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**Original Article**

# Wales' participation in the OECD PaRIS survey: exploring the logistics of a large-scale patient-reported outcome survey

**Michal Pruski[1,2,*], Sarah Puntoni[3], Kathleen Withers[1,4], Sally Lewis[5,6]**

[1]CEDAR, Cardiff and Vale University Health Board, Cardiff CF14 4UJ, UK
[2]School of Health Science, University of Manchester, Manchester M13 9PL, UK
[3]Value Transformation, NHS Wales Performance and Improvement, Cardiff CF15 9SS, UK
[4]School of Engineering, Cardiff University, Cardiff CF24 3AA, UK
[5]Kintsugi International, Crickhowell PO15 7FX, UK
[6]School of Management, Swansea University, Swansea SA1 8EN, UK
*Corresponding author. Michal Pruski, CEDAR, Medicentre, University Hospital of Wales, Heath Park, Cardiff CF14 4UJ, UK. E-mail: michal.pruski@wales.nhs.uk

## Abstract

***Background:*** **The Organisation for the Economic Co-operation and Development (OECD) undertook the Patient-Reported Indicator Survey (PaRIS) to understand if current healthcare delivery and policy were meeting people's needs. Although the UK as a whole is an OECD member, Wales participated in the PaRIS study independently of the rest of the UK since healthcare is a devolved matter to the Welsh Government and Wales is internationally acknowledged for its work implementing Patient Reported Outcome Measures.**

***Methods:*** **Here, we describe and reflect on how PaRIS was implemented, discussing both the initial field trial and the final survey, which targeted GP practices and patients over the age of 45. We detail the governance structure used for the project, the various parties that cooperated to implement the project, and the stakeholder engagement approach utilized. We also provide descriptive statistics of the sampled GP practices and patients.**

***Results:*** **Out of 199 surveyed GP practices, 75 responded to the survey. Out of 109 600 sampled patients, 25 839 responded to the survey, out of which 7 706 patients were from the 75 recruited practices and met the PaRIS inclusion criteria. Participants were representative of the population of Wales with respect to urbanization levels, sex, as well as ethnicity. GP practices were provided with infographics, giving them insight into their patients' health compared to patients' health across Wales. While the OECD flagship PaRIS report has now been published, further work is being undertaken in Wales to utilize the available data.**

***Conclusion:*** **Wales achieved one of the most comprehensive datasets of all PaRIS nations, despite its small size. The data offered the participating GP practices an opportunity to understand how they and their patients compared to other practices across Wales. The data are now being employed to understand population health and drive policy change and healthcare improvement initiatives across the nation.**

**Keywords** PROMs, PREMs, Surveys, Value-Based Healthcare

**Key Messages**

- Wales achieved 137% of its OECD recruitment target despite its small size.
- Wales utilized PaRIS as an opportunity for broader healthcare service improvement and evaluation, expanding the project's original scope.
- Several strategic and operational recommendations are presented based on Wales' experience in overcoming implementation challenges.

# Introduction

## Brief overview

In 2017 member states instructed the Organisation for the Economic Co-operation and Development (OECD) to establish whether current healthcare delivery and policy were meeting people's needs. A person-centred survey, focusing on chronic conditions and primary care, was developed and deployed [1–4]. To support the aim of collecting international patient-reported data, the OECD signed a

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letter of intent to collaborate with the International Consortium for Healthcare Outcomes Measurement (ICHOM). In 2019, the OECD accepted Wales' entry into the Patient-Reported Indicator Survey (PaRIS), independent of the UK, making it one of 19 countries to deploy the survey in 2023. This article describes the approach taken by Wales and the lessons learned.

## Background

Wales, one of four nations in the UK, has circa 3.2 million inhabitants and total autonomy in its decision-making on health policy and healthcare delivery. Wales is committed to healthcare improvement and equity, through such means as value-based healthcare [5–7]. The Welsh National Health Service (NHS Wales) is a publicly funded, taxation-based system with the Welsh Government (WG) as the single payer to seven integrated health boards and three trusts via a weighted capitation-based formula.

The national value-based healthcare programme, and subsequent establishment of the Welsh Value in Health Centre (WViHC; now known as the Value Transformation Directorate of NHS Wales Performance and Improvement) in 2021, provided the expertise and infrastructure necessary to deploy the PaRIS surveys. The Welsh healthcare system was well-known to ICHOM through past strategic partnerships in implementing patient-reported outcome measures (PROMs). Since past PROMs implementation in Wales was in the secondary care setting, PaRIS acted as a testing ground for primary care and population level PROMs implementation.

NHS Wales and WG, supported by WViHC, wanted to understand the symptom burden across Wales to determine future service provision within the community and identify the needs of the population. PaRIS provided an opportunity to establish an evidence base to inform decision-making and a baseline for future cycles of data capture. It also offered an opportunity to standardize existing PROMs indicators and develop new surveys, such as PROMs and patient-reported experience measures (PREMs), focusing on patients with chronic conditions.

## Report objective

The objective of this report is descriptive. It provides a practice-oriented account of PaRIS implementation in Wales, examines the response rates and representativeness of the respondent population, and shares lessons from national experience. The report does not aim to provide substantial findings from the survey, but to provide background for future publications and considerations for others who might wish to implement similar projects.

# Methods

## Project governance and actors

The project was run by the WViHC, and the steering group, established to oversee all project elements, was chaired by the Director of the Centre, being accountable for delivery to WG directly. The project was supported by Cardiff University during the feasibility study stage. Ministerial approval from WG was sought for internal governance purposes. Table 1 in Supplementary file 1 describes the roles of all the collaborators in this project.

