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PATIENT REPORTED INDICATOR SURVEYS (PARIS): METHODOLOGICAL CONSIDERATIONS OF A FIELD TRIAL IN SLOVENIA

OCENA IZKUŠENJ IN IZIDOV ZDRAVSTVENE OSKRBE PACIENTOV S KRONIČNIMI NENALEZLJIVIMI BOLEZNIMI: METODOLOŠKI VIDIK PILOTNE IZVEDBE RAZISKAVE V SLOVENIJI

Matija AMBROŽ [1*], **Candan KENDIR** [2,3], **Wienke BOERMA** [4], **Zalika KLEMENC-KETIŠ** [1,5,6]

[1] Community Health Centre Ljubljana, Metelkova 9, 1000 Ljubljana, Slovenia
[2] Organisation for Economic Co-operation and Development (OECD), 2, rue André Pascal 75016 Paris, France
[3] Amsterdam UMC location Vrije Universiteit Amsterdam, Department of Public and Occupational Health, Amsterdam, Netherlands
[4] NIVEL Netherlands Institute for Health Services Research, Otterstraat 118, 3513 CR Utrecht, The Netherlands
[5] University of Maribor, Faculty of Medicine, Department of Family Medicine, Taborska 8, 2000 Maribor, Slovenia
[6] University of Ljubljana, Faculty of Medicine, Department of Family Medicine, Poljanski nasip 58, 1000 Ljubljana, Slovenia

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ABSTRACT

Keywords:
Patient Reported Indicator Surveys (PaRIS)
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Quality of healthcare
Patient experience
Data collection methodology

Introduction: Healthcare systems collect little information about the experiences and outcomes of care from the perspectives of patients. Patient Reported Indicator Surveys (PaRIS) is an OECD initiative to measure the outcomes and experiences of people living with chronic conditions, who are managed in primary care.

Objectives: To evaluate the feasibility of the methodology employed in the Field Trial of the PaRIS survey in Slovenia and propose adjustments to enhance sampling in the Main Survey.

Methods: In 2022, we conducted a cross-sectional observational study in 50 family medicine practices in Slovenia with a target of recruiting 70 patients per practice. We used the Slovenian version of the PaRIS questionnaires, and evaluated sampling and data collection.

Results: The sample contained 21 providers (42.0% response rate) and 454 patients (50.7% response rate). The provider sample did not differ from the population characteristics, while the patient sample differed significantly from the patient population. All providers completed the survey online, in 20.9±11.1 minutes and had 1.5±1.5 restarts. Most patients (74.9%) completed the survey online and needed 36.0±22.6 minutes, and the mean number of restarts was 1.4±2.2.

Conclusion: Based on the results, we recommend conducting a methodology test for quality assessment studies before initiating the main survey. Legal issues should be addressed and considered early when developing the methodology. It is also necessary to be aware of the feasibility of the study in practice, to avoid a low participation rate.

IZVLEČEK

Ključne besede:
ocena izkušenj in izidov zdravstvene oskrbe
primarno zdravstvo
kakovost zdravstvene oskrbe
pacientove izkušnje
metodologije zbiranja podatkov

Uvod: *Zdravstveni sistemi zbirajo malo podatkov o izkušnjah in izidih oskrbe z zornega kota pacientov. Ocena izkušenj in izidov zdravstvene oskrbe pacientov s kroničnimi nenalezljivimi boleznimi (projekt PaRIS) je pobuda OECD za merjenje izidov in izkušenj ljudi s kroničnimi boleznimi, ki so obravnavani na primarnem zdravstvenem nivoju.*

Cilj je oceniti izvedljivost in ustreznost uporabljene metodologije pilotne izvedbe raziskave PaRIS v Sloveniji in predlagati izboljšave vzorčenja in zbiranja podatkov v glavni raziskavi.

