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All hands on deck: Co-developing the first international survey of people living with chronic conditions: Stakeholder engagement in the design, development, and field trial implementation of the PaRIS survey

**Candan Kendir,
Rushay Naik,
Janika Bloemeke,
Katherine de Bienassis,
Nicolas Larrain,
Niek Klazinga,
Frederico Guanais,
Michael van den Berg**

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All hands on deck: Co-developing the first international survey of people living with chronic conditions

Stakeholder engagement in the design, development, and field trial implementation of the PaRIS survey

Candan Kendir¹, Rushay Naik¹, Janika Bloemeke², Katherine de Bienassis¹, Nicolas Larrain¹, Niek Klazinga¹, Frederico Guanais¹, Michael van den Berg¹

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(1) OECD, Directorate for Employment, Labour and Social Affairs, Health Division

(2) OptiMedis, Germany.

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Abstract

OECD's Patient-Reported Indicator Surveys (PaRIS) initiative aims to measure outcomes and experiences of healthcare as part of an effort to improve the value of health system investments. The PaRIS survey, a survey of people living with chronic conditions, is currently being implemented in twenty countries. The PaRIS survey has been developed together with government officials, patients, providers, and researchers. However, the extent of stakeholder involvement varies between countries. This paper reports on the stakeholder engagement in design, development and implementation of the PaRIS survey Field Trial in seventeen countries. Engagement strategies were analysed by target group (patients, providers, or other stakeholders), and engagement level (co-designing, involving, consulting, and informing). The results provide valuable lessons for the implementation of the full PaRIS survey in 2023 and illustrate how stakeholders could be more actively engaged in health services research and policymaking.

Key points

People with first-hand knowledge of the health system—patients, caregivers, and healthcare providers—provide valuable perspectives that are key for designing and implementing effective health care policies. Although the importance of stakeholders' voices in health care decision-making is widely recognised, recent studies show that few countries adequately integrate patient perspectives in decision-making for health care policy and research. For example, a recent OECD study revealed that during the COVID-19 pandemic, only nine of 26 OECD countries actively engaged stakeholders in the design of their pandemic strategies.

In 2017, the OECD launched the Patient-Reported Indicator Surveys (PaRIS) initiative to systematically measure the outcomes and experiences of health care that matter most to people as part of an effort to improve the value of health system investments. The flagship project within the PaRIS initiative is a survey of patient-reported outcome and experiences measures (PROMs and PREMs) of people living with chronic conditions, who are managed in primary care (the PaRIS survey).

The PaRIS survey is the first international survey of people living with chronic conditions and their primary care providers. The project has three different phases: 1) Development phase including the development of survey design and PaRIS questionnaires; 2) Field Trial phase including the implementation of the PaRIS survey in participating countries and testing of survey design and instruments; and 3) Main Survey phase involving the full survey implementation in participating countries.

Inclusive development with countries and stakeholders is a core principle of the PaRIS project. In other words, the PaRIS survey is designed and implemented together *with* patients and providers. Ultimately, the PaRIS survey will amplify the patient voice for use in policy making and enable primary care providers to better understand how to improve the quality of care they provide.

The PaRIS survey is currently implemented in 20 countries. National Project Managers (NPMs), appointed by the countries, implement the survey in their respective countries. To align with national contexts while ensuring international comparability, NPMs work with the OECD Secretariat and an international consortium (the PaRIS-SUR Consortium) to develop national implementation plans, called Country Road Maps (CRMs). These CRMs detail the national context, and strategies for sampling, recruitment and engagement of patients and providers.

This paper reports on an analysis of 17 CRMs for the PaRIS survey and seven semi-structured interviews with NPMs. It describes which stakeholders were involved, how they were involved, and the extent of their involvement during the Field Trial of the PaRIS survey.

The paper assesses civil society engagement during three stages (design, development, and implementation) against the following dimensions: target group (patients, providers or other stakeholders such as researchers and local health authorities), and engagement level (co-designing, involving, consulting, and informing). The results provide valuable lessons for the implementation of the main PaRIS survey, which is planned to take place in 2023, and illustrate how civil society could be better engaged in health services research and policymaking.

Some key lessons learned from this analysis are:

- ***The PaRIS survey has been developed through a process that involved government officials, patients, providers, and researchers or data officers.*** In addition to the engagement activities conducted as part of the study design and the development of PaRIS patient and provider questionnaires, participating countries also engaged in a variety of engagement activities such as establishing advisory boards or gathering input about the recruitment of respondents. Patient and provider representatives contributed significantly to the process from the design phase to the implementation of the Field Trial of the PaRIS survey.
- ***Although many National Project Managers engaged patients during the Field Trial phase of the survey, most engagement activities focused on getting primary care providers on board.*** Of 216 identified engagement activities and plans, approximately half (49%) concerned providers; patients were mentioned in 36% of these activities; closely followed by other stakeholder groups (34%). The many engagement activities aimed at providers can be explained by the stratified design of the PaRIS survey, where patients are sampled through their providers. Given this design, countries had to place significant effort in recruiting primary care providers first in order to access patients. Further patient engagement may be beneficial for garnering sufficient response rates from them.
- ***Patients and providers often played a passive role, as opposed to an active role, in national implementation plans.*** Activities were classified in four ascending levels of engagement, varying from passive to highly active roles: informing (e.g. distributing posters, brochures about the survey), consulting (e.g. gathering input for draft recruitment letters), involving (e.g. having a role in an advisory board), co-designing (e.g. having a decision-making role in the steering group). Half of the activities aimed to inform stakeholders. A smaller proportion (12%) aimed to consult them, while almost one third of the plans (32%) aimed to involve stakeholders. A small part (6%) aimed to co-design Field Trial implementation with stakeholders. Although adequate information is essential, ensuring that patients and providers actively participate in the implementation could further improve successful survey results.
- ***Countries showed promising and innovative ways to engage stakeholders, but only a few implemented a wide range of diverse activities.*** Australia, Belgium, and France planned activities on at least three engagement levels while most countries only planned involving and/or informing. Six countries (Australia, Belgium, Netherlands, Norway, Saudi Arabia, and Wales (United Kingdom)) planned to co-design the implementation of the Field Trial with providers, patients, and other stakeholders. The importance of considering the national context and performing a stakeholder analysis, and of including and actively engaging key stakeholders who are directly concerned by the PaRIS survey was apparent from the Field Trial. This includes patients and providers or stakeholders who might have high influence on decisions (e.g. insurance companies or private sector in certain countries).

The analysis of engagement work in the Field Trial phase resulted in the following lessons for the Main Survey implementation:

- ***Patient and provider organisations demonstrated significant interest and ability to contribute to the development and implementation of the survey.*** Several countries shared inspiring examples of how stakeholders took active roles in national implementation of the PaRIS Field Trial. In Norway, the World Organisation of Family Doctors (WONCA) President agreed to send a letter to encourage primary providers to participate. In Italy, a trade union association helped choosing the best data collection method for elderly people. Wales (United Kingdom) planned to use existing civil society connections, which provide a robust foundation for incorporating patient perspectives in the Main Survey.

- **Effective engagement requires real dialogue with stakeholders rather than one-way communication.** Although providing information is necessary, for example with posters, brochures and publications, this is not enough to create a feeling of involvement and ownership among stakeholders and, as a result, to create support and buy-in to effectively implement the survey. Activities enabling direct feedback such as conversations with patients and providers through a steering board or advisory group could increase engagement
- **The relevance and impact of the PaRIS survey is likely to benefit from sustained and enhanced patient engagement.** Engagement activities focus more often on providers than on patients. Although provider engagement is essential to recruiting respondents and for the sampling of patients, active engagement of patients in implementation will improve the relevance of the survey to patients' needs and, hopefully, increase the impact of the survey.

In its efforts to improve the extent to which health systems are centred on people's needs, the PaRIS survey will generate knowledge that will be used to enhance the relevance and impact of health policies. Methods used in the survey, including those for stakeholder engagement, also have the benefit of engaging civil society in health services research and policy making.

In the Field Trial, several countries have demonstrated how stakeholders, such as patients, providers, and academics are brought together in the development of an international survey to measure patient-reported outcomes and experiences. In moving forward with the roll out of the full survey, countries will benefit from further input from key stakeholders.

Résumé et points saillants

Les personnes qui ont une connaissance directe du système de santé - patients, soignants et prestataires de soins - offrent des perspectives précieuses et essentielles à la conception et l'implémentation de politiques de soins efficaces. Bien que l'importance de tenir compte des voix des parties prenantes dans les prises de décision relatives aux soins soit largement reconnue, des études récentes montrent que peu de pays intègrent de façon adéquate le point de vue des patients dans les prises de décision en matière de politique de soins et de recherche. Par exemple, une étude récente de l'OCDE a révélé que pendant la pandémie de COVID-19, seuls neuf des 26 pays inclus dans l'étude ont impliqué activement les parties prenantes à la conception de leurs stratégies de lutte contre la pandémie.

En 2017, l'OCDE a lancé l'initiative PaRIS (Patient-Reported Indicator Surveys) afin de mesurer systématiquement les expériences et résultats des soins comptant le plus pour les gens, dans le cadre d'un effort visant à améliorer la valeur des investissements dans les systèmes de santé. Le projet phare de l'initiative PaRIS est une enquête sur les expériences et résultats rapportés par les patients (indicateurs PREM et PROM) des personnes vivant avec des maladies chroniques, qui sont prises en charge en soins primaires (enquête PaRIS).

L'enquête PaRIS est la première enquête internationale sur les personnes vivant avec des maladies chroniques et leurs prestataires de soins primaires. Le projet comporte trois phases différentes : 1) la phase de développement, comprenant l'élaboration des questionnaires PaRIS et la conception de l'enquête; 2) la phase d'essai terrain, comprenant la mise en œuvre de l'enquête PaRIS dans les pays participants et le test de la conception et des instruments de l'enquête ; et 3) la phase d'enquête principale, comprenant la mise en œuvre complète de l'enquête dans les pays participants.

Le développement inclusif, avec les pays et les parties prenantes, est un principe fondamental du projet PaRIS. En d'autres termes, l'enquête PaRIS est conçue et implémentée avec les patients et les prestataires. À terme, l'enquête PaRIS amplifiera la voix des patients, en vue de la prise en compte de cette dernière dans l'élaboration de politiques, et permettra aux prestataires de soins primaires de mieux comprendre comment améliorer la qualité des soins qu'ils fournissent.

L'enquête PaRIS est actuellement implémentée dans 20 pays. Les Chefs de projets nationaux (CPN), nommés par les pays, implémentent l'enquête dans leurs pays respectifs. Pour s'aligner sur les contextes nationaux tout en assurant la comparabilité internationale, les CPN travaillent avec le Secrétariat de l'OCDE et un consortium international (le Consortium PaRIS-SUR) pour développer des plans d'implémentation nationaux, appelés Feuilles de route de pays (FRP). Ces CRM détaillent le contexte national et les stratégies d'échantillonnage, de recrutement et d'engagement des patients et des prestataires.

Le présent document rend compte d'une analyse de 17 CRM pour l'enquête PaRIS et de sept entretiens semi-directifs avec des CPN. Il décrit quelles parties prenantes ont été impliquées, comment elles l'ont été et l'étendue de leur implication pendant l'essai terrain de l'enquête PaRIS.

Le document évalue l'engagement de la société civile au cours de trois étapes (conception, développement et implémentation) en fonction des dimensions suivantes : groupe cible (patients, prestataires ou autres

parties prenantes telles que les chercheurs et les autorités sanitaires locales) et niveau d'engagement (co-conception, implication, consultation et information). Les résultats obtenus fournissent des enseignements précieux pour l'implémentation de l'enquête PaRIS principale, prévue en 2023, et illustrent comment la société civile pourrait mieux être impliquée dans la recherche sur les services de santé et l'élaboration de politiques.

Les leçons principales tirées de cette analyse sont les suivantes.