## Projects objectives

The project was designed to deliver three objectives:

1. Collect and share data for the PaRIS study
2. Provide feedback to participating general practitioner (GP) practices
3. Obtained data for health service improvement

## Questionnaire and translation

OECD recognized the experience of NHS Wales in translating questionnaires by the CEDAR research team and agreed that they could be translated locally. CEDAR used the ISPOR principles as a basis for developing the Welsh translation [8]. Cardiff University undertook the survey's validation following OECD requirements and guidelines.

## Eligibility criteria

The OECD inclusion criteria were as follows:

Primary care provider practices were eligible to participate in the study if they: (i) were staffed with healthcare professionals licensed to serve the general population of a community, and (ii) provide ambulatory generalist medical care (i.e. in an outpatient setting), including services addressing chronic care management.

Patients were eligible to participate in the study if they met three eligibility criteria: (i) aged 45 years or older at the time of sampling, (ii) living in a private household in the community (i.e. not in a nursing home or other residential institution), and (iii) having had at least one registered contact with a participating primary care practice—either face-to-face, by telephone or online—for any medical or administrative reason, during the 6 months preceding the selection procedure in the practice information system. OECD selected these criteria as they were particularly interested in gaining understanding of the health status of patients with chronic conditions and the way that access to primary care affects their outcomes, which required patients to be linked to their GP practices [9].

Since in Wales only people's age and GP practice could be reliably ascertained before contacting patients, data from patients who did not meet all three eligibility criteria were also collected and used to support project aims 2 and 3. This resulted in an OECD patient set (patients who met all criteria) and a total set of all respondents (Figure 1). Nevertheless, due to an administrative error, only patients who were at least 46 years old were recruited; those who were 45 years old were not included. Data were collected from both practices (see the standard OECD questionnaire version in reference [10]) and patients (see the questionnaire used in Wales in Supplementary File 2).

## Field trial

A field trial was undertaken to test the PaRIS project processes [11].

GP practices were invited to participate in the field trial via an e-mail sent by NHS Wales Shared Services Partnership (NWSSP), with up to two reminder emails sent two weeks apart, and a phone call. A list of participating practices was provided to HealthWise Wales, a Cardiff University run programme.

HealthWise Wales sent an initial e-mail to its members based in participating GP practices, followed by a reminder sent 2 weeks later. HealthWise Wales utilizes various information sources to ensure that deceased members were removed from their database and provided a facility for prospective participants to be removed from their contact list if they so wished.

GP practices and patients who gave consent to participate were allocated unique identifiers by Cardiff University, which were forwarded to Ipsos MORI. Ipsos MORI generated a unique URL to the relevant questionnaire for each identifier, and Cardiff University sent this to the participating GP practices and individual participants.

## Main survey

CEDAR designed the provider sampling strategy, and Digital Health and Care Wales (DHCW) generated unique identifiers for all GP practices, which were forwarded to Ipsos MORI. Ipsos MORI provided URLs for each practice and forwarded them to the WViHC. The WViHC provided NWSSP with the sample of GP practices selected for recruitment. NWSSP then notified GP practices that the survey was open, and WViHC sent practices their unique identifiers and URLs. These messages also contained sign-posting to more information about the project, a statement that the practice would receive an infographic with insights from their and their patients' data, and informed that eligible patients would be contacted with an offer of study participation. Practice survey completion was monitored based on practice size and location. Non-responding practices from less-represented strata were sent reminders. Up to three reminder messages were sent, and a phone call from WViHC was made to practices which neither completed nor refused to complete the survey.

CEDAR, DHCW, and WViHC designed the patient sampling strategy. DHCW randomly selected patients over 45 years of age from each invited GP practice, based on a list provided by the WViHC. DHCW conducted a death check on the patient list and generated unique identifiers for non-deceased patients, which were forwarded to Ipsos Mori. Ipsos MORI contacted patients via post, signposting them to an online portal, or asking to return a pre-paid card requesting a paper version of the questionnaire and if the questionnaire was to be returned to them in English, Welsh, or both languages, or to contact a helpline for telephone completion. Ipsos MORI also included a minority language card with information in Polish, Bengal, Arabic, and Ukrainian, signposting to a free phone-line facilitating questionnaire completion with a translator; paper or electronic versions of the questionnaire were not available in these languages. Patients were informed of the three uses of the data: (i) the PaRIS study itself, (ii) delivering anonymised feedback to GP practices, and (iii) uses of the data in the health service, including reidentification and linkage. Patients were asked to provide consent to the study and fill out the questionnaire. Patients who did not respond were sent one reminder by post, and a text message after first completing an additional mortality check on these patients. Patients could request to be removed from further communications. The English version of the questionnaire was 17 pages long and consisted of 122 questions, but some questions were omitted depending on respondents' answers to previous questions (Supplementary File 2).

Anonymized questionnaire data from eligible patients were passed by IPSOS Mori to Nivel. Nivel compiled anonymized responses for the purposes of the PaRIS project. Pseudonymized data were also sent by IPSOS Mori to DHCW to be re-identified for service improvement purposes.

## Remuneration

GP practices and patients did not receive financial compensation for participation.

## Information governance

PaRIS was considered a service improvement project, supporting NHS Wales response to the Health and Social Care (Quality and Engagement) (Wales) Act 2020. To accommodate the various purposes of data collection and the specific tasks undertaken by different NHS organizations, several UK GDPR mechanisms were utilized: Article 6(1)(e)—Public Task, Article 6(1)(f)—Legitimate Interests, Article 9(2)(h)—Management of Health and Social Care Systems, Article 6(1)(a)—Consent and Article 9(2)(a)—Explicit Consent. Nivel and Ipsos MORI had data processing agreements with DHCW and WViHC.