Metode: *Leta 2022 smo v Sloveniji izvedli presečno opazovalno študijo v 50 ambulantah družinske medicine, s ciljem povabiti k sodelovanju po 70 pacientov iz vsake ambulante. Uporabili smo slovensko različico vprašalnikov PaRIS. Ocenili smo vzorčenje in zbiranje podatkov.*

Rezultati: *Vzorec je zajel 21 izvajalcev zdravstvenih storitev (42,0-% odzivnost) in 454 pacientov (50,7-% odzivnost). Vzorec izvajalcev zdravstvenih storitev se ni razlikoval od značilnosti populacije, medtem ko se je vzorec pacientov bistveno razlikoval od populacije pacientov. Vsi izvajalci zdravstvenih storitev so anketo izpolnili prek spleta v 20,9 ± 11,1 minute pri čemer so imeli povprečno 1,5 ± 1,5 ponovnih zagonov. Večina pacientov (74,9 %) je anketo izpolnila prek spleta. Čas izpolnjevanja spletne ankete je bil 36,0 ± 22,6 minute, povprečno število ponovnih zagonov pa 1,4 ± 2,2.*

Zaključki: *Na podlagi rezultatov lahko predlagamo, da se pri študijah ocenjevanja kakovosti, test metodologije izvede pred izvedbo glavne raziskave. Pravne prepreke in značilnosti je treba nasloviti in upoštevati zgodaj v razvoju metodologije. Prav tako je treba biti pozoren na izvedljivost študije v praksi, da se prepreči nizka stopnja sodelovanja.*

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***Correspondence:** matija.ambroz@zd-lj.si

1 INTRODUCTION

Healthcare systems that place greater emphasis on the quality of primary care have better clinical outcomes and are more economically efficient and sustainable [1-5]. The patient's experience with the healthcare system is being recognised as an important dimension of the quality of healthcare. It is thus an increasingly common strategy to monitor the quality of healthcare at all levels [6-9].

Tools that assess patient experience enable patients to provide feedback and potentially strengthen a patient-centred health system [10].

A standardised data collection procedure is preferred in international surveys. Due to a wide variety of legal, ethical and cultural differences in primary care, a data collection strategy is adapted for each country in agreement with the consortium [11]. To date the largest international research on the quality of primary care (Quality and Costs of Primary Care in Europe (QUALICOPC)) was carried out in 31 countries between 2010 and 2013, and it included assessment of the patients' experiences [12]. This study was crucial in developing the methodology for future large-scale international studies such as the Patient Reported Indicator Surveys (PaRIS).

In 2017, the OECD launched the PaRIS initiative to systematically measure the outcomes and experiences of healthcare that matter most to people [13]. The flagship project within the PaRIS initiative is a survey of people living with chronic conditions who are managed in primary care, namely the PaRIS survey [11]. The PaRIS survey has seen three different phases: 1) design and development phase (2017-2020), including the study design and the development of PaRIS questionnaires; 2) field trial (2021-2022), including the testing of the PaRIS survey design and PaRIS questionnaires in participating countries; and 3) main survey (2022-2023), including the full implementation of the PaRIS survey in participating countries and data collection [14].

In this paper, we aimed to evaluate the feasibility of the methodology employed in the field trial of the PaRIS survey in Slovenia and propose adjustments to enhance sampling in the main survey. While the manuscript does not present content-related field trial results, it provides a comprehensive assessment of the survey's methodology.

2 METHODS

2.1 Design of the study

The PaRIS survey is a cross-sectional observational study, and the study protocol is described in detail elsewhere [11]. The study presented here took place in Slovenian family medicine practices. Family medicine physicians work either as private contractors or in primary care centres, and both are part of national public primary care system. One family medicine team consists of 1 full time equivalent (FTE) family physician, 1 FTE practice nurse and 0.5 FTE registered nurse. Practice nurses are mainly involved in tasks including administration, appointments, and clinical work, while registered nurses work as nurse practitioners and carry out preventive activities and care for stable chronic patients [15, 16].

2.2 Study population

2.2.1 Providers

We defined providers as primary care practices in line with the study design of the PaRIS survey. In Slovenia one family physician works in one family medicine practice, and the registry of family medicine practices is available online, with the system led by the Health Insurance Institute of Slovenia (ZZZS). We used this registry for random sampling, by assigning consecutive numbers to every physician in the registry and then using a random number generator to select them. The registry contains all family physicians working primarily with registered patients. Physicians that provide healthcare only to institutionalised patients or children, or who practice occupational healthcare services as their primary area of work, were excluded. There were 978 eligible family medicine physicians in Slovenia in February 2022.

