4. and 5. examine the performance in the Field Trial of the patient and primary care practice questionnaire, respectively. Chapter 6. summarises the qualitative feedback from NPMs on the Field Trial. In Chapter 7. , the key findings of the Field Trial are discussed and lastly Chapter 8. summarises the implications for the Main Survey.

[3]The Health Committee consists of country delegates and oversees the overall work of the OECD Health Division.

[4] The Working Party for PaRIS is composed of delegates from OECD Member Countries and welcomes a selected number of non-member countries. The Working Party for PaRIS assists the OECD Health Committee by reviewing the development of PaRIS survey and discussing priorities in terms of the scope and specifications of PaRIS survey.

Box 1.1. Terms used in this report

Primary care

Primary care is defined as the first level of contact for the population with the healthcare system, bringing healthcare as close as possible to where people live and work. It addresses the main health problems in the community, providing preventive, curative and rehabilitative services. Primary care goes beyond services provided by primary care physicians to encompass other health professionals such as nurses, pharmacists, auxiliaries, and community health workers.

Primary care professionals

Primary care physicians, family doctors, nurses, pharmacists, auxiliaries, and other healthcare professionals providing primary care services.

Primary care practices

Practices or facilities staffed with healthcare professionals that are licensed to serve the general population of a community, and provide ambulatory generalist medical care (i.e., in an outpatient setting), including services addressing chronic care management.

Patient questionnaire – PaRIS survey

Survey among primary care service users aged 45 years or older, with or without chronic conditions.

Primary care practice questionnaire – PaRIS survey

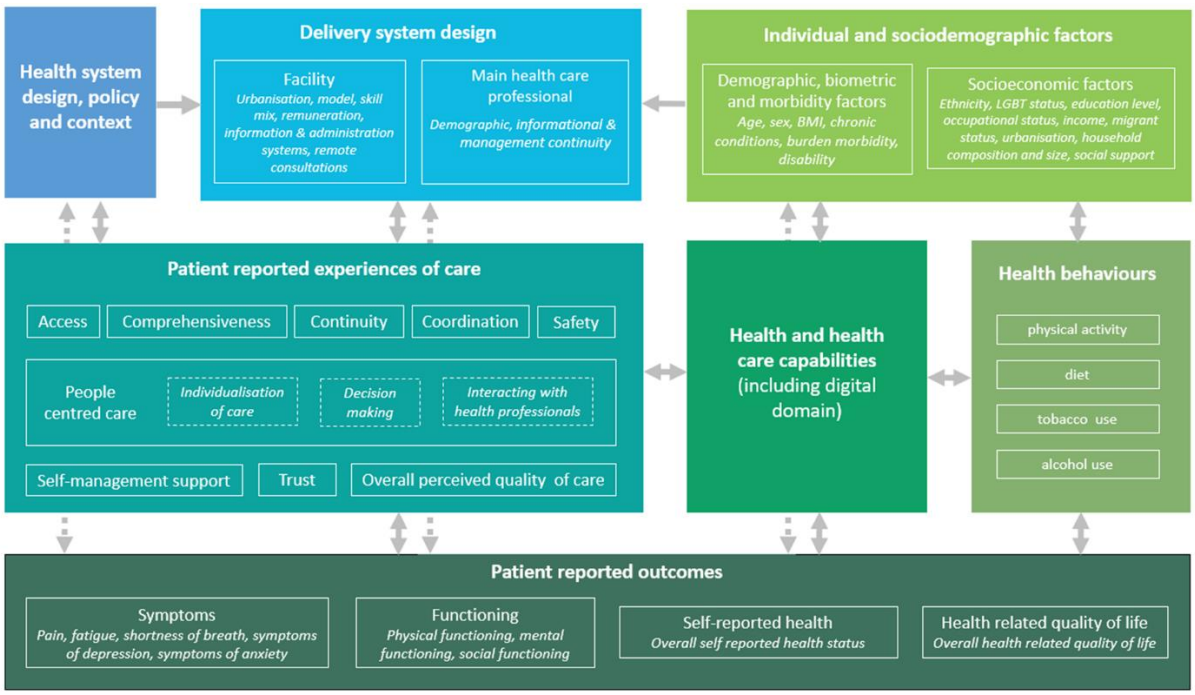
Survey among healthcare professionals serving in primary care practices.

Source: Authors.

1.1. Conceptual framework and research questions

10. As a basis of the PaRIS survey, a conceptual framework was developed through an intensive interactive process with many stakeholders. The development of the conceptual framework will be reported elsewhere. The framework consists of the following domains (Figure 1.1): patient reported outcomes (symptoms, functioning, self-reported health status, health related quality of life); patient reported experiences of care (access, comprehensiveness, continuity, coordination, safety, people-centredness, self-management support, trust, overall perceived quality of care); patients' health and care capabilities; patients' health behaviours (physical activity, diet, tobacco use, alcohol use); patients' individual and sociodemographic characteristics; primary care delivery system (characteristics of the primary care facility; characteristics of the main primary care professional); characteristics of the health system, policy and context.

Figure 1.1. Conceptual framework of the PaRIS survey



Source: Authors.

11. As shown in the framework, it is expected that the care experiences and outcomes of people living with chronic conditions are determined by their personal and condition-related characteristics, their capabilities to self-manage their health and care as well as by their health behaviours. Moreover, it is expected that structural characteristics of primary care practices as well as the way they organise the delivery of chronic care impacts patients' care experiences and outcomes. Finally, characteristics of the health system, policy and context determine how the provision of primary care is organised and chronic conditions are managed in a country.

12. The PaRIS survey seeks to address many questions that are relevant for people living with chronic conditions and their families, primary care professionals, policymakers and health authorities in countries. Reporting by the OECD will predominantly focus on the main questions for international comparison in line with the overall goal of the PaRIS survey, i.e., to help countries to make their health systems more centred to the needs of people living with chronic conditions. To strengthen policy relevance, the results of people living with chronic conditions will also be compared with the results of people without such conditions. As such, data collection and analysis (of the Main Survey) will be guided by the following questions:

- What are the patient-reported outcomes of primary care patients aged 45 and over with chronic conditions, compared to those without chronic conditions, in the areas of symptoms, physical, mental and social functioning, self-reported health, and health-related quality of life? How do these results vary across countries?
- What are the experiences of primary care patients aged 45 and over with chronic conditions, compared to those without chronic conditions, in the areas of access, comprehensiveness, continuity, coordination, safety and people-centredness of care, self-management support, trust, and overall perceived quality of care? How do these results vary across countries?
- How do patient-reported outcomes and care experiences vary for primary care patients aged 45 and over with chronic conditions by background characteristics such as age group, gender,

education level, occupational status, household composition, health behaviours, level of multi-morbidity, disease status and confidence in managing one's own care?

- How do key characteristics of primary care practices relate to the care experiences and outcomes of patients aged 45 and over with chronic conditions?
- How do characteristics of health systems and countries relate to the care experiences and outcomes of primary care patients aged 45 and over with chronic conditions?

1.2. Study design and data collection

13. The PaRIS survey has a nested design: people are 'nested' in primary care practices, which are at their turn 'nested' in (national or regional) health systems in countries. The Main Survey instrument is a questionnaire for people aged 45 years or older to collect patient-reported data, hereinafter the patient questionnaire. An additional survey among their primary care providers (practice level) is included to collect data on the characteristics of and care they provide, in particular related to chronic care management, hereinafter the provider questionnaire. Furthermore, country level characteristics of the health system and the primary care setting will be included. This country level information will be retrieved from international and national databases.

14. The OECD and the consortium developed the patient and provider questionnaires, based on the PaRIS conceptual framework, and in consultation with national and international experts and stakeholders, including the NPMs, country officials, PaRIS Patient Advisory Panel[5] (PaRIS-PP) and the Technical Advisory Community[6]. The development of the questionnaires will be reported elsewhere.

15. The English or French or both source questionnaires were translated in countries' official languages following a validated translation procedure (TRAPD) and were subsequently tested through cognitive interviews with primary care professionals and patients in the participating countries (Harkness, Van de Vijver and Mohler, 2003[3]). The translation process and outcomes of the cognitive testing will be reported in another report.

1.3. Eligibility criteria and sampling

16. Eligibility criteria for primary care practices are that these should be practices or facilities staffed with healthcare professionals that are licensed to serve the general population of a community, and provide ambulatory generalist medical care (i.e., in an outpatient setting), including services addressing chronic care management.

17. Eligible criteria applied to patients are: 1) aged 45 years or older at the time of sampling; 2) living in the community (in a private household, i.e., not in a long-term care facility, healthcare or other residential institution); and 3) having had at least one registered contact with a primary care professional - either face-to-face, by telephone or online -, for any medical or administrative reason, during the six months preceding the selection procedure.

18. All NPMs were asked to construct a sampling frame for the Field Trial based on these eligibility criteria, and to draw a probability sample of eligible primary care practices and patients. National representativeness was highly recommended for the Field Trial but was not required. For all countries the NPMs were instructed to draw samples that were sufficiently large to result in 25 participating primary care

[5] https://www.oecd.org/health/paris/PaRIS-Patient-Advisory-Panel.pdf

[6] https://www.oecd.org/health/paris/PaRIS-Technical-Advisory-Community.pdf

practices and 50 participating patients per practice who met the eligibility criteria. These target numbers were based on statistical simulations carried out on a large dataset of patient-reported care experiences from 34 countries (Schäfer et al., 2011[4]). The simulations aimed to optimise the balance between the reliability of patient-reported indicators and the number of responding primary care practices and patients. For smaller countries a lower target for practices was set (n=10).

2. The Field Trial of the PaRIS survey

Eighteen countries[7] participated in the Field Trial in 2022: Australia, Belgium, Canada, Czechia, England (United Kingdom), France, Greece, Iceland, Italy, Luxembourg, Netherlands, Norway, Portugal, Romania, Saudi Arabia, Slovenia, Spain and Wales (United Kingdom). Data collection in these countries took place in the period of March until November 2022.

19. Information on the sampling and participation of primary care practices and patients in the Field Trial, reported in Chapter 2. , is based on data that were collected from 18 countries. In Chapter 2.4 (participant characteristics), 3. (paradata), 4. and 5. (performance of the questionnaires), the data of 17 countries, who submitted their data by 23 September 2022, were analysed and reported. Random letters (from A to R) are assigned to countries and pseudonymised results from this Field Trial are presented in this report. Three participating countries (Israel, Switzerland, and the United States) are not included in the Field Trial report due to specific reasons with the national implementation plans such as delayed timelines for data collection.

2.1. Sampling and participation

20. This section provides information on how samples of primary care practices and patients were drawn, the size of the samples, the number of participants, and the response rates. This section is based on quantitative data received from 18 countries by 30 November 2022. All 18 countries provided data on the patient survey; 17 provided data on the provider questionnaire. In addition, qualitative information provided by NPMs in their sampling report was used for this chapter.

2.1.1. Primary care practices

21. Regarding the required numbers of participants, all but one country aimed to include 25 primary care practices. Given its smaller population size, one country's target was set at 10 primary care practices. Most countries used a national registry to sample primary care professionals. Two countries (country Q and R) applied a regional approach, mainly because their health systems have a strong regional component.

22. All countries applied probability sampling, except one country which drew a convenience sample. Of the countries that drew a probability sample, ten countries applied stratification, mostly by geographical

[7] Three countries participating in the PaRIS survey are not included in this report, as they did not conduct a Field Trial in 2022 for country-specific reasons.

area/region, practice size or degree of urbanisation; the other countries applied simple random sampling. Sample sizes ranged from 26 to 3,400 practices (see Table 2.1). NPMs contacted selected practices either directly by their own means or through an authority or regional manager in the existing governance structure.

2.1.2. Patients

23. Most patients were randomly selected and invited to participate in the survey. Sampling was conducted by the NPM, the primary care professionals or by a third party.

24. The nested sampling of patients within practices varied somewhat between countries. In some countries, there were primary care practices reporting they could not share patient contact details for sampling and inviting patients. For example, in country I, only four of the 18 practices that participated in the practice questionnaire shared patient contact data for sampling and inviting selected patients. Furthermore, country N had to start its Field Trial late in the process and could therefore only recruit patients from one primary care practice.

25. Patients were contacted through the participating primary care practice either by the professionals working in the practice – facilitated as much as possible by the NPM team – or by the NPM with the authorisation (and sometimes endorsement) of the practice. Other countries contacted patients directly as their legal frameworks and national registries allowed this for research purposes.

26. A target of 50 participating patients per participating practice was set for all countries. To reach this target, samples of 150 to 400 eligible patients per practice were drawn.

2.2. Participation numbers and response rates

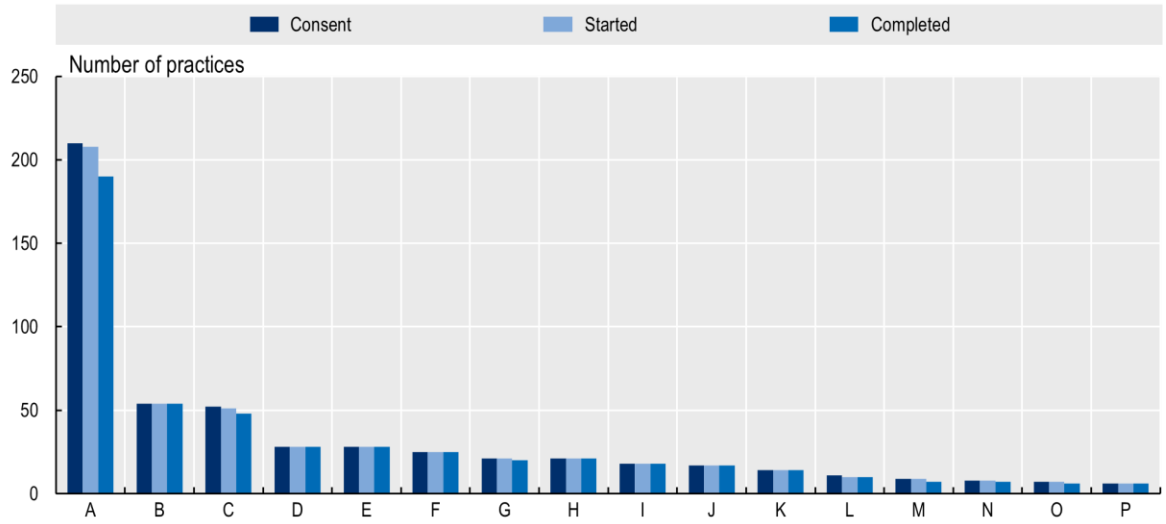
2.2.1. Primary care practices

27. By 30 November 2022, a total of 570 primary care practices from 17 countries had given consent to participate in the survey. 540 primary care practices completed the survey out of the 566 practices that started to fill in the provider questionnaire (95%; see Figure 2.1), which means that drop out was generally low.

28. Figure 2.1 provides an overview of the participating practices per country. It shows that seven countries reached their target of 25 (or 10) participating primary care practices. Country A had the highest number of participating primary care practices, but these were only invited for the practice survey; they were not asked to sample or invite patients for the patient questionnaire[8].

[8] In Country A, the Field Trial was conducted differently from what is planned for the Main Survey, as the sampling procedure that is envisaged for the Main Survey was not possible due to limited time available for the Field Trial (Country A entered the PaRIS survey at a rather late stage). Therefore, the patient and provider questionnaires were piloted in separate samples that could not be linked.

Figure 2.1. Overview of participating primary care practices per country



Note: Country names are pseudonymised in the x-axis. Country Q had not submitted data from primary care providers by 30 November 2022.
Source: PaRIS Field Trial Data 2022

29. The overall response rate among primary care practices across countries was 32%, which was close to the target of 35% set in the 'Sampling guidelines for the Field Trial'. However, Table 2.1 shows that the response rates between countries varied considerably, ranging from less than 5% for some countries to 96%. There are several explanations for the considerable variation in response rates. First, countries applied different methods to approach primary care providers. For example, one country contacted primary care providers by phone, engaging in personal conversations, a labour-intensive method that yielded high response rates. Conversely, in another country, thousands of primary care providers were presented with a pop-up on their screens upon connecting to their registration system. This method cast a wide net but resulted in lower response rates, illustrating the trade-off between reach and engagement.

30. NPMs reported that the main reasons for not participating were lack of time of practice staff (in some countries due to the summer holidays) and hesitance to share patient data because of privacy concerns. NPM's were also transparent about the survey being a Field Trial, several NPMs reported that primary care providers may be less keen on participating in a Field Trial than in the Main Survey.

Table 2.1. Number of sampled and consented primary care practices, and gross response rates per country

	Sample size (n)	Consent (n)	Response rate
Country F	26	25	96%
Country R	27	25	93%
Country B	64	54	84%
Country C	100	52	52%
Country A	500	210	42%
Country H	50	21	42%
Country K	50	18	36%
Country J	75	17	23%
Country E	131	28	21%

Country I	142	18	13%
Country D	300	28	9%
Country O	76	7	9%
Country N	125	9	7%
Country G	400	21	5%
Country M	397	14	4%
Country L	250	11	4%
Country P#	3 400	12	<1%

Note: Country names are pseudonymised. Country Q did not submit data from primary care practices by 30 November 2022. #Approximately 3,400 practices received an email including a link to request for more information. It is unknown how many read this invitation. Of the 51 practices that did receive information and were approached, 12 participated.
Source: PaRIS Field Trial Data 2022

2.2.2. Patients

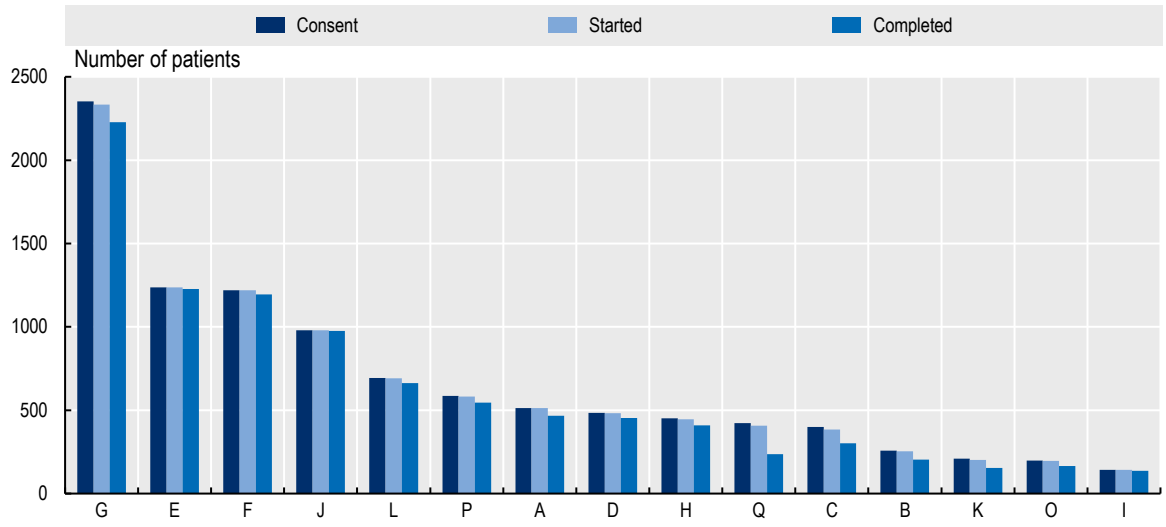
31. By 30 November 2022, a total of 11,999 patients from 18 countries had given consent to participate in the survey. Figure 2.2 provides an overview of the numbers of participating patients per country. It shows that 17 countries did not reach the target of 1250[9] (or 500) participating patients, which is mainly due to countries not reaching their target for participating primary care providers. Country G had the highest number of participating patients (2,360).