## Data analysis

Descriptive statistics are provided for the GP practice and patient populations. The survey's datasets were linked with other nationally held data sets for the purposes of health service improvement, but this is not discussed in this manuscript.

## Ethics

PaRIS was implemented as a service improvement and evaluation project, and ethical approval was not required.

# Results

## Field trial

The field trial originally contacted 251 GP practices, but due to a low response rate, an additional 146 GP practices were contacted, resulting in a total of 397 practices (note that the field trial was carried out in 2022, when there were more GP practices in Wales than at the time of the main study) [12–14]. Out of these, 19 practices (5%) gave consent for participation, but only 13 (3%) completed the questionnaire. Five hundred sixty-four people were contacted, out of which 30 (5%) provided consent, but only 24 (4%) completed the questionnaire.

The field trial team provided the following feedback on the process, as per OECD requirements. It would have been useful to have advance notice of the target sample size and specification. A centralized submission for providers in Wales would have simplified the process, while still allowing patients to be matched to GP practices. It would be useful to be able to check URLs without this registering as an abandoned questionnaire attempt and to see at what point the survey was abandoned. Combining the consent and participation processes could have resulted in less participant drop out. Clear time frames and enough time were needed for question modification and for localizations to be approved.

## Main survey

Three hundred and ninety-one GP practices were identified via data derived from prescriptions issued in Wales. The NWSSP Age and Gender Patient Counts (January 2023) dataset was analysed

**Table 1** Comparison of respondent stated ethnicity between all respondents, OECD respondents and data from the 2021 population census [16].

| | All respondents (*n* = 25 839) | OECD respondents (*n* = 7706) | 2021 Census data (%) |
|---|---|---|---|
| African | 59 (0.23%) | 21 (0.27%) | 0.6 |
| Any other Asian background | 88 (0.34%) | 27 (0.35%) | 0.7 |
| Any other Black, or Caribbean background | 11 (0.04%) | 6 (0.08%) | 0.1 |
| Any other ethnic group | 45 (0.17%) | 12 (0.16%) | 0.9 |
| Any other Mixed or Multiple ethnic background | 50 (0.19%) | 22 (0.29%) | 0.4 |
| Any other White background | 381 (1.47%) | 119 (1.54%) | 2.7 |
| Arab | 45 (0.17%) | 13 (0.17%) | 0.4 |
| Bangladeshi | 19 (0.07%) | 9 (0.12%) | 0.5 |
| Caribbean | 29 (0.11%) | 11 (0.14%) | 0.1 |
| Chinese | 83 (0.32%) | 17 (0.22%) | 0.5 |
| Gypsy or Irish Traveller | 1 (0.00%) | 0 (0.00%) | 0.1 |
| Indian | 89 (0.34%) | 30 (0.39%) | 0.7 |
| Irish | 130 (0.5%) | 43 (0.56%) | 0.4 |
| Pakistani | 47 (0.18%) | 21 (0.27%) | 0.6 |
| Roma | 4 (0.02%) | 2 (0.03%) | 0.1 |
| Welsh, English, Scottish, Northern Irish or British | 22568 (87.34%) | 7149 (92.77%) | 90.6 |
| White and Asian | 47 (0.18%) | 13 (0.17%) | 0.5 |
| White and Black African | 18 (0.07%) | 6 (0.08%) | 0.3 |
| White and Black Caribbean | 22 (0.09%) | 9 (0.12%) | 0.4 |
| Not answered | 2083 (8.06%) | 169 (2.19%) | N/A |
| Multiple responses | 20 (0.08%) | 7 (0.09%) | N/A |

Note that the data from the census was available to one decimal point accuracy. N/A, not applicable.

to identify practices which were unlikely to recruit the required number of eligible patients (<100 patients of an age ≥45 years), such as university providers. This resulted in the final sampling frame of 382 providers (98% of all practices). Assuming a response rate of circa 37%, based on experience from England and the literature, 201 (53% of all practices in the sampling frame) providers were selected for approach via stratified random sampling proportionate to the relative size of the strata to achieve the OECD target for Wales of 75 provider responses [9]. The selected practices were representative of the degree of urbanization across Wales (Table 2 in Supplementary File 1). During the project, two practices had merged or closed, which meant that one provider that had completed the provider survey had to be excluded, as we could not reach out to their patients who had been dispersed across multiple providers. Consequently, while 76 (38%) of the initial 201 practices provided full responses, the final figure is given as 75 practices out of 199 practices (38%). A total of 125 practices provided at least partial responses (62%).

Using DHCW's Welsh Demographic Service register of all Welsh residents who are registered with a GP in Wales or England, 1 497 017 eligible patients over 45 (reference date: 7 December 2023) were identified across Wales. Patients who were 45 years old were excluded due to an administrative error. It could not be confirmed from the data whether these patients were living in a private household or had recent contact with a GP. Using the 199 sampled practices, 400 patients from each practice were sampled on 5 July 2023. Another 400 patients were sampled on 15 August 2023, from each of the 75 OECD practices. Consequently, a total of 109 600 patients were sampled (7.3% of all eligible patients), out of which 60 000 (55% of all sampled patients) were from the 75 OECD practices (Figure 1). This resulted in 25 839 respondents (24% of all sampled patients), with 7706 (30% of all respondents and 13% of all sampled OECD practice patients) of these being from OECD practices and meeting all the eligibility criteria. Consequently, Wales achieved 137% of its OECD patient recruitment target [9].