As this was a field trial, we aimed for 25 family medicine practices in a final sample. Based on previous studies, we estimated at least a 50% positive response rate from the contacted family physicians, and thus to achieve the target we invited 50 practices to participate.

2.2.2 Patients

All patients aged 45 years old or more, living in the community and having had any contact (including via phone or email) with the practice in the six months preceding the study, were eligible to participate. People living in a long-term care facility, healthcare or other residential institution were excluded, as were those in the terminal phase of illness or with an advanced cognitive impairment.

Sampling of patients was random, and we aimed at 70 patients per practice. Practices autonomously generated a list of eligible patients, utilising either a random number generator or systematically selecting every Nth patient. Each eligible patient was first contacted by the practice and given the necessary information about the study, and could then provide informed consent and contact data if they wanted to participate. After that, the information gathered by the practice was sent to the researchers.

2.3 Data collection

To collect data, we used the PaRIS provider and patient questionnaires.

2.3.1 Provider questionnaire

The provider questionnaire includes 40 questions and defines the structure and characteristics of the team providing primary care and of the provider responsible - the family physician. The questionnaire was developed by the OECD and an international consortium (PaRIS-SUR consortium) in collaboration with patients and provider organisations, including the World Organization of Family Doctors (WONCA), and other stakeholders [11]. The questionnaire covers domains related to care delivery such as urbanisation, practice type, care model, information and administration systems, remote consultations, skill-mix, and remuneration. The estimated time for completion is 10-15 minutes.

2.3.2 Patient questionnaire

The patient questionnaire includes 121 questions addressing individual and sociodemographic factors, health and healthcare capabilities, health behaviours and lifestyle, Patient Reported Outcome Measures (PROMs) such as symptoms and functioning, and Patient Reported Experience Measures (PREMs) such as coordination of care and safety. The PaRIS patient questionnaire is based on the PaRIS conceptual framework and consists of validated and established tools, already described elsewhere [11]. The estimated time to complete the patient questionnaire is 25 minutes.

2.3.3 Translation and cognitive testing

The PaRIS questionnaires has two source questionnaires in English and French. The base for developing the Slovenian questionnaires was the original English versions developed and cognitively tested by the PaRIS consortium. We first translated the original English questionnaires into Slovene using the TRAP-D approach, as recommended by the guidelines [17]. The resulting questionnaires were then cognitively tested using the four-stage model of cognitive testing developed by Tourangeau [18].

Cognitive testing was only performed on questions that were identified as necessary for testing by the consortium. Changes were incorporated in the final version of the field trial questionnaires.

2.3.4 Data collection process and contact strategy

After acquiring the sample of providers those who were selected were contacted via post in which they received information about the study and an invitation to participate. Within a week after sending the invitation letter, all providers were contacted again via phone by the research team. Those who agreed to participate received a link to the survey for providers and a spreadsheet to sample their patients. The practitioners had a month to sample 70 eligible patients. They were reminded weekly by the research team via email to complete the survey and provide the completed spreadsheet (Figure 1).

Symbolic incentives were used to motivate physicians to participate, such as one-time free registration to national congresses of primary care and feedback information for their team.

The patients in the sample were contacted via their preferred method. All patients who provided an email address received the survey link via email. Those who did not provide an email address received the survey link via SMS. Those who did not provide either an email or telephone number, or who opted for a paper survey, received this via the regular mail system. Non-respondents who provided an email address received a reminder via email for two consecutive weeks after receiving the link to the survey, and those who did not give an email address received two reminders via regular mail.

2.4 Evaluation of results

For the quality check of the samples, we identified the characteristics of the provider and patient population and performed chi-square and independent samples t-test. For the providers, we used the data from the aforementioned list of practices. We performed the sample check according to geographic distribution (10 health regions) and status of the providers (public or private with a concession). For the patients, we used the data from the participating practices with regard to the age and gender of their registered patients who were age 45 years or older.