- **L'enquête PaRIS a été élaborée dans le cadre d'un processus impliquant des représentants gouvernementaux, des patients, des prestataires et des chercheurs ou des responsables des données.** Outre les activités d'implication des patients et des prestataires menées dans le cadre de la conception de l'étude et de l'élaboration des questionnaires PaRIS, les pays participants se sont investis dans diverses activités d'engagement telles que la mise en place de conseils consultatifs ou le recueil de commentaires sur le recrutement des répondants. Les représentants des prestataires et des patients ont contribué de façon significative au processus, de la phase de conception à l'implémentation de l'essai terrain de l'enquête PaRIS.
- **Bien que de nombreux chefs de projet nationaux aient impliqué des patients pendant la phase d'essai terrain de l'enquête, la plupart des activités d'engagement visaient à obtenir l'implication des prestataires de soins primaires.** Sur 216 activités et plans d'engagement identifiés, environ la moitié (49 %) concernait des prestataires ; des patients étaient mentionnés dans 36 % de ces activités, suivis de près par d'autres groupes de parties prenantes (34 %). Le grand nombre d'activités d'engagement à l'attention des prestataires peuvent s'expliquer par la conception stratifiée de l'enquête PaRIS, où les patients sont échantillonnés par l'intermédiaire de leurs prestataires. Compte tenu de cette conception, les pays ont dû déployer des efforts significatifs pour d'abord recruter des prestataires de soins primaires afin d'accéder aux patients. Un engagement supplémentaire des patients pourrait être bénéfique pour obtenir des taux de réponse suffisants de la part de ces derniers.
- **Les patients et les prestataires ont souvent joué un rôle passif, par opposition à un rôle actif, dans les plans de mise en œuvre nationaux.** Les activités étaient classées en quatre niveaux croissants d'engagement, allant d'un rôle passif à un rôle très actif : informer (par exemple, distribuer des affiches ou des brochures sur l'enquête) ; consulter (par exemple, recueillir des commentaires sur les projets de lettres de recrutement) ; impliquer (par exemple, jouer un rôle dans un conseil consultatif) ; co-concevoir (par exemple, jouer un rôle décisionnel dans le comité de pilotage). La moitié des activités visaient à informer les parties prenantes. Une proportion plus faible (12%) visait à les consulter, tandis que près d'un tiers des plans (32%) visaient à impliquer les parties prenantes. Une petite partie (6%) visait à co-concevoir l'implémentation des essais terrain avec les parties prenantes. Bien qu'une information adéquate soit essentielle, s'assurer que les patients et les prestataires participent activement à l'implémentation pourrait améliorer encore les résultats déjà concluants de l'enquête.
- **Les pays ont déployé des moyens innovants et prometteurs pour impliquer les parties prenantes, mais seuls quelques-uns ont implémenté un éventail large d'activités variées.** L'Australie, la Belgique et la France ont planifié des activités sur au moins trois niveaux d'engagement, tandis que la plupart des pays ont seulement prévu d'impliquer et/ou d'informer. Six pays (Arabie Saoudite, Australie, Belgique, Norvège, Pays-Bas et Pays de Galles (Royaume-Uni)) ont prévu de co-concevoir l'implémentation de l'essai terrain avec les prestataires, les patients et les autres parties prenantes. L'essai terrain a mis en évidence l'importance de prendre en compte le contexte national, d'effectuer une analyse des parties prenantes, d'inclure et d'engager activement les principales parties prenantes qui sont directement concernées par l'enquête PaRIS. Cela inclut les patients et les prestataires ou les parties prenantes qui pourraient exercer une grande influence sur les décisions (par exemple, les compagnies d'assurance ou le secteur privé dans certains pays).

L'analyse du travail d'engagement dans la phase d'essai terrain a permis de tirer les leçons suivantes pour l'implémentation de l'enquête principale.

- **Les organisations de patients et de prestataires ont montré un grand intérêt et une grande capacité à contribuer à l'élaboration l'implémentation de l'enquête.** Plusieurs pays ont partagé des exemples inspirants sur la manière dont les parties prenantes jouèrent un rôle actif dans l'implémentation nationale de l'essai terrain PaRIS. En Norvège, le président de l'Organisation mondiale des médecins généralistes (WONCA) a accepté d'adresser une lettre encourageant les prestataires de soins primaires à participer. En Italie, une association syndicale a aidé à choisir la meilleure méthode de collecte de données pour les personnes âgées. Le Pays de Galles (Royaume-Uni) a prévu d'utiliser les liens existants avec la société civile, conférant une base solide pour intégrer le point de vue des patients dans l'enquête principale.
- **Un engagement efficace nécessite un véritable dialogue avec les parties prenantes plutôt qu'une communication à sens unique.** Bien qu'il soit nécessaire de fournir des informations, par exemple au moyen d'affiches, de brochures et de publications, cela ne suffit pas à créer un sentiment d'implication et d'appropriation parmi les parties prenantes et, par conséquent, à susciter le soutien et l'adhésion permettant de déployer efficacement l'enquête. Des activités permettant un retour d'information direct, telles que des conversations avec les patients et les prestataires par le biais d'un comité de pilotage ou d'un groupe consultatif, pourraient accroître le taux d'engagement.
- **La pertinence et l'impact de l'enquête PaRIS bénéficieraient probablement d'un engagement soutenu et renforcé des patients.** Les activités d'engagement se concentrent plus souvent sur les prestataires que sur les patients. Bien que l'engagement des prestataires soit essentiel au recrutement des répondants et à l'échantillonnage des patients, l'engagement actif des patients dans l'implémentation améliorera la pertinence de l'enquête par rapport aux besoins des patients et, espérons-le, augmentera l'impact de l'enquête.

Dans le cadre de ses efforts pour accroître les performances des systèmes de santé en améliorant la mesure dans laquelle les systèmes de santé sont centrés sur les besoins des personnes, l'enquête PaRIS générera des connaissances qui seront utilisées pour améliorer la pertinence et l'impact des politiques de santé. Les méthodes utilisées dans le cadre de l'enquête, y compris celles qui visent à impliquer les parties prenantes, ont également l'avantage de faire participer la société civile à la recherche sur les services de santé et à l'élaboration des politiques.

Dans le cadre de l'essai sur le terrain, plusieurs pays ont démontré comment les parties prenantes, telles que les patients, les prestataires et les universitaires, sont réunies pour élaborer une enquête internationale visant à mesurer les résultats et les expériences rapportés par les patients. Pour aller de l'avant avec le déploiement de l'enquête complète, les pays bénéficieront d'une contribution supplémentaire des principales parties prenantes.

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List of acronyms / abbreviations

ACSS	Administração Central do Sistema de Saúde
CRM	Country Road Map
CSO	Civil society organisation
EFPC	European Forum for Primary Care
EPF	European Patients' Forum
GP	General Practitioner
HCRW	Health and Care Research Wales
MoH	Ministry of Health
NPM	National Project Manager
NIPH	Norwegian Institute of Public Health
P3CEQ	Person-Centred Care (P3C) Experiences Questionnaire
PaRIS	Patient-Reported Indicator Surveys
PaRIS-PP	PaRIS Patient advisory Panel
PPG	Public Partnership Group
PROM	Patient-reported outcome measure
PROMIS	Patient-Reported Outcome Measurement Information System
PREM	Patient-reported experience measure
WCEC	Wales COVID-19 Evidence Centre
WONCA	World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians

1 Engaging civil society in health research and policy

This chapter defines civil society engagement, explores its importance in health policymaking and research, and focuses on the civil society engagement activities supporting the development and implementation of the PaRIS survey.

Civil society: what it is and why it is important

1. Although the term civil society was previously considered to comprise non-governmental organizations, the term has been expanded to include a diverse variety of organised groups (OECD, 2021^[1]). These may range from activist groups and community associations to social enterprises and trade unions (European Observatory on Health Systems and Policies, 2017^[2]). Generally, civil society organisations (CSOs) can be classified as interest groups, community organizations, or social partners. Box 1.1 presents selected definitions of civil society.

2. Policymakers have engaged with civil society to improve relevance and impact of policies. Civil society can be engaged in evidence development and agenda-setting by providing expertise, policy development, advocacy, mobilisation, consensus-building, and watchdog work. Civil society can also be engaged in service provision and formal governance through standards development and enforcement, self-regulation of professions, and social partnerships (European Observatory on Health Systems and Policies, 2017^[2]).

3. OECD member countries have long been working to engage CSOs in dialogue and consultations systematically (Wood and Fällman, 2019^[3]). Among 32 OECD countries, 15 reported that their central government or Ministry of Health (MoH) consulted CSOs or individuals on the issue of countering disinformation in 2019 (OECD, 2021^[4]). During the COVID-19 pandemic, 20 out of 26 OECD countries

consulted stakeholders on the design of strategies both for the response to the pandemic and the recovery period (OECD, 2021^[4]). Most countries used widespread information campaigns to inform stakeholders about the response to the pandemic (19 out of 26) and the recovery period (16 out of 26). Yet, only nine countries actively engaged stakeholders in the design of response strategies throughout the COVID-19 pandemic.

Box 1.1. Definitions of civil society

“A wide array of non-governmental and not-for-profit organisations that have a presence in public life, expressing the interests and values of their members or others, based on ethical, cultural, political, scientific, religious or philanthropic considerations. Civil Society Organisations therefore refer to a wide of array of organisations: community groups, non-governmental organisations, labour unions, indigenous groups, charitable organisations, faith-based organisations, professional associations, and foundations.”

Source: World Bank

“Civil society is seen as a social sphere separate from both the state and the market. The increasingly accepted understanding of the term civil society organization is that of non-state, not-for-profit, voluntary organizations formed by people in that social sphere.”

Source: European Observatory of Health Systems and Policies (2017)

“A civil society organisation is any non-profit entity organised on a local, national or international level to pursue shared objectives and ideals, without significant government-controlled participation or representation. CSOs include foundations, co-operative societies, trade unions, and ad-hoc entities set up to collect funds for a specific purpose. CSO umbrella organisations and CSO networks are also included.”

Source: OECD Development Assistance Committee (2019)

Although the role of civil society is growing in health policymaking and research, active engagement is still limited

4. CSOs, and the people and interests they represent, are key partners in health systems strengthening (WHO, 2021^[5]). The strong intrinsic argument for involving patients and health care consumers in decision-making processes for health care is clear: if health care is directed towards people’s health needs, outcomes and experiences, then they are the source to inform health care decisions (OECD, 2021^[6]). Further, there is a growing evidence base supporting civil society engagement demonstrating that involving patient voices in decision-making can help to improve the relevance and quality of some aspects of health care (Bombard et al., 2018^[7]; The University of Toronto Priority Setting in Health Care Research Group, 2008^[8]; Groene and Sunol, 2015^[9]).

5. In the policymaking context, literature points to the influence of civil society actors in agenda-setting and policy implementation activities, with less attention provided to the activities CSOs perform in their advocacy capacities and shaping policy discussions (Gómez, 2018^[10]). As of 2021, only 11% of the countries (three out of 27) reported that patients had a formal role in at least four of five key decision-making areas of health policy (OECD, 2021^[11]). Although the importance of patient voice in health decision-making is recognised, most countries still lack the capacity and institutional directives to integrate patient perspectives more inclusively in decision-making for health care policy and research.

6. Engagement of civil society, particularly patients and providers, has become increasingly recognised as an important contribution to improve outcomes in health services research (Groene, 2012_[12]). In the health research environment, CSOs are understood to influence priority-setting and research commissioning, engaging with research review processes, and partnering with academic institutions in formal research (Sanders et al., 2018_[13]).

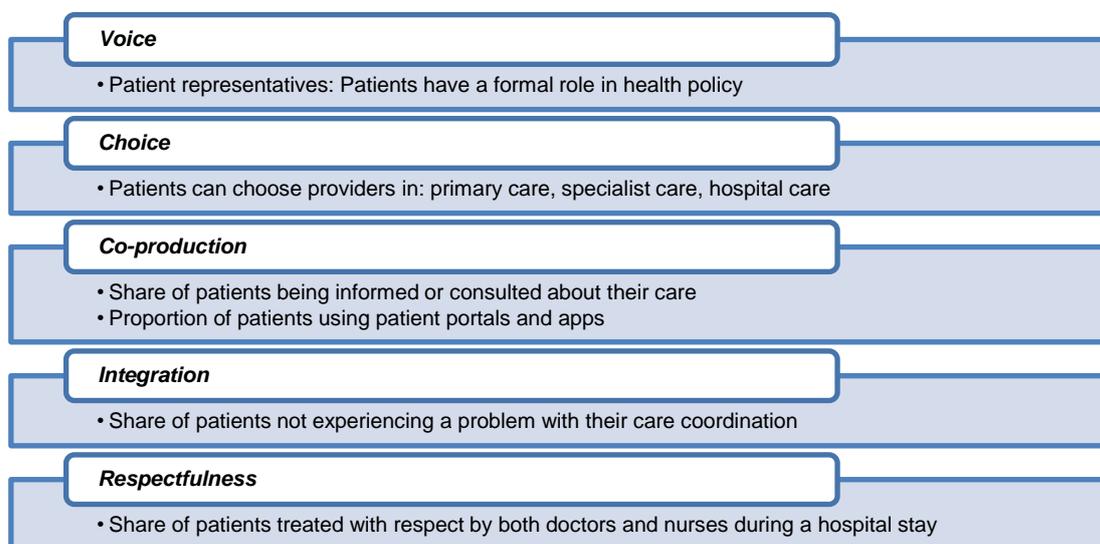
7. A growing number of research funding agencies now require stakeholder engagement in funded research projects. For example, Methodology Standards for engaging patients in research developed by the US Patient-Centred Outcomes Research Institute (PCORI) documents five steps for patient engagement in research: 1) developing study questions and study design; 2) identifying the study population and choosing interventions, comparators, and outcomes; 3) developing strategies for recruitment and retention of study participants; 4) conducting the study; and 5) analysing results and disseminating research findings (PCORI Methodology Committee, 2013_[14]).