There was a lower response rate from patients in the 46–54 age group, and a higher response rate from the 65–74 age group (Figure 2). Females represented 49.04% of the overall respondents and 54.33% of the OECD sample, while males represented 43.68% of the overall sample and 44.37% of the OECD samples; 7.28% (*n* = 1881) in the overall population and 1.3% (*n* = 100) in the OECD sample selected 'other' as their self-reported descriptor. There was a slight underrepresentation of patients from urban cities and towns, with an overrepresentation of patients from rural towns and fringes among the OECD respondents, but not among all respondents (Figure 3). The response rates were good from all ethnicity groups, except from the Gypsy and Irish Traveller population (Table 1).

# Discussion

## Learning from previous experience

While the field trial offered an opportunity to learn how to overcome some of the challenges presented, it was run by Cardiff University, whilst the main study was run by WViHC and DHCW. Consequently, some of the field trial's practical lessons, such as those regarding identificatory and online platform set-ups, had to be re-discovered. This highlights the importance of using previous learning in future project iterations.

## Leveraging information governance for project utility

A major challenge was deciding which legal mechanisms could be used for the project to proceed [17]. While other mechanisms were originally considered, it was finally decided that existing GDPR mechanisms were sufficient to allow each of the organizations involved to undertake their tasks. The project was within DHCW's public task remit as per WG instructions, and in the remit of healthcare services' public task and management of health and social care systems grounds. Because the PaRIS project did not explicitly focus on people with chronic conditions, patients' medical records did not need to be accessed to determine participation eligibility, making information governance arrangements easier. As such, broadening the scope of the project and allowing patients to self-declare chronic conditions, rather than utilizing medical records to identify this information, simplified information governance arrangements and extended the usability of the data for secondary analysis and quality improvement (QI).

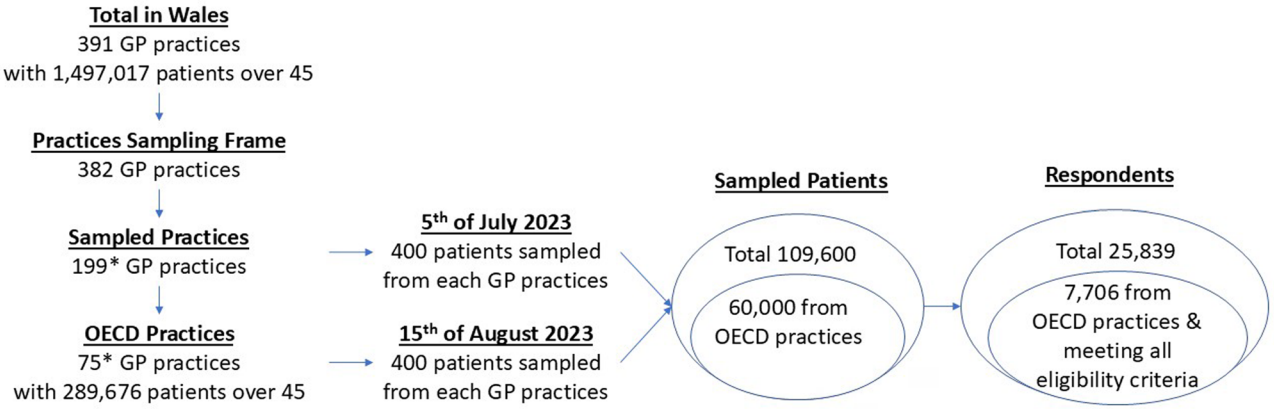


**Figure 1** Diagram of the sampling approach. *Originally 201 practices were sampled, and 76 responded, but this reduced due to practices closing or merging.

## Obtaining a representative sample

To achieve a high response rate from a diverse range of people and providers, emphasis was placed on stakeholder engagement (e.g. the letter sent to patient participants; Supplementary File 3) and monitoring responses to enable targeted follow-up, since those filling out the survey gave up 20–30 minutes of their time to complete and return the questionnaire and so needed to understand the value of this project.

WViHC dedicated resources to a communication and engagement strategy targeting various stakeholder groups, following well-known strategies for implementation buy-in [18]. (i) A webpage was set-up within the WViHC website and included sections on frequently asked questions for both patients and GP practices, and the project's privacy notice [19]. Letters sent to GP practices contained signatures of key primary care community leaders to add credibility. Social media posts highlighting the benefits which this survey could bring to patients, their families and NHS Wales were used to raise awareness of the project across the wider population [18, 20]. (ii) WViHC engaged with primary care leaders in Wales to gain their support for the survey. Since under GDPR legislation GPs in the UK are data controllers, primary care leaders were asked how best to approach the information governance challenge of data capture. Support was gained from the General Practice Committee of the British Medical Association to ensure that the project was not placing extra burdens or risks on GP services. The President of the Royal College of GPs in Wales sent out communications in support of the survey. Primary care policy leads in WG and the Assistant Medical Directors clinically leading primary care in the health boards were also kept informed. (iii) A stakeholder engagement event was staged early in the roadmap to ensure buy-in from policy and healthcare leaders. (iv) A close working relationship was developed with the technical support teams participating in the project. (v) Finally, various third sector organizations, such as charities and patient support groups, were provided information about the project and asked to share it with their members to mobilize support for the project [21]. Use of such trusted leaders and organizations as intermediaries in reaching out to participants has been known to facilitate engagement even in the most challenging of projects [22].