For the evaluation of data collection, we used the following variables:

Mode of completion, participation time for the e-survey, number of restarts with the e-survey, method of access to the e-survey, return code (partial/complete), and type of device used to complete the e-survey. The appropriateness and feasibility of the methodology were assessed using predefined criteria, including achieving at least 80% of the target sample size and a response rate exceeding 30%.

The research team systematically documented reasons for non-participation by directly querying both providers and patients.

3 RESULTS

3.1 Response rate

On the providers' side, 21 family medicine practices of the 50 sampled practices participated in the study (42.0%).

The family medicine practices managed to recruit 896 patients, out of which 454 responded to the patient questionnaire (50.7%) (Figure 1).

3.1.1 Characteristics of the participants

Most providers that completed the questionnaire were family physicians, working in the public sector, located in a city and in a solo practice (Table 1).

Most patients were female, 60 years of age and older, with secondary education, retired and living in a rural area (Table 2).

Figure 1. Schematic presentation of the process of recruiting of family physicians and patients.

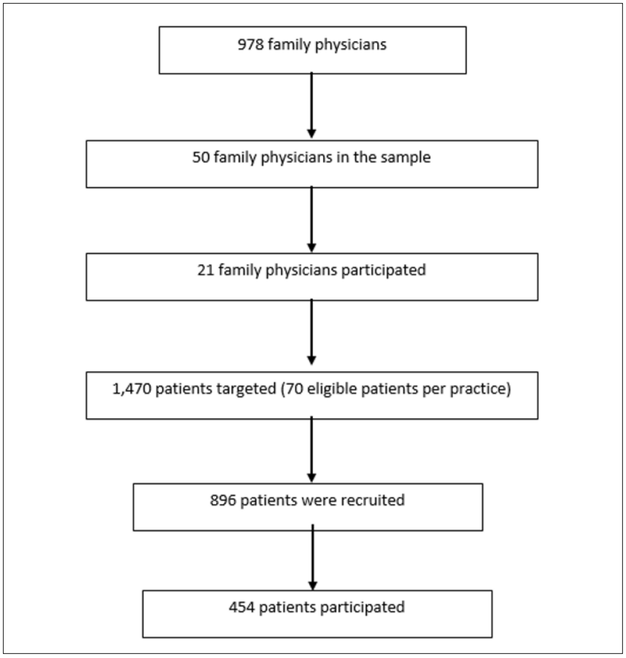

Table 1. Characteristics of the providers.

Characteristic	N	%
Professional background		
Family physician	18	85.7
Family medicine trainee	3	14.3
Type of practice		
Public (in a primary care centre)	10	47.6
Private with a concession	3	14.3
No answer	8	38.1
Practice location		
City	9	42.9
Town or suburb	5	23.8
Rural area	7	33.3
Work type		
Solo practice	16	76.2
Group practice with own patients	4	19.0
Group practice with shared patients	1	4.8

Table 2. Characteristics of the patients.

Characteristic	N	%
Sex		
Male	170	37.4
Female	249	54.8
I prefer not to say	2	0.4
Not answered	33	7.3
Age group		
44 years old or younger	2	0.4
45-49 years old	32	7.0
50-54 years old	45	9.9
55-59 years old	69	15.2
60-64 years old	74	16.3
65-69 years old	95	20.9
70-74 years old	61	13.4
75-79 years old	27	5.9
80-84 years old	13	2.9
85 years or older	4	0.9
Not answered	32	7.0
Education		
Primary school not completed	9	2.0
Primary school	52	11.5
Vocational school	123	27.1
Secondary school	230	50.7
University education	19	4.2
Master’s degree or doctorate	54	11.9
Not answered	35	7.7
Employment status		
Self-employed	14	3.1
In paid employment	150	33.0
Looking for work	4	0.9
Looking after the home	7	1.5
Unable to work due to sickness or ill-health	16	3.5
Retired	227	50.0
Other	2	0.4
Not answered	34	7.5
Living area		
City	105	23.1
Town or suburb	69	15.2
Rural area	245	54.0
Don’t know	1	0.2
Not answered	34	7.5

3.2 Sampling evaluation

The size of the provider population was 978 and the size of the sample was 50. There was no significant difference between the sample and the population regarding geographical distribution and status of the practice (Table 3).