Several frameworks explore the involvement of civil society in health policy and research

8. People with lived experiences of health care conditions, or other first-hand knowledge, can provide important perspectives to improve policymaking or research (NCD Alliance, 2018_[15]). To leverage this value, a variety of different mechanisms can be used to facilitate meaningful involvement of patients and patient groups in research and policy making (NCD Alliance, 2021_[16]). Meaningful participation of patients and patient groups in health policy and research are explored in different frameworks.

9. The OECD's Framework on People-Centred Health Systems identifies five key dimensions: ensuring voice, choice, co-production, respectfulness, and integration of care (OECD, 2021_[11]). These five dimensions are depicted in Figure 1.1. This framework explores whether patients are involved across different dimensions of people-centred health systems and the extent of their involvement in each dimension. For instance, the indicator on voice identifies the extent to which patients have a formal role in health policy making by assessing whether patients have a formal role in: (1) licensing of pharmaceuticals, (2) coverage or reimbursement, (3) health technology assessment, (4) decisions related to service planning, and (5) definition of public health objectives. However, it does not explore the different levels of engagement for each subject (e.g., whether the patient has a role in decision making or is consulted regarding a specific topic).

Figure 1.1. Five dimensions of the OECD's Framework on People-Centred Health Systems and patient-reported indicators with examples of indicators for each domain



Source: (OECD, 2021^[11])

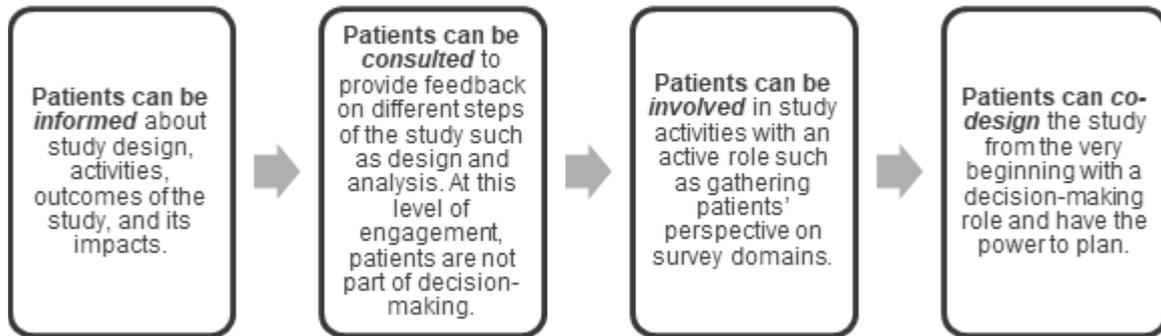
10. A typology of different ladders of civil society participation was defined by Arnstein in late 1960s. (Arnstein, 1969^[17]). Eight types from most engaged to least- *citizen control*, *delegated power*, *partnership*, *placation*, *consultation*, *informing*, *therapy*, and *manipulation*, show the extent of citizen's power in determining the end product. Among those, citizen control, delegated power, and partnership describe the degrees of citizen power with decision-making or full managerial power. Placation, consultation and informing demonstrate degrees of tokenism by allowing citizens to hear and have a voice. Therapy and manipulation show the level of non-participation by educating citizens rather than allowing their participation. Although Arnstein's typology provides an in-depth analysis of the level of citizen engagement, in practice, it might be difficult to differentiate different ladders in health research and policy.

11. Another example of a frameworks to engage with communities in the health sector, including patient and provider groups was developed by Bertorello et al., who posit a range of levels of patient involvement in research projects, ranging from simply being informed about the progress of research to participating in its development as co-designers (Bertorello et al., 2019^[18]).

12. The level of engagement and potential for positive the impact on the outcome increases when one goes from informed to co-design (Bertorello et al., 2019^[18]). While there is often a need to include several different levels of engagement in an action plan: informing is a prerequisite as an enabler to the other levels, but not enough on its own.

- *Informing* represents the lowest level of engagement consisting of sharing results of the finished work on study design, activities, and outcomes of the study. The objective of *informing* is simply to distribute the outcome among patient representatives.
- *Consulting* has some room for providing feedback but patients still do not hold an active role in decision making. The objective is to make sure that the final product is acceptable by patients.
- *Involving* describes having a role in advisory activities and reference groups. The objective is to ensure relevance to patients.
- *Co-designing* is the highest level of engagement, where people have the power to plan and actively participate in decision making.

Figure 1.2. Examples of different levels of engagement in a survey



Source: Authors adapted from Bertorello et al (2019).

The PaRIS survey empowers people to shape health policy across countries

13. In support of national initiatives to create more people-centred health systems, the OECD launched the Patient-Reported Indicator Surveys (PaRIS) initiative to systematically measure outcomes and experiences of health care that matter most to people in a way that could be used to inform policy-making. The flagship project within the PaRIS initiative is a survey of patient-reported outcome and experiences measures (PROMs and PREMs) of people living with chronic conditions, who are managed in primary care (the PaRIS survey). The PaRIS survey is the first of its kind to assess the outcomes and experiences of people managed in primary care across different countries. The most rapidly growing group of health care users in OECD countries are people living with chronic conditions, the majority of whom receive both acute and long-term health services in primary care settings. The PaRIS survey aims to fill a critical gap in knowledge, by collecting patient generated data on access to care and waiting times, quality of life, pain, physical functioning, and psychological well-being, among other dimensions.

14. The PaRIS survey collects data from three complementary sources:

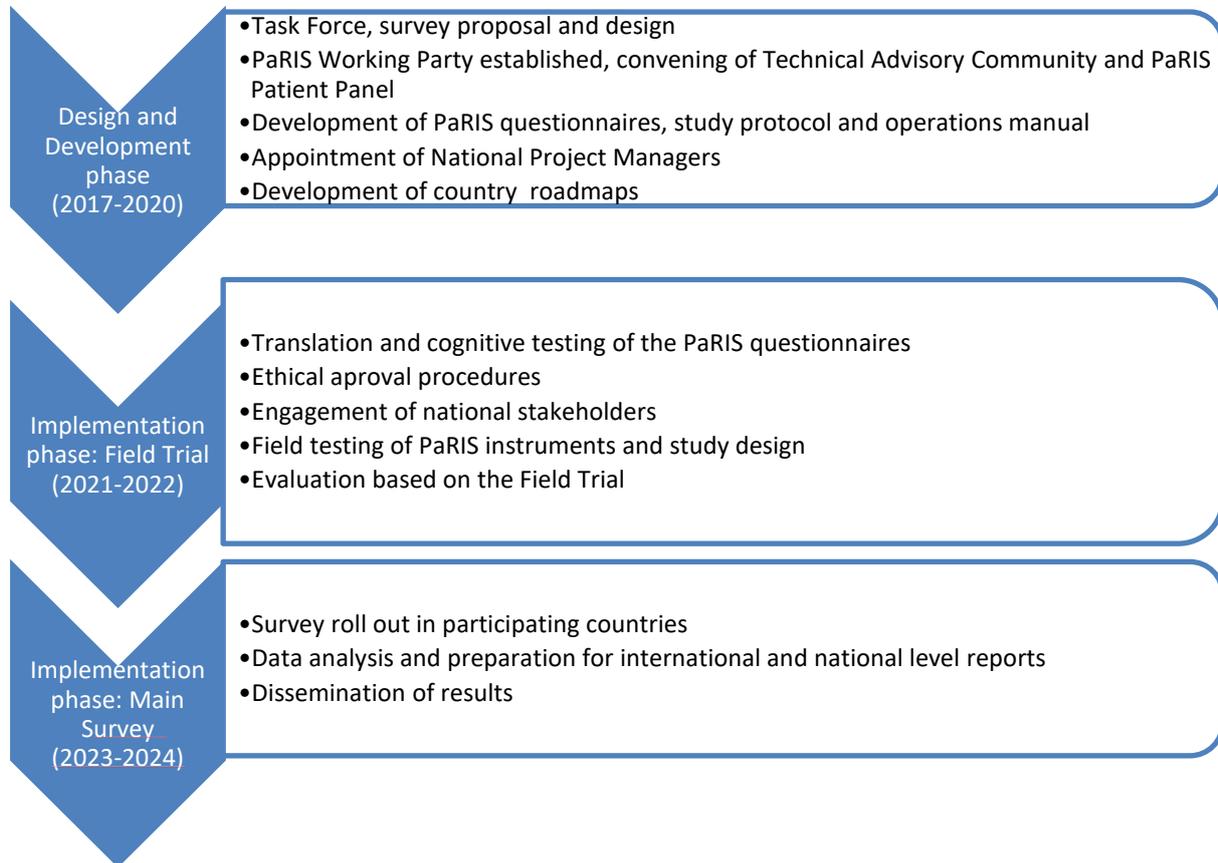
- A patient survey collecting information on outcomes and experiences of individual patients as well as background information such as health behaviours and sociodemographic variables;
- A primary care provider survey collecting information on health services delivery at health care facility level, complementing the patient survey;
- A policy investigation finding existing sources regarding national health system characteristics and collecting information from national counterparts about the characteristics of primary care systems in their respective countries.

15. The PaRIS survey is being rolled out in three steps: *Design and Development Phase (2017-2020)*; *Field Trial (2021-2022)* and *Main Survey (2023-2024)* (Figure 1.3). During the design and development phase, the Secretariat worked with key stakeholders to define the objectives and develop the initial study design. In this phase, the Secretariat also contracted an international consortium, the PaRIS-SUR Consortium¹, to help with the development of survey instruments such as questionnaires as well as survey operation manuals such as guidance on sampling. In the Field Trial phase, countries worked with the

¹ PaRIS-SUR Consortium: NIVEL, Exeter University, Ipsos, Avedis Donabedian Research Institute, OptiMedis AG. For more information, please visit <https://paris-sur.org/>

PaRIS-SUR partners for the implementation of the PaRIS survey in their respective countries. With the lessons learnt from the Field Trial, countries will conduct the Main Survey in 2023.

Figure 1.3. Global timeline of the PaRIS survey project



16. As of Q4 2022, twenty countries (Australia, Belgium, Canada, Czech Republic, France, Greece, Iceland, Israel, Italy, Luxembourg, Netherlands, Norway, Portugal, Romania, Saudi Arabia, Slovenia, Spain, Switzerland, Wales (United Kingdom), United States) are currently implementing the survey. OECD’s Health Committee² and the Working Party for PaRIS (WP-PaRIS)³ oversee the design, development, and implementation of the project. The WP-PaRIS also includes the chair of an OECD coordinated patient advisory panel and a provider representative as part of the process of inclusive development.

Engaging with key stakeholders contribute to the success of the PaRIS survey

17. In an effort to increase relevance and value of the PaRIS survey for stakeholders, the OECD has engaged civil society from the beginning. Three main groups of stakeholders for the PaRIS survey were identified: (1) patients, giving them an opportunity to communicate their outcomes and experiences; (2)

² Health Committee consists of country delegates and oversees the overall work of the OECD Health Division.

³ Working Party for PaRIS consists of country delegates, oversees the PaRIS project, and reports to the Health Committee.

providers, enabling them to better understand how to improve the quality of care they provide; and (3) other stakeholders (e.g. researchers and advocates), bringing their experience and expertise to improve the study methodology and implementation.

18. Participation of civil society, particularly patients, in the development and implementation of the PaRIS survey to capture patient outcomes and experiences has been a core principle of the study design. First, it will improve the *relevance* of the survey because patients have an experiential knowledge; they are experts on their own lives, needs and interests. Therefore, they know best whether what is asked in the survey are issues that matter to them. Second, it will contribute to the *methodological quality* of the survey; patients are the ones who are expected to fill out questionnaires, so they know best whether questions are well understood. Third, it might contribute to *better response rates*; patients know best how they want to be approached and invited and what would make them decide to participate or not. Moreover, if patient organisations are convinced that the survey is beneficial for patients and endorse the initiative, this may positively influence response rates and the policy impact of the survey overall.