32. Of the 11,885 patients who started to fill out the questionnaire, 10,894 completed it (92%), implicating an overall drop-out of 8%. Figure 3.2 shows that the proportion of patients who dropped out varied across countries (from 0% to more than 20%). The NPM from country Q reported that the relatively high drop-out is probably due to the fact that the first group of patients [10] invited for the PaRIS survey were previously hospitalised patients who were asked to fill out the PaRIS questionnaire after first completing another questionnaire. The NPM's team from country C interpreted this high drop-out as a result of the length of the questionnaire and, to a lesser extent, to the lack of previous experiences with completing such questionnaires in the country. Furthermore, both country Q and C only offered the online version of the patient questionnaire for the Field Trial (see Table 2.3), which may not be the ideal way of filling in the questionnaire for all invited patients. Three other countries with a relatively high drop-out (Country K, R, B) also only offered the online version of the questionnaire.

[9] In Country A, the Field Trial was conducted differently from what is planned for the Main Survey, as the sampling procedure that is envisaged for the Main Survey was not possible due to limited time available for the Field Trial (Country A entered the PaRIS survey at a rather late stage). Therefore, the patient and provider questionnaires were piloted in separate samples that could not be linked.

[10] Country Q submitted additional patient data in December 2022. Contrary to the first set of patient data, this second dataset included data from patients who met the eligibility criteria and had been recruited in accordance with the PaRIS guidelines.

Figure 2.2. Overview of number of participating patients per country



Note: Country names are pseudonymised in the x-axis.
Source: PaRIS Field Trial Data 2022

33. We calculated the (gross) response rate by dividing the total number of patients who gave consent by the sample size as reported by NPMs in their sampling report. Table 2.2 shows that the response rates for patients between countries varied at lot. However, the accuracy of the response rates is questionable as some countries did not have access to up-to-date patients' contact information. This means that a substantial number of sampled patients were not reached. In addition, some countries did not propose alternative methods of data collection such as paper-and-pencil surveys (see Table 2.3), which could also lead to lower response rates by some groups of patients. As seen in Table 2.2 and Table 2.3, countries with the highest response rates offered two methods of data collection (e.g., country A used both online and paper-and-pencil methods). There were also variations in communication and stakeholder engagement strategies between countries, which could have an impact on response rates (Kendir et al., 2023[2]). Nevertheless, it should be concluded that, in general, the response of patients was lower than expected (target was set at 50%) .

Table 2.2. Response of patients per country

	Total patient sample			Patients per practice		
	Sample size (n)	Consent (n)	Response rate	Mean	Minimum	Maximum
Country A	702	512	73%	-*	-	-
Country H	896	453	51%	23	2	55
Country P	2 382	1052	44%	87	57	150
Country L	1 700	694	41%	69	47	97
Country G	5 839	2360	40%	117	97	133
Country F	3 040	1219	40%	49	45	52
Country R	2 890	788	27%	36	4	136
Country J	4 340	980	23%	58	12	77
Country I	668	143	21%	36	28	43
Country O	1 150	198	17%	33	25	42
Country D	3 454	484	14%	18	2	64
Country E	10 323	1237	12%	45	8	52
Country K	3 006	338	11%	18	7	39

Country M	698	71	10%	5	1	19
Country C	10 000	531	5%	11	1	22
Country Q	7 893	423	5%	-*	-	-
Country B	15 422	506	3%	8	2	19
Country N	1 250	10#	<1%	10	10	10

Note: Country names are pseudonymised. * patient data not linkable with practice data # data from one primary care practice at this stage
Source: PaRIS Field Trial Data 2022

2.3. Data collection and administration mode

34. Twelve of the 18 countries that submitted data used the central online platform created by the consortium for data collection; six countries used their own (decentral) platform.

35. Regarding the administration mode, both questionnaires (for primary care practices and patients) were designed for online administration. To improve access to the patient survey, countries were recommended to also offer a paper-and-pencil version to patients. Additionally, two countries offered a telephone interview as alternative to the first two options.

36. Table 2.3 provides an overview of the data collection platforms used, and the administration modes offered for the survey in the countries. All practice questionnaires were administered online, in line with the PaRIS study protocol. Two thirds of the patients' data (7,588 / 11,999; 63%) were collected via the online questionnaire; 1,955 questionnaires were completed on paper (16%). Country E and F offered the patient questionnaire by telephone, as this better suited their citizens' preferences and values. Country N intended to offer both online and paper questionnaires, but as there was only one practice with patients participating in the Field Trial at the time, only the paper questionnaire was offered to patients.

Table 2.3. Overview of data collection approach

	Overview of data collection approach	Primary care practices	Patients		
		Online	Online	Paper	Telephone
Country K	Centralised	+	+		
Country L	Centralised	+	+	+	
Country R	Decentralised	+	+		
Country D	Centralised	+	+	+	
Country G	Centralised	+	+	+	
Country A	Centralised	+	+	+	
Country C	Centralised	+	+		
Country O	Centralised	+	+		
Country Q	Decentralised	+	+		
Country I	Decentralised	+	+	+	
Country P	Centralised	+	+	+	
Country J	Decentralised	+	+	+	
Country B	Centralised	+	+		
Country N	Centralised	+		+	
Country E	Decentralised	+			+
Country H	Centralised	+	+	+	
Country F	Decentralised	+			+
Country M	Centralised	+	+		

Note: Country names are pseudonymised.
Source: PaRIS Field Trial Data 2022

2.4. Participant characteristics

37. This chapter provides more information about the participants in the Field Trial. Participating primary care practices are characterised based on the location of the practice in the country and the type of practice. Participating patients are characterised according to gender, age, education level, the country they are born in, and the number and type of their (self-reported) chronic conditions.

38. This chapter is based on data provided by 499 primary care practices (in 16 countries) and 9,359 patients (in 15 countries), which were submitted by 23 September 2022. The information is based on the data provided by participants who completed the questionnaire.

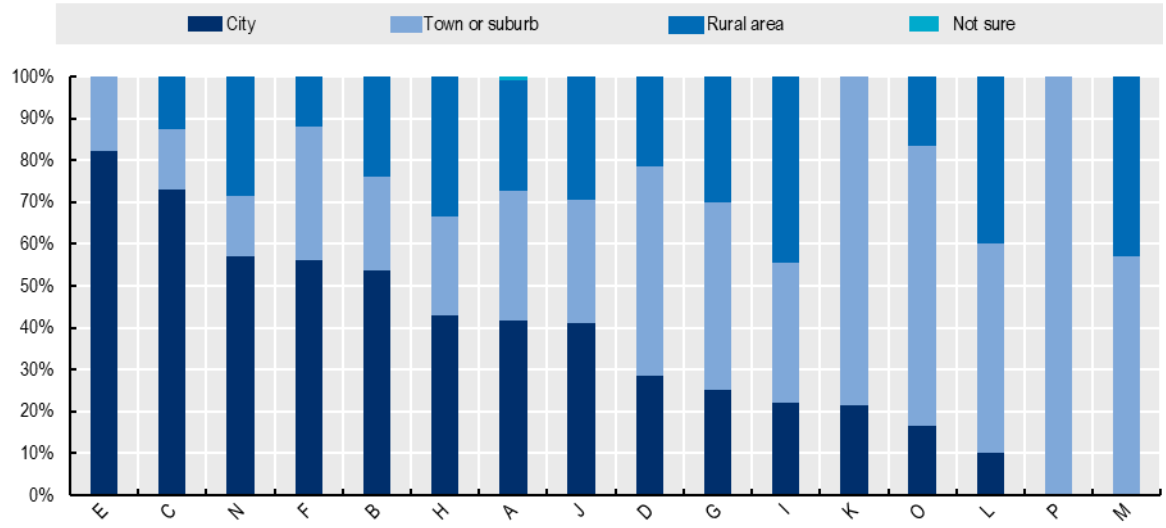
2.4.1. Characteristics of participating primary care practices

39. In this section the primary care practices are described according to some basic characteristics, such as location and practice type.

Location

40. The 499 participating practices are distributed differently according to the urbanisation level of their location in countries (Figure 2.3). The share of practices located in cities ranges from 0% to 82%. With regards to participating practices located in towns/suburbs, the percentages range from 14% to 100%. The highest percentage of participating practices in rural areas was highest 44% and the lowest was 0%.

Figure 2.3. Location of participating primary care practices, distribution per country



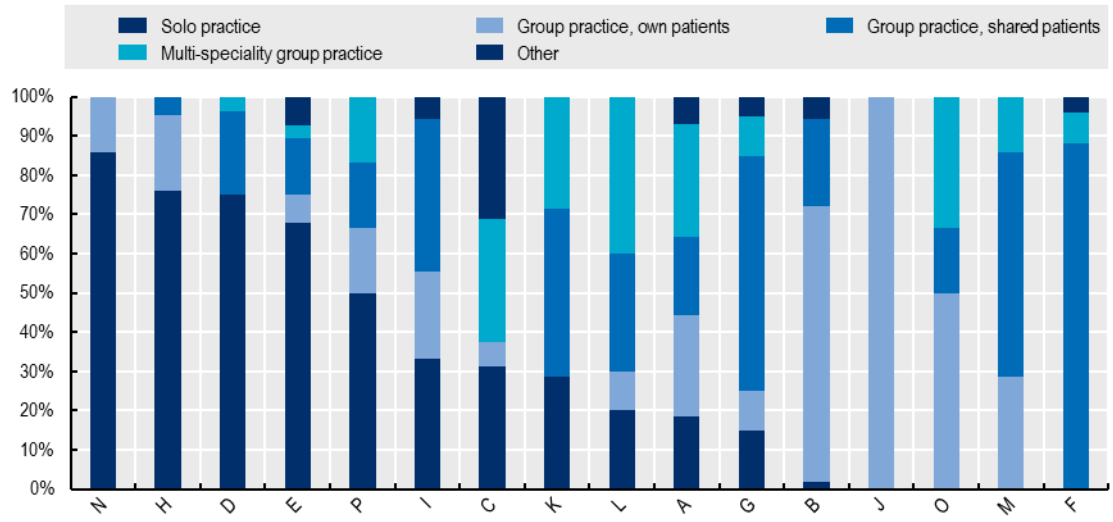
Note: Country names are pseudonymised in the x-axis.
Source: PaRIS Field Trial Data 2022

Practice type

41. The distribution of participating practices according to practice type also differs between countries. For example, as represented in Figure 2.4, in the first four countries, a large majority of the participating practices are solo practices, whereas in the latter four there are no solo practices participating. This relates to the fact that some practice types are more common in some countries than in others. However, this

does not mean that the observed differences are representative for the population difference between the countries[11].

Figure 2.4. Type of participating primary care practices, distribution per country



Note: Country names are pseudonymised in the x-axis. Other category combines the count of respondents that self-reported other and not sure.
Source: PaRIS Field Trial Data 2022

2.4.2. Characteristics of participating patients

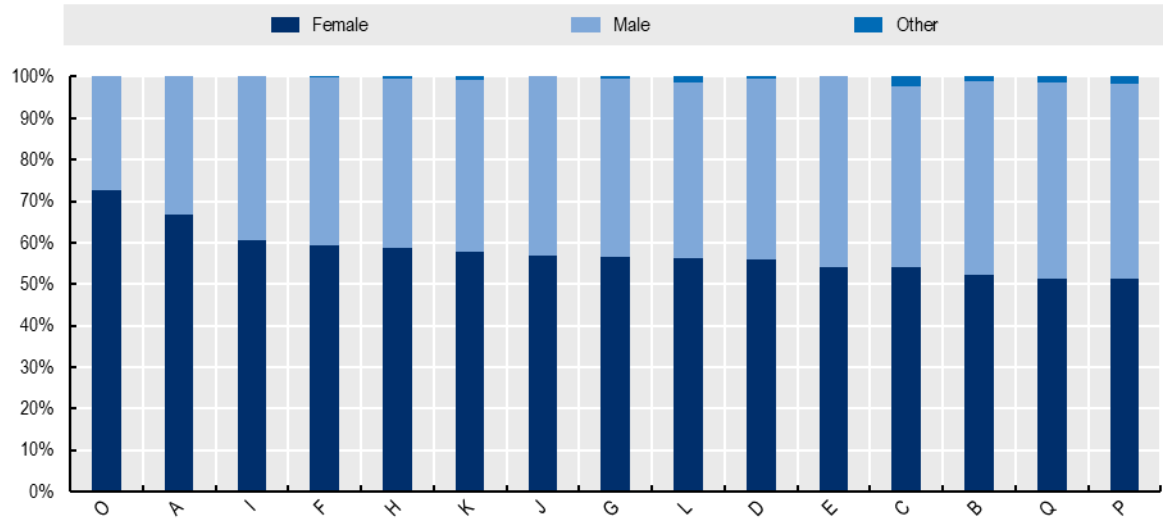
42. This section describes the participating primary care patients according to some basic characteristics: gender, age, level of education, country of birth, and number and type of self-reported chronic conditions.

Gender

43. Figure 2.5 shows that in all countries the majority of participating patients were women, which is to be expected as the proportion of women over the age of 45 is slightly higher than that of men, women are more likely to use primary care services and to participate in surveys than men. However, in country A and O the proportion of women was much higher than in the other countries. Only a few patients self-reported as non-binary (n=1) or with another gender identity (n=8); some preferred not to say. These are combined in the category 'other' in Figure 2.5.

[11] Representativeness of primary care practices at country level was not a requirement for the Field Trial.

Figure 2.5. Gender identity of participating patients, distribution per country

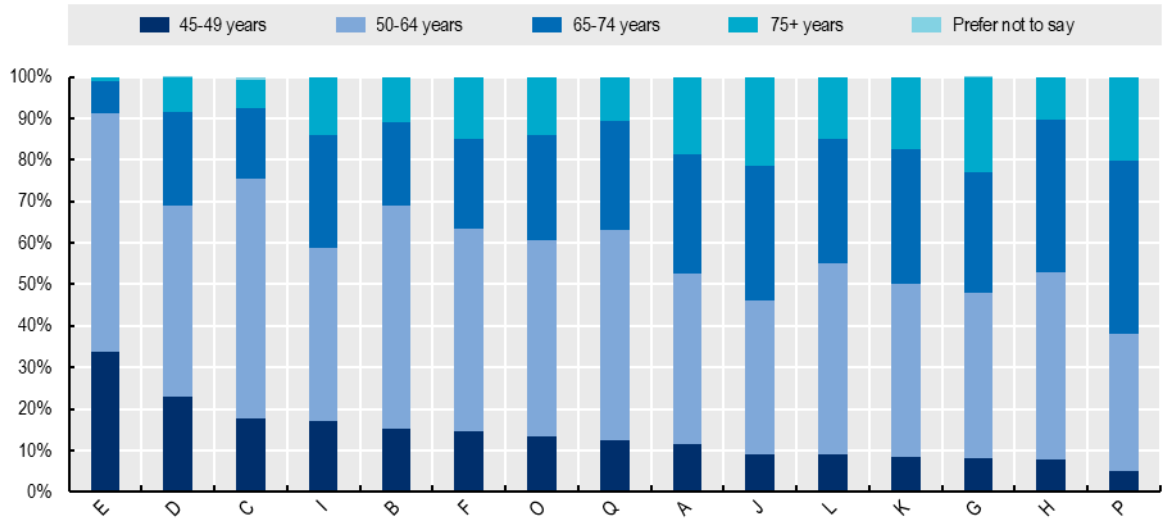


Note: Country names are pseudonymised in the x-axis. Other category combines the count of respondents that self-reported non-binary, other and prefer not to say
Source: PaRIS Field Trial Data 2022

Age

44. Figure 2.6 shows that in all countries except country P, the largest group of participating patients were aged 50 to 64 years. Country E had a rather young participant group, which was expected given the relatively young population of the country.

Figure 2.6. Age of participating patients, distribution per country

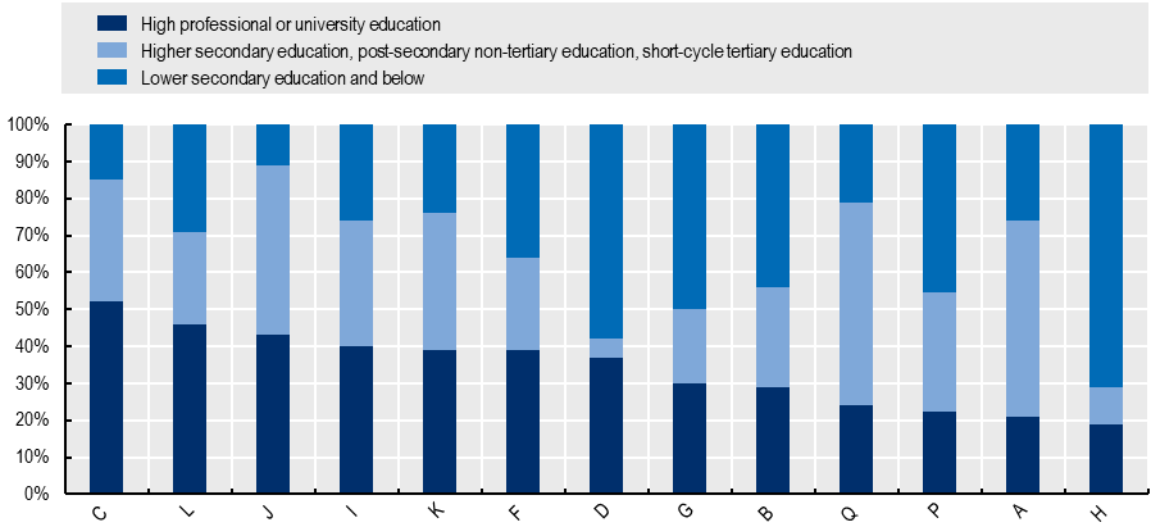


Note: Country names are pseudonymised in the x-axis.
Source: PaRIS Field Trial Data 2022

Education level

45. There are substantial differences between countries in the distribution of the participating patients by highest level of education attained. For example, as shown in Figure 2.7, 40% or more of the participating patients in the first four countries had completed education at high professional or university level, whereas in the last four countries it was less than 25%. In Countries D, G and H, 50% or more of all participants had not completed any education or left school after completing primary or lower secondary education. The percentages shown in Figure 2.7 should not be interpreted as reflecting the distribution of educational attainment of the population aged 45 and over in each country.