Since Wales has a more elderly population than England [23], and 3.3% of residents of Wales do not speak English or Welsh as their first language [16], it was important to support the inclusion of different groups in order to obtain a reliable picture of health needs across the nation. This was facilitated by allowing responses via paper, phone or digitally, and by providing a minority language phone translations line (although no responses were collected via this line in the end). While the overlap between paper and digital questionnaire collection methods is not always perfect [24–26], the use of these various response options might have facilitated obtaining results from a broader demographic [20].

Finally, the sample's representativeness was also enhanced by sampling from a wide geographical area. This was a consequence of the Royal College of GPs in Wales requesting patients to be sampled from all 199 practices. Broad patient sampling was also a result of an inability to a priori determining if participants met the second criterion of living in a private household Consequently, data were gathered from a representative subset of the population (Figures 2 and 3 and Table 1), which supported project objectives 2 and 3.

However, there is an unavoidable risk that any subgroups within the sampled population will not be representative of that subgroup (e.g. patients with specific diseases), and this needs to be assessed during any data analysis. Moreover, because of the small size of Wales and the reliance on large practices to achieve representativeness, it might be challenging in the future iterations of the project to achieve such representativeness without getting the buy-in of the practices that participated in this first iteration.

Those implementing similar projects should not underestimate the importance of stakeholder engagement and making the survey accessible to respondents. While broadening the scope of data collection might make the project more resource intensive, it can result in a more comprehensive data set and reduce the need for future supplementary data collection, as well as utilize the momentum of an already substantial project. Though such an expansion of an existing project to fulfil additional objectives is thought to be only possible if data linkage can facilitate these objectives, which in Wales was facilitated through DHCW's data management functions.

## Adaptation of implementation to local data

While Chapter 7 of the OECD PaRIS report describes the data and methodologies, including the differences between participating nations [9], Table 2 highlights the key differences between OECD

stipulations and the implementation in Wales, as well as the rationales for these.

The sampling strategy had to be adjusted due to local data availability. Data on practice types (e.g. solo or group practice) were not available, and hence practice size was used as an alternative measure. Similarly, only Rural Urban Classification was available at the appropriate geographical level and hence used in designing the sampling strategy rather than the rural/urban classification [15]. Moreover, there was no readily available data for gender, so sex at birth was used. No data were available for level of education, but the question was asked in the iteration of the questionnaire used in Wales (Supplementary File 2), and could be used in post-hoc assessment of representativeness of population against the 2021 census data, though the later utilized a lower level of granularity of education categories [28,29].

The methodological challenges resulting in deviations from OECD stipulations were not unique to Wales, and the PaRIS project explicitly acknowledged the need to tailor implementation to each country's circumstances [9]. While the inclusion of practice type and respondent education might have increased cross-national comparability of data and further minimize sampling bias, local adaptations helped to manage bias of the overall sample [17], which was further reduced through stratified random sampling. The OECD noted that Wales' 'implementation model has been very successful in reaching primary care practices and patients from across the country, meeting all standards and processes required by OECD and achieving one of the largest and most comprehensive datasets across all participating countries, despite its small population size' [30]. As such, considering appropriate alternative data types can help achieve an appropriate respondent sample, with further bias minimized via randomizations.

## Operationalization of results

Since Wales employs a Prudent Healthcare strategy, the PaRIS project was not seen as something imposed onto the healthcare system. Rather, it fitted the strategy already adopted in Wales, and offered an opportunity to advance it. Hence, if anything, the PaRIS eligibility criteria seemed restrictive. When implemented, data from a wider patient group were gathered, such as those not from the 75 OECD practices, to facilitate use as benchmark data for local QI and potential future OECD projects. This was both a challenge and an opportunity; it meant that a larger quantity of data had to be handled, placing a greater demand on project resources. Nevertheless, it also made it easier to get stakeholder buy-in, as it provided incentivized participation due to potential participant benefits in the form of future health services improvement [18]. Expanding the use of the data and the sampled population facilitated this unique opportunity, which would have been hard to implement without the impetus provided by the OECD.

Before the release of the OECD PaRIS report, in December 2024, the 76 OECD practices received infographic reports on how their practice compared with all the OECD practices which took part in Wales (the one merged practice received the report based on the patient populations of the original two practices), with practices' patient data compared to all patients who responded in Wales (not just patients from OECD practices). The reports' structure (see Supplementary File 4 for an anonymized example) was based on the work of a task-and-finish group, which agreed on the key performance indicators and the language used in the report, utilizing the OECD template and ensuring that the feedback data could not be used to identify specific patients. Provision of this feedback highlighted that the implementation of the project in Wales was undertaken with a primary aim of service improvement, which would not have been possible without linking patients to GP practices. Therefore, the ability to link patients to practices can increase the operationalization of the collected information.

While it is within the remit of individual GP practices to initiate local QI initiatives, the data have already been used for secondary analysis to gain a better understanding of the patient population on a national level [31,32]. With appropriate data governance,

**Table 2** Differences between OECD stipulations and the implementation in Wales.

| OECD stipulation | Implementation in Wales | Difference rationale |
|---|---|---|
| Sampling frame required the use of specific measures of urbanisation (DEGURBA at local authority level) [27], practice type (solo, group with own patients, group with shared patients, or multi-specialty practice group) and education level. | In Wales, the rural/urban classification was used at lower layer super output area level [15], practice size was used instead of practice type, and no proxy or alternative measure was used instead of education level | The sampling frame used in Wales replicated as closely as possible the requirements stipulated by OECD, while using data that was already available, as the collection of this data would not be feasible before the surveys' implementation |
| Patient inclusion criteria | Wales used >45 years, rather than ≥ 45 years | Administrative error |
| Being able to assess the effect of primary care on patient outcomes | Wales also gathered responses from patient respondents whose GP practices did not complete the GP practice survey | Expansion of the dataset allowed for a more comprehensive survey of the population of Wales, whose data could be used in further service improvement projects additionally to the data from GP practice-linked respondents being used for PaRIS |
| Anonymized data | Anonymized data sent to OECD, but respondent re-identification used for service improvement purposes | Ensuring PaRIS data is protected to the highest standard to prevent re-identification, while ensuring that data can be used locally for linkage as part of service improvement initiatives |