19. Primary care providers' involvement has also been considered as an important component of the PaRIS survey's implementation. Providers are engaged in various roles, as informants (by completing a provider questionnaire themselves), as partners of the local research team (amongst others, by selecting and recruiting eligible patients) and as stakeholders or end-users (results of the survey could inform about their performance and be used for further development of chronic care management provided by primary care providers). The support of primary care providers could also be used to leverage improved response rates among patients, as patient may be more likely to respond when it relates to their individual primary care provider or and if their provider visibly supports the initiative.

20. Another reason to involve providers in an early stage relates to high workloads and limitations in terms of dedicated time to engage in research activities within the context of a regular practice day. Many providers may choose to opt out if the value of the study for patients and themselves is not immediately clear and a time commitment away from frontline services is involved.

This report

21. This report describes the engagement activities that took place in the design and development phase and the implementation of the PaRIS Field Trial. Future contributions are planned and expected for the evaluation and analysis of Field Trial data, implementation of Main Survey, and publication and dissemination of PaRIS results. Throughout the paper, the term civil society is replaced by stakeholders for the PaRIS survey engagement activities. This allowed us to be more flexible while assessing the engagement activities with any group other than the MoH or its representative in the PaRIS survey. Patients and primary care providers are also included in the broader stakeholder group.

22. This project describes the types and scope of civil society engagement and stakeholder engagement, in the development and Field Trial phases of the PaRIS survey, using it as a mechanism to assess and distil best practices. The results of this work were discussed with National Project Managers (NPMs) to review and improve their implementation plans for the Main Survey. The work also contributes to the broader efforts of the OECD to work with its member countries in engaging CSOs.

23. This report is structured as follows: Section 2 explains the methodology used to identify and analyse the engagement activities throughout the PaRIS survey; Section 3 presents the findings of the work; Section 4 shows some case examples from selected countries; and Section 5 provides future directions and recommendations for the implementation of Main Survey.

2 Evaluating the type and scope of stakeholder engagement in the PaRIS survey

This section explains the methodology used to identify and analyse the engagement activities throughout the PaRIS survey.

24. The OECD has worked closely with the key stakeholders in the development of the PaRIS survey for the following purposes: 1) defining objectives and main questions for the survey design; 2) developing conceptual framework, survey instruments, participating in focus groups and cognitive testing; and 3) implementing the survey, dissemination and evaluation.

25. Table 2.1 presents the purpose of stakeholder engagement and related activities throughout the PaRIS survey for selected key activities. The main purposes of design activities were formulating the objectives and main questions to optimise the relevance of the PaRIS survey. The overarching aim of engagement activities on a national level was to adapt the survey to national contexts while generating awareness, increasing response rates and decreasing burden.

Table 2.1. The purpose of patient and provider engagement in the PaRIS survey

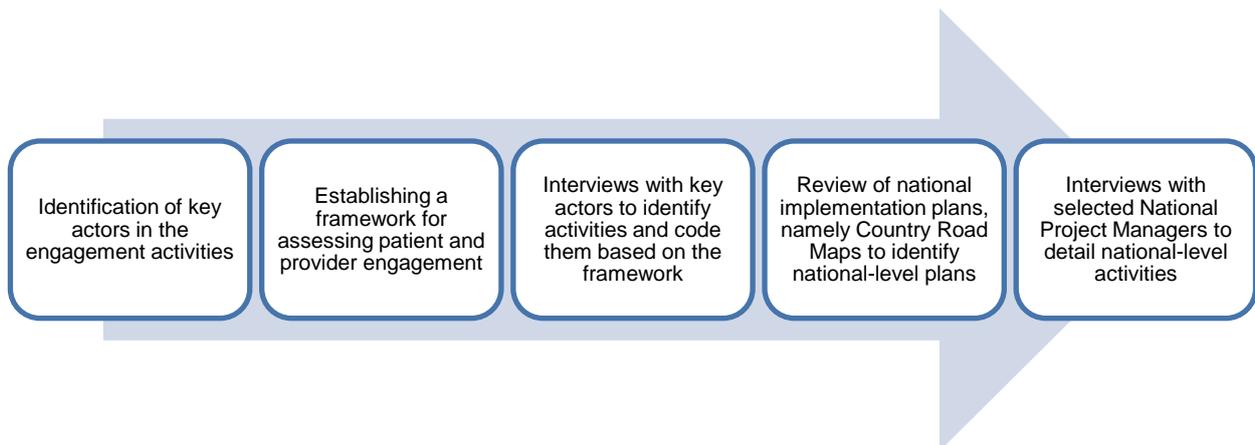
Key steps (Year)	Activity	Purpose of stakeholder engagement
Design (2017-2020)	Development of study proposal Development of study design International workshops	Formulating objectives and main questions and study design that address patients' concerns
Development (2021-2022)	Selection of relevant items and scales from existing questionnaires, including a Delphi process Identification of tools Screening existing questions on patient involvement in development process Focus groups Cognitive testing	Including items that are relevant to patients, that are understood by patients Avoiding unnecessary burden on patients and providers
Implementation (2023-2024)	Development of country-specific implementation plans Recruitment Dissemination of the survey Evaluation	Ensuring relevance of PaRIS survey at national context Increasing response rates by patients and providers Avoiding unnecessary burden on patients and providers Improving the implementation of the Main Survey with feedback from Field Trial

Note: The table includes the key steps that were completed at the time of writing.
Source: Authors.

Five main steps helped identify engagement activities throughout the PaRIS survey

26. Five main steps were followed to identify, analyse, and report engagement activities in the PaRIS survey. Figure 2.1 shows the main steps: (1) Identification of key actors in the engagement activities; (2) Establishment of a framework; (3) Interviews with key actors; (4) Review of Country Road Maps; (5) Interviews with selected NPMs.

Figure 2.1. Five steps in the identification and analysis of engagement activities



Source: Authors.

27. Three key actors- *the OECD Secretariat, the PaRIS-SUR Consortium, and the NPMs* led engagement activities in the PaRIS survey. The OECD Secretariat has led engagement activities throughout the PaRIS survey by convening advisory panels from CSOs. The PaRIS-SUR Consortium has

engaged with CSOs as well as individual patients, providers, and other stakeholders such as researchers and experts in the design and development activities. NPMs primarily led engagement activities mainly in the implementation of the PaRIS survey in their respective countries, as well as in the aforementioned development activities. Key actors facilitated the identification of the key informants, who were interviewed to identify and assess the engagement activities.

A framework to assess the engagement activities

28. Annex A shows the framework based on rapid literature review of existing tools to assess the engagement activities. Stakeholder engagement in the PaRIS survey was assessed in three stages (design, development, and implementation) against the following dimensions:

- **target group**- patients or providers or other stakeholders such as researchers or local health authorities,
- **activity level**- international, national, subnational level, individual or a combination of them,
- **communication channel**- group meeting, bilateral call, written feedback,
- **engagement level**- co-designed, involved, consulted, and informed,
- and **purpose of the engagement** and **expected outcome of engagement activity**

Online interviews were conducted to identify development activities

29. Two separate online interviews were conducted with Exeter University and OptiMedis, the PaRIS-SUR consortium partners who led the development of patient and provider questionnaires. Consortium partners received relevant materials summarising the aim of the study and including the draft framework in advance of the call. The interviews were structured as the following: a short presentation of the aim of the study and clarification of terminology; presentation of identified main activities and addition/deletion/modification of the list; discussion on the content of each activity, the purpose, activity level, and the engagement level; and a summary of the outcomes. Consortium activities concerning development of PaRIS survey questionnaires were analysed by using the framework (Table A A.1). Following the interview, Consortium partners received a copy of the completed analysis grid and were provided an opportunity to make final comments.

National-level engagement plans were identified in the country road maps

30. NPMs have worked with the Consortium partners and the OECD Secretariat on the implementation of the PaRIS survey in their respective countries. To ensure international comparability, the Consortium provided the agreed PaRIS standards to countries, including those for sampling and data collection, to countries.

31. Each country developed a national implementation plan, called a Country Road Map (CRM). CRMs are action plans of national-level implementation of the PaRIS survey, which are drafted by NPMs and their collaborators and that translate the international standards into the national context. The purpose was ensuring relevance of the PaRIS survey at national context, increasing response rates by patients and providers, avoiding unnecessary burden, and improving the implementation of the Main Survey with feedback from the Field Trial.

32. The analysis of CRMs provides a high-level overview of engagement activities that are envisaged by NPMs even before the implementation begins. Box 2.1 includes the list of countries that had finalised their CRMs on 1 September 2022, and that are, therefore, included in the analysis. CRMs were analysed

by using the analysis grid based on the framework (Table A A.1). Relevant activities were mainly identified in the section dissemination and engagement, and elsewhere where relevant.

Interviews with selected national project managers provided complementary information

33. To complement the scope of the engagement activities, online semi-structured interviews were scheduled with selected NPMs and their collaborators where relevant. The authors invited NPMs from Australia, Czech Republic, Italy, the Netherlands, Norway, Portugal, and Wales for interviews to detail their engagement activities. The interview questions covered the broader activities on stakeholder engagement at policy level, the definition of roles and operationalization of engagement activities in the PaRIS survey, communication channels used for engagement activities, and future projects on stakeholder engagement (Annex B).

Box 2.1. Seventeen countries finalised their Country Road Maps for the Field Trial, which are included in the analysis

- Australia
- Belgium
- Canada
- Czech Republic
- France
- Greece
- Iceland
- Italy
- Luxembourg
- Netherlands
- Norway
- Portugal
- Romania
- Saudi Arabia
- Slovenia
- Spain
- United Kingdom (England and Wales)

Note: Israel, Switzerland, and the US are not included in the analysis due to revised timelines for the implementation of the PaRIS survey.

3 Engagement activities in the design, development, and Field Trial implementation of the PaRIS survey

International and national networks of patients and providers as well as other stakeholders such as researchers contributed to the design, development, and implementation of the Field Trial. This section provides an overview of these activities. The section also focuses on action plans identified in the CRMs for the implementation of the survey. The aggregated results are presented to illustrate the frequency of activities by key step of the PaRIS survey, country, engagement level, and target stakeholder.

Various stakeholders were engaged in the design, development, and implementation of the PaRIS survey

34. Among 216 identified engagement activities and plans, providers comprised the largest group. Providers were identified in almost half of engagement activities and plans (49%) in the design, development and Field Trial implementation of the PaRIS survey. Patients were mentioned in 36% of the activities, closely followed by other stakeholder groups (34%). Other stakeholder groups included researchers, independent statutory bodies, data management companies, and local health authorities.

Designing the survey plan with patients, providers, and other key stakeholders

35. The representatives from patient and provider organisations (European Patients' Forum⁴ and WONCA⁵, respectively) as well as individual providers were involved in the Task Force in 2017 and provided input on the study proposal and study design. These meetings included discussions on the target patient group- *which chronic conditions to include*, key domains of the initial framework- *what to measure*. The Task Force actively contributed to the development of the initial study proposal as adopted by the Health Committee.

36. An international PaRIS Patient Advisory Panel (PaRIS-PP) (Box 3.1), convened by the OECD Secretariat and participating countries, advised on survey design, implementation, and activities related to patient engagement (OECD, 2021^[19]). The purpose of the Panel has been to engage with patients in a systematic way to ensure that the PaRIS survey meets patients' needs and includes relevant questions which provide meaningful results (see Terms of References in Annex C). The Co-Chair of the PaRIS-PP has represented the group in the meeting of the Working Party for PaRIS (WP-PaRIS) and has provided regular feedback on the key steps of the project.

Box 3.1. The PaRIS-Patient Advisory Panel includes representatives from international and national patient organisations

- Consumers Health Forum of Australia
- European Patients' Forum (EPF)
- International Alliance of Patients' Organizations (IAPO)
- Pan-Canadian Patient Council for the Primary and Integrated Health Care Innovation Network (Canada) (PIHCI)
- The National Health Council (US)
- The NCD Alliance
- Alianza Chilena de Agrupaciones de Pacientes (Chile)
- Irish Platform for Patient Organisations, Science & Industry (IPPOSI) (Ireland)
- The European Public Health Alliance

Source: <https://www.oecd.org/health/paris/PaRIS-Patient-Advisory-Panel.pdf>

37. WONCA representatives participated in discussions on study design and proposal from the beginning of the project and provided feedback from the perspective of family doctors. The purpose of their involvement has been to improve the relevance of the PaRIS results in their role as service providers to their practice populations, as well as to increase response rates among providers and patients. A WONCA representative has also attended the WP-PaRIS meetings regularly to ensure the relevance of the PaRIS survey to primary care providers.