Figure 2.7. Education level of participating patients, distribution per country

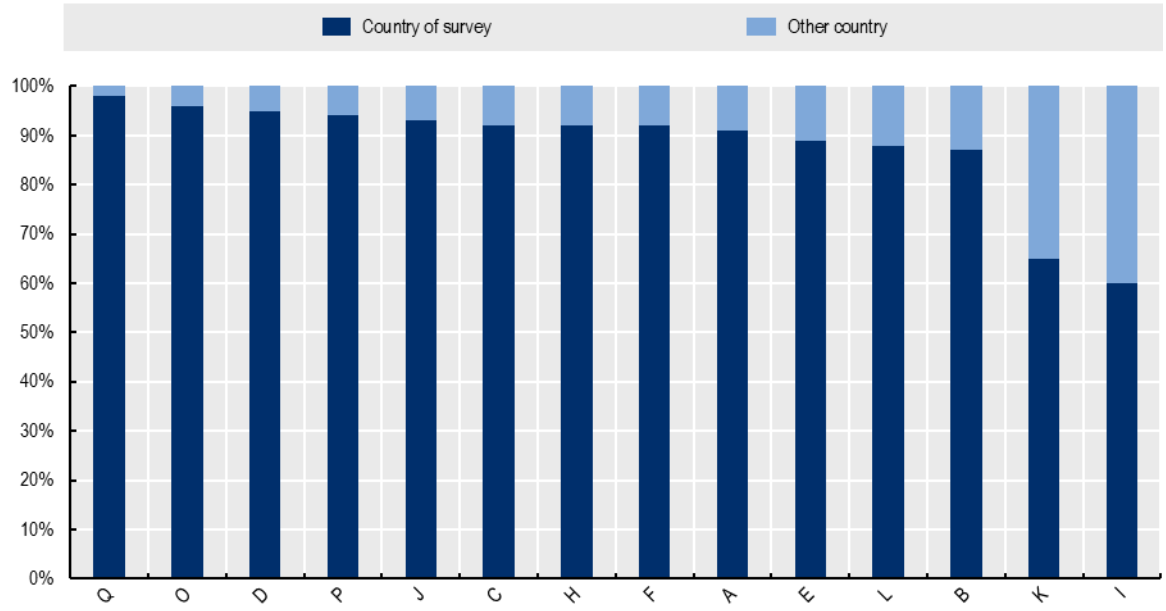


Note: Country names are pseudonymised in the x-axis. Data are missing for Country O (not received) and Country E (used own coding system; will be converted for main stage).
Source: PaRIS Field Trial Data 2022

Country of birth

46. Figure 2.8 shows the proportion of participating patients who were born in the country where the survey was conducted or in another country. It shows that in most countries around 90% or more of the participating patients were born the country of the survey. Country K and I had a much larger proportion of participants that were born in another country, 35% and 40% respectively. This is consistent with the demographic profile of these countries.

Figure 2.8. Participating patients born in country of survey versus other country, distribution per country

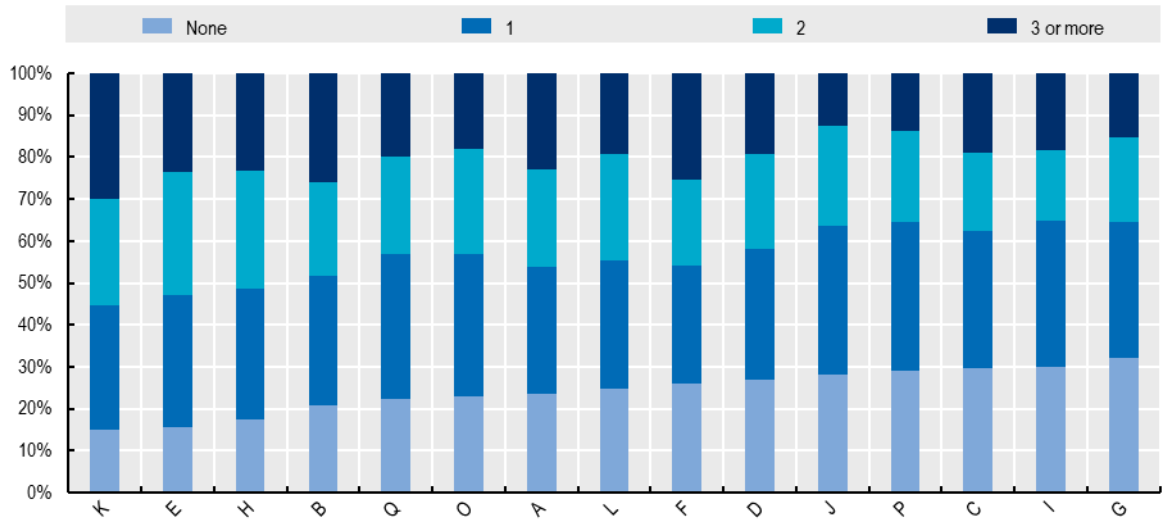


Note: Country names are pseudonymised in the x-axis. Data are missing for Country G, because country of birth was considered difficult to ask without a full legal review first.
Source: PaRIS Field Trial Data 2022

Number of chronic conditions

47. Figure 2.9 shows the proportions of patients who reported having chronic conditions (or not). Based on previous studies, it was expected that around 70% of the participating patients would have at least one chronic condition, which seems to be confirmed for most countries. In the first three countries, the proportion of participants reporting at least one chronic condition was even higher (>80%). Figure 2.9 also shows that multimorbidity, i.e. having at least two or more chronic conditions, is more commonly reported by PaRIS Field Trial participants than having one condition in most countries.

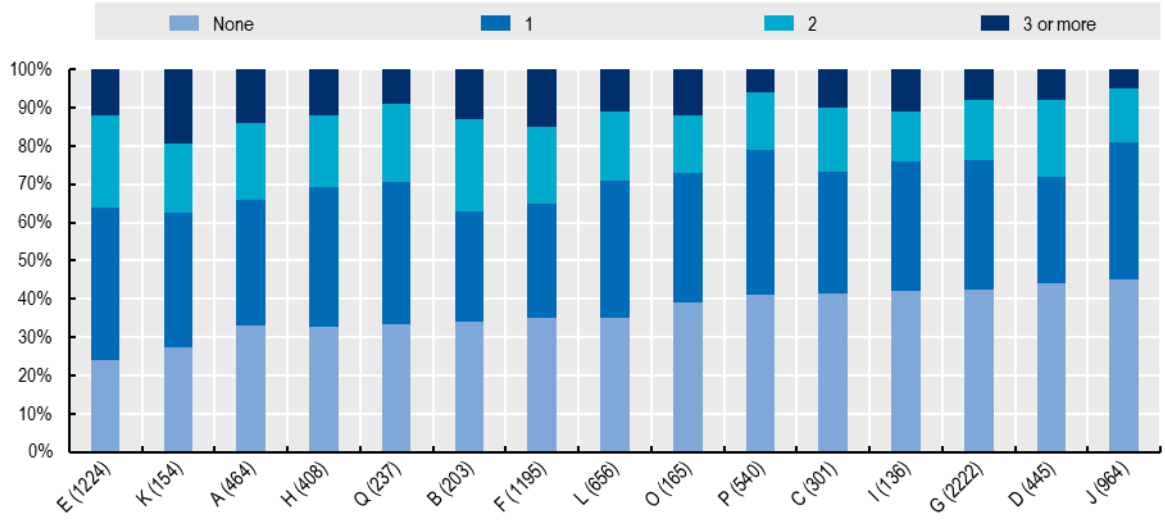
Figure 2.9. Number of chronic conditions reported by participating patients, distribution per country



Note: Country names are pseudonymised in the x-axis.
Source: PaRIS Field Trial Data 2022

48. One of the most common conditions is high blood pressure (see Table 2.4). Figure 2.10 shows that excluding high blood pressure decreases the proportion of participating patients reporting at least one chronic condition in most countries by around 10%, except for countries D and J (17%), and countries O and H (16%).

Figure 2.10. Number of chronic conditions (excluding high blood pressure) reported by participating patients, distribution per country



Note: Country names are pseudonymised in the x-axis. Total sample size denoted in parenthesis
Source: PaRIS Field Trial Data 2022

Type of chronic conditions

49. Table 2.4 provides information on the types of chronic conditions reported by the participating patients in each country. The table reflects the previously mentioned high prevalence of high blood pressure among the participants in all countries. It also shows that for many conditions the proportions reporting the condition vary across countries. This may be partly because the numbers of participating patients were still low in some countries by the end of September 2022. Nevertheless, some observed differences may deserve further exploration. For example, a remarkable observation is the high proportion of participants in Country E who reported to have diabetes (51%), which is much higher than in other countries.

50. Some other notable observations are the substantial differences in reported arthritis or problems with back or joints; the prevalence ranges between 13% and 38%. Further research is needed to get a better understanding of such differences, for example, whether they reflect differences in the prevalence of the condition between countries, cultural differences in the reporting of such conditions, differences in translation or differences in the patient samples drawn in each country. In this respect, further examination is also needed to better understand the differences in reporting of mental health conditions (ranging from 7% to 34%).

51. Also noteworthy is the high proportion of participants in Country Q who reported to have cancer (27%). This is probably due to the deviating sampling frame that was used in Country Q, which sampled a first group of patients who had been hospitalised previously and who were enrolled in a continuous web survey on patients' hospitalisation experience. This means that the sample from the first group[12] was biased towards people with more serious conditions for which they had recently been hospitalised.

[12] Country Q sampled another group of patients at a later stage, whose data were not all received by 23 September 2022, and are thus not included in the analysis.

Table 2.4. Prevalence of chronic conditions reported by patients per country

	High blood pressure	Cardiovascular or heart condition	Diabetes (type 1 or 2)	Arthritis or problem with back or joints	Breathing condition	Alzheimer disease or other cause of dementia	Depression, anxiety or other mental health condition	Neurological condition	Chronic kidney disease	Chronic liver disease	Cancer
Country K	53%	21%	23%	34%	20%	1%	23%	6%	4%	1%	11%
Country L	42%	18%	17%	34%	11%	1%	11%	7%	2%	1%	7%
Country D	47%	11%	14%	27%	16%	0%	11%	8%	3%	2%	5%
Country G	35%	10%	12%	30%	14%	1%	13%	3%	2%	1%	6%
Country A	39%	20%	15%	29%	17%	0%	17%	7%	2%	2%	9%
Country C	38%	14%	20%	24%	12%	1%	14%	4%	2%	0%	7%
Country O	45%	26%	8%	13%	18%	1%	19%	7%	3%	1%	9%
Country Q	36%	23%	10%	14%	12%	1%	7%	4%	6%	1%	27%
Country I	37%	18%	8%	25%	10%	1%	16%	6%	4%	4%	5%
Country P	38%	16%	13%	23%	12%	1%	7%	4%	2%	0%	10%
Country J	44%	17%	11%	20%	13%	-*	8%	5%	-*	-*	9%
Country B	45%	14%	14%	37%	14%	0%	34%	4%	3%	2%	8%
Country E	44%	12%	51%	38%	11%	1%	7%	4%	3%	1%	2%
Country H	57%	25%	18%	37%	15%	0%	12%	4%	3%	1%	7%
Country F	39%	13%	13%	38%	13%	2%	23%	7%	5%	3%	7%

Note: Country names are pseudonymised. *Because of a risk of identification due to very low numbers, Country J[13] recoded these cases and included them in the response option 'other chronic condition' (data not shown), when submitting their data.
Source: PaRIS Field Trial Data 2022

[13] Country J submitted anonymised patient data, whereas other countries submitted pseudonymised patient data, for which a data processing agreement was signed between the country and Nivel (Contractor).

3. Paradata

This chapter provides information on the patient and practice questionnaires, the modes of administration used by patients in each country, in relation to their age. It also reports on the time taken by patients to complete the online questionnaire, in relation to the language in which the questionnaire was offered, their age and the number of chronic conditions reported.

52. Based on data provided by 499 primary care practices (in 16 countries) and 9 359 patients (in 15 countries), which were submitted by 23 September 2022, this chapter provides more information on how the PaRIS Field Trial was conducted in each country. Section 3.1 focuses on the practice questionnaire and reports the time taken by primary care providers to complete it. Section 3.2 focuses on the patient questionnaire.

3.1. Practice questionnaire

3.1.1. Completion time

53. Table 3.1 shows the time (in minutes) taken by primary care providers to complete the practice questionnaire. Data are shown only for countries that used the central data collection platform. As Country L is the only country that provided data before 23 September 2022 using more than one language, the results are shown for both language questionnaires separately.

54. The median time to complete the questionnaire is around 20 minutes for all countries. However, the time taken by individual respondents ranges from less than ten minutes to more than half an hour in nine countries, and more than an hour in four countries. These long completion times are most likely due to the daily practice of primary care, i.e., the online questionnaire is completed between patient consultations or other tasks and remains open until the final questions are answered.

Table 3.1. Time (in minutes) for completing the online practice questionnaire by providers per country

	N	Median (min)	Minimum (min)	Maximum (min)
Country L – language version 1	5	12	4	167*
Country P	6	12	9	25
Country M	7	12	9	17
Country C	48	16	6	45
Country L – language version 2	5	17	10	24
Country H	21	18	8	48

Country K	14	19	8	41
Country D	28	19	8	84
Country A	190	19	6	231*
Country O	6	21	15	51
Country G	20	24	8	53
Country B	54	24	6	141*
Country N	7	28	10	46

Note: Country names are pseudonymised. * Long completion times are most likely due to the daily practice of primary care, i.e., the online questionnaire is completed between patient consultations or other tasks and remains open until the final questions are answered.
Source: PaRIS Field Trial Data 2022

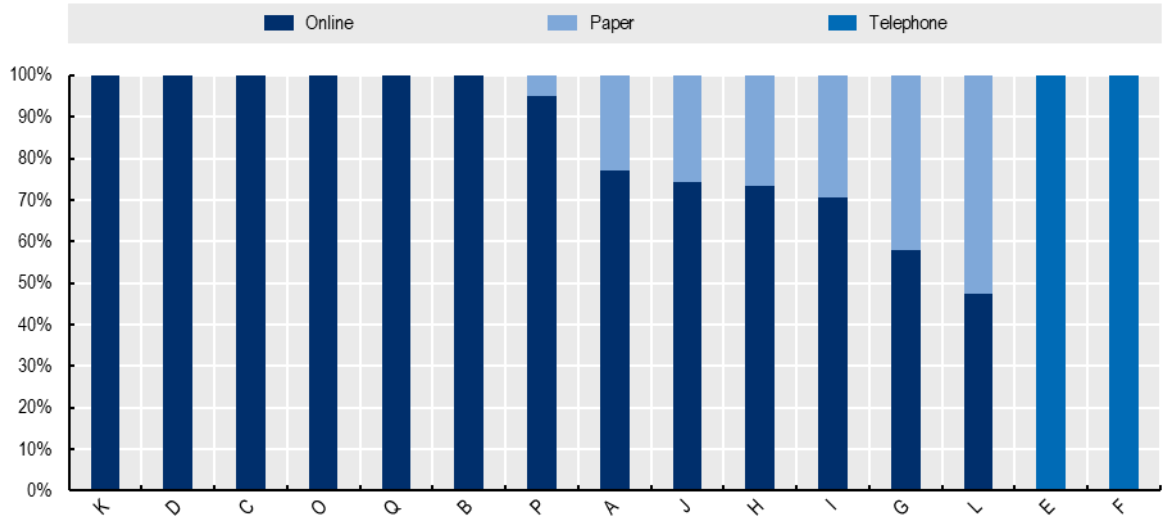
3.2. Patient questionnaire

3.2.1. Administration mode

55. Online is considered as the preferred mode of administration for the patient questionnaire, but countries were encouraged to also offer a paper questionnaire to improve access to the survey, or to consider other modes of administration to ensure the survey is as inclusive as possible.

56. Figure 3.1 shows that 13 out of 15 countries offered the questionnaire online. Six countries offered only online administration of the questionnaire. Seven countries also offered paper questionnaires. Two countries offered the patient questionnaire in a telephone mode, as this better suited the preferences and values of their citizens.

Figure 3.1. Administration mode for responding to the patient survey, distribution per country



Note: Country names are pseudonymised in the x-axis. Countries E and F only offered the telephone mode as this better suited the preferences and values of their citizens.
Source: PaRIS Field Trial Data 2022

3.2.2. Administration mode according to patients' age

57. Table 3.2 shows the distribution of age groups within each mode of administration offered by the countries. Additionally, Table 3.3 shows within each age group the distribution across the different administration modes that were offered. The latter table only includes countries that offered more than one

administration mode for the patient questionnaire. Table 3.3 shows that in all countries, except country A, the proportion of patients completing the questionnaire on paper increases by age. The extent to which paper questionnaires were offered – or how difficult it was for patients to receive a paper questionnaire – varied between countries.

Table 3.2. Distribution of age groups of participating patients within the administration mode(s) offered by countries

		N	45-54	55-64	65-74	75 and older	Total
Country K	Online	154	23%	27%	32%	18%	100%
Country L	Online	313	32%	34%	26%	9%	100%
	Paper	346	12%	33%	34%	21%	100%
Country D	Online	453	39%	30%	23%	8%	100%
Country G	Online	1291	22%	33%	29%	16%	100%
	Paper	916	15%	24%	30%	32%	100%
Country A	Online	359	26%	27%	28%	18%	100%
	Paper	107	20%	30%	30%	21%	100%
Country C	Online	301	38%	37%	17%	7%	100%
Country O	Online	165	27%	34%	25%	14%	100%
Country Q	Online	235	27%	36%	26%	11%	100%
Country I	Online	96	40%	34%	21%	5%	100%
	Paper	40	8%	15%	43%	35%	100%
Country P	Online	517	12%	27%	42%	18%	100%
	Paper	28	0%	11%	32%	57%	100%
Country J	Online	723	21%	30%	33%	16%	100%
	Paper	247	13%	17%	32%	38%	100%
Country B	Online	203	38%	31%	20%	11%	100%
Country E	Telephone	1218	64%	27%	8%	1%	100%
Country H	Online	301	23%	38%	33%	6%	100%
	Paper	108	6%	22%	48%	23%	100%
Country F	Telephone	1192	29%	34%	22%	15%	100%

Note: Country names are pseudonymised.
Source: PaRIS Field Trial Data 2022

Table 3.3. Distribution of administration modes used by patients within age groups

		45-54	55-64	65-74	75 and older
Country L	Online	71%	48%	40%	28%
	Paper	29%	52%	60%	72%
		100%	100%	100%	100%
Country G	Online	67%	66%	58%	42%
	Paper	33%	34%	42%	58%
		100%	100%	100%	100%
Country A	Online	82%	75%	76%	75%
	Paper	18%	25%	24%	25%
		100%	100%	100%	100%
Country I	Online	93%	85%	54%	26%
	Paper	7%	15%	46%	74%
		100%	100%	100%	100%
Country P	Online	100%	98%	96%	86%
	Paper	0%	2%	4%	14%
		100%	100%	100%	100%

Country J	Online	83%	84%	75%	55%
	Paper	17%	16%	25%	45%
		100%	100%	100%	100%
Country H	Online	91%	83%	66%	40%
	Paper	9%	17%	34%	60%
		100%	100%	100%	100%

Note: Country names are pseudonymised. Only countries that offered the patient questionnaire in more than one administration mode are included in the table.
Source: PaRIS Field Trial Data 2022

3.2.3. Completion time

58. For patient questionnaires completed online via the central data collection platform, the completion time was recorded automatically. Based on these data, Table 3.4 shows how long it took patients in the different countries using the central platform to complete the online questionnaire. It was expected that patients would take around 25 minutes to complete the entire questionnaire, with some variation resulting from the answers given, as some questions were not applicable to all patients and could therefore be skipped.