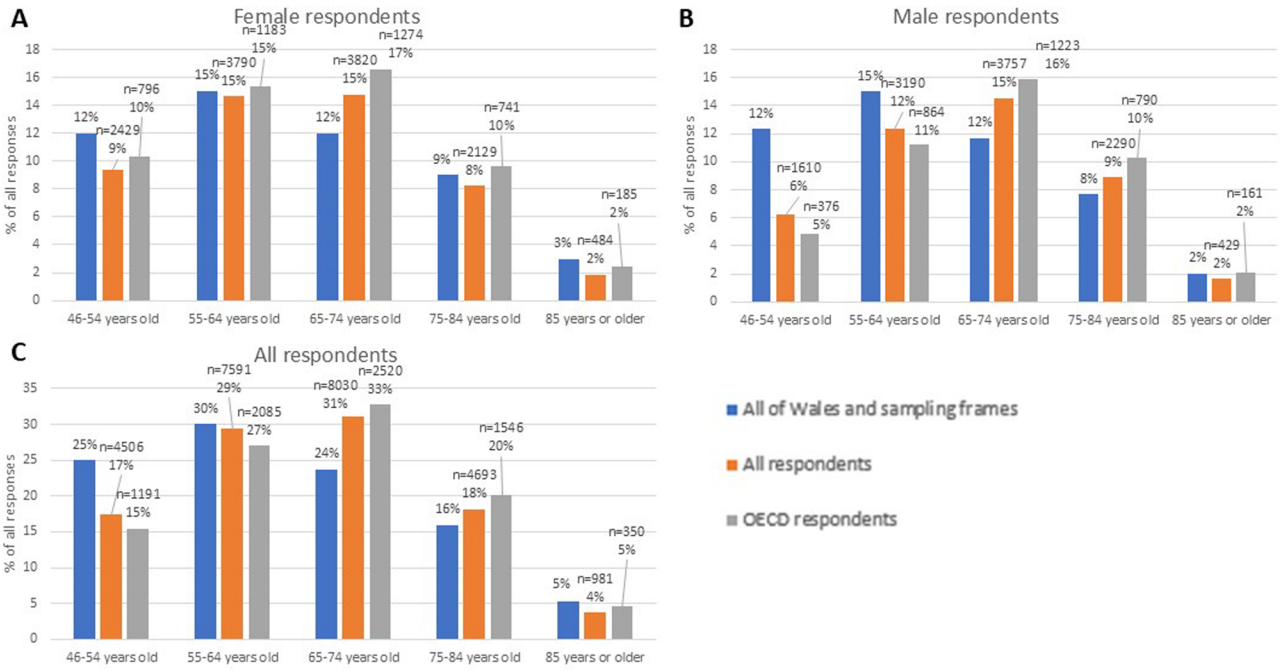


**Figure 2** Age and sex at birth comparison of patients eligible for sampling, and sampled patients. Some patients had their sex at birth classified as 'other' (see main text); these patients have been included in panel C data. Some respondents (between 0% and 1% of all presented categories) did not provide their age or provided multiple responses. The 'all of Wales and sampling frames' category is an amalgamation of three data tables, with variability not exceeding 1% between items in these three tables. The mid-point value was presented in the figure for these items, as this had minimal impact on accuracy, but allowed to greatly simplify the figure for ease of understanding; therefore n-numbers are not presented for this group.

arrangements and facilities to link data between patients and practices, data from such large-scale projects can be used to drive both local and national projects.

## Limitations

An administrative error resulted in patients who were 45 years old not being included in the survey. As such, while the PaRIS inclusion criteria specified that respondents should be 45 years or older, the patient sampling frame used in Wales meant that respondents were 46 years or older (Table 2). The PaRIS project had a cut-off of 45 years due to a focus on patients with chronic conditions and the inclusion criteria needed to balance inclusion of all service users with chronic conditions against the difficulty associated with collecting data from a larger population. As the PaRIS report highlighted, with gender differences in reported health outcomes and prevalence of chronic conditions, lowering the age requirement to 40 might have included more women with menopause related symptoms, as well as be more informative for countries with younger populations, such as Saudi Arabia [9]. However, if all age groups were included, the logistical burden of such a project might have been prohibitive for successful implementation.

Another limitation was that only GP practices were surveyed in Wales, and other primary care practices, such as urgent care centres, community pharmacists and optometrists, were excluded. Depending on the structure of national healthcare systems, GP practices are likely to represent the largest proportion of primary care providers. However, the exclusion of other types of primary care providers means that the survey results do not provide a complete picture of the primary care landscape in Wales. While practices with less than 100 patients aged ≥45 years (2% of GP practices) were also excluded, this did not result in any bias, as all of the excluded practices had no patients within the target age range.

Finally, the absence of a stronger conceptual framing of this implementation constrains the generalisability of the findings. Consequently, the contribution of this paper is primarily experiential and practice-oriented, rather than theoretical.