Developing the PaRIS questionnaires with input from stakeholders

38. In the design and development phases of the PaRIS patient and provider questionnaires, the PaRIS-SUR Consortium engaged with various stakeholders including patients, primary care providers, and

⁴ <https://www.eu-patient.eu/>

⁵ <https://www.globalfamilydoctor.com/>

experts in various activities, including the international workshops, selection of relevant items and scales from existing questionnaires—including a modified Delphi process—identification of tools, and cognitive testing of instruments. Patients were part of decision-making by getting involved in the discussions on *what to measure* and *how to measure* outcomes and experiences in the survey. The PaRIS-SUR Consortium also convened an international group of experts from academia on primary health care research, health policy, ethics and privacy (OECD, 2022^[20]). These experts advised the Consortium on different stages of the PaRIS survey and provided feedback on study design, development, and implementation. Representatives from professional organisations such as the European Forum for Primary Care (EFPC), and the WONCA Europe network on Quality and Safety in Primary Care (EQUIP) were also consulted to gather input on earlier versions of the patient and provider questionnaires.

PaRIS source questionnaires demonstrate examples of patient engagement in the development of survey instruments

39. The PaRIS questionnaire is mainly composed of existing survey items (Boer et al., 2022^[21]). Therefore, we assessed the extent to which such items were developed with the participation of patients. Among essential questionnaires, the PROMIS (DeWalt et al., 2007^[22]) and P3CEQ (Sugavanam et al., 2018^[23]) instruments showed effective examples of engagement with patients in the development of the tools. The next section details the findings of patient engagement in the development of the PROMIS questionnaire and the P3CEQ tool.

Engaging the spectrum of patient experiences in the original development of PROMIS item banks

40. The PROMIS-10 Global Health survey is a 10-item questionnaire instrument aimed at providing a holistic view of patient-reported outcomes of chronic disease. It forms a subset of the larger item banks developed for the Patient-Reported Outcome Measurement Information System (PROMIS) by United States National Institutes of Health (NIH)-funded researchers affiliated with the University of North Carolina at Chapel Hill, Stony Brook University, and Evanston Northwestern Healthcare, a clinical research centre. Two patient engagement activities have been identified in the development of the PROMIS item banks: a set of focus group interviews to ensure domain coverage, and cognitive interviews for testing individual items.

Ensuring a wide coverage of chronic condition domains through targeted patient focus groups

41. As part of the Qualitative Item Review (QIR) process in the development of the PROMIS item banks, two to four focus groups were convened for each domain of conditions covered by PROMIS researchers to evaluate items from extant questionnaires. The PROMIS research team sought to confirm domain definitions, and to identify common language related to the domain, to ensure that the vocabulary and thinking patterns of patients as well as gaps in coverage of items and domains were captured from patients themselves. During each focus group, the research team identified language used by patients and emergent themes in chronic condition domains using content analysis from session recordings, notes, and recall. The focus groups confirmed the direction of the PROMIS domain definitions and introduced important ideas that the research team would later incorporate into new item banks, such as the PROMIS-10 Global Health subset. In this first wave of item testing, the results of focus groups also served to cut down items in the overall question bank and were followed up with analysis by content experts to decide on further calibration and inclusion of PROMIS items in the overall measure.

Calibrating items for patient comprehension through retroactive “probing” cognitive interviews

42. To further calibrate individual items included in the preliminary PROMIS question bank, the research team conducted cognitive interviews for all items as part of standard methodological practice. All

PROMIS items were reviewed through five cognitive interviews, where the overall question bank was divided into sets of 30 items and subjected to interviews with 5 individual patients. While cognitive interviewing queried patients regarding conventional considerations like language, comprehensibility, ambiguity, and relevance of items, a unique “retrospective verbal probing technique” was employed by trained interviewers to solicit focused responses from patients. The technique involved asking patients to complete a paper-and-pencil version of their set of PROMIS items during the interview, while the interviewer probes further into the basis of each of their responses. While the research team foresaw limitations in the richness of unstructured patient feedback, the method was selected for its ability to identify problematic items and clarify those not easily understood or answered across interviews. The probing technique also permitted the research team to examine decision and response processes of patients, including the effects of individual motivation or interests of social desirability in completing items. From cognitive interviews, patient comprehension of PROMIS items was confirmed, and moved forward into field testing to systematically calibrate items in the active implementation context.

Involving patients and providers in the development of the P3CEQ source questionnaire

43. A substantial component of the PaRIS survey questionnaire is comprised of empirically-tested survey instruments well-documented in the health policy and outcomes measurement literature. The P3CEQ, or Person-Centred Care (P3C) Experiences Questionnaire, is one such instrument developed by researchers at Plymouth University in the United Kingdom to provide an evaluation framework for person-centred health care delivery. As part of its development, authors implemented a “co-designing” process involving stakeholders in care delivery to ensure the questionnaire captured the interests of the people delivering and receiving care during evaluations (Sugavanam et al., 2018^[23]).

Identifying candidate survey tools through workshops involving a variety of care stakeholders

44. To develop the P3CEQ, the research team sought to identify measures most likely to capture “person-centredness” in the clinical setting. As part of its “co-designing” approach, the team set up a first workshop evaluating 7 pre-selected existing measures of integrated care, and invited a group of patients, providers, carers, healthcare commissioners, and social care representatives to select 3 of these measures in small group meetings. Through the use of a voting process during this workshop, the group selected 3 measures as being most acceptable for assessing integrated care delivery and to be moved onwards for modification into the preliminary P3CEQ instrument.

Selecting relevant items from existing questionnaires with a greater focus on patient voice

45. Following the first workshop, three additional workshops were convened to select items most relevant to person-centredness in care settings. The second workshop included a similar variety of stakeholders to the first: patients, providers, healthcare commissioners and social care representatives. The third and fourth workshops narrowed to focus only on patients, as a means of further refining the survey instrument to account for patient needs. During these three workshops, participants were consulted for comment on each of the 3 identified measures regarding their content, language, length, layout, and relevance to the lived experiences of people in healthcare settings. With the feedback received from these workshops, the research team selected the LT6 questionnaire of the three identified measures and elected to modify questions regarding broader conceptions of health involving ‘well-being’, social care as part of the health system, and perceptions of the usefulness of information received during care. The research team also added questions to the LT6 base measure regarding holistic care, information management, and care planning.

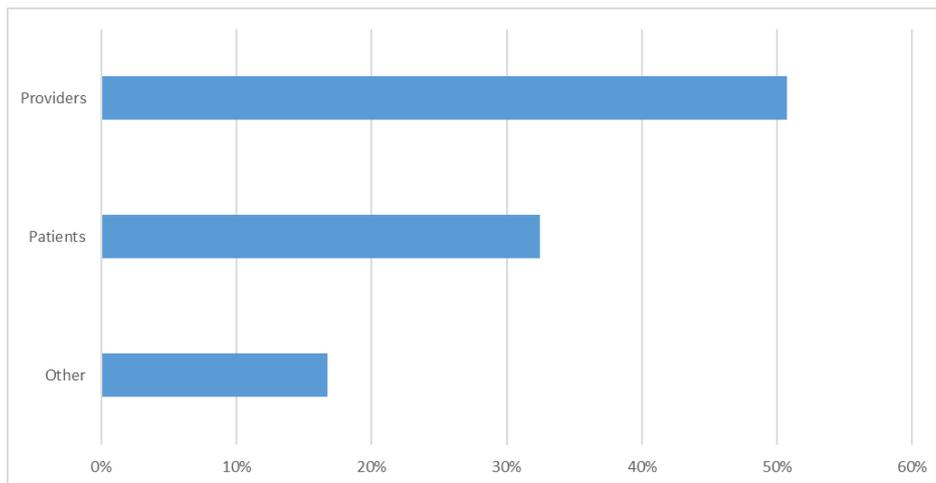
Conducting cognitive testing to ensure patient comprehension and effective data on patient experiences

46. As with standard methodological practice in survey instrument development, the research team pursued cognitive testing with the modified LT6 questionnaire—now the preliminary P3CEQ instrument—to determine whether selected questions generated responses and information from patients as intended. Individual interviews were set up with a pool of patients experiencing a long-term condition or multiple long-term conditions to be conducted by trained facilitators. Based on responses delivered by patients, the research team modified the preliminary P3CEQ instrument to create a final version. The language and length of the P3CEQ was confirmed during this process, while the inclusion of a trigger question regarding care plans to reduce the number of main questions asked to all patients.

Implementing the PaRIS survey in the participating countries

47. CRMs included various stakeholders in the national engagement plans (Figure 3.1). Similar to efforts at the international level, providers were the main target of engagement plans in the CRMs (51%), followed by patients in more than a quarter of plans (32%) and other stakeholders (17%).

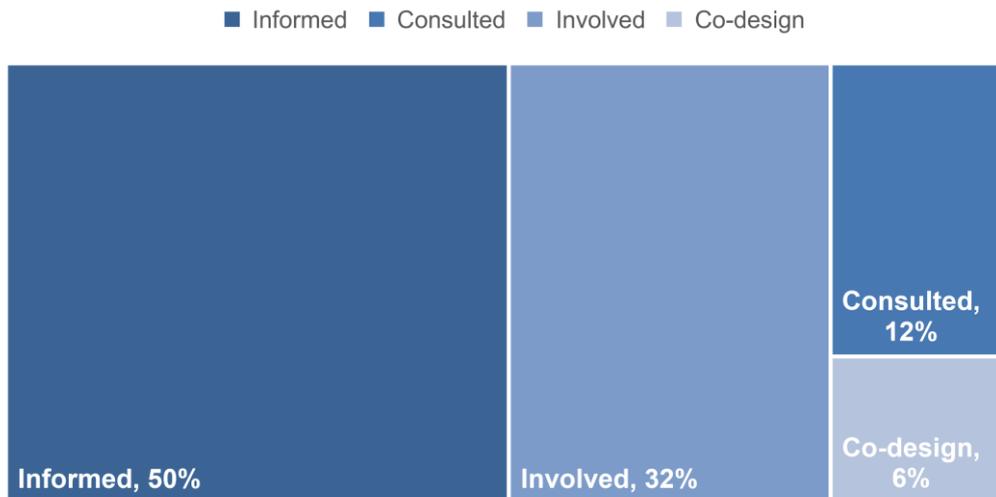
Figure 3.1. More than half of national engagement plans targeted providers in the Country Road Maps



Note: Consolidated engagement plans from seventeen Country Road Maps

48. Countries engaged with stakeholders at various levels (Figure 3.2). Half of CRMs (50%) planned to inform stakeholders. While a small proportion (12%) planned to consult them, many plans (32%) mentioned involving stakeholders. Only a small part (6%) planned to co-design Field Trial implementation activities with stakeholders.

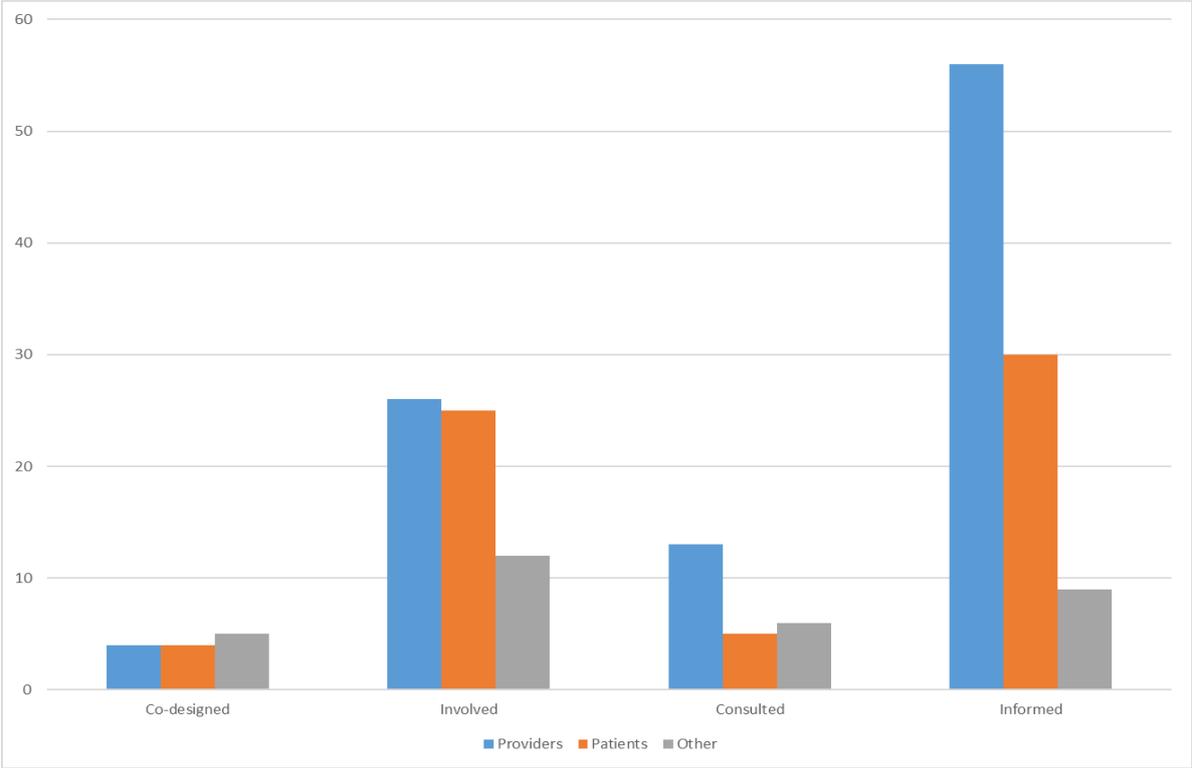
Figure 3.2. Majority of engagement plans aimed to inform stakeholders



Note: Consolidated engagement plans from seventeen Country Road Maps

49. CRM plans showed similar engagement levels for providers and patients except for consulting and informing (Figure 3.3). Among the activities which aimed at co-designing, similar numbers of plans were identified for providers (2%), patients (2%), and other stakeholders (3%). As for involving stakeholders, providers and patients were mentioned in 13% of CRMs whereas other stakeholders were mentioned only in 6% of CRMs. The engagement activities which aimed at consulting or informing, providers comprised the largest group (7% and 29%, respectively), which was followed by patients (3% and 15%, respectively) and other stakeholders (3% and 5%, respectively).