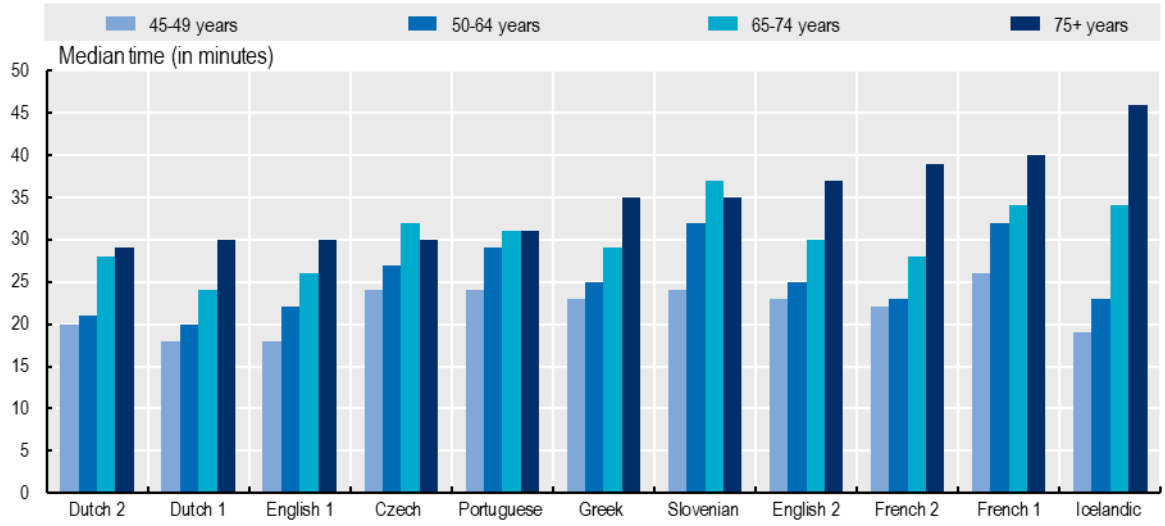
59. Table 3.4 shows that the median time ranged from 24 to 33 minutes across countries. As with the practice questionnaire, there may be many factors influencing completion time for the patient questionnaire, such as translations and patient characteristics (e.g. age, health literacy, digital literacy, presence of chronic conditions and functional limitations). Figure 3.2 and Figure 3.3 show the extent to which completion time appears to be related to patients' age and number of chronic conditions.

Table 3.4. Time (in minutes) for completing the online patient questionnaire per country and language

	N	Median	Minimum	Maximum
English 1	1291	24	7	232
Dutch 2	173	24	5	214
Dutch 1	517	24	10	193
French 2	140	25	5	144
Greek	302	26	6	179
English 2	154	27	12	196
Icelandic	165	27	12	162
Czech	453	28	8	271
Portuguese	203	28	12	156
Slovenian	301	33	12	227
French 1	359	33	12	188

Source: PaRIS Field Trial Data 2022

Figure 3.2. Median time (in minutes) to complete the online patient questionnaire, distribution according to age groups

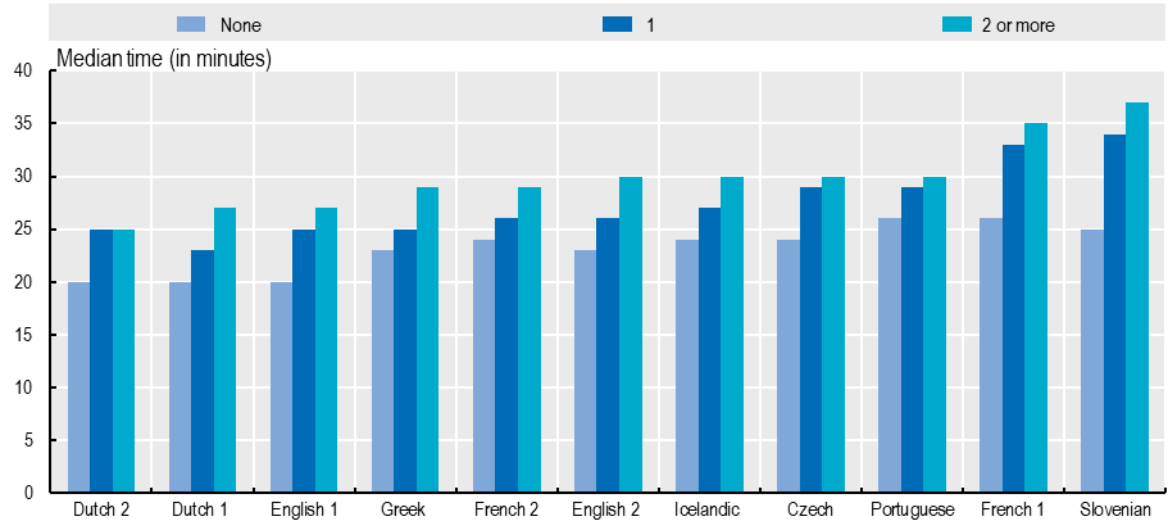


Source: PaRIS Field Trial Data 2022

Completion time according to patients' age

60. Figure 3.2 shows that older people took longer to complete the online questionnaire than younger people. Figure 3.3 shows that patients with chronic conditions took more time to complete the online questionnaire than patients who did not report a chronic condition. This is partly because some questions were not relevant to people who did not report a chronic condition and were therefore not asked to them. In addition, functional impairments related to the chronic condition(s) may have an impact on the completion time; it is likely that people who have some types of visual or motor impairments will take more time to complete the online questionnaire. Furthermore, people with (multiple) chronic conditions are on average older than people without such conditions or with one chronic condition. The differences observed may therefore partly reflect age-related differences between participants, for example in educational level, health or digital literacy.

Figure 3.3. Median time (in minutes) to complete the online questionnaire for patients without chronic conditions and patients with one or more chronic conditions



Source: PaRIS Field Trial Data 2022

4. Performance of the patient questionnaire

This chapter is based on data from 10 145 patients who answered some or all the questions, i.e., all patients who provided valid data. The data from 15 countries were submitted by 23 September 2022. In section 4.1 the performance of the questionnaire items is described. Section 4.2 reports on the construction of scales based on sets of questions/items that are expected to measure certain constructs (latent variables). It also evaluates the reliability of the constructed scales. In section 4.3 a first exploration of the construct validity of these scales is described.

4.1. Performance of questions

61. Supplement 2 provides an overview of all questions of the patient questionnaire and their performance in terms of the proportion of missing answers and the distribution of valid answers. Main observations are described below.

4.1.1. Missing answers

62. Proportion of missing answers[14] were reviewed for each item and considered proportions of 10% or higher indicative of poor performance of the question in terms of applicability to the responding patients or understandability. As shown in Supplement 2, from the total set of 118 questions, there were only three questions with 10% or more answers missing. Box 4.1 provides an overview of the questions with 10% or more missing answers.

[14] This refers to missing values indicating that the respondent should have answered the question (the question was applicable) but did not do so.

Box 4.1. Questions of the patient questionnaire with 10% or more missing answers

Which of these categories does your household net income usually falls into? (13% missing answers)

The highest proportions of missing responses, ranging from 21% to 48%, were found in three countries. In other countries, the proportion of missing answers was relatively low.

This question was selected from OECD Financial Literacy Questionnaire. A reason for the high proportion of missing answers in some countries may be the sensitivity of the question; asking about income may be considered impertinent. Large population surveys conducted in the USA and Australia have reported missing data on income ranging from 10% to 33% of all cases, depending on many factors including how specific income was asked.

How many children under the age of 18 live with you, in your household? (10% missing answers)

Country-specific analyses show that the highest proportion of missing answers was 30%, followed by 24%.

This question was selected from the OECD Financial Literacy Questionnaire. This question may have been difficult for some respondents to answer, as the meaning of 'household' may not have been entirely clear. For example, a respondent who lives separately from his/her children (most of the time) may not be sure what to answer, especially if (s)he shares parental responsibilities. The question may also be considered sensitive in such cases.

How many people aged 18 and over live with you, in your household? (11% missing answers)

Country-specific analyses show that the highest proportions of missing answers were 49%, followed by 26%.

This question was also selected from the OECD Financial Literacy Questionnaire. Possible explanations for the relatively high number of missing answers in some countries may be similar to those described above. In the case of people aged 18 and over, it may also be difficult to answer the question if adult children live elsewhere to study while still being financially dependent on their parent(s).

4.1.2. Distribution of answers

63. Supplement 2 shows that many questions had a fairly normal, bell-shaped distribution of valid answers, with a few exceptions such as question 12 (How would you rate your pain on average?), of which the distribution is skewed to the left (many people indicate to have no pain at all and scored 0). This is not an indication of poor performance of the question, but most likely a good reflection of the level of pain that can be expected in the target population of the PaRIS survey.

64. There are several other questions with a somewhat skewed distribution, but this is also understandable from the nature of these questions. For example, when asked if they needed physical care or support, such as help with eating, dressing, bathing, moving around the house or assistance outside the house such as using transport (question no. 114), 86% answered 'no'. This is most likely a good reflection of physical status of the target population of the PaRIS survey, and not an indication of a possible ceiling or floor effect (i.e., that a large proportion of responses fall into the most extreme category, which does not measure the true value well).

65. All questions with a relatively high proportion of answers in the same answering category were reviewed, which led to adjustment of the answer categories in one item. This is question no. 70: "How many different medications as prescribed by a doctor or a nurse are you taking on a regular or ongoing basis?" This question has a large proportion (62%) of all answers in answering category '1-4 medications. Splitting this category in two may increase the variation across respondents, and thus the informative value of the question. The answering categories have been revised accordingly in the Main Survey.

4.2. Scale construction and reliability

4.2.1. Methods

66. The patient questionnaire contains questions that assess several constructs as outlined in the conceptual framework (Figure 1.1). These are constructs in four domains: 1. patient reported outcomes, 2. patient reported care experiences, 3. patients' health risk behaviours, and 4. patients' capabilities to manage their health and care. In three of the four domains (except for the third domain) the questionnaire included at least one measuring instrument that had proven to be reliable and valid to assess the specific construct in several countries. Furthermore, the patient questionnaire included (sets of) single questions, either from other questionnaires or newly developed, to assess all other constructs of the four domains mentioned above.

67. In this section we focus on the performance of the validated measuring instruments. For the patient-reported outcome measures, we also conducted some exploration of the reliability of sets of questions, for example on pain or depressive symptoms, that had not been previously combined to assess certain concepts. This was done to assess whether these questions could be combined into a scale.

68. Both single-level and multilevel analyses were conducted. The single-level analyses allow comparison of the performance of the instruments with the results of other studies in which they have been used. The multilevel analyses do more justice to the nested structure of the PaRIS data, and therefore better inform how the measuring instruments will perform in the PaRIS survey.

Single-level analysis

69. Single-level analysis consisted of factor analysis and reliability analysis. For already extensively validated scales, confirmatory factor analysis was used. For scales that had been validated to a lesser extent in other studies, exploratory factor analysis was conducted.

Confirmatory factor analysis

70. We estimated the extent to which the data collected in all countries reflected the (multidimensional) construct that the instrument was designed to measure. The results of this analysis are shown in the row entitled 'Overall model – all countries together' (Table 4.1 and Table 4.3).

71. Next, we estimated a series of models to get insight in the extent to which the factor structure remained invariant across countries (multigroup confirmatory factor analysis). If this is not the case, comparing the scale scores between countries is possible, but the results may be difficult to interpret, and further examination of the differences in the factor structure between countries may be needed. We tested a series of three models, which are specified in Box 4.2

Box 4.2. Four models used in factor analysis

Four models were applied in analysing the confirmatory factor analysis. These models are used to assess whether the relationships between observed variables (e.g. an answer to a specific question) and underlying factors (e.g. a scale for quality of life) are consistent across different countries.

- The **overall model:** in this model there are no restrictions related to factor structures in specific countries, the model 'ignores' the country level.
- The **configural model:** This model assumes that the basic structure of the factors (or underlying constructs) is the same across countries. However, it allows for differences in the specific relationships between the observed variables (indicators) and the underlying factors, as well as differences in the measurement error of these indicators, across countries.
- The **metric model**: This model is more restrictive than configural model; It not only assumes that the basic structure of the factors is the same across countries, but it also requires that the strength of the relationships between the observed variables and the underlying factors (known as factor loadings) is similar across countries. In other words, it assumes that the way in which the observed variables measure the underlying factors is comparable across countries.
- The **Scalar model:** This is the most restrictive model among the three. In addition to the restrictions of the other models, it also requires that the error terms are comparable across countries.

Source: (Van de Vijver et al., 2019[5]; Davidov et al., 2014[6]; Cieciuch et al., 2016[7])

Exploratory factor analysis

72. Exploratory factor analyses were conducted to gain insight into the dimensionality of the measuring instrument. Promax (oblique) rotation was applied to interpret the identified dimensions, considering that they would be correlated given the nature of the patient-reported constructs.

Reliability analysis

73. Cronbach's alpha, a measure of internal consistency reliability, was calculated for each of the (sub) scales of the already validated instruments. Cronbach's alpha was also calculated for sets of questions that had not been used in previous studies to assess a certain construct. In the latter case, it was done for exploratory purposes, i.e., to get some first information on whether such questions could be combined in a scale at a later stage (e.g., Main Survey).

Multi-level analysis

74. Multi-level analysis consisted of estimation of the reliability coefficient (comparable with Cronbach's alpha in the single level model), but now not only at the patient level, but also at the primary care practice and country levels. The reliability of the constructs at these higher levels is important to allow multilevel regression analyses to answer the main research questions of the PaRIS survey. These analyses were conducted for all scales, for which we also calculated Cronbach's alpha.

4.2.2. Patient-reported outcome measures

Factor structure

75. Among the patient-reported outcome measures (PROMs) included in the patient questionnaire there were three previously validated scales for which we tested the presumed factor structure by means of confirmatory analysis: the PROMIS Global – Physical Health and Mental Health scales (Hays et al., 2009[8]), and the WHO-5 Wellbeing Index (Topp et al., 2015[9]). The results are summarised in Table 4.1. The table shows several measures that give an indication of the model fit: the Chi2coefficient, the Root Mean Squared Error of Approximation (RMSEA), the Standardised Root Mean Squared Error (SRMR), the Comparative Fit Index (CFI) and the Tucker Lewis incremental fit Index (TLI). High Chi2-coefficients point to worse model fits, but this coefficient dependents highly on the number of observations, and therefore it is not a good indicator for model fit in large studies such as PaRIS survey. RMSEA and SRMA values lower than .05 or .08[15] and CFI and TLI values higher than .90 are generally considered to indicate a good model fit. Supplement 1 provides detailed information on the fit indices. The PROMIS Global – Physical scale (four items) showed a good model fit when the data from all countries were taken together, with standardised factor loadings between .65 and .71. The series of multi-group confirmatory factor analyses demonstrated that the factor structure held well across all countries (configural invariance). For one country, high modification indices were found, pointing to a deviating factor structure in this country. The metric model showed more substantial misfit, as the SRMR increased substantially. This means that the factor loadings were not similar across countries. In other words, the items related stronger to the underlying latent variable in some countries than in others. Naturally, the more restrictive scalar model fitted even worse.

76. For the PROMIS Global – Mental scale (four items) the model fit estimated with the data of all countries together was similar to the previous scale, except that the RMSEA was higher. The standardised factor loadings were all acceptable. Testing the configural model across countries showed that the presumed factor structure fitted reasonably in most countries, except for two countries where the large modification indices pointed to a deviating factor structure. The metric model showed a substantial increase of misfit (SRMR), which means that the factor loadings were not similar across countries. The more restrictive scalar model could neither be held.

77. For WHO-5 Wellbeing index the data of all countries taken together fitted the presumed factor structure reasonably well, similar to the previous scale (with RMSEA being the only indicator above its critical value). All standardised factor loadings were high. The modification indices pointed to correlated error terms of two WHO-5 items. Allowing these items to correlate (not shown in Table 4.1) substantially reduced the Chi2(from 802.221 to 117.891 at the cost of one degree of freedom), the RMSEA (from .13 to .05) and resulted in a smaller range of factor loadings (.76 - .81). Similarly, the results of the multigroup confirmatory factor analyses improved significantly by allowing these error terms to correlate. Nevertheless, the metric (and scalar) model did not fit well across all countries; three countries had large SRMR values, pointing to substantial misfit of the metric (and scalar) model.

78. The consortium will further examine the structure of these reputable measuring instruments in the participating countries, to prepare for the data analysis of the Main Survey. This includes a more in-depth analysis of the deviating factor structure found in some countries and Item Response Theory analysis.

[15] Some authors argue that the critical value for these indices should be .05; others also accept values between .05 and .08.

Table 4.1. Test of model fit for PROMIS Global – Physical, PROMIS Global – Mental, and WHO-5; results of confirmatory factor analysis

	Chi2	df	P	RMSEA	SRMR	CFI	TLI	Standardised factor loadings
PROMIS Global – Physical (four items; N=9880)								
Overall model – all countries together	146.566	2	<.001	.09	.02	.99	.96	.65 - .71
Configural model across countries	253.419	30	<.001	.11	.03	.98	.94	
Metric model across countries	528.382	86	<.001	.09	.11	.96	.96	
Scalar model across countries	2656.717	142	<.001	.16	.15	.78	.86	
PROMIS Global – Mental (four items: N=9884)								
Overall model – all countries together	312.324	2	<.001	.13	.03	.98	.93	.58 - .83
Configural model across countries	367.526	30	<.001	.13	.03	.97	.92	
Metric model across countries	712.930	86	<.001	.11	.13	.95	.95	
Scalar model across countries	2623.839	142	<.001	.16	.16	.81	.88	
WHO-5 (five items; N=9801)								
Overall model – all countries together	802.221	5	<.001	.13	.03	.97	.94	.75 - .83
Configural model across countries	1095.566	75	<.001	.14	.03	.97	.93	
Metric model across countries	1422.766	145	<.001	.12	.15	.96	.95	
Scalar model across countries	2678.324	215	<.001	.13	.16	.91	.95	

Note: High Chi2coefficients point to worse model fit, but this coefficient dependents highly on the number of observations, and therefore it is not a good indicator for model fit in the PaRIS survey. RMSEA and SRMA values lower than .05 or .08 and CFI and TLI values higher than .90 are generally considered to indicate a good model fit. See Box 4.2 for clarifications of the different factor models
Source: PaRIS Field Trial Data 2022

Reliability

79. Table 4.2 contains an overview of all PROMs included in the patient questionnaire, including their reliability as assessed in a single-level model and a multi-level model. The table is structured according to the distinguished concepts of the domain 'patient reported outcomes' of the conceptual model. To provide a full overview of all concepts in this domain, single-item PROMs are also included in the table, but internal consistency reliability does not apply to these items.