The sample and population of patients differed significantly regarding gender and age (Table 4).

3.3 Data collection evaluation

All the providers completed the survey online. They mostly used a desktop computer and accessed the survey via a link sent by email (Table 5). The providers completed the e-survey in 20.9±11.1 minutes and had 1.5±1.5 restarts.

Most patients completed the survey online (e-survey), others used a paper-based questionnaire. They mostly accessed the e-survey via a link sent by email and used a smartphone to do so. Only a small percentage of patients left the e-survey incomplete (Table 5). The completion time was 36.0±22.6 minutes and the mean number of restarts was 1.4±2.2.

Table 5. Data collection evaluation – providers and patients.

Characteristic	Providers N (%)	Patients N (%)
Mode of completion		
Online	21 (100)	340 (74.9)
Paper	0	114 (25.1)
Method of access to e-survey		
Link via email	21 (100)	199 (58.5)
Link via SMS	0	141 (41.5)
Device used for e-survey		
Desktop	18 (85.7)	127 (28.0)
Smartphone	2 (9.5)	195 (43.0)
Tablet	1 (4.8)	17 (3.7)
Unknown	0	1 (0.2)
Return code		
Complete	21 (100)	420 (92.5)
Partial (incomplete e-survey)	0	34 (7.5)

Table 3. Provider quality sample check.

Characteristic	Number (sample vs. population)	Pearson chi-square	Degrees of freedom	p value
Geographical distribution		0.151	9	**1.000**
Region 1	5 vs. 100			
Region 2	4 vs.74			
Region 3	2 vs. 33			
Region 4	5 vs. 100			
Region 5	15 vs. 303			
Region 6	7 vs. 142			
Region 7	3 vs. 55			
Region 8	3 vs. 53			
Region 9	3 vs. 56			
Region 10	3 vs. 62			
Status		0.009	1	**0.926**
Public	36 vs. 710			
Private with a concession	14 vs. 268			

Table 4. Patient quality sample check.

Characteristic	Number (sample vs. population)	Pearson chi-square	Degrees of freedom	p value
Gender		6.954	1	**0.008**
Male	170 vs. 84944			
Female	249 vs. 95749			
Age group		98.120	8	**<0.001**
45-49 years old	32 vs. 19672			
50-54 years old	45 vs. 11343			
55-59 years old	69 vs. 15712			
60-64 years old	74 vs. 14526			
65-69 years old	95 vs. 14544			
70-74 years old	61 vs. 12801			
75-79 years old	27 vs. 16070			
80-84 years old	13 vs. 8791			
85 years or older	4 vs. 7378			

3.4 Reasons for non-participation

Some of the providers refused to participate in the study due to the workload expected from them regarding the sampling and data collection. They stated that they were overburden with their usual work and did not have time to engage in the survey.

Some of the patients refused to participate due to low interest in the survey, the questionnaire being seen as too long for them, and not having enough time to complete it.

4 DISCUSSON

4.1 Main findings

The evaluation of the PaRIS survey field trial in Slovenia showed satisfactory results regarding the sampling of providers and data collection among them. However, the sampling of the patients and data collection among them did not yield the desired evaluation outcomes, the main problem being the small sample size.

The response rate of the practices was satisfactory. The literature shows that the response rate can vary significantly (from 20-80%) [19–21], although there are several methods that can be used to improve it [14, 20]. We used personal contact and reminders, which seemed to be effective.

The survey was mostly completed by family physicians. This was expected, as the physician is a team leader in primary care practices in Slovenia, and access to the patient list through the physician was required for further sampling. Regarding the work type of the practice, most providers were in a solo practice. Here, it should be noted that in Slovenia around 70% of the family medicine practices are in community health centres, and 30% work as private practices with a concession [22].

Family physicians in health centres are practicing in their own practice with their own registered patients, working with a team of their own nurses. However, a health centre composed of a family physician, practice nurse and registered nurse is not considered as a group practice in Slovenia. A group practice in Slovenia is described as a practice where two or more physicians are working in the same practice with other healthcare professionals [23]. Hence, what is considered to be a group practice in the international PaRIS survey was recorded as solo practice in Slovenia.