Figure 3.3. Engagement plans varied from co-designing to informing among different stakeholders



Note: Consolidated engagement plans from seventeen Country Road Maps

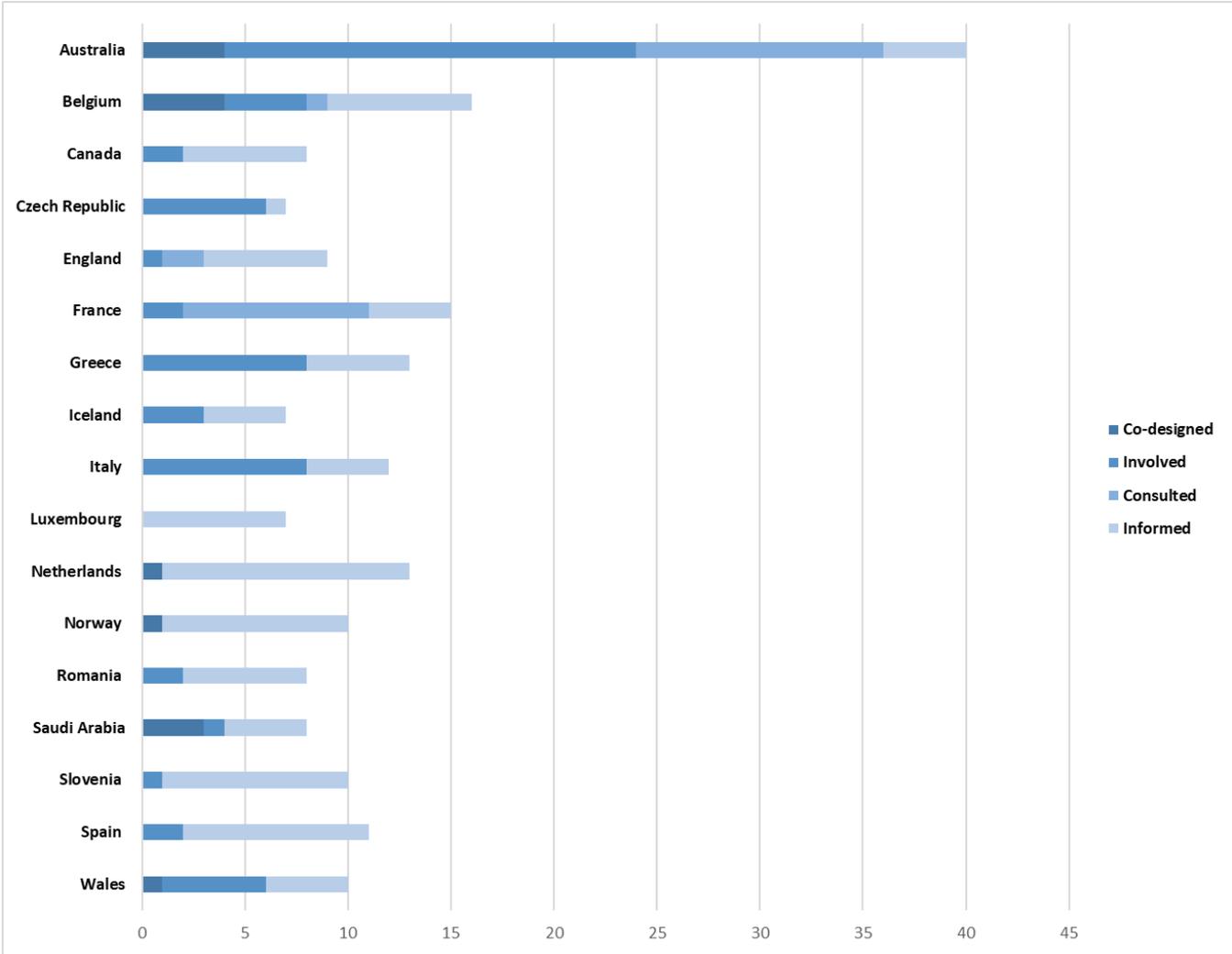
50. Some countries like Australia, Belgium, and France planned to use at least three different engagement levels while most countries planned activities at the “involving” and/or “informing” levels (Figure 3.4). Six countries (Australia, Belgium, Netherlands, Norway, Saudi Arabia, and Wales) planned to co-design the implementation of the Field Trial with providers, patients, and other stakeholders. Most countries had at least one activity at involvement level. All countries had at least one engagement plan which discussed informing providers and patients.

Figure 3.4. While all countries planned to inform stakeholders, six planned to co-design with them



51. The number of engagement plans, as well as the use of different engagement levels showed unique approaches across countries. Some countries like Australia, Belgium, England, France, Saudi Arabia and Wales had extensive plans across all engagement levels. Other countries like Canada, Czech Republic, the Netherlands, Norway, Romania, Slovenia, and Spain centred most of their plans on one engagement level. The degree to which countries employed preferred engagement levels (co-designing, involving, consulting or informing) differed widely. Three countries, Greece, Iceland, and Italy described engagement plans with activities at two different levels (informing and involving).

Figure 3.5. Number of planned engagement activities per engagement level varied across and within countries



4 Case studies demonstrating the operationalisation of stakeholder engagement activities

Countries formed new bodies or used existing networks to engage with stakeholders in the PaRIS survey development and implementation. This section describes engagement activities from seven selected countries, namely Wales (United Kingdom), Czech Republic, Norway, Italy, Portugal, Australia, and Netherlands. Wales (United Kingdom), Czech Republic, Australia, Italy, and the Netherlands show the examples of how existing patient bodies are mobilised for the implementation of the PaRIS survey. Norway, and Portugal provide examples of creating a new advisory body for the PaRIS survey. These examples are based on interviews with NPMs.

Wales will engage its existing civil society connections in the Main Survey

52. In the wake of the COVID-19 pandemic the Wales COVID-19 Evidence Centre (WCEC), funded by the Welsh Government and Health and Care Research Wales (HCRW), was established to inform evidence-based policy decision making in Wales. HCRW regularly engages with the public and patient organisations. The WCEC did this in two ways: by consulting a diverse range of patient and public groups in research prioritisation, and by setting up a Public Partnership Group (PPG) which empowers patients as core partners in prioritising, conducting, and mobilizing health research. These activities provide a robust foundation for incorporating patient voice as Wales embarks on delivering the PaRIS survey.

Involving underserved patient groups in research prioritisation

53. In deciding on research priorities, the WCEC involved patient groups to ensure that limited resources during the COVID-19 pandemic response were targeted towards equitable access to health services. Through its research prioritisation programme, the Centre focused on the needs of underserved patient groups, setting up a range of workshops for children and young people, disability advocacy groups, ethnic minority support groups, and the local housing authority in Cardiff. A series of face-to-face and online workshops were run with these groups, focusing on exploring experiences of the COVID-19 pandemic in Wales and views on the most important research priorities. Follow-up online ranking surveys were sent to the various groups to identify the top ten research priorities. Once priorities were selected, patients were further consulted on opportunities for research and knowledge mobilization. A fourth round of the research prioritisation programme is set to begin in autumn 2022 and expand its inclusion to unpaid carers of patients as vital yet under-researched stakeholders in patient care.

Engaging patients as core partners in knowledge translation and policy impact

54. In addition to determining research priorities, a PPG comprised of ten members works directly with the WCEC Core Team. Any citizen in Wales is eligible to apply, and members of the PPG are selected through application and conversations with Centre staff. To ensure the widest access to patients with health care services across the whole of Wales, meetings are held online, and comments are exchanged through email and online collaboration platforms. By assessing priorities for work programmes, providing feedback on evidence synthesis reviews during the development of protocols and analysis, and informing knowledge dissemination strategies for briefings to Welsh policymakers, the PPG allows patients to help shape the policy impact of health services research across Wales.

Use of existing patient networks for the PaRIS survey

55. As the PaRIS Field Trial is underway in Wales, patient engagement continues to be a priority. In developing robust patient engagement platforms through the WCEC research prioritization programme and the PPG, Wales intends to leverage its existing patient networks to support engagement activities and patient stakeholder involvement in the implementation of the PaRIS Main Survey. HCRW views the PaRIS survey as an important tool for garnering feedback from patients less often voiced in other health system analyses. In the Main Survey, it expects to target patients exhibiting lower care-seeking or lower self-activated behaviour due to diminished access to, or knowledge of, health services in their community, and select facilitators familiar with these contexts to deliver the survey. Capturing the voice of those most difficult to reach in deprived areas and rural communities remains a priority of health policymaking in Wales, and the PaRIS survey has an important role in supporting this vision.

Czech Republic consulted a Patient Council for the development of PaRIS questionnaires

56. As a key component of PaRIS-related patient engagement activities, the NPM for Czech Republic consulted a Patient Council, established by the MoH in 2017. Patient representatives from the Patient Council had the opportunity to comment on the development and implementation of the PaRIS survey in Czech Republic. The NPM plans to consult the Patient Council again in the Main Survey.

The Patient Council systematically engages patients in the processes of the Ministry of Health

57. The Patient Council is an advisory body composed of patient representatives who can be nominated by patient organisations. The Council is composed of representatives from existing patient organisations representing a broad range of diseases and chronic conditions and supported by the Promotion of Patients' Rights Unit. Representatives serve for four years in the Council with meetings held quarterly. There are currently 24 members. All members are sent drafts of legislative and non-legislative documents which they may comment on and, in so doing, are able to shape the form of these documents from the beginning of the process.

58. The Unit follows the activities of the MoH closely to identify working groups where patients' input would be beneficial. Following some discussions, patient representatives can be nominated by the Patient Council into working groups at the MoH and have a role in the decision-making. The Council may also initiate the establishment of working groups of the Council, where patient organisations from across the segment meet and discuss topics of importance to them. They may pass on recommendations to the Council and if adopted they are presented to the Minister.

Patient representatives are rigorously selected from existing patient organisations

59. Every four years, the MoH launches a call for representatives to join the Patient Council. The Ministry established key principles for selecting representative patient organizations. By law, a patient organisation is defined as a non-governmental organisation with a majority of members comprising patients, family members or caregivers. If the organisation is not member based, patients must have an influence on the management and decision-making processes of the organisation. Patient organisations must demonstrate transparent financing – where they receive funding from must be visible on their website or annual reports.

60. If multiple organisations representing the same diagnostic group apply, the Ministry invites these organisations to discuss representation on the Council and come to a consensus on the selection of a representative.

The Promotion of Patients' Rights Unit uses different communication channels to communicate with the Patient Council

61. The MoH uses communicates with the Patient Council in various ways. Quarterly meetings are held at the MoH for patient organisations (whether part of the Patient Council or not) discussing what the Ministry is planning, identifying current topics of interest and convening Ministry representatives working on those portfolios. Closer coordination with the Patient Council is achieved through e-mail, MS Teams and through an instant-messaging group with the Chairperson and Vice-Chairs of the Patient Council. Through their website (<https://pacientskeorganizace.mzcr.cz/>), the Unit engages with a broader audience and shares updates with patient organisations and other stakeholders.

62. To support capacity-building of patient organisations, a Patient Hub—comprising a physical space and an online platform has been created. Serving as a space for learning, networking, and coworking, the Patient Hub supports the education and training of patient organisations in learning the characteristics of Czech health system such as health and social system and reimbursement mechanisms. The funding for this project comes from national, EU or EEA and Norway grant schemes.