80. Considering a reliability coefficient of above .70 to indicate good reliability, Table 4.2 shows that all (multiple item) PROMs can be reliably assessed at patient level (both in the single-level model and the multi-level model), except the concepts of fatigue and sleep (coefficient of .70 and below). However, the two items combined to assess fatigue and sleep had never been designed to form one scale. The Field Trial results confirm that the two items to assess fatigue and the two items to assess sleep should be treated as separate indicators. As the two items about fatigue are part of measuring instruments (PROMIS® Scale v1.2; WHO-5) that are needed to assess other constructs of the PaRIS survey, both items will be kept in the Main Survey patient questionnaire. Of the two questions to assess sleep, the WHO-5 item will be kept for the same reason, whereas the single Sleep Disturbance question of the PROMIS Item Bank v. 1.0 – Sleep will be removed to reduce the number of questions in the questionnaire for the Main Survey.

81. Table 4.2 also shows that none of these patient-reported outcomes can be reliably assessed at practice level. A low reliability at practice level means that conclusions about any potential differences between practices (within countries) in their patients' experiencing symptoms, functioning or health related quality of life cannot be drawn, at least not with the low total number of practices participating in the Field Trial. Regarding the reliability of the constructs assessed at country level, the results are better, though still not sufficient to allow drawing conclusions on differences between countries. However, higher numbers

of participating practices and patients in the Main Survey will improve the reliability at country level sufficiently. The consortium has developed an evidence-informed proposal for the required numbers of participants in the Main Survey to allow cross-country comparisons, based on simulations using the Field Trial data.

Table 4.2. Patient reported outcome measures in the Field Trial and reliability of (multiple item) constructs (overall model)

	Single-level reliability	Multi-level reliability		
	Cronbach's alpha	Patient level	Primary care practice level	Country level
Symptoms				
Pain (two questions: PROMIS Adult Short Form v1.0 - Pain Interference question and PROMIS® Scale v1.2 – Global Health question; question no. 11, 12)	.72	.87	.54	.51
Fatigue (two questions: PROMIS® Scale v1.2 – Global Health question and WHO Well-being Index (WHO-5) question; questions no. 10, 16)	.70	.56	.33	.61
Shortness of breath (single question taken from PROMIS Item Bank v. 1.0 – Dyspnea; question no. 8)	-	-	-	-
Sleep (two questions: PROMIS Item Bank v. 1.0 – Sleep Disturbance question and WHO Well-being Index (WHO-5) question; question no. 9, 18)	.67	.67	.36	.54
Symptoms of depression (three items: one from PROMIS® Scale v1.2 – Global Health and two questions from the WHO Well-being Index (WHO-5); question no. 13, 14, 17)	.78	.77	.45	.65
Symptoms of anxiety (two items: PROMIS® Scale v1.2 – Global Health question and WHO Well-being Index (WHO-5) question; question no. 13, 15)	.73	.72	.35	.72
Functioning				
Physical functioning (PROMIS® Scale Global Health – Physical Health Summary Score; four questions: question no. 3, 7, 10, 12)	.77	.76	.57	.60
Mental functioning (PROMIS® Scale Global Health – Mental Health Summary Score; four questions: 2, 4, 5, 13)	.80	.79	.52	.77
Social functioning (two questions from PROMIS® Scale Global Health; question no. 5, 6)	.80	.77	.39	.70
Self-reported health				
Overall self-reported health status (PROMIS® Scale Global Health single item; question no. 1)	-	-	-	-
Health Related Quality of Life				
WHO Well-being Index (WHO-5); five questions: question no. 14, 15, 16, 17, 18)	.89	.88	.47	.55
Overall Quality of Life (PROMIS® Scale Global Health single item; question no. 2)	-	-	-	-

Source: PaRIS Field Trial Data 2022

4.2.3. Patient-reported experience measures

Factor structure

82. Among the patient-reported experience measures (PREMs) included in the patient questionnaire there was one previously validated scale: the Person-Centred Coordinated Care Experiences questionnaire (P3CEQ) (Sugavanam et al., 2018[10]; Lloyd et al., 2019[11]). This scale aims to assess the extent to which people with chronic conditions experience person-centred coordinated care in their interactions with healthcare providers. A total scale score could be calculated, but it is also common to construct two subscale scores, one for the experienced person-centredness of care, and one for the experienced care coordination.

83. To assess the factor structure, we tested the fit of a series of models in which all items assessed one dimension (total scale) and models in which specific items were assumed to assess two dimensions: experienced person-centredness and care coordination. Since many P3CEQ items are scored dichotomously or at an ordinal scale, we applied generalised structural equation modelling (generalised SEM), which limits the available goodness of fit indices. The Akaike Information Criterion (AIC) shown in Table 4.3 is the only indicator that provides some information on how well the data fit the various models to test for invariance of the factor structure across countries. Lower values of AIC indicate better model fit.

Table 4.3. Test of model fit for P3CEQ; results of confirmatory factor analysis

	Df	AIC
P3CEQ total		
Overall model – all countries together	36	175 046.9
Configural model across countries	539	166 565.9
Metric model across countries	399	167 226.8
Scalar model across countries	50	174 448.0
Experienced person-centredness of care		
Overall model – all countries together	31	144 214.4
Configural model across countries	464	138 383.4
Metric model across countries	352	138 659.3
Scalar model across countries	31	144 285.2
Experienced care coordination		
Overall model – all countries together	17	87 640.2
Configural model across countries	254	83 162.1
Metric model across countries	184	83 531.8
Scalar model across countries	31	86 72.3

Source: PaRIS Field Trial Data 2022
Note: See Box 4.2 for clarifications of the different factor models

84. Given the limited information about the factor structure provided by generalised SEM, we also conducted exploratory factor analysis, to get more information on whether the data reflected the presumed two-factor structure of the P3CEQ.

85. The initial exploratory factor analysis (not shown) resulted in only one factor with an eigenvalue[16] larger than 1 (2.77); the second largest factor had an eigenvalue of 0.24. This suggests that the P3CEQ as included in the Field Trial assessed one, unidimensional concept of person-centred coordinated care experiences, rather than two distinct but related concepts, experienced person-centredness and experience coordination of care. We subsequently repeated the exploratory factor analysis, now forcing the data to fit a two-factor model (eigenvalues similar to above). Table 4.4 shows the factor loadings after oblique rotation. As a rule of thumb, factor loadings higher than .40 are considered sufficient, and factor loadings lower than .30 are considered weak.

86. The table shows that five questions (59, 60, 61, 63-66, 68) loaded sufficiently on the first factor, of which four belonged to the original experienced person-centredness subscale (Lloyd et al., 2019[11]). Question 57, which assesses the extent to which a person experiences that their care is organised in a way that works for them, loaded on both factors in the original UK validation study, but did not load

[16] The eigenvalue of a factor indicates how much of the variance is explained by this factor. Its value is derived by summing the squared correlations of each item with the factor. In general, factors with eigenvalues >1 (more than the variation of one single item) are considered to be viable to be included in the analysis of a scale.

sufficiently on the first factor here. Of the five questions presumed to assess the level of experienced care coordination (57, 54, 63-66 combined, 67, 68), only question 57 loaded moderately on factor 2.

87. The consortium has slightly revised the formulation of some questions and/or answering options of the P3CEQ for the Main Survey and will decide on the use of the two subscales, besides the total score, based on how well the slightly modified P3CEQ questions perform in the Main Survey.

Table 4.4. Factors loadings of P3CEQ questions; exploratory factor analysis (solution constrained to two factors, with ProMax (oblique) rotation); N=7169

Question # in Supplement 2	Question in patient questionnaire	Factor 1: experienced person-centeredness	Factor 2: experienced care coordination
59	Discuss what is important	**.67**	-.06
60	Involved in decisions	**.56**	.12
61	Considered 'whole person'	**.43**	.26
72	Repeating information	.01	.37
57	Care joined up (organized in a way that works)	.31	**.46**
54	Single named contact	.13	.34
63-66 (combined)	Care planning (overall)	**.44**	-.01
67	Support to self-manage	.39	.32
68	Information to self-manage	**.53**	.19
40	Confidence to self-manage	.04	.22

Note: Bold marking indicates a factor loading above .40.
Source: PaRIS Field Trial Data 2022

Reliability

88. Table 4.5 provides a full overview of all concepts of the patient reported experiences domain in the conceptual model, and by which questions they have been assessed in the patient questionnaire. The table follows the sequence of the concepts as outlined in the conceptual framework. Almost all PREMs included in the patient questionnaire are (sets of) single items that were not intended as a Likert scale, which implies that internal consistency reliability as assessed by Cronbach's alpha does not apply. Therefore, reliability coefficients are only provided for the P3CEQ total scale as well as its intended two subscales (the presumed two-dimensionality to be confirmed in the Main Survey).

89. Considering a reliability coefficient of .70 or higher to indicate good reliability, Table 4.5 shows that the P3CEQ total score shows good internal consistency reliability at patient level, both in the single-level and the multi-level analysis. This also holds for the person-centredness subscale. The reliability of the care coordination at patient level in the multi-level analysis is somewhat lower than .70.

90. For both the P3CEQ total scale and the subscales, the reliability at practice level is not sufficient to allow comparisons between practices within a country. This is also not the purpose of the international PaRIS survey. In case of a country-specific interest, it would require these countries to increase the number of participating practices substantially in the Main Survey. The reliability at country level of the P3CEQ total scale and subscales is good enough to allow cross-country comparison of patients' experiences with person-centred coordinated care.

Table 4.5. Patient reported experience of care measures in the Field Trial and reliability of the P3CEQ total scale and subscales

	Single-level reliability	Multi-level reliability		
	Cronbach's alpha	Patient level	Primary care practice level	Country level
Access (five questions: three questions from the OECD Patient Experience Set and two from General Practice Patient Survey (GPPS); question no. 75, 76, 77, 78)	-	-	-	-
Comprehensiveness (single question from P3CEQ; question no. 61)	-	-	-	-
Continuity of care (five questions: one from OECD and four developed by the consortium; question no. 48, 49, 51, 52, 72)	-	-	-	-
Care coordination (five questions; P3CEQ Experienced Care coordination subscale; question no. question no. 54, 57, 63/64/65/66 combined, 67, 68)	.70	.64	.47	.80
Safety (three questions modified from Patient-Reported Experiences and Outcomes of Safety in Primary Care (PREOS); question no. 39, 73, 74)	-	-	-	-
Person-centeredness of care (eight questions; P3CEQ Experienced person-centeredness of care subscale; question no. 40, 57, 59, 60, 61, 67, 68, 72)	.76	.71	.51	.78
Individualization of care (two questions: one from P3CEQ and one from the Medicare Current Beneficiary Survey (MCBS); question no. 59, 62)	-	-	-	-
Decision-making (two questions from the P3CEQ; question no. 60, 69)	-	-	-	-
Interacting with healthcare professionals (three questions from the OECD Patient Experience Set; question no. 89, 90, 91)	-	-	-	-
Self-management support (six questions: two from the P3CEQ and four developed by the consortium; question no. 20, 23, 26, 28, 67, 68)	-	-	-	-
Trust (two questions; one from the GPPS and one developed by the consortium; question no. 92, 117)	-	-	-	-
Quality of care				
Perceived quality of last consultation with primary care professional (single question from the OECD proposed Set of Questions on Patient Experiences with Ambulatory Care; question no. 93)	-	-	-	-
Perceived quality of medical care received from the primary care centre in the past 12 months (single question modified from the Commonwealth Fund International Health Policy Survey 2016 (CWF2016IHP); question no. 80)	-	-	-	-
Person-centred coordinated care experience (ten questions: P3CEQ; question no. 40, 54, 57, 59, 60, 61, 63/64/65/66 combined, 67, 68, 72)	.77	.71	.52	.78

Source: PaRIS Field Trial Data 2022
Note: Almost all PREMs included in the patient questionnaire are (sets of) single items that were not intended as a Likert scale, which implies that internal consistency reliability as assessed by Cronbach's alpha does not apply. Therefore, these cells are left blank.

4.2.4. Health behaviours

91. The domain 'health behaviours' in the conceptual framework focused on four health/risk behaviours: physical activity, diet, tobacco use and alcohol consumption. All four constructs were assessed by one or two questions that were not intended as scales. Table 4.6 provides an overview of the questions included in the patient questionnaire that were aimed to assess the four constructs.

Table 4.6. Health behaviour constructs and related questions in the Field Trial

Physical activity: single question modified from IPAQ SF; question no. 19
Diet: two questions modified from the European Health Interview Survey; question no. 21, 22
Tobacco use: two questions modified from the European Health Interview Survey; question no. 24, 25
Alcohol consumption: single question modified from the European Health Interview Survey; question no. 27

Source: PaRIS Field Trial Data 2022

4.2.5. Health and healthcare capabilities

92. The domain 'health and healthcare capabilities' refers to patients' capabilities to (self-)manage their health and healthcare, including their digital skills to do so. One existing instrument was selected in this domain to assess patient profiles based on their preferences for health information, the 10-item Consumer Health Information Preferences Scale (also known as the Porter-Novelli Scale) (Maibach et al., 2006[12]). In addition, patients' confidence in self-management was assessed by four questions from the Medicare Current Beneficiary Survey (MCBS) and one question from the e-Health Literacy Scale (eHEALS) of the Commonwealth Fund Survey.

Factor structure

93. Although a previous study (Maibach et al., 2006[12]) has reported on the performance of the 10-item Porter Novelli Scale, the questions had been substantially modified to fit the structure of the PaRIS patient questionnaire. Therefore, we conducted exploratory factor analysis to examine the dimensionality of the scale. Patients' confidence in self-management was assessed by a set of questions from several measuring instruments, which were originally not intended as a scale. For exploratory purposes, to get a first insight in whether these questions could be combined in the data-analysis of the Main Survey data, we also conducted an exploratory factor analysis based on these questions. The results are summarised in Table 4.7.

Patients' preferences for health information

94. The 10-item Porter-Novelli Scale has been designed as a brief screening instrument, originally from a list of 38 Likert scale items aimed to distinguish four 'types' of patients according to their preferences for health information: 1. 'independent actives' (people who place a high value on health information and prevention, and report a high degree of self-efficacy for understanding health information), 2. 'doctor-dependent actives' (people who also attach high value on having health information, but find it more difficult to understand and more often prefer their doctor to make healthcare decisions), 3. 'independent passives' (people who are less engaged in prevention and do not tend to seek out health information, but retain decision-making authority for themselves), and 4. 'doctor-dependent passives' (people who are also less involved in prevention and health information seeking, and tend to rely on their doctor to make healthcare decisions) (Maibach et al., 2006[12]).

95. The ten questions of the scale have not been designed to assess four distinct dimensions; they rather contribute more or less to the four identified patient profiles. Therefore, we conducted an exploratory factor analysis without forcing the model to a pre-set number of factors. This resulted in two factors with eigenvalues larger than 1. The first factor (eigenvalue 2.44) covers patients' preference for health information and for taking an active role in managing their health and care ('active engagement'). The second factor (eigenvalue 1.45) covers patients' preference to rely on health professionals and to take a more passive role in information seeking and decision-making ('rely on health professionals'). Table 4.7 shows the factor loadings.

Table 4.7. Dimensionality of 10-item Porter-Novelli Scale to assess patients' preferences for health information; results of exploratory factor analysis

		Factor loadings	
Question # in Supplement 2	Question in patient questionnaire	Factor 1: active engagement	Factor 2: reliance on health professional
33	It is important to me to be informed about health	**.69**	-.08

	issues		
34	I need to know about health issues so I can keep myself and my family healthy	**.68**	-.08
38	I try to understand my personal health risks	**.61**	-.15
31	I actively try to prevent diseases and illnesses	**.48**	-.06
36	My health professionals and I work together to manage my health	**.48**	.35
37	When I read or hear something that is relevant to my health care, I bring it up with health professionals	**.45**	.33
30	Most health issues are too complex for me to understand	-.22	**.65**
35	I have difficulty understanding a lot of the health information that I read	-.21	**.65**
32	I leave it to health professionals to make the right decisions about my health	.19	**.59**
29	I rely on health professionals to tell me everything I need to know to manage my health	.30	**.46**

Note: Bold marking indicates a factor loading above .40.
Source: PaRIS Field Trial Data 2022

Patients' confidence in self-management

96. The exploratory factor analysis of the four questions of the MCBS combined with the question from eHEALS resulted in one factor with eigenvalue larger than 1 (2.75). The factor loadings of all questions are high (above .60), with only one lower loading (.43), which is still considered acceptable (Table 4.8). This analysis confirms that the construction of one scale to assess patients' confidence in self-management based on these questions could be considered for analysis of the Main Survey.

Table 4.8. Dimensionality of combined questions (MCBS and eHEALS) to assess patients' confidence in self-management; results of exploratory factor analysis

		Factor loadings
Question no.	Patients' confidence in self-management capabilities	Factor 1: confidence
41	How confident are you that you can follow instructions from health professionals about how you should care for yourself at home?	.82
42	How confident are you that you can follow instructions from health professionals about how to change your habits or lifestyle?	.76
43	How confident are you that you can identify when it is necessary for you to get medical care?	.72
40	How confident are you that you can manage your own health and wellbeing?	.66
44	How confident are you that you can identify when you are having side effects from your medications?	.61
45	How confident are you in using information from the Internet to make health decisions?	.43

Note: Bold marking indicates a factor loading above .40.
Source: PaRIS Field Trial Data 2022

Reliability

97. Table 4.9 includes the internal consistency reliability of the three health and healthcare capabilities constructs. The table shows that the two identified dimensions of the Porter Novelli Scale show acceptable reliability in single-level analysis, though Cronbach's alpha of the second dimension is slightly lower than

.70. The patients' confidence in self-management construct shows good internal consistency reliability in single-level analysis. Like the previous scales, the reliability at patient level is somewhat lower in the multi-level analyses, in particular for the second dimension (reliance on health professionals) identified for the Porter Novelli Scale. In contrast, this 'subscale' seems to be reliably assessed at country level. Further examination of the three constructs of patients' health and healthcare capabilities is needed to decide on their use in the Main Survey analysis. Further analysis is needed to understand the extent to which patients' preferences to rely on health professionals for health information and healthcare decision-making are related to culture or country-/health system specific characteristics.