## Comparison with other surveys

The 'Time to Talk Public Health' initiative aimed to recruit residents in Wales who were at least 16 years old for regular engagement to inform public health policy and practice [33]. It recruited people via telephone, face-to-face and social media advertising, and recruited 2137 participants for its 2025 survey. The 'National Survey for Wales' ran between April 2022 and March 2023 and also recruited those who were at least 16 years old [34]. It covered questions regarding social activities and well-being, as well as some health-related questions, and had a telephone and an online component. It reported 12 000 participants. The HealthWise Wales cohort is a database of individuals in Wales at least 16 years old who have stated that they are willing to engage in research projects, but it is not a study in itself [35]. The project aims to recruit 50 000 members and has been used to recruit participants for PaRIS field trial. HealthWise Wales members can choose to participate in projects, but some data is routinely collected, with one study reporting data from 27 869 participants [36]. As such, the PaRIS project recruited more participants than its OECD target stipulated, but the overall recruited cohort is also larger than other comparative studies carried out in Wales [9]. Even with

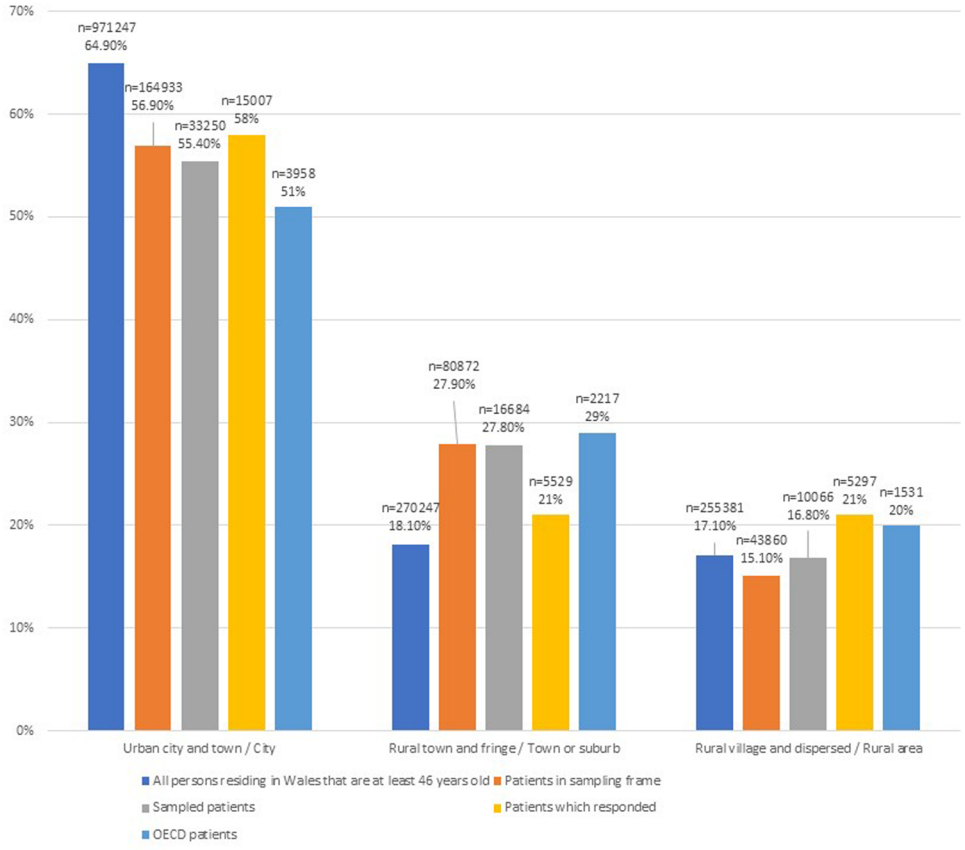


**Figure 3** Comparison of the urbanized distribution of patients eligible for sampling and sampled patients. Some patients had invalid postcodes making it unable to allocate a degree of urbanization to their locality (76 patients among all residents in Wales at least 46 years old, and 11 patients in the sampling frame). Analysis was undertaken according to the Rural Urban Classification.[15].