63. The Czech MoH is exploring means to financially support patient representatives to ensure continuous education and peer support in health policymaking long-term.

The PaRIS reference group has been an essential engagement strategy in Norway

64. Engaging with patients and providers has been a key priority for Norway. To ensure that the PaRIS survey is relevant for the varying needs of patients, the Norwegian Institute of Public Health (NIPH)⁶ has convened a reference group to include all relevant stakeholders. Comprising patient organizations, hospitals, directorates of health, general practitioners (GPs), and other active stakeholders, the PaRIS reference group has provided a forum for advice and support to NIPH researchers in discussing the translation of the PaRIS questionnaire, as well as in recruiting patients for cognitive testing. The group has met five times since August 2020 and discussed the relevance of survey questions to patient and provider needs, as well as the translation of technical terms to native and minority languages.

Recruiting patients and providers with the support of engagement partners

65. Norway has planned a national distribution of the survey, working with the MoH, directorates of health services, and health facilities to access a broad reach of the patient and provider population. The PaRIS reference group has informed the survey's outreach to stakeholder communities as Norway prepares for the Main Survey in 2023.

66. The PaRIS reference group has facilitated the recruitment of patients and providers. Both prior to and following cognitive testing of the PaRIS survey instruments, the NIPH discussed patient and provider recruitment with its PaRIS reference group. Members of the reference group contacted their respective personal and professional networks for individuals meeting eligibility criteria for completing the cognitive interviews. Stakeholders used different modes of communication. For instance, one GP referred four of their patients for cognitive interviews, while another GP sent letters to other GPs in other health regions in Norway to invite them for provider cognitive interviews.

67. In preparation for the Main Survey, NIPH is further expanding its reach to providers and their patients through its collaboration with the WONCA Norway.

Italy has involved a broad group of civil society organisations in the PaRIS survey

68. Moving beyond the target groups for the PaRIS survey, Italy has expanded its engagement strategy to include broader groups of citizens, health care providers, and local health authorities. Two key partners for expanding its reach include CSOs such as Cittadinanzattiva and the largest trade union of retirees in the country. Italy has also worked with local GPs, nurses and other care provider associations to recruit a larger number of GPs for the PaRIS survey.

Using evidence-based research to plan citizen engagement activities in health policymaking

69. The Italian NPM team for PaRIS used evidence from research to inform their decisions on the implementation of the survey. The team employed discrete choice models to better understand the role of incentives on citizen involvement in health policymaking initiatives. Results from their study found that citizens were most strongly motivated to join the survey when they felt assured that their voice was heard

⁶ The Norwegian Institute of Public Health (NIPH) is a research institution closely affiliated with the Norwegian Ministry of Health providing key public health research and analysis regarding public health issues in Norway.

by the initiative. The team also conducted a 10-item paper survey questionnaire among 2000 retirees of a trade union, who are 65 years and above, to understand the propensity of an elderly population to use Internet-based technologies for answering surveys. Results found an increase in the use of the Internet among a patient cohort aged 65-75 years compared to conventional survey methods, with a lower propensity for such technologies among those aged 76 years and above.

Cittadinanzattiva provides citizen-led evaluation of health services in Italy

70. In the PaRIS initiative, Cittadinanzattiva has provided feedback about the survey process, with a particular emphasis on the use of survey data and advising on the revision of the questionnaire for additional national items. Cittadinanzattiva (<https://www.cittadinanzattiva.it/>) provides independent and unsolicited advice to regional and national health authorities regarding citizens' experiences of health services. As community health service activities are increasingly organised at the regional level, following recent national reforms, Cittadinanzattiva volunteers cooperate with local health authorities to capture the experience of patients. Volunteer members of Cittadinanzattiva can occupy several roles in this capacity. They act as formal evaluators by visiting health facilities, register observations, take notes, and complete checklists, to examine the quality of health services from the citizen point of view. Cittadinanzattiva often publishes reports on their activities in the health sector and other essential community services. Participating volunteers may also be recruited by local health authorities to be part of their board and provide oversight and review of health service policies.

Consulting the retirees' trade union to effectively use technology in reaching elderly populations

71. With the institution of the Italian NPM, beginning informally in 2019, and following the establishment of a formal relationship since 2020, collaborations with the trade union have yielded opportunities to develop new knowledge on patient engagement activities. For instance, as survey technology has developed with an emphasis on Internet-based tools and applications, reaching elderly patients without equal access to technology increasingly poses a challenge for receiving feedback on health services serving them.

72. With the objective of using the PaRIS survey tools in a permanent observatory of patient outcomes and experiences, civil society engagement continues to be a key priority for Italy. Feedback from civil society and CSOs will be used to improve the performance of the health system.

Portugal leveraged its existing civil society bodies for the PaRIS survey

73. The *Administração Central do Sistema de Saúde*, or ACSS⁷, is the body in the ministry charged with the commissioning of health services to providers, either based in hospitals, or in primary health care trusts where 2000-3000 patients are served by a given provider. As the ACSS determines the quantity and assesses the quality of services commissioned, each cycle of procurement involves representatives from professional organisations, along with other civil society groups and representatives from other MoH institutions (*Comissão Técnica Nacional*⁸).

⁷ <https://www.acss.min-saude.pt/>

⁸ https://www.acss.min-saude.pt/wp-content/uploads/2019/12/Regulamento_Interno_v_retificada_20191113.pdf

Developing new indicators with the support of civil society commissioning groups in the ACSS

74. Aside from commissioning health services, the representative groups involved with the ACSS are consulted about the evaluation of healthcare services delivered in Portugal. Around 1-2 times per year, the ACSS engages with organisations affiliated with the commissioning process—such as health professionals associations and CSOs—to advice on the development of new healthcare indicators for which the MoH will collect data. For this process, the ACSS first issues a technical proposal at the beginning of the commissioning cycle. Next, after discussions with technical experts on the effectiveness of the indicators and their confirmation, the ACSS brings the proposal to representative organizations to generate additional insights. These often include groups representing patients, GPs, and family nurses, to include a wide variety of patient and provider knowledge of measurement needs.

Leveraging existing engagement channels for Portugal's PaRIS survey advisory board

75. With this formal and established process, the PaRIS implementation group has leveraged its connections with representative organizations to form an advisory group for professional organizations and civil society engagement during the implementation of the PaRIS survey in Portugal. The group had its first meeting in February 2021 and discussed localisation and translation of the survey to country-specific terminology, cognitive testing, and inclusion and exclusion of questions from the source instruments. In the Field Trial phase, communication project, and to support the board's ownership of the co-designed project.

76. Portugal will discuss lessons learned from the Field Trial within the MoH, the PaRIS advisory board, providers that participated in the field trial to consult on adjustments before embarking on the Main Survey in 2023.

Consumer engagement is a key component of Australia's health policymaking

77. As interest in patient-centred care has grown over the last decade in Australia, governments across the country have considered health consumer participation in the planning of health services. In particular, standard practice of the Australian Department of Health and Aged Care includes the involvement of consumers on every committee developing policies relevant to patients, such as the Mental Health Consumer Forum. For major policy changes, new federal policies are developed in consumer-involved committees and open to public comment or can be moved to a Senate Committee for further examination. Consumer engagement and partnerships with consumers additionally extends to safety and quality standards for health services. The National Safety and Quality Health Service Standards developed by the Australian Commission on Safety and Quality in Health Care (the Commission), a national body co-funded by the Commonwealth government and state and territory health governments, has developed a standard to assess public and private health service organizations for building effective consumer partnerships and develop, implement and maintain systems to support partnering with consumer.

78. Primary health care policy in Australia is a responsibility of the federal Commonwealth government, therefore, 31 Primary Health Networks organise collaborative policies between GPs interested in integrated care, safety, and quality safety.

Supporting patient involvement in PaRIS survey development through the Patient Advisory Group

79. As Australia delivers the PaRIS Field Trial, its extensive experience with health consumer engagement on quality measurement has informed the development and implementation of the PaRIS

survey in the country. A Patient Advisory Group set up by the Commission responsible for the development of safety and quality indicators for each hospital in Australia, regularly recruits patients from across the Commonwealth, and was adapted to advise on indicator development for the PaRIS Survey. The chair of the Group is a representative of the Consumer Health Forum, a national organisation advocating for consumers' interests in the Australian health system. Through these collaborative channels, consumers have been involved in PaRIS indicator development through participation in technical working groups, the Patient Advisory Group, engaged through GP-led networks, and contacts of the Consumer Health Forum.

80. In Main Survey, Australia intends to leverage its local partnerships with Primary Health Networks to build relationships with GPs and patients during data collection. With the support of PaRIS, Australia is building its first consistent national primary health care data infrastructure, and health consumers are at the heart of this strategy.

The Netherlands engaged its Healthcare Consumer Panel in testing the PaRIS questionnaire

81. In the Netherlands, patient engagement in health services and policy research is led independently by NIVEL, the *Netherlands Institute for Health Services Research*, with the support of funding from the Dutch MoH, Welfare and Sport. While engagement is consistently seen as an important task in health policymaking, the Ministry remains interested in understanding when to include the public in the policy development process, such as during its development of its recent *Right Care at the Right Place* policy on the transfer of patient care between providers.

82. In a new NIVEL report (Kemper et al., 2022^[24]) published in September 2022, researchers note that the most effective public engagement strategies focus on health policy with a high proximity to patients' local communities, or in frequented environments like their GPs as opposed to policies shaping tertiary care. NIVEL regularly organises *Citizens' Councils* to convene patient discussions on specific healthcare issues and inform health policymakers of health consumer opinions. In order to recruit patients to *Citizens' Councils*, NIVEL pulls from its *Healthcare Consumer Panel*, comprising over 11,000 online members of the Dutch general public above 18 years of age.

Netherlands signalled the necessity of greater engagement with civil society in Main Survey

83. During testing of PaRIS survey questions in the Netherlands, NIVEL engaged members from this Panel to review the questionnaire. While NIVEL was able to promote the PaRIS Field Trial through the support of patient organizations signal-boosting to partner groups through websites, newsletters, and other communications channels, provider-led promotion to patients was limited. Recruiting GPs remained a significant challenge for NIVEL in accessing patients for the delivery of the PaRIS survey: a higher number of practices were contacted than expected in order to secure their involvement. By building and maintaining personal contacts with GPs, and working with provider-validated patient lists, NIVEL has been able to work on behalf of GPs to communicate with patients for patient recruitment.

84. NIVEL intends to adapt its communications with patients and providers to be more personal in Main Survey. Through a letter from NIVEL to GPs informing them of the Main Survey distributed in several provider settings, and the publishing of scientific publications, NIVEL aims to convert the interest of every GP in the Field Trial into strong engagement in the Main Survey to keep the momentum built from earlier engagement strategies.

5 Building on the lessons learnt from the Field Trial: Recommendations for the Main Survey

In support of efforts to improve the people-centredness of health systems, the PaRIS survey aims to contribute to relevant and impactful policies to increase the value of the care patients receive. The survey development and implementation has included many examples of how stakeholders, namely patients, providers, and academics could co-develop an international survey to measure patient-reported outcomes and experiences.

85. As explained in section 1, the value, credibility and success of the PaRIS survey depends highly on engagement with key stakeholders. Informing patients and providers about the survey is a minimum requirement for successful implementation, but consulting, involving, and even co-designing activities are necessary components of ensuring the survey is a shared effort and builds support for key stakeholders.

86. Patients, providers, and other stakeholders such as researchers or data officers have co-developed the PaRIS survey. In addition to the engagement activities in the study design and development of instruments, participating countries also reported a rich variety of engagement activities. Stakeholders contributed significantly from design to Field Trial implementation. Inspirational examples from case studies in the paper show that co-development of a large-scale international survey is possible with the efforts of all countries and stakeholders.

87. Although many NPM teams engaged patients in their implementation work, most engagement activities focused on getting primary care providers on board. The focus of engagement activities on providers is understandable given the stratified design of the PaRIS survey (sampling patients through

their providers). This means that countries focused their efforts on recruiting primary care providers first in order to access patients for data collection. However, given the goal of the PaRIS survey to voice peoples' outcomes and experiences, PaRIS survey results will benefit from greater and more effective patient engagement.

88. Stakeholders more often played a passive role as 'receivers' of information, rather than active roles as 'co-creators' of information in national implementation plans. Empowering patients and providers with a greater say in the implementation of the survey could further improve the relevance of survey results to them.

89. Several countries shared promising and innovative ways to engage stakeholders, but few demonstrated a variety of engagement activities across levels. While planning engagement strategies, it is important for countries to consider their national context and perform a stakeholder analysis. It is essential to actively engage with key stakeholders who are directly concerned by the PaRIS survey such as patients and providers or those with significant influence on decision-making in health policy (such as insurance companies or other private sector entities in some countries).