98. Furthermore, as previously mentioned, larger numbers of participating patients and practices in the Main Survey will positively impact the reliability of the constructs at all levels. Therefore, it is expected that the reliability of the three constructs at country level will be sufficient to allow between-country comparisons, in addition to analysis of the variance at patient level.

Table 4.9. Health and healthcare capabilities measures in the Field Trial and reliability of constructs

	Single-level reliability	Multi-level reliability		
	Cronbach's alpha	Patient level	Primary care practice level	Country level
Patients' preferences for health information (Porter-Novelli Scale)				
PNS Active engagement (six questions; question no. 31, 33, 34, 36, 37, 38)	.73	.66	.12	.56
PNS Reliance on health professionals (four questions; question no. 29, 30, 32, 35)	.68	.44	.50	.91
Patients' confidence in self-management (six questions; question no. 40, 41, 42, 43, 44, 45)	.78	.72	.26	.60

Source: PaRIS Field Trial Data 2022

4.3. Construct validity

99. First steps were taken to examine the validity of the main constructs assessed by the patient questionnaire by examining the extent to which these constructs are related to each other as might be expected. This should be considered a preliminary exploration, as a review of the existing evidence on the relationships between the constructs is needed to develop more specific hypotheses. This will be done in 2023 in consultation with the OECD Secretariat, the Technical Advisory Community, the authors of the original scales and other experts.

100. Table 4.10 shows the strength of the relationships between the four domains that were expected, based on experience and common sense. We expected the various PROMs to be moderately (.30 - .50) to strongly (>.50) correlated. Similarly, this was expected for the various PREMs and health and healthcare capabilities. Regarding patients' health behaviours, we expected significant, but less strong associations, reasoning that some people will have healthier lifestyles in general than others, but also acknowledging that the four specific health/risk behaviours do not necessarily go together.

101. PROMs and PREMs were expected to correlate weakly (.10 - .30) or moderately (.30 - .50), depending on the specific measures at stake. Furthermore, we expected weak correlations between health/risk behaviours and PROMs, and between health and healthcare capabilities and PROMS, reasoning that many other factors (e.g., genetic, demographic, socioeconomic, morbidity) impact patients' reported health outcomes, in addition to health/risk behaviours and capabilities.

102. PREMs were expected to correlate more strongly with patients' health and care capabilities than with their health/risk behaviours. The reasoning was that the extent to which patients prefer and are able to play an active role in managing their health and care will influence their care experience, whereas their health/risk behaviours are expected to have less of an impact on their care experience.

103. Finally, patients' health and care capabilities were expected to correlate weakly with health/risk behaviours.

Table 4.10. Expected strength of the associations between patient-reported indicator domains

	PROMs		PREMs		Health/risk behaviours		Health and care capabilities	
	Expected	Observed	Expected	Observed	Expected	Observed	Expected	Observed
PROMs	++/+++	++/+++	+/++	-/+	+	-/+	+	--/++
PREMs	+/++	-/+	++/+++	-/+++	+	-/+	+/++	-/++
Health/risk behaviours	+	-/+	+	-/+	++	++	+/++	-/+
Health and care capabilities	+	- -/++	+/++	-/++	+/++	-/+	++/+++	+++

Note: Observed strength of the association is shown in parenthesis when available. + means a weak (.10-.30) correlation, ++ means a moderate (.30-.50) correlation, +++ means a strong (>.50) correlation.
Source: PaRIS Field Trial Data 2022

104. Supplement 4 provides an overview of the bivariate correlations between all constructs in the four domains as assessed by the patient questionnaire. Depending on the nature of the variables, these are Pearson correlations (between two continuous variables) or Spearman correlations (between ordinal variables). By exploring these correlations and focusing on the relationships between constructs within and between the four domains, the following observations can be made.

105. As expected, PROMs correlate rather strongly with each other (range between .47 and .82). In contrast, PROMs correlate only weakly with PREMs (range between -.27 and .28). This also holds for the correlation between PROMs and health/risk behaviours (range between -.39 and .28) and between PROMs and health and healthcare capabilities (range between -.36 and .36). The correlations with PREMs appear to be weaker than expected.

106. PREMs correlate weakly to moderately to each other, except for person-centred care and care coordination (.82), person centred coordinated care experience and care coordination (.92) and person-centred coordinated care experience and person-centred care (.96), which is understandable given their origin (all P3CEQ (sub-)scales with even some overlapping items between the two subscales). The other correlations between PREMs ranged between -.09 and .72. As expected, the correlations between PREMs and health/risk behaviours were generally weak (range between -.25 and .16), and stronger between PREMs and health and care capabilities (range between -.27 and .32).

107. Finally, patients' health and healthcare capabilities were correlated weakly with their health/risk behaviours (range between -.11 and .27). Here, a somewhat stronger correlation was expected.

5. Performance of the practice questionnaire

This chapter describes the performance of the questionnaire for primary care practices. Section 5.1 describes the performance of each question in terms of the distribution of answers and the proportion of missing answers per question. Section 5.2 explores whether possibilities to construct scales based on sets of questions in the questionnaire, and how reliably these scales assess certain concepts of the conceptual framework. In section 5.3 a first exploration of the construct validity of these scales is described. This chapter is based on data provided by 529 primary care providers who responded to all or some questions of the practice questionnaire (thus all who provided any valid data), which were submitted by 23 September 2022 (at that time collected in 16 countries).

5.1. Performance of questions

108. Supplement 3 provides an overview of all questions of the practice questionnaire, the question numbers, and their performance in terms of the distribution of answers and the proportion of missing answers in the total dataset. The Field Trial version of the practice questionnaire consists of 40 items, of which six are loop items consisting of multiple questions, each with the same answering categories, resulting in a total of 58 single questions.

5.1.1. Missing answers

109. The table in Supplement 3 shows that for most questions (55 of the total of 58 single questions) the proportion of missing answers is lower than 10%. This proportion accounts only for the questions that were applicable to the responding professionals. The only three questions with 10% or more missing answers were questions related to COVID-19 (questions 51 to 53). These questions are excluded from the Main Survey questionnaire.

110. Furthermore, several questions included a ‘not sure’ answering option. The table in Supplement 3 shows that for most of these questions this option was chosen by less than 10% of the responding primary care professionals. This is also an indication that the questions and (other) answer options were sufficiently applicable and understandable. There are four exceptions described in Box 5.1.

Box 5.1. Questions of the primary care practice questionnaire with 10% or more answering 'not sure'

Can your practice produce the following information about the patients in your practice using a computerised system (e.g., clinical information system)? (15% answering 'not sure')

This question refers to the clinical information system of the practice; some respondents were not sure whether the system could produce some lists with patient information. The percentage of respondents who answered 'not sure' may be a good reflection of the situation, rather than an unclear question or unclear response options.

Can your practice electronically exchange any of the following information with any health care professionals outside the practice? (11% answering 'not sure')

This question was also about the practice's clinical information system. It assessed whether it allowed exchange of certain types of patient information with other care professionals (outside the practice). The fact that 11% of respondents were not sure may be a good reflection of the situation, rather than an unclear question or unclear response options.

Does your practice review indicators on the following aspects of your patients' care? (13% answering 'not sure')

It seems likely that some respondents may not know whether all aspects mentioned in the response options are being reviewed.

How are patient care plans used in your practice? (11% answering 'not sure')

The percentage of respondents who answered 'not sure' to this question may be a good reflection of the situation (the respondent does not know how they are used), but it may also indicate a lack of clarity about what is meant by the question. Therefore, the consortium reviewed the qualitative information collected during the cognitive testing interviews, which confirmed that the care plan questions were not well understood. As a result, these questions we modified for the Main Survey to improve understanding and clarity.

5.1.2. Distribution of answers

111. In terms of the distribution of the (valid) responses, Supplement 3 shows that for most questions the responses are well spread over the different answer categories, so that there is no indication of a possible ceiling or floor effect (i.e., that a large proportion of the responses fall into the most extreme categories, which does not measure the true value well).

112. For eight questions, more than 75% of all responding primary care professionals selected the same answer. In many cases this is understandable given the nature of the question, which asks about a rather common practice (e.g., question 6 on making home visits). This is also the case for four questions on medical record keeping (questions 18, 19, 20, 21). Although 80% or more of the answers received from all countries may fall into one category, this does not have to be the case in each country. For example, 89% of all responding providers answered that medical records are kept electronically (question 18), but in two countries the primary care professionals reported electronic record keeping significantly less often (53% to 67%). Furthermore, primary care professionals and countries may wish to strive for 100% use of

electronic records, and this may also be the case for other questions with more than 75% of all responses in the same category. For example, the question on the provision of self-management support through verbal information during and after the consultation (question 39). In these cases it could be argued that it is still a relevant question as long as not all responding primary care professionals in all countries report providing self-management support in this way.

113. Regarding the question on the types of chronic conditions of patients for which care is provided (question 27), it is likely that the question was not interpreted as intended. The aim of the question is to gain an insight into the types of chronic conditions that are commonly managed in the primary care practice. However, the question could have been interpreted differently, as it only asked whether patients with certain conditions received care from the practice, not necessarily whether this was care for their chronic condition(s). Therefore this question was reformulated for the Main Survey.

114. Finally, on the COVID-19 question that showed less variation (question 46): the majority of professionals answered that the practice provided care for people with COVID-19 symptoms, which is most likely to be a good reflection of the situation at the time. However, as the COVID-19 situation has changed in terms of prevalence, burden (use of primary care, acute care and hospital services), vaccination and management, the questions on the impact and management of COVID-19 are no longer part of the Main Survey questionnaire.

5.2. Scale construction and reliability

115. The questionnaire for primary care practices consisted of many single questions, either self-developed or taken from other questionnaires, as internationally validated scales to assess certain concepts from the PaRIS conceptual framework were not available. However, to answer a core question of the PaRIS survey, i.e., the extent to which characteristics and processes of primary care are related to patients' experiences and outcomes, it would be helpful if certain questions could be combined in a scale to assess specific concepts. For this reason, the consortium undertook exploratory analyses, on which we report in this section. It should be emphasised that none of the questions we combined were originally intended to form a scale. Thus, poor performance of a scale does not indicate poor quality of the questions themselves; it may imply that these questions would be better treated as single questions in the analyses of the Main Survey data.

116. Box 5.2 shows the sets of questions for which performance as a scale was explored. Many of these questions were nominal variables. Therefore, for each question, we indicate the reasoning we followed to arrive at a score (right column in the box).

Box 5.2. Concepts of the conceptual framework and selected sets of questions of the practice questionnaire

Access to primary care services

Does the practice you work in offer medical services to patients without an appointment?	No=0, yes=1.
Which types of patients do you offer medical services to without an appointment?	The more types of patients, the higher the score.
Which of the following out-of-hours options does your practice provide to your patients?	The more options, the higher the score.
Does at least one physician or other healthcare professional from the practice make home visits?	No=0, yes=1.
Does your practice offer phone, video or other online methods for consultations to patients?	The more methods, the higher the score.

Time available for patient consultations

How much time is scheduled in your practice for: • consultations for a newly registered patient • regular and follow-up consultations • urgent consultations • home visits (excluding travel time) • phone consultations • video consultations • consultations using other remote options (e.g., e-mail, text message, messaging through patient platforms)	For each item: the more time, the higher the score.

Medical recordkeeping

In which formats do you keep patient medical records in your practice?	(Only) on paper=0, (also) electronic=1.
For which types of patients are medical records kept in your practice?	The more types of patients, the higher the score.

Which, if any, of the following information is normally included in patients' medical record?	The more information, the higher the score.
Are medical records available when patients are seen?	The more frequently available, the higher the score.
When new patients join your practice, do you receive their medical records from their previous practice?	The easier access to previous records, the higher the score.
Information system functionalities	
Can your practice produce the following information about the patients in your practice using a computerized system?	The more types of information, the higher the score.
Which, if any, of the following tasks are routinely performed in your practice using a computerised system?	The more tasks, the higher the score.
Can your practice electronically exchange any of the following information with any healthcare professionals outside the practice?	The more types of information, the higher the score.
Care coordination	
Do you provide care in your practice (e.g., regular appointments, tests and reviews) for patients with any of the following chronic conditions?	The more conditions, the higher the score.
How prepared is your practice to coordinate care with other health and social care providers for patients with one or multiple chronic condition(s)?	The better prepared, the higher the score
How prepared is your practice to coordinate care with other health and social care providers for the following groups of patients? • Patients with one or multiple chronic condition(s) • Patients with severe mental health problems • Patients with issues of addiction/substance misuse • Patients in need of palliative care • Patients in need of long-term care • Patients in need of social services in the community	The better prepared, the higher the score.
To what extent are referral letters (electronic or on paper) written in your practice when patients are referred to another medical specialist?	The more frequently written, the higher the score.

After the follow-up visit to another specialist, how often does the practice receive timely referral information (electronic or on paper) from this specialist in the following ways?	The more frequently received timely, the higher the score.
Use of individual care plans	
How are individual patient care plans developed at your practice?	The more comprehensive the involvement process, the higher the score.
For which patients are patient care plans developed at your practice?	The more (types of) patients, the higher the score.
How are patient care plans used in your practice?	The more ways in which plans are used, the higher the score.
Use of individual care plans	
How are individual patient care plans developed at your practice?	The more comprehensive the involvement process, the higher the score.
For which patients are patient care plans developed at your practice?	The more (types of) patients, the higher the score.
How are patient care plans used in your practice?	The more ways in which plans are used, the higher the score.
Self-management support	
Which of the following statements describe how self-management support is provided to patients with chronic conditions?	The more ways self-management is supported, the higher the score.
How often are the self-management goals of your patients with chronic conditions recorded in their medical records?	The more frequently recorded, the higher the score.
How often are your patients with chronic conditions given written instructions (either electronically or on paper) about how to manage their own care at home (e.g., instructions on what to do to control symptoms, prevent flare-ups, or monitor their condition at home)?	The more frequently given written instructions, the higher the score.

Source: PaRIS provider questionnaire

5.2.1. Reliability

117. Multilevel reliability analyses were conducted to estimate the internal consistency reliability (comparable to Cronbach's alpha in a single level model) of each of the sets of questions at the practice level and the country level. The results are shown in Table 5.1

118. Good reliability is indicated by a reliability coefficient of .70 or above. The table shows that all question sets result in a reliable scale at country level, and most also at practice level. With a larger number of primary care practices per country participating in the Main Survey, the practice level reliability will automatically increase. Further examination of the validity of the constructed scales will be necessary before deciding on the use of these scales in the analyses of the Main Survey; nevertheless, the reliability of most of the constructs seems promising.

Table 5.1. Reliability of the practice constructs at practice level and country level

	Practice level	Country level
Access to primary care services	.58	.83
Time available for patient consultations	.73	.92
Medical recordkeeping	.79	.91
Information system functionalities	.78	.95
Care coordination	.83	.87
Use of individual care plans	.63	.72
Self-management support	.65	.81

Source: PaRIS Field Trial Data 2022

5.3. Validity of practice scales

119. Regarding the patient questionnaire, the consortium took a first step in exploring the relationships between all the concepts of the PaRIS conceptual framework that were assessed with the practice questionnaire. In contrast to the previous chapter, we did not formulate any à priori expectations about how strongly the different concepts of the practice questionnaire would be related. Supplement 5 provides an overview of all the bivariate correlations between the questions, or, in the case of sufficient reliability, the constructs created in section 5.2. Below we describe some general observations based on the information in Supplement 5.

120. In general, the correlations between the items used in the practice questionnaire are rather weak. The items in the *access to care* category are weakly correlated with each other and with the items in the other categories. The highest correlations are observed with the *skill mix for chronic care management* category (-.41 to .38).

121. The items in the *time available for patient consultations* category also display only a weak correlation with the other categories. However, the items within the category generally show weak to high correlations with each other (.02 to .60).

122. The items in the *medical recordkeeping* category strongly correlate with each other. With regard to the other categories, the strongest correlations are observed with items in the *information system functionalities* category (-.27 to .30).

123. For the *information system functionalities* category, two subcategories can be distinguished. The items relating to information system functionalities correlate strongly with each other, as the items relating to the *electronic exchange of information*. The correlations between the items of the two subcategories are

negative, as expected. The correlations of the items of this category with the other categories are generally weak (except for the *medical recordkeeping* category, see above).

124. The items in the *skill mix for chronic care management* category correlate weakly among each other, and with the other categories. The items within the *care coordination* category correlate strongly with each other in terms of the items about the type of chronic condition for which coordination is provided. There is a much weaker correlation between these items and the other items in the category (e.g., who is in charge, the writing of referral letters etc.), as well as between the latter items amongst themselves. The correlation with items from other categories is rather weak in general.

125. The category about *the use of individual care plans* has only a weak correlation of items within the category, except for the high correlation between the development of individual patient care plans and the item about the patients for which care plans are developed (.70). The correlations between this category and others are generally weak.

126. The items in the *self-management support* category correlate moderately with each other. There are weak correlations with other categories, except for some items in the *information system functionalities* category (-.02 to .56).

127. A more comprehensive review of the scientific literature on how structural characteristics and processes of primary care are related to each other and to patients' experiences and outcomes is needed. Since several questions, in the practice questionnaire, were revised or removed, further analyses of practice-level constructs and items were not conducted at this stage.

6. Qualitative evaluation

This chapter summarises the general reflections on the PaRIS survey and Field Trial implementation and analyses some of the most frequently signalled issues and possible solutions to address them in a panoramic qualitative way. This chapter is based on the information from Field Trial evaluation reports, provided by NPMs. These reports were received from 18 countries. Furthermore, the chapter includes information discussed with NPMs, the OECD and the consortium during the Field Trial evaluation meeting on 14 and 15 September 2022 in Paris. NPMs from all but one of the participating countries attended the meeting.

6.1. Fieldwork process and evaluation

6.1.1. Approach to data collection

128. As mentioned in section 2.2, data were predominantly collected using the online central data collection platform. Two thirds of the countries that participated in the Field Trial used this platform ('centralised approach'); one third chose a 'decentralised approach', i.e., used data collection mechanisms created in the country itself. The main reasons for countries to opt for a decentralised approach were:

- National regulations that prohibit or make data sharing outside the country more difficult;
- Characteristics of the national health system and geopolitical divisions;
- Building on an existing infrastructure in the country (e.g., developed for a national survey);
- Preference to manage the survey and control its progress locally.

129. Countries that applied a decentralised approach experienced various challenges during the Field Trial, particularly in relation to the use of resources, the time schedule and the challenge of combining their own approach with following the standardised protocol for the PaRIS survey.

130. For the consortium it was also more challenging to support countries following a decentralised approach, as guiding materials had to be relevant and tailored to different national realities.