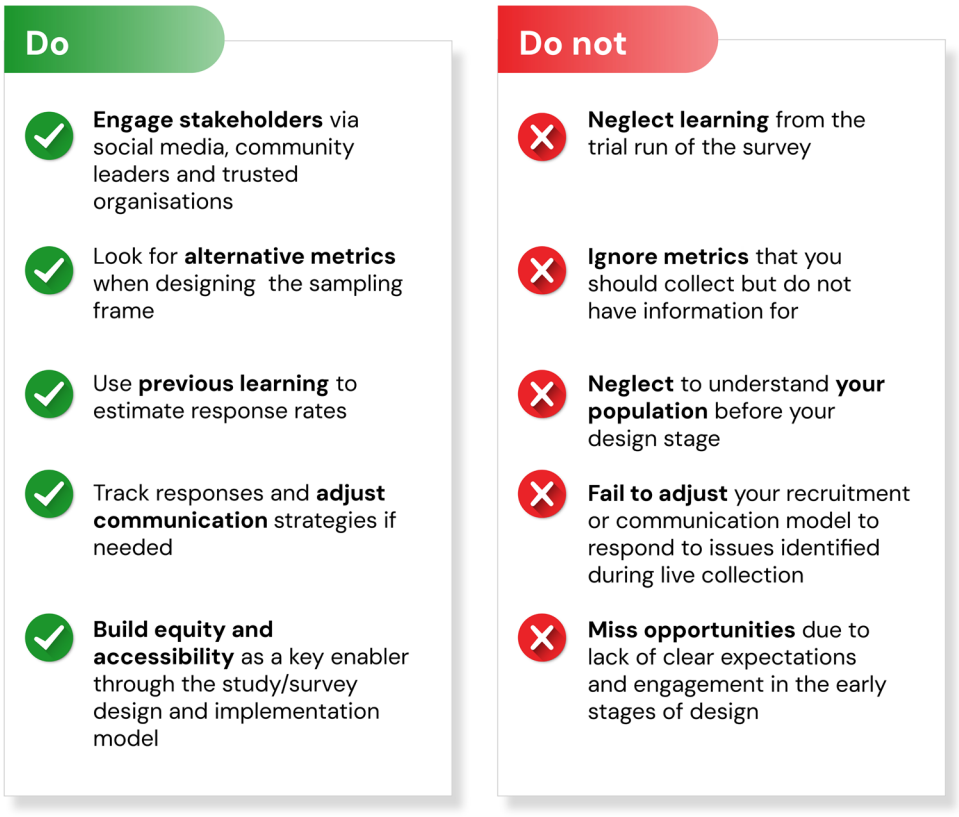


**Figure 4** Checklist of operational study implementation recommendations.

**Table 3** Strategic recommendations for nation-wide survey implementation.

| Recommendation | Rationale |
|---|---|
| Consider broadening project scope | If a broader project scope eliminates the need to utilize patient's medical data at the sampling stage, then this might make information governance arrangements simpler, while also allowing the date to be used in a broader range of quality improvement initiatives |
| Make the survey accessible to patient by offering different modes of filling it out | Inclusion of both digital and paper version of the questionnaire prevent bias due to digital exclusion and facilitate completion for those who prefer to use electronic means of completion |
| Support participation of minority groups by inclusion of minority language options | Reduce the risk of data bias by ensuring that those from minority groups are informed of the survey and can be supported in completing it, e.g. through the means of a free-of-charge interpreter service |
| Disseminate awareness about the survey, including its purpose; utilize social media | It is important that respondents understand the purpose of the survey and the potential benefits that it will being. To facilitate this, general awareness about the project needs to be created and accessible language used. Geographical targeted social media adverts were useful in increasing uptake in regions that were otherwise less represented. |
| Monitor responses to ensure a representative sample | Monitoring responses throughout data collection can enable further targeted follow-up and awareness raising, e.g. in geographical areas with low response rates |

respect to HealthWise Wales study that recruited 27 869 participants, it is worth noting that the present study only recruited those who were at least 46 years old, so had a lower number of eligible respondents.

## Recommendations

The OECD required the use of several facilitators for increasing response rates, such as the use of multiple modalities for questionnaire completion, local adaptation of the survey and the use of reminders. Nevertheless, our experience suggests that some other facilitating tools could be used to improve engagement with such surveys.

From the outset, it is important to define all use cases for the data. This is crucial, as it will support the development of an implementation plan for immediate and future study needs. Knowing the use cases will allow the questionnaire to be tailored, support creation of a data analysis plan, and also define the stakeholder engagement needs. Moreover, if planning to use the data internally to drive service improvement and resource allocation, make this commitment explicit and public, as it can help get buy-in from those who might otherwise not wish to participate in something that appears like a political or academic exercise. Such a commitment is likely to facilitate engagement with healthcare professionals, with whom you need to build trust, whether as explicit participants or gatekeepers. You need to convince them as to the benefits of participating in this project. Communication must be clear and targeted, meaning that the language used and the benefits highlighted might differ between stakeholder groups, so that it is meaningful to the individual recipients. For example, plain and simple language is generally encouraged when communicating with the lay public, as it helps ensure equity and accessibility, but might not be appropriate when communicating with more specialist stakeholder groups. Ensuring equitability and accessibility during the design and implementation stages is key to obtaining an as representative sample as possible. A checklist of operational do's and don'ts is presented in Figure 4, and further strategic recommendations, together with rationales, are presented in Table 3.

## Further work

This article outlined the setup of the PaRIS project in Wales. Throughout the project, the participants have completed a range of questionnaires regarding their health and the healthcare services they have received. Further analysis of this data will be presented in future publications.

# Conclusions

Because the project's scope extended beyond supporting day-to-day clinical practice, several obstacles needed to be overcome for its successful implementation; the lessons learned in overcoming these obstacles can inform future implementations of similar projects. Identifying appropriate governance mechanisms and getting stakeholder buy-in through good communication and engagement from the early phases of the project were key to successful project implementation. These activities guided the survey design to ensure it was accessible, as well as raising awareness of the project. Importantly, a broadened project scope that eliminates the need for accessing medical information at the sampling stage might ease information governance requirements, while broadening the potential impact of the project, though at the cost of demanding more implementation and analytic resources. Focusing on ensuring that the results of the survey were representative of the population of Wales, through sampling design and response monitoring, meant that the obtained data will be used not only for the PaRIS project, but also for various healthcare service improvement initiative across Wales.

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## Author contributions

Michal Pruski (Formal analysis, writing—original draft), Sarah Puntoni (Conceptualization, writing—review & editing), Kathleen Withers (Supervision, writing—review & editing), Sally Lewis (Conceptualization, writing—review & editing)

## SCOPUS author number

Michal Pruski: 57188695504

## Supplementary data

Supplementary data is available at *IJQHC Communications* online.

## Conflict of interest

No potential competing interest was reported by the authors.

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## Data availability

The participants of this study did not give written consent for their data to be shared publicly, so due to the sensitive nature of the research supporting data is not available.

## Ethics

This was a service improvement and evaluation project, and did not require ethics approval.

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