The sample size of the patients was much smaller than anticipated, which is probably a consequence of how the GDPR is interpreted in Slovenia. With this, practices are not allowed to send the contact information of their patients to researchers without the patients' consent. This forced the researchers to adapt the international methodology, and to ask the practices to both sample the patients and acquire their informed consent. As expected, this placed a significant additional burden on the practices, which then failed to provide a sufficient patient sample size.

All the providers accessed the questionnaire online, and in the literature no significant differences were found regarding the mode of survey [19, 21]. The survey was completed by the providers in 20 minutes, whereas we anticipated 15 minutes would be needed. However, we still consider this feasible.

A quarter of the patients completed a paper questionnaire. Others completed an online survey via link sent by email or SMS. A meta-analysis showed that the response rate to online surveys is approximately 40% [23], and this is consistent with our results. On the other hand, the literature shows that using a paper questionnaire does not yield a lower response rate [24]. This might indicate that paper questionnaires can now be dropped, but this would be a mistake as some respondents still prefer paper versions [24]. Patients on average needed 36 minutes to complete the online survey, while there is no data on the time needed for the paper questionnaire. We expected that the online survey should be completed in 25 minutes, which turned out to be rather optimistic. The literature shows that questionnaires should include 25 to 30 questions, and be possible to complete in 30 minutes [24, 25]. In the case of longer questionnaires, we can expect a larger percentage of non-responders, a larger amount of missing data, and an increase in providing answers automatically with the last items [24, 25]. In our study, only a small number of patients left the questionnaire incomplete, which indicates that although the questionnaire was long, it was still manageable.

4.2 Strengths and limitations

One limitation of the study was that we could not evaluate the same indicators on the paper-based survey. It is thus possible that we missed some lessons for the main survey. Another limitation is the missing characteristics of the population and sample, which would have helped with regard to detecting additional significant differences. Moreover, the patient sample did not reflect the characteristics of the population, and there was also a problem with sampling according to inclusion criteria, as two patients were younger than 45 years old, although this could be due to an error when completing the questionnaire. Therefore, we cannot assume that the patient sample was representative, and one solution might be to omit this age category within the questionnaire.

4.3 Implications

We evaluated the sampling method of the practices as satisfactory, so no adjustments will be made for the main survey. The same is true for data collection of the practices.

For patient sampling, the evaluation indicated the need for revision of the methodology to achieve a better response rate. We are thus planning to provide the practices with printed survey invitations for patients containing a QR code with the link to the online questionnaire. This seems to be a good method of data collection [26]. We also plan to provide the practices with paper questionnaires. The practices will draw up a patient sample as in the field trial, but will not need to obtain the patients' informed consent for sending the contact information. Instead, the practices will mail either the QR code or a paper questionnaire to the patients in the sample. With such methodology, we expect a lower burden on the practices and higher response rate. On the other hand, such an approach will make it impossible to only send the reminders to the non-respondents.

Shortening the patient questionnaire might also contribute to better response rates.

5 CONCLUSION

This study provides insights into the methodological challenges when conducting a cross-sectional observational study on patient outcomes and experiences in Slovenian primary care. The results suggest a need for pre-testing the methodology of quality assessment studies before the main survey, enabling researchers to refine their approaches for optimal results. Early consideration of legal issues in methodology development is essential. Additionally, awareness of study feasibility is crucial to mitigate low participation rates.

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ETHICAL APPROVAL

The study in Slovenia was approved by the National Ethics Committee (No. 0120-260/2021/3).

CONFLICTS OF INTEREST

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

AVAILABILITY OF DATA AND MATERIALS

The data that support the findings of this study are available from OECD. Restrictions apply to the availability of these data, which were used under license for this study. Data are available from the authors with the permission of OECD.

ORCID

Matija Ambrož:
https://orcid.org/0009-0008-3406-5693

Candan Kendir:
https://orcid.org/0000-0001-6877-4836

Wienke Boerma:
https://orcid.org/0000-0001-7698-0015

Zalika Klemenc Ketiš:
https://orcid.org/0000-0002-0270-1754

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