6.1.2. Responding to the questionnaires

131. Several NPMs mentioned that completing both the practice and the patient questionnaires took participants more time than expected, and that this may have led to drop-outs. Other NPMs did not report issues related to the survey length, at least not for the practice questionnaire.

132. In the case of the patient survey, some NPMs commented that the period in which patients had to complete and submit the questionnaire was an issue. NPMs indicated that some patients were willing to participate but needed more time and asked for an extension of the deadline for responding to the questionnaire. Also, some NPMs reported that patients were keen to add comments about their experiences in open ended questions.

133. From the providers' perspective, some NPMs indicated that primary care providers were interested in having more insight into their own results and outcomes, as well as more insight into how they compare with the average results of the country. Nevertheless, NPMs also mentioned in some cases a low interest of providers in the practice survey and providers being critical about the relevance of several questions in the practice questionnaire. Some NPMs mentioned that some questions in the practice questionnaire could be answered directly by the NPM itself for the whole country and could be removed from the practice questionnaire.

134. Regarding the mode of data collection, some NPMs noted that some questions in the patient questionnaire were difficult to implement by telephone interview because of the many response options that the interviewee had to remember and consider when answering. It was suggested that the online interface could be improved by including a specific option for telephone interviews, to add instructions for interviewers.

135. NPMs mentioned that improving the engagement at the provider level is fundamental for successful implementation of the PaRIS survey, as primary care providers are the channel through which patients can be reached. Thus, low participation of primary care providers has a direct impact on the number of patients who are invited to participate in the PaRIS survey.

6.1.3. Facilitating communication between countries

136. Some NPMs requested the possibility to have a library available to access the materials prepared by other NPMs (e.g., country roadmaps, information on country-specific issues, posters, information letters, webpages), as this could inspire and help to improve their own materials and to diversify their engagement strategies. In the meantime, the consortium has been working on this; country roadmaps, translations and localisations of the questionnaires as well as country-specific questions have been made available to all NPMs in the MS Teams environment.

137. NPMs also recommended to strengthen the communication among NPMs, as the active sharing of experiences, insights, and information was perceived to be useful. Suggestions that were made were, for example, monthly webinars to exchange experiences and to know each other's progress, Q&A sessions with NPMs, and promotion of the MS Teams chat option. Similarly, the consortium is working to meet these needs, and it is actively promoting the use of the MS Teams chat for information and knowledge sharing between NPMs. Q&A sessions have been organised for NPMs to meet and share experiences.

6.2. Communications and engagement strategies

6.2.1. Survey among primary care professionals

Communication and engagement strategies

138. To engage and recruit primary care practices, most countries applied a mixed strategy using various communication modes. In four countries only one communication mode was used. In many countries primary care practices were approached via email (12 countries) and/or telephone (11 countries). In three countries postal mail was also used to reach sampled practices. In all countries, except one, the sampled practices received periodic reminders after the initial invite. These reminders were sent using the

same channels as had been used for the initial invitation. In roughly half of the countries a mixed strategy was also used for the reminders, usually a combination of emails and phone calls.

139. Other strategies that were put in place in some countries to increase participation of primary care practices included working with the practice-based research and learning networks in the country to spread the word and encourage colleagues to participate; providing financial incentives; searching endorsement from Colleges of Medicine or academic institutions; and searching for collaboration with regional health authorities.

140. Overall, the communication strategies in the countries were more likely to target primary care practices selected to participate in the survey, rather than to reach the primary care sector in general for a broader engagement in the PaRIS survey. Few countries used social media or traditional media to promote the PaRIS survey. In two countries public events (conference, workshop) were organised to foster the engagement and participation of primary care practices in the survey.

Interest in participation and measures to improve participation

141. More than 60% of the NPMs (n=11) reported that primary care practices in their catchment area were interested in participating in the survey. In countries where practices were less willing to participate in the survey, a wide range of possible reasons for this were mentioned by the NPMs. These included the impact of COVID-19 – not only in terms of staff availability, but also staff fatigue and burnout – ; the fact that in some countries the survey was launched during summer holidays; lack of incentives (financial or non-financial) to participate; the length of the questionnaire; not knowing what questions would be asked in advance; lack of time; confidentiality or privacy concerns; and lack of engagement with government-initiated surveys.

142. To reduce these barriers to participation, NPMs took corrective measures, such as: intensifying the recruitment strategy (e.g. sending more reminders than initially planned); extending the data collection period; increasing the sample size; emphasising and explaining the soundness of the privacy policy and data protection in place; offering symbolic non-financial incentives; and adapting written communication materials (making them shorter and more attractive).

143. Sixteen (of the 18) countries established support services to help practices complete the practice questionnaire. In some countries this was a formal telephone helpline where questions could be answered, and concerns could be addressed in real time. In most countries, this was a dedicated e-mail address or a website with a FAQ section.

6.2.2. Patient survey

Communication and engagement strategies

144. In general, NPMs decided to approach patients the same way as primary care professionals. However, as patients' email addresses were less readily available, the use of email to contact patients was lower than for practices (emails were only used in eight countries). Alternatively, in five countries a text message with a link to the questionnaire was sent to patients, a method which was not used for the practice survey in any country. In two countries, automated text services were used to send the questionnaire. In eight countries, postal services were used to reach sampled patients with an information letter and a paper questionnaire. To inform patients about the PaRIS survey, the NPM of one country sent a link to a website with information about the survey, a FAQ section, and an introduction letter. Some NPMs chose to design information leaflets to be distributed by primary care professionals in their practice rooms.

145. In five countries, a difference from the practice questionnaire, was the choice of not sending reminders to sampled patients. This applied to countries where email addresses were not available and

sending reminders by post was considered too time-consuming and costly. In all other countries, two or three reminders were usually sent.

Interest in participation and measures to improve participation

146. Since NPMs did not contact the sampled patients directly, they received limited feedback from them and were unable to assess patients' willingness to participate in the survey. The only indicator is the response rate, which has been reported in section 2.2. Reasons, reported by NPMs, for lower-than-expected patient response rates were:

- poor quality of the available patient contact information;
- challenge of implementing a standardised data collection protocol in countries with a decentralised health system, requiring working with many stakeholders, which took up a lot of time and other resources;
- patients' concerns that the invitation was a phishing attempt/spam;
- conducting the survey during the summer (holiday season in some countries);
- limited time to complete the questionnaire;
- length of the questionnaire;
- patients' limited digital skills, especially among people living in rural areas.

147. From this list the most frequently mentioned reasons were the poor quality of patients' contact information and patients' limited digital skills, reported by four and three NPMs, respectively.

148. Some of the individual strategies employed to increase patients' response rates were also implemented to increase the response rates of primary care professionals: launching more reminders than initially planned, extending the data collection period, and increasing the sample size. Notably, one NPM signalled that reminders sent on Friday were more effective. Other strategies that were used were: providing paper questionnaires to the primary care practice so that patients could be asked to complete the questionnaire during their visit to the practice[17]; relying on staff (doctors or nurses) who were familiar to the patients to call them; increasing the visibility of the survey in a television talk show; using official communication channels from the Ministry of Health to increase credibility; and having regular meetings with patient associations.

6.3. Sampling

149. The PaRIS survey protocol requires the use of probability sampling. NPMs received sampling guidelines, supporting documentation, and one-to-one guidance by a consortium contact point to help them create their sampling framework and procedures. This section summarises the issues and barriers that NPMs faced in drawing their samples for the Field Trial. It also provides suggestions on how to overcome these issues for the Main Survey.

6.3.1. Practice sample

150. In all but one country, probability sampling was applied to draw the practice sample(s). Table 6.1 summarises the issues and barriers reported by the NPMs in relation to drawing the practice sample(s), as well as their suggestions to overcome the issues encountered. Some of these are already standards of

[17] In general, this approach is not recommended, as it may lead to response bias, especially if practices also sampled their visiting patients.

the project, so the fact that the NPMs reported them as potential improvement actions – rather than as a mandatory requirement – suggests that the OECD and the consortium need to emphasise on the importance of NPMs following the protocol and guidelines for the Main Survey.

Table 6.1. Sampling of primary care practices: identified barriers, problems, and suggestions to address them for the Main Survey

Identified barriers and problems	Suggestions for the Main Survey
Registry and sampling frame	
Problems in contacting providers (due to outdated contact details in sample source, no use of institutional emails, etc.)	• To have PaRIS regional coordinators to locate a channel of communication and an effective contact. • Have a second check of the contact information before the beginning of the field work and shorten the time between the sampling contact and the implementation of the survey.
Including practices that did not meet the PaRIS survey criteria of primary care practices	• Sample sources will be clean to avoid the inclusion of practices that do not meet the inclusion criteria. Alternatively, if some countries cannot fully ensure this process, they can include some initial questions to filter out practices that do not meet the criteria.
Absence of registries of primary care practices	• Some countries can develop convenience sample approaches ensuring maximum representativeness. These specific approaches will be considered in a one-to-one basis in the preparation of the country roadmaps for the Main Survey.
Response rate and potential bias	
Low response rate	• Use a more personal contact and communication strategy. • Improve the promotion of the PaRIS survey before the recruitment phase, including engagement with professional organisations/ scientific societies and professional opinion leaders, as they can be key agents, both as advisors and as communication allies. • Having local recruiters/representatives throughout the country. In some cases, NPMs may need to secure additional funding. • Small incentives for providers, financial and non-financial, such as offering a feedback report of the practice results. An online central feedback platform will be created for the Main Survey by the consortium.
Not achieving sample representativeness or not being able to assess sample representativeness	• Sampling will be weighted for the Main Survey to ensure representativeness of the underling population. In other cases, the NPM will complement the sample source or sampling strategy to include pockets of practices that where not covered in the FT.
"Self-segregation" of practices or health centres that do not want to be evaluated	• Small incentives for providers, financial and non-financial, such as offering a feedback report of the practice results. An online central feedback platform will be created for the Main Survey by the consortium.
Respondents	**Suggestions to avoid those issues**
More than one questionnaire filled in per practice	• A preventive approach is to use unique links for each practice questionnaire; this avoids the possibility of multiple responses for a single practice.
Professional filling in the questionnaire does not have all required information to answer the practice survey	• Specify criteria for practices to consider when selecting a professional to complete the questionnaire. This has been successfully done in some countries for the Field Trial, for example, by addressing specifically the invitation to the coordinator of the practice.

6.3.2. Patient sample

151. Table 6.2. Sampling of patients: identified barriers and problems, and suggestions to solve these for the Main Survey summarises the main barriers and issues that were reported by the NPMs on sampling of patients for the Field Trial. It also includes suggestions to overcome these issues for the Main Survey. These have been collected by reports of the NPMs or are considerations that have already been included in the design of the Main Survey.

Table 6.2. Sampling of patients: identified barriers and problems, and suggestions to solve these for the Main Survey

Identified barriers and problems	Suggestions for the Main Survey
Translations	
Questionnaire not available in all relevant languages for the country	• NPMs can translate the questionnaires to minority languages. The consortium will provide translations in some languages if they are of interest to several countries.
Ethical or legal issues and registry-/sampling frame related barriers	
Restricting data protection regulation in some countries; prohibition of sharing patient data, even under public interest exceptions	• Countries may sample from practices for which patients have a data sharing agreement (this is feasible in countries in which such agreements cover a wide enough and representative proportion of the patient population).
Patient registries in practices do not include email addresses or mobile phone numbers	• Contact patients by post letter and reminders by SMS / reminding telephone call by a doctor or nurse from practice.
Previously mentioned issues cause additional work for providers, and this in turn creates a delay in timing to deliver information.	• Carefully plan activities and provide support to practices (e.g. trained assistants visiting the practice or providing real-time online support).
Response rate and potential bias	
Primary care practices that refuse to give access to patient information or provide insufficient information about the sample	• Provide written information to practices explaining whether and how they can share patient information for the PaRIS survey. The OECD Secretariat has drafted a short note (available in the folder with supportive materials for NPMs on the Teams channel), which NPMs can share with the practices. • Consider incentives for practices to invest in providing complete and up-to-date contact information, for example, feedback information for the practice.
Potential selection bias due to less contact details of/accessibility issues for older people or people with lower socioeconomic status	• Consider other means of inviting patients to participate in the survey, facilitate/strengthen the use of paper questionnaires, consider additional modes of administering the patient questionnaire, and support through telephone helplines.
Providers may be reluctant for patients to be recruited, if they feel the patient survey is too burdensome or difficult for patients, if they perceive the patient is too ill or unable to complete the survey, and if there are no incentives for patients to participate	• Provide more information why it is important that all patients included in the sample can participate (principle of inclusiveness), emphasise that patients can make their own decision to participate or not; that they can ask a family member/carer to help them complete the questionnaire, or use the telephone helpline.
Low response rates	• Start engagement with stakeholders, including patient and carer associations, at a very early stage, organise events and/or use other communication means (publications, social media, newsletters) for the months before the launch of the Main Survey to increase visibility, relevance and impact.
Difficulties to assess the representativeness of the patient sample, especially for those countries with no central patient registry. Or impossibility of checking representativeness until post-hoc, due to limitations in patient registry information.	• If representativeness cannot be assessed, it should be made clear where the chosen sampling and recruitment strategy may have caused bias. This also holds for the data collection method. It is essential to avoid any bias as much as possible by choosing and improving the quality of the sampling frame as much as possible, by applying various recruitment methods, as patients have different preferences and behaviours, and offering the questionnaire also on paper, or by telephone, and offering translations or the help of a translator; all to maximise inclusiveness and accessibility, and minimise selection, recruitment and response bias.
Period of the survey	
Low response due to launching the survey during the holiday season	• The data collection period for the Main Survey began between April and October 2023, to ensure that all countries planned their data collection before or after the holiday season.
Mode of communication	
Online invitations marked as spam	• Apply various methods to invite and remind sampled patients, to avoid that sampled patients miss the invitation. Consider the possibility of a follow-up call from a doctor or nurse of the practice with whom the sampled patients are familiar.

6.3.3. Sampling materials

152. NPMs reported a general satisfaction with the sampling materials and made some suggestions for improvements in preparation of the Main Survey, summarised below.

Providing more detailed guidance

153. NPMs indicated that it would be useful to provide more specific guidance on:

- the probability sampling approach and the different sample designs of countries;
- examples of acceptable sampling approaches; and
- further clarity on the process of recruiting practices to complete the survey.

154. These suggestions have been considered in revising the sampling guidelines for the Main Survey and are being addressed in the training sessions for the Main Survey.

Clarifications

155. NPMs requested some additional clarifications on specific details, particularly on:

- what is considered a valid 'contact' with a primary care practice (selection criterion for patients);
- who should sign the sample declaration (the NPM or the party who is conducting the recruitment).

156. These points are being discussed in the training sessions with the NPMs and are described in the Survey Operations Manual for the Main Survey.

Supportive documents

157. NPMs generally positively valued the supportive documents. There was a comment to improve the randomisation spreadsheet: an NPM noticed that formulas in the Excel spreadsheet could be disrupted if the selected sample was edited after being pasted into the spreadsheet. This sheet has been revised for the Main Survey to avoid these issues.

Streamlining

158. NPMs suggested that the number of documents to be completed should be reduced and consolidated as much as possible. The consortium is currently revising documents (e.g., Sample Report and Evaluation Report) to avoid duplication of information that NPMs need to provide.

Timings

159. NPMs requested to have access to an overall Gantt chart with a calendar to the Main Survey. This calendar has been provided by the consortium after it was approved by the OECD.

160. NPMs suggested to review the timings in which NPMs are requested to submit information. Particularly in the Field Trial, the timely submission of the sample declaration form seemed difficult. In many countries, the recruitment of practices was still ongoing, but NPMs did not want to delay sending the access link to the survey to practices that had already accepted the invitation.

Teams channel

161. NPMs requested to make the Teams channel more intuitive, if possible. They appreciated having a single document with all key documents linked to this and would prefer similar guidance for the Main Survey. The consortium has provided an overview page to facilitate access to all documents. The Survey Operations Manual for the Main Survey now includes an overview of all supportive materials, with direct links to these materials.

162. NPMs suggested to indicate version numbers or dates more clearly, to ensure they use the latest versions of the documents in the Teams channel. The consortium has created a new environment for the Main Survey, which includes (only) the latest versions of all documents.

163. Finally, several NPMs requested to share the Field Trial country roadmaps between countries to facilitate mutual learning. As a result, all (approved) country roadmaps have been made available in the Teams channel for NPMs.

6.4. Survey guidance: training sessions, manual and supportive materials

6.4.1. Training

164. The training sessions for NPMs, especially the instruction videos, were considered helpful to resolve doubts. The general evaluation score was 8.2 (on a scale from 1 to 10). Figure 6.1 shows the average evaluation scores of the various training sessions offered.

165. The majority of the NPMs did not have a strong preference regarding the mode in which they received the training. Many of the NPMs participated in both sessions and watched the video recordings of other training sessions. Around 40% of the NPMs preferred to watch the recorded sessions, which relates to the fact that they are in different time zones or have a lot of other work obligations.

Figure 6.1. Average evaluation scores of training sessions (scale 1-10)

166. The principal suggestions for the Main Survey were to encourage and facilitate knowledge exchange between countries in group sessions or Q&A meetings, to improve and support communication between NPMs and the consortium, or to organise meetings with the consortium partner and Ipsos.

6.4.2. Survey Operations Manual

167. Regarding the Survey Operations Manual, the overall impression was that it was complete and comprehensive. It was also considered useful to have a written overview of all the documents, as material that could be easily shared. Some elements for further improvement that were mentioned:

- Include an overarching workflow diagram, including each stage of the field process to support a comprehensive understanding.
- Ensure consistency of language and terminology throughout the document and facilitate the navigation through the large amount of documentation for the project.
- Keep links to Teams documents updated.
- Provide additional clarity about which processes and steps are essential and where there is flexibility for country-specific adaptations.
- Consider how the communications about the target patient population of the survey could be improved; it was difficult to communicate that the focus was on the experiences and outcomes of people living with chronic conditions, while the invited patients did not necessarily have a chronic condition.
- Improve the materials supporting the decentralised approach.

168. These suggestions have been considered in revising the Survey Operations Manual.

6.4.3. Supportive materials

169. Regarding the materials to support the field work, and specifically regarding the workplace on MS Teams, a general reflection that arose for some NPMs is to consider including a small informative video of how to navigate all the resources on Teams, if possible. The already existing 'PaRIS Files Overview' was considered useful, but there was a sense of overlapping or missing information, that could be solve with the suggested video. For the future, it could also be considered to include the information regarding the date of the latest version, to keep everyone informed in a central place within MS Teams about all newly added materials and updates in materials. Also, reinforcing the communications and follow-up of the steps and project tasks is a priority, as not all NPMs are aware of the materials available and the timelines of the project.

170. Some information and instructions that NPMs would appreciate to receive before the Main Survey are the following:

- More information on registering paradata;
- Information on whether the online questionnaires could be completed in two stages or in a second session, to improve data completeness and avoid drop-outs;
- How to send email invitations to participate in the survey securely;
- How to track the number of questionnaires completed at national level for decentralised countries;
- Data cleaning instructions for decentralised countries;
- Translation guidelines: more information on the iterative process, the deadlines for the various steps and the possibility to validate some localisations.