90. The Field Trial phase provided an excellent opportunity for countries and NPMs to evaluate the impacts of these activities and to exchange and learn from one another. As countries learn from this experience, the results of the Field Trial with support the optimisation of stakeholder engagement during the Main Survey.

91. Figures presented in this document are meant to fuel discussion of civil society engagement rather than to assess the performance of countries. Engagement activities identified in CRMs may be underestimated or overestimated as the documents used in our analysis reflect action plans rather than observed activities. Additionally, some countries may depict a low number of activities in our analysis, but may otherwise comprise effective strategies in their particular context. Box 5.1 summarises the cautions readers should consider while interpreting these results.

Box 5.1. Disclaimers for the interpretation of results

- CRMs are action plans and actual activities conducted may differ from these action plans.
- Some engagement activities that took place in countries before the implementation of the PaRIS survey may not be included in CRMs.
- In some countries, NPMs are also practicing primary care providers. This could significantly contribute to the engagement of providers as NPMs may have privately mobilised their own networks of providers. However, such informal activities are not reflected in the analysis.
- For some countries, CRMs were the only source of information available for analysis. For these countries, we shared figures alone instead of describing their activities in detail. Although the number of activities provides a good indication of the engagement of civil society, the quality and effectiveness of the activities is not explored and may influence actual engagement levels.

Recommendations for the Main Survey

Learnings from the Field Trial yielded three main lessons for the engagement activities in the Main Survey

92. Based on the exploration of engagement work in participating countries, the following recommendations could be adopted for the Main Survey implementation:

93. **Patient and provider organisations demonstrated significant interest and ability to contribute to the development and implementation of the survey.** Several countries shared inspiring examples of how stakeholders took active roles in national implementation of the PaRIS Field Trial. In Norway, the World Organisation of Family Doctors (WONCA) President agreed to send a letter to encourage primary providers to participate. In Italy, a trade union association helped choosing the best data collection method for elderly people. Wales (United Kingdom) planned to use existing civil society connections, which provide a robust foundation for incorporating patient perspectives in the Main Survey.

94. **Effective engagement requires real dialogue with stakeholders rather than one-way communication.** Although providing information is necessary, for example with posters, brochures and publications, this is not enough to create a feeling of involvement and ownership among stakeholders and, as a result, to create support and buy-in to effectively implement the survey. Activities enabling direct feedback such as conversations with patients and providers through a steering board or advisory group could increase engagement

95. **The relevance and impact of the PaRIS survey is likely to benefit from sustained and enhanced patient engagement.** Engagement activities focus more often on providers than on patients. Although provider engagement is essential to recruiting respondents and for the sampling of patients, active engagement of patients in implementation will improve the relevance of the survey to patients' needs and, hopefully, increase the impact of the survey.

National Project Managers discussed the findings of this work to expand their engagement activities in the Main Survey

96. The NPMs from twenty participating countries met on 14-15 September 2022 in Paris to discuss the Field Trial evaluation of the PaRIS survey. In a dedicated session, the findings of this work were presented to NPMs. Following the presentation, NPMs discussed the best practices from the Field Trial and possible directions for the Main Survey concerning the engagement of patients, providers, and other stakeholders. The key outcomes of the discussions and the recommendations for the Main Survey were:

- Best practices from the Field Trial highlight the additional value of using existing networks and getting support from patient and provider organisations in the implementation and engagement plans.
- Personalisation of engagement is helpful when reaching out to stakeholders for the first time. Personalised engagement strategies for key stakeholders can help with getting them on board and personalised invitations for patients coming from their GPs can increase participation to the survey.
- Reporting back the results of Field Trial and Main Survey to patients and providers is important to maintain the engagement of stakeholders in the long term.
- PaRIS can be included in the broader quality improvement strategies in the countries. To increase the relevance of PaRIS results for policymaking, synergy with other quality improvement activities need to be considered.
- Meaningful participation of each stakeholder group should be central in engagement activities. It might not be possible, or necessary, to co-design with all stakeholders. Engagement of stakeholders needs to be considered on a case-by-case basis and different levels varying from co-designing to informing can be used by NPMs.
- Other stakeholder groups that might participate in the implementation of Main Survey are data officers, communication experts, librarians, researchers- economists, sociologists, health insurance companies, other relevant committees and groups working on a similar subject (e.g. quality improvement, indicator development, primary care, PROMs and PREMs.), and regional and local authorities.

- Given the goal of PaRIS survey in making health systems more people-centred and improving quality of primary care for people living with chronic conditions, patients should have an active role in decision-making.

Conclusion

97. Some countries demonstrated inspiring examples of engagement with stakeholders during the implementation of the PaRIS survey. Yet, this was not the case in all countries. In the Main Survey, the participating countries will build on the previous achievements and expand on the engagement. It is essential to collaborate with key stakeholders to refine the survey design and instruments with the contribution of patients, providers, country officials, technical experts, and other relevant stakeholders.

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Annex A. Framework for assessing stakeholder engagement in the PaRIS survey

Table A A.1. Framework for assessing stakeholder engagement in the PaRIS survey

Key steps (Year)	Activity	Target stakeholder (Patients, providers, other)	Activity level (International, national, subnational, individual)	Communication channel (group meeting, bilateral call, written feedback, social media, posters, etc.)	Engagement level (Informed, consulted, involved, co-designed)	Purpose of the engagement	Expected outcome
Design (2017-2020)	Development of study proposal						
	Development of study design						
	International workshops						
Development (2021-2022)	Identification of candidate tools						
	Selection of relevant items and scales from existing questionnaires, including Delphi process						
	Identification of tools						
	Cognitive testing of survey instruments						
Implementation (2023-2024)	Development of country-specific implementation plans						
	Recruitment of survey respondents						
	Dissemination of the survey						

Source: Authors tools based on rapid literature review on existing

Annex B. Semi-structured interview guide

- Could you describe major activities of your Ministry of Health/institution to engage with civil society in health policymaking?
 - How does this operate?
 - Who is involved?
 - What are the responsibilities of the group members participating in these activities?
 - How are they selected?
- What are the communication channels commonly used to engage with civil society?
 - Direct dialogue (calls, meetings, etc.)
 - Indirect dialogue (written exchanges, online surveys, etc.)
 - One-way communications (posters, leaflets, presentations, publications, etc.)
- (optional based on the interviewee's profile) How familiar are you with the implementation of the Field Trial?
- Have these existing civil society engagement activities shaped the implementation of the PaRIS Field Trial? How so?
 - Do you have any plans to modify this strategy for the Main Trial?
- Do you have any plans in the future regarding engagement of civil society in health policymaking in general?

Annex C. Terms of References – PaRIS Patient advisory Panel

To inform the PaRIS survey of patients with chronic conditions, the OECD will create a Patient Advisory Panel. This Patient Panel will advise the Secretariat, the international contractor and the Working Party for PaRIS on the development and implementation of this survey to help ensure that the project delivers value for patients.

These draft Terms of Reference describe the objectives, roles and tasks of the Patient Panel.

Introduction and motivational Statement

The objective of Patient Reported Indicator Surveys (PaRIS) is to support the creation and collection of state-of-the-art, internationally comparable patient-reported indicators to advance high performing, people-centred health systems. Within the framework of PaRIS, the OECD is building an international survey of patients with chronic conditions who receive primary care (the PaRIS Survey). The PaRIS Survey results will shed light on the status of people living with chronic conditions, and will produce information that enables all stakeholders, such as patients, clinicians and policy makers, to understand variation in health outcomes and health care experiences and to identify policy actions to improve care.

To do this, incorporation of the patient voice will be essential in all phases of the project. The need to incorporate the patient voice is reflected in the guiding principles of PaRIS initiative as a foundational building block of making health systems more people-centred.

This effort will complement other PaRIS initiatives, including country level activities within participating countries, to strengthen the involvement and empowerment of patients in their own health care and to promote the patient-centredness of the PaRIS initiative overall.

Objectives, roles and tasks of the Patient Advisory Panel

Objectives

Patients are experts in their own lives, needs, concerns and views, which play a central role in PaRIS. The main objective of the Patient Panel is to promote the patients' voice and provide their unique expertise as the project is developed. More in particular, this means that the content of survey questionnaires is relevant for patients, data collection takes place in a way that minimises burden for patients and that communication about the project promotes value for patients.

Roles and tasks

The role of the Patient Panel is to advise the Secretariat, who will take full responsibility for its own decisions. The Secretariat aims to convene a panel that reflects the voice of a wide variety of patients. Members will serve on the panel in a personal capacity, conveying their personal perspectives and the perspective of the patient populations they represent. PaRIS-PP members do not serve as representatives of organisations. Members are knowledgeable about the views, interests and concerns of patients.

The PaRIS-PP will advise on:

- The content of patient questionnaires, particularly concerning the relevance for patients;
- Strategies for engaging and communicating with patients about PaRIS
- Standards that participating countries should adhere to for patient engagement
- Ways to maximise value for patients and the policy impact of survey results
- Other items as determined, by the Secretariat, the Contractor, the PaRIS Working Party, or the PaRIS-PP itself

The Secretariat will primarily consult the PaRIS-PP through web-meetings, but also in in-person meetings and in written consultations via an online-community on an ad-hoc basis. In some cases, the Secretariat may decide to do consultations with the wider patient community and will ask members to share this with their network.

On occasion, the chair may be asked to report to the PaRIS Working Party on the activities of the PaRIS-PP and receive mutual feedback.

Members and composition of the panel

The PaRIS-PP will contain approximately 8-12 members. Members of the panel should be well-connected to a community / organisation of patients and have a basic understanding of the main steps to be followed in survey research.

Criteria:

- Lived experience, or representative of patients for lived experience, with one or more of the chronic conditions to be studied in the PaRIS Survey;
- Availability and ability to participate in PaRIS-PP webinars or meetings;
- English language;
- No conflicts of interest (see Section on Declaration of Interests Below).
- Additional desired criteria:
 - At least basic understanding of survey methods and health systems research;
 - Relationships with international, national, regional, or healthcare stakeholders.

The Patient Panel will, to the extent possible, include members from all regions of the OECD and be representative of the patient populations surveyed.

Timeline and meetings

The Patient Panel will meet twice annually via webinar. Additional web-meetings, teleconferences, and in person meetings may be required. In some cases, the Secretariat may ask the panel for written input.

The specific schedule of meetings will be further discussed with the panel. The panel will be created before March 2020.

The purpose of the PaRIS Patient Panel (PaRIS-PP) Conflict of Interest Policy is to protect the OECD from any suggestion of impropriety. The policy establishes standards of conduct for PaRIS-PP participants in the exercise of any power or the performance of any duty or function on behalf of the OECD and the PaRIS Initiative. It is intended to support the OECD's integrity, to promote its goals and to enhance public, stakeholder and donor confidence in OECD and those associated with it.

Declaration of interests

Conflicts of interest may arise when a PaRIS-PP members personal, business, occupational or professional interests' conflict with those of the OECD. A real conflict of interest occurs when, in the course of their PaRIS-PP functions, PaRIS-PP members are privy to PaRIS-PP decisions, documents or

transactions that provide opportunities to obtain personal, business, economic, occupational or professional benefits for themselves and/or third parties. An apparent conflict of interest exists when there is a reasonable perception on the part of well-informed persons that a PaRIS-PP member is in a conflict-of-interest situation.

PaRIS-PP members must agree to act in the best interests of the OECD PaRIS initiative and the project's objectives. PaRIS-PP members are required to disclose the nature and extent of any existing or potential conflict of interest, real or apparent, when they accept to serve on the PaRIS-PP. This includes declaring links to/funding from external funding sources that might be in conflict with the objectives of the PaRIS initiative.

PaRIS-PP members will be required to complete a disclosure statement which will be updated annually or whenever a change occurs. If PaRIS-PP members are not sure what to declare, or whether their declaration should be updated, please contact the OECD staff for guidance.

How Conflicts of Interest will be handled

Reports of conflicts of interest should include the nature and extent of the conflict. If a PaRIS-PP member faces a real or apparent conflict of interest:

The PaRIS-PP member should declare the interest at the earliest opportunity. If a conflict of interest (real or apparent) is declared at the start or during a meeting, this will be recorded by the OECD Secretariat and the PaRIS-PP Chair. Once a conflict of interest has been made known, the OECD Secretariat and PaRIS-PP Chair will act on the information in one of the following manners depending on the extent and nature of the conflict. They may allow the PaRIS-PP member to participate in activities the standard manner. They may preclude the PaRIS-PP member from the discussion of certain topics. They may, under certain circumstances, ask for the members resignation from the PaRIS-PP.

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