171. These suggestions were considered for the Main Survey; some have been addressed – or will be addressed – in the (recorded) Q&A sessions for NPMs, others in the supportive materials that have been prepared for the Main Survey (all available in the Teams channel for NPMs).

7. Discussion of the main findings

172. In this chapter we discuss the main findings of the Field Trial. Section 7.1 focuses on the sampling processes and subsequent recruitment of primary care practices and patients. Sections 7.2 and 7.3 focus on the performance of the questionnaires for patients and primary care practices respectively. In section 7.4 we discuss the experiences of NPMs with the Field Trial data collection and the support they received.

7.1. Sampling and recruitment of primary care practices and patients

173. All countries that participated in the Field Trial applied probability sampling to sample primary care practices, only one country used a convenience sample. Sample sizes ranged from 26 to 3,400 primary care practices. Response rates of practices ranged from less than 5% to 96%. Despite the overall adequate sample sizes, only seven countries reached the target of 25 participating practices[18]. The main reasons for practices to not participate were, according to the NPMs, lack of time of practice staff and hesitance to share patient data because of data protection and privacy concerns. This suggests that timing of offering the survey, clear communication with practices on the legal basis to share patient information, and reducing the workload for practices as much as possible are crucial to maximise the participation of practices.

174. Sample sizes for patients ranged from 698 to 15,422 and response rates varied between less than 1% and 73%. Few countries reached the target of 1,250[19] participating patients, which was mainly caused by the low numbers of participating practices. The highest number of participating patients was 2,360, followed by 1,237.

175. Overall, the sample sizes were adequate. Therefore, rather than increasing the sample size, it appears that more intensive engagement and recruitment efforts could increase the number of participating practices and patients.

7.2. Survey questionnaire for patients

176. In total, 10,894 patients in 18 countries completed the patient questionnaire. In all countries, most of the participating patients were women. The distributions of participants' age, education level and number of chronic conditions varied substantially between countries. For example, participants in one country were on average much younger than in other countries. Two countries had a relatively large proportion of participating patients that had not completed any education or had only attained primary or lower secondary education (71% and 58% respectively), while the share of patients with higher professional or university education was very high in other countries (52% and 46%). Part of this variation in participant characteristics may reflect true differences in the eligible patient populations of countries, but not for all

[18] For two countries the target was set at 10 participating practices.

[19] For two countries the target was set at 500 participating patients, due to a lower target set for participating practices (10 instead of 25).

observed differences. National representativeness was, however, not a requirement for the Field Trial. The Main Survey may provide a better insight into the extent to which the eligible patient populations in countries differ according to sociodemographic characteristics and reporting of chronic conditions.

177. The median time to complete the online questionnaire for patients ranged between 24 and 33 minutes between countries. There is substantial variation in the time it took respondents to complete the questionnaire. The completion time seems to be related to patients' age (older patients need more time) and number of chronic conditions (persons reporting chronic conditions need more time). Caveats apply, e.g., people reporting chronic conditions had to answer more questions and were on average also older than people who did not report one or more chronic condition(s). Drop-out rates were low (8% in total), which suggests that for most participants completing the survey online the questionnaire was not too long. However, as mentioned, for older patients and patients reporting multiple chronic conditions completing the questionnaire took more time. Information about how long it took participants to complete the paper or telephone survey is unknown. Some NPMs indicated that the length of the questionnaire was a reason for drop-out or nonresponse in their country. The length of the questionnaire will therefore be considered in the revision process of the questionnaire for the Main Survey.

178. From the total set of 118 questions for patients, there were only three questions with 10% or more missing answers. These were questions on household income and the number of children and adults in the household. The percentage of missing answers on these questions varies considerably between countries, which suggests that these questions are more sensitive or more difficult to answer in some countries than in others. Therefore the translations and localisations of these questions should be carefully reviewed. Furthermore, the answers to most questions in the patient questionnaire show a fairly normal, bell-shaped distribution. Skewed distributions are mostly explainable and there is no need for revision, with the exception of a question about the number of different medications, which will be revised to re-distribute the response options.

179. In most countries, the majority of patient questionnaires were administered online, except for two countries where the patient questionnaire was administered exclusively by telephone interview and one country where more participants completed the questionnaire on paper. Six countries offered only online administration of the questionnaire. Most of these countries also had a relatively high drop-out of participants (persons who started to fill in the questionnaire but did not complete). This underlines the need to offer patients an alternative way to participate in the survey, and to not rely exclusively on online administration. Inclusiveness is a key principle of the PaRIS survey, which should guide the selection of appropriate recruitment and data collection modes.

180. Regarding the performance of the internationally validated PROMs (PROMIS Global – Physical and Mental health scales, and WHO-5 Wellbeing Index), confirmatory factor analyses revealed that the scales performed reasonably well when the data from all countries were combined. However, the hypothesised factor structure of the three scales was not invariant across countries.

181. All (multiple item) PROMs included in the patient questionnaire could be reliably assessed at patient level, except for two sets of two questions that we combined to explore their scalability. These sets of questions (on fatigue and sleeping problems) had not been designed to form a scale. One of the questions related to sleep was removed, which appeared redundant as a stand-alone question, and will treat the other three as single questions in the analyses of the Main Survey.

182. For the PREMs, the validated scale included was the Person-Centred Coordinated Care Experiences Questionnaire (P3CEQ). As we made adaptations to the questionnaire to fit the structure of the patient survey, exploratory factor analysis was conducted to examine its dimensionality. This resulted in one factor that accounted for most of the variance in the data, suggesting a unidimensional concept. Since the P3CEQ aims to assess two separate dimensions (person-centredness and care coordination), we calculated both the reliability of the total scale and the two presumed subscales, which were overall

good. Some questions and answering options of the P3CEQ will be modified for reasons of consistency and decisions on the use of the subscales will be made later, based on the data from the Main Survey.

7.3. Survey questionnaire for primary care practices

183. In total, 540 primary care practices in 17 countries completed the practice questionnaire. There was substantial variation in the characteristics of the participating practices between countries. This applies to the degree of urbanisation of their location and practice type. The extent to which these differences reflect actual differences in geographical distribution and practice type has not been examined, as the number of participating practices was low in many countries and national representativeness was not a requirement for the Field Trial.

184. The median time to complete the practice questionnaire was around 20 minutes in each country. There was substantial variation in the time it took respondents to complete the questionnaire, but this does not appear to be a cause for concern. Longer completion times were probably caused by respondents leaving the online survey open and completing it in-between other activities during their daily work. As almost all providers who started to fill in the questionnaire also completed it, there is no evidence that the practice questionnaire should be shortened.

185. From the total set of 58 (single) questions in the practice questionnaire, there were only three questions with 10% or more missing answers. These questions were related to the COVID-19 pandemic and will not be part of the Main Survey questionnaire. There were also four questions to which at least 10% of the respondents answered they were 'not sure' of the answer. For two of these questions, pertaining to the clinical information system of the practice, and a question on reviewing indicators to monitor patient care, the relatively high percentage of 'not sure' answers is most likely a good reflection of the actual situation. The fourth question, on the use of patient care plans, was probably not well understood, and will therefore be revised for the Main Survey. Furthermore, another question (not showing a high percentage of missing or 'not sure' answers) will also be revised, as it was deemed likely that the question was misinterpreted. This is the question on the type of chronic conditions for which care is provided by the primary care practice.

186. The data of some questions of the practice questionnaire were combined to explore whether it would be possible to treat them as a scale in the Main Survey. All seven scales constructed in this way showed good reliability at the country level, allowing their use to make country comparisons. Four of them also showed sufficient reliability at practice level; for three scales the reliability at practice level was lower than the critical value of .70. It is likely that the practice level reliability of these scales will be higher in the Main Survey because of the higher number of participating practices in each country.

7.4. Supporting the data collection

187. Most of the data were centrally collected via the online platform provided by the consortium. In general, the experiences with this tool were positive. The same holds for the sampling guidelines and other tools provided to support the sampling process.

188. NPMs made some suggestions for improvements in preparation for the Main Survey, and these will be – and have already been – considered. There was a suggestion to carefully consider the number and timing of supportive documents. In general, NPMs understood the need for these documents and felt they were clear. Suggestions about the ease of navigating the MS Teams channel for NPMs and the folders/document structure have been followed up by the consortium.

189. NPMs also expressed a need for more channels of communication and exchange between NPMs to share information and experiences. A specific request was to get access to the country roadmaps of

other countries. The consortium has therefore created this option in the Teams channel for NPMs. Some NPMs were also interested in monthly webinars to meet and learn from each other, which also indicates a need to strengthen communication among NPMs. Promoting the use of the Teams channel for communication seems a sensible first step to achieve this.

190. The training sessions, the Survey Operations Manual and related supportive materials provided by the consortium were valued by the NPMs.

8. Implications for the Main Survey

This chapter provides a summary of the changes that are proposed to the survey methods, questionnaires, guidelines and support based on the lessons learned from the Field Trial.

191. All changes are aimed to improve the implementation of the PaRIS survey in the mainstage. NPMs play a key role in the actual improvement process by optimising their survey methods (e.g., recruitment strategies, administration modes for the patient survey), and broadening or intensifying their stakeholder engagement strategies to ensure maximum uptake and impact of the PaRIS survey in their country. Below we provide an overview of the key actions to reinforce the Main Survey.

8.1. Questionnaires

8.1.1. Patient questionnaire

192. The wording, the number or the content of answering categories for several questions in the patient survey were modified. An example of a change in the number of answering categories is the question on the number of prescribed medications the respondent takes on a regular or ongoing basis. Because of the high proportion of answers in the answering category '1-4 medications', it was decided to divide this category in two, '1-2 medications' and '3-4 medications'. In addition, some introductions to questions were altered. For example, it was necessary to emphasise on several sections in the questionnaire that the questions referred to primary care rather than healthcare in general. Furthermore, the question on age was moved to the beginning of the questionnaire, to check whether the respondent was indeed aged 45 or older, before answering all the questions. Finally, some questions were omitted from the questionnaire. This is the case for the Sleep Disturbance question (from the PROMIS item bank). It was removed because it could not be used in a scale together with the WHO-5 item on sleep and was redundant as a stand-alone question.

8.1.2. Practice questionnaire

193. The questions in the practice questionnaire underwent some more changes than those in the patient questionnaire, as not all questions appeared to be applicable or understandable in all countries. All questions on the impact and management of COVID-19 were excluded to reduce the length of the questionnaire, also considering that these questions were less relevant than at the time of the development of the Field Trial questionnaire. Furthermore, changes were made to questions on the use of patient care plans and on the type of chronic conditions for which care was provided, as these questions appeared to be unclear or multi-interpretable.

8.1.3. Scale performance

194. Some internationally validated scales were selected for the patient questionnaire to assess main outcomes of the PaRIS survey, particularly the PROMIS – Global Physical and Mental health scales and the WHO-5 Wellbeing Index. Theses scales were found to show differences in the factor structure across countries. The consortium will further examine this – ahead of the analysis of the Main Survey – by conducting further analyses of the deviating factor structure found in some countries, and probably Item Response Theory (IRT) analysis. IRT analysis allows for a more fine-grained analysis of scales at item level.

8.2. Sampling

8.2.1. Sampling method

195. As outlined in the Main Survey sampling guidelines, probability sampling is required; a convenience sample of primary care practices or patients will not suffice. This is because the PaRIS survey results need to be representative for participating countries' primary care practices and persons aged 45 or older who use their services. Extrapolation of the survey results to the entire target population of the PaRIS survey in a country can only take place when all eligible patients have a chance to participate and selection and nonresponse bias can be minimised and corrected for.

196. Regarding the latter: to be able to assess national representativeness of the participants in the survey and to correct for potential selection or nonresponse bias, it is necessary that NPMs provide detailed information on the sampling frames and the sampling methods they will use for the Main Survey. The consortium has therefore revised the sampling reporting template, now including more concrete, structured questions. The new template also includes several tables that should be completed by the NPMs, to gather (aggregated) data on some basic characteristics of the practices and patients included in the sampling frames and samples. Being aware that filling these tables may take quite some effort and time from NPMs, the requested information is essential to ensure the external validity of the country results of the PaRIS survey.

8.2.2. Sample size

197. Analysis of the Field Trial data showed that the numbers of participating practices and patients in the Field Trial were not sufficient to guarantee reliable estimates of the main outcome measures at all levels (patient, practice and country level). Besides the reliability at patient level, the reliability of the constructs at country level is particularly important to allow comparison of the results across countries. Therefore, the consortium has developed an evidence-informed proposal for the required number of participants in the Main Survey, based on simulations using the Field Trial data. It has been calculated that with on average 100 participating practices per country and 75 participating patients per practice the reliability of all main outcome measures (PREMs, PROMs) will be sufficient at country level to allow cross-country comparisons. These numbers will also ensure a high reliability of the constructs at patient level, and possibly also sufficient reliability at practice level. Reliability at practice level is however less important, as the international PaRIS survey does not aim to compare patients' care experiences and outcomes between practices within a country.

8.3. Engaging stakeholders

8.3.1. Primary care providers

198. The Field Trial has shown that the engagement of primary care professionals is essential for successful implementation of the PaRIS survey. The NPMs have made several suggestions on how this could be achieved based on their experience with the Field Trial and that of other NPMs. One of the suggestions is to create a network of local field coordinators within the country, with strong central coordination. To enhance this strategy, fluid communication is fundamental to track progress and share potential solutions for challenges, for instance by organising regular follow-up meetings with the local coordinators. The OECD has also provided guidance on how NPMs could strengthen stakeholder engagement, emphasising that both primary care professionals and patient representatives are key stakeholders of the PaRIS survey (Kendir et al., 2023[2]). The World Organization of Family Doctors (WONCA) offered help by sending a recommendation letter to their member organisations in participating countries. NPMs are encouraged to contact these member organisations for support and they may refer to the WONCA letter in doing this. Furthermore, NPMs could always approach the OECD Secretariat and/or the consortium with country-specific requests for help or support.

8.3.2. Patient representatives

199. NPMs may also need to strengthen their strategies to engage patients and their associations in the PaRIS survey. As mentioned above, the OECD has provided guidance on how NPMs could identify the main stakeholder audiences, including patient representatives, in their country, and involve them at the highest possible level, i.e., not just informing them, but co-designing the survey implementation and exploitation in their country to maximise relevance and impact. This is also expected to increase the response of patients on the survey.

8.4. Recruitment of participants

8.4.1. Primary care practices

200. The recruitment of primary care practices has proven to be challenging in many countries. However, the Field Trial showed that the primary care sector was not yet optimally involved in the design and implementation of the PaRIS survey in all countries. NPMs are therefore strongly advised to engage primary care providers more widely and at a higher level in the PaRIS survey, as it can be expected that this will positively impact the willingness of primary care practices to participate. This will also increase the impact of the survey on policy and practice development in countries.

201. Regarding the timing of the recruitment of practices, it was suggested by some NPMs that inviting practices to participate should not start before they can access the survey, to minimise drop-out between recruitment and participation. These NPMs also mentioned that practices find it difficult to commit to participate in the survey if they do not have a clear picture of the activities and related timeline. This means that everything should be ready before starting to invite sampled practices. Other NPMs indicated that they need more time for recruitment than what was available for the Field Trial. For the Main Survey there will be more time available for recruitment and data collection (April until October 2023 for most countries), but any delay or a longer data collection period is not possible, because first results will have to be reported already in January 2024 at the conference for Health Ministers.

8.4.2. Patients

202. The Field Trial showed that in several countries the response of patients was lower than expected. This means that NPMs may also need to change or intensify their strategies to recruit patients. Strengthening the engagement of patient representatives in the national design and implementation of the survey (as mentioned above) can be seen as an important step in this, as it will increase the visibility and credibility of the survey for people who are invited to participate. In addition, several recruitment strategies have been suggested and tested by some NPMs. A reminding telephone call made by a doctor or nurse from the patient's practice seems to be highly effective. Directly offering a paper questionnaire to subgroups of patients (e.g., older people or people living in rural areas), besides a link to the online survey, may also improve the response among these patients. The Field Trial suggested a higher drop-out of patients (starting but not completing the questionnaire) in countries that offered the questionnaire only as an online survey. This means that offering a paper questionnaire to all patients who cannot or do not want to participate online – which is standard protocol – is expected to increase the response and will also enhance the inclusiveness of the PaRIS survey. This may also hold for offering other administration modes in some countries and creating a helpdesk in all countries.

203. The Field Trial also made clear to some NPMs that they need a stronger Information and Technology (IT) team for the Main Survey, because operational elements such as massive sending of invitations, communications, coordination of telephone lines require more IT expertise and time than they had initially thought.

8.5. Communications and working with NPMs

8.5.1. Use of the Teams channel

204. The consortium has implemented several suggestions of NPMs regarding the MS Teams channel. NPMs have been granted access to an overall Gantt chart with a calendar to the Main Survey. The Teams channel has also been improved to be more intuitive and easier to navigate. For the Main Survey, the document directory in the main folder was retained – and updated –, as NPMs indicated it was a helpful tool. As requested by NPMs, version numbers of documents are now clearly indicated in the title of documents.

205. Some NPMs requested an instruction video on how to navigate all the resources on Teams. This cannot be achieved at the moment, due to time constraints. Moreover, during the Field Trail and preparation of the Main Survey, NPMs have gathered experience on working in the Teams environment. However, it is certainly worth considering developing instruction videos for future cycles of the PaRIS survey.

206. Most NPMs were keen on strengthening their mutual communication, to share information and experiences. The consortium has taken steps to facilitate this, such as enabling NPMs to access the approved country roadmaps of other NPMs and organising Q&A sessions. In this way NPMs will get more insight into how the PaRIS survey is implemented in other countries and learn from other NPMs on how they engage key stakeholders, and sample and recruit participants. In time, and when available, other documents will be shared to stimulate the transfer of good practices, for example, regarding publicity, engagement and exploitation strategies.

8.5.2. Survey Operations Manual and supportive materials

207. To give a comprehensive overview of consecutive stages of the Main Survey, the Survey Operations Manual for the Main Survey includes a schedule of when various tasks need to be completed.

Furthermore, as not all NPMs knew that respondents could complete the online questionnaires in two or more sessions, this has been emphasised in the revised Survey Operations Manual.

208. Regarding the documents for NPMs, the several technical issues were solved to ensure the Main Survey data entry will proceed smoothly. In response to another suggestion, a separate file for the registration of paradata has been compiled.

209. The consortium is still working on solving some issues related to the survey implementation in decentralised countries. One of these is how the track of surveys replied and completed at national level could be monitored. Also, the data cleaning instructions for decentralised countries were not always known or correctly applied in countries. Furthermore, access to or the registration of paradata (e.g., the online survey completion time) needs to be improved in working with decentralised countries.

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